Out of Time, Out of Place: Pastoral and Theological Implications for Parents of Extremely Premature Infants

by

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Abstract

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This thesis is an original exploration of the experience of parents in the wake of their child’s extremely premature birth, using grounded theory analysis. Biographical narratives, intercultural frameworks, and anthropological models offer insights into the identified experience of dislocation which find some integration through theological metaphors of exile and return; and faith, hope and love. A pastoral care strategy is developed in response to the disruption experienced.

The last five decades have seen rapid growth in the extent and incidence of premature birth, such that the thresholds of viability have been steadily pushed back to the point where babies only slightly more than half way through a normal gestation are resuscitated and hospitalised for extended periods. At the same time the percentage of births which are classified as premature has increased to more than 10% of all live births. Whilst extensive research has been undertaken – and continues today – investigating the impact on the child born at such margins of viability, little research exists investigating the impact of this experience on the parents who will ultimately care for and nurture these premature infants through to adulthood. The parent experience is at the centre of focus for this study.

This research has been undertaken through an on-line discussion list, comprising members drawn from different countries from around the world, and a repository of over 60,000 email postings during the period under consideration (1996-2003). The methodology employed in this study is that of an unobtrusive researcher, utilising grounded theory analysis of an on-line resource interpreted through a pastoral-theological framework of interpretation and understanding.

The research findings reveal that parents suffer a significant experience of dislocation which leaves them unable at the time of discharge to reintegrate into the world they knew and experienced prior
to the experience of premature birth. The existing literature which informs the parent experience of premature birth is shown to be both misleading and inadequate, failing to prepare parents for the experience, and providing no helpful insight for the parents’ social community which would enable or foster support during this crisis, and in re-adjustment to home life subsequent to discharge.

Different epistemologies are explored in an effort to develop a framework for understanding this experience of displacement and disconnect and to develop an interpretive grid which provides the basis for a strategy for pastoral care of parents. Biographical narratives, intercultural frameworks, and anthropological models offer insights into the nature of the preparent experience, which ultimately highlight the impact of social isolation which flows from the hospital experience. Two theological metaphors: exile and return; and faith, hope and love provide interpretive insights which serve as a basis for developing a pastoral response to the parents.

The practice of pastoral care within the current setting is examined in light of the principles of pastoral care within the christian tradition, with particular view towards the ways in which care can be facilitated towards helping parents cope not only with the journey within the hospital setting, but also with the attendant impact on personal identity and values, and in relationship with their wider communal setting.

In the concluding chapter, recommendations for change which provide strategies to address the social disruption and isolation, and which provide frameworks for assisting parents in addressing the multifaceted losses associated with extreme premature birth are offered.

Gary D Heard
March 2010
Statement of Authorship

This thesis contains no material published elsewhere, or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma, and is the original work of the author.

No other person’s work has been used without due acknowledgement in the main text of the thesis.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in the thesis were approved by the Human Research Ethics Committee of the Melbourne College of Divinity.

Gary Dean Heard
10 March 201
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A journey in research and discovery such as this is time-consuming, complex, and impacted by many different people and factors. Out of the curious admixture which is my life, a number of people have been strategic in the journey which this thesis represents.

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Chapter One

Entering the World of Premature Parenthood

Introduction

Since the 1960s there has been a rapid advance in the discipline of neonatology. The threshold of viability for pre-term infants has been steadily pushed back such that babies now born at slightly more than half normal gestation are resuscitated and admitted to Neonatal Intensive Care Units (NICUs) for extensive treatment and care. One in seven births which take place in Australia today is considered to be premature.¹ Considerable and extensive research has been focussed through this time on issues which pertain to age of viability and resultant levels of disability for preterm infants, and associated treatment regimes. The Royal Women’s Hospital in Melbourne is presently undertaking a landmark longitudinal study to determine developmental outcomes through to adulthood. The world of prematurity’s focus has been firmly on the child, especially in the clinical medical purview.

This “modern medical miracle” of “tiny babies” has been the subject of much media attention, celebrating the power of medical technology to save such tiny lives, creating a public awareness of the medical capabilities in the field, but in a limited and romantic sense. Neonatology is largely seen as the field which demonstrates the wonder of modern medical technology to save lives.

In the background, out of the public view, debate continues about treatment regimes, ethical concerns related to resource allocation within the medical sector, and pro-life issues related to discontinuation of treatment. The parents remain largely invisible, if not grateful onlookers.

Research in this study is focussed on articulating and analysing the experience of parents in the face of premature birth, with particular attention to the pastoral and theological themes which emerge from the experience.

¹ Occurring at less than 37 weeks’ gestation.
My own introduction to neonatology and the world of extreme prematurity came as a consequence of the birth of our third child, who was born at just over 24 weeks gestation, and subsequently spent 176 days in hospital prior to discharge, with still a number of unresolved complications. During the time of hospitalisation, our focus remained squarely upon every nuance in his journey, everything invested in getting him home in a healthy state.

It did not take us long to realise that the experience was not merely about the health of our son. The birth of only one of our three children can be described as something approaching “normal,” with ten years of infertility and then eight months of bed rest (including a lengthy ante-natal hospital stay) for my wife leading up to the birth of our first child. The impact of these events on our own understanding and outlook continue to this day. It was no simple return to “business as usual,” as we struggled to adapt to, recover from, and comprehend the experience. The journey was seminal and formative for us as a couple and as a family, and its impact so profound – and prolonged – that I was caused to question what common threads existed for families in similar situations.

The first insight that the event was broader than the impact on our third child came through our second child, who was only nine months of age when her younger brother was born. Rachel had begun talking in the weeks prior to Samuel’s birth, but following the birth she withdrew into her shell, returning to pre-verbal expressions. It was over two months before she began talking again.

This caused me to ponder the ways in which the experience of extreme prematurity changed us, and what impact had been identified for others in similar circumstances. In what ways did the experience impact the life choices, the ultimate concerns of parents? How did they view their time in the hospital setting, and what would they have done differently with the value of hindsight? I wondered at the impact on the broader family, both immediate and extended. Beyond the impact on my own daughter’s speech development, there were pressures on family, social and work dynamics for an extended period. The hospital experience was in many ways disjunctive. We lived a life outside of the hospital which bore little resemblance to the life within it. What of these experiences were common to others? What strategies were employed to cope?

This study maintains its primary focus on the parents, seeking to examine the ways in which the experience of extremely premature birth transforms their outlook, and the ways in which pastoral care can support them in dealing with their response. For family members, the experience of premature birth in general, and extremely premature birth in particular, represents a significant interruption or alteration to the way in which they have seen their life’s story unfolding. This is not
necessarily true for the child, for whom the birth experience becomes the foundation for their life – as they have no other experience.

This study recognises and affirms the place of parents as the primary care-givers for the child, as those responsible for maintaining primary long-term care of the child into the community and into adulthood. The lack of research attention to the impact of an extended NICU experience (customary when an infant is born at less than 28 weeks gestation) on the parents in particular is a glaring omission, given that it is the parents who assume total responsibility for the child post-discharge. If, as this research project clearly demonstrates, the experience is intensely profound and disruptive for many parents, it is incumbent upon us to ensure that appropriate care and support resources and strategies are in place for parents to assist them in understanding the impact upon them of the process and setting in which medical care for their child takes place, and to support them in making the transition from the highly structured and well-resourced hospital setting into the community and their home. Concern for the child must flow also to the parents, given the importance of parental nurture and care in the longer-term health and well-being of the child. Concern for parent wellbeing is underlined when considered in light of the prevailing body of evidence which demonstrates that the outcomes for extremely premature children are lower than their term counterparts on almost every measure. To parent a child born at the extreme end of prematurity is to assume responsibility for a child who, on the weight of evidence, is likely to need greater support and care across a broad range of spectra, for a period far in excess of the time spent within the NICU. The attention of the clinicians to improving the outcome for infants is a tacit admission of the extra demands placed upon parents where there are enduring issues for the child.

Yet these concerns are striking by their absence from current research. Although support groups for in-hospital settings are emerging, transitional support remains critical and notable by its paucity. The voice of parents and of family members who have journeyed through the NICU with an infant has for too long been missing. The primary focus – until recently, the sole focus – of care has been upon the child, with its implicit assumption that healing the child heals the family. This ignores that … there is a sense of meaning and human purpose that is shattered by the very existence of a child’s suffering, and it cannot be healed simply by treating the burn… A true ethic of care will minister to this deep crisis in meaning, and not simply attempt to dull or view the physical, emotional, and spiritual pain associated with the experience.²

The experience of premature birth needs to be respected as one which confronts issues beyond the narrow clinical-medical paradigm, and yet remaining fundamentally linked to it, impacting not only the child, but also the parents and wider family. In treating the physical needs of the neonate, symptoms emerge within the family and social networks which need to be understood. To observe first hand and engage with the struggles of another is a seminal experience. When the one suffering is the most fragile of all and the embodiment of many important hopes and dreams, we are confronting issues much more fundamental to our humanity, because suffering is a sort of “boundary experience” that forces us to confront questions about our own human limits… when you suffer, you want to know why, for how long, and who or what is responsible. If you ask that question broadly enough, you wonder about God and religious experience, whether in emotional, resentful, dismissive, ironic, debased, or intellectual ways. Suffering is a catalyst for … religiosity.3

Flow of Thesis

This thesis does not follow the usual structure – which typically commences with a literature review before moving on to matters of methodology and findings of the research – for three reasons. The first is that the process of theological reflection is thoroughgoing, and not limited to the chapters where theological metaphors, images and terminology are explicitly employed. Each aspect of the investigation is critiqued for its implied values and subsequently brought into dialogue with other traditions which offer interpretive insights. The thesis thus reflects a dialogical approach in which information and traditions are explored and evaluated on their own merits, and then in dialogue with each other. The thesis, therefore, moves in a spiral towards its conclusion, in which previous explorations and considerations resurface with different dialogical partners.

The second reason for this structural difference emerges from the desire to place the parent experience at the centre of the dialogue. As the launching point into the thesis has been the author’s own experience, chapter two begins with an exploration of the primary source material to discern whether the depth and significance of the parent experience of prematurity is one unique to the author or more broadly held. Commencing at this point enables the research to move outside the personal yet unarticulated experience of one individual and become grounded in the broad experience of parents. Central also to the practice of pastoral care is the ability to listen. Beginning at this point reflects this priority. These observations are then brought into dialogue with different traditions.

The third catalyst for a different structural approach is a response to two distinct contexts in which the investigation is placed: the Neonatal Intensive Care Unit (NICU) on the one hand, and the wider social setting (the home life) on the other. That the first experience of parents is shaped within the context of the NICU led me to explore the medical literature addressing the parent experience (which is addressed in chapter three). The factors and approach undertaken by the medical care teams articulated in this chapter demonstrate an important disconnect with the actual experience as articulated by parents, the reasons for which are preliminarily explored in chapter four, utilising narrative theory as a starting point for interpreting this disconnect.

The second setting in which parent experience is lived out subsequent to birth is in the wider community setting, where the perception of the experience of childbirth in general, and of premature birth in particular, is shaped by the available popular literature. Chapter five explores the birth and parenting literature, together with popular media reports in order to understand the perspective of premature birth which parents carry into the experience and which shapes the response of the wider family and community towards parents.

Having explored the breadth of parent experience and expectations surrounding it, chapter six explores the parents’ capacity to shape the experience of premature birth and respond to the circumstances they face. By addressing the dimension of power, I seek some understanding of the source of the depth of frustration expressed by parents and of the isolation evident in the primary source material. In this chapter the focus is primarily upon the NICU setting.

Chapter seven broadens the perspective into the wider community, articulating the nature and source of loss and grief in general, in order that the experience of parent loss and grief might be understood and explored within this broader framework of understanding, recognising that in the case of premature birth the reality of loss experienced by parents and the consequent depth of parent grief is yet to be openly acknowledged, socially accepted or publicly mourned. In this chapter, I seek to give voice to this grief, underlining its intensity and breadth within the broader understandings of loss and grief.

Chapter eight begins to weave the threads of exploration together, initially through the narrative framework, but with additional reference to intercultural perspectives, seeking to affirm the importance of context and to engage more actively the social dimensions of narrative and existence, and to recognise the spiritual underpinnings on which such are built.
In chapter nine, the discipline of practical theology comes into direct focus, canvassing the available models and practices of practical theology before seeking to apply them to the situation of parents of premature infants. Two biblical themes for theological reflection provide a doorway into understanding this experience, taking account of the multiple settings at work: exile and return; and faith, hope and love, both providing conceptual frameworks for understanding the totality of the parent experience across the two distinct contexts.

The necessity and practice of pastoral care for parents within the NICU setting is the subject of the next chapter, addressing four central themes of care.

The final chapter makes practical recommendations, concluding with a brief post-script which returns to my own personal journey which was the catalyst for this research.

**METHODOLOGY**

**Unobtrusive Researcher**

In bringing an intensely personal experience of the world of extreme prematurity to this project, a major challenge was to avoid simply making it an expression of my own experience. To allow the voices of others to emerge, I needed to find a space where I might enter a conversation without actually shaping it. The discovery of a significant resource in the public domain provided opportunity to remain unobtrusive as a researcher, with all its attendant advantages. In this case, the quality and extent of the original data source serves to ameliorate many potential distortions. By immersing myself in the primary source material – a communal conversation which extends over a seven year period – I have become attuned to the nature of the Preemie-L community and its patterns of monitoring. The large number of member contributions provides ample opportunity for verification of common experiences, which are themselves shaped within a unique context. Not limited by experience within a single NICU, a narrow cultural framework, or particular family structures, the strength of the list’s reliability as a source is greatly enhanced. Through being immersed in this community of practice, rather than engaged in its conversation, I find myself in the place of a broker, opening new possibilities for meaning for those inside the community, as well as

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4 For a comprehensive evaluation, see Allan Kellehear, *The Unobtrusive Researcher: A Guide to Methods* (St. Leonards, NSW, Australia: Allen & Unwin, 1993), 5-6
5 Ibid, 6-7
7 Etienne Wenger describes the place of the broker as someone on the edge of the community who is able to build a bridge between two different communities of practice. Etienne Wenger, *Communities of Practice: Learning, Meaning, and Identity*, Learning in Doing (Cambridge, U.K.; New York, N.Y.: Cambridge University Press, 1998), 109f
for those in the wider setting out of which the Preemie-L community has emerged. The list allows me to stand as an insider of the group, yet with sufficient distance not to be consumed by its culture.

A consequence of this form of unobtrusive approach to research in relation to this project has been the complexity, diversity and sheer number of issues which have emerged from the primary source material, much more than can capably be dealt with in the context of a single research project. I have elected to outline these issues in summary at the outset, in order that the primary focus of the project and its main conclusions are set within the broader relief of the group’s dynamic. It is arguable that many of the attendant issues emerge from the issues which I have chosen as a primary focus, a fact which I hope to demonstrate. I have been able to sit invisibly in the midst of this group, taking the time to learn the culture and language and, over time, having opportunity to test initial observations against further list contributions by members.

**Qualitative Research/Grounded Theory**

In electing to undertake qualitative research using grounded theory, a personal challenge was to allow the data to speak for itself, given my own experience as a father of an extremely premature infant. Every endeavour has been made to ensure that the material presented represents the list data, occasionally supplemented and illustrated from my own experience, which serves as a point of departure rather than a limit of itself. Where my own experience has entered the explanation, its purpose has only occurred to build on what was already present in the data, and not to introduce new material.

The level of immersion in the raw data has been a function of time and volume. With over 60,000 emails of the Preemie-L list on public record, compiled over seven years (1996-2003) of the list’s life, the process of sifting and sorting has been a significant project in and of itself. It is a time span and volume which has not only enabled me to learn and observe the list culture, but also to monitor its shifts through the years as the composition of the list has changed. The project is one of longitude, allowing observation of phenomena which endures with the passing of time and changing of participants, and recognising what might be unique to particular times and places.

At the same time, this has allowed me to sort through many of my own responses, both to the data presented and in relation to memories it has triggered of my own experiences.

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9 As outlined below, the list membership is drawn from a global constituency.
Grounded theory analysis offers opportunity for physicians, neonatologists, nursing practitioners, pastoral carers and others, both professional and societal, to gain insight into the experience and feelings of those who endure the experience of prematurity with their children. Whilst the patient in the NICU is an infant and therefore the primary focus of care within that setting, the people most impacted by the experience – emotionally, socially, and spiritually – deserve greater prominence in the research and care which contributes to the overall well-being of child, family and community. The current marginalisation of the parental and familial experience in relation to research implies a marginalisation within the NICU framework also. Analysis of this order gives some shape and coherence to parent expressions, reflecting on the hospital experience and its ongoing impact in their lives and hopefully provides a catalyst for more appropriate and effective care strategies.

In the NICU setting, the focus of the parents is turned toward the minutiae of care: oxygen levels, weight gain/loss, monitors, eye exams, blood gasses, balancing work/hospital/home, preparing for discharge, and a range of other matters which all need attention and to be held in balance. It is easy in this setting to lose sight of the big picture: the larger questions of what put us there in the first place, why we have children, and the expectations that are framed within this bigger picture.

Retrospective studies such as this are subject to recurring criticisms because of the faulty and selective nature of memories, and because they do not record what actually occurred within the NICU setting. The clear point at issue in pastoral care is not per se an accurate recounting of what actually occurred within the original event, but in dealing with the implications of that event for the person, remembering that the effect of extreme premature birth on parents can only be told with the passing of time, encapsulated in the enduring feelings and memories which are subject to continuing reflection and retelling in different contexts. Studies interested in the feelings and responses of persons in relation to any event need to take the present response seriously, as care by its very nature needs to commence at the point of meeting with the person. While there may be differences in recollection, both in terms of actual events and in relation to the significance and/or gravity of such events, the impact on the person is the key issue to be considered.

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10 The importance of this is underlined by Kathy Charmaz. “Grounded theory analysis can then provide physicians with alternative understandings of patient’s beliefs and actions than those readily available in clinical settings”. Kathy Charmaz, “‘Discovering’ Chronic Illness: Using Grounded Theory,” Soc Sci Med 30, no. 11 (1990), 1161
On-line research

In a branch of medicine – neonatology – which is highly technological in its conduct, it seems appropriate that the form of research undertaken should adopt a highly technological resource as its basis. The increased proliferation and penetration of the internet into the wider community makes it an ideal vehicle for research of this nature. A wide range of support groups have grown up using email and discussion lists as their modus operandi. Many such groups provide a rich and detailed resource for unobtrusive research, providing opportunity to engage as an observer in a conversation amongst people who have shared a common experience.

Making global connections in this way allows researchers to overcome any challenges related to small cohort size, and those where subjects are separated by distance. With its unique capacity to link people across the globe, internet-based research may provide a unique opportunity to explore that which is common to the human experience regardless of culture and social setting. In relation to issues and experiences where those impacted are few in number, such connections are invaluable in building a community for understanding. In the case of premature infants, parents from more isolated places, and places where the resources for neonatology are far more limited, are given access to a wider cohort of parents who have endured similar experiences.

The major benefit for the purposes of research is that the agenda for discussion is set by the group, not the researcher, who is enabled to listen without compromising the conversation by their presence. Non-contributing members of discussion lists are quite common and are considered benign by the group. Known as ‘lurkers’, they are recognised as having a common interest and are occasionally encouraged to surface on the list, rather than being intentionally driven away. A skilled listener to such conversations can glean information and perspectives which would be much more difficult to uncover in direct interviews.

In traditional interview-based research, outcomes are largely dependent upon the shape and quality of the questions asked by the researcher and upon the interviewee’s self-understanding. All perspective is contained within the context of the interview process, usually conducted within a defined length of time. Such an approach assumes that the subject not only understands what it is that is being asked of them, but also has given some thought to it, and is able then to articulate their perspective. The quality of the research and its outcomes is, in many ways, directly related to the level of self-awareness of both researcher and subject. Internet discussion groups, however, do not

have research as their primary *raison d’être*, instead taking the shape of a support group for like-minded, or like-burdened members. Many develop into communities of practice, in which members develop a deeper passion for developing the group’s expertise and its members’ capabilities. The role of the researcher is to seek understanding of, and analyse the way in which the community operates, learning its language and idiom, to read for express and implied meaning, recognising that the group “produces abstractions, tools, symbols, stories, terms, and concepts that reify something of that practice in a congealed form.” The implicit participation by the researcher in the conversation over an extended period allows each individual post to be interpreted in light of its communal framework, and the collective impression to be appreciated.

The interpretive skills of the researcher are utilised in framing and reframing observations which can be tested through time as well as between respondents. A skilled researcher in this context will become attuned to many facets of the list life, and become somewhat of an “expert” on its culture, developing a greater awareness of it than many participants on the list. It is important then to identify not only what is being said on the list, but also to be aware of its taboos and cognisant of issues which do not surface – the list’s own ‘blind spots’. Whilst aware of the danger of arguments from silence, such absences may raise questions which require more direct methods of research.

A distinctive of internet-based research is in its obviation of certain forms of judgment. Both the physical appearance of the subject, and the manner of their speaking – both in relation to pronunciation and emphasis – are not accessible to the researcher, which forces the researcher to understand the conversant only through what they have written. The absence of a capacity to prejudge on looks and sound allows the thoughts of the writer to stand at the forefront.

At the same time, the researcher needs to be cognisant of the bluntness of plain-text communication, which is the basis of most email. Its capacity for misplaced emphasis is quickly evident to the novice emailer. Responsibility for accurate expression and communication of thoughts, feelings and ideas falls to the author, which reinforces the importance of learning and understanding the group culture, appreciating the ways in which words gain particular use and meaning within the group framework, to discern what is important in the group, the type of list behaviour which is acceptable or frowned upon. Every effort must be made to interpret individual contributions within the broader culture of the group.

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12 Etienne Wenger and William S Snyder, "Communities of Practice: The Organizational Frontier," *Harvard Business Review* 78 (2000), 139-146
13 Wenger, *Communities of Practice*, 59
14 By implicit, I mean as a listener, rather than a contributor.
Members of the list enter the conversation as “people without history.”\textsuperscript{16} Unknown to the group at the point of entry, their contributions to the list become the sum total of their online persona – which means that they are read primarily through the grid of being a parent of a premature infant. It is apparent with time that many contributors expand their persona through the telling of personal stories and introduction of family, friends and acquaintances through the narrative, as the conversation moves from information exchange towards community formation. For the purposes of this research, the key focus is allowed to remain at the forefront. What remains beyond the view of the list reader (and participant) is how much what is expressed online translates into other spheres of each contributor’s world. That issue is, for the purposes of this project, however, moot. That such expressions are warranted and that members seek a place for them to be expressed is indicative of both their presence and potential power. Were they marginalised from their daily experience, the need for them to be given greater public expression is underlined.

A further advantage of on-line research is that interactions between list members are often publicly archived, constituting an open-source for research. This makes research more transparent and capable of review. A researcher’s findings can be compared with the source for verification and evaluation, as well as available for further scrutiny by others. Omissions and distortions by the researcher can be verified against the source, which remains free of the researcher’s imprint. And in the case of continuing lists, their capacity to provide source material for further research continues to grow.\textsuperscript{17}

\textit{Analysis of the Preemie-l List – Our Primary Source}

The primary resource for these investigations is an on-line discussion and support group for premature parents. The group, Preemie-l\textsuperscript{18}, was established by an Australian couple\textsuperscript{19} in the wake of their own isolating and traumatic experience following the early arrival of their second child. Gary and Anne began to search the internet for information to help them make sense of – and to give them some sense of power in – the struggles facing their new-born son, and initially found little of assistance. Within twelve months of their child’s birth, Preemie-l was created. While the list is housed in an Australian server, it draws membership from many countries. Its membership profile is predominantly USAmerican and female, and consequently reflects a skewed socio-economic

\textsuperscript{15} As observed by Kellehear.
\textsuperscript{16} An observation made by Brenda E. Brasher, \textit{Give Me That Online Religion} (San Francisco: Jossey-Bass, 2001) 25. The growing phenomena of identity theft and impersonation is evidence of this de-historicising possibility.
\textsuperscript{17} A complete copy of the archives has been downloaded and stored by the author and is available on request.
\textsuperscript{18} “Preemie-L”.
\textsuperscript{19} Gary Hardy and Anne Casey
profile. Access to the list clearly presupposes access to and ability to operate computers, access to the internet and an ability to express oneself in writing. Given that there is a high correlation between premature birth and poverty, the composition of the list does not reflect well this particular aspect of the NICU demographic. The strong American profile of the group means that a range of issues often appear, such as those related to costs of hospitalisation and access to ongoing support post-discharge, which are not reflected in an Australian setting. I have chosen to focus on matters which appear to have broader implications, crossing social, cultural and, as far as can be construed, economic divides. In addressing pastoral and theological implications, I have sought to focus on those issues and outcomes which reflect more universal outcomes and concerns.

That the membership of the list might not be representative of the average parent of an extremely premature infant does not disqualify or diminish the observations drawn. The issues raised within the forum give an insight into the challenges faced by all parents and wider family members. They serve as a microscope upon the issues faced with the broader framework of premature birth, with outcomes varying in intensity and in relation to the particular circumstances of each family. It is apparent that some of the matters raised in this paper would have parallels in other aspects of health care, such as extended stay in ICU, and in relation to care for family members with a disability.

Preemie-L membership also comprises a significant cohort of long-term members, some whose premature children are now into their teenage and adult years. An even greater number have children born prematurely who are, at the time of their contributions, in primary school, many of those with longer-term issues emanating from their premature birth. This could be regarded as skewing the perspective of the group towards those for whom the experience of extreme prematurity automatically creates longer-term issues to be addressed. Those who join the group for a while and move on after a period of time represent a class of parents whose perspectives are under-represented in the conversation. While this can be seen to limit the effectiveness of this

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20 In May 2000, according to the list-owner Anne Casey, there were over 1000 members signed up to the forum. [http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.0005/Date/article-607.html](http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.0005/Date/article-607.html) Accessed June 2002.
21 Although it needs to be said that the NICU is largely an institution of the Western economy.
22 A statistical profile of the group is not available, due to a number of factors, chiefly
i. The fluid nature of the group’s membership over the course of its life; and
ii. The anonymity afforded by email.
These observations are drawn from information exchanged on the list.
23 There are rare occasions when a participant will indicate reasons before unsubscribing from the group. A common and recurring theme of these is expression of a feeling that those whose children are doing well are not as welcome. This might suggest that the culture of the group itself sustains a negative view of the whole experience. See, for example, [http://home.vicnet.net.au/~garyh/premapril/0194.html](http://home.vicnet.net.au/~garyh/premapril/0194.html) Accessed June 2002
study, it can also heighten its focus, sharpening issues which are present in those for whom the initial journey is much shorter, but the seeds of which still remain.24

As a support group, it is evident that people with identified needs will be more drawn to membership. The greater the need, and the deeper the sense of felt need, the more likely it is that a member will then contribute to the open discussion of the list. This can also be regarded as skewing the data towards the perspective of those for whom the NICU experience was less than satisfactory, either in terms of the process which the parents endured, or in relation to the health outcomes for the child. This is not necessarily of concern, nor does it invalidate the observations of the group, or of this research. The group, in some senses, acts as a magnifying glass or a microscope in relation to the NICU, bringing into closer focus the range of issues and challenges which emerge for many parents. It is incumbent on the researcher and the reader to be careful about universalizing the analysis and applying it across the spectrum. But for the purposes of this research, and for ongoing pastoral care, the issues raised by the group are worthy of attention. Some of these issues may be the fruit of years of unaddressed or unexpressed concerns which may have not reached the present intensity if addressed in the early stages. Lack of awareness engenders a situation where carers may not be sensitised to the concerns, which then fester and multiply. The value of an insight for care is not to be determined or valued by its universality. The gospel imperative is to seek out even the one who has gone astray in order to bring restoration of the individual to the community, and vice versa.

The accounts on which this research is based are open accounts inasmuch as they are provided first hand, and without regard for any questions I might wish to ask. The narratives are raw, emerging from conversation amongst list members, rather than in response to particular questions I might have asked, or wish to have posed. Although from time to time list members will raise questions for general response, I have remained unobtrusive, making no posts to the list. Over the course of the life of the list, commencing in February 1996, over 60,000 individual posts have been made on a broad range of topics, some not directly preemie-related.25 This exceedingly rich vein of shared experience forms the basis for the observations which are drawn in this paper.

24 A complex issue in relation to research into prematurity is contained in this simple observation. In a vast array of areas of research related to prematurity, by the time results of studies and outcomes for infants is available, treatment regimes and technological advance can serve to undermine the importance of certain ‘discoveries’. The rapid development of neonatology, coupled with the slow development of children who are born as the result of its techniques, creates an irresolvable tension for practitioners and researchers alike.

25 The list itself would make an interesting study in the life and dynamics of an on-line community. While ostensibly a support group, relationships have developed, conflicts have erupted, conferences have emerged, and family stories shared. Though the vast majority of list-members never meet, a level of community has been generated where the levels of intimacy and disclosure about a broad range of issues is quite significant - many would say rare.
The interaction on the list covers an expansive range of topics, some not directly related to the NICU experience, but born of a common bond emerging from it. The exchanges on the list reflect much of normal community life: seeking for advice about parenting challenges, sharing the experiences and highlights of particular days and milestones, even to the point of throwing “virtual baby showers” for one another. In some instances it is not so much the content of the messages posted that is important, but the general expression or desire being represented by the interaction. The words are not as important as the yearning which drives the conversation. In this sense, a researcher has to move beyond mere analysis of and reflection on the wording of any particular exchange, but to step back and consider the imperative – personal, social, relational or other – which brings the exchange into this forum.

This research project began in 1999. I became a member of the list at that time, and continue to receive all posts made by members. At that time I commenced reading through the archives of the list, all of which, save for about three months at the end of 1996, were until recently available through the group’s web page. The initial research phase involved reading all posts, making notes and observations as I identified emerging themes, and storing copies on my own computer. When all data and observations was stolen in 2001, I retraced these steps, noting themes and observations as I read. I was conscious of allowing themes to emerge from the data, rather than imposing my own. (This process is outlined in the Appendix.) It is impossible, of course, for the observer/researcher to be entirely absent from the data and their interpretation. Every author carries a predisposition to certain experiences, ideas and values – an antenna, if you like – which ensures that certain data come under notice. The researcher’s preference for writing styles also plays some undefinable part in selection of themes and motifs, along with the particular interests and areas of expertise resident. The selection of “theological and pastoral implications” is indication of my own focus upon the way in which the experience of extreme prematurity impacts upon the world-view of the family, on the way in which the experience forces adjustments upon them, and the type of response which emerges, with a view to giving consideration to the pastoral aspects of care for the family. As a researcher with first-hand experience in this area, my instincts are honed towards expressions and experience which resonate with my own experience. However, I have sought to listen to the voices of the group, and give expression to them. I have largely resisted drawing from

27 Unfortunately, all my working notes were stored on the computer, and never recovered. I held at that time printed copies of all individual email postings which had exhibited themes and ideas for later consideration. These were reconstructed through returning to the original post archives.
28 Kathy Charmaz indicates that all observers ‘suffer’ from their own perspective, but reflects that it need not be seen as a limiting factor, so much as a point of departure for looking at data: Charmaz, “Grounded Theory,” 32
my own experience, except where it provides added detail of interest. The choice not to conduct follow-up interviews in relation to this project is partly a response to the fluid nature of the list membership, but more significantly, indicative of the fertile soil the list itself provides for insight.

It is not my goal in analysing the data, nor in presentation of the summation, to offer a systematic outline of the experience of extreme prematurity from the perspective of the parents or family. The experience of prematurity is so broad as to resist such systematisation, which of itself suggests that the answer to any pastoral challenge is in the production of a response which enables particular needs to be recognised and addressed. Rather, I present here the major themes and issues as reflected in the conversation between members of the forum. While not every family shares any one particular experience, the broad framework within which it occurred is relatively well-understood and appreciated by members of the forum.

The mailing list provides a forum for parents and others to make sense of their extended experience of the NICU, a journey which is further extended for some. Though able to describe at a “reporting level,” the journey often reflects a growing self-understanding through reflection and conversation, in which members develop appreciation and contexts for expressing their experience. The value of the list in providing a broad-ranging and multi-faceted insight into the experience of the family, and particularly the parents - most notably the mother - in relation to the experience of premature birth is evidenced by number of medical professionals taking membership of the list.

**Theological and Pastoral Method**

What is meant by “theological and pastoral themes” in relation to this experience? In stark terms, this study addresses the ways in which the experience of extreme prematurity shapes the perception of and response to unique challenges for parents within the framework of the greater questions of life or, using Tillich’s term, the ultimate concerns, and identifying pastoral resources available for this journey. The available material related to the experience and impact of premature birth in almost every case takes a narrow perspective without any significant crossover in analysis: focussing on the physical and developmental impact on the child, on the resources available for the parents in adapting to the stress associated with premature birth and subsequent hospitalisation, or on the emotional journey associated with prematurity. Models of care devised in response to this analysis are framed within the narrow construct of evaluation afforded by the particular field of exploration: social work, psychology, and nursing being the major fields, alongside first-hand reports and narratives of parents which are yet to be integrated into such care systems. Care is
consequently constructed in the NICU within these fields of vision: adapting and creating practices and support networks for parents within its framework. While these are helpful and do offer support in different aspects of the journey, they are inevitably insufficient in detailing and responding to the broad impact of the experience of prematurity on the parents and the family – as individuals, and as members of a broader community – and ultimately fail to address the whole concerns of the whole person. It is only as we place the parents at the centre of our investigations that we begin to appreciate the care responses which are indicated, and formulate strategies which address the broad range of parent needs. A pastoral approach affirms the parents as worthy of care and attention, recognising that their needs are related to those of their child, but not fully consonant with them.

A pastoral and theological reflection recognises the role of the community in the exercise of care and in the construction of meaning and identity. A pastoral approach embraces the conviction that there is no “value-free” care, affirming the cultural, historical and contextual impact on values, whilst at the same time holding to the notion of transcendence. Theology and pastoral care thus offer an alternate communal-construct: a perspective from outside the frame in which people experience their present struggles and suffering, affirming a multiplicity of perspectives, which consequently shatters illusions and perforates boundaries. They offer an opening and a window into an otherwise closed system of perspective.

Augsburger identifies the unique place in which pastoral care is situated, able to dialogue with, and share perspectives in common with many fields of personal and social understanding, including psychology, philosophy, sociology and ethics.\(^\text{30}\) Sitting at a boundary such as this requires a pastoral approach which embraces a broad perspective, seeking to affirm the full humanity of the person, acknowledging and embracing the insights of individual disciplines, but interpreting them within a holistic framework of human identity and meaning. Whilst pastoral care shares similar focii to many of the therapeutic fields, it brings unique perspectives, concerns and resources to the therapeutic and caring relationship.

The starting point for our thinking about pastoral care makes a significant difference to the way in which care is offered. The pastoral approach adopted here places the parents at the centre of our consideration. Thus, it is the needs and direction of parent concerns which guide the initial response.\(^\text{31}\) This is not to place the parents in isolation, but firmly into context, into relationship with their child, with the hospital and its staff and practices on the one hand, but also in the context


of the family and community relationships which are fundamental to understanding their identity as whole people – outside the NICU frameworks. A pastoral approach seeks to maintain a holistic perspective on the parents, seeking to gain perspective on the NICU as a social system and its impact upon parents’ formation, and as a consequence family formation. The pastoral paradigm is first a listening one. The carer seeks to hear the individual voices and the sources out of which they flow. In this way, the carer seeks to fully understand the person for whom the ministry of care is being offered.  

A pastoral approach seeks not only to proactively and constructively offer and exercise care, but begins in this instance by reflecting on the type of care being offered. The assumption of a care-less environment is as invalid as the assumption of a value-free environment. Through pastoral and theological reflection we give consideration to the impact of available care: an assessment of its strengths and weaknesses, an evaluation of its politics, and a reflection on the values expressed through care. We approach such a task with questions shaped by the practices in which we are implicated – sometimes uncomfortably – recognising that all practices have theories behind them and within them, even if we have hitherto failed to notice or articulate them. These practices so easily become second nature to us that we rarely take the time to abstract the theory from the practice and evaluate it.  

We will initially approach the task of pastoral and theological reflection in relation to the present practice of care around three initial questions:

1. What is the central theme of care as expressed, and how does it align with the needs of the persons concerned?
2. Who is providing care, and what assumptions and priorities are reflected in the care which they exercise? What are the ‘normative horizons’ which shape the provision of care? Christian Pastoral Care affirms the importance of the character and identity of the individual in providing care, and nurtures intentional reflection in order to more consciously understand the impact of their presence and on the ways in which care is offered and practiced. Such reflection is undertaken against the normative horizon of scripture and tradition, in the context of christian community.
3. In what ways does the community context shape the expression of care. Is it helpful, or inhibitive?

32 David K. Switzer, Pastoral Care Emergencies, Creative Pastoral Care and Counseling Series (Minneapolis: Fortress Press, 2000), 28
33 Wenger, Communities of Practice, 73
These three questions build on the framework outlined by Patton, whose three models of care - the classical, the clinical-pastoral, and the communal-contextual - are enfolded into the first two questions.\(^{35}\) Here I build on Patton’s understanding of communal-contextual, by which he means the extension of care beyond the ordained pastor to embrace the care offered by the lay community. Patton, whose starting point is the classical paradigm with its emphasis on the message of care, moves towards a communal-contextual approach, but labours within the individual-as-carer paradigm. Whilst acknowledging the importance of such considerations, it is clear that care and transformation involves much more than the message or character of the person delivering care. The insufficiency of Patton’s approach emerges from its inability to recognise the ways in which communities shape individual members, instead simply reframing the who of pastoral care in a different way. By placing the community in which care is expressed under direct consideration, the focus of evaluation shifts its focus to embrace the structural, cultural and political realm, recognising the forces at work within particular contexts which determine the boundaries of care, and which also shape the understanding of individuals within the boundaries by depicting normality and focusing care towards such outcomes. The purpose of this approach is to articulate the ways in which the present construct of the NICU as experienced by the parents impacts their sense of self-understanding and of their role as parents.

Following a close and continued examination of the impact on people within the system, we will identify the ways in which the policies and practices have emerged to enable care to be offered within the NICU system so that people can pass through it with the minimum of stress and change. But working from the inside-out offers a limited perspective. A second and complementary approach invites a consideration of the global challenges facing individuals as human beings, and evaluating the ways in which the particular situation and system impact upon the expressions of identity and purpose which have been framed within and against the backdrop of this larger system. The development of care practices within the NICU have adopted an approach which revolves around nurturing parents “through the system,” aiming to minimise the stress. This study demonstrates the ways in which this fails to adequately address the impact of the experience of extremely premature birth upon the parents, and fails to connect them back into the larger system out of which they entered the NICU. By turning attention to the larger themes of human identity and purpose, a pastoral and theological study seeks to reconfigure the understanding of premature birth and its impact upon parents, and the nature of care provided within the holistic life framework of parents and families.

\(^{34}\) Don S Browning, *A Fundamental Practical Theology* (Minneapolis: Fortress Press, 1991), 5ff
An intercultural approach asks three different questions, and envisions a different starting point:

- What of the universal experience of humanity is to be found here?
- What is culturally determined about this way of thinking, feeling or behaving?
- What in this experience can be said to be uniquely attributable to this particular person?  

Whilst a theological perspective seeks to evaluate on all three planes, adopting a starting point of the universal experience invites care for an individual within the frame of context and identity. The interpathic respect, understanding and appreciation which flows from conceptualisation of the experience and context in this way, empowers and enables a deep understanding of the experience and the limitations inherent in its present construct. Without consideration of the context, the nature of the message and the character of person and community offering care envisaged by Patton risk being irrelevant to the situation.  

Attention to the ways in which the social system of the NICU has impacted parents flows from my focus on theological and pastoral questions, and allows a broad articulation of the ways in which human identity and purpose is challenged and reformed by the NICU setting. As a consequence the understanding of care moves beyond amelioration of stress and gains a renewed emphasis on empowering parents as human beings within the social world of the NICU.  

The highly specialised, bio-medically focussed, and technologically-driven environment of the NICU enhances the call for theological reflection, as deep questions of suffering, formation, identity and purpose lie very close to the surface, alongside the more obvious challenges of life and death.  

This will require a fresh look at the nature of theology and faith – to consider whether such are the domain only of those with a professed religious outlook, or whether the questions raised reflect something intrinsic to human identity. It is my contention that there is an element of faith – a “confessional beginning point” – at the heart of every perspective on human existence, whether personal or communal. This faith is expressed in communal structures and practices often invisible.

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37 Augsburger describes interpathy as enabling one to enter a second culture cognitively and affectively, to perceive and conceptualise the internal coherence that links the elements of the culture into a dynamic interrelatedness, and to respect that culture (with its strengths and weaknesses) as equally as valid as one’s own. Augsburger, 14
38 "You cannot help people fully unless you also do something about the situation which makes them what they are.”  M J Wilson, *A Coat of Many Colours: Pastoral Studies in the Christian Way of Life* (London: Epworth Press, 1988), 21
39 Lartey, 127
40 Ibid, 171
42 Browning, 45
to participants, who are clearly shaped by it, and who give their own expression to it. My starting point, then, is a comprehensive description of the experience of parents, which unmask the nature of this faith, enabling both an articulation and evaluation of it.

The pastoral challenge includes articulating the unarticulated, giving voice to the silent power of culture, which requires language which is not yet evident within the NICU setting. To this task, theology and pastoral care bring a new language – symbols, metaphors, narratives and images – to the challenges facing parents in the NICU setting. The NICU is in effect a new community of dialogue and engagement, a community in which suffering is not only acknowledged and lamented, but also recognised as bearing a redemptive potentiality. It is a community in which hope and meaning do not require the elimination or control of chaotic elements, but in which a creative dialectic – even a multiplicity of forces and relations – can be acknowledged and engaged. Theology and pastoral care, while speaking out of the christian tradition, do not require a christian context for relevance. Questions of meaning, purpose, identity, formation, illness, suffering and the like are all human questions, fall legitimately within the sphere of theological conversation, and are the grounds for pastoral engagement. In a context in which a new language and a new look at community are indicated, drawing on the experience, observations and traditions of the christian community is not only relevant, but also offers a broad range of alternate perspectives.

The pastoral role and responsibility does not begin where the medical expertise ends. A pastoral and theological framework is built around a thick description of the experience of parenting an extremely premature infant, offers an evaluation of the themes expressed by parents vis-à-vis that offered by the hospital setting, and asks whether this exposes questions about the nature of care and the nature of human identity and formation. The pastoral presence acts to provide a framework of meaning in which medical care takes place.

A final introductory note from the author
Although seeking a level of objectivity necessary for a project such as this, the experience began an intensely personal one. Whilst I have been sensitive to the dangers of reading my own experience into the experience of list members, who constitute my research cohort, I have also been aware that this has been an experience seeking understanding for me. Any personal experiences mentioned have been drawn from my own writings in a personal journal kept through the course of the hospital stay. Whilst my own experience has drawn me to this study, it serves as a catalyst rather than a paradigm.
Chapter Two

The Parents’ Experience in Their Own Words

Signs of Dislocation
Less than forty years ago, what we now call a micro-preemie would have been recorded as a late-term miscarriage, or a still birth. Births at less than 28 weeks gestation and weighing less than 1000 grams were inevitably unviable. Apocryphal tales of grandparents and great uncles born weighing two pounds and kept in a shoe box by the stove were most likely born at later gestations and regarded as growth retarded (or small for gestational age). Developments in neonatal medicine since the 1960s have resulted in a gradual and persistent pushing back of the threshold of viability such that babies born after 22 weeks gestation are now considered for resuscitation and treatment.

The long-term impact of extremely premature birth is the subject of ongoing research in order to determine and measure the impact on the life of the newborn as s/he develops and matures. Incidents of a medical nature within the NICU are regularly monitored for continued refinement of the treatment process. However, an inevitable consequence of providing aggressive treatment for infants born at such early and fragile stages of life is a lengthy, stressful and often traumatic hospitalisation period which draws parents, siblings, wider family and friends into its context, with associated implications for a broad range of work, social, financial and emotional environments. While these two areas develop in tandem – the health of pre-term infant and the concomitant wider social impact – little research is evident in relation to the latter. Given that the intended outcome of neonatal medicine is to deliver a healthy baby into the hands of parents, some consideration ought to be given to the impact on the parents of undertaking such a course of action.

What happens when the hospital doors finally open to release the micro-preemie – with parents – into the world? Is it different to the experience of a full-term birth where the family is reunited in their home within days of birth? What is the impact on the parents, their immediate and wider family, and their social context, when they have spent upwards of 60 days (often significantly more) connected to a NICU unit?

One oft-recited story aired on the Preemie-l discussion group seeks to reflect the impact on parents, and has been adopted by many as expressing something important about the journey which is

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1 Sixty days from birth to discharge would be the most optimistic outcome for a baby born at less than 28 weeks. Few babies are discharged prior to reaching their due date. While 40 weeks is considered a normal full-term gestation, anything from 37 weeks onwards is considered to be a full-term delivery. The best case therefore of 9 weeks is on the latest delivery and the earliest discharge.

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parenthood of a micro-preemie. While the story was written by the mother of a disabled child, it provides imagery which many parents key into.

Welcome To Holland
by Emily Pearl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel.

It's like this . . . When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo, David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes and says, "Welcome to Holland." "Holland?" you say. "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place. So you go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts. But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned." The pain of that will never go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you will never be free to enjoy the very special, very lovely things about Holland.

That parents have come to recognise the journey into parenthood via extreme prematurity as fundamentally different from the journey they associate with a normal full-term birth is a given in discussion amongst these parents. The assumption that a child born at the threshold of viability merely needs to “catch up” masks the magnitude of challenges facing both child and parents in response to the circumstances of birth. That many parents report running their home “like a NICU” for the first weeks, or even months, after discharge, including the meticulous recording of feeding input and output, monitoring heart rate, respirations and oxygen saturation levels indicates that the parents have undergone a radical, yet unintentional, retraining in parenting. A new vocabulary is absorbed, owned and employed which arises from immersion in a clinical medical setting, and the child is invariably viewed through the grid of medicine, rather than of family relationship.

These changes do not necessarily represent a happy picture. While many respondents resonated strongly with the sentiments of “Welcome to Holland” – one family even planting tulips along the

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border of their property as a symbolic reminder of their journey into parenthood³ – equally strong were the critiques and criticisms of the story. One mother suggested a better parallel would be likening it to being hijacked to Lebanon and being regarded as a casualty of war, rather than a vacation,⁴ whilst another likened the NICU to a “medical Vietnam”.⁵

These responses indicate that many parents are left with a deep sense of loss and grief, often resulting in a deep ambivalence about the experience, both for themselves personally and for their child. Parents report that the depth of trauma has resulted in diagnoses of PTSD and clinical depression. But more subtle and more pervasive is the impact on the way in which parents view themselves, the deeper questions of meaning, and the overall experience to which they have been subject. The list includes members who have dedicated many years to the cause of education, advocacy, and support to redress some of their concerns emanating from the NICU experience.

Appearance
The signs that the experience of extremely premature birth is different from the norm are apparent at the outset. Aside from the often sudden truncation of a pregnancy before reaching the third trimester, the normal rituals which surround birth are generally abandoned, and a deep sense of loss is felt, first of all by the mother.

    How I wish their start could have been what we all dream of as parents-to-be, but there's no going back, no starting over.⁶

If there is any doubt about the different path on which they have embarked, it hits when the parents see their child for the first time in the NICU. So taken aback by the sight of their child, they struggle to find human terms in order to describe them. Descriptions of appearance include looking like a “pitiful little alien”,⁷ an “orange baby”,⁸ “a fragile wrinkled up bit of frog”⁹, an alien “borg”¹⁰, a “Frankenstein”¹¹, a Cornish Game Hen¹², a little chicken¹³, a skinned rabbit¹⁴, and a “black and red

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ugly rat. The general sense that the newborn looks ‘more animal than human’ is articulated by a mother who saw her child as a “teeny tiny furry monkey looking thing with tubes and sticky monitors.” More than one mother reported an inability to eat chicken as a result, while one father commented that he’s “eaten steaks bigger than that.”

After initial adjustment to the sights of the NICU setting, many parents reflect that normal full-term babies “look like monsters,” and in later years some express difficulty equating the grown child they now see with the “thing” they gave birth to. The first view is, for many, a great shock: “human beings are not supposed to look like that.” A sense of disorientation permeates this time: “The first time I ever saw you… I remember not understanding what was lying there, under brilliant lights… there was no resemblance to the baby pictures I’d seen in the clinics.”

The view is disruptive, to say the least, as parents struggle to fit the image into their frame of reference. Nothing prepares them for this eventuality. An extremely premature baby is not “just a miniature full term.” When relatives are introduced, they too find the scene confronting and disconcerting. One reports her mother (the grandmother) feeling nauseous in response to how “horrible and scary-looking” she found her grandson. To another mother “it was like a science experiment… to this day I still feel like I got ripped off.”

The confronting and disconcerting appearance of their newborn micro-preemie means that sharing the experience with others could be problematic, particularly for parents who wish to invite others
into the more intimate place of knowledge in order to share the journey and perhaps find some support. Having experienced the first encounter with their child in such a negative way, the risk of alienation at the hands of others is apparent. Already fragile parents struggling to cope with their own response to their newborn are vulnerable to others.

The first time one of our friends came to see her, about 2 days after she was born they treated her like she was going to die, you could of (sic) cut the gloom in the room with a knife, Needless to say we didn't invite anyone else except (sic) my husband's best friend who is a nurse and knew what to expect. What I found the hardest is when people didn't except (sic) her as a person.27

For many parents, the die of isolation is cast in those early days. Unable to share the experience of the birth, struggling to articulate their own response, the wagons are circled, and parents ‘bunker down’ for a long and isolating journey through the NICU. With little time and even less emotional energy for others, the NICU becomes a place where experiences are largely disconnected from the wider social setting.

**Induction**

Before parents make visual contact with their child in the NICU environment, a quantum shift has already become evident. The induction of the unsuspecting parent into the NICU world can be as brutal as it is unexpected. Birth often takes place on a minimum of notice. Although staff might attempt to prepare parents for what lies ahead, the emotional turmoil generated by the critical nature of the circumstances leading up to and surrounding the birth, where the mother’s life might also be at significant risk, coupled with the general difficulty of preparing someone for an experience for which they have little framework for comprehending, makes such preparation hopelessly inadequate. In a matter of hours, an expecting yet unsuspecting parent may find themselves with their newborn child before them struggling for life, having to make decisions about medical intervention to ‘save’ their child. The parent (more often the father) may find themselves placed in the position of having to make critical decisions regarding medical treatment options while still adjusting to the reality of what has happened.

This rapid induction and exposure to the realities is conveyed by a mother as she relates the circumstances surrounding the birth of her twins. She entered the hospital, 26 weeks pregnant, feeling unwell. She was diagnosed to be in labour, with one of the babies’ legs already evident in

the birth canal. As she was rushed into delivery, she recalls a conversation with the anaesthesiologist:

He mentioned surfactant but I didn't know what that was. He mentioned neonatologist and I said "Neo what?" and then a woman bent over me and cited all the scary statistics that I barely absorbed except for the words "40% chance of brain damage". I felt like I had been hit by a car. The premie odyssey had begun.28

The sudden induction into this strange world is cataclysmic for many. There can be no general preparation for this in childbirth. None of the popular handbooks on childbirth gives significant attention to the issue of prematurity. Classes run by hospitals make at best a passing mention of it. The birth experience is, for the majority of parents on the list, a sudden and traumatic event. And once the birth has taken place, they are thrust into a world with an entirely different demand upon them as parents. As one mother expresses it: “Imagine… being asked to make life and death decisions about a baby when you haven’t even had time to realize you are a parent yet.”29

A simple question related to bracketing the experience – when does it begin, or, when does it end – provokes such a wide variety of responses that every response must begin with a qualifying “it depends”. Parents can be inducted into the world of the NICU and of prematurity at merely a few hours’ notice. Others, aware of the high-risk nature of their pregnancy, might spend weeks or even months weighing up the risks and wondering how long the inevitable moment can be postponed, yet still find the moment of induction to be announced a relatively short time before the reality emerges: a reality that remains difficult to adjust to.

This marks the beginning of a realignment in the thinking of the parents. Gone are the ‘traditional’ celebrations and entry into the world of new parenthood. Instead, parents and families are inducted into a strange world, where the rules of engagement are different, and life patterns established and ingrained which change parental perspective well beyond the NICU. It begins a journey of an experience in search of meaning and of language with which to express it.

After being diagnosed in the early weeks of pregnancy with a fibroid tumour, this mother was well aware that her pregnancy would not carry to term. Preparations were made for a premature birth, but her response shows how foreign the experience still was:

I didn't get to see Jessica for 24 hours. Bryan, however, spent a great deal of time with her and brought me pictures and video tape. Nothing prepared me though for the first time I saw

her. She was so small I could not believe it. It was terrifying seeing all those tubes and wires and the respirator on her face was horrible. She looked SO uncomfortable and she was very active, moving and wriggling constantly. They wanted her to calm down to conserve her energy.

I was the most unprepared emotionally.30

Another mother, with at least three weeks’ notice that provided some preparation for the NICU echoes this same sense of alienation.

I finally went to see her about 5 hours later. My first time in a NICU. She was on the warming table, with the heat lights on and tubes coming out of her belly button and mouth. I didn't know what to do or say. I asked the nurse how she was and all she said was, "the Dr. will have a conference with you later, but right now, things don't look good". All I really remember thinking during that visit was, my daughter has no nipples. How naive to think of such a trivial item like that at the time.31

My own experience of induction was both sudden and climactic. It was less than five hours after premature rupture of membranes, 24 weeks into what had until then been an uneventful pregnancy, when I was being asked by a complete stranger whether I wanted my just-born son to be enrolled in a clinical trial for a new drug related to problems I had never been aware of, much less anticipated for my own child. With my wife still in theatre and a six-hour window available for the first administration of the drug, and still deeply in shock at the circumstances which had unfolded during that night, I was acutely aware of my own lack of resources for the journey into which we had been thrust. For the birth of our other two children I had been present in the operating theatre as an observer. For this birth, I had been locked out of the theatre, receiving a brief “viewing” of my newly-born son, wrapped in bubble-wrap, as he was being transported to the NICU. In the minutes that followed, I was taken into an interview room and asked to decide about treatment regimes and was being briefed in relation to such medical problems as PDA and IVH,32 and medical statistics related to survival and neurological damage. It was language with which I would become increasingly familiar in the days ahead. My own journal records something of this experience:

The day whirled like a maelstrom: people, issues, information, organisation, uncertainty. I ran an emotional roller-coaster for the most part of the day, not being able to settle until being alone with Ev in the evening. Telling people being the hardest part. Contemplating the future in any sense brought me to tears. I oscillate between considering that God is asking us to learn what it is to walk through the valley of the shadow of death, to being there at the point and process of creation: still forming, still fragile, ever taking shape. At the moment there remains an air of unreality, occasionally clouded by a deep sense of helplessness bordering on despair, occasionally warmed by the warmth of the sunlight of hope. To simply

32 Patent Ductus Arteriosis (an open duct into the heart which usually closes shortly after birth) and Intraventricular Haemorrhage (bleeding into the brain).
stand by and watch, and pray, goes against everything that I would want to do as a loving, caring father - to do anything, everything I could to help. It is his fight, which I can join in prayer, and offering encouragement. 

Such a situation is not unique. When the birth requires the mother to undergo general anaesthetic it is the husband who steps into the main role, a culturally unfamiliar place. One father reports watching his wife

get in a helicopter and fly two hours away and not know when you see her next if either her or your unborn child will be alive when you get there… [then watching his] wife give birth.. [from 10 feet away followed by] them running out with what you thought was a bloody handtowel, but it’s really … [my] son.

In a separate post, this father reports that the actual decision for his child to be induced was his, a consequence of his wife being both sleep deprived and affected by medication, and later feeling like the umbilical between his bed-bound wife and his son in the NICU. In those early days, his role was central, but as time progressed, he moved more to the periphery as the wife assumed the more central place. Joint list-owner and father Gary Hardy reported the same pattern of initially being at the centre during the initial stages before work and other responsibilities contributed to his moving more to the periphery.

At the time of birth, both father and mother are suffering from shock and the after-effects of childbirth. The first hours appear as a blur, with the result that decision-making authority is largely surrendered to the medical personnel. The range of information available to the parents, and their emotional and physical ability to identify and process the significant data is subject to the

37 This father felt that as a preemie father he was often overlooked and dismissed (ibid.) The place of the father in the NICU is an issue deserving of treatment in its own right, and is addressed in Glenn Affleck, Howard Tennen, and Jonelle C. Rowe, Infants in Crisis: How Parents Cope with Newborn Intensive Care and Its Aftermath Disorders of Human Learning, Behavior, and Communication (New York: Springer-Verlag, 1991); C R Aradine and S Ferketich, "The Psychological Impact of Premature Birth on Mothers and Fathers," Journal of Reproductive and Infant Psychology 8 (1990); W E Freud, "Premature Fathers: Lone Wolves?," in Becoming a Father: Contemporary Social, Developmental, and Clinical Perspectives, ed. J L Shapiro, M J Diamond, and M Greenberg (New York: Springer Publishing Co, 1991); M Hughes and J McCollum, "Neonatal Intensive Care: Mothers’ and Fathers’ Perceptions of What Is Stressful," Journal of Early Intervention 18, no. 3 (1994);
A Long and A Smyth, "In the Palm of My Hand: An Exploration of a Man’s Perception of Becoming a Father to a Premature Infant and the Nursing Care Received in a NICU," Journal of Neonatal Nursing 4, no. 1 (1999);
discernment of the NICU staff. It represents a major disruption to the parents’ perspectives, and a major shift in authority and power, the implications of which unfold in the ensuing weeks and months.

**A Shift of Power**

At the moment of birth, a fundamental power shift is evident. The parent experiences a shift from control to powerlessness, as the loss of control is acutely evident.

…in the course of one hour, I had gone from being professor/supervisor/therapist, to being helpless; hooked up to an IV and a fetal monitor, and completely disoriented. Above and beyond the shock, my identity, who I was, was hooked into my profession, my confidence in my ability to understand, to tolerate ambiguity (yes, I thought that I was very good at tolerating ambiguity!), and to cope. And there I lay, in a hospital bed -- more afraid than I had ever been in my entire life.

I remember being angry that the doctors weren't treating me like a peer…

[the] first weeks were a total blur. That previously competent, confident "Dr. Stein" was really nowhere to be found. The sobbing woman standing over those warming beds, wishing she could breathe for her babies was unfamiliar. The gradual slipping away of my old self during the hospitalization seemed complete. It was hard to even imagine being the way I had been before.39

Another mother’s poem generates a poignant image:

> Can you imagine what it is like
> To lay in your bed clutching only a photo
> Able to do
> Absolutely nothing at all?40

The extreme sense of disorientation creates a vacuum of power, during which time the care of the child is within the auspices of the attending staff in the NICU. It is the parent who enters from the margins, needing to assess the circumstances and situation, and discover an avenue for engagement and involvement in the care of their child. The first meeting establishes the ground rules for engagement, and they are established by the staff. Information is power, and in the first days it is the medical staff who determine which are the important categories of information to process and the ways in which these are expressed. Some parents have reported being deterred from their normal parent instincts – such as to touch their child – by the comments and assessments of staff:

> my son was given a synagis shot … he was crying as anyone would do when jabbed with a needle and I asked if I could hold him to comfort him and was denied with the response "he's been out enough for one day".41


The power is exercised by both the control of access to information and the determination as to which information is appropriate for assessment.\(^{42}\) Later access to charts after discharge often reveals that staff withheld information from the parents. One mother notes how she was "astounded when I got his medical records from the hospital later how much they hadn’t shared with us (like how many times he was resuscitated in the first week.)\(^{43}\) From a different perspective, one father notes his marginalisation to the extent that it was not until his son had been home for a while that he felt involved. “Before that there was always the thought that some day the hospital would want him back.”\(^{44}\)

From this early time forward, a struggle emerges for the balance of power within the NICU. At the outset, power resides almost entirely with the medical staff as a consequence of parent ignorance. Parents simply do not know what to ask, or lack the frameworks for understanding the implications of information set before them, and for understanding their immediate response to the situation in which they find themselves. As time progresses, parents seek to establish a place within the frameworks of care for their child. Although it is done with respect to the knowledge and care of the medical staff, it is apparent to the parents that they are in a marginalised place. “It is one of the most alienating aspects of the NICU, that your baby isn't really "yours", unless a staff member permits it.”\(^{45}\) Individual preferences of staff within the NICU can heighten the sense of alienation for a parent.\(^{46}\) It is clear that the parents are on somebody else’s territory,\(^{47}\) and it is important to understand which side of the line on which the parents stood. This was made plain for a mother who was also a nurse: “I was told I "knew too much", That I was a "mommy" now, not a nurse. That, somehow, I could not be both.”\(^{48}\) Helen Harrison, parent, author and advocate, expresses it in these terms:

“I have heard social workers and nurses say that in no other field of medicine is informed consent more contumuously treated. I would have to agree. In effect, once you are in the NICU, you are a "prisoner" of the ideology of that unit, no matter what it is you think you signed.”\(^{49}\)

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\(^{42}\) Some NICUs required a neonatologist to be present while parents were reading the chart, so as “to explain anything you might not understand”. [http://lists.vicnet.net.au/mhonarc/preemie-l/2002/09/msg00113.html](http://lists.vicnet.net.au/mhonarc/preemie-l/2002/09/msg00113.html). Accessed June 2002


\(^{46}\) One report highlights this ambiguity: “The first time I was able to see James after he was born was very difficult, I was heartbroken to see him so tiny and helpless. The nurse that was taking care of him encouraged me to touch him and talk to him, which I tentatively did, she momentarily turned to attend to her other patient right next to James when a nurse from the other side of the room, who had nothing to do with James' care came and yelled at me saying that I was touching him the wrong way!” [http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.200004/Date/article-123.html](http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.200004/Date/article-123.html). Accessed June 2002


Of her own experience she relates:

Because my husband and I, and my mother who was with us much of the time, did not want to be seen as "bad parents" (or bad grandparents) we rarely spoke up about our feelings. The one time I tried, was early in Edward's course in the unit. We had just been told by a very nice, caring neonatologist that Ed had eleven serious medical problems any one of which could kill him, "so don't even hope." I timidly asked: if Ed's death was inevitable, why was he being kept on a respirator with every bodily function mechanically supported? I said that we wanted no "heroic" treatment. "We aren't doing anything heroic," the nice neonatologist replied. At that moment I felt like Alice when she slipped and fell down the rabbit hole.50

Dr Stanley Klein reports the development of a “parental stereotype” in the minds of health care professionals, in which health care professionals develop a negative view of parents, seeing them as nervous, guilty, anxious, depressed and/or overprotective, a view which begins to develop during their training. It is born of continued observation of parents in stressful situations related to the health of their children. Combined with other factors, the end result is that health care professionals bring unwittingly negative stereotypes (prejudices) about parents to their encounters with parents,51 thus creating a rationale for marginalising parents in the decision-making processes. The different experience of being a parent was, for one practicing fellow in neonatology, quite stark:

the NICU was … the worst thing that ever happened to me. To be on the other side, to be a parent instead of a being a doctor was horrible for me. I felt sorry for my daughter and the things she went through and I was terribly concerned about outcome and complications. But worst of all, I felt that I was not in control. This was my child and someone else was making life and death decisions.52

An example of the way in which this imbalance works against the parents is expressed in this mother’s story:

I had developed severe preeclampsia and by the time I was admitted I was almost completely blind, headaches, pain. My gyn said they needed to take the baby immediately because they were afraid I would have a seizure or stroke. When we asked about our baby, they said he was under 1 lb. This birthweight did not seem viable for a happy life for our child not to mention the suffering he would endure. The neo we met with for about 10 min. said what we believed was true, he had a very slim chance of being able to lead a productive, happy life and he would probably suffer being so small. We did not want our child to suffer. We told the gyn and neo that we would like a DNR (and I'm sure I will get slammed for this.) We were devastated. My gyn said to me (and let me quote), "what kind of people are you? Do you want to kill your baby?" When we asked what the options were, he said, "you can have a c-section and we will do everything in our power to save your baby, or you can go home." Please keep in mind that my condition was very serious. We both would have died. My gyn told us that. Well, I had the c-section and woke 3 days later to a hysterical husband.53

At one stage during their NICU stay this family was referred to as “frontiers,” with the neonatologists expressing that they were “learning” on their child. When, after six months, matters continued to deteriorate, the parents wanted to call a halt.

We had been in the NICU for 6 months and his brain had always looked fine. I demanded an MRI, other tests. Yep, cerebral atrophy. What does that mean? All they could tell us was that his brain had just "stopped growing and we don't expect it to start again." Here we go again. My child is coding every couple of hours, his brain is not healthy, please give my child peace and end his suffering, DNR. This is when an ethics committee got involved. They said we never wanted this child. Please remember I went through 3 years infertility at Stanford to get pregnant. This remark was absurd. They said we could always just give him away. I wanted to hit someone. This is not about us, this is about the quality of life of someone I love and would surely die for to give him good health. They said if we insisted upon the DNR they would take us to court and say we were unfit parents.\(^54\)

The mother’s disappointment is echoed in the value judgments she perceives as being placed on the experience:

the neos and doctors only care for the immediate health problem and not the chronic ones. Once you leave the NICU, you are on your own. It is a success to them. They saved a 482 gram baby and he is home with his family. To us, it is a life changing event.\(^55\)

In the NICU culture, it often appears that the greatest failure is death. While there is concern about the longer-term impacts of children born at the cutting edge of technology, there appears to be an unwritten code which suggests that the only way in which medical knowledge and treatment is able to be improved is by ‘practising’ on children born at the margins. It is this attitude which is exercised at the point where the greatest power belongs in the hands of the clinicians.\(^56\)

An unrehearsed aspect of the lack of power sharing at the outset is that once the decision to resuscitate is made, it is much more difficult to change the course of events. The nature of the decision in relation to life and death between determining not to resuscitate before medical intervention has begun and switching off life support at a later stage is fundamentally different. Given the prime place afforded doctors in making this decision, the likely course in the first instance is biased towards intervention. Parents who have sought to oppose such an approach have

\(^{54}\) ibid.  
\(^{55}\) ibid.  
\(^{56}\) One health professional suggests that the extent of this will be different in different countries. She reports a conference at which ‘foreign’ neonatologists were ‘horrified’ to hear of some of the practices undertaken in American NICUs, practices which “would not happen” in other parts of the world. This reflection from a Society for Pediatric Research Meeting is reported at [http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.199705/Date/article-883.html](http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.199705/Date/article-883.html). Accessed June 2002
met opposition, even when the parents are medical practitioners themselves. At the heart of the issue is that of prime responsibility and “ownership”.

Some nurses were wonderful and told me things about William, showed me things again and again without intimidation and almost made me feel like a mother - they were the reason I felt capable by the time we got home. But even they made me feel like they were sharing him with me - not me sharing him with them. We were the visitors to a little bundle who could have been anyone's…

A shift in the power balance over the ensuing weeks is evident to all parents, but there are key issues within the first hours and days which are largely in the domain of the medical staff. There are times when the most fundamental issue – resuscitation – is challenged by the parents. At this core point, there remains an unresolved tension in neonatal care. Some NICU policies mandate resuscitation if the infant meets certain criteria, regardless of the parents’ wishes. Such one-sided power tends to shift as time goes on, although the experience is not universal.

But the grounds for this power battle have been laid. The terms of engagement lie in the clinical medical domain. If parents are to have involvement in the care of their child, they must learn the language of the NICU, and educate themselves in medical and clinical issues related to their child’s health and ongoing care. Even in the most parent-friendly NICUs, this is not only accepted but also facilitated: access to medical journals and other information is provided for parents. The message is clear: if you wish to be involved in the decision-making related to the care of your child, understand the information on which decisions are made within the NICU. My own journal records this distinction:

[The director of the unit] sat us down at lunchtime and painted a very bleak picture for us - death was so close. We wept bitterly in despair… There is the possibility of neurological damage after the arrest this morning, but at least none has shown up on the ultrasound. …Tears still flow, and the times without tears are slightly numbed with the weight of the burden. [The director] asked us to consider the time when we might call off treatment - which made us realise that we are Samuel’s advocates. We are his voice. We may have to

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57 An extreme example of this is “The Messenger Case”, whereby a father (who was a doctor) was put on trial for manslaughter for turning off life support for their son who was intubated against the parents wishes. Helen Harrison, “The Messenger Case,” Journal of Perinatology 16, no. 4 (1996)
61 After seven weeks, one mother’s exasperation at finding out after the event that tests were ordered and decisions made about her daughter's care, prompted the question, "What say so do I have over MY child?" She responded with, “The only say you have is when she is ready to go home if you take her home or send her to a home.” And then walked away. see also http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-1.0001/Date/article-529.html. Accessed June 2002
62 It is interesting to note that in hospitals where family-centre care is adopted, one of the key expressions is in this area: providing access to medical research and information. It hardly seems “family-centred”.

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decide when it is better to end the struggle. But without us he is left to the mercy of “technocracy”... The possibility of ongoing disability has been raised and [its probability] increased. Dealing with numbers, though, seems so irrelevant when the main equation still has to be calculated: life itself.\(^{63}\)

I recall returning to the director later that afternoon and relating to him that we had no ethical problem with choosing to turn off life support, but that it was for us a question of faith, and that we did not feel that the time was right to let go as yet. He reassured me that they did not believe that it was the right time either, but indicated that they would let us know if and when they did. Although no-one ever returned to propose such a course of action, one of the nursing co-ordinators related to us on the day of discharge the she had “lost count of the number of times I said goodbye to Samuel at the end of a shift because I didn’t expect to see him in the morning.”\(^{64}\) It made me wonder whether the addition of a different perspective in the decision-making processes produced some reluctance on the part of the director to canvass the issue on later occasions.

The power balance can also work in the opposite direction. List-members report times when the medical staff’s advice to stop aggressive treatment and issue a DNR\(^ {65}\) order is refused by the parents. It is a thorny ethical issue which the list does not pick up, but is an important counter-balance to the notion that it is solely medical staff who never see death as a good option.\(^ {66}\)

**Language**

Evidence of parents’ adaptation to this frame of reference can be found in their use of language in relation to describing their children. Many of their posts to the list read like a medical textbook or clinical notes. The level of expertise gained by some parents as a result of the experience is astounding, with one mother reporting that her knowledge exceeded the practitioner in an Emergency Department of a hospital.

When i told them that he was a former 28 weeker, recipient twin of twin to twin transfusion, has Stage 5 ROP with retinal detachments, BPD and Cortical atrophy they were just overwhelmed by the fact that i was using the correct terminology and didn't even know what ROP was! All i remember was telling the ER doc that the x-rays that they took were the best looking to date and he just said that he was sorry that i had to come by my knowledge the way that i had instead of like him through med school.\(^ {67}\)

Many a member’s early posts to the list contain a detailed summary of their child’s medical condition, and demonstrate an ability to read monitors and scans and determine the relative

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\(^{63}\) Entry dated March 1, 1997

\(^{64}\) Personal conversation, August 24, 1997.

\(^{65}\) Do Not Resuscitate

importance of the information revealed by them. Such was the level of knowledge accumulated by
some of the members of the list that the home page carries a link to a summary of the medical
acronyms employed. While this reflects a desire of parents to understand what is happening to
their children, it also becomes part of the equipment necessary for engagement with medical
practitioners in the care of their children. One of the consequences of this is that personality issues,
while still important to parents, are relegated in priority. A recurring question asked by parents of
children in the NICU and beyond is, “what is attributable to their prematurity, and what is simply an
expression of their personality?” In the language of the NICU, there is no place for such a question.

This language also becomes a reference point for comparing experiences. From time to time the list
erupts with a battle over who had the worst journey, or as the list has come to define it, a battle over
the “lowerarchy” on the list: the more difficult the NICU course, the greater the badge of honour to
be worn by the parents. But one parent realises the implications of such conversation:

…this list is not about the medical events in our children's lives, nor is it necessarily about
the severity of the impact prematurity has on their lives, it is about our continual struggle to
understand what has happened to us, and our children, and to cope with *whatever* that
impact may be and to advocate for our children to the best of our ability through information
and collaboration. It is based largely on the comforting knowledge that kind hearted people
who have previously experienced the same *type* of life altering, alienating experience that
you have, can be a great source of strength and support as you try to regain your *own*
equilibrium, and get back on your "emotional feet". Parents will never have the same
experience in the NICU, even if the children they have birthed do… I do not view my
experience in quantitative terms...

But when the only language available to parents to interpret the experience is that of the medical
clinical vocabulary, the necessary tools to communicate the experience to the wider social network
out of which they have come are not necessarily accessible to parents. When this absence of
language is set over against the popular understanding of prematurity – which is largely defined
by the media and is built around a frame of reference which sees such infants as tiny versions of
full-term infants who just need some extra time to catch up – parents find themselves hamstrung in
their ability to communicate the import and impact of the circumstances in which they have been
immersed. It bears the hallmarks of an experience of the numinous: an encounter with or an
experience of something which is, at the outset, beyond the reach of existing language within the
parent’s vocabulary. The major experienced language shift relates to proficiency in medical
terminology, which allows the parents to interact meaningfully within the NICU. But a major

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70 This issue will be addressed more extensively in Chapter 5.
unattended task is the discovery of language which helps parents to convey the experience to other people in meaningful terms: people with whom parents have no common basis for communicating the experience and sharing that understanding. Popular language and mythology serves only to highlight advancements in medical understanding and technology, but rarely conveys the broader emotional, social and philosophical impact on the parents. List members indicate that their involvement on the list is part of the journey towards understanding that impact personally. They leave the NICU well-versed in the clinical obstacles and challenges which their children have faced, but only then ready to begin the journey of understanding and articulating the impact of the experience on themselves. It is a source of frustration to many on the list not only that they are continually confronted by comments which express this ignorance, but that they also struggle to find ways to respond to these comments.  

Rituals

The birth of any child is more than a medical event, and more than a mere matter of reproduction of the species. Human life can be interpreted as an unfolding story, a story which can be told from two directions. These stories help define us as individuals, and create a space and a place for us in the broader community story unfolding around us, and provide a source of meaning as we negotiate the individual circumstances of our lives. Our story can be told from an historical perspective, drawing from our lived experiences to explain who we are and why we have found ourselves in the present. At the same time, we can relate our story from the future: articulating the ideals which are calling us forward, the motivations which also explain our present choices and actions not merely as a product of the past, but as seeds for the future. The present moment can be seen at the intersection of two stories, a creative point which can be interpreted both as a culmination of what has been, and as a seed for what is to come.

Both stories are formed within a social and cultural milieu, and are in turn shaped by them. Each has a degree of elasticity which allows for reinterpretation: different threads can be called forth to explain different aspects of our life journey. It is in fact not a single story line with a single plot, but a multi-faceted story, to a greater or lesser degree integrated around a core narrative. The rituals which each culture develops serve to give individuals and the events of life a place within that unfolding story of life. They are an affirmation of a shared journey. Birth before time jolts the family away from the juncture of these two narratives, and parents are left a sense of grief at what has been lost from that story.

71 DHAC comments (references). The T-shirt produced for the 1999 conference sponsored by Preemie-1 bore an image on its back which conveyed the message “Ban DHAC”.

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When the normal birth rituals are not encountered, the sense of disorientation is highlighted, and the ambivalence about the experience is exacerbated. Already tentative in relation to sharing their child’s birth in the normal way with others, the normal rituals associated with childbirth would at least serve as a doorway for others into the experience:

You know when someone announces they are having a baby, how everyone just get crazy and plan so much to do. Well I did experience that right up until Tajel came unexpectedly early. It seem like people didn't know whether to congratulate me or give me condolences. And what hurt me the most is that I never had a baby shower. I mean this my first child, and you would think everything I went through they wouldn't hesitate… Even now I am sitting here with tears in my eyes because I have been given this feeling like because my pregnancy wasn't GOOD ENOUGH…I have always wanted to experience what everyone else experienced with their pregnancy. Regardless how Tajel came into this world, he is here. Isn't that a reason to Celebrate?72

In American culture, the baby shower is an important ritual, affirming the reality and wonder of birth. It is a celebration of life. The feelings expressed by the above respondent resonated so strongly with the group that, on more than one occasion, a virtual baby shower was thrown for a list member. The reason for this reluctance to throw a baby shower in the traditional manner is articulated by another member, highlighting the uncertainty of the place in which they found themselves:

My very best friend from Ohio told me one day "We were going to send you a package with baby gifts but we don't know if she is going to be okay so we are going to wait" I can see her point, she didn't want me to have baby stuff around to remind me if she were to die.73

And yet, these gifts and other acknowledgments are apparently needed more when a child is born in this way. When the mother is discharged from the hospital, the parents go home ‘empty-handed’. No children. No cards, flowers, gifts. Just a daily journey (sometimes more frequently, sometimes less) back to the hospital. For the parents it can feel like they haven’t had a baby. Often at the time of birth – due to its suddenness – there have been no preparations for the child’s arrival in the home, so there are no symbols in the home of their child. One mother echoes the feeling of emptiness this generated:

When the girls were in the NICU … I often felt like I didn’t really have babies.74

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Birth rituals affirm the arrival of the child and their place in the wider community as well as in the family. When the anticipation of this event is strong, its absence is felt even more acutely, not for its own sake, but for what it symbolises:

I don't know about you folks, but missing my baby shower for Nolin was one of the most hard-hitting "losses" I suffered when Nolin came early. More than the absence of a baby shower, parents report receiving no cards, no flowers, and in some cases, no visitors while in the hospital. One respondent reported a neighbour sending a donation to the Children’s Hospital in their name, an act she usually associated with someone dying. Another reported receiving a “funereal flower arrangement” and a “Get Well Soon” card, neither of which acknowledged the birth. The lack of acknowledgement of her son was a critical issue for this parent.

A significant number of mothers reported the absence of flowers which usually accompany the birth, indicating that friends and relatives didn’t know whether to celebrate the birth, and if so, what would be most appropriate. On the other hand, one mother found the flowers to be a denial of the reality:

I received so many flowers when James was born. All saying congratulations. I really appreciated the flowers. It was so loving of my family. (I saved each flower. Crazy, huh?) But at the same time, didn't anyone realize what was going on here? Congratulations that you couldn't hold a baby to term for the 3rd time! Congratulations that your "fetus" is in the NICU looking like some wierd (sic) mechanical contraption. Congratulations that your baby might die any minute. Congratulations on your failure!

To congratulate or not to congratulate? To celebrate or not? The social and emotional fragility of parents at this time, along with the physical vulnerability of the child means that celebrating the birth needs to be understood in a different light:

I had a hard time accepting any congratulations for a long time, I was just so sad for my baby, and for myself for being in this situation. BUT, if they hadn't have said it, I think that in the long run I would have been upset for not having any recognition for his birth. It just took a long time to accept this.

And for some, there can be a ray of light in the midst of all the ambivalence:

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No one but my mother truly acknowledged Austin right away. I got lots of flowers, but they were all generic arrangements. I understand that people didn’t know what to say, how to react, or what to do. It’s not their fault. There was one exception: the morning after I had Austin, my mom came to the hospital with a light-blue-themed flower arrangement in a mug that said "Proud new mom of the newest kid on the block" along with some "Congratulations/Baby Boy" balloons. Of course, that is still my favorite mug. After all of the commotion of Austin’s birth which was in the evening, then the "recovery room," and sleeping for a little while, she was the one who made me realize that I was a mom. 

The birth announcement – another ritual associated with childbirth – becomes another source of angst, and highlights the tensions confronting parents. Many parents indicated that they chose not to announce the birth in the traditional way (newspaper notice or sending cards). This in part stemmed from the uncertainty about the child’s future, and echoes the response (or lack of) from the wider family and social network. One mother indicated that it took her until 14 months after birth to send out the last of the birth announcements, although some were posted 12 months earlier. A major hurdle to be confronted by parents when considering the announcement relates to the nature and amount of information to convey. One mother has since designed and marketed a range of cards for announcing a premature birth.

The sense of dislocation is evident in the variety of responses to these rituals. Having been forced out of the normal pattern of childbirth, normal responses affirming the birth are sometimes received as showing a lack of understanding of the unique circumstances. Parents crave the recognition of the birth of their child, yet in a way which recognises the critical and precarious nature of the events. In the absence of established social and cultural rituals for such circumstances, family members and members of the wider social network are at a loss as to knowing an appropriate or culturally acceptable way to respond, preferring silence or apparently ‘harmless’ and ‘bland’ alternatives. Medical technology has moved society beyond its established rituals in this area.

Nursing staff play a critical in these early stages in helping parents to celebrate the arrival of their child. Inviting the parents to see their child as beautiful, taking pictures and placing name cards above the warming table which was their child’s ‘home’ are just part of a pattern of care which signify an attempt to normalise and humanise the birth experience for parents. Parents reported nursing staff greeting them with congratulations and comments on how beautiful their child looked – all an effort to confirm the arrival of the child. Parents often receive this initial welcome with a

82 These can be seen at http://www.nicuseries.com/. Accessed 8 November 2009
degree of skepticism, particularly in light of their own perceptions of their child, as outlined above. Nursing staff have also introduced other rituals in celebration of milestones unique to the NICU, assisting parents in recognising and celebrating their child’s progress, as well as public holidays of the ‘outside world’.  

Many parents found later rituals to be much more helpful and meaningful, as the traditional rituals relating to the birth of a child seemed somewhat mawkish and out of place. The precarious nature of the attending circumstances make traditional celebrations seem less appropriate, yet the absence of recognised alternatives, coupled with the general population’s ignorance about the circumstances and setting in which parents found themselves contributed to, even generated, the deafening silence experienced by most parents. This lack of popular understanding of the relative experience of parents of micro-preemies surfaces again later outside of the hospital in social settings, adding to the anger and isolation felt by parents. Many mothers report having encountered a general belief that having a premature baby is easier than a full-term one. When sharing birth stories, mothers are often confronted with a sense that they have missed something terrible by avoiding the last three months of pregnancy, and have been fortunate to have a baby born so prematurely. The initial response of shock and withdrawal occasionally evolves into a confronting response.

I usually say something like "Gee I'd take the pain of a 'normal' delivery over the TERROR of delivering early anydway. You see, you got a few hours of pain. I got months of sheer terror. I got to worry if my baby was going to live, and with what problems. You got to hold your child as soon as it was born, I got to watch a crowd of docs and nurses do heart massage, and stick the tiniest thing I've ever seen with needles and tubes, only to be whisked away with only a fleeting glance. I didn't get to hold my child for 3 weeks. For months, I got to watch other people care for MY CHILD and dictate to me when I could hold, touch, feed, diaper, etc. And if you think that isn't enough of an experience, how about the fact that I was actually IN LABOR for EIGHT WEEKS!!"

As much as parents of micro-preemies yearn for acceptance into the mainstream of parenting, it is apparent that the need for some social recognition of the struggle it took to reach that point is important, and any belittling of the experience is acutely felt. This may in part reflect the failure of the social rituals for them at the time of birth: having missed the traditional rituals for incorporation into a new social reality – becoming a parent – entry into the community is fraught.

83 Easter eggs, Christmas Stockings, milestones in weight gain, and month birthdays are some detailed by list members.
84 One respondent, however, reported her gratitude for a ritual performed by an aboriginal tribesman, relative of a friend. The elderly man went into the bush to sing the traditional songs and perform the traditional dance for their son, giving the boy an aboriginal name – Yannanamakka (meaning first man child born). The parents found this affirmation and ritual to be a source of comfort and hope in otherwise hard days. http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9704/Date/article-1015.html. Accessed June 2002
James and everyone had a good time. Except me. I felt like such an outsider! Didn't even feel like I belonged to James. Didn't feel like his mother.87

Many parents report taking the opportunity of the first anniversary for expression in a ritual sense of what traditional rituals affirm at the time of birth.88 The mother of triplets indicated that it was only at this point that she found herself able to celebrate the birth of one of her triplets, who had subsequently died before she had ever laid eyes on her.89

Rituals represent and formalise the individual events of a person’s life in the grander narrative of life and culture. To be involved in these rituals and recognised by them is to have one’s place and experience affirmed in the wider society, in the narrative of progress which they represent. The birth of a child not only represents the ongoing survival of the species, but also the affirmation of ongoing family life, and the graduation of from ‘married couple’ to ‘parents’. Rituals affirm the normality of life experience in the ongoing story. To be alienated from them is to place a question around the place of the child and the family in wider society – to be dis-located. Although alternate rituals have emerged within the NICU, together with the grand narrative of progress, they ultimately affirm the message of the broader community, but fail to connect families into it, as the alternate rituals emerge from the language and achievements important within the NICU, but poorly understood outside of it. In a similar way, use of language in the hospital related to “catching up” and the “NICU roller-coaster ride” affirm in their own way that there is a destination ahead, a return to the place from which they were dislocated by the extremely premature birth of their child. This can create the impression that discharge from the hospital meant the end of the challenges.90 This tangible end-point, held out as a sign of completing the course and resuming normal life, is ultimately illusory for most.91

Although rituals instituted within the hospital are an attempt to provide a sense of orientation to parents in the course of the NICU journey, they mask the sense of alienation from the meta-narrative out of which the family was jolted at the time of birth. The circumstances of birth jolted the parents away from the historical unfolding of their story, thus calling into question the tentative future narrative which they once had held. The rituals are valuable and affirming of progress and

89  ibid.
91  Follow-up studies show that the rate of disability amongst premature infants weighing less than 1000 grams and born before 28 weeks to be above 90%.
milestones within the NICU journey, but ultimately anaesthetising to the broader questions related to the appropriateness of the future narrative which the parents held prior to the birth.

I thought less and less about what competent (sic) human agency could have prevented his terrible prematurity. It took me a long time to reconcile the baby I had with the baby that might have been, and I still get flashes of this feeling sometimes.92

Life after the NICU, depicted in many different ways as resumption of the old dream, is in reality much different. Parents instinctively begin to realise this.

Transition to Home
The significance of the NICU journey becomes starkly evident for some at the time of transition out of the hospital into the home. The birth of any child brings with it an added sense of responsibility, but for many parents, from the moment their child is discharged into their care, the magnitude of what has happened, and the significance of the point they have now reached impacts them profoundly.

When I brought Jessica home I was terrified. We slept in shifts and the first time we both did fall asleep at the same time I woke up in a panic because Jessica did not wake me up. I could not get to the bassinet fast enough. My poor husband woke up from me screaming.93

The burden of responsibility felt at this time, with the heightened sense of vulnerability attached to the child, is for some overwhelming. Having learned to be a clinician-in-partnership, the responsibility of “flying solo” is assumed. This responsibility is more evident when the child comes home attached to various forms of life support.

“Charlie had come home NOT because his condition had improved… but because we learned enough to bring the NICU home with him. The one thing I longed for during that time after discharge was a continued connection to the NICU, even if it meant something as simple as a weekly phone call from his one of his primary nurses. The urge to “report” to someone I trusted was so strong.94

But this was more than a medical transition. After such an extended association with the NICU, consuming the bulk of their emotional energy and ‘discretionary time’, parents have become socialised into the setting, for many months having related to the same coterie of nursing and other staff, conversing about matters at a depth not often encountered in the routine of daily living. It was evident to some that they had become more at home in the NICU than they had in the “outside

world.”95 When asked by another member of the list to detail ways that you got through the experience, i.e. lots of bubble baths, shopping excessively, reading, movies, etc., a mother of triplets (who spent 97 days in their birth hospital requiring a daily 160 km round trip before they were transferred closer to home) outlined the narrowing of her focus:

No time for any of those indulgences. I’d say “Tunnel Vision” and Howard Stern...LOL!!! I had total focus on what was going on in that NICU. Nothing existed outside it (Yes, even Dane and Hal...not good.) I couldn’t be bothered with/handle any other of life's details.96

She further reflected that it was three years before she came to realise that there was an impact on her husband and older son.97

The transition to home is the central dream from the time of birth. It is held out as the sign of success, that the interrupted journey into normal parenthood is now back on track. Yet as the time of discharge nears, apprehension often heightens: “I am so anxious for him to come home, but a little scared… because I feel like we sort of came to depend on the care of the NICU nurses so much that we aren’t going to know what to do.”98 One mother’s response indicates how deeply undermined her confidence had become, declaring that coming home was an awful experience – she was “convinced we were going to kill him.”99 Fear and uncertainty were two characteristics identified by another parent as they reflected on the days after discharge.100 Much of this might be attributed to the sense of “taking over from the NICU” rather than assuming the mantle of parent. Or is it that the NICU has redefined parenting in such a way as to focus on matters on which the parents are made to feel less than capable?101 In the words of one mother, “It takes time to adjust to the realisation that the children "are ours" after hospital.”102 It was a surprise and comfort to many parents on preemie-l to discover how common it was to adopt NICU practices in the home.103

The sense of triumph and achievement on reaching the point of discharge is often muted, shaped for some, at least in part, by the memories of feelings which were attached to the bringing home of previous children. One parent saw her own experience echoed in that of a friend: “I think that the

97 ibid. (http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-1.200001/Date/article-0.html)
homecoming was as anticlimatic for them as it was for us. I found it very hard to leave the safety of NICU even tho I was heartily sick of the place.\textsuperscript{104}

Over the NICU course, parents have a developed dependence upon nurses and doctors for understanding and relating to their child. From the early days, nursing staff spend more time with the child, learning to read responses and personality. In the NICU, for the most part it is someone other than the parent who is able to experience, recognise and explain the child’s developments and achievements through the early days of life. Not able to understand the challenges to be faced, let alone diagnose how their child is reacting, it is the expert medical team, through its many tests, x-rays and machines, which monitor and report progress. Occasionally parent instinct to touch, caress and communicate with the child meets a rebuke from a watchful nurse for “over-stimulating” the child. Parents either fight the system or, more often, learn its language and culture, and become part of the system itself. This creeping process of institutionalisation is not automatically switched off when the hospital doors are closed behind them for the last time (the first time for the child), but are carried into the home environment and into the family social setting where medical technology – through which parents had learned to read the well-being of their child – was no longer available.

The focus on “getting the baby home” also serves to maintain a focus on the well-being of the child during the hospital stay, allowing parents to ignore their own journey. “Its as if when you're in the thick of it, all you think about is getting your babies well enough to bring home. You don't really stop to think about how having a preemie(s) has changed you as a person or affected your marriage.”\textsuperscript{105} In the hierarchy of needs (at least within the parental mindset) attention is entirely focused on the well-being of the child. The transition to home removes a significant time pressure, and changes the social dynamics, with the result that other issues are gradually released to the surface. Maslow’s hierarchy of needs may provide a framework towards understanding this process: when the child’s life is perceived to be under threat, the survival instinct is at its greatest. While in the NICU, the parent continues to exercise the role of guardian and protector, at least in company with the medical staff, but with a clear recognition that there are distinct priorities parents may want to protect. The parents’ focus is clearly upon the “threatened other.” When the “threat” posed by the child’s presence in the NICU is removed, other (social/emotional) needs, previously subsumed because of the perceived greater threat, loom into focus. In the milieu of feelings, emotions and reactions which surface in the wake of the transition, these become increasingly apparent.

\textsuperscript{105} http://home.vicnet.net.au/~garyh/premarnar/0143.html
A dual fragility is exposed at this point. Parents not only find themselves confronting issues which had lain in the background of their child’s struggle as they grew stronger, but the time of discharge also reawakens a fresh sense of their child’s fragility. Having already had this fragility before them for such a length of time, discharge awakens a deep sense that this might recur at any moment, and without warning:

Feeling secure is such a risk. For me, it’s like the stakes go up with every new positive development. His cp doesn’t worry me at all - it’s really no big deal - but it’s the unexpected grief that I truly fear. He was born without any warning at all. Within days, he went from being a strong active unborn babe to a pitiful little alien struggling for his life. And my decline was similar (although my lungs were a bit better).\textsuperscript{106}

The child’s fragility is sensed not only because of the nature of the birth, but has also been reinforced in the parent’s mind as a result of the frequent “episodes” which had been experienced in the NICU.

**Summary**

The focus of efforts within the NICU is to support neonates who have been born before they are capable of sustaining themselves independently of medical support. The overall impact of this experience for parents is complex and lasting. It is an experience for which wider culture does not provide symbolism or a story which honours the parents’ journey. From the moment of first encounter with their newborn, parents are confronted with a strange place and unexpected journey which disconnects them from their own sense of journey and identity in the community. They are introduced to a world with its own language and unique perspective on development, growth and achievement, and whose obstacles are unknown in the wider community. Parents must adjust to a power shift at the outset which changes the language they speak and introduces them to new rituals, even as they grieve the loss of familiar ones. Whilst the moment of discharge is held out as the ultimate goal of the journey, and is treated as such in preparation, its arrival delivers parents to another unexpected place, where they encounter a new sense of fragility and loss. The moment of discharge bears little resemblance to that which would have followed a full-term birth.

\textsuperscript{106} http://home.vicnet.net.au/~garyh/premapril/0146.html
Chapter Three

The Parents’ Experience Through Medical Eyes

The Developing World of Neonatology

Indications that premature birth was a crisis event for the parents emerged as early as 1960, yet remained peripheral to research into prematurity for decades. Parent experience was rarely mentioned in the literature in the 1970s, while at the same time research into technical developments in neonatology progressed at significant rates, pushing the threshold of viability for premature birth to much earlier gestations. The outcome was to push parents and infants into a deeper and more lasting experience of prematurity without giving adequate consideration to the initial and ongoing impact on the parents. Studies which emerged at this time were undertaken within a few days of birth, or retained a short-term focus post-discharge. Two studies with a longer perspective either report no difference between parents of premature infants and those of full-term infants at three years, or place the source of stress in “child problems” identified by the mother, perhaps obviating the need for further research into parent experience.

In the past ten years a small but growing body of literature has addressed the reactions of parents to having their child in the NICU, arguably catalysed by the emergence of popular literature detailing parent experiences. Although parent experience was largely ignored until the early 1990s, it is now more commonplace to encounter articles which begin with reference to the stressful, critical and turbulent nature of the NICU experience for parents. The vast majority of these articles are written from a nursing perspective.

Early studies in the 1990s were almost exclusively framed with the intent of understanding how parents viewed the NICU experience. The overarching and defining theme to emerge was “stress”. A range of stressors and emotional responses are identified, but the key focus is upon the stressors and responses and upon ways in which they might be ameliorated, or assisting parents in dealing

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2 It might be argued that one of the catalysts for this research was a desire on the part of parents and medical practitioners to avoid the grief associated with neonatal mortality, thus suggesting that the parent perspective in the medical literature had its focus on the issue being avoided, with the unintended outcome of walking backwards into prematurity (as far as parents were concerned).
4 A 1998 literature review records all but two studies reporting a time frame less than seven months: Lau and Morse.
5 Ibid.
with them, rather than addressing the more fundamental question of what impact these events have on shaping parent perspectives.\(^7\) In this way, the NICU experience is normalised and considered in isolation from the life framework out of which parents entered the NICU and to which they return post-NICU. The key responsibility of staff in this interpretation is to assist parents in the transition stages – primarily adapting to the NICU environment with the undergirding assumption being that they would automatically adjust back to home life.

Over the past fifteen years there has been a significant change in the demographic of parents of premature infants. Fuelled by the twin advances in neonatology and assisted reproductive technologies, the causes of premature birth have altered significantly, with the result that the cohort of parents who find themselves thrust into the world of premature birth represent a significantly different socio-economic profile than in earlier years. Such factors as prenatal substance exposure, fertility technologies and advanced maternal age also contribute to the changing profile.\(^8\) While early studies reflect the challenges facing teenage or drug-addicted parents whose infants were more likely to enter a NICU following birth,\(^9\) they also refer to a stage when the degree of prematurity was more limited.\(^10\) The normative threshold of viability has been slowly pushed back from around 28 weeks in the early 1990s to a point where resuscitation of a 23-week infant is seriously and regularly considered. This necessitates a cautious approach to early studies in relation to the impact on parents in general and more particularly on the maternal relationship with the child.

The fields of specialty from which research projects have emerged has also shifted. The earliest research emerged from a psychiatric perspective, whereas the majority of present research into parent response is undertaken by the nursing profession. Initially trained to care for the medical needs of the baby, research indicates and catalyses the way in which the nursing role is evolving to embrace the place of the baby in the context of the family, and consequent care for parents. Over the same time frame, the emergence of longitudinal studies has revealed that a premature birth impacts well into the teenage years, bringing long-term parenting challenges into consideration. The contribution of medical practitioners in this area is notable for its paucity, reflecting a primary concern for the bio-medical needs of the infant.

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\(^7\) Is there an assumption that the event can be rendered as without meaning?\(^8\) F C Bennett, "Perspective: Low Birth Weight Infants: Accomplishments, Risks and Interventions," *Infants and Young Children* 15, no. 1 (2002)\(^9\) S T Dormire, S S Straiss, and B Clarke, "Social Support and Adaptation to the Parent Role in First Time Adolescent Mothers," *Journal of Obstetric, Gynecological and Neonatal Nursing* 18 (1989); and R S Hunter and others, "Antecedents of Child Abuse and Neglect in Premature Infants: A Prospective Study in Newborn Intensive Care Unit," *Pediatrics* 16, no. 4 (1978)
A catalyst for broadening of research into the impact of the experience of premature birth may well have been the publication of a number of books by parents detailing their story. *The Long Dying of Baby Andrew*\(^{11}\) and *The Premature Baby Book*\(^{12}\) were released in 1983. Though very different books, their impact was to bring the experience of prematurity out of the highly technical medical and associated journals into forms accessible to parents, at the same time giving voice to what has become popularly known as the emotional journey of NICU parents. In both books, the authors were motivated by an experience in which both the process and the outcomes left them angry and feeling somewhat manipulated, reflecting a desire to articulate a parent perspective on a situation where they were largely considered to be outsiders and observers.

In spite of this shift, the preponderance of research remains focussed on the NICU, viewed through bio-medical models of understanding, in which parent experience is regarded as incidental. The assumption of most medical research is that the delivery of a healthy infant to the parents at the end of a NICU journey will allow parents and family to journey ahead unaffected by the experience.

**Describing the Impact on the infant**

Many studies into the long-term impact on infants give no consideration or discussion of the impact of the data on the parents and families. To gain insight into the impact of extreme prematurity on the parents, we need understanding of the infant child who is discharged into the care of parents. The medical literature gives us a comprehensive insight into and appreciation of the impact on the child of an extended NICU stay, both in the NICU and post-discharge.

Using the WHO definition of health as a basis for measurement, Klassen et al concluded that NICU children and their parents experienced poorer health outcomes than their full-term counterparts,\(^{13}\) an experience which is not isolated to children born at the threshold of viability. The health outcomes for children born prematurely covers a broad spectrum of concerns. At the time of discharge from the NICU, many newborns are still considered to be “medically fragile,”\(^{14}\) a phenomenon increasing

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\(^{12}\) Helen Harrison and Ann Kositsky, *The Premature Baby Book: A Parents’ Guide to Coping and Caring in the First Years*, 1st ed. (New York: St. Martin's Press, 1983) Although Harrison and Kositsky are nurses, it was Harrison’s experience as a mother of a premature infant which catalysed her into writing this book.

\(^{13}\) A F Klassen and others, "Health Status and Health Related Quality of Life in a Population-Based Sample of Neonatal Intensive Care Unit Graduates," *Pediatrics* 113 (2004)

in incidence given the push towards earlier discharge.\textsuperscript{15} Many infants are discharged from hospital into the care of parents who are required to maintain or administer medical attention to their children. These same infants are less likely to be breastfed after discharge,\textsuperscript{16} and can be less responsive as social partners.\textsuperscript{17} The hospital environment often conditions preterm infants to stimulation and care which does not aid the child in development or in regulating their own needs and responses.\textsuperscript{18} Many of these stimuli have been administered in the hospital by other than the parents, whose natural inclinations towards their children differ from those of hospital staff.

At the time of discharge preterm infants usually experience moderate to severe growth failure,\textsuperscript{19} and in the first three years of life exhibit higher rates of neurodevelopmental morbidity, ill health and recurrent hospitalisation,\textsuperscript{20} with the result that preterm infants may well require the care and attention of a number of health professionals after discharge into family care.\textsuperscript{21}

In the longer term and at the lower end of the birthweight scale, Very Low Birth Weight ($\leq 1500$ grams = VLBW) infants are less likely to graduate from high school, exhibit lower mean IQ, higher rates of neurosensory impairments, and subnormal height\textsuperscript{22} - outcomes which have persisted since the 1980s despite improvement in treatment regimes.\textsuperscript{23} There exists a gradient relationship between infant risk and decreasing birth weight, risk which is increased in circumstances where there is a prominent history of ischemic events.\textsuperscript{24} Despite significant developments in neonatal care regimes and available treatment options since the late 1980s, these figures have not changed.\textsuperscript{25} In fact, one

\begin{itemize}

\item\textsuperscript{16} Örtenstrand and others.

\item\textsuperscript{17} L Davis, H Edwards, and H Mohay, "Mother-Infant Interaction in Premature Infants Three Months after Nursery Discharge," \textit{International Journal of Nursing Practice} 9 (2003)

\item\textsuperscript{18} K Koldewijn and others, "The Infant Behavioral Assessment and Intervention Program to Support Preterm Infants after Hospital Discharge: A Pilot Study," \textit{Developmental Medicine and Child Neurology} 47 (2005)

\item\textsuperscript{19} J D Carver, "Nutrition for Preterm Infants after Hospital Discharge," \textit{Advances in Pediatrics} 52 (2005)

\item\textsuperscript{20} S Saigal and others, "Impact of Extreme Prematurity on Families of Adolescent Children," \textit{The Journal of Pediatrics} 137, no. 5 (2000)

\item\textsuperscript{21} S K Ritchie, "Primary Care of the Premature Infant Discharged from the Neonatal Intensive Care Unit," \textit{Maternal Child Nurse} 27, no. 2 (2002)

\item\textsuperscript{22} M Hack and others, "Outcomes in Young Adulthood for Very Low Birth Weight Infants," \textit{The New England Journal of Medicine} 346, no. 3 (2002)

\item\textsuperscript{23} P Anderson, L Doyle, and Victorian Infant Collaborative Study Group, "Neuro-Behavioural Outcomes of School Age Children Born Extremely Low Birthweight or Very Preterm in the 1990s," \textit{JAMA} 289 (2003)

\item\textsuperscript{24} M McGrath and M Sullivan, "Birth Weight, Neonatal Morbidities, and School Age Outcomes in Full-Term and Preterm Infants," \textit{Issues in Comprehensive and Pediatric Nursing} 25 (2002)

\item\textsuperscript{25} Ibid.
\end{itemize}
author suggests evidence of a fundamental shift bringing a lower rate of neonatal mortality through this time matched by a steady increase in the actual numbers of children with disabilities.  

It is likely that the incidence of behavioural problems in VLBW infants will be substantial, although very little is understood about how these problems emerge. The link between developmental delays and the presence of behavioural problems is understood: such children are likely to be less interactive in play, more negative with peers when conflict arises and less likely to gain peer affirmation.

At gestations less than 25 weeks, and birth weight less than 750 grams (extremely low birth weight = ELBW), the picture is even more striking, the long term outcome resulting in 30% to 50% of ELBW infants having a moderate to severe disability, with many having multiple disabilities.

At school age, difficulties with written work have been reported as up to 8 times more common amongst ELBW infants compared to their term peers. The same population exhibits impairments in motor coordination which interfere with academic achievement or activities of daily living at up to 10 times the rate of the general population, and demonstrate increased risk for psychiatric disorders, problems which persist into adolescence. School-age assessments have determined that one in two ELBW children requires special educational services, while a more recent study reports long-term complications in 29% of respondents, a figure determined within limited medical criteria where developmental and learning difficulties are not included. Whilst acknowledging that

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27 K Crnic and others, "Understanding the Emergence of Behavior Problems in Young Children with Developmental Delays," *Infants and Young Children* 17, no. 3 (2004)
31 H MacDonald and The Committee on Fetus and Newborn, "Perinatal Care at the Threshold of Viability," *Pediatrics* 110 (2002)
32 R E Grunau and others, "Prediction of Written Output Ability in Extremely Low Birth Weight (E.L.B.W; ≤800g) Children from Age 4 to 8½ Years," (Poster Session 1440, Pediatric Societies' 1999 Annual Meeting: 1999)
33 L Holsti, R E Grunau, and M F Whitfield, "Developmental Coordination Disorder in Extremely Low Birthweight Children (E.L.B.W; ≤800g) at 8.9 Years," (Poster Session 1443, Pediatric Societies' 1999 Annual Meeting: 1999)
34 A Whitaker and others, "Psychiatric Outcomes in Low-Birth-Weight Children at Age 6 Years: Relation to Neonatal Cranial Ultrasound Abnormalities," *Arch Gen Psychiatry* 54 (1997)
environmental factors were stronger predictors of school outcomes than perinatal complications, a study by Gross et al further noted that environmental influence was more strongly pronounced in children born preterm, a conclusion which brings the impact of the NICU experience on parents and family dynamics firmly into focus.

These outcomes were originally regarded as “risk factors” for subsequent child abuse, a notion which has not been completely disabused, although no consideration seems to have been given to any distinction between abusive behaviour which might have been the cause of premature birth (family dysfunction giving rise to premature birth), and that which emerges as a result of the NICU experience (family dysfunction as a consequence of the stresses associated with premature birth). They do remain an indicator of deeper need for support for parents and children. In spite of this acknowledgement of heightened risk for the child, strategies for understanding the parent experience and for assisting parents have remained a missing perspective in the research. One obvious and enduring impact of this early research has been to create an environment where parents are regarded more as a potential threat, rather than an important and integral part of the process, a theme to which I will return later.

The research paints an undeniable and comprehensive picture in which an extremely premature child will likely emerge as a person whose needs and social interactions vary significantly from the full-term population. Primary care for these children will reside with the parents.

Although the aim of continuing research in neonatology continues to focus on treating children within the NICU with the intended outcomes to match that of normal full-term gestations, it is evident that support and care regimes can no longer maintain the assumption that this is true for a significant minority – if not outright majority – of extremely premature infants and their families. “It should be clear by now that prematurity, especially extreme prematurity, results in substantial intrinsic risk to the developing brain in the absence of overt neuroimaging abnormalities,” which is to say that medical scientific technology is as yet unable to reveal the full extent of the impact of

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40 Hunter and others, ; K H Steele, "Caring for Parents of Critically Ill Neonates During Hospitalisation: Strategies for Health Care Professionals," Maternal-Child Nursing Journal 16, no. 10 (1987); Committee on Fetus and Newborn.
41 Bennett.
prematurity on the human body, even where behavioural challenges are evident. Physiology remains unable to explain the evident behavioural outcomes.

In spite of evidence which clearly indicates that parents of extremely premature children are likely to be raising a child whose needs and challenges differ from the vast majority of full-term children, research into the ongoing implications for the parents is patent by its absence. The developmental research is largely “silied” – dealt with as a means for improving the treatment regimes within the NICU so as to produce better outcomes – while the implications for parents are overlooked, or taken as an indication that there is a need to reduce the stress for NICU parents. This body of data provides a clear indication of the need for care and nurture of parents in both the short and long term, inasmuch as it demonstrates that a parent of a premature infant is likely facing a substantially different life than originally envisaged. Parents who are already suffering the effects of long-term association with a NICU and lower self-esteem in relation to parenting, \(^\text{42}\) are charged with providing for children with high degrees of developmental delay and attendant behavioural management issues.

The clear message is that the impact on parents is not confined to the time of association with the NICU, and that premature birth is a catalyst into a vastly different experience of parenting. The NICU experience needs to be viewed a subset of the broader implications for parents, which invites a more holistic approach to care for parents than encapsulated within the narrow framework of transition programs.

These issues have been avoided in large part by virtue of defining the infant as the patient, obviating responsibility for parents, while debate continues about the place of parents in relation to treatment decisions. It is this marginalisation and ambiguity about the place of parents which contributes to the parental burden. The assumption that parents will cope and adapt needs to be reconsidered.

The outcome for many parents after an extended NICU stay is an existence other than what could be described as the norm following birth of a child. Extremely premature infants often die, \(^\text{43}\) or survive with either severe disabilities which are evident or emergent at the time of discharge, \(^\text{44}\) or confront developmental challenges and delays at a much greater rate than their peers.

\(^{42}\) Crnic and others.


\(^{44}\) M Hack, H Friedman, and A A Fanaroff, "Outcomes of Extremely Low Birth Weight Infants," *Pediatrics* 98 (1996)
Describing the Impact on Parents

The birth of a child is a major life adjustment for parents. Premature birth is an adjustment which stresses most families to the limit of their ability to cope. Changes in attitudes, financial status, daily routines, distribution of household tasks, work and leisure activities, and the marital relationship itself have all been documented as being associated with the birth of a child. When birth takes place prematurely, an entirely new set of challenges emerge – often introduced cataclysmically – leaving little or no time for preparation prior to birth. This serves to isolate parents from extended family, and to create a situation in which the normal transition to parenthood is interrupted. Irrespective of variable factors surrounding the family circumstances at the time of birth – whether related to socio-economic issues, levels of education, age of parent, gender or order of child in the family, or type of birth – high levels of emotional stress are reported, which appear to be unrelated to the degree of neonatal illness. This stress is evidenced in research which shows that mothers of preterm infants record higher levels of postpartum anxiety and depression in the earlier stages, although it is acknowledged that this may dissipate over time. Central to the event is that both parents and child experience a disruption not only to the normal process of relational and physical development, but also to the context in which this occurs.

The word “crisis” is often used to describe the experience of premature birth. From the moment events unfold to indicate an imminent premature birth, a series of critical moments is set in train, beginning before the infant enters the NICU. Shellaberger and Thompson outline five early critical moments: predelivery, labour and delivery, parent-infant separation, infant transport, and initial

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48 Affleck, Tennen, and Rowe.


51 S Gennaro, "Postpartal Anxiety and Depression in Mothers of Term and Preterm Infants," Nursing Research 37, no. 2 (1988)

52 J V Browne and A Talmi, "Family-Based Intervention to Enhance Infant-Parent Relationships in the Neonatal Intensive Care Unit," Journal of Pediatric Psychology 30, no. 8 (2005); R Feldman and others, "Comparison of Skin-to-Skin (Kangaroo) and Traditional Care: Parenting Outcomes and Preterm Infant Development," Pediatrics 110 (2002); B M Melnyk and others, "Improving Cognitive Development of Low-Birth-Weight Premature Infants with the Cope Program: A Pilot Study of the Benefit of Early NICU Intervention with Mothers," Research in Nursing and Health 24, no. 5 (2001)
NICU visit, allowing for two further crises – duration of hospitalisation and discharge – which cover the longest time frames associated with premature birth. Central to their research, however, is adjustment by the parents to the situation rather than longer-term considerations, particularly family life post-discharge.

The disruption to and diminution of emotional well-being in parents impacts their capacity to respond to their children, impacting on the establishment of a healthy relationship with the child which is regarded as optimal for the child’s development, at least at the outset. Finding ways for parents to “parent” is made especially problematic in, and faced with the challenge of adapting to, the highly-technical environment of the NICU. The lack of medical knowledge and expertise, at least at the outset (although parents are shown to work hard to overcome or reduce this deficit), also makes it difficult for parents to understand the issues and complexities related to treatment of their infant. Suddenly immersed into an alien world, parents make a rapid transition in the first weeks following birth, from passive recipients of information to active seekers, spending between 10 and 20 hours a week gathering information, questioning physicians and nurses and seeking information from other sources.

Initially, the challenges of forming an initial parenting relationship may be hindered by poor maternal health which may either have contributed to or flowed from the premature birth. It is further complicated by the presence of a nurse, such that the process of transitioning to parenthood is a highly supervised one.

These internal pressures can be multiplied when considered in relationship to the pressures emanating from the normal lifestyle in which the parents lived prior to birth. In addition to coping with the pressures and culture of the NICU environment, financial burdens and job pressures remain

53 An issue not addressed in the literature, but which is central to some of the considerations of this thesis, and which will be developed later.
57 Ibid.
60 Ibid.
or are heightened. Given the reduced emotional resources and time pressures associated with having a child in hospital, routine matters may come under pressure for lack of attention. Financial expenses associated with hospitalisation can be quite substantial in some cultures.

**Marginalisation**

From the moment of birth and as a consequence of the health and medical needs of the child, mother and child are separated. The mother often finds herself in a maternal or birth unit of the hospital where the absence of her infant is underlined. Poor maternal health following birth often militates against access to her child in the NICU, where the conditions are established almost exclusively for medical and nursing care. Contact between parents and child in the NICU as a consequence are somewhat problematic and artificial – “frustrating, and inappropriate to their needs.” Parents find the sights and sounds of the NICU to be immediately confronting, and the often critical needs of the infant are foremost, leaving parents feeling without opportunity or place for expressing their experiences and reactions. At the same time, the bells and whistles of the NICU environment often stand in the way of parents’ relationship with their newborn infant. Combined with the child’s passive interactivity, an environment exists which significantly militates against relationship building between parents and infant.

Parents tend to initially underestimate the level and importance of different aspects of support, suggesting that they might not seek or value critical support through the early stages. The NICU stay is characterised by ongoing concerns about the baby’s health and future, concerns which persist for a long time after discharge, particularly in circumstances where the infant suffers from severe medical complications. It is this focus on the child which continually pushes parent needs into the background, with the consequence that they are often hidden or overlooked – a marginalisation to which reference has already been made.

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64 D W Davis, M C Logsdon, and J C Birkmer, "Types of Support Expected and Received by Mothers after Their Infants’ Discharge from the NICU," *Issues in Comprehensive and Pediatric Nursing* 19 (1996)
65 A Örtenstrand and others, "Early Discharge of Preterm Infants Followed by Domiciliary Nursing Care: Parents’ Anxiety, Assessment of Infant Health and Breastfeeding," *Acta Paediatrica* 90 (2001)
That the NICU is an environment where the parent assumes the position of an outsider in relation to their child is engendered by:

* the initial lack of medical knowledge by the parents (both in relation to technical and cultural aspects of medical care);
* the unfamiliarity of parents with the highly technical nature of the NICU environment, one which most parents find initially intimidating;
* initial hesitation in relating to a preterm infant, whose size and fragility holds an intimidation with which nursing and medical staff are more familiar;
* greater confidence and competence on the part of medical staff in relating to the infant;
* an enduring culture facilitated by early research which creates the impression of parents as a potential threat to the child's wellbeing by nature of risk factors for abuse;
* early yet enduring attitudes which regarded parents as a vehicle for introducing infection;
* parental ethical and decision-making frameworks, which are often different from the those of medical practitioners.68

Consequently, a significant proportion of parents find themselves with no role in treatment decisions in relation to their child,69 and at best marginalised in terms of overall care.

The marginalisation of parents from the hospital-based care has historic roots in the preantibiotic era when concern about infection was uppermost in hospital strategies. It was initially thought that respiratory disease in premature infants was the result of germs, which made parents into potential carriers. Although its cause was identified in 1949, parents continued to be excluded from contact through to the 1970s. Research at Stanford University began to break down the barriers to parent access to the NICU,70 although nearly thirty years later, despite developments in thinking towards understanding of the importance of environment and relationship to the development of a child, parents remain marginal to NICU practice and focus.71

Yet this marginalisation is also evidenced in the ambiguous place attributed to parents in relation to questions concerning treatment72 and “ownership” of the child73 – ultimately about who has control over treatment decisions for the child. This marginalisation occurs at myriad levels, with tensions between parents and medical professionals about relative perceptions of their roles,74 leaving parents uncertain about what their role should be, and whether their contribution to the overall care

69 Ibid.
72 C M Clarke, "Do Parents or Surrogates Have the Right to Demand Treatment Deemed Futile? An Analysis of the Case of Baby L," Journal of Advanced Nursing 32, no. 3 (2000)
of their child was welcomed. A lack of consensus among nurses about the form and extent of parent participation in care for children is reported by a British study.75

The place of the parents in decision-making about their child is still being debated,76 indicative of a lack of confidence by at least some medical professionals in the parents’ ability to engage with the challenges of the NICU, given the lack of consensus about the status of parents in relation to their child.77 This attitude must be reflected in day-to-day interactions in many NICUs, where the culture and language is shaped primarily, if not exclusively, by the medical professionals, who through use of diagnostic labels can effectively marginalise parents, even to the point of identifying them as the problem.78

Even where there are established protocols and articulated practices which purport to engage parents, a tension remains. A recognised gap exists between perceptions of parents and nursing staff due in part to differences between stated policy and practice,79 to different perceptions of maternal needs and stresses,80 and to the ways in which NICU staff inadvertently underline lack of parent competence for caring for their child.81 The lack of understanding by most NICU staff of what it means to be a parent within the NICU contributes to the focus on helping parents develop the technical skills for medically caring for their child,82 which further serves to redefine the parent-child relationship and impact on family dynamics generally. The different lens through which parents and medical staff view is underlined by studies which show that parents grade the physical impacts of any child disability less than did health care professionals,83 which do not serve to diminish the value of the observation that the impact is greater when a disability is present, independent of family education and financial support.84

75 Ibid, 718-719
76 R J Boyle, “Ethics in the Neonatal Intensive Care Unit and Beyond,” Infants and Young Children 13, no. 3 (2001) cf Shields and others,
78 Ibid.
84 Cronin and others.
This attention to power dynamics has been observed by Irene Hurst, who documents a repertoire of actions employed by mothers in “vigilantly watching over” their child in the NICU. Aware that advocating for their own needs risks diversion of resources away from their infants, mothers adopt a range of strategies to ensure there is a place for them in caring for their child without jeopardising their relationship with staff, as well as helping them negotiate the variable caring standards and professional advice of the many staff with whom parents may interact during their child’s hospitalisation. The feeling of powerlessness and isolation is commonly expressed, with mothers reporting feeling hurt, confused and angry when made to feel unwelcome at their infant’s bedside. The suggestion in one study that practitioners acknowledge and encourage particular emotions which don’t necessarily reflect practitioner priorities reflects present neglect in relation to parent needs.

These data are not surprising in light of Conner and Nelson’s findings of an immense gap in the understanding by medical practitioners of what was most important to parents going through the NICU experience. The most important predictor of parent satisfaction was identified as ‘a sympathetic physician’, and the majority of other factors identified were relationally, rather than technically, based. It seems that the highly technological aspect of the NICU environment and of the treatment regimes available masks more important realities from both parents and practitioners, with longer-term consequences.

Much more research has been undertaken in relation to parents with children suffering chronic conditions which may offer insights into the challenges facing parents, where frustrations have been expressed by parents in their relationships with medical professionals in caring for their child. Echoing many concerns expressed by parents of preterm infants, parents of chronically ill children report marginalisation in the health care of their child and trivialisation of their expertise by health care professionals, in spite of the popularity of family care in medicine. Fisher did,

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86 Hurst’s study details the circumstances of a mother who reported dealing with over 65 different nurses during her child’s hospitalisation in a NICU. Ibid. 73
87 Ibid, 76
90 See for example, C Canam, "Common Adaptive Tasks Facing Parents of Children with Chronic Conditions," *Journal of Advanced Nursing* 18 (2993)
however, note a subtle but significant power shift which occurred when the child was domiciled in the home vis-à-vis the hospital. In the absence of any other considerations, this tension remains an important factor in shaping the impact of prematurity upon the parents. It is a recurring theme throughout the parent literature.

At its core, the experience of premature birth shatters assumptions of invulnerability and control, bringing with it a deep sense of loss, which impacts both parents, albeit in a different way, as parents grapple with the equipment, the procedures imposed on their child, and exposure to other children in similar circumstances, as well as the ongoing interactions with health care professionals. The initial upset to parents’ equilibrium and the pressures placed upon parents in the process of rapid adaptation to the NICU, such that they are able to make informed decisions about their child’s well-being, creates an environment of parent risk which cannot easily be overstated, many of which are regarded as risk factors in relation to posttraumatic stress.

It has already been noted that the NICU environment conditions preterm infants to react in different and less responsive ways to social cues, which gives birth to relational difficulties between child and parents, increasing stress. Earlier research postulated an enduring negative impact on parent-infant interactions, which lasts long after hospital discharge, and having an impact on the well-being of the child and its development. It also needs to be noted that the environment also reconstructs the parent role. When parents are placed at the centre of such highly specialised care, they find themselves to be socially isolated and over-burdened, and under increased stress in all relationships, both with each other and with family, an experience which extends beyond

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93 A theme to which I will return later.
94 G Affleck and others, "Effects of Formal Support on Mother’s Adaptation to Hospital-to-Home Transition of High-Risk Infants: The Benefits and Costs of Helping.,” *Child Development* 60 (1989)
95 G K Auslander, D Netzer, and I Arad, "Parental Anxiety Following Discharge from Hospital of Their Very Low Birth Weight Infants," *Family Relations* 52 (2003)
96 Boyle.
98 Koldeijn and others.
99 Bjöörn Westrup and others, "A Randomized, Controlled Trial to Evaluate the Effects of Newborn Individualized Developmental Care and Assessment Program in a Swedish Setting," *Pediatrics* 105, no. 1 (2000)
discharge into the home, particularly when this requires the presence of technology and/or professional carers. The home no longer becomes a place of refuge, losing its privacy. Parents can no longer see themselves as just parents, instead adopting an amalgam of roles including that of parent, nurse, therapist and advocate. Parents desire to see themselves as parents, yet are keenly aware of their deficiencies in relation to their child.

At the end of each day of hospitalisation parents go home, leaving their child in the care of professionals, underscoring their marginality to the whole process. They are thus cut off from spontaneous interaction with their child and effectively removed from decision-making during their absence, a situation which is only corrected when medical staff members consider circumstances important enough to invoke parent involvement. Some creative efforts to bridge the isolation which parents experience from their child during hospitalisation include use of internet capabilities such as videoconferencing and World Wide Web technologies to allow virtual visits and distance learning. While overcoming isolation at one level, it reinforces the notion of parent as spectator – or invigilator – of medical practice.

**Transition to Home and Life Beyond Hospital**

There is a growing recognition that the impact on parents continues well beyond the hospital setting, with parents indicating a need for extra support and continuity of care after discharge from a neonatal unit, not just for their child but for their own well-being. Many parents comment that the transition to home is treated by hospital staff as ancillary to the overall experience, and often not canvassed in detail during the hospital stay until the day of discharge. Durrie identifies extremely high stress levels at the time of discharge, no matter how well parents are prepared.

Post-discharge, in contrast with the highly-ordered operations of the NICU, parents enter a world where care is uncertain, unregulated, widely dispersed, and administered by professionals with

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104 M Cohen, "The Technology-Dependent Child and the Socially Marginalised Family: A Provisional Framework," *Qualitative Health Research* 9, no. 5 (1999)
105 For an excellent discussion on this, see Kirk, Glendinning, and Callery.
108 A Long and A Smyth, "In the Palm of My Hand: An Exploration of a Man’s Perception of Becoming a Father to a Premature Infant and the Nursing Care Received in a NICU," *Journal of Neonatal Nursing* 4, no. 1 (1998)
limited experience of NICU graduates and their needs,\textsuperscript{111} which is undergirding an extension of NICU nursing practice into the home. Parents are unlikely to find a general practitioner or Maternal Child Nurse with experience in the field of prematurity. Even if they do, they are faced with the challenge of establish a new relationship with a Primary Care Provider\textsuperscript{112} who carries none of the hospital history, causing uncertainty and frustration for families,\textsuperscript{113} highlighting once again the importance of relationship in the overall care expectations and health outcomes of parents and child.

Transition to home can lead to anxiety about assuming full care of the child who until this time has required the care of a professional team. Parents are further confounded by feeding issues, motor abnormalities, irritability, disorganised behavioural cues, intrusive thoughts and painful memories of child’s hospitalisation. Already undermined in confidence, resorting to additional assistance can ease in the transition, yet be harmful to the extent that it may undermine the parents’ sense of self-confidence and competence, threaten parental self-esteem, or engender continued dependency on health providers.\textsuperscript{114}

Parents of children with birth weights less than 750g reported lower perceptions of parenting competence, more difficulties related to child attachment, and higher rates of both child-related family stress and adverse family outcomes. These differences were found even when adjusting for the effects of sociodemographic status.\textsuperscript{115}

The search for normalcy – seeking to shift the family centre away from the vulnerability of their child and shifting the perspective of motherhood from caregiving back to parenting\textsuperscript{116} becomes something of a Gordian knot inasmuch as assistance in caring for the medical needs of their child within the home only serves to reinforce abnormality and parental inadequacy. Parents report that the extension of NICU care into the home, rather than reducing stress on the family, has the opposite effect, although this is not reflected in the specialised literature. In any case, professional help seems more focussed towards normalising the experience than assisting parents in accepting it and working through the questions it raises.\textsuperscript{117}

\textsuperscript{113} Broedsgaard and Wagner.
\textsuperscript{114} Affleck, Tennen, and Rowe, \textit{Infants in Crisis}.
\textsuperscript{115} H G Taylor and others, "Long-Term Family Outcomes for Children with Very Low Birth Weights," \textit{Archive for Pediatric and Adolescent Medicine} 155 (2001)
\textsuperscript{116} M Kay, "Search for Normalcy: Mothers Caregiving for Low Birth Weight Infants," \textit{Pediatric Nursing} 23, no. 1 (1997)
\textsuperscript{117} S. C Swanson and M M Naber, "Neonatal Integrated Home Care: Nursing without Walls," \textit{Neonatal Network} 16, no. 7 (1997)
The learning and adaptive journey of the parents of a premature infant continues upon discharge when, as in the hospital setting, a new set of skills must be learned. Swartz identifies five “reciprocal translations” concerning the process of parenting a preterm infant post-discharge: adapting to risk, whereby the parent must assess each exposure to risk faced by their child outside of the hospital setting; protecting fragility, which includes shielding from hazards (including those which might cause infection), preserving the family – balancing the relationship pressures which the family continues to face; compensating for the past, and cautiously affirming the future.118 Parents’ perceptions of their child have been radically reshaped by their exposure to its vulnerability with the result that parents often rethink – consciously and unconsciously – their approach to parental discipline, and their attitudes to the social networks from which they entered the NICU. Discharged from hospital with a heightened sense of the “vulnerability” of their child leads parents to reassess risks and relationships in the home. This sense of vulnerability is ongoing. By the time a preterm infant reaches preschool, mothers are much more likely to consider their child to be vulnerable, which researchers consider to be a cause of increased utilisation of health care,119 and a factor in the take-up of child care placements.120 Taylor et al conclude that stresses on families are not likely to diminish with age, and may even increase as greater demands are made on the child as they move towards independent functioning.121

**Loss and Grief**

From an early stage after pregnancy is confirmed, a process commences (often in a sub-conscious way) in which parents develop some sense of the child who is forming within the womb, one which grows in clarity and richness as the pregnancy develops. A preterm delivery sparks a time of crisis in which the imagined baby is replaced by a real, much different baby, who requires much more specialised and critical attention than the parents are prepared for, and who demands a different context and style of relationship than envisaged. Aside from the physical needs, a premature baby thus requires very different psychological and emotional attention, at a time when parents are ill-prepared to understand it, let alone offer it.122 Parents are confronted with an often bewildering

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121 Taylor and others, 161
122 K Potter, "Report from 1st International Symposium on Humanized Care Assistance to the Low Birth Weight Newborn Baby & 5th International Workshop on Kangaroo Mother Care," in *1st International Symposium on Humanized Care Assistance to the low birth weight newborn baby & 5th International Workshop on Kangaroo Mother Care* (Brazil: 2004)
sense of loss and grief – the loss of their expected full-term or “normal” child, and exclusion from the normal experiences associated with birth, such as holding the child, breastfeeding, and introducing the child to family and social networks. The absence of accepted social rituals (birth announcements, cards, showers) underlines the sense of loss at the forefront of parent experience, although it might be masked by concerns for their fragile infant. As a result of the often precarious state of the child’s health, parents are unable to celebrate birth in traditional ways, underlining a sense of loss at a number of levels.

It is this sense of loss and grief which marks the starting point of early parent literature, and which is slowly entering the conversations in medical literature, often with its focus on relational concerns between parent and child – attachment and bonding – rather than its impact on parents as individuals. A study by Bachman et al describes the grief process in three phases: entry, connecting, and launching, clearly assuming that once parents attach to the child who was born, the sense of loss will dissipate. Whitfield, however, invites us to consider deeper ramifications:

For parents the NICU is a terrifying place, far from their hopes and dreams for their baby… Most parents exhibit elements of a typical grief response, including numbness, anger, search for meaning, resignation… Many parents are confronted abruptly with having to explore their own value systems regarding life and death issues, impaired survival, and the importance or otherwise of their faith or belief system to make cognitive and emotional sense of what is happening, and to participate in life changing treatment decisions...

The predominant view within the medical literature still reflects a notion of grief as a hurdle to overcome, an obstacle in the way of parent functioning in the NICU, or consider it to be a passing phase or series of stages. This contributes to an environment where the expectation is created that parents will reach a stage of “letting go,” and obviates dealing with the parents’ struggle between accepting the child who was born and the child who had been expected. Davies and Dyer, in separate studies, seek to embrace a broader understanding of loss and grief, whereby loss is not regarded as something to be left behind, but rather integrated to the ongoing memory and perspective of parents. These studies open the doorway to a different interpretation of the overall NICU experience which impacts parent perspectives in an enduring way, rather than an experience

124 Harrison and Kositsky, Premature Baby Book
125 Bachman and Lind.
127 Boyle, considers grief in relation to its impact on parent capacity to offer informed consent.
128 A perspective which dominates the parent literature also. I will return to this later.
129 Davies.
to be transitioned into and out of, or endured and left behind, affirming to medical professionals that parental biographies will need to find a place for the NICU experience, and invites consideration of something broader than transition programs in the care of parents, extending into care for both child and parents subsequent to discharge.\textsuperscript{131}

Holistic notions of loss and grief invite perspectives on the NICU to be considered as part of an overall life perspective, and not siloed as a traumatic incident which can be minimised or removed by returning a child without residual health challenges to parents, an issue I will explore in chapter seven.

\textbf{Developments in Interpretation and Response Formulation}

Initial disinterest in the parent response emanates as a consequence of the primary interest of practitioners upon biomedical concerns, such that the child (as patient) remains the focus, and the NICU assumes its position \textit{in loco parentis}, with an aim of “returning” the child to the parents in a healthy state – a literal description of early practice. The emergence of parent literature broadened this to embrace psychological concerns, recognising and affirming the stresses that premature birth placed upon parents, and seeking to ensure that parents were moved in from the outside, not only in terms of physical presence, but also in recognition of the impact upon their wellbeing. An important first step, and helpful in supporting parents in adapting to the intense NICU environment, it became apparent that important gaps in care for and support of parents in the journey still remained. In more recent days, models of social support have been explored as a response to the perceived inadequacies of a psychological approach which addresses the needs and concerns of parents in isolation from the social context from which they emerged and to which they will return.\textsuperscript{132}

And yet it remains true, almost without variation, that responses to parents’ stress retain their focus on the NICU environment and normalising parents in relation to it. The values of the NICU and its culture are largely accepted as given, with efforts focussed and energies expended on reducing the transitional stresses invariably experienced by parents. Unfortunately many of these efforts continue to disrupt and redefine the nature of home life and normal family relationships, without giving sufficient consideration to the overall impact on parent perspective in contradistinction to parent experience. The search for normalcy is largely interpreted as either a return to life as it was prebirth, or as a continuance of life as it would have been were the child born full-term.

\textsuperscript{131} Dyer continues to explore this notion in Kirsti A Dyer, "Identifying, Understanding, and Working with Grieving Parents in the NICU, Part I: Strategies," \textit{Neonatal Network} 24, no. 4 (2005)

\textsuperscript{132} E A Martinelli, ""Imagine..." A Model of Social Support for Parents of Pre-Term Infants," in \textit{Directions for the 21st Century: Bridging the gap between parents and professionals} (Chicago: Preemie-I, 1999)
Significant pressures have been exerted to involve parents more intentionally in treatment decisions, and towards a place where parents might see themselves as a part of the care team. As commendable and beneficial as this has been, it still has the effect of inculturating parents into a bio-medical worldview, which is a cultural system in its own right, one which serves to reinforce the sense of isolation and disconnection from family social networks. It needs also to be recognised that this shift towards greater involvement is not universal. Initiatives include development of family-centred models of care, and of transitional programs to prepare and support parents for their child’s transition from hospital to home and into community. Many of these have been successful in reducing parent stress, shortening hospital stays and reducing rates of readmission post-discharge. However, it may well be that the indicators which hospitals use to measure success do not adequately reflect many of the needs of parents and families at the time of hospitalisation or in transition to home, as there are few adequate instruments for measuring these levels of satisfaction. Conner and Nelson report an immense gap in their understanding of what matters most and when to parents going through the neonatal intensive care experience, suggesting further caution is needed in analysing the success of such programs.

NICU families are still expected to shoulder a much greater burden following discharge in terms of advanced health care and parenting with much less contact from the professional community, with the pressures for early discharge placing an added burden on parents to develop clinical expertise. Although pressures may have initially come from parents to reduce the length of stay, it is now almost universally assumed that a shorter stay is better for infants and parents. One study reports that the impact of this trend is to bring further pressure on parents, who report anxiety, feelings of depression and fatigue two months after discharge, and stress up to five years following the birth of their child. A 1991 study suggests that parental perceptions of the NICU impact are unaffected by developmental outcomes for their child, suggesting that, in the absence

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136 Conner and Nelson.  
137 Ibid.  
138 Robison, Pirak, and Morell.  
139 See, for example, a review of early discharge where parental impact is not addressed: Merritt, Pillers, and Prows.  
140 M Garel, M Behaud, and B Blondel, "Consequences for the Family of a Very Preterm Birth Two Months after Discharge (English Abstract)," *Archives de Pediatrie* 11, no. 11 (2004)  
141 Cronin and others.  
of ongoing concerns for their child’s wellbeing, the NICU experience still requires some assimilation into parents’ life perspectives. This can be demonstrated in the findings of a study in which the relationship between expectations and stress were examined, highlighting the anomaly that children born between 33 and 37 weeks’ gestation report better health related quality of life than children born at earlier gestations, but that the reverse was true for their parents, suggesting that this might be due to the problems being less severe or not as obvious. In other words, no matter the severity of trauma, or length of hospital stay, parents are required to do some work in relation to honing their own life expectations as a result of their child’s prematurity.

The engagement of different interests has resulted in changes in approach to understanding the NICU experience, both in the nature of research and types of conversation in relation to neonatology. The increasing volume of literature emerging from the parent and nursing perspective has been a significant catalyst for the development of Family Centred Neonatal Intensive Care, and treatment regimes in which the developmental needs of the infant are central (NIDCAP). These have emerged from the concerns articulated by parents and nurses, and have at times been resisted by physicians. Both practices can be understood as efforts to broaden the understanding of the treatment and care culture beyond a bio-medical framework in order to give consideration to the psychological wellbeing of child and parents. Family Centred care works at incorporating and empowering the parents as equal partners in the care of their child, fundamental to which is the notion that “parents must have available to them the same facts and interpretation of those facts as the professionals, including medical information presented in meaningful formats.” In such environments, the parents are encouraged to offer their considerations of the available data and treatment options, affirming the validity of the parent perspective. NIDCAP, on the other hand, involves recognising the place of medicine and nursing alongside developmental, family and organisational psychology – affirming the place of the child in the family from the outset, and seeking to apply understandings of developmental needs at the same time as caring for the child’s biomedical conditions. While medical care for the neonate of necessity remains the central aspect of care, these developments have sought to bring both parent and social perspectives into the NICU, and shift the balance of power in relation to decision-making.

The nature of the shift being demanded and occasioned by such approaches is revealed in one neonatologist’s reflection where she describes a transformative moment when she saw her work as not simply practice of medicine but as part of a partnership in the work of God. Her description of

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143 Klassen and others.
144 As reported by Westrup and others.
the child as “no longer a case to be cured but a human being in formation” reveals the fundamental nature of a biomedical paradigm of care which parents have been at the forefront of seeking to transform. Practical aspects of this shift include structural changes to NICU staff and operations, including the provision of case managers and social workers to provide more holistic and continuous support for parents during their child’s hospitalisation.

The growing body of evidence which demonstrates the deficits of the pure biomedical approach as it impacts the long-term outcomes for the child, and the wellbeing of the parents is evidence that there is still need to broaden the operational and cultural framework, in relation to which the above steps ought to be seen as a commencement, rather than a completion.

**Present and Emerging Issues**

An evident challenge emerging from the literature is a lack of systemic thinking on the one hand, and a commitment to (or captivity by) a narrow range of systemic thinking on the other. In the first instance, the needs of the child have, until recently, been considered in complete independence of the family unit from which the child has emerged. Parent needs are regarded independently of the child’s needs, resulting in parallel strategies for addressing these issues, and until recently, a failure to address the family as a system out of which the child has been born and into which the child will return. The various needs of parents have been identified initially through a bio-medical model to which psychological and social perspectives have slowly been added. It is clear, however, that the bio-medical concerns remain at the centre of consideration, an approach which has caused significant isolation and pain for parents in years gone by.

The limitations of the biomedical model of development are never more evident that in response to developmental concerns uncovered by research, quite apart from those which emerge from distinct and identifiable medical conditions. Child developmental paradigms still give sole attention to technical skills and the process by which these are acquired, with little or no regard being given to the impact of context in infant development. Despite assessments in which it is affirmed that the risk of developmental disabilities in premature infants increases when infants are born into families in poor socioenvironments, practitioners have been slow to recognise the social nature of the NICU environment, and maintain a resistance to transforming this social environment for the

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145 Harrison, "Principles."
147 There could be some mention here of the practice of exclusion of parents from the NICU because of infection risk. The parents are seen as threat and problem rather than as part of the solution and care for their child.
benefit of families and children. A full-term pregnancy is more than the provision of a womb for nourishment and protection. It is also a social setting where the infant is introduced (in an oblique and yet incidental and entirely natural way) to the sounds and movements of life. To recognise that a premature birth removes the child from the environment in which these sounds and other interactions are experienced and placed in a highly-technical setting of necessity impacts personal development, yet I can find no reference to context in analysis of developmental outcomes. In the same way that the child is removed from these settings, so the parents are – to a greater or lesser degree – withdrawn from these same settings, with consequent impact on their ability to return to their settings post-discharge. It is clear that another perspective is needed for the sake of parents and child.

One study suggests that it is in the interests of the child to not only support the parents in the time of hospitalisation, but also frame the practices of care with parents at the centre, as a good home environment is shown to be a protective factor against poorer outcomes in children of lower birth weights. Healthy parenting assists the development of the child, and is itself the result of parents who are reconciled to a particular set of values, beliefs and actions. The social aspects of the NICU itself need to be discussed in light of this relationship between environment and outcomes.

In the second instance, thinking and practice has been framed with the NICU at the centre on the unstated assumption that the NICU experience is a “normal” one which parents simply need to adjust into and be helped in transitioning out. This narrow view of the NICU as a system unconnected to life has left the larger questions of meaning and power at the periphery. “Parent education” within this framework, both on admittance and discharge, may simply serve to reinforce the notion of child as a patient, pressing the parents further into role confusion whilst at the same time serving to underline the medical fragility and vulnerability of the child.

Whilst there have been a small number of studies looking at the levels of distress experienced by mothers and fathers during the initial period, the prolonged hospital stay, and in the transition to home, not enough is known about the different impact and coping mechanisms of mothers and fathers, or the impact on siblings. Aside from the conflicting conclusions in the available studies,150


150 Some of which report greater distress in mothers during these phases (see M A Trause and L I Kramer, "The Effects of Premature Birth on Parents and Their Relationship," *Developmental Medicine and Child Neurology* 25 (1983); D G Benfield, S A Lieb, and J Reuter, "Grief Response of Parents after Referral of the Critically Ill Newborn to a Regional Centre," *New England Journal of Medicine* 294 (1996); Cronin and others; ; Miles, Funk, and Kasper, ), while others conclude there is no difference (see B S Eriksson, "Emotional Reactions of Parents after the Birth of an Infant with Extremely Low Birth Weight," *Journal of Child Health Care* 9, no. 2 (2005) In researching parents of children with
the preponderance of literature reflects maternal concerns and experiences. Literature pertaining to the paternal experience\textsuperscript{151} tends to be almost incidental, reflecting specific aspects, or noted as being understudied.\textsuperscript{152} Some important cautions can be noted. Callery warns that the way in which the term “parent” conflates the experience of mothers and fathers disguises differences in their responses.\textsuperscript{153} Hall cautions against considering that perceptions and responses were identical,\textsuperscript{154} citing an earlier study in which mothers and fathers perceived their child’s condition in the same way, but responded differently.\textsuperscript{155} A study noting the ways in which the use of Kangaroo Care by the mother had a positive impact on the dynamics between the father and the infant as well as other family relations, provides an important insight for research, demonstrating how one change in approach impacts a broad range of relationships, both in the NICU and the family.\textsuperscript{156} Systemic considerations such as these are rare in the literature, and remind us that the implications of any one change have flow-on effects.

It is also apparent that the question of power within the NICU is central, yet not openly discussed. At its worst, the issue relates to where ultimate authority resides in relation to resuscitation and life issues,\textsuperscript{157} but includes consideration of the ability of medical staff to undertake treatments and care regimes without reference to the parents. While many of these have their roots in relational issues, they often have their roots in a culture of practice which assumes a marginal place for parents in the overall care of the child.

**Summary**

It is recognised that parent involvement is an essential feature in providing quality care for children,\textsuperscript{158} and that parents, for the most part, are working at less-than-optimal level within the chronic illness, reference is made to a study by S Katz and T Krulik, "Fathers of Children with Chronic Illness: Do They Differ from Fathers of Healthy Children?,” *Journal of Family Nursing* 5 (1999) which demonstrated that fathers have a more difficult time than mothers in adjusting to a child’s chronic illness due to the child’s physical limitations caused by the chronic illness. See L A Goble, "The Impact of a Child’s Chronic Illness on Fathers," *Issues in Comprehensive Pediatric Nursing* 27 (2004); K Jackson, B Ternestedt, and J Schollin, "From Alienation to Familiarity: Experiences of Mothers and Fathers of Preterm Infants," *Journal of Advanced Nursing* 43, no. 2 (2003); Eriksson, Callery.\textsuperscript{153} Hall.\textsuperscript{154} L Copeland and D Clements, "Parental Perceptions and Support Strategies in Caring for a Child with a Chronic Condition," *Issues in Comprehensive Pediatric Nursing* 16 (1993)\textsuperscript{155} R Feldman and others, "Testing a Family Intervention Hypothesis: The Contribution of Mother-Infant Skin-to-Skin Contact (Kangaroo Care) to Family Interaction, Proximity, and Touch,” *Journal of Advanced Nursing* 17, no. 1 (2003) One couple was charged with manslaughter as a result of their disagreement with the medical staff about continuing treatment. As a last desperate act to have their wishes heard, they disconnected life support on their own initiative. Harrison, "Messenger Case,” Callery.\textsuperscript{158}
NICU settings. This is perhaps most evident at the outset, where they are suffering significant duress while having to negotiate a new parenting role within unfamiliar frameworks. Pressures which contribute to reluctance on the part of parents to admit need for support are evident, pressures which affect mothers and fathers in different ways, and which leads parents to describe the experience in extremely negative ways, carrying at least residual effects over into the home environment, both during hospitalisation and following discharge. The response proposed within the medical literature is to work harder and smarter at assimilating the parents into the culture of the NICU and as far as possible engage them as part of the care team, whose primary goal is to discharge the child from hospital as one largely free from consequences of their premature birth. This presupposition is clearly based on an illusory dream, given the rate of disability and developmental delay evident amongst premature infants, and the evidence of enduring impact of the experience on parents.

The exploration using biomedical/psycho-social models of care can only take us so far. Questions of meaning and identity appear to be key aspects in relation to parent ability to cope and form adaptive strategies which enable them to reconnect with their “home” communities. The focus for further investigations needs to be framed with attention to the activities and beliefs which enable parents to form understandings of the NICU experience which can be integrated into parent understandings of identity, meaning, and family.

Before exploring the public perception of premature birth and understanding the message that is conveyed to the wider community about the parent experience of prematurity – which forms a backdrop against which expectations are formed – I will focus attention upon the disconnect between the parent experience as articulated by the list conversation and that which appears in the medical literature.

159 The differences in parent experience between mothers and fathers remains a neglected area of research, hardly surprising given the broad neglect of parent experience.
Chapter Four
A Narrative Framework for Interpreting Parent Experience

A Gap in Understanding
It has long been the assumption from the perspective of medical practice that once the treatment of the body’s “dysfunction” has been appropriately addressed, the integration of personal life will follow naturally thereafter.¹ In the face of such an assumption the focus of medical care is primarily – if not exclusively – directed at treating the cause of hospitalisation, and any supplemental care is directed towards assisting the patient (or in this case, the parents) in adjusting initially to the realities of hospitalisation and finally in the transitions to home. This implies an assumption of ‘interrupted’, ‘deferred’ or ‘suspended’ development, by which it is assumed that the physical ailment requires or necessitates a pause in the normal developmental flow until physical health is restored. Questions of meaning are obviated by the belief that normality of life flows naturally from normality of physical function, and by the way in which the medical task is defined. The evidence emerging from the comparison between the understanding and interpretation of the experience of parents who give birth to an extremely premature child as expressed by parents themselves, and that which is expressed in the medical literature suggests that this is not the case. The parent response to the major NICU narratives (the “roller coaster ride” narrative, the “catch up” narrative) is characterised by an attempt to subvert or redefine them, if not an outright rejection of them. The medical literature maintains the assumption that the experience is marginal to parent identity and understanding, and focuses on systems and practices which serve to ameliorate the stresses which emerge from the experience.

In the literature we find a common but not shared grasping for understanding in the face of a cataclysmic and open-ended event, one which is neither limited to nor bounded by the period of hospitalisation. The existence and expression of stress upon the parents is evident from both bodies of literature, but the deep reservoir of anger that finds expression in the parent literature clearly emerges from something much more profound and of greater substance than unrequited and undiminished stress. This is partly born from the shared expectation in relation to interrupted, deferred or suspended development. Parents, along with medical staff, enter the hospital with the unspoken assumption that this is a moment to be endured, and once discharge is reached, normal life will be taken up once again. That the experience of prematurity varies widely needs to be both acknowledged and affirmed, and the dynamics at work contributing to the different interpretation of

¹ Khushf. 35
and reflection on experience can be attributed to a range of factors, including parent expectations, health and progress of the child, NICU policies and practices, relationship between parents and medical staff (as a whole or individually), length of hospitalisation, advice available and given, and resources available – to limit expression to those factors at work within the NICU itself. Yet in the face of this variability, there remains clear evidence that experience of parents attending to the needs of their premature infant calls for a more substantial response and framework for understanding.

The medical literature both recognises and affirms the profound impact which premature birth and the journey through the NICU brings, yet struggles to articulate and express the source of the enduring stresses which parents experience, which is consequently missing in the research. Studies about parent impact are considered within the time frame of hospitalisation and end shortly after discharge. Consequently efforts to address and counter stress are founded (and founder) on both a limited understanding of its causes and a confined framework and timeline of understanding. It is apparent at the same time that many parents are found to be groping for words to express the experience and its continuing impact in their lives. The events surrounding birth and ongoing hospitalisation are more than a temporary interruption to personal or familial equilibrium. There are enduring impacts in the life of parents and family members, as well as for the premature infant. Khushf’s reflection that a child’s suffering shatters the sense of meaning and human purpose that cannot be healed simply by tending the physical wound\textsuperscript{2} push us to investigate at a deeper level – challenging us to step back and reflect upon deeper questions of human formation and development.

The Unique Place of Parents of Premature Infants

By turning our prime focus to the needs of parents, we are undertaking a unique journey. In the case of a premature birth, the parents are neither ill nor regarded as NICU patients, even while there remains some ambiguity in relation to describing the nature of the condition facing their child. Beyond the threats emerging from having been born too early for independent viability, the condition of the child is not easily described as that of being ill or carrying a disease.\textsuperscript{3} The parents’ presence in the NICU remains ancillary to the main task assumed by the NICU – the rehabilitation and growth of a child born too early for independent living, a task framed in such ways as to define its conclusion in terms similar to full-term birth – the discharge of the baby into the independent care of the parent(s). Such a construction of the medical task conceptually marginalises parents in a

\textsuperscript{2} Ibid, 37

\textsuperscript{3} Something which creates ambiguity for both parents and physicians: patient focus is on describing the illness, doctors on treating disease, discussed in Evan Willis, *Illness and Social Relations: Issues in the Sociology of Health Care* (St. Leonards, NSW: Allen & Unwin, 1994) 145ff
multitude of ways and lays the groundwork for the continuing angst which is the parent experience post-NICU.

Irrespective of the ways in which the condition of the child is described, the parents are neither receiving treatment from nor regarded as being under the care of the Neonatal Unit in which their child is hospitalised, yet their connection with the treatment and condition of their child is pivotal to their being. If we are to gain insights into understanding the parents’ plight, we must give attention to the place of parents and the impacts on their well-being which are not strictly formed within the usual parameters of the doctor-patient relationship.

While the parents are generally not ill (peri-natal maternal care notwithstanding) over the course of an extended NICU stay, it is beyond question that the parents are suffering as a consequence. The parent literature shouts this reality. They are wounded in voice — being unable on the one hand to articulate in meaningful terms to others about the circumstances they and their child face, and on the other to understand the situation of and the treatment applied to their newborn, and they are wounded in place. Their place in the NICU community is acknowledged, yet poorly defined. That their child’s situation is critical is implicitly understood at the outset, yet the implications and consequences of this hospitalisation also impact upon parent identity and function in the most profound ways, impacting upon every aspect of their being.

First hand accounts of serious illness articulate the ways in which the world and life they had known were no longer tenable: “the destination and map I had used to navigate before were no longer useful…” Parent literature echoes this reality in its own ways: “all three of us had been catapulted into an odd and unknown universe where the natives spoke their own language;” one parent speaking of life after birth as a “scrambled life;” another noting that “gradually we understand that everything about our lives has changed.” Such expressions are concomitant with one adult describing the experience of disability as having “destroyed the structure of my life.” Critical illness leaves no aspect of life untouched, drawing in deeper and complex questions of meaning and purpose, impacting the family as well as the “designated patient.” Whilst in the NICU

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4 It might be worth exploring later the other aspects of woundedness, at least in these terms. These wounds include wound to their narrative, wounds to the plausibility structures, wounds to the landscape.


7 Timothy Smith, Miracle Birth Stories of Very Premature Babies: Little Thumbs Up! (Westport, Conn: Bergin & Garvey, 1999), 86

8 Rochelle Barsuhn, Growing Sophia: The Story of a Premature Birth (Minnesota: A Place to Remember, 1996), 18


intensive efforts are focused on the physical needs of the newborn, the parents have commenced their own journey in which all aspects of life are drawn into consideration. That parents on the discussion list reach for a narrative (“Welcome to Holland”) as a basis for understanding and articulating their journey is indicative of a deeper quest for meaning which is shared in common.

**The Pathway to Parenthood**

As they approach the birth of a child, parents undertake a keenly anticipated, largely expected, popularly-understood and articulated journey. While preparing for the birth, parents experience a series of loose rituals and socially-defined expectations which give expression to and shape the expected transition accompanying birth and the changing family dynamic. This is a well-worn social path – almost a rite of passage in Western society. Many tasks are undertaken in preparation for and expectation of birth, and in anticipation of the change which it will bring. Cues will have been taken from wider family and social circles.

The birth of a child is a wonderful metaphor for the interactive way in which meaning emerges in the life of humans – a curious interplay between that which we create and the way in which it shapes us – representing the ongoing dialectic of life in which we are both creators of the world and formed by the world in which we live. Kegan conceptualises this as being engaged in a lifelong process of evolution or adaptation of embeddedness and disruption, best illustrated by the reality of birth which disrupts the harmony of embeddedness in the womb yet invites us to explore a new reality in which we seek to bring a sense of coherence and organisation. Thus an interactive ebb and flow of life brings new risks and opportunities as we are leveraged from one sense of embeddedness to another – the lifelong motion in personality. At different stages of the journey, suggests Kegan, “we may hear grieving, mourning and loss, but it is the dying of a way to know the world which no longer works, a loss of an old coherence with no new coherence immediately present to take its place. And yet a new balance again and again does emerge.” Kegan describes this journey as “the evolving self.” It is out of this framework that I will begin an analysis of the parental experience.

**Biographical Narratives**

Denzin posits that our lives are organised around a personal biography: a narrative which gives meaning and purpose to the individual projects within our lives, under the rubric of a greater narrative. A life is thus

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12 Ibid, 266
an unfinished project or set of projects. A person attempts to organize those projects around his or her identity or personal biography. Lives are biographical properties. They belong not just to persons, but also to larger social collectives, including societies, corporations, and, for some, the world-system… Every life is a moral, political, medical, technical, and economic production.\(^\text{13}\)

It is, he suggests, this biographical narrative and structure which gives both stability and purpose to our identity or, to use Kegan’s term, creates a broad sense of embeddedness.

While acknowledging that there is no clear window into the inner life of a person, Denzin identifies moments which leave marks on people’s lives, which he terms *epiphanies* – experiences which manifest a person’s character and alter the fundamental meaning structure of a person’s life, in either positive or negative ways. Denzin regards lives as being shaped by key moments which leave permanent marks and expressed in different types of truth reflecting the events that have occurred (which he refers to as *facts*), the lived experience of those events (*facticities*), and the narratives which deal with these (*fiction*). Against this background, Denzin interprets the role of the biographical project as to uncover the forces that shape, distort, and otherwise alter problematic lived experiences. Denzin maintains his focus firmly on the rear-view mirror, ignoring the future possibilities which are an inherent impact on these lived experiences. The key limitation of his approach lies here: both in its singularly retrospective focus, and in its limitation to the articulated narrative.

Where Denzin’s analysis falls short is in his assumption that the real self is only present in discourses about past and present.\(^\text{14}\) Human identity is indeed formed out of stories which make sense of who we are in the present and which anchor us in our past, giving meaning to our present circumstances. Human identity is also strongly framed within some form of teleological perspective: a future towards which we are working, and which we are endeavoung to create. This future finds its seeds in the stories we choose to tell about our past and present, and may well begin to explain the ways in which such a future is consonant with and fundamental to our present identity. The articulation of the present and depiction of the future determine the selection of stories from the past as much as the way in which these stories are told, both in relation to the emphasis placed on particular stories and elements within them, and to the way in which the stories are resolved. These stories not only explain who we are in the present and how we came to reach this point in the journey, but they also carry seeds of a future identity – an indication of who we are becoming. In many cases this future identity remains unarticulated and assumed, only revealed in

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\(^{13}\) Norman K. Denzin, *Interpretive Biography*, Qualitative Research Methods Volume 17 (Newbury Park: Sage, 1989), 29

\(^{14}\) Ibid, 24
explicit terms when it is either realised, or no longer seems attainable.\textsuperscript{15} Yalom suggests that the most profound concerns that a person experiences are ultimate concerns that are rooted in the past but are \textit{primarily related to future projections}.\textsuperscript{16} The framework for this narrative future is often dictated by the broader cultural setting in which we live and flows from its values. We invariably live our lives not only as a composite of past events and interpretations, but also within the framework of an unwritten and often unspoken future.

While Denzin acknowledges that no reading or writing of a life is ever final,\textsuperscript{17} he fails to explicitly acknowledge the tentative and formative narratives which are already in seminal form within the human psyche, a narrative which is formed against and informed by particular cultural, familial and personal backgrounds. While Denzin resists this notion explicitly,\textsuperscript{18} he does recognise the presence of turning-point moments which shape our identity, thereby implying both a new present and a differentiated and hitherto unforeseen future. But by reading biographies only as texts of past events, Denzin ignores a significant aspect of the process by which an epiphany makes its mark on a person’s story – whether and in what way it is integrated into the new, post-epiphany narrative. An assumption of smooth integration is assumed, if not implied, even while acknowledging that lives are permanently marked and occasionally turned around by various circumstances,\textsuperscript{19} ranging from major events, which touch every fabric of life, to those which provide meaning in reliving the experience. Whilst joining with Denzin in acknowledging the difficulty of making clear and unambiguous statements about the inner life of a person,\textsuperscript{20} we should also acknowledge the power of the unspoken narratives which shape our identity and expectations.

**Multiple Narratives**

Bruner’s useful distinction between a life as lived, a life as experienced, and a life as told\textsuperscript{21} not only points to a multiplicity of narratives at work and a pool out of which narratives are selected and shaped, but also serves as a warning against forcing a single, integrated narrative onto a situation or individual, whilst at the same time reminding us of the power of particular narratives to exert influence at different times. We need to be wary of assuming a single coherent narrative or set of

\textsuperscript{15} Polanyi uses the term ‘tacit’ to describe that part of our knowing which guides our choices but which we are unable to give account for. The term ‘tacit’ is used to explain that which is both unexamined and unable to be explained. Michael Polanyi, \textit{The Tacit Dimension} (Garden City, New York: Doubleday, 1966)


\textsuperscript{17} Denzin, 46

\textsuperscript{18} Ibid, 46

\textsuperscript{19} Ibid, 22

\textsuperscript{20} Ibid, 14

\textsuperscript{21} Ibid, 30
values—any one person’s set of values will not always be in harmony,\textsuperscript{22} with either the broader societal values, the context of particular engagement, or in the inner values held by an individual.

In fact, it would be more appropriate to recognise and affirm the multiplicity of narratives which impinge upon a person at any one time. For any individual there may be a number of parallel narratives, which entertain points of contact with one another, and serve to support each other in their unfolding. Thus a narrative attached to a workplace runs alongside that attached to family and to personal formation, each of them making contact with each other. There will be times when the narratives are in conflict, requiring of the individual an evaluation of priorities. It is also recognised that there will be some narrative overlap whereby the same narrative purpose is nurtured and developed in two different settings, albeit via different means. Attention to the context in which the narrative is formed and played out affirms the ways in which personal narratives are not only interlinked, but also connected to the narratives of others. No personal narrative exists outside of a particular context, and as individuals move between different contexts, they will be required to attend to the different demands of each particular setting, as well as the different opportunities offered.

Macleod reflects on the distinction made by ward sisters of the person they know in crisis and the “real person,” recognising that people in a hospital context are different from they way they are in their daily lives outside of the hospital context,\textsuperscript{23} suggesting an adaptability to different surrounds and contexts. In different contexts for short periods of time we are able to suspend aspects of identity which are superfluous to the setting, without necessarily compromising the overall understanding of self. Every community creates practices which are harbingers and sources of meaning: producing “abstractions, tools, symbols, stories, terms, and concepts that reify something of that practice in a congealed form.”\textsuperscript{24} Individuals immersed in such communities become subject to the meaning embodied in its practices. While Wenger analyses the creation and exchange of meaning within the context of a community of practice—a locally negotiated regime of competence\textsuperscript{25}—within the wider community, his observations equally apply at the macro level: people are part of communities as the result of a mutually-negotiated and agreed set of meanings, which cover a wide range of processes that include making, designing, representing, naming, encoding, and describing, as well as perceiving, interpreting, using, reusing, decoding, and

\begin{itemize}
  \item \textsuperscript{23}Martha MacLeod, “On Knowing the Patient: Experiences of Nurses Undertaking Care,” in \textit{Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease}, ed. Alan Radley (London: Routledge, 1993) 191
  \item \textsuperscript{24}Wenger, \textit{Communities of Practice}, 59
  \item \textsuperscript{25}Ibid, 137
\end{itemize}
recasting. Individuals forge and negotiate meaning in a pluralistic culture and lifestyle against a number of backgrounds and in a number of settings.

Multiple stories may thus be entertained in parallel by one person at any one time, with the capacity to draw from the narrative deemed appropriate to the setting. In our pluralistic, multi-focused lives, we are habitually changing narratives according to the setting in which we operate: work, sport, social, educational and communal settings all command their own plausibility structure which we happily accommodate to inasmuch as it coalesces with our own meaning-making, or at least does not interfere significantly with it. We do not demand complete coherence, either of the setting in which we operate, nor of ourselves as humans. We happily suspend certain values and aspirations for a time in order to attend to others. This is not uncommon in a society where we live in a variety of communities, each with its own practices, values and ideals. In order to participate in community, an individual is required to adapt or subject their narrative to the narrative of that particular group. We learn to operate within community frameworks, while still maintaining our personal narrative agendas.

It is the nature of biographical narratives in Western culture to be both open-ended and multifaceted. Given that it is rare for an adult in the West to have a single focus or context for their life, or even a single framework within which it is exercised and understood, the assumption of a multiplicity of narratives needs to be both recognised and integrated into our thinking. A person’s work life, social life, and family life offer different narrative pieces and narrative locations which need to be explored for common ground and connectedness. As a consequence, many aspects of our life narrative remain piecemeal and are developed in uneven and halting rhythms. Some narrative themes may even lie undeveloped for extended periods of time. Consequently, in the light of particular life events, other aspects of our life story which remained hitherto dormant, or considered only in brief, can be rekindled in our memory and subject to re-evaluation. This includes past events or dreams which had been earlier shelved – what Charmaz calls “past futures”26. Discarded or abruptly ended narrative lines retain a dormant power.

It is therefore evident that, in addition to Bruner’s three distinctions, we need to recognise a life imagined, and a life hoped for, adding further complexity to our understanding of human identity. These aspects are often held within a life lived in what Denzin terms “the deep” – the feeling, moral, sacred, inner self.27 While not readily accessible in the normal course of events, they are

26 Charmaz, “Grounded Theory,” 45
27 Denzin, 28-29
exposed in the unfolding of major epiphanies, and are a source of greatest angst when they are under threat.

The power of these unarticulated and dormant narratives needs to affirmed and explored, noting that the parent experience of premature birth cannot be understood in isolation from them.

**Illness Narratives**

A number of writers have explicated Denzin’s theories in the context of the experience of illness. Kleinman, a medical practitioner, recognised the limitations of the biomedical framework in adequately expressing the impact of a physical ailment upon an individual, particularly in the context of a chronic illness. He noted that illness became a harbinger for revisiting meaning in the life of a patient. Depicting illness as speaking with a multiplicity of voices, he noted that a range of potential and actual meanings emerge when an individual is confronted with an illness experience, meanings which are appreciated within the bounds of relationship. Thus, they belong to more than the patient alone: touching spouse, child, friend, and caregiver amongst others. At the same time the ill person is marked with cultural meanings which may mark them with either stigma or social death, thus pushing the person to the margins of their (pre-illness) world. In this context, argues Kleinman, the sick person creates meaning which remakes the disordered natural occurrence of illness into a domesticated and controlled cultural experience, perhaps even tinged with a political commentary which highlights the marginalisation and expression which the chronically ill feel. “Illness, together with other forms of misery sometimes brings a kind of passion and knowledge of the human condition, giving an edge to life.”

Kleinman highlights the inability of the biomedical paradigm to embrace such life understandings as central to its task, let alone recognise any potential redefinition, preferring to ritualise the experience through the clinical case notes which set the parameters of interpretation for the practitioner, but which are of little help for the patient in dealing with questions of meaning and purpose. The patient is expected to be passively compliant with the treatment regimes of the hospital setting (whilst ironically expected to be an active collaborator in the treatment whilst an outpatient.) In the situation where biomedical and behavioural paradigms predominate, there is little room for or encouragement towards an exploration of meaning which emerges for the patient and the family in response to the diagnosis of chronic illness. Kleinman urges a multi-disciplinary

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29 Ibid, 87

30 Ibid, 171
investigation into the structure of illness meanings, integrated into the wider field of medical research. Recognising that most of the care for illness is delivered by the family, including which medical practitioners to seek advice from, and whether a change is needed, he sees a need to understand the structure of illness meanings – the manner and process by which patients make illness meaningful – and the various reactions and interactions which occur in the process. Kleinman’s framing of this journey as primarily individual is in some respects inconsistent with his observation that questions of meaning emerge for both the patient and the family. He has, however, opened an important window on illness meanings.

Health is for most people defined in functional terms, rather than in relation to absence of illness. While able to carry on our normal everyday activities, most people consider themselves healthy. It is when we are rendered incapable of continuing in our normal existence – regardless of whether ill health is regarded as preventable – that there is an impact on identity, and as its impact grows more severe or chronic, the threat to spoil identity and diminish the person increases.31 Pierret would argue that this is but one way in which health is viewed and interpreted, noting that the notion of health is viewed through a number of prisms,32 sometimes viewed without reference at all to the personal or social context.33 Such abstract or political notions of health require an emotional and physical distance not evident when illness threatens one’s sense of being and connection to social context. Radley draws a link between people’s response to illness and their beliefs and practices evident from their social groupings, affirming the place of illness as a catalyst for interpreting relationships in their social order.34 The capacity of illness to impact upon our social setting and our relationships within it are central to the understanding of illness narratives. Bellaby employs the concept of liminality as it applies to the transition between illness as separation from one’s original state towards incorporation, where the long-term implications of (in this case) a closed-head injury are incorporated into a new state of being.35 To view illness as a liminal event is to invite an interpretation of its implications on a wider scale than the physical realm, and to understand the power of ill health to redefine our social setting and social standing. It is our place in the world which is at stake: the social world, the economic world, and the world of ideas, values and intentions.

In reflecting on illness narratives, Bury affirms that “we experience, understand and order our lives as stories that we are living out.” He posits three types of narrative formation which take place in the face of illness: contingent narratives, moral narratives and core narratives. Through core narratives we are able to “account for events and give shape to them in terms of the way in which they feel they relate to self and others.” He notes two aspects to interpreting illness: the categorical view and the spectral view. A categorical view is marked by a clear-cut onset of the illness, and by characterisation in terms of difference from known or putative normal states, in which the onset and course of the “disease” is relatively clear-cut. On the other hand, a spectral view of illness is a function of the social process, where the illness itself is emergent in character, and a function of the social process. From this perspective, the views of the respondent move backwards and forwards between the lay perceptions and a growing familiarity with medically-based ideas.

In the case of an extended NICU stay it appears that lay perceptions and lay narratives risk becoming almost entirely subsumed to the medical terminology and perspective, as witnessed by the parents who run their homes “like a NICU” when they are discharged from the hospital setting. This is the result of parents being immersed into the NICU culture over an extended period, thereby not only allowing them to become familiar with the terminology and practice of the NICU, but also to be inculcated and retrained in its culture, a theme to which I will return.

Bury argues that the occasion of the illness occasions a “biographical disruption,” leading to a re-examination and reassessment of issues which may have occasioned, but were at least associated with, the onset of the illness. Familial, personal, and work-related issues are identified as key aspects for review, with the aim of normalising the experience – which may mean either keeping the pre-illness lifestyle and identity intact – or incorporating the illness into a changed lifestyle. Bury acknowledges the multiple uses and functions of illness narratives relative to individual circumstances.

Illness narratives, in all their variety, thus have a common touchstone. Although in this instance it is the child who occupies the notionally ill space, many of the characteristics described in first-hand illness narratives are reflected in the parent experience. Three aspects of loss suffered in bereavement described by Attig are clearly reflected: parents “suffer a loss of wholeness in three

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37 Ibid, 279
interconnected ways: Loss shatters the patterns of our present lives, disrupts the narrative flow of our autobiographies, and leaves us feeling disconnected from larger wholes of which we have thought ourselves part.”

In order to understand the loss of coherence, it is important to reflect upon the way in which meaning is initially constructed.

Acknowledgement of the reality of illness narratives is silent testament to the existence of parallel narratives which unfold side-by-side in the same place and emerging from the same circumstances. Illness narratives as told by the patient are fundamentally different in nature and content to the medical narratives which describe the pathology of the patient’s illness (and recovery): two different stories emerge from the same experience, with fundamentally different foci and emphasis. Each narrative will privilege particular information and measures, and evaluate them accordingly. The circumstances themselves are only part of the formation of meaning and identity which are subject also to the perspective of the person articulating the experience. We might then pause to reflect on the ways in which meaning narratives are constructed.

**Construction of Meaning**

Much of the knowledge we hold about our place in the world is innate – that which comes from doing, skills which are revealed only when we face a unique problem – an informal yet loosely structured knowledge which emerges from our engagement with our surroundings and from our interactions with people over time, a knowledge which is partially encapsulated by the term “habitus.” Habitus is a form of cultural artefact which emerges from within a community of practice, emerging from continuing practice. Such practices are not merely action determined by rules, but symbolic, purposeful strategies with many layers of meaning. Our identity is formed over a lifetime by regular habits we undertake, formed from an early age: saying grace at meals; saying “please” and “thankyou,” and shaking hands upon greeting are just some of the ways in which we are inducted into culture. We acquire a sense of how to behave, as expressed in the practical attitudes, preferences and actions of those around us.

The habitus is shaped in part by the roles and rituals upon which life’s progress is marked and celebrated. The presence of these markers in cultures is well-noted. They are ways of marking progress through life, including transitions into adulthood, and of being welcomed into the community, and finding one’s role within it. Although this function has traditionally been a role

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39 MacLeod.
40 Etienne Wenger’s term: Wenger, *Communities of Practice*.
played by religion in the West, such rites and rituals still exist apart from the church setting. Baby showers, weddings, 21st birthdays, obtaining a licence to drive a car, graduating from high school – these are recognised markers of progress in life, celebrations of achievement and affirmation of moving from one stage into another, all artefacts of habitus.

The grief expressed by many parents of premature infants surfaces in part from the loss of rituals to which they have attached the event of childbirth – pointing to their importance in the construction and affirmation of identity and meaning. These rituals, not only those associated with child-birth – baby showers, birth announcements – mark significant moments, and serve not only to acknowledge the movement along life’s narrative pathway, but also to recognise and affirm individuals and families in the broader societal narrative. Families of the Christian faith find the experience of baptism/christening to be an important connection in this regard, which serves to underline the importance of rites and rituals in not only shaping our narrative but also in affirming our movement along its pathways.

In a complex society, individuals are subject to a diverse array of values and expressions. An individual’s sense of identity and meaning is constructed against the backdrop of a multiplicity of sources and interactions, each formed over against and in response to the expressions of the other, and each varying in their breadth and focus of influence. Here I will explore three general “levels” at which formation occurs: culture, family and personal. These are in some senses, but not exclusively, hierarchical.

Building Blocks of Understanding

Culture
In earlier times, Western culture was much more monolithic in structure and nature. Across a national landscape there were largely agreed and accepted values and aspirations which citizens held in common. The cultural shift from modernity to post-modernity has witnessed a splintering of this, due in part to the development of highly multi-cultural and globalised communities. Nevertheless, the influence of culture cannot be ignored, as it forms the milieu out of which an individual’s sense of meaning emerges, and with which it continues to dialogue.

Culture not only impacts the values which we hold, but also the ways in which we think about such values, the thought processes by which such values are attained, and the language which is
employed to express them. Culture is, in effect, a set of codes along with the rules for using them and articulating them. Culture is the ground out of which criteria of truthfulness are established, and creates ideological force and pressure on individuals to construct their stories in particular ways with particular emphases. It is absorbed early, in the stories told to children, and through the media to which they are exposed. These stories and images of childhood are often held innately through adult years, exerting a powerful force often multiplied by its subtlety. These stories convey powerful images of good and evil, of winners and losers, and of idealised futures and dreams, shaping such perspectives at an early age with an often enduring perspective. Whether the familial story is shaped by culture or in opposition to culture, it is nonetheless shaped in awareness: the cultural narrative is known and understood.

In this context, it is important to understand the broader cultural backdrop which informs parents entering the NICU. In the following chapter, we will identify the ways in which the background provided by broader culture creates a misconception about the experience of extreme prematurity, and provides an ill-informed, if not misleading script. The treatment of extreme prematurity in the popular pregnancy literature, together with the popularised notion of premature birth as a litany of “miracle” stories, or as a journey for the child alone, masks the deep ambiguities and struggles which characterise the NICU experience which is the predominant experience of parents and child. For the most part without any personal or familial knowledge of the challenges of extreme prematurity, the framework of understanding is dictated from this broader culture: the messages conveyed through media about prematurity in the narrower instance, and the broader attitude to medical technology. This goes some way to explaining the shared perspective between families and medical staff of “interrupted narratives” that surround illness and hospitalisation, laying the groundwork for much of the anger and frustration which is expressed in the parent literature.

**Family**

The family remains the primary centre for most people in developing an understanding of the world and an appreciation of one’s place in it. Every family develops and reproduces its own descriptions and imaginings of the world in which the family lives, each successive generation reframing and reforming these depictions in the light of the changing broader cultural framework, and in light of personal reflections on the experience in their family-of-origin, and their engagement with the world. Each family unit negotiates its new perspectives and values out of the interplay of the

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44 Denzin, 77
changing nature of the family relationships over time, the backgrounds out of which the parents have emerged, and societal pressures. While we might want to draw a distinction between family scripts, rituals, myths, stories and legends, it is sufficient for the purposes of this paper to recognise that families form their own sense of identity and purpose which provide a framework for assimilating and responding to various life events. These frameworks provide an important foundation of understanding for all individuals.

Most scholars would suggest that the familial narrative has greater sway on an individual, given that the process of socialisation primarily occurs through family interaction, where children learn the dominant scripts in society, but it is often hard to distinguish the familial narrative from its wider cultural setting. However, such is the pervasive influence of our communications and entertainment industries in the 21st century that it is difficult for any individual or family to avoid being strongly influenced by popular culture. The vast majority of the population is regularly exposed to the communications media: television, internet, cinema and music, each creating an environment for understanding the major themes of life and their impact on an individual. The familial context may offer an interpretive framework and stance, but the narrative itself is inevitably established within the wider cultural setting. This is true whether the individual family is part of a strong sub-cultural grouping or not. Family scripts are embedded in, or formed in response to, the larger socio-cultural environment.

Byng-Hall indicates that family scripts are also embedded in a hierarchy in which cultural mythology gives primary meaning to all other aspects. Although changes in the lower order meanings occur, they do not easily shift the primary mythology of culture. At many levels, he suggests that the meanings support and maintain each other. From the time of birth, the process of induction into this family perspective is begun, initially in the patterns of interaction which are established at the outset with the infant. These patterns and other aspects of care are impacted by the parents’ experience, as well as the influence of the extended family. In addition, seeds are sown about hopes and expectations for the future, themselves influenced by all these factors. In this emerging interaction, a new family perspective is shaped, influencing both parents and child in terms of their way of understanding the world. A family’s larger system myths and beliefs are

48 Byng-Hall, 58
49 Ibid, 223
shaped as a curious amalgam of wider culture, an intergenerational legacy, and ongoing experiences, occasionally formed by a critical incident. \(^{50}\) As individuals grow, family provides a framework in which they have learned to deal with pain, conflict and uncertainty. As such, the family is an operational and dynamic system. Ultimately a notion of an “ideal family” is formed against the backdrop of wider culture. While the closeness of individual family members to one another shifts from time to time, and the level of intimacy and depth with it, the family remains an operational system, carrying and perpetuating its own values and ideals. Just as families have myths and beliefs about individual members, specific relationships, and the whole family, which constrain members views of reality and organise interactions, so families and larger systems have myths and beliefs, regarding one another and their relationships with each other, which either facilitate change or function to maintain the status quo. \(^{51}\)

In responding to the challenge of an extremely premature birth, the ability of the family in responding constructively faces a number of problematic challenges:

As already indicated, **the framework of understanding and preparation provided by the broader culture is inadequate, if not entirely misleading.** The resources provided by the wider community in preparation for such an event are misleading if not non-existent at the macro level.

**The event of premature birth is something for which most families have little or no framework for dealing with the challenges to meaning and identity.** The lack of personal or familial experience of prematurity undermines the normal processes of support and care which surround family members in times of crisis. At the worst, the birth of a premature infant presents most families with an event for which they have no perspective, no script, and no pattern for coping. \(^{52}\)

Whatever understanding is held is gained through the broader cultural perspective, as filtered through the media. Overcome with a sense of loss and grief for a child who was not born, \(^{53}\) they are faced with the task of constructing understanding and garnering resources for a journey for which they have little or no framework of understanding. They are entering a world they not only do not understand, but also a world in which they are cut off from the normal resources of meaning-


\(^{51}\) Ibid, 72


making in the face of a circumstance where popular culture’s preparations have been inadequate, if not misleading.

The NICU experience serves to isolate the couple from the broader family resources because

1. **Access to the NICU is limited.** Visitation policies often restrict access to a limited number of family members. Some family members will distance themselves from the NICU for their own personal reasons. The NICU rarely becomes an experience which the broader family enters in any significantly direct manner.

2. **Time pressures make meaningful contact with wider family problematic.** Given that the family is the primary source of learning through interaction, the marginalisation of the broader family from the NICU mitigates against this from an early stage. By obviating the wider family, marginalising the parents, and critically injuring the parents in their ability to parent qua parents and not as pseudo-medical staff (not to mention the social isolation which the NICU imposes on the infant), parents are hindered and hamstrung in their capacity to integrate the experience into their broader sense of meaning and their social world.

3. **Parents struggle to articulate the experience in meaningful ways to family members.** Remarkably, most care for illness is delivered not in biomedical institutions or by professional practitioners but by the family. This lay arena of care also includes advice from friends and others about what to do, when to seek professional care, where to go for it, and whether to follow the advice of current professional care givers or change to other practitioners. The inability of parents to invite the broader family into a first-hand experience, coupled with their inability to give adequate voice to their experience, isolates them from the prime source of care, support and meaning-making. The NICU not only isolates the most important form of care in the hospital, it consequently erects barriers which inhibit the capabilities of the wider family to actively and knowingly enter care when the child is discharged. A new critical story has unfolded away from the gaze of the broader family. The capacity to induct the wider family into this story is impacted against the backdrop of the broader cultural perspective on prematurity, even if it is mitigated by the snippets of information which emerge from the NICU.

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54 Kleinman, 259f
In each family, the closeness and depth of relationship varies from person to person. As an operational system, what affects one member affects not just other individuals within the system, but the whole system itself. In times of illness, the family is at the front line of any crisis of meaning - one person in a family cannot mourn and change without evoking mourning and change in all the relationships of the family. Parents are then caught between adapting to a changed relationship with their newborn child, and pressures concomitantly emerging within their wider family network. Exigent circumstances require that the latter are inevitably sacrificed to the needs of the child.

Both the Western medical model and most Western psychotherapy are grounded in the premise of the autonomy of the individual. Augsburger identifies a range of assumptions which emerge from this broad premise:

- The individual can create personal meaning independent of social entanglements;
- The personality can separate itself from its family emotional heritage;
- The individual has the power to look unafraid at the insecurities of a helpless childhood;
- The individual has the transcendence to review the crises of life objectively and dispassionately;
- The individual has the capacity to channel sexuality, aggression, rage, egotism, and greed toward creative goals;
- Freedom and growth come from cutting loose from imperfect parents, siblings and family roles; and
- The individual can face suffering without avoidance, death without denial.

All of which rises from the individual powers of the fully realised autonomous self.

These assumptions obviate the need for a NICU to create space for, or to facilitate, wider family engagement in the realities of the NICU. The prevailing assumption is that individual parents are capable of adapting to and assimilating the NICU experience without disruption to or resourcing from other relationships and personal capacities.

The biomedical model of care limits its focus even more narrowly to the attendance to the needs of the physical body. In relationship to care for the infant, this results in a disconnection from the needs of the parents, and the child vis-à-vis the parents, from the practice of medical care. Thus engagement with the hospital system has a number of narrowing impacts on the resources available for families in times of need. The family world becomes colonised in medical reports and charts.

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56 Ibid, 148
57 Patton, 129
58 Augmenting Augsburger’s point from Augsburger, , in which he argues that most western psychology is so grounded.
59 Ibid, 365f
which become the sum total of understanding about the patient and the circumstances to be faced. They are trusted for their objectivity, and assume a totality beyond their innate capacities.

Hospital systems and the flow of information within them revolve around reports and charts. Although it is not unusual for families to engage with larger systems over an extended period, the written reports frequently assume authority for the totality of the truth of the situation, rather than as a view from a particular perspective. These reports rarely conceptualise issues which engage families in the context of the system. This is an agreed perspective, as indicated by the anger expressed by parents when observations about their apparent responses to the situation are recorded in charts and reports. The ambiguous relationship between parents and hospital leads to resistance by some parents at being characterised as a patient through having observations about their engagement in the NICU being recorded, reported and encoded in such a way, yet it is difficult to avoid the conclusion that this marginalisation contributes to the lack of understanding concerning the place of parents in the system and the impact of the experience upon them. When a family is required to interact with larger systems for long periods of time, the boundaries of the family must shift, sometimes profoundly, in order to accommodate the continual presence of larger systems. In the highly individualised view held in the West, it is easily forgotten by parents and institutions that family scripts are embedded in, or formed in response to, the larger socio-cultural environment. On the other hand, once the family accepts that their meaning system about the problem is socially constructed, it becomes possible to deconstruct.

A word of caution: we need be careful here of ascribing a singular set of family values and identity. At the time of entering the NICU it is reasonable to assume that a family has already embarked on a transition, either by virtue of the length of the marriage relationship or by virtue of a prospective addition to the family. The strain placed upon this emerging and formative set of family values needs to be recognised. Sturniolo points to at least four basic ways that the marriage is strained by the event: the diagnosis awakens powerful emotions in both parents, the child may become the symbol of a shared failure, the organisation of the family is altered completely (at least for the duration of hospitalisation), and the situation creates a multitude of opportunities for conflict. To speak of family frameworks for a young married couple or family is to acknowledge the family backgrounds out of which they have come and the formative environment they are in the process of

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61 Imber-Black, 165
62 Ruiz and Atwood, 90
63 Sturniolo, 108
establishing. Family frameworks are dynamic, and subject to the culture out of which the family emerges.\textsuperscript{64}

\textit{Personal}

In addition to recognizing the place of broader culture and familial values in providing building blocks for identity and meaning, we continue to affirm the individual differences which are often regarded as the foundation of Western thinking and value. In contrast to absolutising the individual, we recognise that an individual’s values and identity is framed within, against the backdrop of, and in dialogue with the broader culture, present family setting, and the family of origin.

The process of interpretive biography places the personal perspective of the individual at the centre of investigation. Denzin articulates the framework in these terms: “a basic question drives the interpretive project in the human disciplines: How do men and women live and give meaning to their lives and capture these meanings in written, narrative and oral forms?”\textsuperscript{65} In similar ways illness narratives seek to recover the individual voice which is often subsumed to the illness or disability itself, placing the individual at the centre of investigation. The ways in which the individual’s narrative perspective is formed is an important part of the investigation, given that it is a primary way in which individuals make sense of experience.\textsuperscript{66} The danger with narrative and biographical approaches lies in the investigative focus on the individual, and the events which shape the individual. The impact of culture and family are in danger of being overlooked, assumed, or regarded as an obstacle to individual fulfilment. The narrative and biographical perspective is at home at the personal level, yet it is in danger of missing the context in which these perspectives are formed. The personal values of an individual cannot be adequately understood without reference to the cultural, historical and familial perspective out of which an individual has emerged.

Denzin anchors personal identity in the cumulative experience of epiphanies: key moments – often moments of crisis – which leave indelible marks on the lives of individuals. As we give voice to these experience, he argues, we shape our humanness and our sense of self.\textsuperscript{67} It is this view of personal value which also underpins illness narratives – that it is found in the stories we tell about ourselves that our value as individuals is described and shaped. These stories, the metaphors we

\textsuperscript{64} Thus the extended family influence is greater in some cultures, where the roots of family frameworks run both deep and wide.
\textsuperscript{65} Denzin, 10
\textsuperscript{66} C K Riessman, \textit{Narrative Analysis} (Newbury Park: Sage, 1993), 4
\textsuperscript{67} Denzin, 78ff
choose\textsuperscript{68} and the words which shape them not only allow and create connections with others, they also create a sense of moral value. The interplay between broader cultural, familial and personal perspectives serves to remind us that “no reading or writing of a life is ever complete or final. We must prevent words like autobiography, biography, and biographical method from assuming a force which gives a presence to a centred life that it cannot have.”\textsuperscript{69}

Some of our personal identity appears to us as a stranger:\textsuperscript{70} we are often unaware of the values we hold and that which has given shape to them until they are revealed by dint of circumstance. Personal identity and its expression in narrative form are not synonymous. Both are fluid constructs, a mixture of mystery, mantra and mythology, continually shaping and being shaped by present experience against the background of the broader culture and familial heritage out of which they have grown and in which they are embedded. It is in the process of seeking to articulate our identity that we embark upon the journey of understanding. Much of our value system remains innate, often buried deep within the unconscious,\textsuperscript{71} never complete or final, neither coherent nor linear in the expression.\textsuperscript{72}

What factors then contribute to the ongoing shape of our personal identity and value system? In addition to the broader relational and contextual contribution of culture and family, various personal factors are evident. Some of the contributors to personal identity include: gender, economic and social class, education, race, language, loss and suffering, play, imagination and dreaming, technology, myth, metaphor, allegory, parable, fantasy, and vision (a list which must be taken as indicative rather than exhaustive).

A number of these factors may well be regarded as products of wider or familial culture, yet are also variants at the personal level and warrant attention here. In the face of all other things being equal, the personal differences which emerge in such areas do impact the ways in which a person constructs meaning and identity. There is no such thing as human nature and identity which is independent of culture;\textsuperscript{73} the myth of the absolute individual must be exposed for what it is: a misleading and empty premise. No man (or woman) is an island. Yet the ways in which each

\textsuperscript{68} Susan Sontag, \textit{Illness as Metaphor ; and, AIDS and Its Metaphors}, 1st Anchor Books ed. (New York: Doubleday, 1990)
\textsuperscript{69} Denzin, 46
\textsuperscript{70} Parker Palmer’s image, Parker J. Palmer, \textit{The Company of Strangers: Christians and the Renewal of America’s Public Life} (New York: Crossroad, 1981), 125
\textsuperscript{71} Augsburger.
\textsuperscript{72} Denzin, 44f
\textsuperscript{73} Clifford Geertz, \textit{The Interpretation of Cultures} (New York: Basic Books, 1973), 14
impacts upon the overall perspective of the individual are diverse, rendering a unique image in each case.

**Gender** impacts our personal identity and value system. Perceived differences between the genders run deep through all cultures, and continue to impact the ways in which value is ascribed and adopted. Gender issues are always present in any significant relationship and often there are also inherited myths that affect the way individuals are perceived and engaged. Individuals are invariably looked upon differently according to their gender, and this in turn shapes their own perspective on the world and their place in it. Gender is more influential than are economic and social class in determining a woman's power.

**Economic and social class** are not only about power in broader society, but also have a considerable impact upon personal perceptions and the ways in which these are given voice. Blair notes that middle-class respondents, relative to working-class respondents, not only appear to use more mentalistic language in describing their personal experience of distress, but they also appear to interpret others’ distress in more mentalistic terms, attribute more psychological causality to the onset of distress, and give more value to psychological strategies for dealing with distress, demonstrating just one aspect of the way in which economic and social class shape the expression of narrative for an individual.

**Education** impacts the ability of the person to articulate their story, but also the imagery and language by which it is expressed. The type of education, the level of formal education and the disciplines in which study has occurred all serve to shape the ways in which individuals view the world and their place in it.

**Race** All ethnicities bring a rich and diverse heritage, each with its own rules of interaction and metaphors of meaning, along with a unique experience of engagement with the wider world. In Indigenous Australian culture, a man is forbidden (out of respect) from speaking with his mother-in-law, and is required to marry a woman with a particular skin name. In many Asian cultures, young people are not allowed to look into the eyes of an elder, instead bowing their head to the ground in respect while talking with an elder. Race dictates the ways in which individuals are allowed to engage with other members of society, and creates power structures and rules of engagement, providing a framework of meaning out of which an individual constructs their own

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74 Patton, 49  
75 Ibid, 50  
76 Blair, 42
narrative sense of the world. Individuals cut the cloth of their racial heritage to their own narrative identity.

**Language** Different languages offer different ways of expressing reality, and also carry limitations. Different languages have expressions for experience which are not available in others. The ability to articulate an experience helps shape the ways in which we value it. This includes the symbols available to us. Where no words exist to explain a reality, the capacity of an individual to harness it is diminished. New languages not only provide new words for explaining the world, but also offer a new construction of the world.77

**Loss and Suffering:** the experience of loss leaves its scars upon the psyche of all individuals. The ways in which we understand and interpret these losses, both in terms of cause and impact, shape our value system. Loss makes demands upon individuals to revise their assumptions about the world and their place in it.78 This broader category embraces that which illness narratives articulate: the experience of suffering in all its forms shapes our view of the world and the perspective of our place in it. No two persons experience and interpret loss and suffering in the same way. The same event can become a catalyst for very different narratives in different individuals, even those who hold a close and deep bond.

**Play, fantasy and vision:** Whitehead explores the ancient notion of play as creation, exploring the way in which play shapes reality and our place within it.79 In play we imagine reality, and our place in it, anew, by testing the limits and exploring both mobility and possibility. Writing from within the discipline of practical theology, Whitehead explores the way in which meaning is made where there is no ready-made answer within the tradition of our experience. After exploring the challenge of the interplay of tradition, culture and personal value, and reflecting on the authorities in our lives, Whitehead suggests that through play we begin to imagine different realities, to test the limits of present realities. Play and imagination are linked but not identical. Through play we begin to imagine an alternate reality, an alternate story. Wenger describes imagination as our capacity of “expanding our self by transcending our time and space and creating new images of the world and ourselves.”80 We are enabled to dream about possibilities and toy with them. To dream in such a

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77 Byron J. Good and Mary-Jo Del Vecchio Good, ““Learning Medicine”: The Constructing of Medical Knowledge at Harvard Medical School,” in Knowledge, Power and Practice: The Anthropology of Medicine in Everyday Life, ed. Shirley Lindenbaum and Margaret Lock (Berkeley: University of California Press, 1993), 97-98
78 R Goldsworthy and A Coyle, "Spiritual Beliefs and the Search for Meaning among Older Adults Following Partner Loss," Mortality 4, no. 1 (1999), 21
80 Wenger, Communities of Practice, 170
way is to allow oneself to be liberated from the present reality for a time. To be more than mere flight of fancy, however, we must return to the present reality in order to begin mapping a pathway to this imagined alternate. Bettelheim uses the term fantasy to describe that which in young minds fills the gaps in understanding, though whether it need be limited to young children ought to be questioned. Such fantasies are rarely fully discarded, and always have an ongoing impact on the shape of one’s identity and sense of meaning. Adults required to fill gaps in understanding are not beyond the creative realms of fantasy as an avenue of exploration.

**Imagination and Dreaming** Lester suggests that imagination is essential to maintaining hope - our identity not only being influenced by the past that we "re-collect" but also by the future that we "pro-ject". We cannot separate "who we have been" and "who we are now" from "who we imagine we are becoming." Imagination and dreaming gives form to an as-yet-unseen future growing out the present. While hope remains we refuse to stop imagining, regardless of the situation.

**Technology** Lupton exposes the shift in thinking about the body as an engine to regarding it as a computerised system whose code needs to be understood, reflecting the shift in technology from mechanics to computers. In profound ways the technology which is available to us and with which we engage not only serves to shape the ways in which we interact with the world, it also creates capacities to see ourselves and the world in different ways, with different paradigms at work. New technologies and techniques such as artificial intelligence, cloning, cybernetics and genetic modification represent vital challenges to Western culture’s understandings of what it means to be human.

**Myth, Metaphor, Allegory, Parable** The range and type of stories to which we have been exposed impacts our understanding of the world in which we live. Bedtime stories told to children are much more than entertainment: they paint a picture of the world, offering interpretations of good/bad, right/wrong, responsibility and power. The particular stories which an individual has heard and imbibed will shape their identity and response to events and issues in later years. These are effectively filters and lenses through which we interpret and perceive reality. As important as it is to

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82 Andrew D Lester, *Hope in Pastoral Care and Counseling* (Louisville: John Knox Press, 1995), 65
83 Ibid, 36
85 Graham, Walton, and Ward, 167
understand the way the person creates the world, we must also understand the way the world creates the person.  

An individual’s narrative will be shaped by a unique interplay of these individual aspects. The ways in which particular perspectives impact upon the overall narrative world in which an individual seeks to live out their life is not easily articulated. An identification of the factors at work at this level serves to demonstrate the depth and breadth of resources available in constructing (and reforming) individual narratives, but also serves to demonstrate how difficult it can be to include certain life aspects into a narrative, and why events can be disruptive. The experience of premature birth, as an example, does not readily appear in the type of imaginings which these factors represent. The poverty of language for describing the event, the likelihood of such an experience, the application of technology, and the available myths and metaphors for example, provide little fertile soil for constructive and realistic consideration ahead of the event itself, and in many instances are misleading in their representations. The resources available at the broader cultural level and the familial level are inadequate at best, and often misleading and therefore of limited value in constructing a personal narrative apropos of entering the field of neonatology at a personal level, and therefore require an adaptation of narrative in situ, under duress, and where the primary narrative lines are steeped in the biomedical tradition.

The Nature of Narrative Understanding

The idea of life as narrative is powerful. A narrative construct helps an individual to make sense of particular experiences, placing them within the context of a broader life understanding, allowing them to draw meaning from and give meaning to other aspects of existence. By articulating experience in narrative form, we also gain capacity to reflect upon experience, whilst at the same time being empowered to exercise some control/mastery over it. The danger lies in overreaching, by stretching the metaphor too far, giving narrative forms a rigidity, singularity and coherence which is enticing but not reflective of reality. Personal narratives are never fixed, whether in illness or in health. They reflect the human characteristic of mortality and ambiguity, growing and changing according to the individual and their circumstances, as well as the tools for expression. As such, all narratives remain both contingent and flexible, subject to revision as circumstances change. Life narratives are always in formation and deformation, always at risk, ever subject to and impacted

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86 Kegan, 3, 114
88 Bury, 279
by our experience. All narratives, including scientific narratives,\(^{89}\) maintain an element of or an opening to the chaotic.

I have already noted that individuals invariably sustain, entertain and nurture multiple narratives in parallel, each capable of sustaining multiple meanings, seldom attaining or maintaining a single coherent, integrated narrative. These narratives lines are ever formative by nature: open ended, capable of multiple application and attribution. Whether individuals yearn for a meta-narrative – an overarching story in which all other narratives find their home – is a matter for current debate. The complexity of issues and contributors to our overall sense of identity which work towards ascription of meaning in the world, together with the pluralistic settings in which we live out or lives, mitigate the notion of a single, integrated narrative of meaning and identity. Although many aspects of our narratives are expressions of the broader cultural and familial milieu, a unique combination of factors serves to construct a uniquely individual perspective on the world. That some aspects are held in common with other individuals establishes connecting points which create a platform for engagement, dialogue and co-creation, but the unique construct and alliance of perspectives makes each individual narrative like no other. Yet we cannot escape the reality that all understanding is also transactional, communicative, and profoundly social. Meanings are not simply about one particular individual’s experience, but are also very much about social networks, social situations, and different forms of social reality. Meanings are therefore both shared and negotiated,\(^{90}\) maintained-in-relationship. No matter how much we evolve as individuals, we are always still embedded, always connected to others.\(^{91}\)

As individuals endeavour to juggle these multiple narratives, they retain the seeds of conflict, both intrapersonal and interpersonal.\(^{92}\) Kegan may well be right in suggesting that the mental burden of modern life may be nothing less than the extraordinary cultural demand that each person, in adulthood, create internally an order of consciousness comparable to that which ordinarily would only be found at the level of a community’s collective intelligence.\(^{93}\) Why it is that meaning-making falls in a particular way for a particular individual often appears to defy logic. Some of our meaning-making is completely idiosyncratic and falls under no governance or regularity other than the regularity of our unique personalities.\(^{94}\)

\(^{89}\) Rayna Rapp, "Accounting for Amniocentesis," in *Knowledge, Power and Practice: The Anthropology of Medicine in Everyday Life*, ed. Shirley Lindenbaum and Margaret Lock (Berkeley: University of California Press, 1993), 71

\(^{90}\) Kleinman, 185-186

\(^{91}\) Kegan, 257

\(^{92}\) Lester, 39


\(^{94}\) Ibid, 206
All understanding, whether narrative or otherwise, is also fundamentally practical in nature, serving to give meaning to the life choices we make, to provide a framework of legitimacy for our present behaviours and our future endeavours, and to facilitate decision-making by determining boundaries and horizons for particular courses of action. Whilst all our practices have theory behind them and embedded in them, the deepest question which our personal narratives address is that of how we should live and why we do live in a particular manner. Rarely are we given opportunity to think and act practically in fresh ways. No narrative emerges de novo. Much of our practical wisdom and understanding is assimilated early and lies buried deeply, often in the unconscious, contained in metaphor, image and narrative pieces.

Byng-Hall suggests that scripts are embedded in a hierarchy: Cultural mythology – Family myths and legends – Family script – Episode or scenario – Act of communication – whereby the beliefs at the top of the hierarchy give meaning to all those below. While accepting his premise that changes in the lower order do not easily change those higher in the hierarchy, I would emphasise that cultural mythology has its origins in and has developed from the “ground up.” It is the age and breadth of acceptance of cultural mythology which gives it power, but it ever remains subject to common acceptance and practice across the community. Cultural mythology is not easily or quickly transformed or overthrown, but the genesis of such shifts is invariably in what he terms “lower order” meanings and actions. But such cultural mythology is in no wise deterministic. Individual acts of communication and individual episodes, while embedded in a particular cultural mythology are not captive to it.

In this dynamic framework individuals build meaning in a variety of ways:

**adaptive**, where the values of the environment in which we are found are unknowingly or unwittingly absorbed;

**constructive**, where values are built as intentionally and knowingly according to individual capability and circumstance;

**reactively**, in response to particular situations and circumstances which emerge in life – more often unexpected or irruptive events;

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95 Augsburger, 262
97 Mudge, "Thinking in the Community of Faith: Toward an Ecclesiological Hermeneutic," 109
98 Browning, 11
99 Byng-Hall, 58
disruptively, whereby an individual is forced to abandon previous meanings in the face of overwhelming evidence, or a cataclysmic event in which the prevailing image of the ultimate environment is destroyed or fails; and reconstructively, whereby an individual begins to refashion a sense of meaning in the wake of disruptive elements.\textsuperscript{100}

I concur with Denzin’s summary on narratives:

1. stories always come in multiple versions, and they never have clear endings or beginnings;
2. stories are grounded in a group’s culture where criteria of truthfulness are established;
3. the stories told are never the same as the stories heard;
4. stories are shaped by larger ideological forces which put pressure on persons to establish their individuality (and self control) in the stories they construct.\textsuperscript{101}

In addition to reaffirming the future implicit in these stories, I would also reaffirm that individuals hold not only multiple versions of stories but also multiple stories in parallel, some of which remain unarticulated. These may be the most powerful narratives of all.\textsuperscript{102}

These life narratives, or, perhaps more correctly, loose collections of vignettes, serve to explain the world to us, to put individual events and occurrences within a broader framework. They connect us with the past, a narrative woven from key events in our lives, and key stories which we have heard. They enable us to interpret the world in the present moment: making sense of the manifold events and pieces of information which flow past us. A narrative contains images of an ideal future, and any number of means by which it might be achieved. Life narratives are effectively plausibility structures, serving to provide a meaning framework for the unfolding pieces of our lives. They are strong and supple, able to withstand singular and punctiliar events which might attack their very fabric, and bend to accommodate unforeseen realities. Some discordant details can pass through without changing or distorting the narrative itself. A strong narrative often has the benefit of years, sometimes of generations, and evidence of a strong socio-cultural framework to reinforce it. There are always cracks in this structure – all humans are vulnerable to the destruction of the framework – and thereby the collapse of their sense of self, and their place in the world. Yet while this viewpoint stands, while the narrative structure holds, it enables us to sift and evaluate information and events, giving meaning to and reinforcing the overarching narrative, casting aside that which is regarded as of no significance, or held pending further developments.

\textsuperscript{100} A response to James W Fowler, \textit{Stages of Faith: The Psychology of Human Development and the Quest for Meaning} (Blackburn: Collins Dove, 1981), 29
\textsuperscript{101} Denzin, 77
\textsuperscript{102} Atwood, 9, reflecting Foucault, and Browning, 281
But I strongly resist that notion that all pieces weld into a single coherent narrative. Use of the term “narrative” can be misleading and diminishing of the forms of understanding which are embraced by the term. A narrative life is rarely a monolithic or even an integrated structure, but more a collection of loosely connected ideas which serve to provide a framework for understanding one’s identity and purpose. Though the term implies a storied form of understanding, this is only one part of the way in which meaning is carried forward. A life narrative may be a collection or mosaic of stories, some holding greater significance than others, depending on the setting, but it may also be influenced by images, impressions, emotions and memories. A life narrative, or part of it, does not need to be able to be articulated in order for it to have influence over an individual. It might even be argued that the unarticulated narratives have greater power for the lesser understanding attached to them. Attwood argues that the most powerful knowledge is often the most taken for granted, acknowledging that we are generally unaware of the story which shapes our knowledge.103

Life narratives are not abstract constructs, they issue forth in lifestyle choices, in customs and conventions which determine our behavioural priorities and choices. They issue forth in *a habitus* – the regular habits of life and performance – which are not merely an outflow of our narrative but serve to reinforce its validity.

**Questions which remain**

Given that individuals entertain multiple narratives in parallel, we need to consider the relationship of the multiple narratives to one another. Are they mutually exclusive? Related to context? Are there common elements which underpin their apparent variety? How are conflicts between these narratives resolved, or are they left unresolved – a matter of continuing tension? Are some narrative threads able to be cast aside without destroying the overall scope and structure? Is there a ground out of which they all rise – a deeper narrative or worldview which sustains these multiple narratives in synthetic harmony, adding strength and diversity to each other?

The use of “narrative” as a metaphor has its limitations, not the least of which is that it imposes an artificial linearity to a person’s life, suggesting a cogency and coherence which is in reality an artificial construct. The use of “narrative” as a rubric for interpreting and explaining the meaning which people do ascribe to life is both helpful and limited. But we need to recognise that the notion of narrative is a modernist construct which imposes a sense of both linearity and coherence to an otherwise fragmented and piecemeal work-in-progress. The idea of narrative is a helpful tool in detailing individual meaning-making and identity, but needs to be moved out of its one or two-

103 Atwood, 1-9
dimensional frame in order to represent the rich diversity of a person’s experience, and honour the ongoing nature of meaning-making. Narratives are by their nature limited to words, which are themselves captive to a cultural milieu and limit the capacity to express the fullness of experience. The words themselves are metaphors for reality.

A clue to the relationships between the various narrative strands which form part of an individual’s identity is found in the switch from narrative to spatial language at moments of deep crisis. Individuals at critical moments do not speak of losing their story, but of losing their map. One writer describes the experience of an act which occasioned physical disability as “destroying the structure of her life.” NICU parents describe their life having been “scrambled,” as having been “catapulted into an odd an unknown universe.” Here we find an indication of a different perception of reality and identity. I would argue that Denzin’s basic exploration concerning how people give meaning to their lives and how they capture those meanings are in reality two different questions compressed into one. Denzin hints at other dimensions of a person’s identity as he reflects on the surface and deep aspects of a person’s life, but explores no further. Bruner’s distinction between a life as experienced, lived, and told also points to a deeper pool from which these aspects are drawn. The problems of what he terms biographical illusion and biographical coherence inevitably flow from both the employment and limitations of a narrative construct. While acknowledging the incompleteness of any biographical method, he remains with it.

Without denying or destroying the narrative imagery, we need to ask ourselves what lies beneath this constructed narrative perspective. Is there a different, image-based metaphor which might give greater strength and context to the work of meaning-making? The use of spatial imagery in the NICU both by parents and staff, (this is also used by Frank and Sontag in their approach to illness – losing their “map”) suggest the existence of a map for meaning-making – an assumed geography for the narrative world.

I would argue that the use of “map” is qualitatively different from the notion of narrative, exploding as it were the demands of narrative for a coherent and integrated viewpoint. The use of “map” invites a consideration of the perspective on the world in which these narratives are being lived out, and recognise the diversity of landscapes and settings for this lived world. “Map” speaks of the terrain out of which the stories are uttered, recognising and affirming that the narrative is played out

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104 Morris, 3
105 Mehren, 52.
106 Denzin, 28-9
107 Frank, At the Will of the Body
108 Sontag.
in a real terrain – on a constructed stage. When this “map” is ruptured by a particular event, the narratives lose the ground out of which they grow – the environment which makes them plausible and viable. Conception in this spatial construct also allows for diversity, and for a degree of incoherence, flowing from a changing and/or diverse landscape. The person’s life could then be seen as an exploration of the space. Recognition of the diversity of this world allows a degree of comfort with an inability to integrate all aspects of their domain. Continuing exploration is expected which allows one to suspend judgment on the greater picture. While there remains a capacity to return to safe and known space, an individual can explore uncertain grounds with a degree of comfort and security. Yet a deeper question remains: what happens when the journey shifts the landscape, or destroys one’s understanding of the landscape? Note the ways in which territoriality and spatial imagery is used by both parents and medical personnel in describing the experience: “Welcome to Holland,” and the “roller-coaster ride,” suggesting that the narrative also entails journey and exploration of new worlds.

The use of a conceptual “map” may be an indication that the speaker is moving into that area of personhood which Denzin describes as “the deep,” at the level Denzin describes the “person as a feeling, moral, sacred, inner self.” Further consideration needs to be given as to whether there is an underlying plausibility structure which allows narrative constructs to stand; whether there is something unspoken and as yet unidentified which gives strength and lays a foundation to the narratives by which we express ourselves, and what the nature of this plausibility structure might be.

Summary
For the purpose of this investigation narrative insights offer helpful pointers towards the challenges being faced by parents of extremely premature infants. It provides a conceptual bridge between different evaluations emerging from the medical literature vis-à-vis the parental discussions by identifying the different narrative elements which are employed in addressing the needs of parents and infant in the NICU, and the different landscape which underpins them. Narrative analysis enables us to recognise that the situation out of which parents have emerged into the NICU setting along with the NICU setting itself, and the one to which they return after discharge, are socially-constructed settings, framed by often unspoken values and stories which create expectations. It also helps us identify the presence of a narrative within the NICU and explore its long-term implications for parents, identifying the areas of dissonance which underpin some of the continuing challenges for parents post-NICU.
Evidence of the parental search for a narrative which helps them address their situation is apparent in the data in the adoption of the *Welcome to Holland* story, and the types of discussions in search of alternate constructs where the use of play and imagination in on-line discussions, particularly through virtual baby showers and the *Imagine* thread have sought to overcome the deficiencies in their present understanding and articulation of the situation. The highly technological environment of the NICU deeply impacts the ways in which parents frame their understanding of their child and future pathways for development. Tensions which emerge from the dialogue and engagement with broader cultural assumptions as well as family narratives are also in evidence. But it remains apparent that parents are still not able to articulate their story in satisfactory terms. The *Welcome to Holland* narrative is borrowed from the experience of disability. The highly technological and biomedical narrative has left the parents frustrated and isolated. The lack of connection with “normal” family narratives is a source of continuing angst and frustration.

But left unanswered is what it is that parents are searching for. Meaning? Normality? Power? Identity? Resources? In the multiplicity of needs which are discharged with child from the hospital, there is a vacuum which demands more resources than seem to be available to parents, and which does not provide a framework for evaluating the experience and redefining their journey. There remains a sense of lostness which seems to be encapsulated in the notion of having lost their “map” – their ability to read the world and identify their place in it. That a group such as Preemie-l takes a central place in this journey challenges us to address the assumption of individualism which underpins much narrative analysis, and invites us to question whether it is possible for an individual to create a new narrative, and if so, how this impacts on the relationships to family and wider community?

Narrative analysis has helped to confirm the depth of the challenges to be faced. I will now turn my attention to more fully articulating the public perception of prematurity.
Chapter Five

Parents’ Experience Through Popular Literature

The world of prematurity is largely foreign to parents prior to being immersed in it at a personal level. Given that the response to any event is shaped against the background of information and understanding which we bring to the experience, we must recognise that parents who enter the world of prematurity have an instinctive perception based on their experience and exposure in the wider culture, and in the narrower community of expectant parents and their families. This perception is further shaped by the materials in the public domain, and by the antenatal literature to which parents have exposed themselves in preparation for childbirth. Given the highly technical and specialised nature of the field of neonatology, it would be unusual, though not impossible, that new parents of a premature infant would have an intricate understanding what is involved in the aftermath of a premature birth.

In seeking to address ourselves to the source of understanding and information available in preparation for, or as background entering the world which ensues subsequent to premature birth, we need to examine the sources of understanding which inform the experience in preparation, and articulate the perception of the experience which they encapsulate.

In the normal course of events once a pregnancy is planned or discovered, recourse to resources usually takes the form of books and magazines, medical advice, and family support. In relation to prematurity in particular, given the relative newness of neonatology as a medical field, recourse to family experience is likely to be minimal at best, in which case the background is filled from less personal sources. The source materials in the public domain thus take on greater importance. Two primary source materials are evident: pregnancy and childbirth literature; and media reports of premature birth. It is out of these two primary sources that the popular understanding of prematurity grows, to which we now turn our attention.

The journey of pregnancy and into childbirth as a whole is a narrative which is strongly shaped in the public domain, reflecting strong cultural tendencies. Given the breadth of experience, the increased levels of education, and networks of family support, the perspective is shaped more specifically in response to a dialogue between technical literature and personal experience. An individual couple or woman would be more likely to know someone who has experienced childbirth and therefore able to supplement the less personal knowledge available in the literature. Childbirth is much more a part of the cultural conversation in certain age groups than premature birth can ever
hope to be. For this reason, the childbirth literature takes on a greater role in providing background information for women and couples who enter the world of prematurity.

The way in which this literature shapes perceptions of the nature of pregnancy and of premature birth, together with the profile of premature birth and development, is the product not only of the type of information presented and the manner of its presentation, but also in the relative attention provided to particular aspects of the pregnancy and birth experience: those which are privileged, those which are ignored, and those which are given scant attention. It provides an initial framework of understanding out of which the vast majority of parents enter the world of prematurity.

**Pregnancy and Childbirth Literature**

My research into the pregnancy literature began with the top ten selling books in the category “Pregnancy and Childbirth literature” from a major Australian bookselling chain. Three books on that list were “baby name” books. Only one of the ten books dedicated an entire chapter to premature birth – six pages of a total 588 pages. While noting the causes and risk factors for premature birth, and briefly addressing issues related to feeding, feelings and follow-up support, the experience of premature birth is normalised by the statement, “All the information in this book is as applicable for babies who have been premature or sick as it is for any other baby.”

The top selling book, whose author declares that she gave birth to a child who was nearly 7 weeks premature, places the experience of premature birth in the same category as having a multiple birth, in an overall contribution featuring no more than half a dozen lines. The only book in this group addressed to fathers makes no reference at all to premature birth, a perspective which is repeated in the only book authored by a male, which focuses more on the developmental years from one to four years of age. The other two books on this list are written by the same author, Kaz Cooke, who also makes minimal reflections on the experience of prematurity. Cooke devotes only two pages of her more recent book to premature birth, which was compiled using responses from a survey undertaken by over 900 parents. Physical and emotion difficulties pertaining to premature birth are acknowledged in a cursory manner with a strong reassuring tone. Her earlier work, more

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110 Gary Heard, email: 18/05/09 1:50 pm, by Kate Jones, Re: Book Sales Information, Angus & Robertson Publicity. Melbourne.
112 Ibid, 26–27
113 Tizzie Hall, *Save Our Sleep: A Parents' Guide Towards Happy, Sleeping Babies from Birth to Two Years*, Rev. ed. (Sydney: MacMillan, 2009)
114 Peter Downey, *So You're Going to Be a Dad* (Pymble: Simon & Schuster, 2005)
115 Christopher Green, *Toddler Taming*, Revised ed. (Sydney: Random House, 2006)
a personal journey through pregnancy and childbirth, makes only passing reference.\textsuperscript{117} The overall tenor of this corpus of literature is strongly reassuring, with nothing of substance related to the experience of premature birth. Parents relying on this material to develop their understanding prior to birth would assume that premature birth is only marginally different from a normal full-term birth experience, with some short-term question marks hanging over their child’s health and wellbeing.

Given the paucity of reference to premature birth in these best-selling books, I continued the search through the more prominently displayed books on the sales shelf, choosing a further fifteen books for examination, out of a large and growing corpus of available literature to inform prospective parents about the life developing \textit{in utero}. Due to improvements in, for example, ultrasound technology, what was once held primarily, if not exclusively in the human imagination is now accessible via detailed photographic imagery,\textsuperscript{118} as well as explanation.

The captivity of the pregnancy and childbirth literature to the biomedical narrative is apparent not only in the voluminous information provided in all books on the biological changes which are happening as the child within\textsuperscript{119} develops (although not always using technical medical terminology), but also in the minor emphasis given to the emotional and relational journey into parenthood and the implications for values and identity which accompanies a developing pregnancy.\textsuperscript{120} The prevailing and predominant focus in thirteen of these supplementary books, and in four of those from the list of best-selling books is the week-by-week development from conception to birth, giving these books much more of the feel of a science text book than of a handbook for pregnancy, childbirth, and ultimately parenthood. This calls into question the ultimate nature and purpose of pregnancy literature, given that the preponderance of information pertains to details which, while they might serve to demythologise the prenatal experience, or be of some prurient interest to the parents, are matters over which they have little control, and which are the product of natural growth and development. The week-by-week analysis of the foetal growth perhaps is more a testament to the power of scientific research than background information for preparation for childbirth and parenthood. Naomi Wolf questions the political nature of pregnancy literature, suggesting that the literature is disempowering of women, offering a romantic and

\textsuperscript{117} Kaz Cooke, \textit{Up the Duff: The Real Guide to Pregnancy} (Ringwood: Viking, 1999)
\textsuperscript{118} See for example, the photographic essay by Alexander Tsiaras, \textit{From Conception to Birth} (London: Vermilion, 2002)
\textsuperscript{119} I use the term intentionally, well aware of the distinctions between embryo and foetus. The pregnancy literature’s most profound contribution is to humanise what science has sought to downplay. By adding face, personality and human shape to early embryo, the level of attachment to the “child within” is increased.
\textsuperscript{120} Although there are three books from our list of top ten selling books which embrace this perspective.
ultimately dissatisfying perspective on the whole experience. Her critique suggests a political agenda in which medical institutions control the flow of information and determine the ways in which the experience of pregnancy, birth and motherhood can be legitimately described, offering an often-illusory sense of control over the journey.

The detail provided on the development from conception to birth in these volumes is often comprehensive, both in relation to the physical development of limbs and organs, and in relation to interactive abilities – such as responsiveness of the foetus to noise and sleep patterns, and comprises well over half of the information provided. Ancillary matters, if addressed, are subjugated to these details and included only after full attention has been given to them. Such ancillary matters include pregnancy complications, multiple births, risk factors, and potential developmental issues. Only five of the books surveyed address issues pertaining to fathers, family values and identity, emotional and spiritual issues, or cultural rites of passage which might impact upon the way in which childbirth is approached, and which the new family life which ensues is embraced. Pregnancy and childbirth literature assumes, for the large part, that its work is complete at birth.

One is forced to conclude that this literature primarily serves to reinforce the level of knowledge held by the medical profession, and by implication, the power of the profession when it comes to alleviating concerns and helping mothers give birth. That the literature is primarily produced by medical practitioners (doctors and, occasionally, nurses) is no accident (although it is notable that only three of the seven books in the top ten list are so authored). This subliminal message is reinforced when information about possible interventions to assist in a healthy full-term birth are detailed. This literature subtly conveys the message that if things go wrong, they can be fixed, and that with the right approach, nothing will go wrong.

Regardless of authorship, however, the level and quality of information related to premature birth is piecemeal, inconsistent and partial at best. Premature birth is given scant and perfunctory attention in all but one of the publications examined. At best, the references are passing, reflecting an

122 Ibid, 16
123 Ibid, 2
124 Kaz Cooke, Tizzie Hall, and Peter Downey have no professional qualifications in this field.
125 An apparent conflict evident is that while pregnancy literature seeks (perhaps unwittingly) to humanise the developing embryo at ever-earlier stages in order to protect the health interests of the foetus, a counter-argument used to justify abortion – that an embryo is not a human being – is potentially undermined, at least at an emotional level.
126 Including surgery prior to birth to address potentially life-threatening issues in the foetus.
127 The exception being Dame Karlene Davis and Practical Parenting, *Your Pregnancy Week-by-Week* (London: Hamlyn, 2005)
assumption that the information is of little need. Statistics related to the incidence of premature birth varies widely across the various volumes. Yet even acknowledging the rate of premature birth within the surveyed range of 5%-11.5%, the attention given within the literature does not approach the proportion of actual births, with even the most detailed information available covering less than 2% of the total space in the book addressing premature birth. Only one volume offered any significant dedicated space to the experience of premature birth – four pages in a dedicated section – whilst others made no reference at all, including two volumes addressing infertility, a known risk factor in premature birth.

Consistent with its approach to birth in general, the literature covers the issue of prematurity with a broad and casual sweep, downplaying the attendant risks and suggesting outcomes not in keeping with that articulated by the available medical literature. Authors make first mention of prematurity in the week-by-week anthology of a pregnancy at week 24, where reference to the threshold of survival occurs, and ignore premature birth from that point onwards.

Varying degrees of attention are given to the causes of premature birth, and these are rarely collated in one place, often addressed as a by-product of other issues. One single statement stands out for its honesty in the literature:

In the United States, 9 percent of all live births are preterm. And these 9 percent are responsible for 75 percent of neonatal deaths not due to congenital anomalies. In fact prematurity is the leading cause of neonatal death… The technology to save premature babies has greatly advanced within the last decade, but often such infants survive with handicaps and at very great expense.

This statement stands in stark contrast to others which seek to wash over the realities which this statement exposes:

“After the 20th week, when the fetus may be able to live outside the uterus – even if only with a lot of help from the neonatal nursery staff and high-tech equipment – the event is labelled a preterm birth.”

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129 Davis and Practical Parenting, Your Pregnancy Week-by-Week, 262
130 Ibid, 262-265
131 Debra Fulghum and Bruce and Samuel Thatcher, Making a Baby: Everything You Need to Know to Get Pregnant (New York: Random House, 2000); Zita West, Plan to Get Pregnant (London: Dorling Kingsley, 2008)
133 Heidi Murkoff, Arlene Eisenberg, and B.S.N. Sandee Hathaway, What to Expect When You Are Expecting, 3rd ed. (Sydney: Harper Collins, 2003), 489
“While premature babies face early difficulties, it is important to keep in mind that nearly two-thirds of premature babies who survive will either grow up to be completely normal or will have only mild or moderate problems.”

“Sometimes… there may be problems in the baby’s development. But thanks to the technology of ultrasound and advances in medical treatment, many of these problems can be treated and eliminated.”

“Most babies born preterm, including those born at 24 weeks, are completely normal.”

“Babies born at 25 weeks have a reasonable chance of survival, although would have to spend many weeks in the neonatal intensive care unit.”

“In modern NICUs the tiniest premature babies – even ones born at only 24 or 25 weeks and weighing barely 450 g (1 lb) – can be helped to thrive.”

At 26 weeks, the fetus has a good chance of survival should labour occur then… The survival of “such a preterm baby weighing less than 1 kg depends upon a variety of factors.”

Authors either hide behind survival rates, and avoid reference to the post-birth experience in the NICU, long-term outcomes for children and the implications for the family, or narrow the focus to the issue of lung development and breathing as the major (and by implication only) challenge facing an extremely premature infant. Such references are usually found in the specialised sections at the rear of the book, rather than in the context of the first mention of possible survival at 24 weeks in the earlier sections. The casual reader could well be excused for overlooking the incidence and implications of premature birth – an experience that one in ten will know personally. The “softened lens of pink haze” obscures a realistic view of premature birth throughout much of this literature.

Given the severe under-representation of premature birth across the literature, we note authors who seek to broaden the perspective – even if they only allow two or three pages – with reference to possible developmental delays, disability, parental anxiety (even if the greatest challenges

134 Annie Deans, ed. Your Pregnancy Bible (Camberwell: Penguin, 2007), 373
135 Peter M Doubilet, Carol B Benson, and Roanne Weisman, Your Developing Baby: From Conception to Birth (Sydney: McGraw-Hill, 2008), 147
136 Lees, Reynolds, and McCartan, 235
137 Carol Fallows, Having a Baby (Milsons Point: Transworld, 2005), 49
138 Dr Miriam Stoppard, Conception, Pregnancy and Birth (Camberwell: DK, 2005), 345
139 Doctors and Staff of the Royal Hospital for Women, The Pregnancy Book (Sydney: HarperCollins, 1999), 97-98
140 Naomi Wolf’s term: Wolf, 3
141 Carol Fallows and Shayne Collier, A Commonsense Guide for Australian Parents (Millers Point: Murdoch, 2004), 122
to be faced at home are regarded as size of clothes and nappies!); the “scary, sterile world of the NICU,” where preemies can suffer a wider range of physical, neurological and developmental difficulties, and early arrival can be overwhelming, bringing feelings of guilt and grief. Such references, however, appear as mere appendices or footnotes to the soothing biomedical narrative, and are dangerously misleading. Any parent suddenly immersed into the decision-making environment in the immediate aftermath of a premature birth would be both under-informed and ill-informed if they relied on the pregnancy and childbirth literature widely available today.

**Summary**

Whilst our focus is on the way in which the understanding of premature birth is shaped in the public domain, it is instructive to recognise that the perception of pregnancy and childbirth as a whole is shaped in ways which are ultimately dissatisfying to many women. We do well to give some consideration of the purpose of such literature.

It is worthy of further contemplation to consider the relationship of such literature to the doctor-patient relationship during pregnancy. Is it to alert parents to potential issues, or provide calming advice which, for the most part, is the appropriate response to normal events? In any case, the advice given reinforces the privilege afforded to the biomedical narrative and its preference for treatment towards survival:

> if [you go into labour] before the last month, the baby may need special care at birth. So call your doctor or midwife, or go straight into hospital. It is best for the baby to be born in a centre that has intensive care facilities, with a neonatologist standing by in case the baby needs help with breathing.

The advent of pregnancy and birth books with a wider focus embracing the conversation about values, feelings and relationships is an emerging indication that pregnancy literature in its classic form does little for many in the preparation towards parenthood.

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143 Stoppard, 345
144 Ibid, 349
146 Ibid, 315
147 Davis and Practical Parenting, *Your Pregnancy Week-by-Week*, 263
150 Reflected in the presence of writings by Kaz Cooke and Peter Downey in the top ten sellers
Prematurity in the Press

Early developments in the field of neonatology fit comfortably into the “good news” category for both the press and the medical world. As an emerging field, and with most outcomes seemingly offering a happy alternative to a still-birth, the world of prematurity has been in the vanguard of publicity in relation to development of the interface between medical science and patient impact. Whereas routinely infants born at 34 weeks gestation would have died at birth 50 years ago, the threshold of viability has been progressively pushed back to the point where infants born at 23 and 24 weeks’ gestation are routinely considered for resuscitation and treatment, with over half reaching the stage of hospital discharge. During the developing years, these events were often reported in a manner not unlike science fiction where children weighing “less than a tub of margarine,” “able to fit into an adult hand,” and in the second trimester of pregnancy have been able to be sustained from birth through to discharge into the care of parents. At the surface level what once would have been a time of deep grief for a child who has died at birth becomes a life celebrated as being rescued from death. The subtitle of an article in the Australian Women’s Weekly in April 1986 sums it up: “A decade or so ago these tiny babies would have died but today’s medical expertise and technical facilities enable such premature babies not only to survive but to thrive and lead active lives,”151 a thought reinforced by an article from Mother and Baby in the same era, which describes premature birth survival as one of the great medical success stories of the decade.152

Until recently the tone of these articles was overwhelmingly positive, optimistic and upbeat, lauding the accomplishments of medical technology and underlining how children born at such thresholds of viability overcame the odds and live healthy, vigorous lives, whilst ignoring or downplaying the depth of struggles and any related disabilities involved. In order to understand the way in which premature birth appears in the press today, three searches were conducted using the Factiva database.153 The first two searches focussed on “Group: Aust News Major Papers.” The first search asked for two terms: preemie or premmie, which returned three articles, only one of which was relevant to this study. A second subsequent search used the required term "born," and at least one of "premature baby NICU 'Intensive Care' ". This search returned 669 articles, which I read the summaries for relevance and selected 66 to read in full. Of these there were 19 relevant and not repeated from the first search. A third search was conducted, extending the search to “Group: Aust titles – all”, searching with the required term “birth” and at least one of the words “premature baby.” This returned 1452 articles, sorted by relevance. I chose the first 50, out of which 4 were

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151 Gwen Lyle and Eileen Alderton, "Babies Who Survived against All Odds," Australian Women's Weekly, April 1986
152 "Premature Babies - Gently Does It ", Mother and Baby late 1980s
repeated from the second search, 12 were not relevant, which left 7 articles related to the release of a book, and another 27 which were directly relevant to our investigations – a total of 54 articles.

The selected articles were grouped into four categories: **publicity and fund-raising, Bonnie Babies Foundation, news reports, and analytical pieces**. Those related to publicity and fund-raising account for 15 of the 54 articles, raising the profile of Vision Australia and International White Cain Day, publicising a fund-raiser for a NICU foundation, raising funds for further research, or for NICU equipment, for the Bonnie Babies Foundation, publicising hospital refurbishment undertaken by corporate sponsors, and the release of a new book entitled *Small Miracles* by the founder of Bonnie Babies Foundation. These articles build on personal stories to raise awareness and develop sympathy for the cause, with a strong “feel-good” emphasis – triumph in the face of adversity. Such stories carry some indication of the baby’s struggles through the early days, but end with an “all is well” outcome, even when disability is mentioned. The death of two triplets and a brain bleed (IVH) and perforated bowel for the surviving triplet is summarised in the parent’s own words with “I would not change it, I would do it again…,” and a 23-week baby now only seven weeks old is declared to be “lucky,” by a medical staff member though requiring a special ventilation machine for three weeks and still some time away from discharge. It is only when other complicating factors appear, such as a rare chromosomal disorder, that parental effusiveness is absent.

The extensive publicity given to the **Bonnie Babies Foundation** flows from a book release, resulting in seven different articles. The Bonnie Babies foundation seeks to “raise public awareness and important funds for medical research and equipment and to counsel families after the loss of a baby.” The tension between publicising pregnancy loss through death against that through premature birth is a difficult one to maintain, such that the stories contained in five of the articles do not pertain to premature birth, including the founder’s own story which led to the creation of the

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154 To which I will return later in this chapter.
158 Anthony DeCeglie, "Angel Kiss of Life," *Sunday Times* 13 September 2009
160 Jill Pengelley, "Hospital Is Home for Tiny Adelaide," *The Advertiser* 17 September 2009
162 Hinde.
163 DeCeglie.
164 Pengelley.
The launches of the book in Sydney, Hobart, Adelaide, and Newcastle all carried personal stories of neonatal death. The involvement of then Federal Opposition Leader Malcolm Turnbull and his wife Lucy, who experienced several miscarriages and the premature birth of their second daughter enabled the melding of the two aspects of the Bonnie Babies Foundation’s work in its publicity in a national paper. The foundation’s efforts to keep its message open to a wide audience is reflected in part of its emphasis for National Babies Day, with a focus on thankfulness and celebration for the safe arrival of almost quarter of a million babies each year. This public balancing act across different experiences is clearly designed to attract people of all experiences to the work of the foundation, in order to raise awareness, a difficult task. The reporting shows the difficulty of gaining profile and understanding of premature birth as experienced by the parents when compared with neonatal death. The naïve observer might wonder at the coupling of infertility, miscarriage stillbirth, and premature birth as similar experiences, as reflected in the journalistic emphases in the articles.

*News reports* were generated when an event of an unusual nature takes place – something which pushes the boundaries of experience or understanding, reflects unique settings or circumstances of a personal nature, or which challenges the health infrastructure, accounting for 34 of the articles. It is clear that premature birth of itself is generally no longer considered to be newsworthy. Generally for a story to receive wider or extended coverage, it needs to bear an *unusual or notable element*, pertaining to: a human interest aspect pertaining to an advancement in medical treatment regimes; political issues; or report on new research. Only one article in the selected period simply related the story of a premature birth, appearing in a free weekly free local newspaper of limited circulation. The story conveys a mixed tone for a baby who has experienced a grade four IVH, potential shunt surgery to drain the blood, bowel surgery, with longer-term potential impact on his learning abilities and motor control on his right side. While reporting that the parents “wouldn’t wish any of the drama they’ve experienced on their worst enemy,” the summation that “for now everything is OK and he’s doing all right” suggests that the struggles are over at 9 months.

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166 Sarah Marinos, "A Mother's Love," *Herald-Sun*, 3 October 2009
167 Mark Metherell, "Talking a Comfort to Parents in Their ‘Silent Sorrow’," *The Sydney Morning Herald*, 4 September 2009
172 Held September 17 every year.
173 Kate Lemmon, "Babies in Full Bloom for Spring," *The Queensland Times*, 19 September 2009
174 Outside of the city in which it occurs.
175 Gaining coverage for more than a single day.
176 Better known as “human interest stories.”
177 Sheree Hoddinett, "Kobi Now All Smiles," *Caboolture News*, 2 September 2009
of age. Summary statements such as this downplay the enduring struggle which is the experience of many parents, and downplay the ongoing nature of the problems. While for the parents in present situation in comparison with the early struggles might seem less significant, there remain significant differences in comparison with a healthy full-term birth. These statements reflect changed parent expectations as a result of the hospital stay.

There were 13 human interest stories in which the main focus of the article was on the premature birth and circumstances surrounding it, and 11 such stories where prematurity was ancillary to the main aspect of the article, 5 articles addressing political issues surrounding prematurity, with the remaining 6 articles reporting on current research discoveries.

The human interest story which received the most prominence reported the attachment of a pacemaker to a 25-week premature baby girl weighing 541 grams at birth, and was picked up by the major daily newspapers in two cities, circulated by AAP, and appeared in a syndicated weekly paper - not at the time of birth, but when an internal pacemaker was successfully inserted to replace the initial externally-placed piece which had been implanted at birth some 137 days previously. The depth of information in the story varies from a focus on the pacemaker with the only comment pertaining to the girl’s health as “she now weighs a relatively healthy 2.7 kg,” to a more expansive report which details the parents’ nine unsuccessful pregnancies and her continuing journey in the NICU requiring a ventilator to breathe. All of the articles convey a tone of thankfulness and a positive outlook, with the expressed goal of having the child home for Christmas. All other issues are ignored, preferring to focus on the girl’s survival as a result of this first-time treatment.

Two other stories received attention in more than a single article:

The first story pertains to the unattended stillbirth of a child in an Intensive Care Unit, to which the mother had been admitted suffering swine flu. The first article reports the father’s impression that hospital staff had “told him his child would have a good chance of survival if he was born premature” at the time of his wife’s admission the previous day. A follow-up article two days later reports an obstetrician opining that nothing could have changed the outcome: “When the

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180 Michelle Carnovale, "Tiny Baby's Spirit Soars," Oakleigh Monash/Springvale Dandenong Leader, 28 October 2009

181 "Tiny Heart."

182 McArthur.

mother is severely ill, the baby will be severely ill as well… even if it has immediate neonatal attention, I just don’t feel it could have survived,” she is reported as saying.\textsuperscript{184} The report of conflicting medical opinion about premature birth is set against the belief that death is a greater tragedy.

The second story reports the premature birth of a boy to a Malaysian woman travelling on a domestic flight. Both articles reported that the mother and child will receive lifetime free flights, though one article did not report the gestational age of the child.\textsuperscript{185} The second article provided confusing information about the birth suggesting the mother was “27 weeks pregnant, 11 weeks short of full term.”\textsuperscript{186} No direct information about the well-being of the child, or the mother’s state was reported.

Two further articles related to the death of a premature infant. One reported compensation awarded for the death of a twin as the result of a medical mistake five days after a 10-week premature birth. The trauma suffered by the mother is entirely attributed to the death, the article reporting that the mother “suffered depression, post-traumatic shock disorder and panic attacks after her son’s death,”\textsuperscript{187} symptoms reported by many parents of premature infants. Another death at 30 weeks’ gestation at a Newcastle hospital is reported first as a warning to pregnant women before outlining the details of medical care which were reviewed after the death, resulting in changes to hospital practices. While acknowledging that hospital practices were insufficient, the article closes with a warning that maternal age and smoking makes a pregnancy high-risk.

The balancing act between medical certitude and premature uncertainties also appears in a letter response written by a paediatrician seeking clarity on developmental concerns related to a six-month old baby born 8 weeks premature. The response begins with definitive statements about what the baby should be doing, allowing for correction due to prematurity, then shifts gear, outlining factors which may affect the development, and then concluding that “it is difficult to predict how premature babies will progress in their development as they may seem fine on discharge from hospital but problems may arise later.”\textsuperscript{188}

The final article in this category emerges from the death of a mother who delivered 13-weeks prematurely after being put into an induced coma from which she never recovered. The child, now

\textsuperscript{184} Flip Prior, "Death of Baby Boy 'Coudn't Be Helped'," \textit{The West Australian}, 7 September 2009
\textsuperscript{185} "Baby Born on Flight," \textit{Hobart Mercury}, 24 October 2009
\textsuperscript{186} "Born on a Plane," \textit{Geelong Advertiser}, 24 October 2009
\textsuperscript{187} David Killick, "$300,000 Payout for Baby Death," \textit{Hobart Mercury}, 23 September 2009
nine weeks old is reported as having “grown from a fragile premature newborn to a healthy baby.” The prognosis and analysis of the wellbeing for the premature infant is subsumed to the thankfulness that she is alive and a connection to the dead mother, whose congenital condition was exacerbated by pregnancy and swine flu. The premature birth of this daughter is set in contrast to the death of her first son twelve years previously at 18 days from complications arising from premature birth.

It is clear that these human interest articles where there is a main focus on premature birth that there is no interest in the overall impact on parents or the long-term implications of premature birth for the child or the family, save that it is communicated as an alternative to death.

In articles where premature birth is mentioned in passing, information provided about the experience is negligible. Stories include: a women who consumed up to 15 oranges a day to avoid premature birth as a result of rhesus complications; a prison education program teaching parenting skills to young men, including how to change nappies on dolls down to the size of premature infants; and a woman against whom charges of causing grievous bodily harm to her child were dropped because the head injuries “might have been received during her premature birth.” The issue of “social induction” was brought to public notice as a consequence of the decision by an AFL footballer and his wife to induce the birth of their child so as to avoid clash with any finals matches. An indepth follow-up article nine days later explored issues surrounding the choice, suggesting it “puts babies at risk and sends a dangerous message to other parents,” and concludes with the curious statement, “Because of the uncertainty of due dates, early induction can lead to premature birth.” Other stories report the plight of a police officer who alleges harassment within her own command led to the premature birth of her baby; a report on burnout among working women, which reports a woman returning to work a week after the premature birth of her second child; a request for assistance for a mother of triplets; a focus on baby obsession

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189 Evonne Barry, ""Keep Talking to My Baby If I Can't" Final Gift of Love," *Sunday Herald Sun*, 4 October 2009
190 Doug Gillett, "Mother of Nine's Medical Miracle," *South Burnett Times*, 25 August 2009
194 Gemma Jones, "Another Officer Cries Foul," *Daily Telegraph*, 16 September 2009
195 Rebeca Marshall, "Are You Heading for a Burn-Out? Women Need to Learn to Say 'No'," *Sunshine Coast Daily*, 6 October 2009
196 "Trio Proves a Handful," *Progress Leader*, 27 October 2009
questioning how to know when you’ve had enough children, an article written by a mother who had just brought her second son home from hospital after a premature birth which required more than 100 days in a NICU, yet who was immediately thinking about the next child, and an article relating the experience of spending a night in the Royal Children’s Hospital Intensive Care Unit, during which the author encounters a sleeping toddler who looks comfortably at home in the hospital, noting that he had spent 296 days the previous year between the Royal Women’s Hospital and the PICU at the Royal Children’s hospital subsequent to his premature birth.

These human interest stories are typically one-dimensional in their approach, offering little insight into the complexity and intensity of the premature birth experience for parents, even though it requires something “out of the ordinary” to gain media attention, which remains the sole focus of reporting.

The five Political issues articles add limited insight into the understanding of the parental experience of prematurity. The provision of NICU beds in Queensland was the subject of two of the articles, one article noting the decision not to devolve NICU beds to local centres so that more mothers are able to be closer to the hospital where their premature baby is being cared for, and noting that maternity services are co-located with NICU cots. A second article, reporting the pressure on NICUs, reported the rate of premature birth and its increasing incidence world-wide, noting the “higher rates of learning difficulties, cerebral palsy, sensory deficits and respiratory illness compared to children born to term.” Although prominently suggesting the strain on NICU services is caused by IVF multiple births, the article’s analysis is inconsistent with its opening blunt statement. The third article in this group intentionally confuses miscarriage, stillbirth and premature birth reflecting a bereaved mother’s desire to have the end of her pregnancy at 18 weeks and four days considered a birth, and her daughter’s life – and death – honoured. A fourth article compares the experience of a mother giving birth in a private hospital with another giving birth in the public section of the same hospital, in which it is incidentally reported that the second mother’s child was born six weeks premature. The final article in this group addresses questions of access to assisted reproductive technology for large families, a conversation in response to news that a Queensland couple have eleven children under the age of seven, even though the father can produce

198 Belinda Heggen, "Domestic Goddess," Eastern Courier Messenger, 4 November 2009
199 Grant McArthur, "Our Guardian Angels," Herald-Sun, 7 November 2009
200 Des Houghton, "Backflip on Baby Facility Blasted," The Courier-Mail, 12 September 2009
201 Suellen Hinde, "Premature Demand - I V F Multiple Birth Spike Puts Strain on Hospitals," The Sunday Mail, 1 November 2009
202 "A Way to Overcome Grief," The Observer, 11 November 2009
no sperm. Two sets of quadruplets were born, and most recently another set of twins, raising the risk profile for premature birth.\textsuperscript{204}

Six reports on new research provide varying insights into the world of premature birth. A Murdoch Children’s Institute Study detailing the differences between children born 10 or more weeks premature against those born at more than 36 weeks’ gestation is the basis for one article which outlines concerns about behaviour and socialisation, concerns which increased according to the level of prematurity. A number of probable causes are identified, including separation from the parents in the NICU, the NICU environment itself, parental stress, and physiological effects of being born premature. The article concludes with a quote from a grateful parent of twins who indicates that she has a lot of support and “one or the other might not have even been here, so we are pretty lucky really.”\textsuperscript{205} A link between abortion and subsequent premature birth is reported in a Canadian study, detailing a 93\% increased risk of premature birth subsequent to having more than one abortion, and a 36\% increased risk after a single abortion,\textsuperscript{206} whilst an Australian study is reported as demonstrating that there has been a decline in multiple births resulting from assisted reproductive technology, thus reducing the risk for premature birth,\textsuperscript{207} a factor noted in a report suggesting that it is not career choices which is the reason why more older women are turning to IVF for their first child.\textsuperscript{208} World Health Organisation research is reporting one in ten of the world’s babies born prematurely – nearly thirteen million. While rates are highest in Africa, North America follows in second place, which “produces headlines about miracle babies and leads to a false sense that modern medicine conquers prematurity – without acknowledging lifelong problems,” the article notes.\textsuperscript{209} The article also notes that the report likely underestimates the problem by examining singleton births to mostly healthy women. Outlining of risk factors in the article serves to alert to potential problems earlier, although the author of the article notes that the best approach notes that factors begin well before the third trimester and emphasises “care for infections and chronic conditions, better diet and family planning so the mother is healthier before she conceives.” The final article reports survey results which show that mothers who had to leave their babies behind in hospital in a special care nursery or a NICU “were among those who had the toughest maternity experience.”\textsuperscript{210} This group of articles moves towards a more authentic picture of the challenges

\textsuperscript{204} Janelle Miles, "The Great Baby Debate," The Courier-Mail, 14 October 2009
\textsuperscript{205} Nick Miller, "Growing up No Easy Thing for Those Born before Their Time," The Age, 21 August 2009
\textsuperscript{206} "Prem, Low Weight: Abortion Risk for Next Bub," MX, 17 September 2009
\textsuperscript{207} "More I V F Babies but Fewer Multiple Births: Baby Being Checked with Stethoscope," Australian Broadcasting Corporation (ABC) News, 24 September 2009, which stands in contrast to the assertions in a political article cited above: Hinde, "Premature Demand."
\textsuperscript{208} Renee Viellaris, "It's Not the Job, Baby," The Courier-Mail, 25 September 2009
\textsuperscript{209} Lauran Neergaard, "Thirteen Million Babies Born Premature," AAP Bulletins, 5 October 2009
\textsuperscript{210} Jen Kelly, "Separation So Hard to Bear," Sunday Herald Sun, 15 November 2009
facing parents who have premature infants, although the distinctions between those born at earlier gestations and later ones isn’t apparent.

The collection of analytical pieces stimulates reflection on the practice and policies which underpin the approach to premature birth, seeking to encourage public debate about the issues, which accounts for the final four articles. These began with and emanate from a major analysis by Richard Guilliatt, sparking a series of articles and letter responses which brought some of the complex questions of care for premature infants born in the “Grey Zone” into the public domain. Guilliatt anchors the question in the McFadden’s story, whose daughter Annie was born at 23 weeks and survived with significant disabilities. Guilliatt notes the media’s “love affair” with these “modern miracle babies” and its tendency to ignore the long-term prognosis, highlighting deep misgivings expressed among nurses which had been reported in a recent lecture, and misgivings amongst some neonatologists, countered by the more positive perspective of a leading neonatologist in Perth. The article raises questions about whether it should be a decision made by doctors, whose perspective on disability is more pessimistic than parents, and whose understanding of the lives lead by the children after they leave the ward is acknowledged as being limited. The article outlines variations in rates of disability depending upon the hospital and concludes with a defensive statement from the parents defending the life of their child. Implicit in the article is the notion which links parental struggle with disability alone, rather than the very nature of the experience itself.

This significant piece prompted two follow-up articles and a number of letters. The first article merely encouraged more discussion on the use of medical expertise resources in the light of the problem of disability rates. The second response supported the thrust of the original article and lauded its “balanced view of the potential outcomes for these tiny babies,” although the parental perspective is again notable by its absence. It is in the feedback section where the parental experience is finally recorded. Seven letters are published, four of which are from parents of premature infants. It is in these letters that the discussion is broadened to underline that the experience for parents does not end when the child is discharged from hospital, and that parental choice should be given greater weight in decision-making. One letter suggests that the true debate

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211 Though the four categories total 61 articles, I have double-counted the Bonnie Babies Foundation articles in the publicity and fundraising category, as it is a subset.
212 Richard Guilliatt, "Saving Annie," The Australian, 12 September 2009
213 The three week span of gestation from the beginning of the 23rd week through to the end of the 25th week – the period in which our own son was born.
214 "We Need to Debate Medical Priorities," The Australian, 14 September 2009
215 Janet Green, "Tragic Fate of 'Miracle Babies'," The Australian, 19 September 2009
216 "Feedback," The Australian, 26 September 2009
should be about the support families of those born at such gestations receive. All but one letter was supportive of the thrust of the original article.

**Summary**

It is only possible to conclude from the publicly available and accessible literature that the depiction and description of the parent experience of premature birth is woefully inadequate. The major emphasis remains on a full-term normal birth experience, with some reference to the physiological experience of premature birth in both the pregnancy literature and the press, and at best a passing reference to the parental journey. More than one parent indicated that they derived no understanding of premature labour and birth from the literature they had read or the consultations they received. Such lack of understanding not only causes significant added stress for the parents, but also contributes to fractures in friendships and wider family relationships, itself a subject of a lengthy thread of conversation on the list. The absence of a publicly accessible narrative or insight into the parent experience of premature birth is not only impacting the preparation of parents, but also on the reactions of the family following birth, and the ability of the parents to reintegrate into social and support networks following discharge from the hospital.

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Chapter Six
Parents Living Through Their Experience

In every caring relationship, the distribution of power impacts the way in which care is expressed and the outcomes of that caring relationship.¹ When this caring relationship embraces institutional frameworks, the interpersonal care offered is impacted by the added dimensions of the institutional power framework. Upon entering the NICU, parents engage with an organisation which has ordered procedures and protocols which entrench a certain discourse which ultimately validates particular forms of power and practice. The key measure of success determined by this discourse is the discharge of the child from institutional care into the care of the family. The purpose of this chapter is to explore the dynamics associated with the power shift identified in chapter two, and identify parent capacity to engage with and shape the discourse, and hence the direction of their own journey. By exploring the types of power which are validated, and the ways in which they impact upon parental engagement with the NICU and the consequent preparation for discharge, I hope to offer insight into parental resilience and capacity to assume responsibility for their family life in the home setting. Individual and parent capacities to shape their own narrative and to formulate a response to exigent circumstances are central to the ongoing health and wellbeing of the parents in the first instance and ultimately the family as a whole.

I undertake this exploration of power in recognition of its contextual importance in pastoral care,² and in full recognition that every community is structured and organised in ways which privilege and preference particular forms of power. This is as true of the family setting as it is of the hospital. Parent capacity to enter and engage with the NICU power structure is our focus, noting that family power structures are under stress at this point, as they are called to face a situation for which most families lack any substantial preparation. The discourse which is adapted from the childbirth literature leaves parents without a framework for interpreting the events and integrating them into their own narrative. From the outset there is an engagement between a wounded power structure (the family) and an entrenched power structure (the hospital).

Consideration of power is important because it impacts the capacity of parents to construct and maintain their own narratives – their sense of meaning and identity – within the confines of the hospital journey. In order to be active participants in constructing their lives post-birth, consideration of parental power helps us understand their relative capacities for self-care in the face

¹ Elaine L Graham, Transforming Practice: Pastoral Theology in an Age of Uncertainty (London: Mowbray, 1996), 49
of their child’s struggles. As a dynamic, shifts in power are to be expected with changing circumstances. In addressing the question of power within the hospital setting with particular attention to parental capacity to exercise power in their own familial interests, attention will be paid to the balance of power and its impact upon parental capacities both within the hospital and over the longer term. I begin by considering the types of power evident, and then give attention to their operation within the NICU.

**Power Relations in the NICU**

Every community operates within a unique network of power relations. Power exists in relationship and is capable of being utilised in productive, coercive, and oppressive ways. Patton offers an introduction to the exercise of power in pastoral settings by suggesting four types of power: *coercive power*, which serves to maintain the status quo; *expert power*, as observed in professional relationships; *legitimate power*, which is bestowed upon and flows from the holder of an office; and *referent power*, which flows to another by association with one who has power. I would suggest that the exercise of power is far more complex, and varies according to the setting in which action is anticipated. In the context of a Neonatal Intensive Care Unit, the array of power and influence serves to reinforce a particular way of being and doing.

**Knowledge Power**

What marks NICU relationships from the outset is the possession of knowledge by medical staff which purports to address and resolve the health crisis facing parents and the child in the aftermath of premature birth. This knowledge is, in the eyes of parents, life-giving and invites submission to this power for the purposes of delivering a healthy child to the parents, something which did not occur naturally in the normal course of pregnancy. This largely technical knowledge is multi-faceted, embracing knowledge about the normal course facing a premature infant, ability to interpret information and apply treatments, and an implication of knowledge about what is in the best interests of child and family in the longer term. At the outset, the understanding of this knowledge is held simply by parents – without understanding of the complexities involved in reaching their desired outcome.

**Informational Power**

Allied to knowledge power, informational power is reflected structurally in who has access to and ownership of information (including medical records and charts), who determines the relevance of

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2 Patton, 40
3 Ibid, 53
particular pieces of information and which information needs to be supplemented or sought, as well as who evaluates the information and determines the course of action subsequent to it. In the hospital setting, this power is reflected in the capacity to order medical testing, including the timing and nature of testing, as well as the capacity to interpret the information and apply any subsequent courses of action in relation to the information revealed by the test data. This power flows from an assumed level of competence and accreditation, and from the institutional frameworks.

**Positional Power**
Structured organisations distribute power by allocating it to holders of particular positions within the institutional framework. Role definitions are constructed which determine the extent and limits of the power and the lines of accountability to ensure that such power is utilised in appropriate ways. A role definition provides both frameworks for operation and allocates tasks within those frameworks. In a large institution such as a hospital, these power distributions are constructed hierarchically, with deference given to those higher up the ladder. Positional power is related to knowledge power and informational power inasmuch as those who are given office also have access to information and knowledge which is privileged by the position.

**Charismatic Power**
Even in the context of positional power, particular persons are afforded greater power by the charism they bring to the position. Those who engender a deeper sense of trust by the strength of personal respect and the depth of relationships engendered are availed of increased power out of the unique matrix of power sources available. A particular person’s charism can reflect the depth of respect flowing from an amalgam of knowledge, experience, and relationship, and even relational dynamics such that two people holding the same position at different times exercise power in different ways and with a different level of authority.

**Referent/Relational Power**
Referent power is received through relationship with the one who is afforded power by virtue of other factors. This power can be referred or inferred to another on the basis of either formal or informal channels. In the context of the NICU, much of the hands-on decision-making power is deferred to nursing staff by the neonatologists. Nurses, who are at the interface between parents and child, have this referent power behind them in their ability to direct the interactions, together with the knowledge and informational power. This serves to entrench nursing and medical priorities above those of parents in the first instance. A highly structured institution such as a NICU has detailed policies for the referral of power and the circumstances under which it might be deferred to
another. Such policies are usually based upon levels of expertise, but an informal network of referent power can emerge in the relationships of trust and the perception of parents as to the capacities of particular staff.

**Institutional Power**

In any interaction with medical staff, the institution is ever present. The presence of the institution cannot be overstated, given its capacity to determine particular relations of power in order to advantage and entrench particular exercises of power and conversely disempower others. Such determinations are ostensibly made with the therapeutic outcomes at the forefront of thinking – outcomes which are evaluated according to the biomedical criteria which underpins its operations – yet the capacities of an institution to act in order to protect its own interests cannot be ignored.

Every institution implies – if it doesn’t clearly articulate – a particular set of moral values, which are served, supported and defended by the power structures. While our primary gaze is focussed on the medical institution, we should acknowledge other institutional forces operative in the background, including that of the family, educational systems, and even other community organisations which are formative for the family, such as church. All of these are, in this case, subject to the primary institution which is the hospital.

In the case of the hospital, this institutional power is felt most keenly at the interface between the NICU and the parents, as it includes the power to determine access to the NICU, which includes timing of access, terms of access, and the number of people afforded access at any particular time. In addition, the institution has the capacity to move the location of the child, without discussion with the parents – an action which can be distressing for parents.

**Emotional Power**

In identifying the emotional issues involved in the circumstances of a premature birth, we are recognising a key component of the power distribution at work in the NICU. Where issues of life and death are present, the stakes are at their highest. The construction of the narrative surrounding the birth is such that the keys of life and death seem to be placed into the hands of the medical staff and the hospital in the moments surrounding and immediately following birth. In such circumstances, any action which might be perceived as having the potential to compromise the best treatment available to their child carries significant risk for parents. Any desire on their part to challenge, reinterpret or realign the existing power structures raises the question of whether this might somehow compromise the quality of care or the flow of information to parents in relation to
the wellbeing of their child. This power is present because of the emotional investment by the parents in the wellbeing of the child, and is not to imply that manipulation is orchestrated by the medical staff. Emotional power flows from imagined threats as much as from real ones.

**The Importance of Timing**

At first glance, whilst timing seems to be an odd issue to address in the context of power, it is important at this juncture to note the ways in which the circumstances of most premature births contribute to an initial establishment of power relations which is difficult to disrupt. By the time parents have adjusted themselves to the realities post-birth – having to deal with the physical recovery from the birth as well as any attendant shock – medical staff have already embarked upon a trajectory of treatment and a trajectory of narrative interpretation. Whether or not parents are cognisant of the full implications of decision-making in anticipation of a premature birth, responsibilities in the first hours and initial trajectory following birth rests firmly in the hands of medical staff, sometimes in opposition to stated parent desires. What these cases highlight is that the capacity of parents for decision-making at the time of birth is compromised by their ability to be present physically, and in some cases emotionally, which creates something of a vacuum. In the absence of a mediating influence, medical staff make decisions as a consequence of their own decision-making frameworks.

**Narrative Power**

The ways in which stories are told about the experience sets the initial framework for understanding, and sets the initial parameters for understanding roles and expectations. Whoever has the power to tell the story controls its direction and purpose. It is important to note the lack of reference to parent stories in medical literature, where evaluation of the experience is based on medical and nursing observations, and the narrative frameworks emerging from those traditions. Parent stories, if included at all, are limited to the hospital setting. The longer-term narrative is consequently determined by medical frameworks, with images of progress and ultimate success determined by bio-medical discourse. Capacity to influence the narrative, the elements to be included, its direction, and the key determinants remains important. The family narrative is more important to the parents in the longer term, while the elements in the purview of the medical staff are determined much more by the institutional frameworks.

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4 A rare outcome, but one which has been the subject of litigation in both the United Kingdom and the United States. In two different instances, the doctors disregarded parental advice – once by refusing medical treatment requested by the parent, and the other by administering treatment against parental wishes. Pauline Challinor Mifflin, *Saving Very Premature Babies* (Edinburgh: Elsevier Health Sciences, 2003), 69
Though not an exhaustive list, it demonstrates the complexity of power dynamics operative within the hospital setting, and to explain at least in part why parents find it difficult to exert influence over the direction of discourse within it. The NICU is a complex and well-established power relation which engages with parents singly (rather than as a cohort) at a moment of intense vulnerability, underpinned by a belief that the NICU is capable of delivering outcomes consistent with parent expectations. The capacity of a single individual or couple to influence the way in which decisions are made and NICU life is conducted is measured against this complex and established power structure. At the same time the capacity of an individual family to gain back control over the discourse which has been established from the outset by medical considerations is equally problematic. Any influence is more likely to emerge from engagement within the power structure than from critique from an appositional standpoint or from the outside – an issue which is central to our understanding of the impact on parents. Note at this point Graham’s observation of the ways in which moral ambiguity around suffering feeds into a reliance on the technical power of the medical profession, which tends to obviate suffering as a matter of concern, and which serves to reinforce the scientific narrative. This serves to reinforce the power of the medical institution and exclude the perspectives of those who are subordinated to such established care regimes.

A Double-Edged Sword: Ambiguity

Power structures exist to serve a particular end, with the result that certain achievements and developments are facilitat ed by the ways in which power is auspiced and protected and measured in value according to those anticipated outcomes. For this reason individuals willingly surrender freedom and power to a surgeon whose skill serves to offer relief from a particular malady or injury. This involves surrendering ourselves to the hospital setting in the knowledge that doing so offers a chance at restored health and vitality, even when that surrender means loss – for a time – of things which are held to be valuable. It may well be argued that any efforts towards reclaiming some of those lost freedoms and privileges – changing the power balance – within the context of hospital care might compromise the capacity of the system to deliver what it considers to be optimal outcomes: that there are short-term trade-offs for longer term gain. Such an argument is predicated on the (mistaken) belief that the system is incapable of improvement, and that patient concerns are antithetical for the types of outcomes which the medical institution would prefer. While there is no avoiding the power trade-off which inevitably occurs when engaging with a large institution, the need to question and adjust the balance is an important part in improving the overall quality of care being delivered.

5 Graham, Transforming Practice, 49
6 Ibid, 124
It is important to note that the sense of parent powerlessness is not evident to parents through the early stages of the journey. The critical nature of the care needed in order to sustain life gives way to an agreed process of care, whereby power is placed into the hands of medical experts. Certain assumptions allow this to occur without parents feeling any sense of loss of power. What begins in perception as an act of liberation ultimately eventually becomes one which could easily be characterised as an act of oppression inasmuch as it often prevents the development of a fully human expression of parents and child in relationship. While he does not refer specifically to this issue, Freire’s analysis indicates the cause of this parental blindness: “Submerged in reality, the oppressed cannot perceive clearly the “order” which serves the interests of the oppressors whose image they have internalised.” The inability of parents to clearly perceive this order at the beginning is a product of their emotional and physical status at the outset, and tensions which emerge with the passing of time may well be indicative of parents recovering an ability to evaluate the environment and wishing to shape the values being expressed.

The key argument here is that the trade-off for the life of the child includes a sacrifice by parents to particular aspects of the journey. It is evident, however, that the outcomes for the child and for the family often fail to meet the promise of the early days following birth. Both the long-term developmental outcomes for the child and the patterns for family life subsequent to discharge are substantially different from those which accompany the usual pattern for that of a healthy full term child. In order to redeem the place of the parents in the overall construction of care within the NICU, and honour the ongoing life narrative of which the NICU is but one part, it is important that we not only recognise the power structures which serve to marginalise parents, but also to highlight the various ambiguities which serve to contribute to the disempowerment of parents, and to articulate the other ways in which parents are marginalised in the overall system of care.

**Ambiguity and Place**

As already noted, multiple narratives have their genesis in the plurality of settings in which individuals operate. Each setting has its own rules – operates as a community of practice – which not only provides a meaning framework for individuals to participate, but also allow individuals to develop and shape their own narratives, and further their individual journey along its pathways. The power of place – of context – is an important factor in the shaping of a particular narrative strand.

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When parents enter the Neonatal Intensive Care Unit (NICU), they bring a particular understanding of birth, family and child – expectations about their child, themselves, methods of interaction and engagement, and connections with wider family – reflecting present expectations and future hopes. It quickly becomes clear that none of these have a place within the institutional framework of the NICU and as a result of the unforeseen circumstances facing their child and themselves as parents. At this point the entry of a new context becomes the major determinant in shaping the rules of engagement between parents, family and child over the course of the NICU stay and the capacity of the parents to reflect on and adapt their narrative expectations to the surrounds.

A number of barely articulated ambiguities surround the work and setting of the NICU which impact upon all the major participants in the experience, but which ultimately serve to sideline parents in the overall construct of the care regime. Parents invariably find themselves marginalised in the conception of the NICU, discovering that they are regarded neither as patient nor as primary carer of the child. In many cases it appears that parents are regarded as irrelevant to the well-being and healing of the fragile infant, whose place is itself the subject of a range of ambiguities. As recently as 2003, questions have been raised in medical literature about “ownership” of a child whilst in the NICU, a discussion framed within the context of who holds the “best interest” for the child in the NICU.

In addition to this ambiguous relational space, parents find themselves in a deep yet ambiguous emotional space wherein they experience a loss of an expected full-term child, yet are simultaneously faced with the struggle for life of the child for whom they had once held different expectations. Feeling an intense calling to their now fragile newborn, they are faced with the need to deal with the loss of the full-term child, at the same time as they need to contemplate how to relate that sense of loss to the child now before them. The exigencies of the circumstances, whereupon they may be called to make decisions in relation to care without a necessary framework for understanding the longer-term implications of those decisions, often mean that they are unable to find time or space for grief in their bewilderment, struggling to make sense of the place in which they now exist.

Kaplan and Mason identified four psychological tasks facing parents at this time:

1. Anticipatory grief (preparing for the possible loss of the child)
2. Acknowledging the perceived ‘failure’ to deliver a term infant

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8 Ibid, 38
9 Shields and others.
3. Initiating a process of relating to their child, and
4. Recognising that the special needs of their premature infant are temporary. The ambiguity facing the parents is inherent in tasks 1 and 3, which at once require two very different perspectives on the child’s present and future. When combined with the acknowledged grief inherent in task 2, and the growing realisation that task 4 is based on an erroneous premise, parents are led into a liminal space without any clear sense of direction and future, and with marginal capacities to be active creators in responding.

The ambiguity surrounding the parent role has its genesis in the transition from expectations surrounding a normal full-term birth vis-à-vis those which emerge subsequent to a premature birth. Every aspect of interaction is changed, from the setting in which the interaction between parents and child takes place to the intervening factors which inhibit free contact and relationship. In this state of redefinition, the complexity of power dynamics has a significant impact upon the relationship which parents have with medical staff and upon their capacity to shape that relationship, in a context where decisions are demanded about the detail of care afforded the neonate, whilst parents’ ability to function is impaired for physical and/or emotional reasons. A default deferral to the specialist knowledge of medical staff about the medical needs of their child means that parents are often unaware of the questions they are supposed to ask, and of the appropriate place for their own requirements in the context of medical care. An ambiguous place for parents in the NICU is obvious from the outset, and therefore complicates their ability to approach medical staff for assistance in terms of their own role and requirements. Parents may also be compromised by their desire not to draw staff away from the care of their child, or risk the care of their child were they to experience turbulence in their relationship with the medical staff.

Another set of complexities and ambiguities for the parents arises from the relationship with their wider community. The simple question “How is the baby doing?” is not an easy one to answer, both reflecting and challenging the common assumptions about linear progress associated with highly technical medical fields, thus undermining the parents’ sense of place within their familial and social networks.

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10 Cited in Lau and Morse.
11 Martinelli, “‘Imagine...’ A Model of Social Support for Parents of Pre-Term Infants.”
12 Linda Lane, “‘How’s the Baby Doing?’ Struggling with Narratives of Progress in a Neonatal Intensive Care Unit,” *Medical Anthropology Quarterly* 10, no. 4 (1996)
The NICU is at once an intimidating and alienating place for parents, packed with deep ambiguity which serves to disorient and marginalise parents at the outset of their experience, and to engage in familiar ways with their wider community of family and friends. Already unsettled by the often-unexpected premature arrival of the child, parents enter an ambiguous place for which they are ill-prepared. These ambiguities are reinforced in numerous ways:

**Ambiguity of Space**

The physical construction of the NICU is arranged to facilitate primary interaction between medical staff and the neonate. No obvious place is provided for parents who are seemingly relegated to a role not unlike that of a visitor alongside the bed in improvised seating. No physical comforts are available to the parents, who must leave the NICU in order to attend to any of the normal functions of living. The parent is at best marked as an outsider in the NICU, with many indicators that they are regarded as visitors to another’s domain.

This sense of being an outsider is articulated by a father who is himself a fellow in neonatology:

> I felt compelled to share with all of you for whom the NICU was terrible experience, that it was the worst thing that ever happened to me. To be on the other side, to be a parent instead of a being a doctor was horrible for me. I felt sorry for my daughter and the things she went through and I was terribly concerned about outcome and complications. But worst of all, I felt that I was not in control… In my opinion: It is okay to have mixed feelings about the NICU, sure NICUs save lifes (sic) but it comes at no little cost for some parents.¹³

Most NICUs discourage interaction between the parents, and few facilitate relationships with other parents which could be a source of support.¹⁴ Filled with uncertainty about their own sense of place and the situation facing their child, the NICU parent community would be ideally placed to provide a sounding board and support network as new parents seek to find their way together as equals. By discouraging interaction with other parents and their child, parents are further marginalised and disempowered, inhibited in social interaction with other parents who hold much in common.

**Ambiguity of Role**

No immediate functioning for parents qua parents is available at the outset. The fragility of the child and the attendant medical exigencies initially place the parents in a state of complete dependence for the care of their child. Given the highly technical environment in which their child is housed, and the specialised expertise required to attend to, interpret and respond to the cues provided by this

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¹⁴ Discouragement of parental interaction in the NICU is reflective of a misguided view that wounded parents cannot be agents in each other’s healing and care.
environment, the parents are left with little space to be parents, and no cues as to any role they might expect to take up.

These circumstances serve to create an environment of maternal dissatisfaction at the outset, at the same time creating an uncertainty which impinges upon the parents’ relationship with their child, and with the medical staff of the unit, as well as bringing into question their understanding of their own (assumed) role. The inevitable consequence of this is that parents accept the terms of engagement set by the institution, both in terms of access to their child, and in learning the language and priorities of the environment as a point of entry in establishing a role for themselves amidst a growing comfort with the environment of the NICU.

Ambiguity of Experience
The experience of premature birth conjoins traditionally unrelated experiences: the joy of birth, the grief for loss of a full-term pregnancy and the associated child: the liminal space where the child is born but not fully-formed or capable of sustaining life, which is a continuing experience in light of the odds of survival. It is uncertain whether this is a birth to be celebrated, or held in suspension awaiting further clarification. This ambiguity is further underlined by the deep sense of ambivalence at first sight of the child, with descriptions often reflecting both shock and cognitive dissonance. The social mores surrounding birth fail to adequately embrace this experience, conveyed to mothers in the lack of usual social affirmations which follow birth. Parents report receiving no gifts, having no baby shower or receiving celebratory cards. What is traditionally a joyful time is one of grief mixed with hope. It is as though parents and community are in suspense, awaiting a definitive outcome.

Ambiguity of Language
Typically, what is an ambiguous experience also lacks the language to communicate the nature of that experience with significant others. This language is used to connect the experience into the narrative frameworks of those in our social networks. The simplicity of language of a premature birth, conveying statistics of weight and length, serves to reinforce the stereotype of a small baby, whose major challenge is simply to catch up. This language is the cause of much angst amongst list

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15 Inability to hold the baby soon after birth or to have an active expression in decisions about the care of the child are associated with an increase of up to 15-fold in expressed maternal dissatisfaction: Stephanie Brown and others, Missing Voices: The Experience of Motherhood (Melbourne: Oxford University Press, 1994), 70-74
16 A response identified by one parent in particular: http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-1.199705/Date/article-883.html
18 http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-1.199707/Date/article-515.html
members in conversations with strangers and sometimes family members, giving rise to comments related to the fortune of missing the last uncomfortable months of pregnancy and the discomfort associated with vaginal birth of a full-term child. The use of traditional birth language is available, yet fails to convey the significance of the event. This inability to convey in language which fosters understanding and support is frustrating and ultimately alienating, 19 and heightens the sense of isolation in facing the realities.

But the language to express the reality to the social network is just one aspect. The language which surrounds the child in the NICU is of a different order to that facing the normal adjustment following birth – a language which is both highly technical and specialised, and working entirely within a biomedical framework and largely devoid of relational context. The ambiguity flows also from the metaphors which are employed to introduce the NICU experience to premature parents, indicating a ride which is anything but smooth and predictable. The removal of certainty, combined with an appeal to trust the medical staff is a marginalising experience at best. Although there is a general acceptance that uncertainty dominates the NICU experience, both academic and popular literature attribute the confusion experienced by parents to their psyche rather than to the situation itself. 20

Ambiguity of Narrative Future/Framework

Leading into the birth of a child, parents have a script which is largely familiar and organised. It is a well-worn pathway within the culture, itself part of a larger cultural narrative. The experience of childbirth and the early bonding days, while largely romanticised, creates a sense of expectations which normalise much of the experience. There is no such narrative available for parents of premature infants.

It is immediately apparent that parents are unable to follow the traditional frameworks surrounding birth, initially when unable to hold the child after birth, and underscored when the mother is discharged and the family leaves the hospital without their child. The longer the child’s hospitalisation, the greater the disconnect for parents as they lose contact with the initial narrative framework which gave meaning to their impending experience. Initially encountered as loss of an ideal present and future, extreme premature birth risks giving way to the loss of an entire meaning framework within which their lives are constructed. This is not immediately apparent to the parents, who are absorbed in the immediacy of the challenges facing their child in the short term, but who

19 Larney, 73
20 Lane, 639-640
are also generally unaware of the depth to which they had absorbed the narrative framework surrounding childbirth from the broader culture. Over time, parent identity is subsumed to the culture and practice of the NICU, such that subsequent to the child’s discharge, the majority of parents run their home like a miniature NICU, continuing all the measures to which they have become socialised for determining the well-being of their child. The transition from an unarticulated narrative about childbirth to an unarticulated narrative about caring for a premature infant is tacit, yet substantial.

This ambiguity ultimately includes a paradox: there is a strong parental desire to be seen as “normal” in the wider community, yet at the same time express deep anger toward those who diminish the experience of prematurity. The imagery of “catching up” and “small babies” serves to undermine any broader cultural understanding of the deep scars which the experience has left.

**Medical Ambiguity**

Neonatology, perhaps more than any other branch of medicine, is subject to constant evaluation, review and revision, as treatment regimes are refined when longitudinal data reveal the long-term consequences of previous treatment regimes upon children. Drugs and practices honed in relation to treatment of adults is continually adapted to those for whom there are no equivalent benchmarks established, as “normal” development takes place away from the gaze and assessment of many biomedical instruments (and beyond their reach) – *in utero*. Working at the threshold of life regularly raises questions about appropriateness of “heroic measures” to save a child’s life, and marginalises questions about death and its place. The dynamics are geared towards regarding the medical environment as a place where children’s lives are “saved,” with implied gratitude on behalf of parents who would be otherwise bereaved. Medical technology and knowledge engenders assumptions of certainty and confidence which encourages parents to place confidence in medical staff. Complications emerge when the uncertainty surrounding the appropriateness of treatment regimes arises. One neonatologist writes: “We need to recognise that the family is struggling with the meaning and significance of uncertainty in their child's care. They have not led to expect disagreements or differences of opinion or practice within the team, and naturally conclude that somebody must be wrong.” Parents are conditioned to expect something less than ambiguity in the treatment applied in their child’s care, yet the reality is that neonatology is a continuing exploration of medical capabilities at the margins of life against unknown norms.

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But at the same time illness itself appears to be marginalised within the NICU setting, with the overarching image of premature infants provided by the medical team largely depicted through the image of the “tiny baby” who simply needs to “catch up.” The parents are clearly not regarded as ill, even if the circumstances giving rise to premature birth have had deleterious impacts upon the mother for a short period of time. The framing of the NICU practices conceptually as providing an alternate uterus to allow a child to grow until it is capable of sustaining itself in the care of its parents defines it more developmentally than as remedial, palliative or curative care. Alongside all these ambiguous variables a deeper medical ambiguity surrounds the seminal life: the ELBW infant in the care of a NICU is often born at gestations where late-term abortions are permitted, prompting questions about the line of viability which medicine ascribes to life.

Medical researchers have been successful in avoiding linking the stigma of “abnormality” associated with artificial reproductive technology and neonatal care, but in so doing have masked the challenges to be faced by the child and the pain endured by parents. The hidden nature of the true experience of prematurity within the NICU, while it works to mitigate the chances of premature infants being stereotyped with technological-type labels and thus avoiding the stigmatising characteristics often associated with disease and disability, comes at the cost of concealing the depth of struggle and the nature of the challenges associated not only with prematurity for the child, but also with the experience of prematurity for the parents. As a consequence, there is no societal framework for healing and readmittance into the wider community – no narrative connection for parents.

A Marginalised Child?

Of more profound concern is whether the infant itself is ultimately marginalised. The premise on which the NICU functions is that of a large biotechnical incubator, seeking to provide what the uterus would have given the child had it been carried to full term. All things about the progress of the child are assessed through strict biomedical terms, which are framed around normalised values, without any reference to individualisation or socialisation. The ultimate determinants of treatment and of interaction with the child are the numbers provided by machines and tests. The more intuitive relational reading of a child’s state takes a distant second place. It is as though the child were still in utero – out of sight and out of range of contact – and much of the medical treatment is

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22 Extremely Low Birth Weight
23 It is interesting to note that the experience of premature birth remains a field where medical terminology has eschewed the traditional battle language associated with major health issues (the war on cancer, etc.), yet many parents have picked up the battle metaphor to give perspective on their experience – often describing the NICU itself as a war zone. See Sontag.
24 see Lupton, ch 2
conducted along these lines. Relational and psychological issues are largely marginalised, although the advent of Kangaroo Care has done something to redress this.\textsuperscript{25} In order to relate to their child and engage meaningfully with the medical staff, parents must learn the language of the NICU, and learn to relate to their child through its framework. It is not until the child is discharged from the NICU into the level 2 nursery that engagement with the infant as with a full-term newborn is conceptualised as the framework of normal practice. This has the longer-term implication of reframing the parent relationship as one of carer/patient rather than parent/child.

**Affirming the Power Imbalance**

Power operates in order to privilege certain ways of seeing and acting, whilst marginalising others. The circumstances surrounding parents’ entry into the NICU, the physical construction and practices of the NICU marking them as outsiders and requiring them to find a role for themselves in order to be active participants in the care of their child, together with the deeply entrenched culture of practice and decision-making within the NICU can deliver no other result than the marginalising of parents. The NICU practice is a regime of limited competence as far as parents are concerned. All decisions are framed as medical decisions – when, how and how much to feed, care of the physical needs of the infant, nursing and other contact – determined under medical guidelines, thereby rendering the parents at worst irrelevant and at best dependent upon the competence of others. This is further underlined by NICU requirements that parents be excluded from the vicinity at the time of doctors’ rounds on the basis of the privacy of other patients within the NICU. This has the effect of keeping parents in the dark about the exact nature of medical deliberations and assessments about the progress of their child, and therefore powerless to impact the shape of the decisions made as a consequence. Whilst recognising that many social relationships are constructed on the basis of unequal power in order that specific outcomes might be achieved,\textsuperscript{26} the long-term implications of this power imbalance are so significant as to warrant further consideration.

The ultimate outcome of these pressures – the power systems operative in the NICU and the ambiguities operating within the parental frame – is to push the two apart; to leave parents uncertain and disempowered against an entrenched system of operation, which imprints its perceptions of reality on the child and family. Over the course of an extended NICU stay, parent engagement with their child and understanding of its needs have been reframed. The power of place – the power of a community of practice – to shape the way in which one sees the world is powerfully demonstrated, such that when parents leave the hospital they bring the NICU home with them, bringing with them

\textsuperscript{25} Although it is admitted that kangaroo care does not have universal acceptance.

\textsuperscript{26} Willis, 3
an image of their child interpreted through biomedical paradigms – a child so vulnerable as to require the care of a large team of experts, a child who has learned to relate primarily through instrumental touch, and parents whose major contribution towards the care and nurture of their child has been to fit in with the NICU practices. Parents have learned to regard the world and their child in a new way, a way which has no connection with the hopes and dreams – with the narrative lines they carried during the earlier stages of pregnancy – before the NICU left its mark. And they often leave with warnings about the dangers awaiting their child, biomedical dangers such as infection which while offered as protective advice for the physical wellbeing of the child (as determined through the biomedical paradigm) invariably become barriers to reintegration as parents and child leave the NICU world and seek to make their way in a world they had left behind months before.

**An Oppressive Regime?**

To define the experience of parents within this framework as one of oppression might seem strong, yet the more vehement parent responses have resorted to defining the experience in terms of oppressive regimes. Freire’s description of characteristics of situations of oppression in Latin America offers some confronting insights when considered in relation to the parent experience of the NICU. Freire notes situations where the actions of one inhibit another’s capacity as a responsible person, where actions prevent others from becoming fully human, where there is continual deference to authority, even where the individual has something valid to offer, and situations where there is a sense of fatalism, an inability to articulate what one desires as an alternative, emotional dependence, where one is prevented from engaging in one’s own acts of inquiry, where reality is perceived as dense, impenetrable, and enveloping, and an inability to create one’s own world. Friere demonstrates the ways in which myths seek to preserve the status quo by suggesting that the system itself offers hope to all who are part of it in spite of its fundamental flaws and bias towards certain power operatives within the system, who see the call for “liberation” as sacrificing important common goals. The presence of such myths underlines the highly rational basis for much abuse of power.

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27 Noted in chapter 2.
28 Freire, 31
29 Ibid, 33
30 Ibid, 39
31 Ibid, 40
32 Ibid, 40
33 Ibid, 42
34 Ibid, 58
35 Ibid, 77
36 Ibid, 114
37 Ibid, 109ff
While characterising the construct of a NICU as an oppressive regime may well prove to be too broad a brush to describe the experience of all parents, we need to recognise the factors within the power distribution which leave some parents feeling as though they have no space within the system to collaboratively construct an alternate reality. Freire highlights the source of hope:

To surmount the situation of oppression, men [sic] must first critically recognise its causes, so that through transforming action they can create a new situation – one which makes possible the pursuit of a fuller humanity… However, the oppressed, who have adapted to the structure of domination in which they are immersed, and have become resigned to it, are inhibited from waging struggle for freedom so long as they feel incapable of running the risks it requires….

In order for the oppressed to be able to wage the struggle for their liberation, they must perceive the reality of oppression, not as a closed world from which there is no exit, but as a limiting situation which they can transform.\(^{38}\)

In becoming part of a NICU for the sake of their child, parents enter a community of practice where the ability to negotiate meanings is minimal, where a “locally negotiated regime of competence”\(^{39}\) is established, and in which parents need to demonstrate such competence in order to participate. Parents are left with little choice about the degree of buy-in to this community: its language, assessments, values and practices. This community not only determines the competencies by which one finds acceptance, but also determines what is marginalised and what is excluded in order to gain acceptance. Parent capacity to become part of the team which cares for their child depends upon their willingness to buy in to this community and its ways of being and doing. At the time of discharge, however, many parents find themselves continuing to operate as though under its roof, even though they have reverted to their own home setting.

**Summary**

It is, however, both easy and tempting to characterise the exercise of power in black and white terms. As with any power regime, it is dependent on a range of factors, not all of which are in the control of any single party. The NICU is set up in ways which facilitate the actions of the NICU staff, and for many people this works well. However, in articulating these areas of power and marginalisation, it is hoped to identify points of potential improvement, not only for parents in their experience of the NICU, but also in helping facilitate healthier outcomes for parents upon discharge and of children in their development. Given the importance of parents in the long-term development of children, there are strong reasons for reflecting on ways in which parents and family narratives might be given room within the NICU setup and practices – more than simply allowing parents to

\(^{38}\) Ibid, 24-25

\(^{39}\) To use Wenger’s term: Wenger, *Communities of Practice*, 137
take part in medical treatment decisions, but also in determining patterns of interaction with their child during the hospital stay, and in finding support in addressing the broader issues of identity and purpose which are ultimately challenged by the experience.

The questions which parents pursue in development of their own humanity and family life are largely outside the frame of reference of the strict scientific purview. Augsburger notes the ways in which science provides theories that order the perception of the universe according to universal natural laws, in contrast to religion which is called upon to explain the miraculous, the mystical, the meaning that must be derived from the transcendent. The key place of interaction and meaning-making is in what Augsburger terms “middle-zone issues” which embrace such wonders as understanding or preventing misfortunes, making sense of illness and congenital defects, understanding failures in business, crops, marriages, or interpersonal relationships, which he describes as “power issues,” or Freire might categorise as “empowerment issues.” A consequence of the scientific worldview dominating the power structures of the hospital is that it takes away the capacity of parents to construct meaning in the face of suffering and ambiguity. Whilst not essential for determining the biomedical responses to the needs of a premature infant, such questions are fundamental to the ongoing and human needs of the infant and the parents, as well as the wider community of which they are part. The cost of marginalising and excluding these considerations and discussions as part of the journey of prematurity – a conversation ideally engendered at least amongst parents in the same place at the same time – is far greater than the cost of adjusting the system to ensure that such matters are addressed. They remain an essential part of parental identity and narrative formation.

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40 Augsburger, 274ff
Chapter Seven

Parents Living with the Consequences of Premature Birth

Introduction
The concerted focus in the hospital journey on reaching the point of discharge, and the consequent supporting of parents through the transitions overlooks the deep impact which premature birth has on parents from the outset and deep marks which premature birth leaves on parents long after discharge. The consequences of premature birth in terms of the child’s continuing growth and development are evident in the professional literature, but not in terms of the impact on parents. The notion of parent loss and grief in circumstances where a baby still lives has not been explored, and creates an environment where it remains unacknowledged and unaddressed, both within the hospital and in the wider community. Unacknowledged grief is known and identified as “disenfranchised grief,”¹ and its effects can be both profound and prolonged. In this chapter, I explore the nature of this grief, and the ways in which its impact on parents is evident, from the time of birth, through the duration of hospitalisation, and long after discharge.

Grief and Childbirth
The birth of a child is a marker for family change: a symbol for a life status that has been lost and the point at which a new stage of life has emerged. It will always remain so. It marks a transition point for every family, which results in the leaving behind of a particular family dynamic as a consequence of the embrace and welcome of a new member. Whilst there is an inevitable sense of grief which emerges from such a transition, its intensity is muted by the joy and expectation of moving into a new dynamic which has been expected and prepared for, and for which there is social affirmation. To speak of grief in relation to the birth of a child – a grief which may well be at the heart of or a major catalyst for post-natal depression – is therefore not out of place. In the case of an extremely premature birth, however, this grief is rooted in perspectives and incidents which unfold in relation to the birth, and subsequently. A parent in such circumstances, while still enfolded in a transition for which there is broader community understanding, nonetheless experiences an acute sense of loss, both anticipatory and actual, although it remains a grief without visible public focus. Parent loss and grief in these circumstances is both diverse in its expression and deep in its roots. It is a grief which finds its initial focus in the loss of the experience of the last stages – the third trimester – of pregnancy, and of lost anticipation of the joys and struggles associated with such

stages. While parents of full-term children are wont to identify avoidance of this stage of pregnancy as something over which to rejoice (due to escaping the discomforts of being stretched and limited physically), parents – mothers – of micropreemies speak of an acute sense of loss, often expressed in violent terms. This appropriates at one level to a loss of a rite of passage into parenthood (of which the uncomfortable third trimester is part), but is also coupled with a loss of security, which is linked to and emerges from the child’s fragile health. But the loss is not only experienced in terms of lost months of pregnancy, it spreads itself more broadly and reaches greater depth. Parents grieve a child who has been lost – the full-term healthy baby who was expected at birth. Premature birth sets the parents on a vastly different pathway than they had anticipated and planned, and every step which exposes this shift becomes a reminder of what has been lost, and therefore a catalyst for renewed grief. Grief is hence associated with the discharge of the mother from hospital, with breastfeeding and pumping, and almost every aspect of caring for the child in the confines of the NICU. Every milestone celebrated also serves as a reminder of the different pathway which has been unfolding before them. There are also significant social ramifications to be negotiated.

Neonatal irregularities in general are poorly understood and socially marginalised. Parents who experience anything other than the birth of a healthy child find themselves without permission or context in which to share their grief. In the public mind, babies are to be celebrated, with the resultant stigmatisation and/or silence enclosing those who are unfortunate enough to give birth to a child outside of normalised parameters. Stillbirth, deformities and disabilities, coupled very closely with neonatal morbidity, confront a stony and discomfited wall of silence and denial. Discounted grief is identified as one of the most unique aspects of newborn death.

Arguably the least of all these is the birth of an extremely premature infant. Caught between loss and a safe place, parents have no permission to grieve a loss. It is clear to everyone that they have avoided the death of their child, who is present and alive (if not for all to see). Yet parents hold no certainty about the child’s immediate or long-term future. Rates of disability and death amongst the earliest survivors, together with a contingent medical prognosis through the earliest weeks, establishes an environment which is characterised by a depth of uncertainty which undermines the ability to hold a normal celebration such as usually accompanies a healthy full-term birth. This uncertainty also underlines the fact that parents are unable to identify or quantify their loss, and are faced with an unstable floor on which they stand to assess the future, or articulate the present.

2 Like having the baby ‘ripped from my stomach.’
The nascent field of neonatology is yet to be reflected in the materials addressing the needs and grief of parents. Grief researchers have increasingly turned their attention to newborn death, miscarriage, stillbirth, SIDS and disability, where the reflection is on dealing with the loss of a child, both through death and in loss of an expected child, and the recognition of the depth of grief is articulated. The most recent publication which embraces the experience of premature birth ambiguously brackets it with infertility, miscarriage and stillbirth. The unique dual loss associated with premature birth has yet to receive the attention it warrants. Parents, faced with the dual and conflicted task of watching over and participating in the care of their newborn, whilst at the same time – perhaps unknowingly – grieving the loss of time spent pregnant, together with the loss of many of the social aspects of pregnancy and childbirth, and concurrently living with the tentative nature of their child’s situation in the present, must consider the real-yet-still-potential challenges ready to unfold before them. The loss and grief experienced by parents in such circumstances is complex and profound, yet essentially fluid and ambiguous.

The initial focus on the nature of grief provides a framework in which a description of the nature of grief associated with the death of infants will lead into an expression of the experience of parents of extremely premature infants. I will identify ways in which parents are presently inhibited in expressing and dealing with loss and grief, and explore ways in which expression might be enabled. It does need to be noted that the breadth and complexity of grief is such that a comprehensive articulation is beyond the scope of this chapter.

Models of Grief
Early Formulations

Initial formulations of grief models were predicated on the notion that grief is a process by which the dead person is left behind so that life can continue to move on. Freud’s reflections of grief as freeing the bereaved from attachments to the dead person reflect the highly individualised notions of grief which permeated the greater part of the twentieth century. Lindeman’s recognition that grief

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5 I have not been able to identify any writings pertaining to grief of parents around birth events which recognises the grief of parents who experience premature births.
6 Stanfield-Porter and The Bonnie Babies Foundation,
could be acute\textsuperscript{10} spurred deeper investigation into the experience, initially through Freud’s frame of attachment/detachment. Bowlby’s work in this field is better known for its implications related to early attachment following childbirth,\textsuperscript{11} which has proved to be somewhat of a mixed blessing – creating an environment rich with expectations of bonding, and thereby laying the ground for a sense of maternal loss. Parkes identified two factors which are important in the overall reaction to loss: the social response (stigma) and deprivation (loss of beneficial relationship with the deceased).\textsuperscript{12} Kübler-Ross’s analysis of grief experienced by patients facing their own death\textsuperscript{13} marked a watershed in understanding, introducing the concept of “stages” of grief, and marking out a strongly biomedicalised symptomatology and pathology for understanding experienced grief. A strict interpretation and adaptation of Kübler-Ross’ analysis led to a rigid application of and expectation surrounding grief, marking it out as a defined emotional pathway through loss to recovery of an independent life. As a consequence the idea that mourning unfolded in predetermined phases became accepted as nothing short of truth.

The profound influence of a bio-medical framework is evident from the earliest formulations of Western understandings of grief, such that grief is conceived of as an infliction having symptoms and stages, a problem which requires “getting over,” or at least “getting through.” These early formulations regarded grief as a wound to be healed,\textsuperscript{14} and were continually refined into a well-constructed framework for understanding and facilitating the healing of grief. Hagman identifies components which emerged into a type of the standardised model which grew out of and around such presuppositions:

\begin{itemize}
  \item There is an identifiable, normal psychological mourning process;
  \item The function of mourning is a conservative and restorative one rather than a transformative one;
  \item Mourning is a private, intrapsychic process rather than a social and relational one;
  \item The affect of grief arises spontaneously from within the individual, and denial or suppression of grief leads to pathological states;
  \item Mourning has normal, standardised characteristics, rather than being unique and personal.
  \item Mourning is painful and sad rather than involving a range of affects;
  \item The central task of mourning as detachment (decathexis) rather than continuity;
  \item The vicissitudes of psychic energy are the basis of the standard psychoanalytic model; the meanings associated with the loss are not emphasised.\textsuperscript{15}
\end{itemize}

\textsuperscript{10} E Lindemann, “Symptomatology and Management of Acute Grief,” \textit{American Journal of Psychiatry} 101 (1944)
\textsuperscript{13} Elisabeth Kübler-Ross, \textit{On Death and Dying} (New York: Macmillan, 1969)
\textsuperscript{14} C M Parkes, "Bereavement and Mental Illness," \textit{British Journal of Medical Psychology} 110 (1965)
But there was a growing discomfort with this conceptualisation of grief. Questions were asked as to whether death did indeed end a relationship – whether bonds were severed by death, or instead reformulated. The recognition of cultural differences in grieving challenged the uniform understanding embraced in the West, which seemed to be reduced to a linear timeline of phases in which the mourner is essentially disempowered – a victim who must “passively negotiate a sequence of psychological transitions forced on them by external events.” The implication that grief events eschewed any sense of challenge to meaning or identity was also called into question, along with a reflection on the social implications for individuals and communities. The experience of grief was slowly being recognised for its capacity to reshape our understanding of self and the world, alongside our relationship with the deceased.

Recent years have evidenced a growing recognition of the complexity of grief, not only in terms of the range of emotional reactions (which can have physical implications), but also in terms of the individual differences which accompany each experience of grief, both in terms of the circumstance giving rise to it, and in relation to the personality of the person concerned. The growing breadth of understanding embraced the recognition that grief does not merely arise from a response to a singular and punctiliar loss (the death of a loved one), but also from a complex and connected series of losses. This reframing cannot be considered apart from the understanding and embrace of the individual as a person whose meaning and identity is shaped in interaction with the context in which they live and in interaction with others.

The writings of Judith Viorst almost unwittingly opened the door for a broader conception of grief. Although still primarily focussed around death and recovery from the loss, Viorst conceptualised the notion of loss as an important part of shaping our own identity and taking control of our own destiny. Still very much in the attachment school: “All of our losses hark back to the Original Loss, the loss of that ultimate mother-child connection,” Viorst concludes that our losses and gains are inextricably mixed; that there is plenty we have to give up in order to grow. The shift from loss through death here appears almost as a postscript, as she affirms transitions through which we must pass in growth which involve leaving parts of our selves behind.

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19 Viorst, 24
20 Ibid, 368
While the focus on an individual’s grief is important, a model of isolated and individualised mourning does not recognise the communal nature of our identity, and hence the communal aspects of our grief. The death of an individual has an impact on a network of relationships whose complexity increases with size. For every person added to a relationship, the complexity of interrelatedness increases. Between two people there are two relationships, which increases to six when a third person is included, and to twenty-four when a fourth person is added. Consequently, the loss of one member of a group impacts more than a single relationship, having an impact upon the entire network. The consequences of this for understanding grief are profound. It demonstrates and reminds us that every grief has a social impact which disrupts not just the individual, but the community as a whole. Grief then must be recognised as more than adjusting to the loss of one person in an inter-personal relationship, but dealing with a changing community, and renegotiating those relationships in the light of the loss. Grief is experienced as both a personal and a social phenomenon, initially isolating us, as we feel our own loss most personally in its acute phases. But grief not only is a catalyst for altered social relationships, it also has the capacity to join us to fellow mourners, as we share a loss in common, and gives us some common ground in renegotiating relationships in the wake of loss. An understanding of grief must embrace the primary potential for alienation: the changed circumstances in which grief emerges causes a rupture in the communal connections – the fabric of relationships which hold people together. Grief is at first isolating, as the sense of loss towards the individual circumstances also impacts the relational structure.

**Grief as Relearning**

Attig’s conception of grief as relearning the world shifted the focus away from severing attachment and re-introduced a social dimension to our understanding of grief. In contrast to perceiving grief as adjustment to the loss of a single relationship, Attig invited us to recognise the ways in which grief is a response to an event which disrupts a pattern of living to which we have become accustomed. This has the effect of changing grief from an injury which evokes predictable and ordered responses, instead affirming that no two people grieve in the same way or experience the death of someone as the same loss. Attig challenges the notion of helplessness in grief – that grief is more than something that happens to us (although this much is true) – by affirming that grief is a process through which we work our way through a crisis in self-identity.

Although we have little to no choice in bereavement, choice pervades our grieving. As we address our tasks, we again and again choose among alternative steps into our futures. We

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21 It is arguable that the number increases to nine distinct relationships: not only the two individual relationships with others that each person has, but a separate relationship with the other two as a pair. In any case, the increased complexity is evident.
22 Attig.
23 Ibid, 47
do not, and cannot, cope with the whole world at once. There are always new landscapes to
confront and new challenges to address. As we choose, new options open up before us.
Reshaping our daily lives and changing course in our biographies are ongoing projects,
ever finally settled. Bereavement humbles us as it teaches us how easily what we have
thought to be settled can be undone.  

Rose suggests that meaning and dialogue are at the heart of mourning as we negotiate our way
through the crisis of meanings by which a person’s life is given structure and substance. Bereavement brings a loss of wholeness and a loss of connectedness which our relationship with the
deceased facilitated and nurtured. The choices that are made in response to the unfolding experience
of loss are potentially both reactive and creative, individual and dialectic in nature.

Not all losses are the same. How one reacts in response to bereavement is dependent on the
meaning assigned to that loss, and to the depth of relationship with the deceased. The more deeply
intertwined one’s life is with the deceased, the greater the rupture to personal identity and
functioning, and consequently the more significant the experience and work of grief becomes. The
intensity of grief is also contingent upon the level of investment a person holds in the status quo.
The narrower or more inflexible one’s view of the world and one’s place in it, the more difficult it
becomes to adapt in light of the changes emerging in the wake of significant loss. The nature and
circumstances of the loss will also impact upon the way in which grief is experienced and
expressed. A traumatic and unexpected loss will be experienced in a different way to a peaceful and
anticipated one. On this basis, the death of a child is more likely to evoke acute responses than the
death of an aged person.

Attig suggests that the challenges of grieving are especially compounded for children who
experience bereavement while still effectively in the midst of “learning the world” for the first time,
arguing that their limited emotional experience and psychological development disadvantages
them. This is not a view I support. Rather than viewing what is essentially an emerging
perspective and perception as a deficiency, I would argue that these are potential strengths which
enable children to negotiate the challenges of grieving with greater resilience and creativity,
regardless of the intensity of the loss. The capacity of children to “relearn the world” may be greater
for the plasticity of their conceptions. Learning the realities of death and loss at an early age might
be regarded as painful from the perspective of an adult who encounters death from the first time, but
for the child offer opportunity to incorporate an understanding of one of the primary realities of life

24 Ibid, 55
25 Quoted in Hagman, 22
26 Attig, 126
at a formative stage. The child is invited to build the reality of loss into their still-under-construction conception of life and the world, rather than to rebuild what may be an integral and long-standing aspect of it, which is more likely to be the task facing an adult. Attig’s downplaying of children’s capabilities in this area perhaps reflects a Western experience where death is rarely encountered until later in life. It must be said, nonetheless, that the experience of a significant loss can have long-term impacts on a child, if the support and care in the wake of loss is not in evidence.

In moving away from a limited notion of grief as severing a relationship, it is increasingly recognised that the challenge to be faced involves renegotiating the relationship not only with the deceased, but also the world at large, whereby mourners maintain a dynamic presence and connection with the deceased. In this conception, grief does not end, per se, though will not necessarily be a continuous experience, as the nature of the loss experienced is understood only with the passing of time. A loss, rather than being a single event, is experienced as a series of losses or realisations. Grief work, then, requires enormous amounts of energy, and time.

In grief we inevitably confront our own mortality – the human limitation in the face of death and loss is exposed most powerfully, along with the transitory nature of life itself. We have lost control of our world inasmuch as we have been unable to prevent the loss of someone dear to us. Assumptions we have carried about our world may well be exposed as erroneous or insufficient to the situation, and we are forced to re-evaluate. We encounter the continuing and unrequited absence of a loved one, which evokes pain and anguish. There are multiple aspects of the world we are forced to rethink. Commencing with our relationship with the one who has died, we are also forced to rethink ourselves in the light of that relationship as it was, and going forward. We are forced to rethink social relationships which involve the deceased, or which were impacted by them. We learn to see the world afresh in their absence, and how we should live in the world as a consequence.

In grief we confront the relativising of what had assumed the place of being ultimate. In this process, Kegan argues that we leave behind a consolidated sense of our self before we can reappropriate it into part of a new self – a self which is always embedded. The grief process, then, is in part a response to a loss of embeddedness. “We may hear grieving, mourning and loss, but it is the dying of a way to know the world which no longer works, a loss of an old coherence with no

28 Ibid, 53
29 Kegan, The Evolving Self, 232
new coherence immediately present to take its place. And yet a new balance again and again does emerge.”

**Narrative Frameworks**

No exploration of grief is complete without consideration of the narrative forms which we employ to provide a meaning framework for our lives. Narratives are one of the ways in which we can conceptualise and articulate life’s coherence. Literature addressing loss of health and well-being explores the ways in which illness narratives help in the reconstruction of life in the wake of serious health issues. The experience of grief is encountered through a loss of life story: grief is a response to a loss of a conception of the world which no longer works. The narrative which is our life has reached an unexpected juncture, either in timing or the manner of change. Thus the present context and the future narrative must be renegotiated and rethought. We grieve not just for a changed present, but a lost possibility. Grief work thus framed involves renegotiating the future even as we renegotiate the present. In grief we rehearse past stories which give meaning and purpose to our understanding of the person who has died and the life that we shared together. But we also put to bed potential yet unfulfilled future stories.

Cultural aspects of grief are important not only in giving permission for the ways that we might grieve, but also in providing resources for our journey in grief, and in setting an agenda for the purpose of our grief. Attig and Gunzberg identify the Western penchant for seeking to relieve or ameliorate the distress and anguish of suffering, whereas other cultures might encourage vocal expression of grief, or embracing a “broken heart” in our grief. Grief is at first silent. While some cultures encourage open and immediate expression of grief, it is the initial shock which gives birth to silence. Most non-western cultures encourage quick and voluble release. Western cultures do not encourage or invite open expressions of grief. The danger here is of repression. There are not only different cultural responses to death, but also different cultural resources for dealing with the loss, which may well invite the question of whether a key step in grief is to first relieve the distress or to encourage a journey towards a full experience of the loss and pain which emerges. Worden’s model

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30 Ibid, 266
31 Attig, 144
33 Stroebe and others.
of grief would suggest the latter.\textsuperscript{35} In this model, Worden identifies four important tasks in the unfolding of grief in order for a “successful recovery from grief”\textsuperscript{36} to occur:

1. accepting the reality of the loss;
2. experiencing the pain of grief;
3. adjusting to the environment in which the deceased is missing; and
4. withdrawing emotional energy and reinvesting it in another relationship.

While a limited view of grief, this model affirms the importance of owning the pain and identifying the loss. I would want to expand the last two tasks and interpret them more broadly to include aspects of interpretation and negotiation, which seem much more empowering than the current formulation which reflects a passive-responsive approach.

\textit{Spiritual Dimensions}\textsuperscript{37}

Because grief evokes questions of deepest meaning, it needs to be affirmed as a spiritual experience. In grief we face ultimate questions: the meaning of life and death, and of the purpose of our existence. Attig asserts that grief embraces the search for the transcendent,\textsuperscript{38} as we encounter our human limits. To grieve is to evaluate one’s understanding of the world in light of experienced loss, and to explore whether one’s understanding provides a framework for accepting the loss and renegotiating one’s place in the present and in the future in light of that loss.

In addition to renegotiating one’s understanding of the world, the bereaved are also pushed to renegotiate relationships in the light of loss, which includes learning to reconnect with others in the changed environment, and without the presence of the deceased. These changed relationships also are reflected back in a reinterpretation of one’s own identity in the light of the loss. Reflection on what the loss means for them as a person, may include questions such as: How did I contribute to the loss? Did I realise the true value of what I had prior to this loss? How do I incorporate this experience and reflection into who I am and my life’s direction? In this way, grief is recognised as a catalyst for a fresh search for meaning – a search which begins with the value system, narrative understanding or script which guided action prior to the loss, and if deficient, begins exploring what changes might be intimated by the loss.


\textsuperscript{36} While I dislike the bio-medical implications in Worden’s use of the term here, this does not mitigate against the value of the perspective on the tasks of grief.

\textsuperscript{37} The term “spiritual” is used here to embrace the human capacity for relationship with both the sensory world and that which transcends sensory experience. A more detailed exploration of the term appears on p 209.

Our willingness and ability to embrace loss and change is fundamental to our wellbeing. Loss and suffering are inevitable, and need to be integrated into our life understanding. Those who experience loss need to be affirmed as people bereft, but also with creative power to renegotiate their place in the world and create a new future in the wake of loss.

In its complexity, it can be affirmed that:

- Grief has personal dimensions.
- Grief has communal dimensions.
- Grief is potentially endless, but not continual.
- Grief is a response to an event which has changed our world.
- Grief is a response to an event which has changed our conception of self.
- Grief involves a search for meaning in the wake of loss.
- Grief involves retelling past stories and recasting future stories.
- The potential for unresolved grief is always present.
- The context in which loss is experienced and grief is expressed is important to its unfolding.

**Parent Loss and Grief**

The grief associated with the loss of a child is potentially the most intense and enduring of all experiences of grief, unlike any other loss. The death of a child poses unique threats to a family, making the potential for the grief of parents to be particularly severe, complicated and long-lasting. A body of research documents the ways in which grief resulting from the loss of a child is more severe when compared to other losses, due to its complexity and prolonged duration. The loss of a child involves issues and dynamics that set up the parents for possible diagnoses of unresolved, pathological or abnormal grief. The evidence suggests that the intensity of parental grief shifts over time, reappearing spontaneously after times of absence, tending to fluctuate over

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42 Rando, "Parental Bereavement," 46
time rather than gradually diminishing. Drawing on the work of Lazare, Rando suggests five issues with which parents contend which inhibit their capacity for grief. These include:

- **Guilt**

  Guilt is a common and frequent reaction in bereaved parents, feelings which may be closely related to their sense of responsibility for the child’s well-being, and their consequent sense of helplessness for not having been able to somehow prevent the child’s death. Guilt is reported to be especially common in mothers. Many parents feel as though they have actually caused the death of their child, or at least contributed in some way – a sense which grows as the initial shock wears off.

- **Loss of an extension of self**

  There is perhaps no greater symbol of the extension of our own sense of being than in the birth of a child, which becomes the embodiment of many parents’ hopes and dreams, and an important link to the future. A child in many ways symbolises the family future. The death of a child embodies the death of a great emotional, spiritual and personal investment for which there are few parallels. Giving birth to a child is arguably the most deeply intertwined of relationships most adults will experience, the connections running through the deepest convictions held. The loss, then, strikes at the very core of identity-in-relationship for the parent.

- **Reawakening of old loss**

  Every subsequent loss has the potential to rekindle old losses and cause us to revisit them. No loss is limited to a particular time and space, and every subsequent loss invites us to continue the journey of exploring. This may be due in part to the nature of the relationship with a newborn, which exists as much in innate potential, hopes and dreams, making the loss more difficult to articulate. The reawakening of old losses may well serve as a proxy for a loss which is much more difficult to articulate and express.

- **Multi-faceted loss**

  The loss of a child is multi-faceted, which impacts not only present relationship and actions towards the individual, but also changes many other relationships. A child carries numerous meanings for a parent, and impacts not only the relationship between the parents, but also the relationship the parents have towards others, including the wider family.

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44 A Lazare, "Unresolved Grief," in *Outpatient Psychiatry: Diagnosis and Treatment*, ed. A Lazare (Baltimore: Williams & Wilkins, 1979).


• Idiosyncratic resistance to mourning

A number of factors idiosyncratic to child loss contribute to a reluctance to grieve: the nature and role of the parent-child relationship and the sense of failure it gives rise to when severed; the fact that the loss is so unnatural and unfathomable; the loss of support encountered in the spouse and other individuals in society; the fact that the family is permanently changed and "lost" to some extent; and the parent's observation at close hand of bereavement overload of those s/he loves. Most importantly, the loss of a child is such an overwhelming assault on the self, resulting in a marked decrease in self-esteem, the shattering of parent identity, and the negation of hopes for immortality, that it significantly interferes with the bereaved parent's ability to address and complete grief. Parents simply cannot cope with it very well. These are factors that are generally encountered. Factors idiosyncratic to the individual parent can be expected to compound any resistance that already exists.47

The parent response is also complicated and extended by social contexts and pressures.48

• Social negation of the loss. When an infant dies, there is a lack of social validation of what the parent has lost, which leaves bereaved parents without social support in working through their grief, while receiving little, if any, confirmation of the loss. Too frequently there is a social negation of this type of loss, an absence of social support and/or funeral rituals to help promote realisation, to confirm the loss and to provide an opportunity for nurturance from others.49 As one author bluntly declares our societal belief: “Babies don’t just die anymore. Or at least that’s what most of us have come to believe from our experience. It isn’t a topic of conversation when it does happen.”50

• Socially unspeakable loss. In the case of infant mortality, an uncomfortable yet solid wall of silence surrounds the loss. The loss of a child is out of the expected order of events. It is natural for a child to expect to mourn the death of a parent, less so (at least in Western cultures) for a parent to expect to bury their child. The experience thus threatens innate securities which are threatened when spoken.

• Social isolation. Few people feel comfortable with parents in grief over the death of a child. The resultant social isolation multiplies the experience of parent grief and loss, and ruptures the social networks in which parental and familial identity is found and formed. Without open access to expression of grief within that community, the sense of isolation is heightened, either by alienation from the group, or as a result of the inability to share their

47 Lazare.
48 Rando, "Parental Bereavement," 52f
49 Ibid, 47f
50 DeFrain, 88
pain with the social network. In affirming grief as a social and communal experience, social isolation is a critical issue for parents seeking to understand and negotiate their loss.

- **Assumption of the role of the strong one.** In the family setting, parents bear the social and familial expectation of being strong for their children. Particularly where there are siblings, there is an innate pressure to “be strong” for the sake of the other children, which mitigates parent capacity for exploration and expression of grief. In no other role except that of the parent are there so many inherently assumed and socially assigned responsibilities. Parents are to be all-loving, all-good, all-concerned, totally selfless, and motivated only by the child and his/her welfare. The loss in many ways constitutes a failure to sustain the basic function of parenthood. In addition to grieving for the loss of their child, parents are confronted with the need to relinquish all of the hopes, dreams, and expectations that they had for and with that child, and to be present to and for one another in their grief, whilst shielding siblings from their pain.

The presence of a partner (which is not always the case) adds complexity to grief as couples not only have to deal with their personal responses, but also its impact on their relationship. Such grief not only places great stress on the relationship, it also makes the capacity to express and understand one’s grief more difficult. As family members usually make sense of their grief by talking to one another about their loss, pressures which inhibit communication and expression of grief in the family inevitably complicate the grief experience. Social conditioning for one partner to assume the role of the strong one inhibits their capacity to express and explore their grief. Parents potentially lose their most valuable support in times of grief – each other – losing what is their most therapeutic resource. In the case of a sole parent, the grief experience is different again.

Questions of meaning in relation to the life of a child who dies before life has begun, or for a child who dies in infancy are notoriously difficult to address. The absence of any meaningful explanation – at societal through to the personal level – contributes to the shape and complexity of the grief experienced. The absence of constructive and empowering cultural narratives in the face of a child’s death impoverishes and isolates parents in the grief experience.

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53 To call this a loss might overstate the case for many. However, the capacity to support one another is invariably diminished in the dynamics of personal grief within the marriage relationship.
54 Rando, "Unique Issues," 31
Because the birth of a child is so intricately woven into a range of transitions already being experienced, even in preparation during pregnancy, the death of a child (or an unexpected termination of the pregnancy) interrupts a transition. Coupled with the fact that the loss is unexpected or unanticipated often sparks more intense grief,\(^{55}\) significant questions are posed for the parent about direction of change, and about capacity to return to pre-expectation identity. The agony of grief and suffering is intensified in bereaved parents because they not only grieve for the loss of the child, but also for the hopes and dreams invested in that child,\(^ {56}\) and for the related identity that they were already embracing and assuming in the face of the potential hopes and dreams embodied in the child. As parents “move into their grief,” the complexity of their bond with the child becomes expressed in the complexity of their grief.\(^ {57}\) In anticipation of the birth and the journey through pregnancy, soon-to-be-parents have begun to negotiate their way to a new identity, leaving behind an old way of being in preparation for a new. Death of the baby cuts across this journey, but does not allow a return to the once familiar “pre-pregnant place.” The pathway ahead is closed, yet there is no turning back.

It is easy then, to concur with Worden who views the death of a child as a special type of loss which requires "additional understanding and intervention modifications which go beyond" his general principles for helping people work through their grief. For example, he recommends careful handling of information about the death, sensitive intervention by professionals, allowing parents to actualize the loss of the child by viewing the dead body, clarification of the cause of death, information about subsequent emotional reactions, and other sensitised responses. An important limitation with Worden’s model is its lack of a clear social/communal dimension to grief, a function of its framing within the counselling relationship. Rando also argues that Worden’s model has limitations when applied to the experience of loss of a child:\(^ {58}\) a lack of a social dimension to care, as well as in the affirmation of loss being identified. The failure to account for the interrupted transition in identity and family dynamics is another key deficiency.

**Unique Aspects surrounding Neonatal Death**

The circumstances and implications of neonatal death are varied. To speak of loss of a child is to speak of a range of divergent losses. Miscarriage, stillbirth, disabilities, deformities and abnormalities, SIDS, and accidental death are examples of the range of losses to be experienced in

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\(^ {55}\) Ibid, 12  
\(^ {56}\) Rando, "Parental Bereavement," 48  
\(^ {58}\) Rando, "Parental Bereavement," 47
relation to the child alone. Impact on subsequent parental fertility is another complexity which ought to be considered in grief of this kind. Yet even within the particular “categories” of neonatal loss, there is considerable variation. The response to miscarriage may depend upon the length of gestation, and upon the subsequent ability to bear children. A late miscarriage (categorised as a stillbirth) evokes a different response to a stillbirth at full term. The impact of SIDS bears its own marks, as does the birth of a child with disability. When the loss of a child occurs in a medical setting the expression of grief is more complex. Implicit in medical education is the assumption that every death is a failure, either of the physician or of medicine itself.\(^{59}\) Lietar draws attention to the implications of this for care of parents subsequent to miscarriage, whereby respondents indicate the abrupt withdrawal of the obstetrician from the relationship,\(^{60}\) while other research indicates that long-term grief may be the exception rather than the norm for miscarriage, and may be mitigated by subsequent births, and possibly social pressure.\(^{61}\) The complexity of grief associated with the loss of pregnancy or through neonatal morbidity requires carers to be attentive to the particularity of circumstances, the expressions of grief and the context in which grief unfolds.

Given that the primary focus of this paper is on the grief of a particular neonatal loss, some brief examples are offered here to illustrate this complexity.

Pine and Brauer note that mothers’ feelings were often sacrificed to the anxieties of others, inhibiting not only their capacity to reach out for emotional support after the death, but also diminishing the quality of available support. The failure of society to understand the mothers’ feelings often led to anger and frustration on their part.\(^{62}\)

In addition to Lietar’s observation that a mother’s grief is often compounded because the woman has only an image to grieve, we should recognise that for many others this image is no more than a concept or a hope. When a woman does not have a viable foetus, she has nothing to see or hold, and neither does the community: there is no social identification with or expression of what has been lost. While the bereavement response will find its roots in the dreams and ideals the parents held for the unborn child, many of them will have remained unarticulated and unidentified. It will be difficult to identify what the unborn child had come to represent for the parents, which could include hope for resolution of an intrapsychic conflict; replacement of someone who has been lost;

\(^{62}\) Pine and Brauer, 74
someone who will need and love the parent; someone with whom the parent can compensate for his/her own deprived childhood; evidence that the parent is mature, sexual, or attractive; or a weapon in a relationship with someone else, without discounting the possibility that the child may well have been imagined as a way of dealing with a former loss. Much of the loss is intangible and inherently symbolic, meaning that part of the grief journey will require identification and articulation of what are now shattered hopes and dreams. Where the loss occurs before there has been announcement of the pregnancy, the capacity for this to take place within the normal social environment is more problematic. Early miscarriage in particular has generated no external connections for the pregnant mother and expectant parents. Social support is therefore limited at best. Such a loss can seem like the “passing of a dream.”

Neonatal loss, which is seminal in many ways, may explain the long-lasting need for parents to tell their stories, continuing at least ten years after the death. Such stories become more fully formed with time, indicating a growing understanding of the nature of loss experienced, as well as being a vehicle for maintaining a link with the dead child in their present lives. Though grief is enduring, it is not constant, nor unchanging. It varies in its intensity and focus, with research suggesting that it often intensifies in the third year.

Parent grief may be complicated also by the romantic notion that parents must always unconditionally love their child, and that such love precludes feelings which might be negative or indifferent. Against such a romantic image of parenthood an expression of anger might be inhibited by the feelings of being unfaithful or unfit parents.

The suspicion of being judged by one’s nearest and dearest also potentially complicates the grieving of a parent, whose consideration for the impact on and response from their partner can be difficult to negotiate. Being able to negotiate grief personally alongside the grief shared as a couple is a difficult task when already deeply impacted by the loss event.

Neonatal death is often a sudden loss (particularly in the case of SIDS and miscarriage). There is absolutely no opportunity to prepare for the death, in which case the ground is laid for a traumatic and intense initial grief reaction.

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65 Pine and Brauer, 74
The social situation can be difficult terrain for bereaved parents to negotiate, particularly when their setting is replete with other young families. It is not uncommon to report jealousy towards others who still have children, or who can have children easily. Encountering others who are pregnant or have recently given birth can reignite the sense of grief and loss. When that birth has occurred in dates concomitant with either the due date or time of death of their own child, the grief reaction can be acute. A subsequent pregnancy can be a frightening experience.67

The complexity and strength of the grief response has been encapsulated in the term “chronic sorrow” which Olshansky68 first used to describe the never-ending process of parental bereavement in response to life with a child who is disabled, but which has been adapted to the grief response in other neonatal losses. Klass reinforces the message expressed by bereaved parents that “you don’t get over your grief,” to which they often add, “but it doesn’t stay the same.” The message to newly bereaved parents is unequivocal: “It will always hurt, but it will not hurt the way it does now,”69 which is reinforced by other studies.70 Another way of expressing this long-lasting experience is embodied in the term, “shadow grief,”71 – a grief which shadows parents through many days.

In affirming that society does not adequately allow for the grief and mourning which follows the loss of a baby, we also need to recognise that the capacity of society to recognise the grief attached to a parent who has a child is therefore even more suspect.

The Loss and Grief Experienced by Parents of Premature Infants

In the case of parents of premature infants, many of the factors associated with parent loss and grief are heightened and intensified, in part due to the fact that there is little understanding or affirmation of the loss experienced by parents of a premature infant. The presence of an infant, albeit hospitalised, is testament to fact that the parents have “celebrated” the birth of a child. Arguably, at the outset there is no clarity as to whether there has indeed been a loss, while parents cling to the tenuous nature of their child’s life. Their emotional investment is initially in the new life of the child, fighting to retain or rescue what was almost lost. The survival and protective instincts which are operative at the outset mask the realities of loss which emerge when the initial shock gives way to a broader focus and perspective. This is not a miscarriage or stillbirth or even at the earliest stages recognised as the birth of a disabled child. The loss of being pregnant is often encountered

67 DeFrain, 169
69 Klass, 89
70 Romanoff, 252
socially as a plus, avoiding some of the discomfort associated with the latter stages of pregnancy, and the accompanying implication that the birth of a smaller baby is also regarded as being “easier” on the mother. The loss of an expected full-term child by these parents is socially unspeakable, implicitly bearing implications of rejection of the child who was born, and ingratitude for the medical assistance which turned a likely death into life. Parents whose child spends an extended period hospitalised in a NICU are subject to a lengthy isolation from their normal social context, extended and compounded after discharge by a desire to protect their child from possible infection. The circumstances experienced by parents in the NICU coupled with a period of extended yet unarticulated or unacknowledged grief, leaves the parents with little energy for re-socialisation subsequent to discharge. And with a vulnerable infant to care for, parents need to be strong, their focus maintained upon their child’s needs to the likely detriment of their own.

This social rupture inevitably finds expression in frustration towards wider family and friends, whose lack of appreciation for the circumstances being faced, both in hospital and post-discharge contribute to the depth of grief expressed. This grief increases the sense of disconnectedness from others and becomes a catalyst for further social withdrawal.72 Parents who have not borne an infant prematurely do not want to hear the stories of parents of premature babies,73 and family members are rarely any different74 - which can strain or even fracture family relationships.75 The end result of this isolation is that parent grief in relation to premature birth remains unexplored. The literature related to grief surrounding neonatal events and premature birth has until recently been scarce.76

In this next section I will explore ways in which premature birth is a compendium of different losses, both long-lasting and wide-ranging in its impact upon the parents, noting that the challenges of grief are multiplied when the journey takes place apart from a community. Some grief is

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common to large groups, whilst others isolate us from them. Premature birth falls into the latter category.

Aspects of Loss and Grief
In the conversation which has been the Preemie-l list, one encounters diverse expressions of grief. In this section, I will seek to frame these expressions in ways which give insight to the depth and complexity of grief which is experienced. Whilst aware that framing categories in this way risks being viewed as the outer limit and acting as a type of paradigm with a potential for the rigidity which came to accompany the stages of grief articulated by Kübler-Ross, I find value in affirming the diverse experiences and expressions of grief which have emerged in the preemie-l community and offering them as a window into the complex and multi-faceted grief which is expressed. Some aspects are more overtly and directly encountered in the conversation, others are revealed in the context of list members reporting encounters with others outside the list. Note here that I am exploring the expression of grief, rather than its meaning.

Emotional
Grief is almost universally experienced in some capacity as an emotional response, which can be directed externally or internally. The expression of parents’ grief runs across a deep and broad range of responses, with one parent describing a “cyclone of feelings following the premature births of our children.” The initial grief begins for many from the moment of birth, emerging and growing in the days which follow. Anger is perhaps the most commonly referenced in the range – tumult – of emotions which emerge: anger, pain, guilt, fear, regret and worry, sit alongside feeling sad and cheated, even a sense of jealousy for other parents, and humiliation, in the midst of loss. Anger is focussed externally in many directions for different reasons: when directed towards medical staff it can be acute, either for failure to act, or for making determinations without reference to parent preference or consultation. Even where communication is comprehensive, anger can emerge at the apparent impersonal and clinical way in which it is framed, or anger may emerge

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“at the ways in which statistics mask the reality of the individual experience,”86 or at the system for the way in which the child’s experience is handled administratively.87 The emotional response can be overwhelming: “the scope of the situation is really beyond comprehending, no matter how much people may “talk” to you.”88 The impact can be extensive and enduring: “I know my head was in a fog and my body/mind/soul was completely numb for many months (four months in the NICU and about 2 years after he was home),”89 which may contribute to an inability to appreciate what happens with the child’s progress.90 At its depths, it can resulting in burn-out.91 either leaving a parent with a low emotional reservoir, with a resultant hyper-sensitivity to others around them,92 or with a complete emotional and physical disconnection from what is taking place,93 and a loss of perspective.94 Flashbacks and recurring dreams can add further stress and limit the regenerative capacities of parents.95

Perhaps most universally expressed and wide-ranging internal response is the guilt96 which is carried. Guilt may present as a feeling of inadequacy on the part of the mother as a result of her being unable to carry the child to term,97 which is a single part of a deep and enduring sense of failure98 even where there is no apparent medical reason to explain the cause of the premature birth.99 This guilt emerges from an intimated sense that the parent could have changed the outcome

for their child, and includes guilt for such considerations as: not picking up on signs and visiting doctor/hospital earlier,\(^\text{100}\) for falling ill while pregnant,\(^\text{101}\) for considering not allowing doctors opportunity give the child a chance at life,\(^\text{102}\) or for not choosing a high-risk pregnancy doctor.\(^\text{103}\) Such guilt which finds its genesis in the journey’s beginnings proves very difficult to shake,\(^\text{104}\) and reflects an artificial appreciation of power of many parents to alter outcomes.

The catalysts for guilt change as the journey unfolds: parents report guilt for being home doing normal life tasks whilst the child remains hospitalised,\(^\text{105}\) a response not unrelated to the inability to spend more time at the hospital,\(^\text{106}\) even when it is result of the need to care for other children.\(^\text{107}\) Breastfeeding also appears as a significant source of grief\(^\text{108}\) and guilt,\(^\text{109}\) built often around unrealistic expectations (even in full-term infants).

Comparison guilt also emerges. In the Preemie-l community some parents confess a feeling of guilt for the positive progress of their child in comparison with others, with the expressed feeling that they are isolated on the list by other parents.\(^\text{110}\) But such grief can also emerge from sources outside the immediate context. Sharing the experience of premature birth can evoke the grief stories of others, who find some sense of permission to reveal their own birth tragedies, often long-held secrets. The revelation of these still-births\(^\text{111}\) and miscarriages by older women\(^\text{112}\) triggers an unexpected grief reaction for parents and adds layers of complexity to the emotional journey. In my

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own circumstance as pastor of a church at the time of our son’s premature birth, there were a
number of women over the age of seventy who revealed their continuing grief over the death of a
child through still-birth or miscarriage. The comparison between the inevitable stillbirth of bygone
years and the nascent hope in the present is both complicating and confusing for some parents.

The feeling of guilt can change shape with the passing of time, particularly related to the contingent
nature of long-term outcomes. There is a continued “waiting game – wondering what will
develop,” which can evoke a later sense of guilt and grief when it becomes increasingly obvious
that there are long-term problems, often creating conflicted feelings about survival: wishing that
perhaps the child had died… and feeling guilty about such wishes. The longer term challenges
compound the impact of guilt, as parents may feel compelled to take on more therapies and
appointments for their child in part at least to satisfy themselves in order to avoid the charge that
they didn’t do enough for their child. This is not unrelated to the parents’ sense that they are
being watched and judged: inviting the presumption that others consider that the premature birth
was the parents’ fault, even though no such implication is evident. When parents confront the
inevitable exhaustion which follows from trying to maintain a demanding schedule and cut back on
the therapies for the sake of their own well-being, feelings of guilt are compounded afresh.

The significant emotional impact creates a surreal air for many, one which was exposed by a
unique thread of discussion. Invited to express their thoughts on the experience by opening with the
word “Imagine…” many parents responded, opening up unacknowledged feelings for some,
whilst for others it was cathartic to be able to express these thoughts.\textsuperscript{122} The emotional impact can be summed up as “overwhelming” for many.\textsuperscript{123}

\textit{Contextual (in the NICU)}

The context in which particular responses emerge are important considerations for understanding the needs of parents and the implications of the responses. There are at least four significant contexts to consider for understanding parent grief in relation to premature birth: the hospital setting, the home environment (including family relationships), work, and the wider social setting. I will focus here on grief which emerges within and in response to the hospital setting, recognising that much of the grief expressed finds its genesis here. Memories of good\textsuperscript{124} or inconsiderate\textsuperscript{125} handling of parents lives long,\textsuperscript{126} whether at the time of birth,\textsuperscript{127} during the hospitalisation\textsuperscript{128} or from therapists following discharge,\textsuperscript{129} meaning that the response of medical staff can be critical.\textsuperscript{130} Thoughtless comments by medical staff can have a lasting impact.\textsuperscript{131} Even such simple decisions as where a mother is placed subsequent to birth can make a significant impact on the initial emotional experience - mothers report being placed next to the nursery or amongst other mothers who have delivered full-term babies and the stress that it brought.\textsuperscript{132} The encounter with a full-term child can reignite the deep grief,\textsuperscript{133} although not always.\textsuperscript{134}

\textsuperscript{122} \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9704/Date/article-823.html} last accessed 27 April 2007; \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9704/Date/article-836.html} last accessed 27 April 2007
\textsuperscript{123} \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9708/Date/article-382.html} last accessed 22 January 2009
\textsuperscript{124} \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9702.gz/date/article-251.html} last accessed 27 April 2007
\textsuperscript{125} \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9706.gz/Date/article-150.html} last accessed 27 April 2007
\textsuperscript{126} \url{http://home.vicnet.net.au/~garyh/prejune2/0025.html} last accessed 22 January 2009
\textsuperscript{127} \url{http://home.vicnet.net.au/~garyh/prejune2/0037.html} last accessed 22 January 2009
\textsuperscript{130} \url{http://lists.vicnet.net.au/mhonarc/preemie-l/1997/12/msg00169.html} last accessed 23 February 2007
\textsuperscript{131} \url{http://lists.vicnet.net.au/mhonarc/preemie-l/2002/09/msg00057.html} last accessed 7 May 2007
\textsuperscript{133} \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9707/Date/article-64.html} last accessed 27 April 2007
\textsuperscript{134} \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9707/Date/article-63.html} last accessed 27 April 2007. Our own unique circumstances meant that our second child was only nine months old at the time of our third child’s birth. To have a baby to hold while in the hospital setting was a source of comfort to my wife in the days following birth.
The early focus in the hospital on the many physical demands and needs of the infant is seminal in framing much of the experience: “It’s as though the baby becomes a collections of symptoms and conditions rather than a little human being.” The physical focus often results in parents seeking reassurance in the measurements of weight as a sign of progress. Where parents are not aware of the different developmental rates and milestones which usually accompany premature infants, the grief can be compounded, particularly when parents see other children progress more quickly through the system.

Parents quickly adapt themselves to the hospital system, and learn to feel at home in its environs. The hospital context quickly becomes the frame in which care is embodied and also determines the ways in which parents engage in their child’s ongoing care. Parent attachment to the hospital setting takes on such significance that parents often express grief at feeling a distance from child while in hospital, connected not only to the allegiance to their child, but also to reliance upon the medical diagnosis. Some parents take the pragmatic approach: it is just what needed to be done to save their child, although the level of involvement by parents in the whole process itself can be a cause of continuing pain. For the mother, providing breast milk often provides the first avenue to express care: “one thing I can do that can be measured.” Due to the difficulty many mothers experience in producing breast milk, either initially or at different stages of the journey, the potential for grief is inherent.

Parent involvement in decision-making in the NICU is a complex topic. Parents want and need some sense of involvement in the care for their child, yet the complexity of decision-making and technical nature of much of the information which is shared makes this problematic, particularly at times of high stress, such as the time surrounding the birth. Even where information is presented
thoughtfully, it is difficult for many parents to absorb,\textsuperscript{144} with the result that later reflection on the choices that were made elicit complex grief responses. The choice of life and death for another is never an easy one, and therefore can be traumatic both in the first instance and upon later reflection,\textsuperscript{145} complicated further when there is a dawning realisation of the limitations associated with medical abilities.\textsuperscript{146} There are times when the fears and limitations on the medical staff can add to the weight of expectation. Though isolated instances, parents have reported rebukes for their emotional states, reporting that tears have been discouraged in NICU\textsuperscript{147} because they were “bad for the child.”\textsuperscript{148} Whether this is indeed to protect the infant or to deal with the discomfort of the staff, the impact on grief by the added burden of responsibility is unarguable.

When the time comes to transition to another aspect or location of hospital care, a new sense of unease develops. Parents grieve the loss of intensive care when moving from the NICU to a Special Care Nursery where the staffing ratio is lower,\textsuperscript{149} and the intensity of community is different – parents miss the relationships they have developed with the NICU staff.\textsuperscript{150} This is often experienced anew after discharge, when facing a different level of care than expected: “I found it very hard to leave the safety of the NICU even though I was heartily sick of the place.”\textsuperscript{151} Parents carry with them an expectation that the child’s medical history demands extra attention/care,\textsuperscript{152} with the resultant observation that on reflection the NICU experience was easier than post-discharge.\textsuperscript{153}

Ultimately the realisation that they have only received a partial message through their time in hospital becomes a key element of the parent response: when the false correlation between survival and health is exposed is a key moment for them.\textsuperscript{154} Access to complete copies of the medical records subsequent to discharge can trigger renewed grief responses as the reality of the journey is

\textsuperscript{144} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9704/date/article-416.html last accessed 27 April 2007
\textsuperscript{146} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9703/date/article-373.html last accessed 27 April 2007
\textsuperscript{149} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9706.gz/Date/article-156.html last accessed 27 April 2007
\textsuperscript{150} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.0002/Date/article-222.html last accessed 7 May 2007
\textsuperscript{152} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9706.gz/Date/article-164.html last accessed 27 April 2007
\textsuperscript{153} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.0002/Date/article-428.html last accessed 7 May 2007
reflected upon afresh.\textsuperscript{155} Similarly, one parent noted in response to the production of a support book upon discharge – while a potential source of encouragement and nurture – that it made no mention of the emotional challenges or financial challenges, retaining a focus on the medical challenges and warning signs.\textsuperscript{156} It is when parents are released from the confines and constraints of the hospital that they begin to re-evaluate their perspective on that journey.

Special cases need also to be noted. Grief is often complicated in the event of a multiple birth, where the death of one child is complicated by the journey of the other through the challenges of prematurity,\textsuperscript{157} or when the progress of the individual infants in multiple birth is markedly different. The implications for parents’ grief are not insignificant and prompts one to ponder whether this means that aspects of grief are “forgotten” or deferred. At what stage are parents supported in addressing the grief responses which arise? Where there are different outcomes for the children in a multiple birth situation, the complex nature of the grief response is evident.

Other contextual complexities include where an IVF pregnancy leads into premature birth,\textsuperscript{158} the complex nature of grief when one twin dies and the other suffers significant disability,\textsuperscript{159} and the shift from an expected home birth,\textsuperscript{160} or even for a normal birth,\textsuperscript{161} into the highly technical environment of the NICU, and when birth of a premature baby renders the mother incapable of having more children.\textsuperscript{162} Attention to the context not only requires consideration of the physical environs, but also to the particular circumstances of each family.

\textit{Social (identity in community)}

The stony wall of silence confronting neonatal circumstances outside of normal parameters is first encountered in the immediate aftermath to the birth, which generally people fail to acknowledge,\textsuperscript{163} or respond to with some ambivalence, not being sure whether to offer congratulations or

\begin{itemize}
\item \textsuperscript{156} http://home.vicnet.net.au/~garyh/premapril/0088.html last accessed 21 January 2009
\item \textsuperscript{157} http://www.vicnet.net.au/~garyh/arcmarch/0128.html last accessed 21 January 2009
\item \textsuperscript{159} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.199808/msg00820.html last accessed 23 February 2007
\item \textsuperscript{160} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.199911/article-61.html last accessed 3 May 2007
\item \textsuperscript{161} http://lists.vicnet.net.au/cgi-bin/lawgate/PREEMIE-L/archives/preemie-l.1999911/article-467.html last accessed 3 May 2007
\item \textsuperscript{162} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.199911/article-467.html last accessed 3 May 2007
\item \textsuperscript{163} http://www.vicnet.net.au/~garyh/arcmarch/0280.html last accessed 21 January 2009
\end{itemize}
condolences.\textsuperscript{164} Many parents report receiving no gifts, no cards, and no baby shower,\textsuperscript{165} or even when they were acknowledged and congratulated, there was a suspicion that it was being done without an appreciation of the depth of struggle to be faced as a consequence.\textsuperscript{166} Insensitive comments which emerge as a result compound the grief experience, particularly when they convey a lack of any real understanding of the struggle,\textsuperscript{167} or because of the tendency to minimise the pregnancy and childbirth experience of the mother,\textsuperscript{168} which has been known to evoke an aggressive response from parents,\textsuperscript{169} or foster social withdrawal, which is one parental response to the uncertainty about what to share, with whom and how much.\textsuperscript{170} A complicating factor in social recognition is the potential for assuming that parents of premature babies suffer no loss. Just as in the case where people can assume that because a baby was never born, the couple has nothing to grieve,\textsuperscript{171} so it can easily be assumed that because a child was born and lives, parents of a child born prematurely also have nothing to grieve. The loss is hidden – the parents have a visible child, and what is lost was not born, and is not visible. In some cases, it is possible to announce the birth before anyone noticed that the pregnancy, compounding the disbelief.\textsuperscript{172} On the other hand, the healthy appearance of child can mask the depth of struggle which took place following birth.\textsuperscript{173}

Pregnancy and childbirth is a series of social experiences which bring their own celebrations along with a series of both official and unofficial rites of passage. Stories of babies, birth and family are told and retold with pride. Thus parent grief is not merely associated with the missed aspects of pregnancy: emptiness,\textsuperscript{174} and missed kicks,\textsuperscript{175} but also the social aspect of being pregnant,\textsuperscript{176} which

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\item \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie.l.archive.9707/Date/article-513.html} last accessed 27 April 2007
\item \url{http://home.vicnet.net.au/~garyh/premapril/0164.html} last accessed 21 January 2009
\item \url{http://home.vicnet.net.au/~garyh/premapril/0171.html} last accessed 21 January 2009
\item \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie.l.archive.9707/Date/article-829.html} last accessed 27 April 2007
\item Ellen Fish Lietar, Miscarriage, in Theresa A. Rando (ed), Parental Loss of a Child, Illinois: Research Press, 1986,
\item \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie.l.archive.9705.gz/Date/article-690.html} last accessed 27 April 2007
\item \url{http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie.l.archive.9705.gz/Date/article-815.html} last accessed 27 April 2007
\item \url{http://lists.vicnet.net.au/mhonarc/preemie-l/2002/02/msg00431.html} last accessed 7 May 2007
\item \url{http://www.vicnet.net.au/~garyh/arcmarch/0467.html} last accessed 21 January 2009
\end{enumerate}
includes such simple aspects as the wearing of maternity clothes. 177 Seeing other heavily pregnant woman serves as a reminder to many of what they have missed, 178 a grief which can also find expression in terms either of a desire to have another go at being pregnant, 179 or to underline that they never want to risk the experience again. 180 Many report dark thoughts towards others who are pregnant, they being perceived as a symbol of their failure and isolation. 181 Parents who have a subsequent premature birth can carry extra grief and guilt for repeating the experience – having known the risks beforehand, 182 or bear a lack of confidence in relation to the development of the pregnancy. 183

Comparing their birth stories with those of their (full-term) peers – a not uncommon ritual amongst mothers – is problematic. 184 Any apparent trivialising of the experience can stir up deep reservoirs of anger. 185 In the same way, the inevitable comparisons between children creates an environment where loss can be exposed, particularly when prematurely born children are compared with the development of full-term peers, 186 not to mention the comparisons which emerge when comparing their actual experience with what text books say a child of that age should be doing. 187

Many parents choose social isolation in order to cope and recover, 188 partly due to encouragement by medical staff to protect the infant’s fragile health. Such advice is problematic. Re-entering the real world has been described as an experience of shell-shock, 189 reflecting as much the depth of emotional stress as the social isolation which hospitalisation has fostered – just part of the difficulty

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of emerging from hospital and returning to public life\textsuperscript{190} – which underlines that parents have lost their sense of belonging, and now feel “out of place” where once they were comfortable.\textsuperscript{191} One father articulates the feeling that his support networks vanished at the time.\textsuperscript{192} Other parents report feeling sad, lonely, lost, disconnected as a consequence of the experience.\textsuperscript{193}

The social isolation is cogently expressed by one mother: “I can tell you that it is a grief like no other. It will take you places you never wanted to go. It feels like your baby died, but the crib is not empty. Your dream of a healthy child would certainly shatter. But there would be no funeral.”\textsuperscript{194} Pregnancy and childbirth books marginalise parents of premature and disabled infants,\textsuperscript{195} giving little or no idea of the survival chances of children born at extreme limits of viability, with the consequence that there is little informed response amongst peers, and therefore a lot of uninformed fear,\textsuperscript{196} and “blissful” ignorance. Yet parents want their stories to be validated, at least on the list discussion with other parents, which often resulted in a battle for recognition of the depth of struggle faced, and the individual nature of the struggle faced, even it is an experience shared in common with other parents. This came to be referred to as the “lowerarchy,”\textsuperscript{197} where one’s story would be “bettered” by more harrowing tales – a clear call for some social affirmation of the unique struggle and its depths. Individuality of experience is to be maintained in the social world of premature parents.

Grief’s greatest rupture is social – it disconnects us from one another, and in the case of premature birth we are disconnected from the communities which have nurtured our stories and identities, and shaped our expectations leading into the birth. Having lost connection to the narrative and the community, the capacity to develop resilience and draw on communal strength is greatly diminished. Continuing to work during the hospital period – one way of maintaining social connection – can create extra strains due to reduced ability to function in a work role as much as it can give parents space from the pressure of close focus upon their child. For the mother, this might


\textsuperscript{192} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/premie-l.0005/Date/article-966.html last accessed 7 May 2007

\textsuperscript{193} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/premie-l.0001/Date/article-198.html last accessed 7 May 2007

\textsuperscript{194} http://home.vicnet.net.au/~garyh/premay/0092.html last accessed 21 January 2009; see also chapter 5.


\textsuperscript{197} http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/premie-l.archive.9708/Date/article765.html last accessed 22 January 2009
not be possible, either due to already arranged maternity leave (endured with no child at home), or to the pressures of caring for other children.

It is in the wider social sphere that grief faces new challenges, due to the child’s growth and development. The birth story can barely be left behind, as parents may be required to explain the story to educational teams, or confront developmental assessments which reinforce the impact of the premature birth on their child. Similarly the home may no longer be a haven, as a consequence of the loss of privacy due to home support which invariably serves as both support and a reminder. It is evident that a continued rehearsing of the story remains a part of the grief process, including reflection on what could have been done differently to avoid the outcome. Even improvement in the child’s development is problematic, potentially meaning they will slide back through the gaps in the system because therapies are withdrawn as a consequence.

But a paradox remains: as premature infants often spend a longer time appearing to be in the baby category, parent grief can also be extended, yet when the worst appears to be over and there is nothing more significant to report/deal with, it is not uncommon for parents to feel lost - a curious mixture between grief at what has been lost and gratitude for progress made.

The key social question resonates in the voice of one mother:

“OK, so now my universal, unanswered question...WHY DON'T PEOPLE HAVE THE SAME REACTION TO OUR TRAUMATIC EVENT??? One theory of mine is that because our children were in the NICU, isolated, that since very few people actually saw them, smelled the unit, heard the noises and held a teeny, tiny, fragile, but tough as nails beautiful preemie, the image in folks minds is that of the 11 or 12 inch doll baby at Toys R Us.”
Relational (family)

The social impact of grief is felt most acutely for many parents in relation to their families. The isolation which comes in grief and in the whole experience is at least in part due to being separated from the baby for long periods, and because of time pressures associated with presence at the hospital, separation from family networks. This leaves parents on many occasions with no-one who truly knows their situation to talk to about what was happening. The disconnect which is evident during those early days in hospital can have longer-term implications in family relationships. Coupled with the usual advice upon discharge to minimise risk of infection, this isolation can continue for some time once the hospital has been left behind.

In the closest relationships, the mere logistics for maintaining relationships in crisis are problematic. Siblings may be excluded from the NICU depending on local policies. Limited visitation rights in some NICUs make it difficult to invite family into the circle of experience in a meaningful way. Tensions reported with wider family are not uncommon, noting that family support can cause greater stress, and increase the grief response. The need for parents to own and tell the story in their own way is one aspect of feeling in control of the circumstance, hence when wider family members seek to take some ownership of the story, particularly in the early vulnerable stages, there can be stresses introduced and deeper grief expressed. The presence of wider family can be somewhat problematic, particularly where blame can be introduced, where there is a lack of

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acknowledgement by wider family, or when there is a sense of being judged or evaluated by the progress of the child. It is not uncommon for parents to express feeling a sense of accusation from others in the extended family, and even from older full-term children because child doesn’t thrive. Dealing with the grief of family members might also come at the expense of the parents’ own grief. When this occurs in relation to those who might have been expected to provide support, parent isolation is underlined.

The experience of premature birth can have a significant impact upon the marriage relationship, particularly where the partners’ responses are radically different either in timing or intensity. While marriages can deal with the stress, it is sometimes affected by an out-of-the-blue diagnosis. Tension between the different parent journeys associated with prematurity can also emerge.

### Psychological

The experience of extreme premature birth can have a deep and lasting psychological impact upon parents, whereby moments of the journey are still relived and vividly recalled many years later. The length of recurrence of remembrance and reflection has been summarised succinctly in such statements as, “It is an enduring feeling lasting years,” and, “it took a long time to reconcile the baby I had with the baby that might have been.” On the other hand, the potential for denial is evident, blocking out memories of the event and their impact: denial about how small and fragile the baby was, and how life has been impacted. The early impact on bonding between parents

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and child is articulated by parents as “holding themselves back” from their child after birth for fear of losing them. This acute awareness that bonding didn’t take place at birth feeds into the grief at what might have been lost. Some otherwise articulate parents find difficulty in articulating their feelings.

Belief that the struggle ended on discharge feeds into the recurrence of grief: “…when he was allowed to go home… we assumed we’d won the battle,” such that when problems emerge in later years, the journey of grief is revisited and rekindled. When no problems are identified at discharge, the belief that none will emerge can be shattered, along with the dawning realisation that the promised two-year-old “catch up” will likely never be met.

Because of the ever-shifting and tenuous nature of the NICU journey for many children born at the margins of viability, parents have learned to expect shifts, living with continual uncertainty, “waiting for the other shoe to drop,” and so keep themselves ever-vigilant for problems, having continually being hit by things that weren’t expected. There is an ever-present fear that something else is about to happen, a fear which has often emerged through horrific events. Some seek to protect themselves by restricting themselves to stories of hope. But even when life appears to be going smoothly, fears deepen. A conflicted perspective endures: “I want my life back… a bad nightmare and I can’t wake up,” linked in part to an inability to forget the images of

their child lying in the NICU.246 A lost sense of normality247 is often reflected in feeling like this will never end,248 whereby life turns into reactions to what is going on around you,249 not knowing when it is an issue related to prematurity, or one that is normal, or whether it doesn’t matter at all.250 This is one part of the ongoing battle to integrate the NICU world with conceptions of life as it should be.251 For many a deep ambivalence about the experience itself endures252 along with reservations about repeating the journey with another child253 - a situation in which husband and wife often reach different conclusions.254

**Functional**

The first and most immediate impact on parent functioning comes in the aftermath of the birth when the initial shock is evident and there is an enormous amount of information and circumstance to process. The capacity to function outside of the hospital setting in those early days is greatly diminished, if not for the diminution of emotional resources alone, then also for the significant time demands associated with birth and hospitalisation. This is a first step in a long journey of seeking to balance work/life/hospital/relationships for months on end during the hospital phase alone.255 This is further compounded by the complicated lifestyle post-discharge and the concomitant emotional exhaustion which is a remnant of the hospital experience for some parents.256 Bringing the NICU home with monitors and alarms, while giving comfort in one way, may also serve to heighten the sense of grief and fear.257 In the same way any continuing treatments/medications/therapies feed into this reinforcement of a different reality from the one anticipated prior to the birth, one which demands greater time commitments, hence bringing greater pressures on ability to function according to pre-birth expectations.258

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It is recognised that parents are called upon to participate in decision-making within the hospital setting while under such pressure. Being in control of – or at least contributing to – medical decisions, not only in the hospital, but also after discharge, including whether and when to seek assistance, places power and responsibility in parents’ hands which can itself intensify the sense of grief, becoming a source of later second-guesses on treatment, the pondering of whether things could have been done differently. Functioning in a quasi-medical role as parent heightens the sense of responsibility for outcomes in a way in which a non-participatory medical model does not. Parents who have spent an extended time watching over their hospitalised child are inevitably emotionally drained.

These complex and often intense pressures impact upon parent functionality in the work place and at home, as well as upon parents’ capacity for decision-making in response to the complex needs of the neonate. These pressures can be expressed in hyperactivity with the result that life is lived at a frenetic pace, driven in part by a fear that stopping will lead to being overwhelmed. The constant pressure impacts upon waking and sleep: “I still wake up afraid that one of my babies will have died in the night. How much of this is normative paranoia … or normal parent worry, and how much is a reflection of the preemie experience, I'm not sure.” This capacity to second-guess, grounded in an uncertainty about what is normal, is evident for many parents. Many seem to operate at a basic level, akin to an auto-pilot:

People would say things to me like "you're so strong. I don't know how you cope." What utter nonsense. What choice did I have? I had two sick children. I HAD to cope. But it's an experience that's changed my outlook on life, the way I relate to other people, the way I perceive hospitals, doctors, and medical care in general.
When the outcome results in one parent being unable to continue working, each day serves as a reminder of the experience and loss, and is a source of continuing grief, not to mention the economic impacts longer term.

Perhaps the least addressed issue is the way in which the experience impacts the way parents function in relation to their child.

One day I was sitting in the living room looking at Emily on the floor thinking about how all of these evaluations made me feel like Emily was just a medical case, a thing to study, to make notes about. I was feeling pretty desperate about wanting my baby to have an identity, to be recognized as EMILY, or as another mother phrased it, my child’s two year life was lived with her holding her breath, as her child’s first name had in reality been “Preemie.”

When memories of the birth experience frame the perception of the child, an overprotective attitude to the child often emerges.

**Memorial**

While the experience of grief is intermittent and shifting, there are apparent moments which parents note as significant in the grief journey. These include anniversaries and birthdays along with subsequent pregnancies and other significant time-related events. Such events serve to bring the grief back into focus and act in a memorial way, kindling memories with stark freshness, and touching tender places where wounds appear still.

The first birthday is regularly reported as a key moment in grief where the original feelings and stark memories come flooding back and the experience is graphically relived. Some have accompanying physical symptoms (heart palpitations and hyperventilating) relating to the stress associated with the approaching first birthday, while others find the first anniversary of due date to be another anniversary which sparks angst. One mother identified the time between her child’s

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birthday and due date as “the void” because of the big emptiness felt.\textsuperscript{271} The first year may be filled with memorial moments which kindle a deep response, as many milestone markers often pass without them being achieved.\textsuperscript{272} Hence the often deep feeling of impending doom,\textsuperscript{273} the “waiting for the other shoe to drop,”\textsuperscript{274} which finds expression as a lurking fear of what might be, of what other medical challenges might emerge.\textsuperscript{275} This grief can resurface at subsequent birthdays,\textsuperscript{276} for some years hence,\textsuperscript{277} with one parent reporting continuing grief as their son approaches his 21\textsuperscript{st} birthday, and speaking of “grief that lasts a lifetime.”\textsuperscript{278} Some find difficulty in giving words to their grief even after an extended period,\textsuperscript{279} while others have no difficulty recounting the exact moments of the events surrounding the birth after some years.\textsuperscript{280} Anniversaries are key moments, whether they be anniversaries of birth, due date\textsuperscript{281} or another critical moment\textsuperscript{282} in the journey. Anniversary of PROM (waters breaking) became a catalyst for remembering and renewed grieving for one mother,\textsuperscript{283} although sometimes anticipation of the first birthday can be more traumatic than the reality of the actual date.

\textsuperscript{273} http://home.vicnet.net.au/~garyh/premapril/0283.html last accessed 21 January 2009
A subsequent pregnancy can feel particularly threatening, bringing with it renewed memories and fears, and a fear that there may be a complete loss of control once again. Reaching the same stages in the subsequent pregnancy where the premature birth began its journey may evoke deep uncertainty and spark painful memories.

The reaching of milestones can be particularly significant, celebration being mingled with deep ambivalence. The baptism of the child is one such moment, as is commencement at school, the arrival of a Social Security card, and even the otherwise simple achievement of getting a child to eat.

Expected memorial moments, notable by their absence, can also serve to trigger a fresh experience of grief, particularly the shifts which take place when the children enter the world where difference from their peers becomes apparent, either at school, or in playgroups. Re-emergence into different social settings can serve to highlight the differing reality by exposing scars or underlining size differences, thereby making this journey public. The physical scars of prematurity are a continuing reminder to both parent and child. That many mothers report having no memory of birth, a blank which can persist for a number of days subsequent to birth and obliterating key memories with a child brings another facet to the experienced loss.

**Triggers**

Perhaps the most difficult grief moments to cope with are the unexpected, either due to their timing or their location. Grief which impacts unexpectedly once again exposes the lack of control which
parents identify as integral to their experience of prematurity, where the social penchant for trivialising the experience is brought to a fresh point of contention. When grief is set off by the portrayal of premature birth in a television show²⁹⁵, particularly if the experience is glamourised,²⁹⁶ its expression can be emotional. Paradoxically, even where the portrayal is realistically depicted, the response can be similar,²⁹⁷ underlining that the memory which is triggered is at issue, rather than the trigger itself. But grief does not always require an obvious trigger, often surfacing in the middle of a seemingly ordinary event: “sometimes I just pull over on the side of the road and cry,” reported one father.²⁹⁸ Unexpected triggers are often found,²⁹⁹ such as when other children inadvertently drawing attention to something which sets memories in train,³⁰⁰ or other household experiences. Smells can trigger both deep emotions³⁰¹ and memories.³⁰² The warming trays on which a premature infant is lain in the days following birth are routinely covered with a plastic wrap used in almost every kitchen, which connects the experience into the everyday life at home in an unavoidable way.³⁰³ For many parents, songs remain a reminder,³⁰⁴ either because they were sung to the child or were heard at key moments of the journey. Many have responded by writing poems,³⁰⁵ or have found

expressions of their experience in such forms cathartic. That critical moments in the journey are more vivid\textsuperscript{306} often masks other moments, which are awoken in memory when unexpected events trigger them.

One of the more particular and dreaded triggers is a return to the hospital setting, either for admission\textsuperscript{307} or for tests.\textsuperscript{308} Where health issues require the child’s return to hospital, parent fragility can be acute,\textsuperscript{309} as wounds can be opened afresh, memories rekindled and uncertainty underlined, though it can also be a cleansing experience.\textsuperscript{310} Hospital-type places can also trigger flashbacks and emotions.\textsuperscript{311} The medical relationship risks being conducted against the backdrop of the NICU experience for some time after discharge.

The uncertainty of the social environment – whereby triggers might be encountered – can be painful. Seeing other pregnant women, hearing stories told by other premature parents,\textsuperscript{312} and hearing other parents share their dreams, can be difficult to bear,\textsuperscript{313} and may reinforce a reclusive lifestyle. The isolation can be increased by unspoken premonitions that may be carried,\textsuperscript{314} which are triggered in the normal social conversations amongst parents. The danger in encountering unexpected triggers is the pressure it may bring upon parents to withdraw in order to protect themselves from moments where they may lose control.

Summary
The experience of grief for parents of premature infants is markedly complex and diffuse. The impact of the losses and ruptures associated with an extremely premature birth has broad-ranging personal, relational and social implications, leaving many unresolved feelings and an uncertain
prognosis for the child. Parent grief is more than a response to a single confined event, but an uncertain and potentially ever-changing response to a situation in flux. Parent grief is also more than a response to its impact on a single relationship, but unfolds in a complex web of familial and communal settings. There are certain losses which can be identified and stated:

It is not so much the medical aspects of the high tech births, but in my case, it is never knowing what a brand new baby looks like, (didn't see my daughters for 14 hrs the first time, and 3 days the second time); never being in labour, though every one rushes to tell me I should be glad to miss that; never breastfeeding (well I did pump for 3 weeks for the first one, but it is hardly the same thing is it?) and just that overall feeling that I have somehow failed to do my job as a baby incubator…

and others which cannot be so easily identified and articulated. It is understandable that parents of premature infants might tend to idealise what a full-term birth is like – a reality that can never be completely erased, and seek to withdraw from more complicated social relationships and settings, particularly when their pain and anguish is not legitimated.

A pregnancy carries with it expectations and hopes as the relationship between parents and unborn child develop prior to birth, expectations which flow into the wider family and social sphere. Premature birth, as a departure from the script, is not only a departure from a personal script, but also from wider family and community also, forcing parents into a pathway divergent from anything they might have inherited or had foisted upon them by family or community. Finding themselves living in a unique individual and uncharted space can become a source for rupture with the wider family. That it is a product not of the parents’ own choosing compounds the grief and isolation which flows from misunderstanding, and serves to highlight afresh the communal and social aspects of all grief, underlining at the same time the lack of resources and support for parents in this unacknowledged aspect of their journey.

It is important to recognise that this grief is not definitively linked to the long-term health of the child. While having many layers, which include contemporary threats to health, developmental issues, battles with labels and social connections, the experience of a premature birth, regardless of outcome, can be the source of long-lasting and significant grief, and a reshaping of perspective for parents and family. Perhaps the greatest difficulty is the inherent contingency of the

journey: “Unlike parents of truly disabled children, we are given a hope and a possibility that our children’s disabilities will resolve… that our children’s disabilities are temporary.” This makes the grief more difficult because it is joined with a hope which may ultimately prove to be false. The losses pile up: “I lost my pregnancy. I lost my choice for natural birth. I lost hearing my child's first cry. I lost holding him right away; and just being able to contemplate him. I lost my dreams of what were to be (and that was a lot!). We, too, were robbed.”

“…this whole preemie experience has obviously destroyed the vision of just what “having a baby” is supposed to feel like and what it represents. Nothing is as I once thought and knew it to be… but it has also left me enriched beyond compare.” There were indeed losses and reported gains, including a new perspective on life and a deep sense of gratitude.

Grief thus gives birth to a short-term view. Looking too far ahead is often too painful or too marked by uncertainty. Parent grief in relation to premature birth must negotiate a number of transitions, each renewing uncertainty and often underlining the implications of the early birth.

Some of the resources which parents found helpful include keeping a journal of the experience, although many find this difficult to continue once the hospital is left behind, due to pressures of time. Others felt that journaling might be too open and threatening for them, concerned about the impact of trying to express what was inside, or found themselves focussed too much on the negative as the only things to write about. Seeking to give words to the experience is a universal challenge which underpins the journaling experience. Re-reading the journal, however, could be a painful experience, abandoned before too long.

Others took to scrapbooking, which many found

to be a helpful grief therapy.\footnote{http://lists.vicnet.net.au/cgi-bin/wg/PREEMIE-L/archives/preemie-1.200105/date/article-321.html last accessed 7 May 2007; http://lists.vicnet.net.au/cgi-bin/wg/PREEMIE-L/archives/preemie-1.200105/date/article-321.html last accessed 7 May 2007} Picking up the pieces of the journey at a later time and memorialising them in a book was found to be cathartic and emotional for many. But these are undertaken at the initiative of the parents, rather than the consequence of a formal embrace of parent grief at the professional level. Lack of awareness at the social level is translated to the personal level for many parents, thus hampering their recovery, and rendering them vulnerable to long-term grief, unacknowledged and unaddressed.

The journey of healing emerges as parents begin to realise that not all is loss, the times when dreams begin to resurface,\footnote{http://lists.vicnet.net.au/mhonarc/preemie-l/1998/08/msg00567.html last accessed 23 February 2007} where they find themselves beginning to respond differently to insensitive comments,\footnote{http://lists.vicnet.net.au/mhonarc/preemie-l/1998/03/msg00636.html last accessed 23 February 2007} where they begin to let go of some of the expectations for their child which had been imposed from other sources and embrace a new reality.\footnote{http://lists.vicnet.net.au/cgi-bin/wg/PREEMIE-L/archives/preemie-1.2002.01/Date/article-193.html last accessed 7 May 2007} For some it might bring revisions about having more children,\footnote{http://lists.vicnet.net.au/mhonarc/preemie-l/2002/05/msg00056.html last accessed 7 May 2007} or the placing of a memorial in the home as a symbol of something which is now past,\footnote{http://lists.vicnet.net.au/mhonarc/preemie-l/2002/03/msg00023.html last accessed 7 May 2007} or when celebrations can be embraced for what they are.\footnote{http://lists.vicnet.net.au/cgi-bin/wg/PREEMIE-L/archives/preemie-1.0002/Date/article-375.html last accessed 7 May 2007} But these are places reached in their own time, destinations and timings as individual as the journey itself. For some it might never be a negative experience,\footnote{http://lists.vicnet.net.au/cgi-bin/wg/PREEMIE-L/archives/preemie-1.0004/Date/article-62.html last accessed 7 May 2007} while for others, the sense of anything positive emerging is anathema, feeling as though the journey is a continuing punishment,\footnote{http://lists.vicnet.net.au/mhonarc/preemie-l/2002/11/msg00045.html last accessed 7 May 2007} getting worse over time,\footnote{http://lists.vicnet.net.au/mhonarc/preemie-l/2002/12/msg00074.html last accessed 7 May 2007} with no end or hope of emergence in sight.\footnote{http://lists.vicnet.net.au/cgi-bin/wg/PREEMIE-L/archives/preemie-1.0005/Date/article-332.html last accessed 7 May 2007} But the experience itself remains a catalyst for grief, regardless of the outcome,\footnote{http://lists.vicnet.net.au/cgi-bin/wg/PREEMIE-L/archives/preemie-1.200104/Date/article-595.html last accessed 7 May 2007} a journey where closed questions do not allow full exploration of what has occurred and continues to take shape.

Parent grief does not unfold in a vacuum, nor is it confined to the hospital setting. Parents of premature infants experience the full personal, social, situational and relational aspects of grief in varying intensity as they seek to identify and articulate not only their sense of loss, but also the
overall experience. The potential for grief to remain unresolved is evident. While the focus in the hospital invariably remains upon the child, and medical resources are prioritised towards the needs of the child, it remains the place where the resources and context for supporting parents in exploration of their grief ought to be most evident. While the focus of parents is towards their child, efforts to support parents in giving expression to their experience while it is unfolding can be important for their own long-term health, and hence their capacity to care for the child. Therapists and pastoral carers, though arguably of little benefit to the child, are a key support to parents during this time, providing a contact outside the limited circle; someone who speaks a similar NICU language and is familiar with the environs and parent experience. A compassionate pastoral carer can assist in facilitating the family's own anticipatory grief and expressing their present grief, helping them develop their understanding of their own personal reactions: their fear, anger, guilt, grief, conflicts, how they differ from one another, and how their reactions affect one another. Helpful care not only begins this journey in the hospital context, but also connects the family in their wider social context, preparing them for a return to the home, work and family setting – promoting and facilitating a new interdependence.

The potential for unresolved grief for parents is high, a consequence of the impact on social constructions and connections which the extended hospitalisation accompanying extreme premature birth brings. The lack of grief counselling within the context of the NICU structurally disenfranchises parent grief. Attention to the particular circumstances and experiences of each parent should form an integral part of the overall care for the child, who will be discharged into the care of these wounded and grieving parents.

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341 Switzer, 99
Chapter Eight
Towards a Restoration of Parent Identity

Our explorations thus far have identified a number of important aspects of the parental journey through extreme prematurity, an experience which is inherently dissatisfying and disorienting, in spite of the contribution of the medical efforts in their child’s behalf. The impact on parent outcomes has long-term implications. Whilst the medical literature identifies and acknowledges the stresses which are involved in the parental journey, the response has focused on addressing needs around the transition into the NICU and journey through the hospital experience, whilst maintaining the assumption that discharge restores parents and family to its place of comfort and normality.

We have also noted that significant and long-lasting health events impact upon the ways in which individuals and families construct their life narratives, an experience which is not limited to premature birth. Biographical narratives provide an insight into the ways in which individuals and families construct meaning frameworks, which provide the background into which the experience of prematurity must be integrated. Illness narratives help us understand some of the challenges to be faced in integrating this experience, with the caveat that the parents in this instance are not physically ill. Perhaps the ultimate contribution of these frameworks is that they help us to recognise the socially constructed nature of this knowledge and therefore offers capacity to shape it in response to differing circumstances.

Popular understandings of prematurity offer little realistic or helpful insight into the challenges to be faced, and few resources for the journey. Within the literature generally explored by parents in advance of birth, the development of and information available for understanding the impact of prematurity on families is dangerous for its absence, or its misleading nature. The capacity to develop a life narrative in which the experience of prematurity, or realistic expectations surrounding the experience, can be integrated is largely absent, with the result that the experience of prematurity invariably comes as alien for parents. It is an experience for which they are vitally unprepared.

Upon entering the NICU we find a power structure which is privileged towards biomedical understandings and practice which marginalises both the parents and the infant as human beings. The purview of much NICU practice is primarily contained within the biomedical construct, and parents are immersed in a way of living and acting which effectively retrains them to view their
child through this prism during an extended NICU stay. Parental capacity to engage with the environment and shape it is dependent largely upon their capacity to enter, understand and speak the language of this world. At the same time, the ability of parents to reflect upon this experience and integrate it into their self-understandings is limited. There is no provision within the NICU setting for this to occur, and the greatest attendant resource – other parents – is often muted or excluded.

The resultant grief experienced by parents is intense, complex, pervasive and enduring. This largely unresolved grief impacts parental capacity to relate to each other, to wider family and their community. It is a journey without publicly acknowledged pain or ritual, and without any clear pathways for resolution. The continuing contingent nature of their child’s well-being creates uncertainty with potential for new experiences of grief on top of the continuing grief emerging from the birth and hospitalisation experience.

Parental responses to the experience of premature birth exhibit strong parallels with religious experience. Parents and family are subjected to an experience which does not fit within the conceptualised and preferred framework of life understanding. They see, feel and handle aspects of life for which nothing had prepared them. From the initial image of their newborn child onwards, they face the challenge of seeking first to survive, then to make sense of this experience, and to integrate it into their whole world-view, yet clearly lack the tools or frameworks to undertake such a task constructively. Premature birth is an experience seeking meaning. A new vocabulary and a new language are needed to assist parents in interpreting this experience and the context in which it takes place, enabling them to be proactive rather than merely responsive to the circumstances.

Having already explored some of the available frameworks as categories for understanding this shift, the task in this chapter will be to evaluate these alongside other frameworks of understanding in terms of their efficacy for this particular experience, and for pastoral practice amidst the broader extension of care and support. I will endeavour to “look beneath” these frameworks to determine whether there is a deeper ground of understanding which might explain the deep and continuing angst, and offer hope. Given that human beings do not spend time contemplating what is real and what is known to them unless and until they encounter a problem which challenges the status quo,¹ some reflection on the ways in which this contemplation has given birth to an initial framework of life understanding must form part of an analysis of how this can be adapted to new realities.

Narrative approaches
Biographical narratives provide a creative and explorative prism for viewing life experiences, offering shape and direction to our lives by providing a means of understanding our frameworks of meaning. Such narratives are open-ended in nature, allowing for growth and exploration, being accepted as works-in-progress, constructed with elements of past and present experiences, whilst embracing future expectations. The frameworks provided by biographical narratives acknowledge the potential for multiple co-existent narratives - grounded in different contexts or in different relationships - which are able to be held concurrently without diminishing their inherent tensions, and without requiring a systematic integration into a single perspective, whilst continuing to maintain their open-ended nature. The elements of biographical narratives may well find their genesis in isolated pericopes which are imbued with meaning with the passing of time and integrated more broadly into an over-arching or enduring narrative. As such, seminal aspects of the narrative may emerge as nothing more than images, symbols and events, which are explicatated and developed in the retelling within the social context.

A number of limitations pertaining to biographical narratives impact their effectiveness in supporting NICU parents. The tendency for them to be regarded in individualistic terms without proper attention to the social nature of our being risks ignoring the factors which Denzin initially posits as fundamental aspects of their formation. Narrative theory’s tendency to underplay the importance of the social nature of narrative and identity often leads to a highly individualised conception of narrative which ignores the interplay between people within the immediate social context for forming and validating the key aspects of identity which the narrative comes to represent. This itself creates the potential to de-contextualise biographical narratives and ascribe to them the character of an absolute which may also lead us to overlook the capacity of particular circumstances, experiences and contexts to alter their substance. If we further entertain assumptions about their resilience which do not give proper recognition to potential breaking points, the risk to individual health and well-being is heightened. Too strict a utilisation and conceptualisation of narrative construct in some measure diminishes the nascent and intuitively held aspects of our lives: the unarticulated values and experiences which have a profound impact on our identity and life purpose, much of which is held contingently. I have already critiqued Denzin’s conceptualisation of narrative which eschews any future perspective, a formulation in which narrative biographies are regarded as summaries of what has passed without any consideration of the inherent hopes and passions which give shape to a person’s life.
Biographical narratives are formed over lengthy periods of time, with reflection and dialogue as key parts of their formative process and as a consequence have a deep grounding, and suggest something of an overall perspective – a degree of detachment and objectivity which isn’t always available under exigent pressures such as those accompanying premature birth. Biographical narratives as such take new shape only after reflection before new life experiences are integrated into a broader or reinterpreted framework. Where experiences coalesce in meaningful ways with an already existent frame, the narrative construct is strengthened. When new experiences undermine the structure of this self-knowledge, it is uncertain how the process of rethinking, integration or reconstruction ensues, and under what circumstances a breaking point is reached. The resources for constructing a biographical narrative are not clearly defined, and appear to be at the behest of the individual within their own context. That biographical narratives also seem to be constructed in retrospect, rather than with conscious ability to anticipate and frame present and future experiences (as opposed to hopes and expectations, which are integrated into the narrative) has implications for the way in which carers facilitate reflection on the present circumstance. Seen this way, a biographical narrative can appear as one-dimensional or linear rather than dialectic in nature, highly individualised rather than a social construct. I do, however, note Denzin’s reference to an aspect of humanity beyond that of the surface in which one is engaged in everyday and routine tasks, to “the deep,” where our identity as feeling, moral, sacred, inner selves is shaped, a strong indication that biographical narratives are a window into something deeper within the human psyche.

The adaptive capacity of the narrative approach is evident in the presence of “illness narratives,” which are fundamentally an adaptation of the biographical narrative. Recognising that a significant life event has disrupted the accepted narrative, this approach places illness – usually severe or chronic in nature – at the centre of new reflection upon the circumstances and implications which have rendered previous constructs irrelevant. Illness narratives are primarily shaped in response not only to the illness itself, but also to the social stigmatisation of illness and the tendency to shape the individual as victim. Illness narratives emerge in dialectic relationship with the pre-illness narrative, and are empowering, allowing for individual creativity and proactivity in shaping a constructive narrative against societal frameworks. These narratives, however, emerge only after considered reflection on the changes and challenges of the illness, underlining the slow nature of transformation when shifts take place.

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2 Denzin, 29
3 Ibid, 28-29
From the perspective of the carer, having an antenna for the key aspects of a person’s (or family’s) life narrative will assist the carer in helping the person unpack the ways in which the expectations contained in the narrative shape their response to the present situation. The greatest limitation of biographical narrative theory is that it is unable to articulate a process by which an event is integrated into an overall narrative, or how a particular event or series of events might serve to undermine the narrative perspective as it stands. An understanding of the ways in which narratives are built – how they find relevance and provide growing strength – is in many ways more important than the final shape of the narrative itself. It is the capacity of the sufferer to find words and give voice to their circumstances in the present and themselves in relation to particular experiences that is its ultimate gift to the individual. Narratives provide a meaning framework which engender a particular identity and empower an individual towards particular ends. Knowing how elements of a narrative biography are introduced or reconstructed in the wake of a transformative event is a key attribute available to an individual in times of crisis.

**A Cross-Cultural/intercultural perspective**

It has been common practice for carers to treat social systems as being of “secondary importance in understanding individual behaviour, personal suffering and psychosocial development,” an oversight which has significant impact upon the capacity of the carer to engage in proactive support. Meaningful care requires adequate scrutiny of “the ways patriarchy, capitalism, militarism, sexism, racism, classism, religio-cultural ideologies and other ‘structures’ work in isolation or else in complex concert to initiate or aggravate the suffering of persons.”

Conceptualising and interpreting the NICU journey through the lens of cross-cultural/intercultural interaction provides a framework for evaluating the ways in which such structural values impact upon participants. The *Welcome to Holland* narrative employed by parents in helping to explain this experience suggests a nascent conceptualisation by parents through this grid, with its articulated and inferred notions of entering into a foreign country, with its own unique language, symbols and rules for interaction. Recognising and affirming the NICU as a “community of practice” underlines the presence of special cultural artefacts which are reified into the decision-making system. Larney reminds us that behaviour and belief are meaningless or inexplicable without some attention to context. The need to take social, cultural, economic, political and environmental contexts seriously,
in view of their influence upon people’s life experience and the interpretations they make of it, cannot be overstated.  

Culture is dictatorial unless understood and examined. It is not that humans must be in sync with or adapt to culture, but that cultures grow out of sync with us. When this happens, people go crazy and they don’t know it. In order to avoid mass insanity, people must learn to transcend and adapt their culture to the times and to their biological organisms. To accomplish this task, since introspection tells you nothing, we need experience of other cultures; i.e. to survive, all cultures need each other.

An uncritiqued and an unchallenged culture is potentially unhealthy, threatening the well-being of those who engage with it, or are submerged into it. In the context of the NICU culture, it is clear that the ones who are driven towards “insanity” are the parents, who enter the system as outsiders, live under its tutelage, leave without appropriate debriefing, and find themselves out of sync with the world from which they entered the hospital setting at the time of birth. On the other hand, cross-cultural encounters offer an opportunity for critique of our own cultural assumptions – because it offers the perspective of an outsider, an opportunity identified by Newbigin who describes the possibilities: “…in every human society there is what Peter Berger calls a “plausibility structure,” a structure of assumptions and practices which determine what beliefs are plausible and what are not. It is easier to see the working of the plausibility structure in a culture of a different time or place than it is to recognise it in one’s own.” Augsburger notes that employing a cross-cultural framework offers distinct potential and carries its own risks:

While the knowledge of contrasting perspectives shatters illusions and perforates old boundaries, the collision of cultures may forge new central commitments that weld old assumptions into new patterns. But the encounter with another culture can result in freezing old boundaries, in confirming biases, in asserting the superiority of one’s own assumptions, and thus in reinforcing the cultural encapsulation of an unexamined worldview.

Generally, when two incompatible or conflicting value systems come together, a power battle emerges out of which – within the same context – one will invariably prevail. At the very least, neither culture will emerge from the encounter unmarked. A dominant, or structured, system will prevail over individuals, who will invariably find themselves either adapting to and adopting characteristics of the value system, or being alienated by it. The adoption of the characteristics of the value system is somewhat akin to a conversion experience, by which an individual’s way of thinking, valuing and deciding are transformed. The term “conversion” is traditionally used when an individual is an initiator or at least a willing and conscious responder to an invitation for change.

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6 Ibid, 33
7 Edward Hall, Beyond Culture (New York: Doubleday, 1976), cited in Augsburger, 48
9 Augsburger, 18
Where the change is unwitting, it is akin to being institutionalised – the value system in which one lives and operates imposes its constraints, initially from the outside, but are gradually internalised by the individual. Whether unwitting or intentional, in either case the impact on parents exhibits all the characteristics of a conversion experience. Such transformation in thinking, valuing and acting can only be maintained by a community which reinforces its plausibility and practice,\textsuperscript{10} something which becomes more deeply embedded in parental perspectives the longer their immersion in the NICU community.

Parents do not enter the NICU as a blank slate. They bring their own cultural and value system with them: certain deeply held if not clearly articulated understandings and expectations of what it is to be parents, what a baby looks and acts like when born, and how interaction between parent and child ought to unfold, along with expectations about the medical care to be received, which are themselves a subset of a broader perspective which has been constructed over their lifetime. This expectation reflects a cultural milieu which has shaped their formative environment as well as their family relationship in marriage. It runs deep within their being. Berger and Luckmann note that “it takes severe biographical shocks to disintegrate the massive reality internalised in earlier childhood; much less to destroy the realities internalised later,”\textsuperscript{11} a shock which is a systemic consequence of NICU culture. But what exactly is the nature of that shock? Is it merely an attack on the structure or premise on which a biographical narrative is based, or on something deeper?

**An Intercultural Framework**

Lartey proposes that an intercultural approach to pastoral care and counselling “raises three kinds of questions of the persons and the situations it encounters:

* What of the universal experience of humanity is to be found here?
* What is culturally determined about this way of thinking, feeling or behaving?
* What in this experience can be said to be uniquely attributable to this particular person?”\textsuperscript{12}

These questions are in turn an adaptation of Kluckhohn and Murray's classic text, *Personality in Nature, Society, and Culture*,\textsuperscript{13} which articulates the same tripartite pattern as three fundamental dimensions of being human: (1) the universal, in which every person is in certain respects like all others; (2) the cultural, in which every human being is like some others; and (3) the individual, in which every human being is like no other. To reflect on the cultural interface in the NICU through

\textsuperscript{10} Berger and Luckmann, 158
\textsuperscript{11} Ibid. 142
\textsuperscript{12} Lartey, Living Colour, 36
these three aspects of human identity takes us below the level of a biographical narrative into the deeper aspects of human identity and formation.

At the centre of any treatment regime lies an understanding of humanness which determines the focus and course of therapy. In the NICU we encounter one extremity of this approach, and its impact on both the infant and the family are neither healthy or life-affirming, a consequence which is underlined when we consider the two premises which Augsburger articulates as fundamental to being human: the ability to participate in understanding and shaping the world in which a person lives; and being accepted as a subject and not as a thing or object of someone else’s manipulation.  

It is clear that capacities in both these elements are largely absent for parents and for infants in the NICU setting.

The medical model applied to the care of a neonate within the NICU context approaches an absolutisation of the universal aspect of humanity at the expense of all others, assuming a singular perspective on the infant’s humanity which can be evaluated through blood gases and other clinical assessments to measure well-being, growth and development – usually gauged against standardised norms. This reflects the scientific perspective which seeks to “order the perception of the universe according to universal natural laws.” The participants in the process alongside the infants are afforded no recognition for their uniqueness as individuals or as individuals-in-relationship. The view from the medical perspective is a broad, unnuanced view of our common physicality, at the expense of both the cultural and the individual perspectives, especially that of the parents.

The parents, on the other hand, perceive the experience of premature birth as one which divorces them from realities and life experiences which they had expected to unite them with others, with the effect of isolating them from their social networks. The experience of childbirth and parenthood for these parents – usually ones which find us sharing something of the universal and of the cultural – are experiences which leave them isolated – like no others – so disturbing their social frameworks as to diminish the connections they share with others.

In the usual conceptions of humanness, it would seem reasonable that the three aspects outlined above are held in a type of dynamic tension, a tension which underscores and strengthens our sense of individuality without isolating us from those who are important in helping to shape our identity. Contrary to popular expectation, it is this individuality that binds us in important ways to those who

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14 Augsburger, 239
15 Ibid, 274
are within our immediate social sphere, and in lesser but no less real ways to those who share a similar cultural perspective. If we view this diagrammatically, the three aspects would normally be held in some dynamic tension, thus:

<table>
<thead>
<tr>
<th>Like all others</th>
<th>Like Some Others</th>
<th>Like No Others</th>
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<tr>
<td>(Figure 1: Nature, Society and Culture in balance)</td>
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But within the medical frameworks of the NICU, the infant is regarded with the primary gaze in such a way that the balance is shifted thus:

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<tr>
<th>Like all others</th>
<th>Like Some Others</th>
<th>Like No Others</th>
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<tbody>
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<td>(measured through medicalised norms)</td>
<td>(Figure 2: Nature, Society and Culture in the NICU)</td>
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The impact on the parents leaves them feeling as though the balance has shifted in the opposite direction, such that, by the time of discharge and resumption of life without the hospital context playing an important role, they are made to feel that the paradigm has shifted dramatically in the other direction:

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<tr>
<th>Like all others</th>
<th>Like Some Others</th>
<th>Like No Others</th>
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<tbody>
<tr>
<td>(Figure 3: Nature, Society and Culture from the parent perspective)</td>
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The overall consequence of this is depicted in the stories of parents which underpin this research – they are isolated from their immediate social networks, and find little connection through the social experiences usually held in common with families and community. The perception of their common humanity is severely wounded, veiled behind the memories and experiences of premature birth and the NICU journey.

The shift towards the universal in the medical perspective has been documented by Foucault, who articulates the need of the medical gaze to “abstract the patient” in order to focus on the disease.

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17 Ibid, 7
“If one wishes to know the illness from which he is suffering, one must subtract the individual, with his particular qualities.”

The medical gaze thus “circulates within an enclosed space in which it is controlled only by itself; in sovereign fashion,” concerned increasingly with norms rather than health. Disease becomes the focus, and the individual – the patient – is that through which the text of the disease is read, albeit often in a complicated and confusing state. The analytical structure to this “conversation” produces both a picture and a language about the illness, and not the individual, who is effectively frozen out of the diagnosis.

In delivering a gaze which draws disease away from a metaphysic of evil, the anatomo-clinical method provided a systematic and structured way of identifying and addressing the challenges to health, but by narrowing its focus solely to the physical domain, the view of the whole person ultimately became hidden behind the disease and its structure. With access to increasingly complex and technical equipment to analyse blood composition, organ function and shape, the focus of medical gaze has been increasingly honed towards the information produced by technology away from the physical gaze and social interaction with the patient. In the NICU context, where the ability of the patient to articulate symptoms in any verbal way is precluded, the information which is crucial to strategic interventions and care for the neonate also serves to underline the poverty of conceptualisation as a person-in-relationship. This has the dual impact not only of interpreting health through the prism of information supplied by such technology, but also of adopting the image of the body as a computerised system, with appropriate terminology being employed. The cry of an adult cancer patient resounds with a call to be seen as human: “We came out of this building absolutely aghast at the glibness of this high technology that can tell me to a millionth of something-or-other what’s going on in my blood, but can’t actually see me as a human being. And I want to be seen as a human being: I am a human being…”

Description, in clinical medicine, does not mean placing the hidden or the invisible within reach of those who have no direct access to them; what it means is to give speech to that which everyone sees without seeing – a speech that can be understood only by those initiated into true speech. Whatever precepts are given about so delicate a matter, it will always remain beyond the reach of the multitude.

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The NICU parent, who has realised the importance of learning this technical language and getting to “know” their child in the same way that the medical staff (and the

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18 Ibid, 15
19 Ibid, 35
20 Ibid, 71
21 Ibid, 139
22 Ibid, 141
23 Ibid, 242
24 Lupton, 60
25 Jo Spence, in a documentary on her work in the face of cancer, cited in Ibid, 77
medical analysis) know their child in order to become actively engaged in the treatment regimes, has unwittingly embraced this cultural perspective on being human. The medical gaze only reluctantly moves past the supposition that we are like all others. Universal principles of care and observation dominate the NICU often without appropriate attention to the unique circumstances of the family and of the child.

Learning the language of medicine consists not of learning new words for the commonsense world, but the construction of a new world altogether. The world revealed is one of incredible detail. At ever level, from the molecular to cellular to the classification of diseases, it explodes into greater and greater detail.26

Is it any wonder that parents begin to lose themselves as they immerse themselves deeper into the language and culture of the very environment dedicated to maintaining the life of their child? The irony is acute: in the place dedicated to the saving of infant lives which would otherwise be lost to death, we birth and nurture children and families in a context where our humanity is at greatest risk, a fear expressed by Fukuyama:

It is rather a fear that, in the end, biotechnology will cause us in some way to lose our humanity – that is, some essential quality that has always underpinned our sense of who we are and where we are going, despite all of the evident changes that have taken place in the human condition through the course of history.27

A fundamental tenet of the medical profession is its dedication to the belief that anything that can defeat disease and prolong life is unequivocally a good thing. The fear of death is one of the deepest and most abiding human passions, so it is understandable that we should celebrate any advance in medical technology that appears to put death off. It is an urge which has underpinned the development of neonatology, built as it were on the hopes of aspiring parents.28 But people invariably give at least equal attention to the quality of their lives also—not just the quantity.

The elements of medical analysis, focused as they are on measurements and other clinical observation of symptoms and readings, obviate the larger picture of the patient’s identity and humanity and risk becoming inherently dehumanising. Lost to the medical gaze is the perspective on an individual who is part of a social network. For a neonate this is a convenient—and perhaps somewhat understandable—observation justifiable by the framing of a pregnancy as a biological event and not a social one for the foetus. That the assumption that there can be no loss of social connection for the neonate is justified and maintained on the assumption that a child in utero would

26 Good and Good.
27 Fukuyama, 101
28 Ibid, 67
have been without such connection until birth – an assumption which is faulty at best. On the contrary, “an individual’s interaction with its environment starts well before birth; characteristics we tend to attribute to nature are, by this argument, the product of a complex nature-environment…”

That pregnancy is an experience of social interaction for the developing foetus and not merely opportunity for physical development is an argument I have made elsewhere. The important argument thus is not whether environment affects the kind of behaviour and characteristics that are typical of the human species, but by how much,

Even – especially – in the course of a pregnancy.

With its narrowed focus on the human/technological measurements which characterises treatment in a NICU comes a highly structured system of care management, with decisions undertaken on the basis of information provided through a narrow and defined grid. In short, this is a closed community of practice, a reified world which is “by definition, a dehumanised world. It is experienced by man as a strange facticity, and opus alienum over which he has not control rather than as the opus proprium of his own productive activity.” The reified world of the NICU is, in this way, a dehumanised and dehumanising world, in need of redemption for the wellbeing of its patients and their families and, one suspects, its staff.

A Necessary Diversion?

It could well be argued that this temporary accommodation to the NICU world is essential to the most basic of all questions: life itself. That without this intense application of medical technology, there would be no infant to “take home,” no new family unit to be celebrated, nurtured and restored. The NICU wounds – the social and psychological wounds borne by parents – are temporary side-effects of an otherwise positive project. Parents are, it could well be argued, wounded, not broken, and their resilience will restore them in time. But we need to question whether parental resilience is evident from the data? Is too much being assumed in relation to parental capacities to recover and renew themselves and their family and social connections once the critical period of hospitalisation is passed? Could it also be argued that the social aspect of overcoming prematurity can safely be deferred for the infant until discharge into the wider community?

Foucauldian theory supports the necessity of this power shift in order to fulfil the expectations of both parties, thus restating the assertion of classic fundamentalism that medical dominance is necessary – practitioners taking control of the medical encounter is constructive and positive, rather

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29 Ibid, 136
30 Ibid, 137
31 Berger and Luckmann, 89
than a source of oppression.\textsuperscript{32} In any case, Foucauldian theorists contend that the ideology of greater patient participation has already been adopted by the medical profession into its praxis, with a consequent expansion of the field rather than providing constraints, while still maintaining that the medical encounter depends on a differential of power and knowledge between doctor and patient.\textsuperscript{33} Whilst this may be evident in cases where there is capacity for dialogue and engagement with the patient, the evidence pertaining to the NICU exposes the limitations of this position.

Concerning parental resilience, Fukuyama agrees that there are limits to the plasticity of human behaviour, but maintains confidence in deeply rooted natural instincts, believing that the instincts will triumph rather than let humanity be destroyed, or severely damaged. He believes that at a certain point deeply rooted natural instincts and patterns of behaviour reassert themselves, undermining and overcoming the best efforts of others to transform or subvert them.\textsuperscript{34} But we might ask where the strength of this human instinct is to be found? What is there that engenders its resilience and ultimate triumph? The triumph of the NICU culture is evident for many parents upon discharge, and the power of parents to restore their identity and purpose remains in question. Many are deeply wounded. Is such resilience to be found within the individual, in the marriage or family relationships, or in the aspects of our humanity which are held in common? It is evident that these are greatly diminished within the NICU and damaged to the extent that, for many parents, they are barely accessible even upon discharge. Family and social relationships have been severely impacted by the isolation and experience of the NICU. Certainly for the infant, the statistics demonstrate that leaving socialisation and nurture until post-discharge is insufficient to make up for the limitations of the care regime in the NICU, with levels of disability for neonates continuing at high and undiminished levels for the past two decades, and acknowledged differences in the way that premature children interact with others. On the other hand, for some parents, it is only the maintenance of the (pseudo-)physician role that provides and sustains a measure of security and purpose in the immediate aftermath of discharge. This is evident not only in the type of care being afforded the child at home, but also in the maintenance of systematic measures which many parents continue at home, and the level of competency exhibited and maintained in the medical language of care for their child. That the viewpoint absorbed through lengthy engagement with the medical gaze becomes a comfortable one is evident in the comments of one doctor-turned-patient from a different context:

\begin{quote}
I discovered to my surprise, that I liked presenting my case. It felt appropriate and safe when I discussed my chest growth from a clinical point of view. The familiar role kept my anxiety
\end{quote}

\textsuperscript{32} Lupton, 112 \\
\textsuperscript{33} Ibid, 116 \\
\textsuperscript{34} Fukuyama, 14
at bay and allowed me some comfort in spite of the life-shattering diagnoses we invariably discussed. As long as I could play doctor to my disease, I learned I could at least partially protect myself from the anxiety and feelings of helplessness that accompanied my new status.\(^{35}\)

Over the course of their NICU journey, parents become fluent in the language of the NICU and the hospital, and it becomes a source of comfort to them, but at the same time it is a source of alienation. This new language which gives them competency in the hospital disconnects them from the social world to which they return. It is this failure to be understood by friends and family which is ultimately alienating for them,\(^{36}\) and which multiplies the stress of the experience.

One cause of this alienation is arguably rooted in the absence of a clear and embracing definition of both life and death, a factor which confines the treatment regimes across the medical domain including within the NICU, which is itself a unique medical environment. In the child and adult world, most hospitalisations are of short duration where the focus is brief enough for patients to suspend their life story, in order to allow correction of a physical issue which has emerged. Adults can readily “interrupt” or “suspend” their conceptions in the face of recognised challenges to be faced, and even welcome them as appropriate to restoration on the journey of fulfilling their hopes and dreams. In the case of children or infants being hospitalised, there is usually a clear symptomatology, a recognised pathway which led to the hospitalisation, and an agreed course for investigation. Established relationship patterns between child and parent are already in formation, if not formally established, and there is usually a degree of anticipation. There is an agreed entry point, and a potential exit moment in view, which can be formed in dialogue with parents, and often including the child, who is able to engage in her own care through expressing what is happening to them. Having already identified the problematic potential for NICU staff to eschew a social history for the child, there is a concomitant problematic concern in NICU life as to whether it can assume that there is no parental relationship with the child. I have already described the grief experienced by parents for a child who has been lost – the full-term birth which had been expected. But this child, while different to expectations in terms of its arrival into the world and its prognosis through the early days (at the very least) is intrinsically the same child with whom there has been a developing relationship during the pregnancy, a child in whom many of the hopes and dreams are still invested. A question to be faced for the carer is how and in what ways to affirm this continuity and discontinuity of relationship. It is important to recognise the relationship, as it characterises a central aspect of the parental experience, but the careful journey in both distinguishing the journey and affirming its continuity is central to the nature of care extended to parents.

\(^{35}\) Lupton, 97  
\(^{36}\) Lartey, 73
A Cultural Frame

Augsburger’s analysis suggests that the highly individualised conceptualisation of healing finds its roots in Descartes’ dictum which undergirds much of Western approach to humanity: *cogito ergo sum,*\(^37\) a concept in which it is easy to sub-humanise the neonate and others with limited capacity to think. Augsburger seeks to recover a broader sense of human identity from an intercultural perspective, citing thinkers from different cultural backgrounds and describing ways in which other cultures have identified aspects of our identity which are real for Westerners, but less valued and rarely articulated. As a consequence he moves the centre of identity formation away from the capacity to think to embrace the reality and ability of belonging, participating and sharing:

> The African says, “I participate, therefore I am”; the Oriental, “I belong, therefore I am”; the Palestinian villager, “I reside in this village, therefore I am.”
> The basic philosophy of the African, writes John Mbiti, is, “I am because we are, and since we are therefore I am.”\(^38\)

The basic philosophy of the African, writes John Mbiti, is, “I am because we are, and since we are therefore I am.”\(^38\)

The intercultural focus employed by both Larre and Augsburger restores the place of the communal and interpersonal perspective in the formation and understanding of our identity, affirming the impact of the intrapersonal, the interpersonal, the corporate and the spatial in shaping our understanding of our own humanity, along with the humanity of those with whom we share a narrative. The intercultural perspective affirms that the NICU experience is shaping a pre-formed yet often unarticulated cultural perspective on humanness held by the parents prior to the premature birth of their child, with an alternate (medicalised) pre-formed view of humanness which overlooks the long-term impact on parents of its limited perspective.

Foucault has documented the way in which the medicalised view of our humanness has developed in *The Birth of the Clinic,*\(^39\) in which he argues that the formation of what he terms the medico-scientific gaze has come to define and interpret the body in such a narrow way that no alternates can be entertained, whereby the body is objectified and examined through touch, tests and interrogation. Foucault identifies a shift which began around the start of the nineteenth century away from the practice of medicine with a focus on “health” towards one directed towards “normality.” With the advent of increasingly complex technology to give us more detailed analysis of normality, the language and discourse of medicine has become more deeply entrenched in meeting established norms – such that all individuals are treated alike and treatment is focused towards delivering similar outcomes for all, a discourse which has invariably ignored the deeper questions of

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\(^{37}\) Augsburger, 82

\(^{38}\) Ibid.

\(^{39}\) Foucault, *Birth of the Clinic.*
humanness. Largely developed in interaction with an adult – or at least communicative – patient, engagement with the medical world has long been assumed to be an interruptive experience, where normal life is deferred until norms are re-established as a consequence of submitting to the medical treatment regimes. This “taken for granted” knowledge is the most potent of all.\(^{40}\) It is important to remember, however, that it is not only the medical establishment which takes its knowledge and worldview for granted.

**A Shift in the Parental “Gaze”**

While the medical gaze has been cultivated over centuries, the parental “gaze” which is brought into the NICU is a result of the process of understanding the world and our place in it which is, for each individual, set in train by dint of the context into which they are born. From the time of an individual’s birth, the social structure of that context provides frameworks of meaning and understanding which are gradually internalised as the individual’s first conception of the social world is constructed.\(^{41}\) These frameworks are initially embraced as absolutes, and are continually reinforced by the context and the agents of socialisation within an individual’s social world. We accept our identity – and our understanding of our humanness – as a given over which we have little or no control, and it is experienced in this way.

Over the passage of time, an interplay occurs between the internalised self and the externalised world, between the knowledge which is a social product and a factor in social change, between perception of oneself as inside society and a perception of outside, in order to build a dynamic multi-faceted perception of self as human in the world. The first world is constructed in this dynamic with a firmness which reflects the shape of the individual’s initial relationship with the very first significant others.

The question is whether the absolutised primary understanding of the world of an individual is ever explicitly embraced as such, and whether it is ever cogently and explicitly articulated. Berger and Luckmann argue that very little of this is retained in the human consciousness, but is rather sedimented and congealed in our recollection. The collapse of this understanding is rarely a disinterested critique, more often a critical moment or experience in which its transitory and illusory nature is exposed and our own sense of identity and purpose under threat. We hold a picture of what our lives should be – we hold a narrative framework we expect it to conform to or follow, but do

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\(^{41}\) In this section, I draw heavily on the work of Berger and Luckmann.
not properly understand the foundation on which it stands. Any crisis which forces our life out of
the narrative confines of our world takes us to a place for which we have no foundation, a place
which requires a capacity to reformulate our understandings.

Berger and Luckmann argue that the power of this initial or primary understanding of the world is a
continuing one in a person’s life. The secondary socialisation which comes as a result of our
moving out of the constrained world of our family into the institutionalised frameworks of the
world relies upon the prior existence of the primary world we have constructed. The secondary
socialisation, they argue, presupposes a preceding process of primary socialisation which provides
not only an initial framework for understanding the world, but also the conceptual procedures for
integrating different bodies of knowledge.\(^{42}\) Some of the crises of adult life flow directly from the
recognition that the primary socialised view of the world is not the only one there is. While attacks
on the primary formulation are more critical for the individual, the secondary knowledge is more
readily and easily bracketed to the context in which one experiences them. Both primary and
secondary knowledge are capable of disintegrating, though it takes a lesser shock to undermine the
fabric of a secondary socialisation than a primary one – a world that is “silently taken for
granted,”\(^{43}\) but which is maintained by the social interactions which reinforce the validity of the
primary viewpoint which itself maintains one’s self-identity and the subjective reality which
sustains it. This plausibility structure is the individual’s world.

One of the reasons we are often not consciously aware of the nature of our understanding of the
world is that we \textit{indwell} it: our language, our concepts, our whole plausibility structure. This is a
key reason why no one is conscious of it unless an event transpires to expose its inability to cope
with the reality that is being experienced.\(^{44}\) However, if our primary socialisation lacks any
legitimating apparatus for the whole sequence of transformation, a crisis is multiplied: “What must
be legitimated is not only the new reality but the stages by which it is appropriated and maintained,
and the abandonment or repudiation of all alternate realities,”\(^{45}\) by which the primary realities are
meant. In other words, a social perception of the world needs to be built from the ground up, a
process which requires reinterpretation of past events and their meaning in an individual’s
biography, as well as the process by which such events are imbued with meaning. What is most
striking and salient about Berger’s analysis at this point is his contention that “maximal success in

\(^{42}\) Ibid, 140
\(^{43}\) Ibid, 152
\(^{44}\) Newbiggin, 98
\(^{45}\) Berger and Luckmann, 159
socialisation is likely to occur in societies with very simple division of labour and minimal
distribution of knowledge,\textsuperscript{46} itself an apt description of the NICU social world.

The process of transformation requires social and conceptual conditions which provide an available
plausibility structure which serves as a social base – a “laboratory” – of transformation. Indeed, it is
argued that there is no possibility of radical transformation of this subjective reality without an
identification which replicates childhood experiences of emotional dependency on significant
others.\textsuperscript{47} The new plausibility structure, they argue, must become the individual’s world, displacing
all other worlds, especially the world “inhabited” before this alternation.\textsuperscript{48} It is this perspective
which underpins the authors’ observation that “it is only within the religious community, the
ecclesia, that the conversion can be maintained as plausible… To have a conversion experience is
nothing much. The real thing is to keep on taking it seriously; to retain a sense of its plausibility.”\textsuperscript{49}
To this I would add one further feature necessary to embed an alternate plausibility structure – a
time frame lengthy enough for the new reality to be established in the psyche and to demonstrate
the inability of the old plausibility structure to address the challenges of the new context.

In simple terms, the requirements for deconstructing a primary social structure are:

1. A tight-knit, or closed community, which
2. Displaces all other worlds, with
3. A high level of emotional dependency akin to childhood, and
4. An immersion experience of a duration sufficient to embed this new plausibility structure.

When all of these factors are put together we find strong resonance with descriptions of the
experience of premature birth as articulated by the parents in our cohort. The transformation into the
NICU world is submerged under the critical realities surrounding birth, with the attendant grief and
shock attributed as the cause of initial angst – accepted as being normal and therefore given scant
regard. The crisis hits a second stage when the parents are removed from the social world of the
NICU with its systemic reinforcement of a plausibility structure maintained by the clinical gaze,
and discharged not just from the medical care of the hospital but from a community which has
defined what it is to be human and how best to care for and nurture this humanity in the guise of an
infant born prematurely. Parents and child are discharged with the expectation that they rejoin the
community which sustained them prior to birth but for which there is no longer a significant
resonance which maintains their social bonds.

\textsuperscript{46} Ibid, 164
\textsuperscript{47} Ibid, 157
\textsuperscript{48} Ibid, 158
\textsuperscript{49} Ibid.
And they are discharged into a community which has no structure for them. This is best epitomised in the continuation of care practices learned in the hospital, and the record-keeping which marks many parental descriptions of care for their child in the home. They continue to operate the care structure of the NICU world in the absence of any known structure for premature babies in the wider social world from which they entered this journey. It is NICU structure which has provided them with a framework and practice of meaning, and it is the absence of this context which initiates a new crisis, as they encounter a growing recognition that the plausibility structure of the NICU is unsustainable in the social world outside the hospital. There is no plausibility structure immediately available to parents to enable them to negotiate their way.

If we return to our initial diagram, we can describe how these series of transformations occur within the middle sphere:

<table>
<thead>
<tr>
<th>Like all others</th>
<th>Like Some Others</th>
<th>Like No Others</th>
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(Figure 4: Nature, Society and Culture: the middle sphere)

Before the premature birth of their child, the parents share a particular set of values and experiences – a plausibility structure – with an established network of family and friends. During the time of hospitalisation, this plausibility structure is replaced by that of the medicalised perspective of the NICU world – making the people within the NICU unit into the “some others” with whom they share most affinity, and so displacing and undermining their previous plausibility structure as to make it difficult, if not impossible, to return to in the post-hospital life. Post-discharge, parents begin to recognise that the hospital’s plausibility structure is no longer able to be maintained, but find themselves unable to adapt and return to the structure which they knew and lived by prior to this experience. The ones with whom they now hold experiences and perspectives in common are other NICU parents and NICU staff, with whom they shared no physical or proximal connection prior to the birth of their child, and with whom they will likely have no physical or proximal connection outside the hospital post-discharge. This offers some explanation for the strength of the preemie-l community, as parents find themselves in this same liminal and uncharted space, and are searching for understanding in their isolation, but without being able to name it. Their yearning to be “like some others” drives their search, as they seek to recover their humanness and reconstruct their identity. In short to find a new plausibility structure which makes sense of where they have been and where they find themselves now.
Rebuilding

Because it is not within our normal activities to consciously identify the plausibility structure we have embraced, let alone identify how it has been constructed nor to critique it, humans generally lack the capacity to evaluate the conflicting and apparently irreconcilable conceptualisations which have emerged as a result of their immersion in the NICU world. Parents therefore lack the capacity to reconstruct their world. Their grief is a response not only to the loss of an expected child, but also the loss of a world which no longer works, and the absence of an alternate which allows them to embrace the experience and move into the next phase of life.

To speak of a “capacity” to reconstruct their world is to identify the resources necessary to undertake this task, which involves not only recovering or rebuilding a foundational framework for understanding the world, but which also contains conceptual procedures for integrating different bodies of knowledge, and for sustaining and interpreting secondary knowledge. This is not an idle task, remembering that the primary socialisation which has been destroyed was built over a lifetime of assimilation, integration and reinforcement, and that such reconstruction requires new community connections.

The capacity to build a plausibility structure is evident in reflection upon the way in which the primary socialisation forms a plausibility structure of an infant, and will include language, community, resourcefulness, creativity, and power.

Language is the capacity to give expression not only to that which we have lost, but also to provide frameworks out of which a new structure can be built. An examination of the language surrounding prematurity is one of the ways in which we find avenues of understanding into the parental experience. That there is no simple way of identifying a parent of a premature infant is indicative of a lack of social awareness and social affirmation that the experience is in any way unique. The emergence amongst the list of the term “premie” or “premmie” to describe their child is an indicator of recognition that the journey of a child born prematurely requires separate identification.\(^{50}\) If “knowledge and language are rigorously interwoven,”\(^ {51}\) the absence of language points to an experience which is yet to be known and expressed, and therefore an experience which is suppressed.\(^ {52}\) One of the earliest ways we learn control over our world is by naming – giving words to objects and experiences. In order to begin the process of reconstructing our world, we need

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\(^{50}\) There are names for certain experiences of loss and grief: when parents die, the child is called an orphan, when a woman’s husband dies she is called a widow, and a husband becomes a widower. Yet there is no name for a parent whose child has died. The absence of language points to a hidden reality.

\(^{51}\) Foucault, *The Order of Things*, 86

\(^{52}\) Note also the absence of a unique descriptor for a parent of an extremely premature infant.
to find language. Language includes not only verbal expression, but also imagery, myth and metaphor. Story is also an aspect of language, as the use of the term “biographical narrative” intimates.

**Community.** Expressive capacity does not emerge *de novo*, but is reconstructed from exigent resources: drawn from the social experience of others. In the first instance it is our family of origin whose plausibility structure and associated language is absorbed from our earliest days. But when such a structure collapses, we are forced to search for other resources, from communities which have journeyed where we now journey, and who have faced such circumstances and offer possibilities for alternate conceptions of the world. The preemie-l community has provided a setting in which parents have sought to give explanation and words to their experience, beginning with the medicalised language they have learnt from the NICU, and grappling through the expressions of their feelings and social interactions in search of a richer language and expression. It is in the context of community that the experience, emotions and language are expressed, formed and validated.

**Resourcefulness.** The resources of the available language, developed and nurtured in contexts not familiar with this particular experience, require reinterpretation before reappropriation into this alternate setting. It is evident that the original language was developed without consideration of the circumstances in which it is now being engaged. A certain resourcefulness is therefore required in order to identify, appropriate, reinterpret and even create an alternate language and narrative ideas into forming a new plausibility structure which gives some validation of the experience and allows expression which gives understanding to both those who have endured the experience and to others in the wider community. A new language can only be achieved through a creative dialogue in which a community is enabled to not only access the resources from other people and other settings, but enabled also to reform and adapt them: to interpret and reinterpret them in dialogue with one’s own setting is the product of considerable creativity and dialogue. This is a demanding task, not an idle or casual one, requiring resources not only for the discovery of appropriate and potential alternate discourses, but resources also to interact with them, to play with them, and to shape and reshape them. The formation which is required at this point is individual but not individualistic. It requires a community, a dialogue, an engagement with a trusted other, be it individual at the first instance, but invariably in need of a community to nurture and sustain in the medium and longer term. Inasmuch as it required a strong community to destroy the primary plausibility structure and replace it with an alternate, so will a strong community be necessary to reconstruct a new structure which gives due respect to the realities of premature birth.
Power. Language, resourcefulness, creativity, community… all of these require a delegation of power in order to act, to form, to shape, to offer alternatives. Parents spend much of their time post-hospital justifying the state of their present existence to family and friends; they speak from weakness. Their voice is a minority which carries a message counter to the prevailing cultural perception of premature birth, but their weakness is also a physical and emotional weakness as a result of the extended battle of and with their child towards health. That there is no social legitimation of the depth of their experience is one aspect which stands behind a fracture which is evident with wider family relationships. Without social legitimation, the parental experience of prematurity is continually greeted with a scepticism which ultimately alienates the parents. It is one thing to acquire power within the parental community to begin the journey of legitimating the experience in the eyes of others, it is a larger step to take that to a wider audience.

Power requires structure. The power of the medical gaze is underpinned by a hospital structure which oversees and undergirds a power-sharing according to a particular pattern. The same is true of the experience of primary socialisation. Power structures in families are deeply entrenched before a child has any capacity to shape their own perspective. These structures represent community perspectives. Where is such a structure to be found for parents post-discharge, particularly in a world whose understanding of prematurity is limited? The beginnings of such transformation must be found within the hospital setting, as it is a place which recognises and understands the medical and emotional challenges, and provides a community framework – the parental cohort – for understanding. However, this structure – the parental community – needs to be liberated from the strict medical gaze. An alternate language needs to be allowed access, and support provided to empower parents to begin the creative and constructive process of naming their world. To defer the commencement of this dialogue until after discharge is to leave it to a time when the already limited resources are further diminished.

It is evident that this journey towards recognition and inclusion of a wider language has already commenced within the NICU. The entrance of the language of psychology and social work into nursing and care practices is acknowledgement of the limitations of the medical language and the impact of the experience upon parents. Its insufficiency for the task is rooted in its failure to recognise the collapse of the narrative world which is a common experience; in its failure to understand the impact on the deeper conceptions of our humanity, and the failure to recognise the deconstruction not only of the world as it has been understood by parents, but deconstruction also of the ways in which we integrate new experiences into our conception of the world. It is the
assumptions on which psychological and sociological thought patterns are built which are also lost within the NICU experience. Psychology and social work share the journey of an experience seeking understanding by sharing the common ground. But it is this recognition of inadequacy to the task that once again pushes us to explore a deeper level of meaning, one which enables parents to reconceive their humanity, reconceive their plausibility structures, and reconceive their place within the world.

**A Spiritual Ground**

The loss of an integrated and coherent perspective of one’s identity strikes at the very core of one’s being.\(^{53}\) Lartey uses the term *spiritual* to describe this deeper level of meaning and identity, a term which has to be distinguished from being *religious*, which generally applies to the practice of spirituality within a structured context. *Spirituality* is a term which points to the human capacity for relationship with self, others, world, God, and that which transcends sensory experience, and which is often expressed in the particularities of given historical, spatial and social contexts, and which often leads to specific forms of action in the world,\(^{54}\) of which religious practice is but one expression.\(^{55}\) Biographical narratives are an expression of our spirituality – giving form and context to our self-understanding and shaping the conception of our purposeful action in the world. Plausibility structures are similar constructs which give conceptual frameworks for our relationship with the world in which we live. All theologies, worldviews, and ideologies are expressions of our deepest selves – being expressed in language which enables and forges connections with others and provide a framework for meaningful action in the world.\(^{56}\)

Spirituality is the ground out of which the articulation of beliefs – plausibility structures – grows. It recognises the transience of particular expressions of spirituality, which are regarded as windows by which we have access to deeper inexpressible realities, as well as being one fruit of our rootedness in transcendence. Spirituality is focussed not on a single aspect, but seeks integration of our experiences and a centredness of our being that enables expansion and growth.\(^{57}\) To speak of spirituality is to embrace the apparently universal human capacity to experience life in relation to a perceived dimension of power and meaning which is experienced as transcendent to our everyday

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\(^{54}\) Lartey, 140-1
\(^{55}\) Goldsworthy and Coyle, 22
\(^{56}\) Peter L Berger, *The Sacred Canopy* (New York: Doubleday, 1969), 22f
\(^{57}\) Lartey, 151
lives, although such transcendence certainly may be, and often is, experienced “in the midst” of our everyday lives.58

A spiritual perspective embraces relationship with transcendence alongside the intrapersonal, the interpersonal, the corporate and the spatial, a perspective which underlines the human capacity for relationship at various levels expressed in the variety of historical, spatial and social contexts which form the ground out of which our action as human beings grows and into which our action is expressed. This essentially relating view of our being is much more expansive and embracing than the perspective of the biographical narrative – which itself bears aspects of our spirituality – being much more explicit about the role of context and relationship in the formation of personal identity, and together with the aspect of transcendence keeps a universal perspective in the frame.59 In short, spirituality speaks of the way in which we give form and expression to our humanness in the world, which is essentially and fundamentally relational. We can speak therefore of the spirituality of a community or an institution, which recognises and affirms the spirituality of an institution such as a hospital, an agency or an organization,60 and identify aspects of our spirituality which reflect the three-fold aspects of our humanity referred to earlier in the chapter: spirituality reflects the ways that we are like all others, like some others, and like no others.

Embracing a spiritual ground for our being offers both strength and direction in the wake of an experience as traumatic to our sense of identity as premature birth can be for a parent, being a dynamic concept which conveys the sense of travel, journey, search, quest, purpose or goal, with the possibility of manifesting itself at the same time or the same context in terms of both strength and weakness.61 Embracing a spiritual ground offers parents a language for engaging with their struggles and loss, whilst offering the potential of a community for conversation, one which is not necessarily limited or defined by the experience of prematurity, but with whom the common ground of suffering and loss (in the midst of the broader perception of our humanity) can be shared and explored, thus offering new resources and resourcefulness for the journey. Through embracing a spiritual ground, we avail ourselves of a rich stream of resources for reconstructing our world, and are enabled to enter dialogue with different communities through time and space, containing both the sense of belonging and of dialectic which are important aspects of identity and therefore care.62

58 Ibid, 143
59 We are not suggesting that the notion of transcendence and the universal are coterminus. The link is made here to recognise that to embrace a cultural framework is not to downplay or deny the existence of universal humanity.
60 Lartey, 149
61 Ibid, 143
62 Ibid, 110
Spirituality embraces both solitude and community – affirming the individual and the individual-in-relationship, alongside the notion of transcendence – the “other.”

As we move into the next chapter, I will explore some of the resources of spirituality which offer parents alternative narratives and communities and power in naming and shaping their struggle in order to begin the journey of reclaiming and reconstructing their identity, and restoring their connection to their community, and to themselves. While I will employ aspects of Christian spirituality in this journey, I do so recognising that I am drawing on a particular expression of spirituality, one which is grounded in the Jewish tradition, and whose stories and ideals have found a place within the Western cultural context into which I speak. I do so mindful that “a test of our spirituality must be whether it makes us more aware of the realities of the world, and therefore more ready to respond to them or not,” and embracing Gutierrez’s conceptualisation of liberation theology as a response to the non-person, as opposed to the non-believer. In seeking a spirituality which is liberative, I search for a perspective which seeks to redeem the lost personhood of the infant, and of the parents in the struggles of life in the NICU. One of the most difficult challenges for parents is finding narratives which deal realistically and healthfully with death and disability alongside those attached to loss of community and identity. Whereas wider cultural narratives largely eschew these aspects, spiritual reflection places these close to the centre.

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63 Augsburger, 351
65 As articulated by Lartey, 150
Chapter Nine

Theological Frameworks for Understanding Parents’ Experience

The Practice of Theological Reflection

Theological reflection is at the same time one of the most ancient of practices and newest of disciplines, born of a conviction that God is active in – and revealed in – the historic circumstance of human affairs. The biblical documents are born of – amongst other things – theological reflection upon human history from the beginning, and from the inside; stories of faith related out of the lived experience of human life which have been honed in the context of community – a resource for the practice of theological reflection through the centuries.¹ Theological reflection is a practice which is rich in its diversity of expression, both in articulating the circumstances under which God has been revealed and in its response to those circumstances, giving birth to a wide range of literature and a canon of narrative, poetry, sayings, song, and parable which reflects upon the human circumstance in the light of the character of God, and vice versa. The Bible stands as an accepted framework, resource, and catalyst for theological reflection in the church throughout the vast majority of the Christian era, reflection which continues to rest on the conviction that God can be discovered in the context of and in response to human experience, which has meaning and purpose which can be discovered and lived out.

The formalised disciplines of pastoral and practical theology have over the past two centuries journeyed from a confined focus inside the church towards interaction and engagement with the challenges of life in the wider world. Initially conceived as a dialogue and discipline in the conduct of ministry within the walls of the church – that related to church worship, governance and education – pastoral and practical theology emerged in the relationship between the theory of the Christian tradition and the practice of ministry in the world – its focus on the practice of the faith-community itself, both within the church community and in wider community engagement.² Pastoral and practical theology remains a nascent discipline, emerging as a distinct discipline at the same time as the other field of our exploration – neonatology – in the 1960s.

Pastoral or practical theology can be defined as the place where contemporary experience and the resources of the religious tradition meet in a critical dialogue that is mutually and practically

¹ An artificial distinction is often drawn between historical/traditional theology and practical pastoral theology. Both are grounded in experience. The scriptural texts are reflections on and articulation of the experience of the historical people of God, shaped, honed and refined through communal reflection. They are in no wise abstract constructs on the nature of God.
² Graham, Transforming Practice, 7
One aspect of the uniqueness of practical theology is that the social sciences – psychology, sociology, anthropology, history and their various offspring – inform it. It is this capacity to draw on the insights of a wide range of disciplines as it responds to the realities of the present context that makes practical theology a unique discipline, one which is able to cross boundaries and open up otherwise closed conversations. Practical theology, due to its different angle of vision, provides another understanding of God and the world.

Pastoral and practical theology is not prescriptive or curative, but is first of all descriptive in its practice and formative in its purpose. Recognising the complexity of individuals, communities, and their circumstances, and formulated in response to them, pastoral theology resists offering trite answers, or simply regurgitating old ones without reference to the present context, affirming that a choice is a productive act with consequences to be interpreted and experienced. Theological reflection is a process rather than a product, in which the historical traditions are brought into meaningful engagement with present circumstances, with the result that “theology is revitalized in the practical and direct response of theologians to pain, yearnings, and possibilities of the cultural-historical currents of a time and a people…” Pastoral theology begins with the search we all make for meaning in life, taking with complete seriousness the struggles we engage in to understand ourselves, our culture and the functioning of nature and society; and the connections between them.

Practical theology affirms that every practice is embedded with theory. In seeking a rich description of the present circumstance, pastoral theology seeks to identify and expose the theoretical underpinnings which shape the present experience. It is this process of naming which enables a hitherto amorphous experience to engage with other disciplines and perspectives, establishing common ground with others – restoring aspects of our humanity – in what might otherwise be an isolating – dehumanising – experience. Gustavson speaks of the “surfacing role” of theological reflection:

To be trained in theology should alert one to aspects of discussion that are otherwise hidden… “For what can we hope?”… “In whom can we trust?”… “In what can we trust?”…

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5 Graham, Walton, and Ward, *Theological Reflection*, 5
8 Browning, 5
“What is desirable?”… “What are proper objects of our love?”… theology might not provide answers you like to accept, but it can force questions you ought to be aware of.⁹

A further role of pastoral theology is to open up a closed conversation by introducing aspects of the Christian theological tradition, but it is much more than this. The pastoral theologian is attuned to questions to which the Christian theological tradition has heightened sensitivities, in the same way that a doctor is attentive to symptoms of physical distress.

Factors in Pastoral and Practical Theology

Theological reflection has its genesis in reflection on life in the world, giving birth to the scriptures which have since shaped the church’s theology. Theology in the classical understanding – systematic theology and biblical theology – is a “reflection upon reflection,” whereby the exegesis of these historical texts became the sole and defining source of theological reflection, neglecting the foundational tenet that the biblical texts were themselves the result of theological reflection on life in the world. When theological reflection emerged as a separate course of study under the tutelage of Schleiermacher, it was initially conceived as theological reflection on the tasks of the ordained minister or the leadership of the church, but has since developed more intentionally in critical reflection on the church’s ministry in and to the world,¹⁰ at the one level, and towards the foundational theological reflection on the work of God in the world without specific attention to the place of the institutional church.¹¹

The gap which emerged in early formulations of pastoral theology is evident in the observation that pastors received some help from professional theologians in their role as preachers, but very little in other roles, with the consequence that much pastoral care and counselling came to be framed and informed by the often humanistic psychologists which became their initial theological guide.¹² In spite of advancements in recent years, there is still a tendency for pastoral theology to rest either on the cumulative anecdotal evidence of pastoral ministry¹³ or on the insights of the psychological and sociological traditions for the raw data and frameworks for interpretation and understanding, which is then subject to theological reflection, using paradigms from these traditions in the shaping of thought and practice. Papers such as this are less common than they should be in the discipline of theological reflection, whereby prime engagement with the circumstances of life is the catalyst for

¹⁰ Browning, 35
¹¹ Which is not to suggest that this is done without regard to the theological heritage and traditions which the church still honours, but to indicate that theological reflection upon the work of God in the world does not have to take place within the church or in relation to the formal structures of church ministry.
¹² John C. Cobb, Theology and Pastoral Care (Philadelphia: Fortress Press, 1977), xi
¹³ Which is not insubstantial for many experienced pastors.
and source of theological reflection. Liberation theology and feminist theology are two of the most obvious exceptions to this observation, born as they were from the direct experiences of marginalised peoples.  

Theological reflection takes place in the engagement between the experience of life in the contemporary world, reflective understanding of that experience, and the historical theologies which have informed the church throughout its life. It is tempting to define theological reflection in these stark terms – a dialogue between the Christian tradition and the contemporary situation, but to do so ignores other important factors at work in practical theological reflection. Pastoral theology emerges within circumstances which are framed and informed not only by the contemporary experience and the Christian tradition, but also takes account of the contextual situation of the experience, the broader cultural framework, the individual personality of the people whose experience is being reflected upon (whether it be the personality of a single person or a community), and the person/community undertaking the reflection. It is these last two factors which are the reason why theological reflection retains a dynamism and a vitality which resists a rigid formulation of its enterprise and a universal application of its conclusions. The individual’s personality in the experience, and of the person undertaking the theological reflection impact upon the outcomes, offering some basis for a more universal application, but also providing a more immediately relevant reflection for the situation out of which the theological reflection arose. Theological reflection is able to provide insights which are relevant at the universal, the cultural and the individual level, depending upon the circumstance in which the reflection occurs. It needs to be noted, however, that theological reflection is not the search for a “magic bullet” to cure one’s ills, but a journey in formation against the backdrop of the Christian theological tradition, and thus will have a different starting point and a different impact in each situation. The dynamic tension between tradition/experience/culture/personality is ever-present.

Practical theology should be grounded in a thick and rich description of the experience of life in the contemporary setting, whilst at the same time requiring a thorough exegesis of the biblical texts and a solid grounding in systematic theology. The twin dangers in theological reflection are found in an underinformed analysis of either the present situation or of the historical-theological understanding of the Christian faith. Inadequate understanding of the present reality risks misunderstanding – and therefore misinterpreting – the present situation, with the result that the voice of Christian theology or the application of the theological understandings of the church to the circumstances risks

14 Though Graham suggests that even these might be underrepresented in pastoral literature, inasmuch as we see little of ethnic, cultural and racial diversity explored: Graham, Transforming Practice, 47
irrelevance. In matters surrounding pregnancy and childbirth, this risk has been evident in much of the pro-life response to present conception and birth technologies, whereby there is often a poor understanding of the medical and social complexities of the issues surrounding conception, pregnancy and birth. At the other end, a neglect of understanding of the breadth and depth of the Christian theological tradition can result in a narrow judgmentalism which alienates rather than facilitates engagement and encounter in the present circumstance. As pastoral theological reflection engages public discourse, it needs to recognise that common commitments are shared with many other disciplines which can enrich theological reflection through engagement.

It is best to construe “public discourse” not as a separate realm into which we can and ought to enter tradition-free, but as embodying a commitment to civil exchanges among traditions, many of which have overlapping membership, and which meet on the basis of common concerns.15

Roles of Pastoral and Practical Theology

Given the varied circumstances in which practical theological reflection can be undertaken, there will be a range of functions which such reflection can bring.

Interpretive – The interpretive role of practical theology can be understood as the community of faith giving account of itself and its values to the world,16 and at the same time interpreting the experience of the world from the standpoint of the Christian tradition. This interpretive task is not unique to the Christian faith, and requires the formulation of a response which in turn shapes the reality of the world in which we live.17 Interpreters of not only the world of human affairs, but also of the cultural languages that shape much of everyday life, and of the Christian language.18 Paver regards the interpretive role as central to theological reflection inasmuch as experience by definition runs counter to our expectations, and therefore will challenge our expectations and uncover illusions.19

Ethical/moral – Browning regards the prime task of pastoral theology in ethical terms: concerning itself with the religio-ethical norms which create a normative vision of human life.20 As a

15 Lisa Sowle Cahill, "Can Theology Have a Role In "Public" Bioethical Discourse?," in On Moral Medicine: Theological Perspectives in Medical Ethics, ed. Stephen E Lammers and Allen Verhey (Grand Rapids: Eerdmans, 1998), 59
16 Graham, Transforming Practice, 208
18 Charles V. Gerkin, An Introduction to Pastoral Care (Nashville: Abingdon Press, 1997), 76
19 Paver, 35-38
“theological theory of action,” pastoral theology is concerned with acting in ways consistent with the gospel which the church seeks to live and proclaim. Practical theology leads us into lived engagement with our circumstances.

**Narrative** – Pastoral theology can enable the reconstruction of experience in ways which engage the person in a deeper understanding of themselves and connecting them with the faith tradition. Deeks regards story-telling and conversation as the grounds out of which grow signs of hope in our quest for meaning in our lives, a practice and quest which is both continuing and ever-changing. In embracing the narrative heritage of the biblical and theological tradition, a rich reservoir of resources is available, both from the tradition itself, and in the practices which that tradition represents, including dreaming, imagination, play, lament, dance, and reflection, to name but a few.

**Associative** – Pastoral and practical theology is an engaged discipline, deriving its content not as a disengaged observer, but as one profoundly drawn into lived experience. It is this deep connection with the present which enables connections to be made with the themes and narratives of the Christian tradition in life-giving and life-affirming ways, recognising that not only are the narratives of our lives ever under construction, and laden with meaning, but that our lives also reconstitute the human struggles which reverberate through time. The associative role of practical theology enables connections to be made with our human community, connecting us to the same resources which nurtured others through similar crises and challenges. It is this associative role which is ultimately humanising for individuals isolated by their suffering.

**Conversational Partners**
Practical theology is an engaged discipline. Grounded in human experience, and anchored in the Christian tradition, practical theology encounters a variety of conversation partners, each of which call forth a particular language for engagement, and require a different starting point for reflection.

**Other academic disciplines.** Browning argues that every form of practical thinking shares common validity claims, and sees a main task of practical theology as forming questions which can be

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23 Deeks, 20
24 Ibid, 51
25 Browning, *A Fundamental Practical Theology*, 71f
brought back to the classics for the creation of new horizons of meaning – a prophetic function alongside a correlative function and the establishment of a productive dialogue.26

The church. Practical theology contributes to the understanding of the church’s mission in the world, a mission which finds its roots in the God of creation, the God of Israel, and the person of Jesus Christ. As Christian theology is fundamentally incarnational, practical theology seeks to articulate more clearly the ways in which the church engages its mission in the world by articulating a theological response to the present circumstances in the light of a description which is itself theologically informed.

The wider community – Heitink regards practical theology’s key role in the mediation of the Christian faith in the praxis of modern society, and observes that it is this area that is most underdeveloped in practical theology.27 Paver refers to this partner as “culture,” by which he means “the convictions, values, assumptions and biases that form the context in which the reflection takes place.”28 But the conversation is wider than the theoretical, engaging with real communities and real individuals who embody in some form the “culture” which Paver identifies. Practical theology should engage in a conversation with the broader culture with a view to shaping not only the values it holds but also the conversation in which these values are shaped. Pastoral theology, therefore, needs to find expression in language outside the culture of the church and outside the familiar theological language of our traditions.

Individuals in crisis – This engagement is dealt with more in the following chapter on pastoral care. Pastoral theology informs the practice of pastoral care, which is broader than pastoral theology but never disconnected from it.

The language of practical theology will vary according to audience and conversation partner. The message will have strong connections across the various conversations, albeit in different language, attentive to the different concerns and value structures of the partner. In conversation with the medical field, common ground can be found in the recognition that a doctor may well be a trained expert in the field, but a doctor is also a human being. “Resonating through his professional actions, and crucial in some of them, will be the view of man, an understanding of the meaning of the life at

26 Ibid, 285ff
27 Heitink, 8, 309
28 Paver, 50
whose first or second exodus he is present, a care for the life he attends in its afflictions.”

Power reminds us that faith goes beyond theology, which will open the astute theological inquirer to the possibilities and expressions of theological concepts in unexpected places.

While some might question whether theology and theological reflection has a place within the NICU world, the practical theologian recognises its presence in non-traditional expressions. Hauerwas draws an insightful link which demonstrates the connection, indicating that “the relation between medicine and health, and especially the health of a population, is as ambiguous as the relation between the church and salvation.”

Browning indicates the presence of meaning structures in all practical discourses, including medicine. The clinical-medical paradigm articulates ultimate concerns in diverse ways, both implicitly and explicitly. The question is not whether theology has a place, but about the ways in which theological discourse is conducted. The Christian practical theologian brings unique and critical perspectives to theological conversations which are already present.

Theological Reflection in the NICU

The biblical tradition is rich and deep, containing myriad narratives, metaphors, themes and images which speak to the loss of humanity, and the dislocation of time and place which characterises the premature parents’ journey. Though the field of neonatology and the experience of premature birth are recent phenomena, the quest for our humanity and the deep grief which accompanies suffering and loss are ancient themes. By drawing on the resources of religious traditions, parents are afforded opportunity to connect with “some others,” and begin a journey once again into our common humanity in a way marginalised within the NICU community. By drawing on the resources of the Christian theological tradition, I will seek to demonstrate some of the ways in which this connection can provide meaning frameworks not only for making sense of the experience of premature parenthood, but also of resourcing parents for the important transitions and shifts which mark the experience.

The purpose in undertaking a theological reflection is not to dictate or determine one’s experience, nor to provide a comprehensive theological reflection (something which is beyond the scope of this

31 Stanley Hauerwas, ”Salvation and Health: Why Medicine Needs the Church,” in On Moral Medicine: Theological Perspectives in Medical Ethics, ed. Stephen E Lammers and Allen Verhey (Grand Rapids: Eerdmans, 1998), 75
paper) but to provide some frameworks of thinking which help individuals and communities develop an understanding of their experiences, and to assist in both an evaluation of and reflection on them. A note in my own journal on the day of our son’s birth is illustrative of the way in which thinking theologically about the experience gives a context to the struggle which is not confined to the events contained within the NICU:

The day whirled like a maelstrom: people, issues, information, organisation, uncertainty. I ran the emotional roller-coaster for the most part of the day, not being able to settle until being alone with Ev in the evening. Telling people being the hardest part. (sic) Contemplating the future in any sense brought me to tears. I oscillate between considering that God is asking us to learn what it is to walk through the valley of the shadow of death, to being there at the point and process of creation: still forming, still fragile, ever taking shape. At the moment there remains an air of unreality, occasionally clouded by a deep sense of helplessness bordering on despair, occasionally warmed by the warmth of the sunlight of hope. To simply stand by and watch, and pray, goes against everything that I would want to do as a loving, caring father - to do anything, everything I could to help. It is his fight, which I can join in prayer, and offering encouragement.

Of the many Biblical themes available for reflection on this experience, I chose here to focus on two: exile and return; and faith, hope and love. I chose these as being indicative of the ways in which theology provides creative opportunity to reflect upon the struggles of premature parenthood. I will explore the ways in which these themes of biblical theology have the capacity to empower parents with a pattern of thinking about the experience which provides language and meaning, and lay a foundation for understanding their identity.

**Exile and Return**

In a world increasingly mobile and more deeply dislocated by war and natural events, the number of people forced from their homelands is increasing exponentially each year. The experience of dislocation which follows loss of connection with place is both a present experience and an ancient one. In a world today where people define their sense of place in ways which are less connected to the land, the experience of exile is impacting people who have never left their physical environs.

Exile can be either a physical or a critical exile (often both), a liminal state of existence which reflects that one is perpetually living “out of place,” neither in one place nor another. Edward Said declares exile as “the unhealable rift between a human being and a native place, between the self

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33 Personal Journal entry, dated 28 February 1997
34 I adapt the terms political and critical used by Alain Weaver, which he uses to define the state of being in exile and the mode of standing under dominant yet alien ideologies. Alain Epp Weaver, *States of Exile: Visions of Diaspora, Witness and Return* (Pennsylvania: Herald Press, 2008), 15ff
and its true home.” Writing from the perspective of a Palestinian alienated from his homeland by Israeli settlement, Said affirms the importance of being rooted in a particular place which connects people to their past, whilst underlining the inherent insecurity which exile brings. “Exile is predicated on the existence of, love for, and bond with, one’s native place; what is true of all exile is not that home and love of home are lost, but that loss is inherent in the very existence of both.”

Exile is one of the central experiences recorded in the Hebrew Bible. The people of Israel had lived for generations in a place known to them as The Promised Land. Their experience of the land was deep, and their memory of the land harkened back to the time of the patriarch Abraham. Their identity flowed from the land as much as their understanding of their relationship with God was found through it. Trees, towns, rocks and places all bore particular memories which shaped their identity as a people. Their life practices were honed in this land, sustained by rituals, places and relationships with which they were familiar. They could not conceive of life in any other way. Stories of times before they inhabited the land reinforced its centrality for all aspects of worship and life. When it was first suggested that being taken into exile – forcibly removed from the land – was a possibility that God might bring, there were no lack of voices to denounce the declaration. When the Babylonians ultimately took Israel into exile in 586 BCE, it created a crisis of identity which attacked the very foundation of Israel’s being. They were taken from a place where they were known, where they knew the ground rules, and where the infrastructure nurtured their communal life, and placed in a situation where they were powerless, and where the cultural artefacts and symbols were alien. The first return would not take place until 538 BCE.

My purpose here is not to debate the historical intricacies surrounding the exile in Israel’s history, but to reflect on the significance of these as articulated within aspects of the Hebrew Bible as a paradigm for understanding and appropriating the experience of prematurity. For this purpose, I am asking the question, “How might a reading of exilic events on the side of the victims read?” Having already articulated the ways in which exile and return is an appropriate metaphor for understanding the experience of prematurity – parents catapulted from a known world into the strange land of the NICU until discharged back into the world from which they came – here I seek to explore the experience from the perspective of those taken into exile in Babylon.

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37 Ibid, 185
38 Although the dates are very much open to historical speculation. See Daniel L Christopher-Smith, A Biblical Theology of Exile (Minneapolis: Augsburg Fortress, 2002), 63-65
39 A helpful summary of the issues pertaining to the historicity of exile can be found in Ibid, 27-74, and Andrew Mein, Ezekiel and the Ethics of Exile (New York: Oxford University Press, 2001), 40-75
40 Christopher-Smith, 54
The Babylonian exile raised significant questions of identity and practice for the people: How long are they to be in this situation? Do they seek to retain elements of their old life in the promised land, and if so, how much? How do they relate to those who have power over them now? How do they relate to the culture of this new world? It is a struggle best encapsulated in Psalm 137:

By the rivers of Babylon, there we sat down and wept, when we remembered Zion.  
Upon the willows in the midst of it, we hung our harps.  
For there our captors demanded of us songs, and our tormentors mirth, saying, "Sing us one of the songs of Zion."  
How can we sing the LORD’S song in a foreign land?  
If I forget you, O Jerusalem, may my right hand forget her skill.  
May my tongue cleave to the roof of my mouth, if I do not remember you, if I do not exalt Jerusalem above my chief joy.  
Remember, O LORD, against the sons of Edom the day of Jerusalem, who said, "Raze it, raze it, to its very foundation."
O daughter of Babylon, you devastated one, how blessed will be the one who repays you with the recompense with which you have repaid us.  
How blessed will be the one who seizes and dashes your little ones against the rock.  

This Psalm best depicts the distress, anger and powerlessness of the deported community. Amidst the strong yearning for a familiar place we hear a bitter lament, and a desire for punishment to be visited upon their captors. The resonating question “How do we sing the Lord’s song in a strange land?” raises the central question of identity and practice. The exiles lament not only the apparent absence of God, but also the absence of ways of relating to God. Their minds set upon another place to which they can no longer travel – Jerusalem – they are reduced to tears, knowing that it has been razed by their captors. The lament to which they give voice is for a loss of place, a loss of identity, and a loss of relationship with God.

Place is important not simply because of its physical features, but because of the relationships and values represented, and the shared rituals which nurture a particular way of seeing the world. To speak of exile is not merely to be understood as removal from one’s physical homeland, but removal from an environment which nurtures a particular way of being, of relating, and of living. The homeland comes to represent a life which has been lost, and relationships which are no longer possible. The place of exile is often encountered as a place of judgment, and a place of oppression. Living under new rulers, in a new culture, and with an uncertain conception of relating, is extremely

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Psalm 137, NASB  
Mein, 138-139
stressful, even disastrous. For Israel, the time in exile brought a radical change in the way they defined themselves, arguably birthing much of the literature which now constitutes the Hebrew Bible.

The first experience of exile is loss, which occurs at many levels. “Exile is one of the saddest fates,” wrote Edward Said. “There has always been an association between the idea of exile and the terrors of being a leper, a social and moral untouchable,” marked by the sheer fact of isolation and displacement. For parents of premature infants, it occurs through the relocation of their emotional and relational centre from their pre-birth community into the hospital setting. They are inextricably linked as a couple and a family to the fortunes of their child in the NICU, and they are unable to return to their pre-birth life unless and until this circumstance is resolved. In this case, however, the shift is subtle. The movement into the NICU is generally welcomed as a doorway of hope. It is only with the passage of time and at the time of return that the impact of the experience as exilic becomes apparent. Parents have lived under another power, and their homeland has been destroyed in their absence. Not a physical destruction, but its social fabric – the rules and rituals of relationship no longer sustainable or tenable in their post-exilic world. In the same way that the experience of grief is muted by the focus on the struggle for their child’s survival, so the transformation from local to exile occurs on the other side of the curtain which conceals the NICU experience from the wider community in general, and the social setting of the family in particular. As their child moves from marginal to sustainable life, the way of being in the wider world slowly dissipates around them.

The rise of the lament in Jewish literature reflects the need to give expression to this loss. The many psalms of lament, as well as the book of Lamentations, provide words for the experience and focus for the different aspects of loss experienced in exile. The naming of our losses is a first step in addressing the pain which emerges. Naming gives some power over the experience as it develops a capacity to respond.

But lament is not the only voice in exile. The prophet Ezekiel, sitting in the same place as those whose lament is heard in Psalm 137 – on the banks of the same river – sees a vision of God. In stark contrast to the Psalmist, Ezekiel reports in the same setting: “Now it came about in the thirtieth year, on the fifth day of the fourth month, while I was by the river Chebar among the exiles, the

46 Said, 178
47 Ibid, 183
heavens were opened and I saw visions of God.48 In the same place where one group of people lamented loss of identity and loss of a way of relating to God, the prophet celebrates and declares the contrary. The spatial imagery here is important in many ways. The lamenters in this place have their hearts and eyes turned towards the south – the place from where they were taken into exile. They are looking to the Promised Land – looking back to the place where they were, in the hope and wonder that they might return there. Ezekiel, by contrast, looks to the north, away from Israel, and towards the very direction from where the captors had come to Israel. The north was the direction from which threats appeared. Ezekiel looks to this place and sees a vision of God. Herein lies one of the challenges to be faced in exile – does one set one’s heart on return to the place from where you came, or be open to continuing the journey into new discoveries? The importance of lament is not diminished, but it is a reminder that it is not to be heard as the final word. The ability to articulate one’s pain and describe one’s loss is an important step in the healing process, but without turning afresh to the future and enabled to hear and see other perspectives, risks becoming mired in bitterness and living in a state where one is permanently lost.

Ezekiel tells stories about the experience of exile which focus the key questions to be faced. Confronted with a valley of dry bones, perhaps reflective of defeat on the battlefield, the question is posed to Ezekiel, “Can these bones live?” (Ezekiel 37) reflecting the deepest questions to be faced: Is there life in exile? Will they survive the experience? Is all that has been destroyed lost forever? As their past lies like scattered bones across a field, these questions resonate through the exilic mind, filled with an uncertainty which Ezekiel echoes as he defers to God in response “O Lord God, you know” (Ezekiel 37:3) The ensuing dialogue culminates with a description of exile as death – with the accompanying sense of loss and despair amongst the people – countered with the promise that God would restore Israel to the land.

The prophet Jeremiah undertakes an act which is itself a declaration of hope, directing that a plot of land be purchased in Israel as a symbol to his community that he has confidence in their return (Jeremiah 32). Yet while holding on to this promise of return, he directs the people in exile to seek the welfare of the city to where they had been taken – not to engage in a fight with the captors or remain separate from them, but to make a contribution while they were there. They were not to let the bitterness of lament keep them from making a constructive contribution, and not just on their own behalf, but for the people of the city which had taken them captive. This directive also serves to remind the exiles that they are not without power and that it is possible to live and thrive in exile, rather than seeing it is an experience to be endured and one from which they need to be rescued.

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48 Ezekiel 1:1 NASB
Jeremiah’s injunction to “build houses and live in them,” to “plant gardens and eat their produce” (Jer 29:5) is not to suggest surrender to the culture, but to encourage engagement with it. It is an invitation to familiarise oneself with the culture as one who lives and works amongst it because in this, says God, “I will prosper you.” (29:11) The challenge is not to let the Jews in exile lament their lives away, but to accept their circumstance and make a contribution, not just in their own interests, but in the interests of the community of exile, and those who would come after them.

A significant part of the Jewish identity was tied up in the purity laws which included what they could eat and drink. The maintenance of purity under the law – without the temple and its sacrificial system – was one of the challenges of maintaining identity for the exiles. The prophet Daniel’s determination not to defile himself by eating food outside of that allowed by the law was a demonstration of the capacity to retain one’s identity without compromise and without inviting threat from the captors. Daniel’s refusal to eat the royal rations sparked concern for the one to whom Daniel was responsible (Daniel 1:8f) who was concerned that Daniel’s failure to eat properly would compromise Daniel’s health and the well-being of the steward responsible for him. Daniel suggested a ten-day trial during which time his health emerged stronger than that all others who consumed the normal palace rations. The message of Daniel to those in exile was to be true to your own identity – that being faithful to it would not compromise well-being.

In bringing these reflections into the parent experience of prematurity, I am reminded of the need to affirm the capacity of parents to make a constructive contribution to the NICU community, rather than to be identified as needy recipients alone. Parents have something of value to contribute while in the hospital setting, adding value to the care for their child, but also to contribute towards the shaping of practices which benefit all members of the NICU community, present and future. The capacity of parents to humanise the NICU world for all members needs to be underlined, alongside the ability to help and support each other as parents through the journey, knowing that they share many questions and struggles in common. To bring themselves in all their fullness to the setting will not only add to the NICU culture, it will also assist parents in confronting their own questions about the journey and provide a network which can assist in working through transitions.

Another of the key questions facing the Jews in exile was of duration: how long they would remain there: do they plan for return, sooner or later, and in what way do they seek to bring it about? It is beyond question for the Jews that return must be contemplated – it reflected the ultimate purpose of the exile – so that they might be restored to the Promised Land with a deeper understanding of the importance of maintaining their faithfulness to the covenant. But what return is dreamed? For the
Jews it was ultimately return to a different land from which they departed. The temple had been
destroyed, along with towns and infrastructure. The power balance had shifted as those who
remained behind had worked the land and maintained their communities without those who had
been exiled – those who had been leaders in pre-exilic Judah. Return was not to the place that had
been left behind, but to a different place, with new challenges to be faced and new relationships to
be built.

For the parents of premature infants, we need to ask whether exile is concluded when departure
from the hospital occurs. The fact that discharge planning begins from the time of birth means that
return is central to the thinking of the medical staff from the outset, but we must question whether
the exile experience ends when discharge takes place. This assumption is partly predicated on
parents having accepted that their hospital experience is rightly described as a time of exile – a
point which would be difficult to sustain. It is evident that the current culture surrounding
hospitalisation prevents consideration of the NICU experience as exilic because it is only ever
regarded as a provisional phase – a parenthesis in life – making embrace of the hospital journey as a
period in exile more difficult and the consequent acceptance of any implications problematic. Just
as there is no name for the parent of a child born prematurely, so there is no name to describing the
hospital experience for parents. It also needs to be remembered that for many parents the post-
discharge experience usually means transfer of care from an inpatient community to the care of a
multiplicity of other medical experts. Even if exile has been embraced as defining the experience of
hospitalisation, it is evident that return is not to a land unencumbered with the hospital and its
clinical-medical culture. While exile offers a framework for thinking about and reflecting on the
experience, it is not currently in the parental vocabulary.

Thus the journey of exile and return entertains a dialogue between hope and despair – hoping that
the hospital journey will soon be over yet enduring the daily gyrations in their child’s condition – an
experience which brings hope of departure closer on one day, only to have it pushed into the
distance on another. Not knowing how long the journey will be, and when the end of it is nearing
must be considered alongside the growing realisation that the end of the hospital journey may not
resemble the promise held at the outset. Any sense of assurance is assailed by continuing questions:
What will return look like? Will it ever come? What will our welcome entail? Who will join us in
this journey, and who will pick up with us when it is over? What will this child be like when we
come to take him/her home?
Thus the song of lament may well be heard when the exile is nearing its end and the journey of return begun. Just as the Jews did not return to the land they inhabited before exile, so too the arrival home underlines that parents have reached a different place. The Jews returned to a place where much of their infrastructure had been destroyed. They were not returning to pick up where they had left off, but were starting a new journey in the same place. Return from exile marked restoration of the Jews to the land they left, but not of it. The exiles too had been transformed by an experience which required a reconstruction of life not only in exile, but also upon return. The Deuteronomic code emerged as part of the post-exilic community. Exile brought a new perspective on the pre-exilic way of life and an opportunity to start afresh. “In the case of the exile(s), one of the primary questions that the construction of history attempts to respond to is: What led us here? Even more important, what can we hope for in our future?” It is no different for parents of premature infants.

It is well documented that the exilic journey is marked with pain and loss of an order which can lead to Post-Traumatic Stress. But the same journey which can leave such deep scars is also one filled with creative possibilities. Exiles are afforded an outsider’s perspective on their own pre-exilic culture, and on that of the captors. The experience of exile generates a capacity to draw on the resources and potential critiques of both cultures, with the fullness of their histories and narratives, their rituals and remembrances as resources which enable exiles to interpret their own experience and potentially forge a new future. In Jewish terms, it is possible to view exile as a type of Jubilee, a festival which restored all Israelites to their position as equals in the land.

Though the struggles of exile are intense, from a distance exile and return may appear as a holiday. Those who stayed in the land and worked it during the time of absence may carry little compassion for those whose burden was hidden from their eyes. Return from exile may not be the welcome which the exiles expect, nor the joyous event to be celebrated by those who have waited and worked in their absence. Evidence of this antipathy is there for NICU parents, which has been the source of many ignorant, hurtful and alienating comments. The home land is experienced not as a place of welcome, but one of further alienation.

**Faith, Hope and Love**

The anthropological model of identity outlined in the previous chapter which affirms three fundamental dimensions of being human – the universal, the cultural, and the individual –

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49 Christopher-Smith, 109-110
50 Ibid, 89-94
introduced us to a tripartite way of understanding human identity. The apostle Paul offers another tripartite pattern for understanding human perspective, one which provides insight into the nature of both human action and identity, and offers a model for pastoral formation. This threefold perspective is found at the conclusion of his widely-read homily on love, where Paul speaks of three enduring characteristics, “And now these three remain: faith, hope and love.”  

Often stripped of context, these words have been primarily enlisted in support of the notion of romantic love, rather than about the right use of power – the context in which it appears. Chapters 12 and 14 of 1 Corinthians address the use of power in the Corinthian community, which was being deployed in Corinth to privilege a few at the expense of others. Chapter 13 stands as a reinterpretable grid for understanding how to act appropriately so that all may be built up, rather than a select and privileged few. While the focus of this discourse is ultimately towards the power of love, the trilogy is not accidental nor incidental to Paul’s thought. Faith, hope and love together represent abiding characteristics of human identity and action in the world.

**Faith**

Fowler considers faith to be a generic feature of all human lives. Faith is “our way of finding coherence in and giving meaning to the multiple forces and relations that make up our lives. Faith is a person’s way of seeing him- or herself in relation to others against a background of shared meaning and purpose.” Traditionally and popularly, faith is regarded as the domain of the religious – a set of creeds or dogmas to which one assents as a pattern for belief. “Most often faith is understood as belief in certain propositional, doctrinal formulations that in some essential and static way are supposed to ‘contain’ truth.” Faith, Fowler argues, is not merely a domain of the religious, but a universal quality of human meaning-making, while seeking to draw a distinction between religious belief and faith, a distinction which requires more clarity. Fowler’s efforts to develop a theory of faith development have been called into question because of its propensity to borrow modern metaphors more akin to economics and psychology that shift the centre of faith...
away from the interaction between the human and the divine, and fail to take account of many aspects of religious thinking. Perhaps the greater contribution of Fowler is not to be found in theories of development, but in recognising the universality of faith, thus liberating it from the domain of the religious and affirming its place in all human thought. Fowler develops this thought:

our faith orientations and our corresponding characters are shaped by three major elements of what I have been calling the “contents” of our faiths… centres of value that claim us… the images of power we hold and the powers with which we align ourselves to sustain us… the master stories that we tell ourselves and by which we interpret and respond to the events that impinge upon our lives.

Faith defined in this way represents people’s evolved and evolving ways of experiencing self, others and the world (as they construct them) – a description which bears striking resonance with theories of biographical narratives – the notion that the stories we tell about ourselves define our identity in the world.

Understood in this way, faith is best described as the set of eyes we choose to interpret the world around us – an interpretive frame which gives meaning and order to the realities of our lives. It is “the assurance of things hoped for, the conviction of things not seen” (Hebrews 11:1). It is faith that allows us to move into each day with confidence that we are able to understand and interpret the things that we will experience and which require a response from us. It is by faith that we extrapolate that which we have already interpreted into understandings of events and experiences which are before us in the present, and which we may encounter in the future. Thus in faith we can read the world through the eyes of economics, science, politics, relationships, cosmology… there are myriad ways in which we can interpret the world, by taking the knowledge and patterns we have already understood and extrapolating them to interpret things we have yet to see. The pattern which we choose is a pattern of faith. When we choose to evaluate by means of economics rather than environment, or by science rather than relationships, we have made a faith choice. We have found an assurance of understanding for things which are familiar, and a conviction about those which are not. It is a matter of faith not only to utilise a particular lens for interpreting the world, but also a matter of faith which chooses or prioritises one over the other. It is this choice which brings an inherent sense of value to our understanding of the present, and which itself contains a picture of an ideal future.

60 Fowler, Stages of Faith: The Psychology of Human Development and the Quest for Meaning, 276-7
61 Ibid, 92-93
At the most mundane level, encounters with objects and experiences hitherto unknown are interpreted through the grids of knowledge already available – we seek to make experience fit into our world perspective. Our “eyes” – our value system – imposes a shape upon the reality that creates confidence in approaching it and empowers us to deal with any challenges it may bring. In the NICU, faith is primarily demonstrated through confidence in the clinical-medical worldview which enables medical staff and parents to make sense of the experience of premature birth, and which provides a course of action and a hoped-for outcome for the infant. The clinical-medical perspective can offer an answer to the question of why the child was born prematurely, and articulate a course of action in response. However, this perspective is limited in ways which are inherently dissatisfying, and which cannot provide answers to such questions as “what type of parent can I be in these circumstances?” and “where does this experience lead us after hospital discharge?” The clinical-medical view is a faith perspective which has limitations, yet is given prime place within the confines of the NICU community. A social worker, in contrast, brings a different set of eyes to this situation, interpreting the experience through a different grid, bringing different resources to the challenges to be faced, and depicting a future commensurate with this vision. An economist will run another set of eyes over the situation, making an analysis of the cost and benefits of treatment regimes. Each faith perspective sharpens our focus on particular aspects of reality and dims our eyes to others.

Faith being the eyes with which we choose to view and interpret the world, each of us is enabled to utilise different perspectives for interpretation – more than a single set of eyes. At the simplest level, we view with a single perspective, which reveals reality to us in a particular way. As we mature, we learn to view with alternate eyes, though the primary understanding developed within our earliest family environs provides the overarching grid into which these perspectives are filtered. Most faith perspectives are nuanced in relation to each other. We learn as individuals, for example, to balance the economic demands with the emotional needs of our family, the requirements of justice with compassion. It is in institutional settings where a single set of eyes can potentially dictate the limits of acceptable perspective. Within the clinical-medical frame, it is only the information which can be gleaned or corroborated through clinical processes which gains validity and power. All other perspectives are marginalised to allow the central perspective to carry out its task.

It is important to realise that the various eyes we use to view the world are not always mutually exclusive, but that each of them does contain a capability for interpreting the reality we encounter.
Faith ultimately reflects the plausibility structure upon which our lives are built, consequently revealing the values which undergird our actions and the priorities we have afforded importance in our lives. Faith is not distinct from hope and love, containing within it inherent interpretations of, and implications for, the latter (more on this later). Faith thus provides not only the meaning framework for interpreting the world as it is experienced, but also the frameworks by which new information is processed and integrated.

From the perspective of Christian theology, faith is ultimately placed in Christ: life is viewed and interpreted through the prism of understanding which is shaped and informed by the teaching, life, death and resurrection of Jesus of Nazareth. Faith is filled with possibilities which are grounded in the God who is essentially future in name and character: the God of the Exodus, the God of Exile and Return, the God of Death and Resurrection. Christian faith is grounded in the God who has never let the present circumstance be the final answer, no matter how oppressive and apparently hopeless the situation seems in the face of an oppressor. The strongest and most potent systems of the world have been unable to destroy the creative and future possibilities of God. Christian faith sees the world as moving towards the full purposes of God in Christ, and therefore maintains an openness to possibilities which particular systems of faith might never consider plausible or possible. For parents in the NICU, where a clinical-medical purview predominates, this can have significant implications.

**Hope**

Jürgen Moltmann drew a strong connection between the Christian doctrine of eschatology and hope, denouncing a view of hope which regarded the end as irrupting into the world from beyond its history. Instead, Moltmann regarded hope as inextricably linked with the concrete view of the future which was grounded in present realities and practices in which hope was already alive. Moltmann regards eschatology as pointing to the future which is the ultimate result of present realities.\(^62\) Hope becomes a ‘passion for what is possible’ … because it can be a passion for what has been made possible.’\(^63\) If faith is the way in which we choose to view and evaluate the world today, Moltmann offers an interpretation of hope as the picture of the ideal world towards which we are directing our energies, a hope which is grounded in our present realities – in faith – but not limited to it.

In the same way that Fowler suggests faith to be a universal aspect of human experience, so Moltmann argues hope to be universal. Despair, presumption, inertia, resignation and melancholy

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\(^{63}\) Ibid, 20
all presuppose hope and grow out of surrendering hope.\textsuperscript{64} He further contends that “faith is called to life by promise, and is therefore essentially hope…”\textsuperscript{65} reminding us that no matter which way we choose to view the world we bring an inherent image of its ideal future.

Moltmann underlines the intrinsic place of hope within our faith perspective: “Christian eschatology does not speak of the future as such. It sets out from a definite reality in history and announces the future of that reality, its future possibilities and its power over the future. Christian eschatology speaks of Jesus and his future.”\textsuperscript{66} Thus hope is not a wished-for transformation which comes from outside so much as a desire to see today’s realities come to fruition, recognising that the seeds of this future are recognisable in the present moment. Hope is rooted in the past through our memory of God’s faithfulness, and is empowered from the future from where it receives its vision, and motivates us in the present to live as harbingers of the future.\textsuperscript{67} Thus faith – the way in which we read the world today – and hope – the way in which we see the ideal future – are inextricably intertwined and dependent upon one another.

It is hope which supports the notion of exodus – believing in the possibility of crossing over into new realities – such that we are not merely limited to or defeated by the present.\textsuperscript{68} Such hope does not emerge through abandonment of the present situation, but through a vision of the present situation which is inherently open. Hope declares that the present situation is not immutable. Hope prevents a simple resignation to circumstance. “The present is never our end. The past and the present are our means; the future alone is our end. Hope casts us into ‘the future that is not yet.’”\textsuperscript{69} A hope which is not grounded in present realities is not hope but wishful thinking. Moltmann contends that “hope alone is to be called ‘realistic’, because it alone takes seriously the possibilities with which all reality is fraught.”\textsuperscript{70} In Christian theology, hope is grounded in the death and resurrection of Jesus, a hope which sees the establishment of God’s reign, and the fulfilment of His purposes. It is this irresistible future which underpins Paul’s triumphalism in the face of deepest adversity, (Romans 8:38) and provides strength to face the present, even under physical constraints (2 Cor 12:7f), and to continue to work towards this future which is already, but not yet.

For our knowledge and comprehension of reality, and our reflections on it, that means at least this: that in the medium of hope our theological concepts become not judgments which

\textsuperscript{64} Ibid, 23-26  
\textsuperscript{65} Ibid, 44  
\textsuperscript{66} Ibid, 17  
\textsuperscript{67} Lester, 22  
\textsuperscript{68} Moltmann, 19 Note also the links here with the notions of exile and return.  
\textsuperscript{69} Ibid, 26-27  
\textsuperscript{70} Ibid, 25
nail reality down to what it is, but anticipations which show reality its prospects and its future possibilities.\textsuperscript{71}

\textbf{Love}

Faith is the set of eyes with which we choose to interpret the world; hope is the picture of the ideal future which finds its seeds in faith and towards which faith inexorably points. Love is a symbol of the power by which we transform the present reality towards the goal which is embodied in hope. For Paul, it is the Christian ideal which ought to shape a Corinthian church which is far more interested in the power of domination, a power which privileges those who have over those who are less seemly. It is love which moves Paul from rebuking the Corinthians for “eagerly desiring the greater gifts”\textsuperscript{72} to encouraging them to excel in gifts which build up others. (1 Cor 14:12).

Each set of eyes – every faith – contains within an implied and inherent power which enables its movement from seeing the world as it is to creating or forging the world as it is seen through hope. It is the power of love which forms the basis of God’s transformation of the world (John 3:16). Jesus declares that it is love which underpins the whole of the Law and the Prophets – love for God and love for neighbour, remembering that it is the role of the law to lead us into righteousness. “Love does not shut its eyes to the non-existent and say it is nothing, but becomes itself the magic power that brings it into being. In its hope, love surveys the open possibilities of history. In love, hope brings all things into the light of the promises of God.”\textsuperscript{73}

To return to the setting for our investigations: the clinical-medical gaze interprets illness through a particular grid, and visions a future where disease is eradicated. The power by which this hope is made real is through scientific research and the development of chemical and genetic treatments which allow disease to be defeated – a faith, a hope, and a love. Every faith perspective implies a power (or range of powers) by which its ideal future can be made real. There is often more debate within faith perspectives about the best way to enact this future, reminding us that there is more than one method by which present realities can be transformed into future ideals. We have witnessed debates amongst economists about planned and free market mechanisms for producing the best outcomes, and in more recent times about the best way to combat the challenges of the Global Financial Crisis. In some ways these debates also reveal differences about the ideal future

\textsuperscript{71} Ibid, 35
\textsuperscript{72} A better translation of 1 Corinthians 12:31, which more correctly reads as rebuke and reinterpretation: “But you are desiring the greater gifts. But I will show you a more excellent way.” The way of love articulated in chapter 13 allows Paul to pick up the argument and restate it at the start of chapter 14: “Pursue love, yet desire earnestly spiritual gifts…” gifts which serve others, rather than glorify or elevate an individual.
\textsuperscript{73} Moltmann, 32
which are inherent within the particular perspectives, warning us against a simplistic view of the nature of faith, hope and love.

**The Communal Dimension**

Seeing the world in a particular way, picturing an ideal future, and identifying the power by which one moves from the world as one sees it to the world as one hopes it to be are intricately intertwined, but distinct. Being able to articulate a view of the world as it is, and depict the ideal that it should be renders us impotent without an attendant power which enables a transformation of the present into a future reality. Similarly an inability to see a vision of what the world could be renders any present vision and power without utility, in the same way that an inability to articulate the world as it is leaves one without a ground on which to build the future. While we are able to describe these three aspects individually, I find myself inexorably drawn to the ways in which they nourish and inform one another.

The tripartite view of our perspective on the world is a helpful interpretive grid for analysing the nature of crisis facing an individual or community. The absence or disintegration of one of these three aspects creates a crisis in identity which is fundamental to our sense of purpose. Circumstances which result in us losing the world as we know it, or destroying the possibility of a future for which we had dreamed and in which we had much invested, or leaving us impotent in the face of present challenges such that we are mired as we are and unable to move beyond them strikes at the heart of our being. It is an important pastoral task to attend to these particular aspects of human formation and work in the world and support individuals in the analysis and reconstruction of faith, hope and love.

A clinical-medical paradigm offers an interpretation of the present circumstance and brings with it an ideal future – without disease – and the means towards attaining it – medical treatment. Scientific discourse in general operates within a similar paradigm, with the power of knowledge moving us from the world as we know it to a more perfect world with humans in complete control of their destiny. As helpful as these perspectives are in addressing some of the challenges of disease and human frailty, their perspective is limited and ultimately less-than-fully-human. Despair, lostness and hopelessness find their roots in a loss of faith, hope and love, challenges which scientific discourse ultimately lacks the tools to address. Grief itself finds its roots in the collapse of a world as it is known – a loss of faith – but not necessarily its destruction or downfall. Grief can be a catalyst for strengthened or sustained faith if the vision of world as it is – or of the ideal future – provides a meaning framework which allows the loss to be accepted and integrated without
diminishing the hope to which one is aspiring, or without removing the power to move from the present circumstance into the future. It is theoretically possible to articulate characteristics of faith, hope and love in every epistemology, even ones which are founded on the notion of a future which ends in annihilation. These are questions which are intrinsic to human identity. Whilst fundamentally theological questions, they are universal.

In the experience of prematurity we hear resonance of these losses: the loss of the world as it is known; the loss of a future towards which the family was striving; the loss of a capacity to move from the present into the desired future, a rupture felt more deeply because its impact is to break the family concerned away from the community context in which its identity had been nurtured. Whatever the content of their faith, hope and love, it was shared in common and reinforced by the family and communal setting which had been their home before the NICU exile. The loss of perspective here described serves to sever the family from the source which nurtured and sustained its members, and any critique which is offered meets the stony walls of resistance which had provided protection for the family when they were inhabiting the interior of its walls, something no longer possible in the light of an experience which has undermined significant and critical aspects of the premise on which that perspective was maintained. Such views – whatever their particular paradigm – have power because they are shared views. They are always inexorably communal. It is important to recognise this in order to fully address the process of loss and to creatively facilitate a rebuilding of faith, hope and love.

This communal dimension is evident in the structure of faith, hope and love and is also reflected in the exilic experience, which at the first instance destroys the world as one knows it. Exiles in the immediate aftermath can no longer see the world as they once believed it to be: “By the rivers of Babylon, there we sat down and wept, when we remembered Zion…” The power structures and cultural artefacts are no longer present to sustain their way of life, which is subject to a new cultural setting and a new power structure. There is a new communal context in which to negotiate meaning and identity. Exiles are rendered powerless to remedy these changes and are met with the challenge of reconsidering whether the ideal future they had pictured is still attainable, and if so, what is necessary to bring this about.

The Jews in exile needed to reinterpret the understanding of their relationship with God and the land. Why had this promise of God, both in relation to the land, and in relation to the Davidic kingship, been apparently abandoned? What of their understanding of God and the world over
which God ruled had been mistaken? It was this reflection that lead to the prayers of confession which acknowledged their own responsibilities for exile by failure to keep the covenant.

Summary
These two themes – exile and return; and faith, hope and love – are indicative of the rich reservoir of thought and experience which comes through the theological tradition and which provides the capacity to inform parents’ struggles and give shape to the continuing journey of parenthood in the aftermath of an extremely premature birth. Given more time, I could explore the tradition of lament, the theme of suffering, of death and resurrection; I could the reflect on the stories of David’s struggles during the brief life of his own infant child, or the questions which Job raises in the face of deep distress subsequent to the destruction of his whole world. These are human stories, reflecting the real experiences and struggles within life, and which offer rich and sustaining insights for parents and families faced with the struggles surrounding extremely premature birth, and offer words and images to help frame the experience. But other questions still remain. We could further reflect on the theology of the child, particularly a premature baby, and the place of the family and community in forming our identity. These, however, are not sedatives to the realities of isolation and struggle which typify the NICU journey. Nor are they sufficient expressions of a theology which is profoundly incarnational. It is not an idea alone in which the Christian theological reflection is grounded, but a relationship which reflects the character of God-in-relationship.

Who is it that helps parents who endure the experience of extreme prematurity for their children to rebuild and reinterpret this world? What resources are available to them, and how can a model of care be created which pays attention to this deep crisis of humanity which engulfs parents in this journey? It is to these questions that I now turn attention.
Chapter Ten

Pastoral Possibilities for Parent Care

The Practice of Pastoral Care

The practice of pastoral care is deeply rooted in the Christian tradition and flows out of one of its central tenets: the incarnation – the conviction that God chose to enter the world in Christ and to suffer with us and for us in order to provide the way of hope and redemption. Pastoral care is an incarnated theology and thus an embodied praxis, which resists a narrow conception of care in remedial or palliative terms whereby care is conceptualised solely as a response to an exigent crisis, or as the provision of comfort while the inevitable effects of circumstance unfold. Pastoral care is neither directed towards simple amelioration of stress on the one hand, nor the offer of cure in the face of an existential crisis on the other. Pastoral care pays attention to and addresses the details of a person in a particular situation, but not in isolation of the greater perspective each situation brings as reflective of what is common to all people.¹ The practice of pastoral care is intrinsically linked to the discipline of pastoral and practical theology, both presupposing and including the work of theological reflection, which informs the nature and practice of care being offered and facilitated.

Andrew Lester defines the primary task of pastoral theology as to develop the theological lens through which practitioners of pastoral care and counseling can understand the human condition and organise an effective pastoral response.² But pastoral theology and practice must go further, seeking to assist respondents in identifying and articulating their own journey, giving expression to key values and available resources for making sense of their lived experience, and of their future. In reading the exchanges through the Preemie-I forum, it is evident that resources for this task are present and available for parents and those engaged in pastoral care. A good pastoral carer enables individuals and communities to identify these resources and harness them for the journey. Pastoral care is not advanced by exchanging one set of language and values (in this case, of the NICU) for another equally alien set (for example, theological language). It is rather better articulated and expressed through aiding others to identify and articulate their own value set in language which is native to their world.³ This is the essence of the theology of incarnation.

¹ Patton, 7
² Lester, 2
³ What might be called ‘theology in the vernacular’, as proposed by Graham, Walton, and Ward, Theological Reflection, 14
Traditionally regarded as a practice of care by ordained clergy towards members of the church community, pastoral care faces a continuing tension about its purpose and practice: is it focussed towards the development of discipleship and spiritual formation within the context of Christian community, or does it have something to offer outside the strict confines of the church? Or, to frame the question in another way, can pastoral theology adapt to the questions and presuppositions of wider culture, or is its frame limited to working from, within and back into the community of faith? Does the church have a pastoral care role to the wider community, when it often does not share a faith – a way of viewing the world? Does the Christian faith have anything to offer to people who do not share its perspective? The answer lies in the questions we share in common – the questions which plague every human being in the face of suffering and despair – and the belief that the Christian faith directs itself towards universal questions regardless of time, place and culture – the questions which are raised when our faith, hope or love is found to be insufficient for the circumstances we find ourselves facing. These questions also tend to be the most personal of all.

The practice of pastoral care has been adapted into places where it has become disconnected from its Christian foundation. Pastoral care has been instituted in schools and workplaces where its focus has shifted towards psychological models of development and wellbeing, or towards economic models of increased productivity and efficiency. Pastoral care in wider community settings has moved towards becoming a tool focussed in the direction of facilitating economic, educational, or psychological ends. The lack of a clear and widely accepted definition of pastoral care from within the Christian tradition has allowed it to be adapted in different settings and stripped of its Christian foundation. Pastoral care has been secularised to the point where the unique contribution of pastoral care from its Christian foundations has been marginalised. Efforts to restate these Christian foundations raise the spectre of Christian morality and judgmentalism for sin, rather than being understood through a constructive grid of growth, reconciliation and achievement of one’s potential under God at the individual level, and the power of supportive community to engender growth, maintain hope, and help clarify perspective at the communal level. Pastoral care is not primarily utilitarian; it helps people clarify what is ultimate from what is penultimate or insignificant. Yet pastoral care is also practical, helping individuals and communities to live well and consistently with their values. The practice of pastoral care could best be described as a lived expression of Christian theology in which carer and careseeker encounter each other in order to discern meaning in a given situation, and to identify available resources for responding, in the context of an explicit or implicit narrative which provides overarching direction for living. It is pastoral inasmuch as it is focussed towards nurturing life and wholeness and providing a safe and nourishing space in which...
exploration of life’s meaning and purpose can be undertaken. A pastoral carer demonstrates caring by entering into that life space as a partner, such that burdens and joys are shared, and reflection and resources are brought together to empower individuals and communities and to facilitate movement towards the fulfilment of our common and individual humanity. It is Christian inasmuch as it is undergirded by the conviction that God is present in the midst of life, and a recognition that the way in which God has been revealed gives us insight into the present. Pastoral carers also seek the God-moments in pastoral encounter, where a meeting between two is the context in which God is discovered.

In making the choice in the previous chapter to articulate and explore two theological prisms through which the experience of prematurity might be understood for parents, I have illustrated two ways in which theology can be pastoral. I am not suggesting that these are the only ways to view the experience of prematurity, nor even the most appropriate in any or every circumstance. The imagery of exile and return, and the conception of life narrative through a prism of faith, hope and love provide two different bases for conceptualising and interpreting the parent experience of prematurity and of humanity which give insight into the experience and capacity for shaping a response. These two theological prisms place the parent experience at the centre of reflection and do not require a particular outcome for the child in order to assist parents in reflecting on the experience. Neither do they presuppose a particular worldview or value set. These prisms offer an insight into the nature of the experience in terms which may already be familiar to the parents, and are themselves a doorway for articulating and exploring further, whilst also offering a platform by which one might explore the questions of God’s presence and purpose in the midst.

Because medicine’s primary purpose is honed towards cure not care, physicians have become warriors engaged in combat with what they consider to be the ultimate adversary – death: the medical "mission" is to vanquish suffering. The focus thus becomes the disease or physical condition, not the person. The narrow purview of the clinical-medical paradigm stands in stark contrast to the multifaceted connection which pastoral theology and pastoral care can bring to the hospital situation which is focused on the person, and towards life in its fullness; in many ways restoring the human condition to the human. Pastoral care shares a therapeutic concern, but its

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4 Furniss, 2
5 Though they have been helpful grids for my own developing understanding of the experience.
6 Stanley Hauerwas, God, Medicine and Suffering (Grand Rapids: Wm B Eerdmans Publishing Co., 1990), 101
7 Furniss, 120
8 Courtney Campbell recalls that “Paul Ramsey once rhetorically enquired whether “the purpose of modern medicine is to relieve the human condition of the human condition, by which Ramsey had particularly in mind the illness, disease and suffering all persons experience as their mortal lot. Such an objective not only commits medicine to an impossible task, but one that risks dehumanizing its practitioners and patients.” Courtney S Campbell, “Religion and Moral
focus is more than therapeutic. The final purpose of pastoral care is not healing in the medical sense – although the physical health of the person may well form part of the goal – but integration.  

Pastoral carers recognise that there can be no easy separation of the physical from the spiritual or the social or psychological, which are curiously interwoven in our humanity, and will not abandon the spiritual because it is a dimension which is integral to our humanity.

It is this focus on being fully human which enables pastoral carers to approach suffering with a fundamentally different attitude. Whereas a primary goal of medical practice is to reduce or eliminate suffering at the physical level, pastoral carers engage with it.

Among other things pastoral work is a decision to deal, on the most personal and intimate terms, with suffering. It does not try to find ways to minimise suffering or ways to avoid it. It is not particularly interested in finding explanations for it. It is not a search after the cure for suffering. Pastoral work engages suffering. It is a conscious, deliberate plunge into the experience of suffering.

Christian theology and faith has suffering at its core: the crucifixion stands at the heart of both the Christian message and Christian identity, providing an image of (unjust/unmerited) suffering which has become the symbol of redemptive action, and which stands as a pattern and a bulwark in the face of suffering. Suffering can be faced in the confidence that it is an avenue through which God can be known, and through which future possibilities emerge. In the face of political and religious systems which brought death, the central message of Easter is that even the most powerful systems of the world cannot extinguish the redemptive and life-giving purposes of God. It is this core narrative which allows pastoral carers to enter suffering with hope and compassion.

Pastoral care brings at least two unique aspects to the practice of care. First, pastoral care operates on the assumption that within every human situation there are faith issues that can be addressed. In times of crisis, pastoral care recognises there is opportunity for a person to develop a greater understanding of their faith perspective, which might lead either to a deeper understanding of sacred story, or to an abandonment of previously held beliefs. Pastoral care embraces the dynamic nature of life and faith amidst a myriad of complementary and competing narratives for an individual or community.

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9 Eugene H. Peterson, Five Smooth Stones for Pastoral Work (Atlanta,: J. Knox Press, 1980), 93
10 Lester, 152
A second aspect is unique in the caring professions: pastoral care is both proactive and pre-emptive in the context of a unique relationship with an individual.

As a pastor, you are an integral part of the treatment team, because you have a unique relationship with the patient. The physician, nurse, psychologist, physical therapist, and pharmacist usually lose contact with the patient upon discharge from the hospital or outpatient clinic. You, the pastor, see the person as an in-patient parishioner with medical problems, but you also see the person at home, at church, and elsewhere in daily life. You are part of that daily life.13

While Oates conceptualises pastoral care within the context of a Christian community, the capacity of a pastor to enter the family home, while somewhat culturally marginalised in this time, still affords a unique ability to embrace the person as a human-being-in-relationship in various contexts – not merely confined to the hospital setting – a characteristic which is arguably the greatest strength in consideration of care for parents of premature infants. A further distinction is necessary here: Oates conceives of care for a patient in hospital which continues post-discharge. For the parent of a premature infant leaving the hospital, the home remains a potential setting for encounter which is not generally available to medical staff. The capacity to cross these boundaries is an important dimension of pastoral care which is critical in this instance. It is also this capacity to work across cultures and value systems which is potentially one of the greatest assets which an astute pastoral carer can bring. An ability to work in cross-cultural or intercultural perspectives mean that pastoral carers are well-resourced in ministering to and caring for people with whom they do not share a common worldview or are part of a Christian community, while affirming a common human struggle.

Kean draws attention to one further aspect of pastoral care worthy of recalling – it is a relationship grounded in life’s normality.14 The pastoral relationship is often commenced in non-critical times, in contrast to clinical intervention which largely begins in and is shaped by crisis – particularly so in relation to premature birth. One cannot overstate the impact of shifting the normalising centre of life in this way. Pastoral care brings an understanding of individuals shaped in the normal unfolding of life which fosters understanding and identification of the impact of stress. This further allows pastoral care to be shaped against a broader backdrop of life and relationships, and releases it from a limited or reactive frame.

Paradigms for Understanding Pastoral Care

Patton identifies three paradigms for understanding the ministry of pastoral care: the classical, the clinical-pastoral, and the communal-contextual, which he roughly correlates to three paradigms of

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13 Oates and Oates, 74
14 C D Kean, Christian Faith and Pastoral Care (London: SPCK, 1961), 42
the Christian theological tradition: the classical, the modern and the post-modern. In the classical paradigm, the emphasis is placed on the message of pastoral care. The clinical-pastoral paradigm turns its attention to the persons who are involved in the practice of delivering the message of pastoral care. Patton offers the communal-contextual paradigm as a way of broadening the practice of pastoral care to the whole Christian community, rather than it remaining in the hands of religious professionals, and of bringing the importance of context into the consideration of the practice of care. In simpler terms, Patton invites us to consider the practice of pastoral care in terms of message, person and context.

Patton seeks to recover, by making explicit, the ancient practice of pastoral care where the connection between message, person and context was more broadly and naturally experienced. In the pre-industrial era – where the village was largely a whole-of-life experience – relationship, identity, community and faith were integrated more readily. Care was offered (and experienced) by known clergy from a known church within a familiar context and a shared value system. The Reformation inaugurated a cultural shift in which message could be separated from context – the advent of the printing press making it possible for decontextualised communication to occur on a large scale. The industrial revolution ushered in an era which increasingly broke that nexus. Later development of modes of transport which facilitated increased personal mobility meant that individuals could also experience different contexts concurrently, with the result that the range of depth-relationships shared by an individual or family narrowed significantly, increasing the importance of the nuclear family as the primary source of depth-relationships amidst a larger number of overall relationships in a variety of contexts. Patton’s communal-contextual paradigm invites us recognise that neither the classical nor the clinical pastoral paradigms for pastoral care have given much recognition to context, and that the lack of a uniform context for individuals in the present requires pastoral carers to consider context more intentionally and deliberatively in order to move towards reconnecting message-relationship-context in a heterogeneous culture where consistent relationships outside of family (and arguably work) are less common.

I will use Patton’s paradigmatic outline for evaluating and articulating the pastoral response to the circumstances facing parents of premature infants, approaching the task of pastoral and theological reflection in relation to the present practice of care around three questions:

1. What is the central theme of care as expressed, and how does it align with the needs of the persons concerned?

15 Patton, 4
16 Ibid.
17 Ibid, 39
2. Who is providing care, and what assumptions and priorities are reflected in the care which they exercise? What are the ‘normative horizons’ which shape the provision of care?

3. In what ways does the community context shape the expression of care?

Central Themes of Care

Our investigation has identified a complex and profound need within many parents who undertake a lengthy journey of prematurity in association with a NICU. The response formulated within the hospital setting thus far has been framed in terms of amelioration of stress and towards provision of support for the parents primarily and substantially for the time of hospitalisation, with some increasing concern about transitions into and from hospital at the times of admission and discharge. The present practice of care substantially underestimates the significance of the experience both in terms of depth of critical impact and in time required for adjustment. Care is thus framed around an individualistic and incubational model which assumes the needs can be addressed in the context of individual relationships, or at the broadest, by reference to the nuclear family and its continuing relationship with medical professionals.

I will briefly recap four of the identified key needs which require a care response.

Dislocation

The place which parents inhabit after discharge from hospital is a fundamentally different space from that prior to birth. Parents return to their home and relationships, but have undergone a life-changing experience which has challenged major assumptions about parenthood, childhood, and ultimate concerns which has ruptured the links shared with previously close relationships. Parents face the challenge of coping with misunderstanding on the part of family and friends, with many parents reporting an increased distance from wider family and community, which results in continuing tensions. The inability of parents to clearly articulate their experience in terms which communicate its gravity and depth is a source of frustration and isolation. Living with health contingencies on the part of their child challenges many previously-held assumptions about their future, both short and longer-term.

Loss and Grief

The experience of loss is complex and diffuse, with broad-ranging personal, relational and social implications, leaving many unresolved feelings amidst an uncertain prognosis for the child. The grief of parents is an uncertain and potentially ever-changing response to a situation in flux, commencing within the hospital experience, and extending after discharge into the complex web of
familial and communal settings. Much of parent loss and grief is unrecognised and unacknowledged – a consequence of framing the experience as one which the neonate endures and the parents largely observe.

**Powerlessness**

Care in the NICU is structured in such a way that parents are ancillary to the main task identified in the NICU, and their appointed role within it marginalises them. Their initial capacity to input into decision-making is limited technically and emotionally, with responsibility for care for their child deferred to the medical teams. From this point on, the need for care of parents is acknowledged, and basic provision of care is provided, but is secondary to care for the child. Parental powerlessness creates a tension for parents in terms of advocating for their child, and expressing their own needs within the NICU, whereby perceived parent concerns about potentially compromising care for their child serve to militate against strong advocacy for themselves or their child. The deep emotional investment in their child coupled with the hierarchical and technical power structure in the NICU results in many parents carrying silent burdens.

**Suffering**

Reich describes three phases of suffering. *Mute suffering* involves being speechless in the face of one’s own suffering. When change is considered to be possible, a person enters a phase of *expressive suffering* in which the sufferer seeks a language to express his or her suffering, first of all the voice of lament, then the telling of story. The third language is interpretive – the attempt to interpret and understand the suffering.\(^{18}\) The parent experience as we have identified it is still searching for interpretive language. The creative *Imagine* thread on the list\(^ {19}\) opened a doorway for expressive suffering for parents which unleashed much uncontained frustration, providing a transition out of mute suffering. The *Welcome to Holland* narrative\(^ {20}\) offered an initial step towards interpretive suffering which has yet to be developed in any comprehensive or extensive manner. Much parent suffering is still muted, at least in the public domain, and in many family relationships. This suffering is grounded in either a loss of faith – the collapse of a view of the world which no longer works – or the presence of an ideal future (hope) which seems out of reach, or the loss of

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\(^{19}\) [http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9704/Date/article-613.html](http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/preemie-l.archive.9704/Date/article-613.html) and following posts, last accessed 27 April 2007

power (love) to move from the world as it is presently understood to the hoped-for future. The experience of pain is utterly lonely, without words of its own to describe it.  

The articulation of these four needs pushes the pastoral care requirement well beyond the simple amelioration of stress associated with adjustment into the NICU setting. It points to a complex circumstance into which a simple message will be inadequate to address the complex care needs of parents.

**Messages of Care**

The message conveyed through current care practices in the NICU suggests that the vast majority of problems for the family and the child are confined to the time of hospitalisation and end upon discharge from the hospital. While provision is made for medical referral post-discharge where there are continuing health issues to be monitored, and referral to other specialist support services where there are identified issues, little if any warning about potential longer-term needs for the child, or of continuing issues for the parents is presently included. The message of care in the current context suggests that parent needs can be met within the clinical expertise of the NICU staff. This is clearly an inadequate response to the complexity of needs for both the child and the parents (and the family).

Whilst such an approach exhibits tremendous confidence in the resilience and resourcefulness of parents and in the capacities of the NICU staff, it underestimates the magnitude of the disruption experienced by parents, and creates an environment where parents can be caught off-guard by the intensity of their response, the widespread disruption to their self-understanding of identity and purpose, and a lack of understanding by others. The closure of care from the hospital at the time of discharge can also leave parents feeling abandoned – many parents articulating the sense of loss they feel when leaving the confines of the hospital environment which was ultimately a source of comfort and security in the care of their child. The care environment fosters an unhealthy dependency which, when removed, infers a lack of care.

The central biblical theme for pastoral care is being remembered and remembering.  

![Page 247](image-url)
forget, but to dis-member.\textsuperscript{23} It is this conceptualising of care as remembering which is potentially the most important for NICU families, whose place in their community is at risk as a result of their experience. Remembering affirms the significance of the past for the understanding of the present, which, when collectively acknowledged, links us together in community and consequently provides both support and meaning. Remembering is achieved through telling of stories which recall past realities, integrating them into the present circumstance, thus sustaining hope. The essence of God’s remembering lies in linking present action and previous commitment,\textsuperscript{24} which requires attention to both the present circumstances and previous connections. For NICU parents, re-membering includes acknowledging that they are part of a wider network of relationships outside of the NICU from which they came into the NICU and to which they return post-discharge. The decontextualisation which occurs as a result of the NICU experience stems from a lack of integration of the NICU experience into that pre-existing community, and conversely from a lack of integration of that wider community into the NICU. The NICU experience is presently framed as a parenthesis on life’s journey – something which can be bracketed out and assumed to be isolated without consequence. Ironically, one could observe that in the process of putting one body “back together”, another body – another community – is ignored and dissembled.

A primary message of care should be founded in the acknowledgement that parents who enter the NICU bring a story which has history, fosters a particular way of seeing the world, and nurtures a particular hope – all centred in the present birth experience. A level of respect which considers parents important enough to find a place for their story to be told, and their place in the community to be respected and incorporated into the NICU experience is a foundational aspect of human care. It is the connection which this story brings which reminds parents that they are not alone in the journey, a reminder that the struggle is part of a larger story, and a reminder that we are connected in our suffering and struggle with others. The theological message which stands behind this commitment to hearing is that of a God who caringly creates human beings for relationship and who continues to care by hearing and remembering them.\textsuperscript{25} Human care and community are possible because we are held in God’s memory; therefore as members of caring communities, we express our calling analogically with the caring of God by hearing and remembering one another.\textsuperscript{26}

Without this basic connection in care – respecting one’s story through re-membering – all other messages lack purpose and context. It is only when our connection with others is honoured and

\textsuperscript{23} Ibid, 28
\textsuperscript{24} Brevard S. Childs, Memory and Tradition in Israel, Studies in Biblical Theology (Naperville, Illinois: A.R.Allenson, 1962), 34
\textsuperscript{25} Patton, 5
\textsuperscript{26} Ibid, 15
expressed that the message of exile and return has meaning. It is only in honouring the fact that this present event is part of a larger unfolding that the perspective of faith, hope and love gains relevance. We are connected with others through places and times, and need to be connected back into them when circumstance drives us away. It is the communal context in which a common understanding and shared view of life is nurtured and refined. A key aspect of care is rooted in the maintenance and nurturing of our communal identity – connecting us with important others. These connections are maintained in times and stories, in dreams and actions, in places and memory. The value of any message of care is found in its capacity to bring us back to these connections, or to forge new ones. Celebrating life in the present requires meaningful connection to the past. The present cannot be experienced as present if the past cannot be remembered as past. This may entail discovering and mourning the lost future stories as well as remembering and rehearsing the past stories that were meaningful. It is only when this is honoured that dysfunctional future stories that spring up in the aftermath of the loss can be addressed, allowing for the potential reconstruction of future stories.

Consequently, Christian pastoral care consistently returns to one message which is rooted in the death and resurrection of Jesus – that the future is never closed by suffering and death. Crucified by the political leaders in complicity with the religious leaders and with public support, all hope for Jesus and the disciples seemed to be lost. But the systems which had conspired to crucify Jesus did not utter the final word, which always belongs to God. The resurrection of Jesus is a potent declaration that the power of God is greater than any human systems, which carry the capacity for death even when they are well-intentioned. It is this belief which allows Christian pastoral care to sustain hope, even in the most bereft of moments. It is at the heart of a rich reservoir of image and metaphor, language and interpretation which emerges from the Christian tradition, resourcing care with a rich message.

**Care Providers**

The NICU is replete with well-trained and professional carers, whose expertise and commitment in the medical field is of the highest order. NICU staff exhibit a high level of commitment, both in practical expertise and emotional connection. Nursing staff in particular work hard to incorporate parents into the NICU context. However, given that the care providers are for the most part nursing staff whose primary responsibility is for the care of the neonate, this means that care for parents is not the central focus of their attention, nor necessarily a key aspect of their training. Good nurses

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28 Lester, 51
work to involve the parents in the care of their child and introduce their parents to the child through the initial maze of medical paraphernalia which serves to monitor and support the nascent life. They are often supported by case managers and social workers who attend to the parents’ needs within the hospital confines. The commitment of resources to the care of parents, even on such a limited basis, affirms the parents’ struggles during the NICU stay. The cessation or curtailing of these resources at the time of discharge further underlines the belief that the major struggles have finished, and that parental needs diminish from that time.

The expertise of NICU nursing staff is honed towards the clinical needs of the child, rather than the general care of attendant parents, with the result that care for parents is filtered largely through that grid. General nursing care skills provide a fundamental capacity for care, particularly in the efforts to humanise the experience and provide a contact point for information about the child and an avenue for participation in their child’s care. It also serves as a model to parents of how to care for their child in this critical time. However, the deeper emotional, spiritual and related issues inevitably remain beyond not only their skills, but also their time availability and capacity to attend to parents. The presence of a social worker in the unit provides an alternate contact for talking about emotional and physical needs, and someone who can connect parents in with support services. A good social worker will also attend to parent needs surrounding transition out of the hospital, but their focus also is ultimately defined by discharge, and tailored towards it. As competent as this care is, it is the purview of the care systems which is at issue. The scope of their relative perspectives obviates attention to the deeper and more enduring needs of parents and the issues which they represent. “Neither medicine nor psychology nor social work can ever respond to the final question of why man comes to life, slowly learns to stand on his own feet, attaches himself to someone else, gives life to others, and allows them to continue what he started but will not see fulfilled.”

It is unsurprising, given the available technical expertise which stands behind the present care structure that provision of parent support is largely framed around amelioration of stress, drawing on the resources of the nursing and social work staff available during the time of hospitalisation. This emphasis is strongly reflected in our primary source material, and frustrations with it do not generally focus around the technical skills of the carers. These two avenues of support and care are potentially supplemented by other resources within the hospital structure, including other practitioners within the clinical-medical disciplines, and hospital chaplains. It is no accident that

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29 Nouwen, 47
30 Many hospital environments provide access to counselling and psychiatric services, although their presence in the NICU is not indicated in the primary source material which is the Preemie-l list discussion, which gives pause to
the carers who feature in parent discussions are nursing staff and social workers, for they inhabit the hospital environment, which underscores the importance of the incarnational nature of care, and the importance of community. That the strongest bond is often created with members of the nursing staff also reflects the importance of continuity of relationship, with nurses having most shifts with their child often reflected in the strongest NICU relationships.

The clinical pastoral paradigm reminds us that the person who offers care is critical in the care process. When reflecting on care providers as people we need to examine not only the technical skills they possess, but also the purview of their conceptual frame, along with their character as a person. These first two aspects are systemic issues, while the issue of character represents something much more personal in the care relationship. What is at issue in the current practice of care is not the title of the carer per se so much as the way in which the care offered by nurses, case managers and social workers is framed. This is as critical to the practice of care as the skills they bring, and the relationship they offer. These staff members often develop a strong relationship with parents, but lack the resources and capacities to offer the care which the circumstances demand, ostensibly resulting from an inability to “see” the depth of issues being faced. It is the ‘faith’ of these staff – their view of the world – which shapes their perception of the parental experience and their care response.

Christian pastoral care affirms the importance of the character and identity of the individual in providing care alongside the technical and professional skills, and nurtures intentional reflection on the practice of care in order for pastoral carers to more consciously understand the impact of their presence and on the ways in which care is offered and practiced. For Patton, it is imperative that the clinical pastoral paradigm sustain three important assumptions:

1. the way one cares for others is inescapably related to the way one cares for oneself;
2. pastoral caring always involves being someone as well as doing something; and
3. one can best learn about oneself and how to care for others through experiential and reflective participation in caring relationships.  

Pastoral care cannot be conceived as delivery of a pre-packaged care service, but an interactive engagement which consists of supporting people in the midst of the complicated and often
distressing process of decision-making.\textsuperscript{33} To be with people in such profound and often intense moments requires both character and skills, and an ability to reflect upon and learn within the context of the care relationship. The focus of pastoral care is in allowing the other’s growth and circumstance to guide the carer in formulating a response, supporting the other’s independence and respecting their needs.\textsuperscript{34} Pastoral carers enter as vulnerable persons: “No one can help anyone without being involved, without entering his [her] whole person into the painful situation, without taking the risk of becoming hurt, wounded, or even destroyed in the process.”\textsuperscript{35} There is often a high personal cost to be borne by the carer who will often enter into the darkness of another's pain, loss, or bewilderment, without the defences of detached professionalism. Such an approach to caring can be frightening, costly, unsettling, even distasteful at times, as such circumstances can take carers into the deep shadows in their own lives.\textsuperscript{36} It requires courage to enter into such space, where misunderstanding, appearing foolish, or even failing altogether remain real possibilities, even for the most skilled pastoral carer.\textsuperscript{37} It requires courage to enter both the unknown space, and the known – to face the realities of human limits and loss, and to confront the Christian tradition to inquire what it might have to speak into such circumstance. To realise that more often than not there is no easy or final answer to this question – or even a single answer – but it is one of the questions with which persons of faith should continually be in dialogue\textsuperscript{38} is to leave the pastoral carer vulnerable and requires courage. It is unwise and unrealistic to expect nursing staff to enter this space with parents and continue their clinical practice at the highest level.

The astute pastoral carer is also attentive to the ways in which the social structures impact upon those for whom they seek to offer care. Knowing that individuals are continually formed and deformed by institutional structures and practices, pastoral carers should recognise the social and political implications and consequences of care. There will be times when the only truly pastoral action is political action\textsuperscript{39} – when it becomes necessary to challenge social structures which are unjust or oppressive – which calls for a different type of courage than that which accompanies the call to vulnerability in an interpersonal relationship. The call to care in such ways will more likely surface in such structured social systems as hospitals, where emphasis on hierarchy and formal rules often conflicts with pastoral care's understanding of relationships,\textsuperscript{40} and the narrow focus on

\textsuperscript{33} David Lyall, \textit{Integrity of Pastoral Care} (London: SPCK, 2001), 70
\textsuperscript{34} Mayeroff, 5
\textsuperscript{35} Henri Nouwen, quoted in Augsburger, 368
\textsuperscript{36} Alistair V Campbell, \textit{Rediscovering Pastoral Care} (London: Darton, Longman and Todd, 1981), 26
\textsuperscript{37} Patton, 78
\textsuperscript{38} Ibid, 114
\textsuperscript{40} Furniss, 119
physical healing can impact on a person’s overall sense of identity and being.\footnote{Stephen E. Lammers and Allen Verhey, On Moral Medicine: Theological Perspectives in Medical Ethics, second ed. (Grand Rapids, Mich.: William B. Eerdmans Pub., 1998), 239} Such organisational cultures, which are often secular and empirical in character, may also conflict with the religious perspective of pastoral care, though this will depend upon the particular institutional context and the pastoral relationship.\footnote{Ibid, 61} Pastoral care in such circumstances treads a fine line, seeking to balance support oriented toward the empowerment of careseekers so that they can be agents of change, against the offering of care which provides support and guidance in adjustment towards the existing situation.\footnote{Pattison, 99} Although embracing the notion that pastoral care is empowering at its core, it must be recognised that there will inevitably be times when it is incumbent upon the carer to step in to advocate on behalf of another. When a pastoral carer adopts a highly individualistic approach, or ignores the impact of social structures upon the wellbeing of the careseeker, the capacity to formulate a meaningful care response and support can be severely impacted. On the other hand, there is a risk for carers who are part of the system, or of the care team, that they might become linked too strongly to the status quo, thus compromising their capacity for care,\footnote{Freire, 48} and setting up internal conflicts for the carer. In the face of unjust or unhealthy social structures, the way forward is not to ‘integrate’ careseekers into the structure of oppression, but to partner them in action to transform that structure so that they can become ‘beings for themselves’.\footnote{Carroll A Wise, The Meaning of Pastoral Care, with Revisions and Additions by John E Hinkle Jr ed. (Bloomington: Meyer-Stone Books, 1989), 17}

Carers must be good listeners\footnote{Leech, Spirituality, 21} – the most important aspect of caring – without which a carer leaves the other alone,\footnote{Eugene Gendlin, “Client Centred Therapy: A Current View,” in Innovations in Client-Centred Therapy, ed. David A Wexler and Laura North Rice (New York: John Wiley and Sons, 1974), 215} and without which carers are unable to discern the invitations to care which are expressed.\footnote{James D Whitehead and Evelyn Eaton Whitehead, Shadows of the Heart: A Spirituality of Painful Emotions (New York: Crossroad, 1996), 180} It is easy to turn a hurt person into a stereotype or a caricature, rather than to truly encounter them in their pain.\footnote{C W Brister, Pastoral Care in the Church (New York: HarperSanFrancisco, 1966), 56} To understand what another is feeling/thinking/questioning in the circumstance requires that we truly hear them, else we inevitably impose our own interpretation of the situation and insert our own answers. When we do so we have failed to take the first step of caring – to meet the other in their space. Wise asserts that the basic problems of pastoral care stem from an attitude whereby carers stand back at a safe distance and verbalise a message.\footnote{Carroll A Wise, The Meaning of Pastoral Care, with Revisions and Additions by John E Hinkle Jr ed. (Bloomington: Meyer-Stone Books, 1989), 17} Carers offer themselves first and foremost – not giving faith, hope, assurance, and comfort to people, but seeking to provide the condition within which the other person is most likely to experience one or
more of them, something which is most likely to occur when a carer understands the person to the point where they are able to reflect that understanding back accurately.\textsuperscript{51} To be a good listener requires a humility which prevents the carer from stepping into an omniscient position where it is assumed that one definitively knows what reality is in a given situation for a particular person.\textsuperscript{52} Instead carers are called to exhibit a compassion which asks us to go where it hurts, to enter into places of pain, to share in the brokenness, fear, confusion and anguish. Compassion challenges us to cry out with those in misery, to mourn with those who are lonely, to weep with those in tears. Compassion requires us to be weak with the weak, vulnerable with the vulnerable, and powerless with the powerless. Compassion means full immersion in the condition of being human.\textsuperscript{53}

To be truly attentive to another, carers must develop a healthy and realistic understanding of themselves, and be familiar with their own voices. The practice of active reflection by pastoral carers, both in their role as carer, and in their wider setting as a human being, enables carers to identify when their own needs are being surfaced in a caring relationship, such that they are able to discern them from the needs of the person for whom they are reaching out in care. The capacity to listen to another is enhanced when we understand our own voices. Active engagement in personal reflection on their conduct as a carer, and their own identity as an individual, enhances the carer’s capacity to care, enabling a carer to help another find their own voice for their struggles, which is itself an important step in restoring hope.\textsuperscript{54} Such reflection by the carer is undertaken against the normative horizon of scripture and tradition, and in the context of Christian community, and recognises the interactive nature of care and the impact on the carer. In the Western cultural context, where relationships are shallow, transient or a series of brief encounters, pressure to shape a meaningful message increases as the availability to the person delivering the message is diminished – presence with the other in suffering is exchanged for a honed and well-delivered message. The practice of reflection by the carer serves to increase the available presence of the pastoral carer in the care relationship, and affirms the realities of formation, growth and change for both the pastoral carer and the careseeker. It is a demanding yet necessary task to transcend the values, biases and convictions that form our own cultural contexts in order to fully attend to the needs and circumstances of those to whom we offer ourselves in care.\textsuperscript{55}

Creativity and flexibility are two important aspects of the carer’s character. Given the myriad metaphors available to describe the ways in which a pastoral carer might engage with another in a

\textsuperscript{51} Switzer, 28-9
\textsuperscript{52} Lester, 86
\textsuperscript{53} H J M Nouwen, Compassion: A Reflection on the Christian Life (New York: Doubleday, 1982), 4
\textsuperscript{54} Whitehead and Whitehead, Shadows of the Heart: A Spirituality of Painful Emotions, 168
\textsuperscript{55} Augsburger, 24
care relationship, and equally diverse means available to a carer in formulating their reflection, a carer needs to be somewhat of an artist in shaping their caring relationship and forming their care response. The pastoral image of the wise fool reflects the risk-taking inherent in formulating nuanced care relationships and strategies. The nature of pastoral care as being there to and for the other embraces the mystique of human identity which can only be uncovered in relationship. Thus pastoral carers must take risks in seeking to know and be known, appreciating that the way of naming our emotions is fraught with peril. We frequently fool ourselves by assigning the wrong name to our emotion, or by naively believing that simply naming a mood brings its cure. Yet we cannot abandon the search for names, which is the only way through the thicket of emotion. Humbly, allowing for mistakes and self-deception, we continue to name the feelings that surge through us because naming our emotions makes us less their victims, even as we surrender the fantasy of becoming their masters. By gradually surfacing these feelings, we see what we must do, but such discovery only comes through being prepared to let the words of the circumstance be formed through experimentation and reflection.

The skilled pastoral carer requires at least these three skills:

- An ability to articulate their own assumptions, values and biases;
- An ability to develop and elicit an understanding of the other person’s world-view; and
- An ability to develop appropriate intervention strategies and techniques, with particular attention to beliefs, attitudes, knowledge and skills,

knowing that the personal costs of pastoral care are potentially high, both in terms of the emotional demands of the task and the intellectual and spiritual requirements. It is a demanding task to fully attend to the other, whilst seeking to incarnate the love of God in often unfamiliar contexts. Carers must develop a capacity to utilise and integrate insights from different fields and offer them in care to another, whilst retaining their capacity to theologically reflect upon their actions in relationship.

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56 Augsburger articulates 11 different metaphors for understanding the carer’s engagement: Ibid, 348-368
57 Graham, Walton, and Ward, *Theological Reflection*, 13-14
58 This image has a long gestation originating with Heije Faber, *Pastoral Care in the Modern Hospital*, trans., Hugo de Waal (Philadelphia: Westminster Press, 1971), and re-developed by Campbell, *Rediscovering Pastoral Care* then by Capps: Donald Capps and Don S. Browning, *Pastoral Care and Hermeneutics*, Theology and Pastoral Care Series (Philadelphia: Fortress Press, 1984), 76, and again in Donald Capps, *Reframing: A New Method in Pastoral Care* (Minneapolis: Fortress Press, 1990). A helpful introduction to the development of this imagery through these authors is provided in Robert C. Dykstra, *Images of Pastoral Care: Classic Readings* (St. Louis: Chalice Press, 2005), chapters 8-10.
60 Adapted from C Lago and J Thompson, *Race, Culture and Counselling* (Buckingham: Open University Press, 1996)
Community Context

According to Patton, the *communal contextual* paradigm insists that there are multiple contexts to be taken into account. In choosing to explore the contexts of *race, gender, power, problem,* and *morality,* Patton avoids exploration of contexts which are directly related to physical place. Whilst acknowledging Patton’s broader contexts at work in the NICU, and having already addressed the issue of power elsewhere, there are more immediate concerns of context to consider in relation to care which are directly related to place. A parent in the NICU experiences at least three contexts as part of the journey as a parent of a premature infant: the home and family life before birth, the NICU context during hospitalisation, and the post-discharge family context into which they are reinserted. These three broad areas depict the web of relationship connections which are the ultimate source of disconnect for parents.

In what has already been highlighted in this reflection on the current care providers also underscores the greatest weakness in the present system: a nurse or number of nurses will invariably develop the closest relationship with the parents in the hospital, yet their care is limited to a single context. The addition of case managers and social workers to the care structure in the hospital is a response to the recognition of the importance of relationship to the efficacy of care provided, but still confines the largest part of its work within the hospital setting, without giving due attention to the fullness and complexity of context for the parents, for whom the impact of the experience is not limited to the hospital setting. The immediate context is the one which for the parent bears the heaviest emotional investment from the onset – the NICU. It is here that the focus remains for the time of hospitalisation, ostensibly without consideration by parents or hospital with regard to the impact on the parents’ connection to other contexts. It is this narrow focus which contributes to the depth of struggle faced in the longer term and contributes to the parent experience of dislocation. While parents are heavily invested in an intense emotional and spiritual journey within the hospital, other members of the family context are largely ignorant of and disconnected from the experience. Though parents are discharged from the hospital context they remain profoundly impacted by its values and practices, and in their continuing perspective and thinking, while the wider family has largely sustained the perspectives and values which characterised the pre-birth experience – which the parents once shared quite readily. Whilst acknowledging the particular nature of the hospital

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61 Patton, 40
62 Gender issues need further exploration, given the different ways in which fathers and mothers appear to attend to grief in times of loss, and the preponderance of female voices in our primary source material over against the much more muted male voice; see Tony Walter, *On Bereavement: The Culture of Grief* (Buckingham: Oxford University Press, 1999), 178; C M Parkes, *Bereavement: Studies of Grief in Adult Life*, 3rd ed. (London: Routledge, 1996); and V Thomas and P Striegel, "Stress and Grief of a Perinatal Loss," *Omega* 30, no. 4 (1995) Issues of race aren’t able to be explored from our source material.
environment and giving it due consideration in developing an approach to care, it must be affirmed that parents’ actions in this context are not indicative of their overall perspectives or of their responses within other contexts.\textsuperscript{63} In order to pastorally care for parents of premature infants, there is a need to define and construct a practice of care which recognises the existence and interrelationship of the various salient contexts, knowing that failure to fully understand the parental world or to somehow enter into their life as if we were in some sense living it, we cannot truly care and most effectively act for their well-being.\textsuperscript{64}

This is one of the most critical and complex of issues in relation to prematurity, given the multiple contexts to be considered. I have already identified three different contexts for parents in the journey of prematurity: the home context prior to the birth, the NICU context during hospitalisation, and the home context post-discharge. By home context, I am not limiting interpretation just to the factors inside the home, but to the complex web of relationships which the home represents: a social centre through which the parents relate with wider family and community. To these we could potentially add work, school and other social contexts, but for the sake of this reflection, the symbolism inherent in the three primary contexts will suffice. It is this transition across contexts which epitomises the critical issues of dislocation which parents experience as a result of the journey, whereby they lose the social connections with their pre-birth context as a result of being enculturated into the perspectives of the NICU community.

It is here that the pastoral ability to take initiative and be proactive is valuable – pastors have access which other health professionals do not.\textsuperscript{65} This privilege not only gives the pastor ability to engage outside the hospital turf, but also when either the critical moments haven’t yet arrived, or the initial distress has passed.\textsuperscript{66} Pastors have the capacity to cross boundaries in ways that few others have permission to undertake. While recognising contextually-defined demands, a pastor is attuned to issues related to integrity and wholeness – accustomed to reflection upon the dialogue between the broader landscape of a person’s life and the particular settings in which their lives unfold. The pastoral perspective not only considers the lateral landscapes – those which exist contemporaneously for each person – but also the longitudinal perspectives reflecting the life narratives which inform and unfold for each individual and family, and the particular ways in which contexts, relationships and experiences have served to nurture and shape them into the present and

\textsuperscript{63} Kirkwood, 95
\textsuperscript{64} Switzer, 18
\textsuperscript{65} Paul Pruyser, \textit{The Minister as Diagnostician} (Philadelphia: Westminster Press, 1976), 25
\textsuperscript{66} William B Oglesby, Jr., \textit{Biblical Themes for Pastoral Care} (Nashville: Abingdon Press, 1980), 54
indicatively into the future. These two perspectives are interwoven with the spiritual – the deep identity and purpose which calls us into being and ultimately forms and informs us.

It is this combination of lateral, longitudinal and spiritual which calls the pastor not only into care for individuals within systems, but also for the systems themselves. For a pastor to allow a context to continue practices which harm those it intends to support without challenge would be to avoid a responsibility of care. There is a balance to be negotiated between the call to supplement the care of the NICU community (which is now fundamentally focussed upon the child) by extending care to the parents, consequently reshaping the NICU community such that its care is more embracing of the family and its full contexts, and the call to frame care in ways which recognise the connections between this community context and the home, familial and societal context of the parents in constructive and reconciling ways. The difficulty of the second task is evident in its complexity.

A savvy power structure knows that therapy is always cheaper than social change. A woman spending considerable energy dealing with “her problem” is unlikely to bother the political arrangement. Underlying definitions remain unchallenged; current structures remain in place… In dichotomous thinking we simplify the world, perceiving reality in terms of stark opposites: good and bad, friend and enemy, female and male.\(^{67}\)

A pastor who is attentive to context ought not miss the importance of care for and within that context and concern for its shape and its impact on participants.

It would also be remiss at this point not to identify yet another context which impacts upon the caring relationship: the context of the carer. Pastoral carers are informed, released and constrained by the Christian tradition in general, and the particular community context which has released them for the ministry of care. The concern to be faithful to that tradition and community is at least one aspect for the carer’s ongoing reflection, providing a resource for the practice of care and the shaping of the carer’s skills and persona. Knowing that “every act of pastoral care has a normative horizon”\(^{68}\) and that every pastor is impacted and informed by that horizon is reflected in the carer’s engagement with the context as well as their interpretation of it. While some might see the communal context of the pastor as a liability, given some of the historical issues pertaining to the tradition, the pastor who serves as representative of a community offers something in the care relationship available to no other helping profession: “a supportive fellowship available year-in, year-out, to undergird its work.”\(^{69}\) Pastoral carers must be not only be attentive to the voices of their own tradition, but also to the imagery of and character of God which they seek to represent so that they avoid becoming mere problem solvers or acting as saviour figures.

\(^{67}\) Whitehead and Whitehead, *Shadows of the Heart: A Spirituality of Painful Emotions*, 70

\(^{68}\) Patton, 59

\(^{69}\) Howard J Clinebell, *Basic Types of Pastoral Counseling* (Nashville: Abingdon Press, 1965), 51
A word of warning needs to be sounded here. This study demonstrates the profound impact of context on changing a person’s perspective, thinking and practice. It is the experience of immersion in the NICU, fostered by a high attachment level to its processes and outcomes, which shapes parents’ perspective long after discharge. The NICU context and community is critical to this experience, and must therefore be at the centre of pastoral reflection and intervention. Whilst offering insight into the experience of many premature parents, it is a mistake to assume that an individual’s experience is an exact replica of the summary offered here or of the experience of another individual. To presume to know what a particular parent’s thoughts or reactions to the circumstances at any particular time is to fail to hear them as individuals, and is consequently a failure of care. Pastoral carers must be careful not to absolutise the context or frame hope in relation to a narrow interpretation of the context – they must do more to move beyond a simple focus on merely solving the problem as I have presently framed it. I thus reiterate the importance of the character of the carer as a listener as being fundamental to appropriately understanding the interplay between context and individual.

The communal-contextual paradigm reminds us of the importance of being aware of and paying attention to the contexts which impact upon care for parents. The experienced cultural shift from home to NICU and back to home – exile and return – indicates the need not only for a concern which provides support through the transitions, but one which also provides bridges between contexts, such that return is to a community which is prepared and understanding. This is particularly so for the mother, who is at the centre of care for the child in both the NICU and at home, but less evidently, but without doubt equally important for the father. While the data available to us are scant for fathers, any shift which impacts upon the mother inevitably overflows into the marriage relationship. Apart from any impact upon the father’s worldview, this alone is indicative of the need for intentional support.

**Metaphors for caring**

The functions of pastoral care have been historically defined as concerned with *healing, guiding, sustaining,* and *reconciling.* Clinebell has sought to add a fifth: *nurturing,* with Larney suggesting the additional functions of *liberating* and *empowering.* The latter four functions attend to the communal and dynamic realities facing individuals in order to bring about change in circumstances and structures which stand in the way of developing our full humanity. The ways in which these

70 William A Clebsch and Charles R. Jaekle, *Pastoral Care in Historical Perspective* (Northvale: Jason Aronson, 1975)
71 Larney, 62
functions can be served gives rise to a creative and extensive list of metaphors, amplifying the meaning of pastoral care and facilitating further understanding of the role and function of the pastoral carer. The use of metaphors in describing the carer’s role enables us to “bring together what were previously distinct terms into a new conjunction, representing a disruption of thought and speech: ‘metaphor is thus not so much to adorn everyday language, but also the previous structures of what we call reality.’” Frank and Sontag, in recognising the power of metaphors in healing, warn against absolutising or misusing them. A helpful metaphor in the context of one relationship may be counter-productive in another. It is in the skill and sensitivity, imagination and creativity of the pastoral carer that the appropriate metaphors are recognised or created, and utilised. The use of metaphors for caring also underlines that there are no ready-made answers lying hidden within the tradition. The practice of pastoral care is akin to a dance in which a way forward emerges in the tentative movements and responses which form the pastoral encounter. This is the way in which the Spirit has ever worked through the history of the Christian tradition. Three metaphors emerge as important at this stage of the understanding of parent circumstances among the myriad metaphors available.

- **Pastoral Carer as Exegete/Interpreter**

The first need for a pastoral carer following insertion into a situation is to gain some understanding of what is happening. Pastoral caregivers value each individual’s unique story and seek to hear it without prejudice, knowing that they cannot hope to offer any meaningful relationship unless and until they are able to form some understanding of person and circumstance. Our initial listening, informed by our own professional knowledge helps the carer to form a relationship of understanding and trust which becomes the foundation for care and out of which a shared understanding of the core needs might emerge. Pastoral interpretations can only be tentative, having both the benefit and limitation of being a perspective from the outside, offered to an individual in a care relationship. Gerkin thus envisions the role of the pastoral carer as “interpretive guide,” which is to be understood as more than gaining understanding for the pastor, but functioning as a knowledgeable partner who is through dialogue able to facilitate understanding and therefore empower individuals in their contexts. Gerkin suggests that “the image of pastoral care as

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72 For example, Oden offers nine different metaphors, an initial five: counsellor, physician, guide, liberator, and educator, supplemented with a further four metaphors for dealing with the situational variability: high seas navigator, military logistics coordinator, surgeon, or wrestler in Thomas C Oden, *Pastoral Counsel* (New York: Crossroads, 1989), 48, 117; Augsburger offers eleven metaphors to describe the pastoral relationship: Graham, Walton, and Ward, *Theological Reflection*, 64
73 Frank, *Wounded Storyteller*, 136
74 Sontag, 96-97
75 Graham, Walton, and Ward, *Theological Reflection*, 161-162
76 Paver, 59f
interpretive guidance becomes extremely valuable here. Parents facing the crisis of a birth anomaly need help from their pastor in placing this episode of their lives within the larger framework of meaning of God’s movement in history.”

But I would want to suggest that an interpretive guide offers much more: particularly through the early intense shifts into the NICU setting as parents are seemingly flooded with new technology, new languages, new challenges and new ways of thinking about their newborn. While nurses function as interpretive guides by introducing and explaining the care regime of the NICU, pastoral carers help place the context into a wider framework of understanding, in words and images which can form a bridge between the two different cultural settings which are represented by the NICU and the home.

Religious or overtly theological language is not necessary for this to be spiritually or pastorally significant, nor is the goal to seek certainty. While pastoral care is at one level an expression of theological convictions, these convictions may or may not be verbalised in the pastoral relationship, but serve the important function of informing, motivating and nourishing the carer. The major task of the pastor as interpretive guide in the NICU is to assist parents in visualising the situation in ways which empower them for action, and which enable them to uncover meaning, to build hope and to engage in purposeful action – in short to deliver them from any sense of powerless victimhood by offering and creating (in dialogue) language, imagery and understandings of their circumstance which create new possibilities for action – undertaking what Lyall regards as an important purpose of pastoral care and counselling: “to help people gain a greater understanding of the stories of their lives, to interpret their stories in a new, way, and on the basis of that fresh understanding to find their lives transformed.

As an interpretive guide, the pastor recognises that all human beings engage in interpretation of situations. It is the manner of learning and growth, one which is not limited to those who share within the context of a faith community. The Christian pastoral carer brings the background and insights of the Christian tradition, together with the resources of the therapeutic realm of care to this task. They offer themselves in this role not from a position of authority, but as a servant in dialogue, not imposing their interpretation on the situation, but offering it as a window through which they invite the parents to see afresh. An interpretive guide can utilise a range of techniques in

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78 Gerkin, 113
79 Ibid, 160
80 Pattison, 16
81 Goldsworthy and Coyle, 33
82 Lyall, 50
83 Farley, 11
84 Thomas C. Oden and Don S. Browning, Care of Souls in the Classic Tradition, Theology and Pastoral Care Series (Philadelphia: Fortress Press, 1984), 12-13
order to facilitate understanding. As a paraclete, the pastoral carer comes alongside in the journey, sharing observations and dialoguing with another in order to foster new understandings. This may require the carer to act “as a mirror,” reflecting back so that the individual is able to see themselves more clearly, washing away false self-images which often stand in the way of a clear understanding of the circumstance and their place in it. An exegetical/interpretive role is important for the carer to undertake in order to offer care, and to engage in meaningful care. Offering these insights in the care relationship empowers the individuals in their own diagnosis and response.

- **Pastoral Carer as Story-teller**

  Story-telling is a universal and enduring human phenomenon. Human beings tell stories to make sense of life and to engender connection with others. Families and communities tell stories. Individuals connect themselves into wider groups through stories. The stories that we tell about ourselves and those who are close to us carry our experience simultaneously at several levels – intellectual, emotional, spiritual, and communal. It is through story-telling and conversation that signs of hope in our quest for the meaning of our lives are grounded. When experiences disconnect us from people and places, we are disconnected from the networks and resources which help create and sustain the narratives which shape our lives. In other words, we lose part of the structure which maintains and affirms our identity – people with whom the stories are shared and with whom there is shared meaning. In absence of this framework of sustaining identity, an important caring function is to affirm the story through listening, and to help reconfigure the story and the community which sustains it. Whilst the observation that “suffering’s second and most familiar language is the story or narrative” can be affirmed, we must remember that stories have contexts in which they elicit and express shared meaning. Stories of suffering are told in order to engender connection, to draw a response which builds or nurtures relationships. Being able to form the story is one part of the pastoral challenge. The second step is to connect that narrative with people whose relationship is important enough to sustain these stories, often because that relationship has been important prior to the critical event.

Pastoral care begins with listening for the story, which serves the dual purpose of enabling people to hear their own story aloud (perhaps for the first time), and for the carer to hear it and thus possibly gain a perspective on the multifaceted complexity of their identity. Listening is a core skill in any form of caring, but in this context serves to open up frameworks of shared understanding which

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85 Deeks, 10
86 Ibid, 20
87 Patton, 146
88 Lartey, 72
are grounded in the images and narratives of the individual, something upon which the carer is able to build. These narratives will involve reflection upon past events, observations on the present, and potential future stories. In the critical present, it is likely that all aspects of these narratives will exhibit new tentativeness and expose aspects of grief for that which is regarded as lost, no longer tenable, or no longer possible. To this context the pastoral carer brings a rich vein of biblical imagination – symbolism, imagery and narrative – which can invite participants to see the situation itself, and God in relation to the situation as it is. The temptation towards denial of present realities and towards an escapism which offers to take us out of the situation is always present. It is tempting at times for pastors to seek to minimise the depth of tragedy and despair being faced by the person at the emotional level, and to “let God off the hook” in the face of tragedy and despair at the spiritual level. This is an approach the Psalmists could not allow, even where the implication of God’s complicity in evil was allowed to stand. Their conviction of God’s presence even in times of despair and abandonment was both a focus of grief and a source of hope. It is the carer’s role to function as editorial assistants in the story-making: creating “imaginariaums” to fund creativity. Windquist suggests potential strategies available for exploring future stories: Storytelling; Guided Imagery; "As If" Conversation; Dreams (including daydreams); Free Association; and delimiting pastoral conversation to future tense. The purpose of such exploration is to provide pathways of hope through the valley of trouble – to help fund descriptions of the landscape which both articulate the present turmoil but also open up pathways through to a new future – reshaping and perhaps reconstructing narratives which serve to nurture the parent through this difficult terrain. This must, however, be regarded as only a primary step in the caring process. Stories exist to connect us with others. The pastoral carer must help create platforms where these stories fund renewed connections. It is one thing to tell one’s story of suffering and struggle. It is another challenge to bring one’s community into that story.

An important part of the rebuilding of the narrative to be considered will be exploring the place that parents seek for the expected full-term child who was lost. This will require sensitivity both in determining whether this desire is present, and in the way it is handled vis-à-vis the child who is now theirs. It is one part of the journey in grief through which parents reconstruct and/or reframe their journey in the light of the premature birth.

- **Pastoral Carer as Broker/Bridge-builder**

The most formative experiences for parents of premature infants occur outside of the purview of family and friends – the community which has provided the soil in which key stories have been

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89 Lester, 109f
nurtured, formed and renewed. It is this larger narrative landscape which disappears from the present construct of care, yet which is primary for the parents outside of the hospital. A significant contributor to the isolation felt by parents is this disconnect between their hospital experience and post-hospital perspective and that of their formative community. Given that NICU visitation policies restrict the ability of parents to introduce their community to their experience first-hand, an important function of the carer becomes that of broker or bridge-builder, whereby links are established which enable the parent experience in the NICU to be better understood by their community. Wenger describes the role of a broker as one who is “able to make new connections across communities of practice and enable coordination, and – if they are good brokers – open new possibilities for meaning.”90 In this case, it is shared meaning which becomes the central role of the carer – shared between the NICU parents and their community. Effective conduct of this role may well require shifts in NICU practices related to wider family access, and a greater commitment on the part of members of the wider family networks to be involved in the hospital experience – something which might be difficult to achieve.91 In any case it is important for carers to build bridges between the NICU world (and the parent experience of it) and the parents’ wider community networks in order that steps may be taken towards a shared understanding which provides a ground for articulation of the loss and the expression of grief and pain out of which support and understanding might be found. A pastoral approach which seeks to build a bridge of understanding will enable movement towards a limited socialisation of the experience – at least in key relationships – which provides a greater continuity of community which supports meaning-making. Thus the carer needs to serve as a connector, who is able to introduce others to aspects of the journey.

To adopt the role of bridge-builder will inevitably create tensions with the conduct of the NICU itself, as the parameters for care of parents impact upon the strict bio-medical formation of care practices for the neonate. Concerns about compromise of a safe and sterile environment through the introduction of other visitors, together with concern about greater social interaction on the well-being of the child as measured against biomedical norms will encounter some resistance from a community whose practices and boundaries are well-set and monitored. Acting as a bridge-builder and broker brings political considerations to bear upon the carer, considerations which will vary according to the status of the carer within the hospital community in general and the NICU community in particular. A carer employed within the hospital structure may well be expected to

90 Wenger, Communities of Practice, 109
91 Blank describes the breakdown in ties which occur because relatives find the notion of a child’s mortality to be too threatening: J W Blank, The Death of an Adult Child: A Book for and About Bereaved Parents (Amityville: Baywood, 1998)
support the clinical practices of the hospital first and foremost. One who enters as an “outsider” may be afforded little status or capacity to shape what occurs within the NICU. Such potential personal costs for the carer stand against the cost for parents emanating from the isolation which continues beyond the hospital community. To be a partner and facilitator in building such bridges can become an important aspect of sustaining parents through the NICU journey by nurturing a community of care which crosses the boundaries between hospital and home, which is itself an important step towards healing and hope for the parents. Ensuring that the parents are less reliant on the NICU environment during the time of hospitalisation is potentially liberating and empowering for the parents, without diminishing the emotional connection with what happens to their child.

**Summary**

In many ways the challenges of offering pastoral care to parents of premature infants is emblematic of the challenges of offering care into the changing environment which is the twenty-first century. There is a new language to be learnt, not just in relation to the NICU environment itself, but the language of many parents who have no background of Christian faith. There is a challenge of care for the family in the NICU setting, which may involve support and advocacy, and also leading in cultural transformation within the NICU. Parents who enter a NICU speak many different languages reflecting the various contexts of their lives, and carry a variety of images. The pastoral care role at the personal level is to listen for whispers of grace in these images which might help parents make sense of their circumstance and empower them in retelling and restructuring their own stories in the light of the experience of premature birth. In extending the language and imagery available to parents in the journey, pastoral carers can be partners in empowering parents in an otherwise foreign and intimidating circumstance. This will, however, require carers who are able to hear the messages of their own traditions in new language, and to visualise these messages incarnated in new contexts – in dialogue with parents.

Carers will need flexibility across a range of skills and an integrity of character in order to negotiate a complex emotional, social and spiritual journey. Lives change when “new people open new worlds to us that transform the quality of our consciousness.”\(^\text{92}\) It is part of the carer’s role to be such people to NICU parents, something which places carers themselves at risk of being misunderstood – of being wounded\(^\text{93}\) – in many ways.

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There is also the continuing challenge of attending to a multiplicity of contexts and focii which will shift with the varied challenges to be faced along the journey. There will be times when the measures and challenges remain focussed around the development of the neonate, and other times when there are clear implications about the nature of the challenge ahead for parents and the wider family network. Pastoral carers will need to be attentive to this variability of contextual struggle.

One final point needs to be made about the direction of care: the clock cannot be turned back. One can’t “return to normal” after many experiences of premature birth – but we remind ourselves that the moment of crisis is also a moment for potential growth.⁹⁴ There may well be enduring tensions for both parents and carers at the primary care level, and the wider community context(s). But while the child remains hospitalised, and the context is framed in, through and around the NICU, carers need to be sensitive to other related issues which may emerge.

⁹⁴ Wise, 71
Chapter 11

Recommendations

Though the focus of pastoral care in the previous chapter remained primarily upon the relationship between the carer and the parents, I would be derelict in my duty of pastoral reflection not to bring some recommendations about the overall care for parents who experience premature birth. Given that the number of premature births in the community is significant (approaching one in seven on some measures), some broad recommendations can serve to facilitate a more life-giving and life-affirming journey for all concerned. This project brings six key recommendations towards improving the overall outcome for parents and families:

1. Socialising the experience
2. Providing dedicated pastoral care staff for parents
3. Embracing the Family in the NICU
4. Better Preparation
5. Improved Transitional Arrangements
6. Further investigations

1. Socialising the experience

Premature birth has been somewhat of a “poster child” for developments in health care, publicising the way in which it has turned what would otherwise have been still-births into delivery of a live child into the grateful arms of parents. The attendant publicity has masked the deep struggles endured by many parents during the hospitalisation phase, and the continuing uncertainty about outcomes and developmental milestones which the vast majority of extremely premature infants face. Whilst the feel-good experience might be somewhat diminished by greater exposure of the realities, it will potentially create a climate of better understanding about the experience, and engender some compassion towards parents who travel the journey of extreme prematurity. Socialising the experience through more realistic reporting of stories through the media acknowledges and validates the parent experience without taking away from what the medical care has brought about.

In addition to socialising the experience at the community level, attention should be given to socialising the experience for the family of the premature infant by enabling and facilitating better access for wider family and by providing for a greater degree of informal interaction/stimulation.
between the baby and its family. While there may be clinical reasons to limit or reduce access to the NICU, there are social reasons why parents need to bring significant others along with them for the journey. Through socialising the experience in this way, the levels of support and understanding for parents in their home community are improved. The medical perspective might consider the risks of a more stimulating environment for infants as counter-productive in the short term, which needs to be weighed against the emotional-social development of the child and the building of relationships with the family in the medium term. The social aspect of every pregnancy and its impact on formation of the child needs to be acknowledged and embraced.

The rather unwieldy term oft-used in this thesis to describe “parents of a premature infant” reflects in many respects a clear ambiguity around the experience and a lack of language to identify the unique place occupied by parents in the journey. Though I considered many different terms to shorten this, I was unable to identify a descriptor which seemed adequate. The term ‘premparent’ is one which might offer such parents a succinct nomenclature for noting the unique challenges to be faced. The development and usage of such a term gives language to the social domain which draws attention to the different pathways which life before those parenting a premature infant.

2. Providing dedicated pastoral care staff for parents

The appointment of dedicated Pastoral Care workers/Chaplains to the NICU is an important step in broadening the care framework for parents, and structurally integrating them into the care practices of the NICU. Care should commence with families around the time of birth to provide support in decision-making under high stress and high uncertainty, working in conjunction with medical staff to help address the myriad questions which contribute to the confusion around the time of birth. Pastoral carers are able to offer time to parents in an otherwise pressured context, bringing a broader framework of understanding and a perspective which is informed by but not limited to the clinical challenges. During the course of the NICU stay (and until discharge), these carers would work in conjunction with social workers, case managers and hospital staff to facilitate access to medical information and to facilitate parent involvement in care for their child, whilst at the same time addressing the questions relevant to context, formation, grief, family and communal relations. It is important that such care appointments be structured with a formal reference group outside of the hospital setting so that the carer’s formation and perspective is not limited to the internal political arrangements in the hospital. Such accountability also provides for pastoral carers to extend care into the home and family settings outside the hospital while retaining levels of accountability which are accustomed to such interaction.
3. Embrace the Family in the NICU

Whilst many NICUs are organised around similar principles to adult Intensive Care Units, there has been some moves toward arrangements where babies are housed in individual rooms which allow the family context to be more firmly established. This needs to be encouraged and extended as a uniform practice of care, allowing the family private space which can be decorated to reflect the family’s identity and character. The space for each child should allow room for parents to bring some muted “social noise” into the space which offers potential for the infant to grow socially as well as physically during their hospitalisation. What is suggested here is more than just the noise which could be provided by a radio, but the voices, emotions and interactions of family members, together with some of the sights and smells which accompany them. This might include space for families to share an occasional meal alongside the infant such that there is potential for olfactory stimulation available to the child alongside other neuro-sensory events. There is a balance to be discovered which moves away from the present sterile environment towards one which better recognises the place of the family in the life of the child, and invites some of these aspects of family life into the NICU setting.¹

4. Better Preparation

At this point in history, it seems that preparation for premature birth is limited to the consultation rooms. Pregnancy literature gives little indication of the challenges to be faced, and provides little background for the journey through pregnancy which might help in times of premature birth. This raises the question of the purpose of pregnancy literature: whether it is to inform and alert parents to issues so that they might be better prepared and more ready to engage with and trust the medical staff, or to provide comfort to parents through what is a somewhat uncertain time through pregnancy. Whilst not wanting to create undue alarm, there is a need for parents to have access to better quality information about premature birth and what might be demanded of parents in such an event. Given the significant percentages of births which are premature, and the fact that around 50% of these are idiopathic, more effort to educate parents before the event is warranted. The present literature available for parents significantly under-represents the experience both in terms of space allocated to addressing the issue, and in the way in which the issue is addressed – largely ignoring the impact on the parents.

¹ A recent Scandinavian study provides evidence of the benefits of this approach, although simply embracing the parent-child relationship, it demonstrates beneficial impacts for both the child and the parents in the longer term. Helena Wigert, Marie Berg, and Anna-Lena Hellstrom, “Parental Presence When Their Child Is in Neonatal Intensive Care,” Scandinavian Journal of Caring Sciences 24 (2010)
5. Improve Transitional Arrangements
The shift from the NICU to a level 2 nursery is more than a transition in care arrangements for the child, it is a significant social and emotional shift for parents which can be a critical time for them. Similarly the moment of discharge, while long-anticipated, can be deeply disconcerting for parents, as the child who once required a team of medical specialists to watch over their well-being is now solely in their care. These times of transition mark a deconstruction of levels of care which provide security and comfort for parents, even though parents long for them to end. The availability of pastoral carers, social workers and case workers can be helpful to parents in times such as these, so long as the carers are aware of the ways in which these transitions can unsettle parents. Some of this dis-ease can be alleviated by the recommendations already outlined, as the experience would not be so isolating if members of the wider family are available through the journey, and the extension of pastoral care into the home has been successful in garnering support and understanding from within the parent’s community. Introducing parents to staff who will remain contact points for them during the step-down phases of care in hospital, and who will be available after discharge would also help the transitions the journey.

6. Further Research
This project was initially conceived to look at the impact on families, but the breadth of material available for the parent experience required that it be pared back. The generic nature of parenthood in this research must be acknowledged, the predominant voices being those of the mother. Further research is required to gain an insight into the experience of fathers, and to consider the impact on any siblings. The attendance of parents to a hospital setting for an extended period must create an impact on the remainder of the immediate family, an experience which still needs to find a voice.

Conclusion
The care of a neonate and its family is a complex task, requiring attention to a multiplicity of contexts alongside a range of potential physical, social, emotional and spiritual crises. The focus of these recommendations attends to the dislocation and isolation which most parents experience, seeking to garner resources to support parents and to link their journey into the communities which nurtured them in the lead-up to the birth. They offer potential constructive steps towards parent care

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2 For a thoughtful reflection of the ways in which we can interpret male responses through female ones, particularly in the area of loss and grief, see Terry Martin and Kenneth J. Doka, “Masculine Grief,” in Living with Grief after Sudden Loss: Suicide, Homicide, Accident, Heart Attack, Stroke, ed. Kenneth J. Doka (Washington D.C.: Hospice Foundation of America, 1996)

3 An excellent entry point for understanding the impact on siblings can be found in Myra Bluebond-Langner, "Worlds of Dying Children and Their Well Siblings," in Children Mourning, Mourning Children, ed. Kenneth J. Doka (Washington, DC: Hospice Foundation of America, 1995)
which facilitate parent well-being and towards an integration of the experience into their life-settings, so that parents emerge from the experience with greater resilience, a broader perspective, and a range of resources which support them in the long-term task of caring for and parenting their child – supporting parents *qua* parents through the whole journey.
A Personal Footnote

It has been 13 years since the birth of our third child at 24 weeks’ gestation. This project has emerged from that experience as I sought to uncover some frameworks which would help me understand what the experience of the 176 days hospitalisation which our son – Samuel – suffered, and through which my wife and I limped. There have been times when reading the stories of others have brought tears to my eyes, and rekindled memories of experiences which had long been buried. It has in some senses been a cathartic experience, as well as a painful one.

Both my wife and I kept daily journals through that time, keeping record of thoughts, experiences and other events as they unfolded. But I have not been able to employ these at any depth for this project. In the process of writing the last chapters of this thesis, I ventured into my own journal, but could not make it past Samuel’s first week. It exposed me to events which I had forgotten, and awakened me afresh to the distress of our two older children – one (Caleb) just commencing preschool and the other (Rachel) still a baby, only nine months of age when Samuel was born. I could bear only so many tears before realising that my emotional reserves would quickly drain, further impacting upon my ability to complete this study. Once this project is complete, I will dedicate some time and space to read these journals through, aware that my reactions may well trigger deep emotions and renew further questions.

That brief reading did remind me of one of the reasons I commenced this project, which was left to one side – the impact upon the siblings. Our children’s distress – or at least my observation of it – together with my own sense of conflict in attending to the needs of all of our children – will be a continuing ache, even though they no longer recall it. The overall experience has left its mark upon them in other ways.

Samuel has greatly exceeded the prognosis given to us around the time of discharge, but continues to face some significant challenges. His future remains open, and ours forever linked with him.
Appendix
Summary of Source Materials

Process of Sifting and Labelling Primary Data

The email archives were read in chronological order from the list’s first posts in 1996. Individual posts were selected when the theme was subject to recurring expression, or where the sentiments expressed received the general agreement of the list, and were labelled according to the issue identified in the post. Further emails were selected where they added understanding to the issue, or raised a separate issue not already identified.

The first 18 months of reading resulted in the most productive stage of this research, which reached saturation point in the second half of 2003. I have continued to monitor the posts to the list since that time. Over the past three years the number of posts to the list has declined to the point where the list barely functions, due to the inability to attract new members to the list to stimulate the conversation.

The analysis of these posts is demonstrated on pages 273 and 274, indicating how a label with a brief description is applied to the post (which has been coded according to Volume/Section/Page of the primary data.) The entire summary of these emails runs to 60 pages, and is available on request.

On the following page these themes are presented and sorted initially in alphabetical order. The range of issues identified demonstrates the rich resource which the list provides for insight into the experience. Some preliminary analysis endeavouring to group the labels according to type is demonstrated on pages 275-277.
### Summary of Source Material (examples)

<table>
<thead>
<tr>
<th>Page</th>
<th>Description</th>
<th>Category</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>5A/P/10</td>
<td>Ex preemie wants her own copies of hospital records</td>
<td>Preemie</td>
<td>Information</td>
</tr>
<tr>
<td>5A/P/10</td>
<td>Parent hated having to make a choice re life/death (child died on the day this sent)</td>
<td>Choices</td>
<td>Power</td>
</tr>
<tr>
<td>5A/P/11</td>
<td>“As grateful as I am, my heart sometimes still aches”</td>
<td>Grief</td>
<td></td>
</tr>
<tr>
<td>5A/P/11</td>
<td>Fourth anniversary of her due date brings the “what if's” again</td>
<td>Milestone</td>
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<tr>
<td>5A/P/12</td>
<td>24-year-old ex preemie's birthday still affects mum. Wedding plans bring health scare... “I was back at the isolette”</td>
<td>Milestone</td>
<td>Flashbacks</td>
</tr>
<tr>
<td>5A/P/12-13</td>
<td>First birthday reflections. “Bo was born in this day and I was born again... in a sense. I became somebody else...”</td>
<td>Perspective</td>
<td>Milestone</td>
</tr>
<tr>
<td>5A/P/14</td>
<td>Mother's hyperactivity as the first birthday approaches... no one to talk to, so feelings unexpressed. Pictures of husband as a baby opens grief</td>
<td>Milestone</td>
<td>Grief</td>
</tr>
<tr>
<td>5A/P/15</td>
<td>At six years mum now allows herself to dream of the future</td>
<td>Hopes</td>
<td>Grief</td>
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<tr>
<td>5A/P/16</td>
<td>List of common topics raised regarding Prems in later life</td>
<td>Development</td>
<td></td>
</tr>
<tr>
<td>5A/P/17</td>
<td>Celebration! Dad’s first hold (8 days)</td>
<td>Milestone</td>
<td></td>
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<tr>
<td>5A/P/17</td>
<td>Mum enters NICU and baby's name not there on the board... grief!</td>
<td>Grief</td>
<td>Pastoral</td>
</tr>
<tr>
<td>5A/P/18</td>
<td>Coping with death of a child - references and summary</td>
<td>Death</td>
<td>Studies</td>
</tr>
<tr>
<td>5A/P/19-20</td>
<td>Medical conference summary: 1. Behavioural data 2. CP 3. school problems 4. cognitive outcomes</td>
<td>Studies</td>
<td></td>
</tr>
<tr>
<td>5A/P/20</td>
<td>After 12 months the grief from the loss of one twin is greater than the loss of abilities in the other. But which will be harder over time?</td>
<td>Grief</td>
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<tr>
<td>5A/P/20-21</td>
<td>Made a decision not to resuscitate 23 week preemie (after seven years questions still linger)</td>
<td>Choices</td>
<td>Insecurity</td>
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<tr>
<td>5A/P/21-22</td>
<td>“In my own time” - a recounting of grief</td>
<td>Grief</td>
<td></td>
</tr>
<tr>
<td>5A/P/23</td>
<td>Financial pressures in the NICU... live between husband's work and hospital</td>
<td>Financial</td>
<td>Lifestyle</td>
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<tr>
<td>5A/P/23</td>
<td>Nurses’ noting of parental attendance created a pressure</td>
<td>Power</td>
<td>Guilt</td>
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<tr>
<td>5A/P/24</td>
<td>$10,000 saved for car spent on visiting the NICU</td>
<td>Financial</td>
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<tr>
<td>5A/Y2/1</td>
<td>A growing realisation that their daughter might never grow out of her problems... professionals' empathy distant - mother looks for support</td>
<td>Support</td>
<td>Development</td>
</tr>
<tr>
<td>Date</td>
<td>Description</td>
<td>Category</td>
<td>Subcategory</td>
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<tr>
<td>9/2/6</td>
<td>Difficult to bond. “It was like she was a science experiment”… “to this day I still feel like I got ‘ripped off’” (nearly five years)</td>
<td>Bonding</td>
<td>Appearance</td>
</tr>
<tr>
<td>9/2/6</td>
<td>Two documentaries shatter a growing sense of security while the child is in the NICU</td>
<td>Information</td>
<td>Statistics</td>
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<tr>
<td>9/2/7</td>
<td>NICU &quot;saving our children's lives is only half the story&quot;</td>
<td>Pastoral</td>
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<tr>
<td>9/2/8</td>
<td>“Late” preemie Mum still feels ill-treated, given no warning to look for issues</td>
<td>Transition</td>
<td>Development</td>
</tr>
<tr>
<td>9/2/8</td>
<td>RT refers to NICU as 'foetus farm' in front of NICU Mum</td>
<td>Environment</td>
<td>Doctors</td>
</tr>
<tr>
<td>9/3/1</td>
<td>Discharge needs to inform parents of issues…</td>
<td>Transition</td>
<td>Discharge</td>
</tr>
<tr>
<td>9/3/2</td>
<td>Buying clothes a symbol of accepting the child would live</td>
<td>Symbol</td>
<td></td>
</tr>
<tr>
<td>9/3/3</td>
<td>Mum dressed two dolls in preemie clothes as a reminder</td>
<td>Symbol</td>
<td></td>
</tr>
<tr>
<td>9/3/1</td>
<td>Two interpretations of the same data regarding steroid use</td>
<td>Med Advice</td>
<td>Statistics</td>
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<tr>
<td>cf 9/3/3-5</td>
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<tr>
<td>9/3/6</td>
<td>Follow-up studies on the consequences of prematurity</td>
<td>Studies</td>
<td></td>
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<tr>
<td>9/3/8</td>
<td>Dutch study</td>
<td></td>
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<tr>
<td>9/3/9</td>
<td>Did not celebrate the first birthday, rather celebrated &quot;the day he came home... the day he was really ours to keep.&quot;</td>
<td>Milestones</td>
<td></td>
</tr>
<tr>
<td>9/3/9</td>
<td>Celebrated not the first birthday, but the people who got us through the first year</td>
<td>Milestones</td>
<td>Support</td>
</tr>
<tr>
<td>9/4/1</td>
<td>Homecoming was &quot;anticlimactic&quot;. Found a very hard to leave the safety the NICU even though heartily sick of the place.</td>
<td>Dependence</td>
<td>Transition</td>
</tr>
<tr>
<td>9/5/1</td>
<td>Prior to Liam we always envisioned three children but now we just don't know.</td>
<td>Subsequent</td>
<td></td>
</tr>
<tr>
<td>9/5/1-2</td>
<td>Worn out trying to always be in the NICU. Older son neglected, as well as the husband. &quot;I wish we could have held each other more often.&quot;</td>
<td>Sibling</td>
<td>Marriage</td>
</tr>
<tr>
<td>9/5/2</td>
<td>Conflicted - three older children, and one in the NICU following two months prenatal bed rest. Feels like a failure as a mother.</td>
<td>Sibling</td>
<td>Bedrest</td>
</tr>
<tr>
<td>9/5/3</td>
<td>Resources to help older siblings cope</td>
<td>Resources</td>
<td></td>
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<tr>
<td>9/5/4</td>
<td>Catch-22 medical dilemmas to be faced. Parents torn between two less than optimal choices</td>
<td>Choices</td>
<td></td>
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<tr>
<td>9/5/4</td>
<td>Day 64 in the NICU - emotional burnout</td>
<td>Stress</td>
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<tr>
<td>9/5/5</td>
<td>?cost of getting kids out of the NICU</td>
<td>Stress</td>
<td></td>
</tr>
<tr>
<td>9/5/5</td>
<td>Still reliving the trauma three years on. Tired of endless therapy sessions.</td>
<td>EI</td>
<td>Stress</td>
</tr>
<tr>
<td>9/5/6</td>
<td>3½ year old tells his Mum of his birth experience</td>
<td>Preemie</td>
<td>Flashbacks</td>
</tr>
<tr>
<td>9/6/1</td>
<td>Day 103 - still vented. Hard to see babies come in after her and leave before... “Is there anyone sane out there after going through this stuff?”</td>
<td>Coping</td>
<td>Stress</td>
</tr>
</tbody>
</table>
A total of 96 themes were identified and labelled from the selected posts

<table>
<thead>
<tr>
<th>Themes/Ideas Identified</th>
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<td>Access</td>
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<td>Bedrest</td>
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<td>Birth</td>
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<td>Bonding</td>
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<td>Celebrations</td>
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<td>Choices</td>
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<td>Connecting</td>
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<td>Continuity of care</td>
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<td>Coping</td>
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<td>Death</td>
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<tr>
<td>Decisions</td>
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<tr>
<td>Dependence</td>
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<td>Depression</td>
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<td>Development</td>
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<td>Discharge</td>
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<td>Disempowerment</td>
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<td>Doctors</td>
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<td>Dreams</td>
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<tr>
<td>Early Intervention</td>
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<td>Emotions</td>
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<tr>
<td>Environment</td>
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<td>Ethics</td>
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<td>Expectations</td>
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<td>Faith</td>
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<td>Family</td>
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<td>Fear</td>
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<tr>
<td>Feeding/Feedings</td>
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<tr>
<td>Financial</td>
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<td>Flashbacks</td>
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<td>Follow-up</td>
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<td>Grief</td>
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<td>Group</td>
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<td>Guilt</td>
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<td>Hope</td>
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<td>Husband</td>
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<td>Induction</td>
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<td>Infertility</td>
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<td>Information</td>
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<td>Insecurity</td>
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<td>Inspiration</td>
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<td>Isolation</td>
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<td>Journal</td>
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<td>Labels</td>
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<tr>
<td>Language</td>
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<tr>
<td>Lifestyle changes</td>
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<tr>
<td>List Profile = Group</td>
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<tbody>
<tr>
<td>Marriage</td>
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<td>Media</td>
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<td>Medical</td>
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<td>Medical Advice</td>
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<td>Medical Staff</td>
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<td>Memory</td>
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<td>Milestones</td>
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<td>Myths</td>
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<tr>
<td>Name</td>
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<tr>
<td>Nurses</td>
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<td>Outcomes</td>
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<tr>
<td>Pain</td>
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<tr>
<td>Pastoral</td>
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<tr>
<td>Peace</td>
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<tr>
<td>Perspective</td>
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<tr>
<td>Poems</td>
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<tr>
<td>Post-Discharge</td>
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<tr>
<td>Power</td>
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<tr>
<td>Preemie (ex-preemie’s perspective)</td>
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<tr>
<td>Preparation</td>
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<tr>
<td>Privacy</td>
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<tr>
<td>Questions</td>
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<tr>
<td>Readmission</td>
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<tr>
<td>Rehospitalisation</td>
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<tr>
<td>Relating</td>
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<tr>
<td>Repeat (do it again?)</td>
</tr>
<tr>
<td>Resources</td>
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<tr>
<td>Response</td>
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<tr>
<td>Return visits</td>
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<td>Rituals</td>
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<td>Sibling</td>
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<td>Social</td>
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<td>Social Worker</td>
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<td>Song</td>
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<td>Success</td>
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<td>Support</td>
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<td>Surgery</td>
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<td>Symbols</td>
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<tr>
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<td>Values</td>
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<td>Work demands</td>
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These themes were then grouped according to categories utilising a range of grids.

<table>
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<tr>
<th>According to (loose) Chronology</th>
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<tbody>
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<td>Preparation</td>
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<td>Expectations</td>
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<tr>
<td>Induction</td>
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<td>Birth</td>
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<tr>
<td>Information</td>
</tr>
<tr>
<td>Language</td>
</tr>
<tr>
<td>Medical (Advice, Staff)</td>
</tr>
<tr>
<td>Decisions</td>
</tr>
<tr>
<td>Name</td>
</tr>
<tr>
<td>Isolation</td>
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<tr>
<td>Development</td>
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<tr>
<td>Milestones</td>
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<tr>
<td>Feeding</td>
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<td>Transition</td>
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<td>Discharge</td>
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<td>Post-discharge</td>
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<td>Outcomes</td>
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<td>Memory</td>
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<tr>
<td>Readmission</td>
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<td>Rehospitalisation</td>
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### According to Type of Response

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<tr>
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<tbody>
<tr>
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<td>Grief</td>
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<td>Poems/Songs</td>
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<td>Readmission</td>
<td>Questions</td>
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<table>
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<td>Feeding/Feedings</td>
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<td>Preemie perspective</td>
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<td>Statistics</td>
<td>Return Visits</td>
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<td>Studies</td>
<td>Sibling</td>
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<tr>
<td>Technology</td>
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</tbody>
</table>

### Support:

- Pastoral
- Early Intervention
- Group
- Resources
- Social Worker
- Medical Staff


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