

‘The Interstellar Cold’: Parents’ Experiences of Their Child’s Palliative Care

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Dedication

This Report and our continuing research into paediatric palliative care is dedicated to the memory of some very special children and to their parents who shared their stories with us.

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- ◆ to the South Australian Health Commission Palliative Care Program who saw the value of this study, awarded us the necessary funding and made the administration and use of the Grant so unproblematic.
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- ◆ And most importantly, to the parents who took the time to discuss their experiences with us.

Notation Used Throughout Report

All taped interviews were transcribed verbatim. Grammar and expressions, were not 'corrected'. Each interview was proof-read following transcription for any errors or omissions which were then corrected. Facilitative sounds such as 'Uhuh' or 'Mmm' and hesitations such as 'err' or 'um' were not usually transcribed but words/phrases such as 'I see' or 'right' were.

Quotations from participants interviews are indented in the text of the report as follows:

The speakers are identified at the beginning of the quote as either **Mother:** or **Father:**

Following quoted passages; (Int. #1, p.72) indicates the relevant interview number and page numbers. Oncology / non-oncology denotes the child's general diagnostic classification. Home / hospice / hospital indicated the child's place of death. Home / hospital indicates one child who died while being transported from home to hospital.

Where a section of interview has been omitted by the researchers a bracketed ellipsis is used (...)

Where there is a natural pause in the conversation an unbracketed ... is used and repeated to denote the comparatively longer duration of a pause

AH: Amanda Haller, Research Assistant on this study and the interviewer of the parents

Bold text: Indicates the authors' / researchers' emphasis

Italics text: Within a quote indicates participant(s)' emphasis

Underlined Italics: Within quotes indicates a 'double emphasis'

(laughter), (crying): Indicates participants' behaviours during interview where this was deemed important to understanding

[comments]: Comments in [square brackets] are the researchers' explanatory notes

To preserve anonymity and confidentiality, all names used in this report for parents, children, friends, and professionals are pseudonyms.

1. "The Interstellar Cold"

1.1 *Introduction*

The death of a child is such a violation and disruption of everything in a parent's world that it seems beyond all comprehension. The poet Seamus Heaney writes of a child's death being "like a moment of exposure to interstellar cold" (Roy 1996). This is the cold chill of icy "soul pain" (Attig 1996), of numbing loss which admits no possibility of regaining warmth and comfort, the cold which seems as if it will forever hold a family in the grip of a suspended animation of loss and grief.

Palliative care services have developed throughout the world in order to help both the dying and their families. Palliative care is premised upon the knowledge that while there may be 'nothing more that can be done' in a curative sense, there is still a great deal which should be done. As the World Health Organisation definition of palliative care states:

[It is] The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. (Davies and Steele 1996)

There is some interchangeability between terms such as 'Palliative Care', 'Terminal Care' and 'Hospice Care' within both the literature and palliative care Services. In this report we use the term palliative care to highlight the purposive and positive nature of palliation and also because palliative care does not necessarily imply an imminent death.

1.2 *Paediatric Palliative Care Services and Parents' Experiences*

Adult palliative care services have developed more comprehensively than palliative care services for children and their families. Researchers have suggested that this is not simply because fewer children die than adults, but because the dying and death of a child can be so much more emotionally laden and clinically demanding (Judd 1995; Frager 1996; Goldman 1996; Liben 1996).

The International Work Group on Death, Dying, and Bereavement (1993) produced a position statement on Palliative Care for Children which asserts the importance of a palliative care service for all children and their families. They argue that this service should be:

An individualised, coordinated system of health care which provides continuity of services between the hospital, the home and the community [which] must be developed as soon as feasible after diagnosis.

(International Work Group on Death, Dying, and Bereavement 1993)

They also state that:

This coordinated system must be maintained throughout the illness and death, with follow-up support for family members after death. It is mandatory that this system of care be made accessible to all children and their families regardless of race, sex, culture and/or ability to pay. The system of care must be flexible in providing services in the community, the home, and the hospital. (International Work Group on Death, Dying, and Bereavement 1993)

Previous research has shown that while almost all bereavement is painful, the loss of a child is especially traumatic for parents (see eg, Rando 1986; Arnold and Gemma 1994; Jacob and Scandrett-Hibdon 1994; Thomas 1994). It appears that general features of loss and bereavement are intensified for these parents while recent studies of parents' experiences within the health care system continue to show that a common complaint of parents in respect of professionals is that "no one really understands what this is like" (Darbyshire 1994).

Locally, recent South Australian reports (Ashby, Kosky et al. 1989; South Australian Health Commission 1995) have highlighted the considerable palliative care and bereavement needs of families who have lost a child, yet who may not be receiving the support and care services which can best help them through this immensely painful and traumatic time. It was acknowledged in this 1989 report that "A study of parental needs and patient needs should be done as a matter of urgency (Ashby, Kosky et al. 1989). Such an expressed need for research into this particular area of paediatric palliative care was echoed by The International Work Group on Death, Dying, and Bereavement who concluded their position statement on Palliative Care for Children by noting that:

Experiencing the final stage of life-threatening illness profoundly affects the child and family members; the child's death has long term implications for surviving family members. The scarcity of empirical study of these experiences dictates the need for continued research which focuses on exploring, from a cross-cultural perspective, how the ill child and individual family members experience the progression of the illness, the threat, and the reality of death. (International Work Group on Death, Dying, and Bereavement 1993)

This research study has begun to address this concern in relation to parents' palliative care experiences through systematic qualitative inquiry, an approach with an established tradition in child and family health research (Bernheimer 1986; Darbyshire 1994; Fitzpatrick and Boulton 1994; Baum 1996)

and an approach which is being increasingly used in palliative care research (Clark 1997).

1.3 *The Aims and Purpose of this Study*

The rationale behind this study is that it is essential for professionals to gain a deeper understanding of the experiences of the parents of a dying child in order that they may plan and provide the most valuable, responsive, sensitive and appropriate services to meet their needs. The broad aim of this study is to provide a parent-focused, experiences-based foundation which will help to inform the initiation and development of an integrated hospital and community paediatric palliative care and bereavement service.

The specific aims of the study are:

- To provide a detailed and faithful interpretive account of the palliative care experiences of parents who have lost a child.
- To provide a detailed insight into parents' perceptions of existing palliative care support services.
- To ascertain and articulate the nature of the supports and services which parents themselves believe would be most valuable and helpful for them at this time.

The main purpose of the study is to provide valuable insights into the understandings and experiences of bereaved parents themselves. It is also intended to highlight parents' perceptions of the current state of palliative care and bereavement care provision within South Australia.

Such an exploration and explication of parents' experiences is important in order to:

- Improve current professional understandings of the experiences of bereaved parents, particularly in respect of service provision.
- Inform current and planned professional palliative care educational initiatives and programmes.
- Plan and provide genuinely 'consumer-focused' paediatric palliative care services.

1.4 *The Research Approach and Methods*

This study takes a qualitative and interpretive approach to the central research issues of the experiences and perceived needs of bereaved parents who have been closely involved in providing palliative care for their child. A qualitative design was selected as the most appropriate approach to answer the research question, "What are the palliative care experiences of parents whose child has died?". As Baum (1996) notes, a qualitative approach to needs analysis is particularly valuable for discovering and understanding the meanings of social events and practices and the perceptions and actions of

individuals. Qualitative methods are widely used in paediatric health care and palliative care research as they have considerable strengths in enabling researchers to uncover and interpret the many ways in which people make sense of their experiences related to health and wellbeing and in showing how these experiences influence perceptions of needs and available or desired services.

1.4.1 Selection and Recruitment of Study Participants

The selection of the study participants was a necessarily flexible process which combined the need to find participants with the expressed aim of exerting no pressure upon individuals to participate. The strategy of selecting only 'key informants' was rejected for several reasons. The very term suggests that there are other participants who may be 'non-key informants' and such a presupposition was contrary to an exploratory and discovery spirit. More practically, there was little way of knowing who would prove to be the 'best' parents during interviews. A further danger inherent in the key 'informant' strategy is that 'key' may be assumed to be synonymous with articulate, extrovert or with those who seem to have the most dramatic accounts to offer. The term 'participant' is used throughout as this conveys more of the spirit in which parents and researcher(s) related in this study while also avoiding the unfortunate 'spy' or 'betrayal' connotation which 'informant' suggests.

Sampling in qualitative research is directed at finding information-rich cases rather than towards randomisation and generalisability. Participants were therefore selected to ensure inclusion of parents with experiences relevant to the central study phenomenon ie., that they had participated actively in the palliative care of their deceased child. Participants were invited to take part in the study who had direct experience of the phenomena being studied, who were willing to participate in the study and who were willing to discuss and describe their experiences related to their child's palliative care. [See Appendix 1, Letter inviting parents to participate in the study]

Participants were sought who had experienced the death of their child within the last five years. This criteria was introduced in order to keep the study manageable and to obtain accounts from parents who had more recent experience of palliative and possibly of current service provision.

It is common in qualitative studies for no specific sample size to be stated at the outset, but a total of ten interviews would be considered by most qualitative researchers to be an adequate data set for an exploratory study of this scale. Qualitative sampling does not claim 'representativeness' but it was important in this study to sample for variety across the phenomenon of palliative care experiences. For this reason we interviewed a mixture of six 'urban' families living within a 25km radius of central Adelaide and four more 'remotely located' families living between 25-100km from central Adelaide. Participant families were accessed following consultation with individuals working in a variety of settings responsible for the provision of services to sick children and their families.

1.4.2 Characteristics of the Participating Families

Of the ten families, six of the children who had died were children who had cancer and four were non-oncology patients. It was important to include 'non-oncology' families to counter the imbalance noted by Goldman (1996), where "there is a relative neglect of palliative care in diseases other than cancer, both in clinical practice and the literature". All ten families were 'two-parent' families. The children who had died were five girls and five boys, aged between one and sixteen years old, one was an only child, six were survived by one sibling and three by between two and seven. Two families had experienced the death of a child prior to the death of the child who was their focus during this study, and these same families were preparing for the death of subsequent children.

1.4.3 Obtaining the Interview Data

In-depth qualitative interviews were conducted with each parent(s). The parents were invited to discuss their experiences either individually or together as a couple. Of the ten interviews, seven were with both parents together, while three were with the mother only. These interviews were akin to natural, informal conversation which allowed the participants to speak freely about **their** most salient issues and perceptions. The interviewer did not have a prescriptive interview schedule as an interpretive 'openness' was essential here. They did however have generative or trigger questions related to the central research question.

The interview would usually commence with a very 'focused but roomy' question which would allow the parent(s) to begin to tell their story; a question such as "Would you like to start at the beginning and tell me about John's initial illness and / diagnosis?" Other questions such as, "How did you feel about being involved in making decisions such as when to stop treatment?", "Was there anything that was important to you throughout the palliative care period that you'd like to tell me about?", "What were the sorts of things that John didn't like?", "Can you tell me about the types of things that you appreciated?" "Did you have support during the palliative care period?" "Can you tell me about some of the aspects of everyday living that might have been difficult at this time?", "Can you tell me about some of the things that you really appreciated about services or the way that people related to you that were helpful?" were used as necessary if the parent(s) seemed to 'get stuck' or unsure of what to describe next.

As part of the careful telephone and written explanation of the research which was given and as part of ongoing informed consent, parents were assured that they could choose not to discuss any issue or to stop an interview at any time and for any reason. [See Appendix 2, Parent(s) Information Sheet]. It is possibly a measure of the success of this careful and sensitive approach strategy, that only one approached family declined to take part in the study.

The interviews were carried out at a place chosen as most comfortable and convenient by the parents - which was always their home. Each interview was unobtrusively tape-recorded to ensure the accurate capture of the interview data.

It is worth mentioning at this point that most of the interviews followed a very particular pattern. After the interviewer (AH) had introduced the topic and asked a general introductory question about the child, the participants would tend to take the lead and tell what seemed to be the very pressing story of their child's living and dying. It was not necessary to 'prompt' or 'press' the participants at all to discuss this issue, and indeed what was often found was that the parents' narrative developed such a momentum that possible 'generative questions' and possible topic areas which the researchers had considered were unable to be asked directly as the opportunity did not arise. This does suggest that these parents have a powerful story to tell and that they do wish to be able to do this in an appropriate setting.

1.4.4 Data Analysis and Interpretation

Each interview was accurately and fully transcribed prior to analysis where each interview was analysed in detail and in depth by the researchers (PD and AH). Developing ideas, themes, and findings were discussed with the study's Project Supervision Team (PST) [See Appendix 3, Members of the Project Supervision Team] in order to clarify, challenge and strengthen the interpretive conclusions of the study. The interview data was questioned and contemplated in line by line detail in order to identify and explicate salient themes, patterns, similarities and dissimilarities, observations, events, perceptions, understandings and social practices which illuminate the parents' experience of bereavement and their perceptions of support services.

The interpretive findings of this study are presented in Section 2 in thematic form where the parents' most salient issues and recollected experiences are described with supporting data from the transcribed interviews.

1.4.5 Establishing Trustworthiness and Rigour in the Study

A Project Supervision Team (PST) was established at the study's outset which contributed regularly to critique and discussion of all aspects of the study in order to enhance its quality. In order to ensure the most accurate recording of the research interviews, each was transcribed verbatim. The study's Research Assistant (AH) also checked each taped interview against the transcription and corrected any mis-heard details or other transcription errors to ensure that the printed interview transcripts were as accurate as possible.

In the interpretive phase of a qualitative study, the researchers contend that it is vital that interpretive insights, propositions and 'findings' are grounded in the actual data of the interview texts. For this reason, each interpretive theme

of the findings section of this report is supported by relevant quotations taken directly from the text of the parents' interviews.

1.4.6 The Ethical Comportment of the Study

Ethical approval for the conduct of the study was granted by the Ethics Committee of University of South Australia. It is the researchers' belief however that the ethical comportment of a study, turns more upon the everyday conduct of the study than on the detail of the ethical documentation. The qualitative researcher faces particular problems in relation to informed consent, necessitating not merely informed consent in the usual sense of a signature, but a continuing willingness to participate in what may be a difficult and painful recollection and interview process. Such consent is more processual than the final signing of the traditional consent form. The steps taken to ensure a truly informed process of consent were as follows:

1. The nature of the study was discussed with all parents who expressed an interest in participating in the study interviews. This discussion was supplemented by written information sheets which were given to all parents involved in the study.
2. Participants were assured that the study had no covert purpose or hidden agenda. The research purpose was made explicit as was the need to collect data through tape-recorded conversation and interviews
3. During interviews it was made clear to participants that they may control the interview as they wished, by declining without prejudice to discuss any topic or to answer any question which they chose not to. If, during interviews, participants seemed uncomfortable or distressed, perhaps as they discussed a topic or issue, it was confirmed that they wished to continue with the topic. Parents were told that they could stop or postpone the interview at any point, and that this wish will be respected without question. [The Parents' Information Sheet and Informed Consent forms used are included as Appendices 2 and 4 respectively.]
4. Parents were also offered a copy of their transcribed interview in order that they could check this for transcription accuracy. Nine of the ten families chose to receive and review their interview transcripts. One parent reviewed both the transcript and audio tape of their interview and clarified some of the 'inaudible' parts of the interview.

2 The Study Findings: Introduction

Father: The next time we saw her was in the coffin in Alfred James [funeral directors] and ahh ... that was, that was awesome and nothing I can ... put into words could describe how I felt when I saw her just lying there, it wasn't peaceful. Well she was at peace but I wasn't. You're just used to, you spend all your living, breathing ... moments with her, all the, all the laughter and all the pain and the suffering and the conversations and everything ... and I just couldn't talk to her any more, she just lay there. Just there, and she wasn't gonna open her eyes and ... she was just looking, lying there pale and, and sweet and beautiful but ahh ... I knew she wasn't gonna open her eyes and ... and ... you know ... it was just too much. (Int. #7, p.42, oncology/hospice)

This report provides detailed accounts and interpretations of parents' experiences of caring for and providing palliative care for their dying child. Parents' reasons for consenting to participate in this study were, without exception, a desire to help others, and in particular, other parents and children in the same situation. We hope that health professionals and service providers reading this report will have the opportunity to deepen their understanding of 'what it is like' for parents to care for a dying child. We intend also, that this report will provide an impetus for professionals and service providers which will encourage them to examine and discuss current paediatric palliative care services and professional practices in order that these can be more closely aligned to parents' expressed needs and wishes at this time.

The findings of this study are presented in five sub-sections. Section 2.1 - 'The Meaning of Palliation' recounts parents' experiences of learning that there was nothing more that could be done to save their child's life and the impact that the threat of death had on both themselves and their child. We also highlight how parents' perceptions, beliefs, attitudes and previous experiences influenced their choices when deciding where they wanted to their child to die. Section 2.2 - 'The Nature of Parents' Caring Practices' describes the 'how' of parents' providing palliative care for their child, how the parents increasingly managed the medical, technical and pharmacological aspects of their child's care while simultaneously trying to be 'normal parents' maintaining 'normal' family lives. Section 2.3 - 'Juggling Family Needs' looks particularly at how parents managed work, careers, the child's brothers and sisters and family in general at this extremely difficult time. Section 2.4 - 'Experiencing the Child's Death and Dying' is a lengthy section examining the parents' perceptions, understandings and practices at the heart of this darkness, the time surrounding the child's actual death. The last 'findings' Section 2.5 - 'Parents' Perceptions of Services and Support' describes parent's perceptions and experiences of the professionals and professional services which were available to them at this time.

2.1 The Meaning of Palliation

Mother: As far as the palliative care thing went, well, we just brought him home and did what you gotta do. (Int. #4, p.30)

This section introduces parents' understandings of palliative care. Parents were asked to tell their story of their child's illness and death and in doing so they articulated their understandings of the meaning(s) of palliative care and of the interrelated issues of their child's life expectancy and of deciding upon where they should die when this time came.

2.1.1 Commencement of Palliation - 'Finding out'

During the recruitment stage of the study all ten participant families identified with their child having undergone a period of palliative care. At interview, seven of the ten participating families (four oncology and three non-oncology) were able to locate the commencement of palliation at a specific 'point' of their child's care. For these seven families this turning point was signalled by the child's Medical Consultant informing them that curative treatment options had run out.

Mother: So then it was like well, bring her home to die. And just ... because there was nothing more they could do for her. (Int. #1, p.4, home/non-oncology)

Mother: It was pretty well close to twelve months of treatment that Doctor Horman said 'we can't, can't give her any more treatment, her body's had enough'. (Int. #7, p.14, hospice/oncology)

Parents' knowledge of their child's disease was often exceptionally good. Propelled by the shock of a potentially fatal diagnosis and their desire to understand its meaning, parents sought information from as many sources as possible, leaving no stone unturned. Beginning with the doctors and nurses within their child's treatment circles, parents gathered information from other parents in the same boat, libraries, their professional networks, affiliated service providers and voluntary organisations. One father conducted an extensive literature search using professional journals and the internet. This educative process, in addition to "gut feelings", enabled some parents to determine the efficacy of treatment programs and gauge for themselves the chances of their child's survival. For one such parent the commencement of palliation was coupled with a final attempt at treatment, but with a sense of knowing that it was futile.

Father: We found out she'd relapsed. I mean that's basically what Philip [Medical Consultant] said, there's really not much else we can do. He'd, we did try another lot of chemo but ... you could tell that was just to you know, I guess to just to show us that they were still

trying but we knew that that wasn't gonna work. (Int. #3, p.75, home/oncology)

For nine of the ten families there was a significant time span between diagnosis and commencement of palliation. The shock of being told that nothing more could be done to save the child's life was sometimes softened by doctors' sensitivity in forewarning parents that their child's chances of complete recovery were diminishing eg, 'If there is anything "special" you want to do ... go and do it'. This longer time available and suggestions such as this seemed to help parents adjust to this worst possible news. For one mother however, the shock of diagnosis, identification of palliation and apparent loss of hope coincided:

Mother: She was diagnosed so it was all very quick (...) and they told us you know, straight away that there wasn't much hope to fix it (...) there wasn't much hope so we sort of, well there was no hope, any chance, it was all pretty fast and quick (...) for us. [The time from this child's admission, through diagnosis, to commencement of palliation was only one to two days] (Int. #2, p.3, hospital/oncology)

One mother described the cessation of treatment as a joint decision between the parents and their child's specialist but identified the commencement of palliation as a retrospective understanding rather than as an immediate awareness.

Mother: We made the decision with Doctor Burgan guiding us that we'd stop treatment because he was spending so much time in hospital and losing a lot of weight. Not having a good time. So that was about October and (...) we got out of hospital the week before Christmas or the day before Christmas.

Father: Yep, yep.

Mother: And then, well I guess we were on palliative care unknowingly but from then on we were on palliative care until he died. (Int. #5, p.7-8, hospital/oncology)

For another family, palliation followed an extensive period of treatment. The family however felt that palliative care support and caring human contact were not really made available until their child's condition had become critical. They described this, rather worryingly, in terms of "deserving" and being "allowed" palliative care:

Father: So that's I guess, why the Palliative Care nurse was good because we had that contact. But I guess for that first week we didn't have any contact and then in that second week we had ...

Mother: It was like when we (inaudible)

Father: ... we didn't want a lot of contact we just wanted a bit of ... contact yeah ...

Mother: Just a bit of, yeah ...

Father: ... and like Christine ...

Mother: ... security.

Father: ... coming in, the good District Nurse that was just great. Just someone to come along and ... didn't have to do any nurse-y things just someone that kind of ... someone to give ...

Mother: We just felt like we only deserved the care when ... she was ... started to die. I mean I know she was dying all along but, it got really, really bad so yeah, you're allowed to have care now. Whereas there was a ... like we said that week, in between, we were neither here or there, and it was ... like, what, what was there for us. (Int. #3, p.49, home/oncology)

For the parents of one child with a neurodegenerative condition, understanding the implicit meaning of palliation took some time.

Mother: Well the doctor, I thought was quite up front about it to start with but it, it gradually dawned on us after awhile, it must've taken three months for it to penetrate our thick skulls. (laughter) He said it was a progressive disease or there was nothing they could do about it. And so, he said all we can do is try to ease the symptoms, but it never really penetrated this brain of mine for about three or four months, [that] progressive meant, progressive right to the very ...

Father: End, yeah.

Mother: ... end. (Int. #10, p.36-38, home/non-oncology)

This mother's account of her misunderstanding of the term progressive is worrying, but from the perspective of a parent, unfamiliar with medical terminology, completely understandable. Outside of medical discourse, the term 'progressive' has connotations of improvement, of moving forward, of getting better. Yet the medical sense of 'progressive' is as malevolent and menacing an opposite to this as it is possible to imagine, often euphemistically describing the degeneration and debilitation of a child to the point where parents themselves will say that they scarcely recognise them. For parents to fundamentally fail to grasp the seriousness, significance and implications of a diagnosis of, a progressive neurological disorder, seems an infinitely greater crisis of meaning than an 'average' parent/professional misunderstanding.

2.1.2 *Life Expectancy Predictions - 'How long have we got?'*

When the terminal nature of their child's disease had been identified many parents felt the need to know how long their child had to live as time was now an even more vital issue for them. While it was clearly distressing to discover that their child had only weeks, months or years to live, knowing how long their child had to live helped parents prepare for their child's death

and provided them with direction and focus as they faced the many uncertainties associated with caring for their dying child. 'Not knowing' was hard as these parents described:

Mother: They [doctors] didn't know how long she was going to survive. They didn't have a definite diagnosis so they couldn't make definite predictions and anything. They don't have the answers, they can only speculate basically on what's going on. And that makes it hard because you don't, you know you haven't got that definite answer, they don't know and you don't know you know, what they're gonna die of either basically. You don't know what, what the lead up's going to be because it's only just based on what happened before. (Int.#1, p.14-15, home/non-oncology)

Mother: We didn't quite realise at the time how quick it would be. I think probably once we asked them how long she had and Doctor Mann [Medical Consultant] said 'It could be weeks, days or hours' so (laughter) I don't, you know, where do you go from there? (Int. #2, p.27, hospital/oncology)

Other parents actively sought or were given life expectancy predictions, which could paradoxically be the source of some hope and optimism if they were confounded. Some expressed pride in their child's capacity to pull through critical periods and outlive medical expectations, especially when the child's quality of life was also perceived to be good. When life expectancy predictions proved to be less than the subsequent reality however, parents were distressed. For some it was the shock of their child's demise in an incongruently rapid time frame. For Isobel's mother, the impact of dreaded events was devastating:

Mother: Isobel and I were told the bad news, we just both collapsed, collapsed down in [treatment centre]. Thinking the worst and oh dear, it was, it was just dreadful, just horrible and Christmas wasn't much good. But then she started to get better and I (inaudible) cos Albert [Medical Consultant] said perhaps she would only last perhaps [until] February or March. (Int. # 7, p.15, hospice/oncology)

This life expectancy prediction was followed by a period of apparent recovery and the parents were told that Isobel was "free" of the disease. Isobel resumed her studies and plans for the future were made only to find later that metastases had developed.

Mother: Anyway, he [Medical Consultant] showed us this [scan of lung showing cancerous infiltration] and we just couldn't believe it. Not, to be told that your child is terminal, to be told that they're free and then to be told again you've only got [limited time left] we just, I, I

collapsed after that I just couldn't, I just couldn't take it any more. (Int. # 7, p.22, hospice/oncology)

One mother acknowledged the difficulties that health professionals faced in making life expectancy predictions.

Mother: Doctor Sandford [Medical Consultant] never sort of said she could last five years, she could last seven years. He said 'I just don't know how long she could last'. He *just did not know*. And, in all fairness with the amount of information available, you'd have to be a, a fortune teller or something to have known. (Int. #10, p.59, home/non-oncology)

2.1.3 *Parental Concepts of Palliative Care 'What does it mean?'*

Parents' concepts of palliative care encompassed a wide range of understandings. For some, these centred almost exclusively on the child. Parental aims focussed on making life as normal as possible, fostering quality of life while acknowledging its diminishing quantity and being discerning when choosing symptomatic treatment and/or curative treatment for acute or chronic conditions. The following examples are indicative of these understandings:

Mother: We just came home and tried to make life as normal as possible. (...) Just tried to get on with it as normal as possible. Basically tried to keep it right through positive for her, and normal, which was very difficult at times. But that was sort of our aim, to keep it positive and try to keep life as normal as possible and do as much as what we could. (Int. #2, p.12, hospital/oncology)

Mother: As far as the palliative care thing went, well, we just brought him home and did what you gotta do.

Father: We understood what was happening, like it got to the stage where he [doctor] couldn't give any medication for curing things because it was only going to make things worse, so you might as well just, it was very well explained to us so you knew what to do, just how to make life bearable and quality instead of quantity. (Int. #4, p.58-59, home/oncology)

Mother: She got another really bad infection and then got really oedematous and became cyanosed and dyspnoeic and went into cardiac failure (...) probably from the viral myocardopathy or myocarditis or something but wouldn't, didn't ever sort of investigate because, you know at this stage we were sort of, like it was ... everything's just palliative, just to make her

comfortable not to sort of treat anything and we made a decision that you know, if she did get a pneumonia or something over the winter that we wouldn't treat with antibiotics. (Int. # 1, p.8-9, home/non-oncology)

One mother felt that a lack of information impeded their attempts to live as normal a life as possible given their circumstances. Fear, and wanting to do the right thing caused her and her husband to stay within the safety of their home.

Mother: *Like we stayed home for ten days we stayed home. I mean, we could've taken her out but nobody told us that we were allowed to take her out. We could've got in the car and gone for a drive for half an hour even if she didn't, you know, [if] that's all she lasted out there. But no, we were too scared, we were too scared to, to move out of [home] this is our security and this is where we were safe. But, you know, that, they're the type of things that you need to be told. (Int. #3, p.19, home/oncology)*

This mother's account is a poignant reminder that when a child is seriously ill, or in this case, dying, that parents' everyday understandings and child care practices are undermined and problematised (Darbyshire 1994)¹). What, under normal circumstances, would have been almost instinctive, pleasurable practices to be embraced, such as taking the child out in the car for a trip, have now become fearful and uncertain possibilities, requiring the permission of professionals.

For another mother, the concept of palliative care had a broad focus which encompassed services and treatment teams.

Mother: And palliative care took in everybody and helped all the people to cope with what was happening and managing his pain and just making his last minutes, well I don't know if they made it comfortable for him but at least for us some of it looked comfortable, though the end wasn't but it just made it easier for that time period. (Int. #9, p.18, hospital/non-oncology)

For fourteen of the seventeen parents, caring for their dying child was their first experience of death at close quarters. Their prior knowledge of palliative care philosophies and services were minimal and thus their need and desire for information was great. One father highlighted the extent of this need while also illustrating how the nature of illness, especially in children, can cause a future need to become emphatically immediate.

1 In his study of parents who lived in with their sick child in hospital, Darbyshire (1994) found that even the 'simplest' of child care tasks, such as feeding the child or changing nappies became almost nursing or medical procedures for parents as their meaning had changed dramatically within the 'realm of the experts'.

Father: In terms of the palliative care side of things it was, when the subject was first mentioned (...) I didn't have a clue what it was about. I had a couple [of conversations] with one of the nurses there [hospital] saying what is palliative care? (laughs). You know. Is it just someone coming in once a day or the district nurse, (...) what does the district nurse do sort of thing. And, I don't know (sigh) at this stage it was difficult [to know] what it was, but in a sense they were saying you know, obviously it covers *wide range* of issues but because it was so broad and I guess our immediate needs weren't so defined, it was difficult to know exactly, it's just all, all the support you need at home, thinking sort of what, I mean, how big a support, how big a resource is it you know? What does it really do and what really happens? So the practicalities of what it was about weren't clear to me at that stage but then at the same time I mean the need for it wasn't so imminent either. It was just that you know, we could go home, and the support would be there. We'd be needing more and more of it towards the end but we'd be looking at a good couple of months, or a month or so where he would be pretty good anyway. And then before that even really kicked in the picture had changed very dramatically and all of a sudden we're, we're, both back home again with a great swag of, of things and it was all quick. [child's demise] (Int. #6, p.44-45, home/oncology)

2.1.4 *Location of Care - 'Choosing where your child should die'*

Of the ten participating families, five children died at home, three in hospital, one in a hospice and one between home and hospital. Seven died in the planned place of death, one was coincidental, one unplanned and one family kept their options open between two settings.

The child's place of death was influenced by several key factors. Palliation often came at the end of exhaustive treatment programs that left both parents and their dying child drained and exhausted. Often, children had been 'poked and prodded' and had endured pain to the extent that they reached the stage where they had simply had enough (Amenta 1994). The child's wishes were a major influence on parents' choice of the place of terminal care. In this study, for those children who were capable of indicating a preference, this choice was without exception, to die at home.

Father: She loved a lot of the nurses [and] a lot of the doctors but it [hospital] was just associated with so much pain and so much suffering that (...) I think it was just a combination of a lot of things that she just didn't want any more to do with it. And I think that she'd been away from the hospital for so long that going back was

probably all gonna be, after she, she was already in so much pain and suffering that she just didn't want to ... didn't want any more. Didn't want any more psychological traumas I suppose.

Mother: I mean if she wanted to go back to the [hospital] we would have taken her back but (...) she knew what she wanted, she grew up. These kids grow up so fast ...

Father: Yes she matured very, very quickly. (Int. #7, p.51, hospice/oncology)

The parents' observation that "these kids grow up so fast" and "mature[d] very quickly" is a telling comment in the light of our traditional understandings of children as being 'people' who cannot be expected, either cognitively or morally, to make serious and responsible decisions in relation to their own health and health care². It also speaks of a significant change in parents' and children's perceptions of temporality, from what could be called 'lived time' as opposed to mere chronological time.

Finding a balance between the child's place of death preference and what the parents felt comfortable in doing was successfully achieved by the parents who cared for their daughter at home before transferring her to a hospice for her last thirty-six hours.

Mother: ... she didn't want to die [in hospital] I think she would have liked to [have] died at home. I wasn't very keen on the idea of it and I did tell her and I said 'well how about [the hospice]'. We'd been down to [the hospice] they had like a, a cottage.

Father: Yes

Mother: And I used to take her down there (...) they have lots of massages Isobel liked all that. So she knew of [the hospice] although we'd never been into the actual hospital part and I said to her 'if you get to the stage where we can't sort of help you, would it be all right?' and she said 'yes'. (Int. #7, p.28-29, hospice/oncology)

For another parent, the influences determining the place of death were a combination of the child's wishes and the Medical Consultant's encouragement.

Mother: Yeah, he wanted to come home. He'd been wanting to come for weeks. Because he was so zonked out the last few weeks he, all he just used to do, every time we came in we'd just look at him and [he'd] say, 'I want to go *home*, I just want to go home'. So he was, he was ready to come home. (...) I was a bit frightened of him dying at home, I thought it would be better to be at the hospital where you had all the support and when he

² See Patricia Alderson's ground-breaking work here in relation to children's consent which shows that young children are indeed capable of carefully considering and articulating their wishes and understandings in respect of their own health care (Alderson 1993).

died you didn't have to, like they'd just take over. As it happened it was basically what happened anyway, but you know they explained ... David [Medical Consultant] said he's better off at home and they just virtually said in a way, there's no big drama, and there wasn't but you don't know until you've been through it. It's a bit scary but it worked out all right in the end, but that was just fortunate. [A nurse whom the family had met in hospital and become friendly with was visiting the family at the time of the child's death.] (Int. #4, p.46, 59, oncology/home)

In addition to the child's wishes, parental perceptions, prior experience and beliefs about hospitals and their staff influenced parents' decisions to care for their child at home. The need for a familiar environment; desire for a high standard of care; need for control of post-death events, such as, how long parents could spend with their child's body; freedom to have extended family and friends nearby; and being able to grieve away from the public gaze were the parents' main themes. The following accounts exemplify these concerns:

Father: I think it was more comfortable being here [home] than say being in the hospital (...) if perhaps we'd stayed in the hospital it might have been awkward after he died or something. When you, I was told, I remember hearing that there was a, you know, we could stay, there was a room you could be moved to or whatever, but I guess there is always the feeling of you're in an unfamiliar environment and a concept that perhaps you can't hang around too long or you, you should move off, or if [you] go out you, you know, you can't just sort of come back as you like. Whereas when Oliver died we decided to leave him here [home] overnight and asked the funeral director to call the next morning to pick him up and I think that having that opportunity, which was you know, another fifteen or sixteen hours later, was something that we wouldn't have had perhaps.

Mother: Well we don't know that.

Father: We don't know it but we sort of would have perhaps felt uncomfortable being in a different environment during that time and I think it was just more comfortable.

Mother: Yeah, I think I just wanted to be home, yeah. Sort of just quieter and more private. (Int. #6, p.39-40, oncology/home)

Mother: People think 'how could they ever cope in a situation like that?' [caring for a dying child at home] but because you are in that situation and you're doing it you, you cope because you have to. You've virtually got no choice because if you didn't do it there'd be nobody else that would be doing it. Or I mean, you know that person

would be admitted to hospital or something. But then, the care that you're getting wouldn't be the same as you believe they deserve to get. (Int. #1, p.51, non-oncology/home)

Mother: ... being able to do what you want at the end and not have people say [whispering] 'Oh, you can't do that, it's not the way we do it' or 'it's not done'. And yeah. And just the issue of time, of being able to spend *quality* time at the end. Because even if they have died ... sort of spending time with them until you are ready ... to let go. (Int. #1, p.60, non-oncology/home)

Mother: (...) and also I think there's not the time pressure. You can take things at your own pace in your own home. And as I said before you've got the opportunity where you can get ... friends and relatives and people to come in and ... give them the opportunity to say goodbye to the child as well. And I know, as I said before, all my friends hadn't ever said goodbye to a anyone who died before like that. Other than *going to a funeral parlour* and seeing into the coffin and saying goodbye which is totally different than actually coming into your home and saying goodbye or holding them. And so for us, that was really important. (...) ... in a hospital environment (...) it's just ... you can't be yourself and you always feel a little bit restrained and you can't scream if you want to scream. You can't do things like we did. (Int. #1, p.65, non-oncology/home)

The death of one child with a neurodegenerative condition occurred while on weekend leave from hospital. While the child's death, in the immediate sense, was not expected and the place of death was coincidental, the parents were happy that their child died at home. The concerns regarding hospital death for these parents were protective of hospital staff and young patients.

Mother: ... she was here [home] which I think she wanted and we would have wanted as well and the hospital was pleased that it had saved the kids that upset because when one of the kids has died on the wards, I mean, the rest of the ward knows it and they get really upset. I mean, they were upset when Louise died, but they hadn't sort of, they hadn't had to sort of sit and watch, not actually watch but to sit and wait like. You would think that the way that things turned out, they turned out really as well as you could have organised. (...) Yeah. I would've hated to actually [have] been in hospital. I don't know how I could've coped with that. (Int. #10, p.55-56, non-oncology/home)

The intensity of care was the primary factor influencing the choice of place of death for two of the three children who died in hospital and the one who

died in a hospice. All of these families expressed satisfaction with the care received, and their experiences predominantly contradicted the 'hospital death' beliefs of parents whose children died at home. Satisfaction with the care environment and staff relationships was high. None felt pressured to leave their child's body before they were ready and all felt that the quality of care was equal to, or better than what could have been provided in a home setting.

Mother: We stayed in [the local hospital], they've got rooms and they've just got like, it's like a, got like a sofa bed. It's a huge room. They're absolutely beautiful, the rooms here. And it was a sofa bed and we had a curtain in between and you know, and an ensuite bathroom but we stayed there. It was all in one room. You only had a curtain. So we stayed there, I mean we arrived there and you know they, they supplied us with meals the whole time and we didn't have to think about it. (Int. #2, p.32-33, oncology/hospital)

Mother: We'd said goodbye to her that many times over the last few days that we just spent a few minutes with her [to] say goodbye to her. They rang here [home] and, it was probably all in a matter of five minutes. Roger's [father] two sisters came over with Bradley [parent's son] and we all gave her a kiss and a hug and all had a cry and we spent a bit of time in the room with just, with her and the nurse said we didn't have to hurry or anything and oh yeah, I couldn't tell you how long it was and then Roger's two sisters and my sister and Bradley came here and we just spent a little bit more time with her. (Int. #2, p.40-41 oncology/hospital)

Mother: We weren't there very long, [hospice] but the time we were there they were wonderful. (...) We were constantly kept informed and we couldn't speak more highly of, for other people in at the hospice. They were just, well there was someone there on with her all the time that she was there and, and there was doctors coming and going and so it was very constant care there. (Int. #7, p.35-37, oncology/hospice)

The parents of one child who died in hospital did not identify any specific issues which influenced their preference for a home/hospital or hospice death however, they did express dissatisfaction with the course of events after their child's death. The father of this child was quite distressed that within an hour of his child's death, hospital staff wanted him to make arrangements for a funeral director to collect the child's body. Never giving up the hope that their child would survive and not fully accepting that death would be the outcome of his illness, these parents had not seriously considered post-death funeral options.

AH: So that was the first that you'd heard that you, that these sorts of things would have to be done?

Father: Yeah. I mean I supposed it's the job of a social worker would've, should've been that, knowing that the child's on palliative care that 'hey, you've got to get your act together sometime and this is what, this is the ground rules'. But we weren't told the ground rules. (Int. #5, p.31, oncology/hospital)

2.1.5 *Transitions - 'The hospital was our home'*

Parents embark upon the responsibilities of caring for their dying child with a sense of journeying into the unknown. Making the transition from the treatment phase to the palliative phase was a significant and difficult shift for parents as the focus of attention shifted from cure to preparing for death. The sheer existential horror of realising that your child is going to die, seems to defy attempts to capture its meanings in the semi-professional argot of 'concerns and challenges' that parents faced, but these were very real and included uncertainties about their capacity to understand and help with their child's changing physical and emotional needs; a sense of unreality and disbelief that their child was actually dying; trepidation about the type of death their child would have and feelings of isolation and being alone. One mother expressed this sense of isolation and exhaustion.

Mother: If you talk to people who haven't been through that sort of experience ... they don't understand. I mean, and you talk to someone who's experienced the death of a child or the death of somebody who they've had to look after at the end, *they* understand the problems that you go through and how you just get so *totally* exhausted. (Int. #1, p.51, non-oncology/home)

For another mother and father who provided care for their child at home, this sense of being alone was experienced most acutely on leaving the hospital for the last time. For these parents hospital represented more than a site for treatment. The hospital had also been the place where meaningful relationships were forged with staff based on trust, caring, and support when times were tough. Sharing hopes and fears about their child's future, getting to know staff and being able to laugh with them created an environment in which the parents felt safe.

The staff and the everyday events which occur in the treatment milieu become a part of the family's history and part of a community of care and memory. Most significantly, the doctors, nurses and others involved in the care of the child 'know' what the child has been through and how sick they really are. These were no passing acquaintances or fair-weather friends, but people who had stood beside the child and their family throughout the bleakest despair they are ever likely to know. Conversely, the general public, extended family and friends were not always able to comprehend that a young child with leukaemia for example, might be running around

looking relatively 'normal' and yet be dying. This lack of understanding led to one child's parents being accused of over-dramatising the extent of their child's illness ... "they'd just looked at us just thinking 'what is the commotion about here?' like ... she's not even sick!"

This experience was particularly hurtful for the parents as it trivialised the seriousness of their child's illness and furthered their sense of living through this experience in isolation, unable to draw on the comfort of shared understandings with others. The inability of others to truly understand did result for some parents in lost friendships. 'I guess it's just lack of knowledge but they just didn't understand the disease'. These caring relationships with staff who did 'really understand' were affirming and important to parents and were not necessarily easily replaced. Most parents in the study mentioned that their association with the hospital had extended over a considerable period of time and that their familiarity with the routines, practices and staff enabled them to feel 'at home' there, inasmuch as one can feel at home in a hospital. Thus leaving the hospital was also associated with a great sense of loss.

Father: I guess when we left, probably the sort of big one I'm onto now but yeah ... leaving that hospital knowing you're not coming back and not hearing from them [staff] again.

Mother: The hospital was our home, I mean ...

Father: ... certainly pretty hard for me.

Mother: ... apart from this place, it was our home and it's the only place we felt safe, apart from here. In fact safer there than here really.

Father: Yeah and it's a funny feeling, 'cos you, you know these people for thirteen months and *they are your* friends. I mean, I know that they're doing their job *but* there is a few of them that we certainly became friends with and they certainly are friends with you even though they're doing their job. But then suddenly ... that's it. You don't hear anything from them. (P3, p. 117-118, oncology/home)

At a time of great personal distress and change, parents were often learning to use medical equipment and perform advanced nursing procedures while becoming familiar with new treatment teams and the different services associated with palliative care. Regardless of the place of death, whether home, hospital or hospice, parents described facing these challenges in a state of sheer exhaustion as they tried to provide care or to 'be there' for their child twenty-four hours a day, seven days a week, with no real prospect of meaningful relief or respite.

2.2 The Nature of Parents' Caring Practices

This section identifies the types of activities which parents participated in in order to care for their child and describes the extent to which parents felt

they were able to cope with a situation which, for the majority of parents, was an utterly new experience.

2.2.1 *Equipment and Supplies - 'Gearing up'*

Variations in parent's experiences of caring for a dying child occurred according to the location of care, the intensity of care, the length of time care was required, the types of services and supports available and the extent to which parents experienced conflict between their need to 'be there' for their child in a traditional parenting role and the additional role of providing nursing care. Invariably, providing care for a dying child in the home setting was significantly more complex than in either a hospital or hospice.

A total of five families (ten parents) provided final stage care for their child solely at home. Three of the children had oncological conditions and two a non-oncological condition. Another family cared for their child (oncological category) at home until the last thirty-six hours prior to transferring to a hospice. This blending of care locations was also the experience of one other family whose child's care alternated between hospital and home, with death occurring at home. The three remaining children received all of their final stage care in a hospital however, their parents had provided care at home for varying lengths of time. These parents experiences were similar to those who provided final stage care at home and for this reason they are included in both home and hospital/hospice discussions.

'Gearing up' to come home from hospital was an occasion that some parents remembered for the sheer quantity of equipment that they needed to adequately care for their child. During a home visit, the local doctor of one family commented that the parents 'had more stuff than he had down the surgery'. Medications, needles, syringes, wheelchairs, walking frames, oxygen generators and cylinders, syringe drivers, feeding apparatus, suctioning equipment, toileting implements, central venous site cleaning solutions and dressings were among the array of things parents needed.

Father: When we brought Alexander home the last time we were packing the car up, we had roof racks and everything to get everything in, on and stuff, wheelchairs and everything else, and all these generators and whatever. So we had a pretty good load, we had just enough room to get Alexander in the car.

Mother: We nearly had to leave him behind! (Int. #4, p.45, oncology/home)

Mother: He's had three central lines in, in that period of time. And so, we just geared up the same as we geared up every time we came home from anything else. We were given all the medication and a wheelchair oh, oxygen generator and bottles of oxygen and yeah, we just went into pack up mode and, [were] told how to use everything and where to get more supplies from if we

needed it and stuff. And so we just packed up came home.

Father: And there was heaps of stuff here.

Mother: ... and set up hospital at home. (Int. #4, p.33, oncology/home)

Accommodating equipment in the home was not a major problem for parents, however two families did experience some difficulty with oxygen cylinders. The first was difficulty was geographic. All parents were keen to provide a sense of normality in the child's home life. Rather than being sequestered away in bedrooms, parents (often at the child's request) moved their child into a central location such as the family room or lounge room where they could be 'brought into the body of the Kirk' and included in the general activities of family life. For some children, this is where they spent all of their time both day and night. For others, movement occurred between the child's bedroom and family rooms. The parents of one child who was dependent on oxygen were supplied with a large, heavy cylinder which made transfer between locations more difficult.

Father: I think she needed the volume of air too, that, that they supplied and that was no real inconvenience for her or, or it was a bit because she wanted to move around the house through that eight weeks and we had to take it down the stairs and trying to lug it down stairs and bring into the other room there. But that was no problem, we did that. But that obviously must have been the, the best choice for her as far as supplying air to her and we didn't mind that, that was, we would have done anything. (Int. #7, p.48-49, oncology/hospice)

This father's statement that "we would have done anything" reflects not only the degree of commitment with which parents embraced caring for their child but also their vulnerability which could lead to their gratefully accepting almost any level of service provision. The provision for example of a second oxygen cylinder in this situation - one for upstairs and one for downstairs - would have made caring so much easier for the parents and would have allowed the child greater mobility within the home. It would also have eliminated a potential occupational health and safety hazard which would never be tolerated in an institutional setting.

Marked differences were noticeable between the experiences of parents of children with oncological conditions and those whose child had a non-oncological condition. The period of 'intensive' home care which was provided by the parents of children with an oncological condition ranged from days to months. Within this time frame, parents, although prone to exhaustion, were more able to 'keep going'. The period of care provided by the parents of children with non-oncological conditions, with the exception of one whose child died younger, was years.

This group of parents reported that providing care was more physically and possibly more emotionally taxing. Stefan was a child with a non-oncological condition who had an acute medical problem requiring oxygen.

The addition of this need on top of other multiple responsibilities was enough to push his mother to the limits of her resources. His parents had been providing extensive long term care for three wheelchair-bound children who were totally dependent for all of their activities of daily living.

Mother: ... even the oxygen was enough hassle. We were just getting it all organised where he'd have a big bottle here and everything and even that to me ... was quite enough. I really didn't even want that. I mean I know I had to have it for him but yeah, I obviously hadn't come to terms with him being as sick as he was you know and I just didn't [want] the extra hassle that came with it. Because that, that's what it is. It's all that extra you know, and me being really, really, really tied down you know, whereas I'm tied down already. (Int. #8, p.37-38, non-oncology, home/hospital)

This mother's use of the term "hassle" is noteworthy as she did not use it in its popular sense of a minor irritant or slight nuisance. Her 'hassles' were social, physical, logistic and emotional difficulties and demands which would tax even the strongest and most resourceful (and well resourced) family. After being at home using oxygen for a few weeks Stefan had a cardiac arrest and was taken to hospital by ambulance. Once there, medical teams looked to the parents for direction regarding the continuation of resuscitation attempts. The implications of the burden of care in the family context was uppermost in his mother's mind.

Mother: We [mother and father] both had the same opinion. I mean, I think I said it but I said 'No leave him, don't, don't touch him whatsoever'. Because all I could see then was, we'd had those few weeks of him being here, being on oxygen, knowing that he's going to have to have oxygen for quite some time now, that extra hassle of oxygen, the extra hassle of a *very* sick child plus the other two in wheelchairs and I know in myself I kept thinking ... Oh! this extra work I'm going to have to do you know, the extra load on us all would be you know, horrendous. It would be such a lot. (Int. #8, p.21, non-oncology, home/hospital)

While the "hassle" of oxygen was a significant issue for this mother, this was not her only concern influencing such a monumental decision. Her child's future prospects and quality of life were also significant influences.

Mother: He was, to him he was a whole person, he was a, you know, there was nothing wrong with him as far as he was concerned. And to think that maybe there could have been brain damage or something from bringing him around again, I, I didn't want that. That's not right. And then you've got all that other afterwards ... you know, when *is it* time to, like now, switch off the machine or something and I, I didn't want any of that. We didn't

have to deal with that in the hospital. (Int. #8, p.21, non-oncology, home/hospital)

The availability of equipment was also significant. One parent felt that being able to have equipment at home was a primary factor enabling her to provide home care.

Mother: If I hadn't been able to borrow all the equipment and hadn't been able to give her intramuscular injections every night I mean she would have ... probably needed to be in hospital. I wouldn't have been able to look after her at home. (Int. #1, p.16-17, non-oncology/home)

Parents relied heavily on health professionals to know what their child would need over the ensuing period of care and to help them prepare for this journey into the unknown. Oliver's parents highlighted this need:

Mother: It's very difficult you know when someone says to you oh, you know, 'we're here to help you, what do you need?' and ... you know we, we hadn't done it before, we had no idea.

Father: Like, what do we need?

Mother: What we needed and ...

Father: What's a reasonable thing to ask for? (laughter) yeah.

Mother: Yeah. I mean looking back in those, just those last couple of days there were things that would have been helpful but you know we sort of, we didn't know to ask for them (laughter) because we didn't know what we needed so ... I don't know, if someone had a list or something of you know, the things that people had found that they needed or ...

Father: I mean, if, if, would you, you might want one of these, you might want this. There might be need for this in the next, a little while, so just letting you know that it's here. Or here it is for, in case you need it. So I guess the other issue was being a long weekend in our case because we, he only had a few days to live and it was Thursday of the long week-end coming although we, we didn't realise that at the time, our attention was elsewhere, than the calendar ... I mean some of the things might have been difficult to get hold of perhaps. (Int. #6, p 45-46, oncology / home death)

The rapidly changing nature of children's illness meant however that it was not always possible to anticipate all of the child's future requirements. Sometimes extra equipment was needed or a change of medication or both. For parents living in rural locations, this could mean a long drive with a sick child back to the treatment centre. In addition to 'a long drive down there and a long drive back' problems would occur that would not become evident until the equipment was actually being used in the home. For

example, Susan's mother and father took her to the hospital to be reviewed because the intermittent morphine being administered through her central venous line was no longer providing her with adequate pain relief. They were supplied with a syringe driver which would administer the morphine on a controlled continuous basis. When they arrived home, the parents soon realised that the tubing leading from the syringe driver to the insertion site was not long enough to allow their toddler maximum mobility. In this instance, the equipment provided by the hospital was then adapted by the community nurse.

Father: We needed another extension because [the one] on the syringe ... pusher only has a little cord, probably only 45cm long. And I said to them, must've been like the night after we connected it up, 'this isn't too good is it?' And they brought ... the next night a longer one and we made it a meter and a half long so that when Susan was sitting down on her couch we could have it [the syringe driver] away from her ... or when we were carrying her, I could hold the pumper and Anita [mother] could hold onto her. You know it was so much better than just the little one. (Int. #3, p.94, oncology/home)

Cooperation between hospital-based treatment teams and community agencies was often invaluable in providing assistance to rural parents. Alexander's mother recounted how an unanticipated situation necessitated the replacement of a nasogastric tube and the cooperative process involved in obtaining it.

Mother: Alexander had a nasal gastric feeding tube in, 'cos obviously he couldn't eat at this stage, and so we were feeding him through the pump and his nasal gastric feeding tube blocked up and broke. So that came out and I went down here to see if they had one at our local hospital but they didn't have one. They didn't have a, one for a child his size and that quality. They had ones they put in, particularly under general anaesthetics for, just for you know, a short period of time. So I rang the local doctor to see whether or not he knew where I could get one from. He said not around here but his wife was working at [a large hospital in the city] as doctor of pathology and so we rang [Alexander's treatment centre and a staff member] took one over [to the local doctor's wife's hospital] and [she] brought it home and then her husband brought it out *here*. (Int. #4, p.32, oncology/home)

Similar situations also occurred with 'hard to get' medications as one father and mother related:

Father: And the local pharmacy in the town I mean they helped out there too when we needed a couple more

things. Like we were going through things at a rate and we suddenly realised it was a long week-end coming up you know, we don't want to be running out of the stuff half way through because we knew that with the Ondansetron or whatever that we'd heard before that it was a very hard thing to get, you couldn't just ...

Mother: Well he wasn't using it.

Father: I guess I can't remember what it was.

Mother: He wasn't using it at that stage but what, he was on Maxolon but it wasn't helping so ...

Father: So they, they changed it to Ondansetron but you couldn't just well pop down to any pharmacy and get it, because very few people stocked it because of the cost involved. So he [the pharmacist] rang around and traced down the supplier for the long week-end and ... which came up from, from Noarlunga or somewhere and he arranged for it [to be] brought up to us and stuff so, I mean it was a six pony exchange or something.

Mother: Yeah each chemist would take it a bit further along the line and then someone else would pick it up and bring it on and then Paul [either the local pharmacist or doctor] went to [local township] and picked it up and brought it here for us. (Int. #6, p.23, oncology/home)

Time spent in 'chasing around' for items of equipment and services had a direct impact on parents' ability to 'be there' for their child. This was especially so because firstly, the actual provision of 'hands-on' care was often intense and secondly, parents were acutely aware that the remaining time with their child was precious. Thus, anticipating needs before they became critical was highly desirable, as one father points out:

Father: To have that option to be able to bring him home with that support for that time I thought was good. But you never really understand or comprehend the value of it or the need of it or what's involved in it until probably you're in it and by then it's ... (laughs) ... you're too deeply emersed in providing the care to really sort of go chasing around to tie things up or whatever. (Int. #7, p.56, oncology/home)

2.2.2 *Technical Aspects of Providing Care: 'Nurse things'*

Providing care for a child at home necessitated that all study participants acquired skills akin to those usually performed professionally by nurses. Procedures such as maintaining central venous lines, administering medication by intramuscular and/or intravenous injections, suctioning and nasogastric feeds were the most common of the 'advanced' practices performed by parents. On one occasion Alexander's mum inserted his nasogastric tube when the old one accidentally fell out.

Reasons for taking on the above additional aspects of care were varied however, in all cases these practices facilitated the process of being able to provide care at home. At interview, parents were not asked whether the community services they received were available for home visits twenty-four hours per day, seven days a week. However, a number of parents did indicate that services used such as the Royal District Nursing Service (RDNS), made their first visits of the day at around eight in the morning and the latest visits were around eight o'clock in the evening. Two families understood that they 'did not visit on weekends'. Thus the parents in this study were sole carers during these hours. All of the children required some care around the clock and, as George's parents indicate in the following detailed extract, this care was often intense and demanding, not only in a physical sense but because even a teenager such as George becomes frightened and needs company and comfort from parents day or night.

AH: I don't know if there would have been a typical day of care at that [stage] but could you give me an idea of what you actually did in a twenty-four hour period?

Mother: Well I guess you could start, if you started at midnight ... probably just after midnight he would need to have some physio. This was towards the end. He would need a physio session just after that which would mean that he had to have his, either his ventolin or some of the other ... he was on Mucomyst for a while as well which stunk the house out. So you would do that and we'd have a couple of hours sleep before the next time. Then at six o'clock you'd have to take his feeds off because they would go twelve hours. So you'd take the feeds off and you'd give him his next lot of drugs and let him sleep for a little bit. So you did physio probably every, every four hours and that would depend on whether it was just the, the percussion or if it was putting on one of the machines etc..

Father: Yeah. He didn't have a lot of percussion type physio towards the end.

Mother: No he couldn't stand that.

Father: No. He had this positive pressure system that he had to breath into and he had to do himself.

Mother: Yeah.

Father: Mm. But also during the night depending whether he was on [oxygen] cylinders or the concentrator we might have to ...

Mother: Get up and change that.

Father: You might have to do that yeah.

AH: How would you know if it ran out?

Father: You can hear it stop. (laughter) Hear it stop and you wake up straight away.

AH: Right

Mother: It was like having a baby in the house because you never slept soundly.

Father: And if these pump, his, his pump had an alarm on it.

AH: Right

Father: And umm ...

Mother: That often went off (laughs)

Father: Yeah although there was worse if it disconnected and pumped and you know, a big mess.

Mother: Yeah. Beds to change in the middle of the night.

Father: That was the, that was the worse thing that could happen.

AH: Is this his feed pump?

Father: Yeah.

Mother: Yeah.

AH: So that would alarm as well?

Father: Well it might not alarm if it's pumping all over the bed.

AH: Oh right.

General laughter

Father: But we used to tape it, really tape it up with lots of tape and try and avoid that you know it was ... yeah.

Mother: And then he, he was very often sick as well. He had a lot of vomiting because he just coughed so much. So you'd have that and a lot of the time he wouldn't make it anywhere to actually not make a mess on the bed or whatever because he, it just came and that was it. Especially with the feeds during the night if he had a coughing fit well then obviously there is a lot in his stomach from that.

Mother: But I guess the other thing was he often wanted you with him. He'd wake up crying in the night and he'd want you there. He, he got very frightened towards the end of being alone. So you had a lot of that. [George was sixteen years old at this time] But, there was just lots, there was lots of times where you were actually just doing something and then the physio, by the time you did the physio and got him something to eat and got his tablets it really was starting to overlap in to the next session. Because the, the last thing you wanted was to not give him what he needed.

Father: Yeah and then of course a lot times on a different diet. So you'd be cooking for him or supplementing his food in some way or getting him something. And keeping, just keeping track of the medicines. He was taking about sixty tablets a day I'd say. So you had to have a way of keeping track of all of that.

AH: Did you alternate, did you take turns in giving him his care? How did you work out getting enough or the maximum amount of sleep?

Mother: I probably did more in the night only because I'd go to bed early so Garry would look after him until probably about twelve.

Father: I would do the twelve o'clock stuff and then go to bed.

Mother: I'm the early to bed person (laughs) so then I would, I would probably been in bed just after eight and then when Garry came to bed then I would get up and do the next couple and I would catch an hour or so in between. We didn't have lots of sleep but we had sufficient to keep us going.

Father: Yeah. And we'd alternate.

Mother: That was when he was home. When he was in hospital during the week I would leave here at half past six and go in to see him. And I would help do some of his first lot of his treatment generally in the hospital and then I'd go off to work. I'd go back at lunch time and sit with him an hour and have some lunch with him and then I would go back at night after work and go home about nine. [George's mother also often 'lived in' during the week and went home on the weekend and his father would 'live in' on the weekend] (Int. #9, p.25-30, non-oncology/hospital)

In George's parents' case, visits from the district nurse were only available twice a day during the week because 'they don't come on the weekends'. Oliver's parents, who lived in the country, were taught how to draw up morphine in case they ran out.

She [visiting nurse] came, she was just drawing up the morphine but near the ... in the end we were even able to do that if we wanted to, or if we needed to because the syringes were running out. And then she could only come once a day because of the geographical layout and the syringes, she would make a couple but if we needed to increase the rate they'd run out so she said 'this is what you do if you need to' You know, three o'clock in the morning. (Father 6, p. 26, oncology/home)

For some parents, acquiring 'nursing' skills was a matter of convenience. This was one way of not having to be constrained by community services time structures and of becoming 'self sufficient' enough to pursue family activities such as outings away from home. Other reasons given by parents as to why they chose to take on more of a 'nursing' role included their losing confidence in the competence of nurses during home visits.

Mother: We couldn't go anywhere until they [nurses] came and they just *had no* idea. They, they said to us, 'Oh we don't deal, we, in here at Anytown, we don't deal with children'.

Father: 'It's normally ... this is the first child we've had'.

Mother: 'Normally ...'

Father: 'Normally old people'.

Mother: 'Normally old people'. And I'm thinking oh great - this is giving us a lot of confidence with you guys.

Father: So the next week we went into the hospital and I said to Philip [Medical Consultant] 'Look, can we do it

ourselves?' And he thought it was a good idea. (Int. #3, p.55, oncology/home)

Father: We'd seen it a thousand times, *so what happened* was I said to Philip [Medical Consultant] 'We want to do it ourselves,' and he said, 'Oh, that's no problem,' And we had a little run, one of the nurses in [the treatment centre] did a bit of a run through but we knew that anyway but I mean just a little run through about cleanliness and what, whatever.

Mother (inaudible) and changing a site and everything, because we did that as well.

Father: Yeah, so we, in the end we used to change her site which means we used to have to scrub up and put on the super-duper gloves and not touch anything and all the rest. Which we'd seen done a hundred times, and change her site and iodine her down and then we, we'd change her bungs on the end once a week or fortnight and whatever it was now?

Mother: Mm.

Father: Plus all the drugs we gave her. Plus then, all her anti-vomiting drugs, like the Ondansetron. We'd get IV and we'd just do it ourselves. We'd ... actually from the hospital [after chemotherapy] we'd stop half way home or something ...

Mother: And do it.

Father: ... and give her some because we knew that she's going to throw up in ten minutes (...) so we'd stop at somewhere, get the old alcohol swab out and give it a clean down and it was just easy.

Mother: It was so much easier. Besides she wouldn't take a lot of oral drugs. I mean the Ondansetron tasted horrible and Prednisolone she wouldn't take orally, so we'd give it to her IV. And that was just so much better.

Father: Yeah. And then we knew that Monday she had to have her lines flushed but, didn't have to be at 10 o'clock when the nurse got here if we wanted, I mean time was precious every day. (Int. #3, p.56-57, oncology/home)

In the hospital there was a clear demarcation between 'nurse things' and parental involvement in the child's care. In this context parents assisted in the care of their child in such ways as washing, feeding, toileting and playing. However, parents experience of 'living in' with their children in hospital also enabled them to become conversant, by observation, with many of the professional aspects of their child's care.

Additionally, parents' awareness of cross infection and the importance of maintaining asepsis when performing procedures was exceptionally good. This was particularly evident within the oncology category. The children and their parents were taught this early in the treatment phase, as susceptibility to, and the impact of infection on a child with leukaemia for

example, can be life threatening. Practices such as hand washing prior to changing dressings were considered by parents to be not only common sense but vital elements of competent professional practice. With this knowledge and as the primary protectors of their children, parents assessed the competency of staff. Any health professionals not adhering to these practice standards caused parents and their children to become not merely anxious but alarmed. On a number of occasions parents cited such lapses as the reason why they lost trust and confidence in staff assigned to support parents at home.

Father: First lady [nurse] gets out here and she's ... patted the dog I think on the way in, come in and then she's about to do [flush child's central venous catheter] ... I said, 'Have you washed your hands?' 'Oh, yeah, that's right.' So she's wandered off to wash her hands. And then she's salining the central line and she's gonna go, 'Oh I haven't seen one of these before,' and from that time I just thought ...

Mother: We just cringed.

Father: What are we doing?

Mother: It was like - Oh my God!

Father: Like, and I really kick myself now. We should have just said 'thanks a lot ...'

Mother: Yeah but we didn't know.

Father: 'See ya later ... we'll do it'. But we didn't know any better. And that went on ... flushing ... that probably went on for three weeks I suppose, and it was a different [nurse] each time. And ... we might've got one good one in the middle but thought, oh no this is not worth it. (Int. #3, p.52-53, oncology/home)

The children themselves also assessed staff competence, as this mother explained:

Mother: He didn't like anyone treating him like a kid ... which they [doctors] do tend to do, they patronise. I don't know, he just, I suppose when you've been ill for so long and you've been through so much you get used to what they should be doing and what they shouldn't be doing and way back in the beginning when he had transplant, the first one, they were educated that everything had to be sterile [when] the central line was done he wouldn't let people touch it, he was paranoid you know, like they've instilled in him the (...) the infection side of stuff. And he just saw too much. I mean, we were in intensive care once after the first transplant and one of the nursing sisters was accessing his line, she dropped a syringe on the floor and picked it up and put it back on the trolley. Now he was in intensive care, pretty well zonked out, and he went berserk. He would not let them touch him we had to get the oncology sister from the ward over to access him, he

just wouldn't let them touch him. And ... incompetence, he hated incompetence. (Int. #4, p.19-20, oncology/home)

Alexander's parents were not taught how to give his injections for what they described as "political" reasons, meaning, hospital and professional regulations. This meant that they were dependent upon nurses' home visits, however, they too expressed similar concerns about visiting nurses' standards of practice.

I used to service his central line because Alexander didn't like other people touching it and we had the ... we had to have the (...) nurse around whether we wanted her or him or not, because that's also political. I used to help down at the hospital when the nurses were busy with scrubs and things and I could do his line and I'm sure, quite sure, and they wanted to, at one stage they were going to teach me to give his chemo, his injections but they weren't allowed to in the end, because this political thing ... I wasn't a trained nurse. (...) they were pre-done though. I used to bring them home and put them in my fridge. Then the (...) nurse would come in and give him his injection. Well the first (...) nurse was very good, but we had some that came in that ... didn't even wash their hands you know, unless I'd, I'd tell them, 'Go and wash your hands'. And Alexander didn't like them they would, because he was so paranoid about the cleanliness and, and he'd say (hand gesture) you know, and so we had to have the (...) nurses around but most of the ... stuff I did myself and I'd done it ... for all those years. (Int. #4, p.31, oncology/home)

Parents' experiences indicated that there was greater scope for and acceptance of parents undertaking 'nurse things' in the home environment. When in hospital, although parents may have been capable, "political" and professional issues restricted what they were allowed to do. Being able to get out and pursue 'normal' interests and activities was however, extremely important to children and parents regardless of the place of care and so, finding a balance between meeting the physical, social and emotional needs of the child while observing the institutional and professional regulations required a delicate social balancing in order to stay "on the right side" of professionals (Darbyshire 1994). Nurses who 'bent the rules' for those who were confined to the hospital meant a lot to both the parents and their children.

Mother: And I think that when he had some of his down moments he certainly used to get quite angry that he was in hospital and then when he thought about it he realised that he was probably there because he had to be. But we still went through traumas and, and everything and ... that's where, where some of the, the nursing staff helped him. Some of the male nurses that he'd, he'd really

become attached to. Where they were able to pacify him sometimes, much more so than even we could. They were very good for him because even when he was in and he was really sick, they'd take the time to do something with him.

Father: Mm.

Mother: They could often take him out for a couple of hours which we couldn't only because they could go and, and do all the extra bits and pieces of treatment while he was out, that we couldn't do and that meant a lot to George, it certainly meant a lot to us but it was good for him.

Father: Although occasionally we did sort of bend the rules a bit. (laughter).

Mother: Are you talking four legged creatures? (laughter).

Father: No. I'm talking about giving him his drugs at the cricket.

Mother: Yeah.

Father: Yeah. Only certain people [nurses] were supposed to give the ...

Mother: The IV drugs.

Father: Yeah.

Mother: Yes.

AH: So you assisted there?

Mother: We often, we used to do it outside the hospital so he could stay out.

Father: Mm.

Mother: And it was certainly not desirable. Not from, from the, the hospital's side but between us and the nursing staff we used to manage to do that ... because there were certain aspects of George's life that were really important that no matter how sick he was he didn't want to miss out on them. The cricket was one and the Crows match was another. And it really ... if you didn't take him to those I don't think he would have been nearly as, as even tempered because it meant so much to him, to still be able to do those things and not be ... just left cooped up in bed, so that was kind ...

Father: Yeah.

Mother: ... yeah, we bent the rules. (laughter)

Father: I mean, and there was the dog yeah. Smuggling the dog into the hospital to visit him (laughter)

Mother: He loved, loved his dogs. (Int. #9, p.41-43, non-oncology/hospital)

In more favourable circumstances, parents may have insisted that their children 'stay in bed' until they were well enough to pursue social activities. However, the knowledge that their child was not going to get better prompted a shift in parent's thinking and priorities. 'Where there's a will there's a way' is an apt description of both child and parental approaches to life in the terminal phase. Parental evaluations of what was important to

their child enabled them to subordinate the severity of their child's physical condition in order to enable their fullest possible inclusion in life.

Mother: On New Years Eve we had to go to Adelaide [at Alexander's insistence]. He died [early] February and New Years Eve we had to go to Adelaide 'cos he'd got the money for Christmas from his ... [father's] parents and ... different people and he had to go and spend it on a camera so we, the wheelchairs, oxygen bottles [went] down to Adelaide. We had to go to this special camera shop where his nieces' husband works to get a new camera. That was a, one of Alexander's little friends came and helped me push the ... thing that carried oxygen ...

Father: Yeah. Just prior to his death, not long ...

Mother: ... bottles. It was a week virtually before he died he had to go shopping for a camera.

Father: That was in January wasn't it? We went to ahh, North Arm speedway?

Mother: Yes.

Father: He only lived a couple of weeks after that and ahh ...

Mother: Australia day. So, 26th January

Father: So it was only a fortnight before he died. That's where he wanted to go, wheelchair and everything and ... did not go to sleep or anything all night.

Mother: I thought he'd fall asleep on the way home. He'd be exhausted 'cos it only finished about, he wouldn't leave until the last light went out ... and we got in the car to come home and I thought oh, by the time we get off the road he'd be ... gone [asleep] he talked *all the way home about this driver and that rider*.

Father: One of them he knew because he played footy with him.

Mother: And I couldn't, I couldn't calm him down even when we got home he was that excited. He slept all day the next day but that was all right. And I rang my mother in Queensland and told her where we were going and she said 'do you think he's well enough?', I said 'no, but it doesn't matter'. (Int. #4, p.62-64, oncology/home)

During the treatment phase children were the recipients of a wide range of invasive activities which although aimed at cure, were none the less traumatic. For a number of children this took its toll on their willingness to tolerate procedures unconditionally. As noted in Section 2.1, the child's painful or unpleasant experiences could influence where they wanted to receive their final stages of care. Their hospital experiences could also influence children's expectations in regard to certain aspects of their care. It was explained to Malcolm's mother, by a social worker with an understanding of the impact of illness on children, that making sure that health professionals (and parents) performed procedures in a particular way or sequence was a means by which some children felt able to exercise a

degree of control over the events that were happening to them rather than being merely passive recipients of care.

Mother: When something like that happens to a child [cancer] they, they change (...) I mean Malcolm was very ... much ... well it [was] explained to me that he wanted to be in control of something and he couldn't control his treatment but he'd control perhaps how fast you flushed his line or, or in which order you did things and he'd be very vocal about those sorts of things and yeah, being told that that was quite normal [helped] ... long pause. (Int. #5, p.43, oncology/hospital)

This explanation certainly helped Malcolm's mother to understand, accept and accommodate what might otherwise have been interpreted as uncooperative or difficult behaviour. Parents' accounts indicated that different service providers approached care differently and that this was, at times, unsettling for both parents and their child. For them, this was not continuity of care. One parent suggested that the primary treatment centre could make the transition between organisations and individual service providers smoother by contacting the receiving team and instructing them on 'how we do things' before care was required.

2.2.3 *Parents' Multiple Roles : 'Me the Mum and Me the Nurse'*

When in hospital, parents found themselves trying to carry on with the "normal caring things" that were such an everyday part of being a parent³. Stefan's mother, who lived in with him twice during hospital admissions, described the integration of 'normal' parenting within a hospital context.

Mother: When he was really sick he was in hospital so they cared for things. I was really only caring for his oh, I don't know, I mean I helped with anything that was needed but I was there for all the emotional, all the, the normal caring things that a mother would do. I was always there for him, to sort of ease the, I mean no one likes to be in hospital and being fussed around so, and he was just like that, but you know, you're there to jolly him up and whatever is needed. (Int. #8, p.31-32, non-oncology, home/hospital)

Conversely, there were occasions when parents experienced difficulty in the home, reconciling the activities of providing care with the need to be there for their child as a parent. Episodes of task-induced stress occurred in areas related to getting enough rest, pain assessment and management and

³ 'Live-in' parents in Darbyshire's (1994) study described this in detail. These parents described the distinct difference between what they termed 'basic mothering' and 'technical' activities.

administration of medications. Additionally, educating new treatment teams in the care of the child could also be stressful.

Oliver's mother recounted what for many parents of terminally ill children, will be a familiar and distressing scenario of the struggle involved in giving her child his oral medication which needed to be taken after food.

Mother: One of the very difficult thing things that I was finding that, that, well a few days ... before he ... went back to the hospital [for a scheduled appointment] was that he had medication that he had to take after food and because he was vomiting he didn't want to take ... he didn't want to eat anything and if he didn't eat anything we couldn't give him his medication and ... we were fighting with him all the time over these *rotten* you know, tablets and stuff that he was supposed to be taking. I just found that really upsetting because I thought oh, you know, haven't we got better things to do? (Int. #6, p.18, oncology/home)

Trying to do the 'right' thing medically, yet ever mindful of their limited time left in which to do more pleasant things together, the 'fighting' caused significant upset however, subsequent to the scheduled appointment Oliver's medication was given intravenously. He died however - four days later.

Some parents had difficulty and/or concerns about monitoring their child's pain. All participating parents found it distressing if their child appeared to be experiencing pain. Keeping them pain free was difficult at times because drug tolerance levels would increase and, at the same time as their child's decline progressed, pain levels would also often increase. Isobel's parents, for example, had been trying to admit her into a hospice, but as her mother observed, "the trouble is, somebody has to die in (...) these places" before a bed becomes available. In the intervening time, both parents and child became distressed as a result of the child's pain, to the point where the child was asking her father to end her life.

Mother: Issie died on a, on the Monday, about ... the Thursday beforehand ... she was in a lot of pain and she asked Ken [father] you know, to kill her. She didn't want to be here and that, that really hurt. We, we'd just get the ... she was on Kapanol and we had to break it apart, she couldn't swallow the, the actual capsule but it was all right to pull the Kapanol apart because it's got tiny little granules and she'd get them down. We'd just get the dosage right ... and then the next day it wasn't holding. So she was in a fair bit of pain. (Int. #7, p.28, oncology/hospice)

Mother: Before, we took her down [to the hospice] she was sitting up in bed trying to take the Kapanol apart

and they spilt all over her bed and she ... and we thought

...

Father: She just got upset.

Mother: She got so upset ...

Father: Yeah

Mother: ... that she couldn't ... and she had trouble ...

Father: She said I can't swallow them.

Mother: She couldn't get the Kapanol down.

Father: Because the dosage by that time was, was absolutely enormous and she ...

Mother: Yes. She was taking so many ... so many of these small ... if she could take them straight down that would have been fine but she couldn't. There was quite a lot of these little, little ... so we took her down and ... by this time she was in so much pain they just put her into bed and that's, that's when they gave her so much Morphine, whatever, I, I don't remember what they gave her. And ahh ... that's where she stayed. That was horrible ... yeah. Absolutely dreadful. (Int. #7, p.40, oncology/hospice)

The intensity of providing twenty-four hour care at home was demanding. For most parents support services were limited and/or usually involved help with specific tasks such as administering intravenous medications rather than actual relief care which would enable the parents to have a break. For many children, their care required 'specialised' knowledge and thus normal avenues used by parents of well children were inappropriate. One mother, who works professionally as a trained nurse, described what it was like for her.

AH: How did you feel about having to do the majority of it all by yourself?

Mother: I guess ... well, I've often thought about it but I guess because of my training it was kind of like ... you just do it anyway. Sometimes it was hard to sort of separate ... me the mum, and me the nurse, it almost, you'd almost go into automatic mode and ... do what you had to do and then ... sit and cry later.

AH: Because it was tiring?

Mother: Yeah (crying) I think you just ahh ... the last few months because she was just *so* sick ... but you know, you just ... it almost seemed like you're on call twenty-four hours of the day, seven days a week. And like you know, it's really hard because you think you know, if I was in favour of euthanasia would I want something to be done?, but then you think ... oh no, she's still ... her and she still smiles and ... in between when she's not sick (laughter) she's yeah, so ... yeah. It was hard. (Int. #1, p.22-23, non-oncology/home)

Susan's parents were upset and felt unprepared for the effect of the commencement of Morphine on her demeanour.

Mother: We didn't know what to expect when the Morph ... when they gave her this Morphine. No one told us that ... she'd be irritated.

Father: No Philip [Medical Consultant] probably would've told me over the phone, but it was not the same as someone *being* there.

Mother: Yeah, and explaining things ...

Father: Mm.

Mother: ... to us and ... this is how she's gonna be. I mean she *hated* us. When she went on the Morphine she just *hated us* ...

Father: For the first day.

Mother: ... for the first day. She didn't want to go anywhere near us, she was grumpy.

Father: She was too.

Mother: She didn't want to be *touched*. I mean she walked up until the day she die ... before she died. And she was walking and so she did not wanna be picked up. She'd be so drugged out but no, you do not pick her up. And that was *so* hurtful to us. It was like, you know, we haven't got much time, why, why is this happening? (Int. #3, p.88, oncology/home death]

Parents also found themselves in the unusual and often difficult position of having to educate and watch over the professionals who may not have had the very specific practice knowledge related to the child's particular care needs. One child, whose care alternated between the hospital and home, required respite care over the Christmas period because the hospital ward that she usually stayed in was closed. She had a very rare condition requiring specific care which was not easily mastered.

Mother: She was at the [hospital] most of the time. So she was at the hospice, twice she was at the hospice over Christmas and ah, thinking about it and that was only ...

Father: Because the ward's closed.

Mother: ... because the ward closed over Christmas.

AH: So was that subsequent years was it?

Mother: Yes

Father: Two years running.

AH: Right.

Mother: *That, we could've* done without.

Father: She got worse ...

Mother: I mean ...

Father: ... both times.

Mother: ... [The hospice] was, it's a *fine place*, and I have *nothing* against it at all, *but* you immediately transferred her from one care group into another care group and you had to reteach everybody, how to look after her.

Father: Took them a month to learn and by then she was going back ...

Mother: By the time they got to the end of the month she'd gone down, she went down hill quite a lot when she was in there really ...

Father: Both times yeah 'cos they ...

Mother: ... and not through negligence. It was just *lack* of knowledge of the things that kept her comfortable and the fact that she wasn't really happy there.

Father: We brought her home every day as well (...) while she was there, but she, she was very difficult from the point of view that ahh ... I don't think that anyone has ever seen spasms like this. I mean it's ... I, I went in the hospital once and there was ... what? four of them trying to hold her down! (Int. #10, p.59-60, non-oncology/home)

Although both parents were proficient in caring for their daughter's complex needs, caring twenty-four hours around the clock was impossible because of the intensity of care required and because of the resultant impact that it had on their capacity to have adequate rest as well as being able to care for their other seven children. However, parents it seems, must be seen to be 'coping' and 'managing fine' as the following account highlights.

Mother: Every time the jaw locked open she was fighting for breath, well we were, or Dave was up for three weeks or something ... with her half the night, trying to close her mouth and he got no, no sleep for three weeks, he got ... blue and black eyes and ... still trying to carry on working, and get the kids at school and everything. We had a, a review, monthly review I think with the doctor and Doctor Cooter sort of said, 'Hi, how are you coping?' and Dave says, 'Oh, fine, fine.' I said, 'Look at him', you know, I said, 'Oh, this, this can't go on'. So then, they organised for her to go into [the hospital] I think it was, for a couple of weeks, while they sorted a few things out. (...)

Father: We brought her home every day, but they had her overnight.

Mother: That's the only way we could've got any sleep.

Father: Mm. (Int. #10, p.10-11, non-oncology/home)

It is interesting to note that in this account it is the mother's possibly painful 'admission' that things are not "fine" and that "this can't go on" which seems to be the stimulus for the provision of respite care. It would be a cause for concern if parents were to have to reach 'the end of their tether' in front of professionals in order for respite care or any other support services to be made available.

2.2.4 Pursuing Normality : 'Having a life'

A central tenet of palliative care is that its success is determined not by curative measures but by quality of life concerns. For parents in this study, quality of life was equated with what they and their children perceived to be 'normal' for them or, what was the closest possible approximation to how their child would be in the family context if there were no threat of sickness and death. As such, quality was associated with life affirming activities such as holidays, playing, outings, maintaining friendships, being free of pain and having their sick child at the centre of family life, even if they were not able to actively participate. The following accounts are illustrative how parents kept their child at the centre of the family's world.

Mother: He spent the last week in hospital. He was ... it was during the ...

Father: Two weeks.

Mother: Was it two weeks? He was wanting to go the show [Royal Adelaide Show] and he'd got a fever of some sort and he actually did go the show the Friday before ... he died Sunday and he went to the show on the Friday.

Father: That's what he was like. If he, he wanted to do something he'd ...

Mother: He was determined.

Father: ... he'd do it. (Int. #5, p.13-14, oncology/hospital)

Father: Yeah well, we had him in the room, lounge room here [family home]. I guess, I think part of it was when he first came back [from hospital] was thinking, one it's easier, and two when he had been so much ... he wanted to be out here a bit too because he, in the ward you've always got so much activity, there's the noise and the, the bustle all the time. (...) But because there had always been activity around him that he, when he went back to his own room he sort of felt isolated you know, quiet, too quiet, sort of, off the pace a bit.

Mother: Got lonely.

Father: So he actually asked to come out here and so we set his bed up ...

Mother: No he was uncomfortable in his bed too ...

Father: Bed too, yeah.

Mother: Yeah he wasn't happy in his bed so ... it was just nice if he was going to be in bed all day, you know, just for him to be sort of part of the ... group, the family and ...

Father: So, so his bed was set up, a camp bed was set up by the window there so he could, even if he was dozing or whatever I mean he could always have one ear open kind of thing, he could be aware of what was happening around him, and the general household activity. (Int. #6, p.36, oncology/home)

During the interviews a number of families made reference to a particular point when the child's condition deteriorated to the extent that the child and/or parents no longer felt that they "had a life". For the majority, this

generally occurred days before death and was always when pain and suffering outweighed the child's capacity to find pleasure in themselves and their surroundings.

Father: He was prepared to try anything [treatment]. He just wanted to ... get out of it until right at the very end. About three or four days before he died, he just came up with the statement that 'Am I ever going to be normal again? When am I ever going to be normal again?' well he just deteriorated rapidly over the next couple of days.

Mother: Yeah. And he made comments like 'I can't handle this any more' and, and then, you know, you just, I rang up the hospital and ... he was on little morphine tablets and they just said 'all right, if he's in pain, give him more'. So I did. Then he wasn't, he just, only once he decided that that was enough then that ... was enough. (Int. #4, p.16, oncology/home)

Mother: When Alexander died it was ... it was traumatic but it was a relief because he was ... suffering so much by the end he was. Didn't have a life.

Father: No, and he knew it. That's why he was getting pretty fed up in the last couple of weeks. He was just so weak, he could hardly turn around to have a look at the dogs outside. (Int. #4, p.62, oncology/home)

Mother: Albert [Medical Consultant] said 'if you want to do anything, you do it soon not later, you might have two weeks, you might have three weeks'. So we did take her away for a week.

Father: To Victor Harbour.

Mother: To Victor and she just laid on the bed the whole time. Yeah.

Father: And she was ... she had friends come and visit her and even during those times she was in, in, a lot of pain.

Mother: Lot of pain, yes.

Father: And she had to go to bed while they were visiting her.

Mother: Yes she was ... yes, she just, she virtually collapsed. Well ...

Father: And we wanted to take her out on a couple of occasions she, she made the effort in a wheelchair down with us and ... I even pushed the wheelchair up onto Granite Island up the top and ahh ... that, that was a bit of a bumpy ride for her, see she felt every little bump and ahh ... we knew things weren't really flash then. And we came home and she didn't get out of bed for the next seven weeks. (Int. #7, p.22-24, oncology/home)

Factors determining what was normal for individual children were influenced by their personal experiences of life. Usually they would be

associated with activities outside of the medical context but for one young toddler who had spent a large proportion of her life undergoing treatment for cancer, 'normal' included her experiences of undergoing medical examinations. The importance of maintaining the usual routine, even though it would have no medical or curative benefit, was appreciated by both child and parents. These parents' account illustrates the importance of maintaining and continuing the connection and caring which underpinned even something as potentially upsetting for a child as an examination.

Mother: Philip [Medical Consultant] was wonderful and he had such a wonderful relationship with Susan. Susan loved him and when she started talking and she'd ... he'd be the doc.

Father: Here's Doc.

Mother: Here's Doc. And Susan had this little routine or Philip had this routine. (...) Well we'd play with those lights while he was looking at her, but he had this little routine for checking her ears ... first, the tummy, the ears? tummy? legs?

Father: Mouth.

Mother: Mouth, oh ears, *mouth*, tummy and, and she'd had a little fissure so he used to check her bottom as well. And ... if he did not go in that correct order she'd get really cross with him. (laughter) And like she'd sit there and, and ears, like he'd turn her and she'd sit there and turn around for him. Then she knew exactly what was next, so she'd open her mouth without him saying anything, and then tummy, she'd lift up her top and then she'd turn around and flash her bottom at everyone. (laughter).

Father: We took Susan down like ... on the Friday, she died on the Thursday, we took her down, this is jumping ahead a bit, the Friday before she died ... to have some tablets and she was crook as a dog.

Mother: She was so sick.

Father: And Philip came up and ... he was talking to us and ... I think he checked her stomach and walked off and Susan went ...

Mother: She's going 'doc'. She did call him.

Father: She was going 'doc, doc'.

Mother: And she's really ...

Father: And I said 'Philip, I think Susan wants ya'.

Mother: ... and she's really ... yeah, she was really funny.

Father: And she's getting frustrated like ...

Mother: Yeah.

Father: ... you haven't checked my ears and my mouth.

Mother: And she pointed to them and he just, and ... you could see the tears well up in his eyes. He just said 'Susan how could I forget. How I could I forget', so he did. I mean at that stage there was no point checking anything else.

Father: No, no, no.

Mother: *But* he did. He went through the whole routine and checked her and she was happy. She was fine. (Int. #3, p.42-44, oncology/home)

Here, there seems to be the recognition and realisation in the doctor's reply, that omitting the customary examination may have seemed tantamount to **forgetting Susan**. Here also we see the transformative power of the most seemingly unimportant caring practices and how they resist being understood within the currently prevalent ideologies of effectiveness and efficiency. From the vantage point of one detached from the concerns of Susan and her parents, this 'examination' of Susan could seem like a pointless and unjustified use of expensive professional time. But from within the involved, caring stance which understands that children too are capable of feeling the annihilation of being forgotten and abandoned (Attig 1996), this doctor's examination is an act of profound affirmation and healing.

During the palliative care phase, health professionals were sometimes faced with situations which required them to make choices about whether to prescribe symptomatic treatment or treatment aimed at cure for acute or chronic conditions. In relation to this, one mother felt that it was very important that parents be consulted and were able to participate in decisions because she felt that they were best situated to determine the overall quality of the child's life. This was particularly so for children in the non-oncological category as often the child's physical ability and/or their ability to communicate was impaired. Two families felt that this negatively biased health professionals' interactions with them and also their assessment of the child's quality of life.

Mother: You want ... people to support *your* decisions, not put their decisions upon you because they don't know your kids. And quite often the problem is they only ever see them when they are unwell. They sort of don't get to know them, what they're like really, in between times. (...) I have always thought it is important for them to see, or know about, your kids apart from when they see them really sick. I feel that it gives them a, a better picture of ... how they are and what they are and sort of, what they're like in the family. Because I think that's one of the hard things that, you know, they ever only see them when they're unwell, they have no concept of what they're like, and how they respond and that when they're well. (Int. #1, p.27-28, non-oncology/home)

This mother received help from foster parents whose opinion of surgeons was somewhat lowered because of their inability to see the child as a 'whole person'.

Mother: Sylvia would tell a story about one of the surgeons that did the Nissen's procedure on one of her girls. She says you know, 'typical arrogant surgeon, they

never look at their patients other than the area they're operating on'. One day she went to see him, like this is before the operation or something, and she said to him 'Why don't you ever look at her face?'. (laughter) And he did. He said 'Oh, she's quite a pretty girl isn't she.' I mean she was severely disabled, she was blind and, and she said 'I damn well made him look at her' because she says they quite often do not *look* at the kid, they just see the problem and don't see the whole kid. So she said 'I made him look at her' rather than concentrate on prodding down around the abdomen which was the area that he was interested in. (Int. #1, p.28-29, non-oncology/home)

The following account describes another mother's experience of taking her son to hospital following his collapse. While the actions of the staff could be considered consultative, the mother's interpretation of the experience was that it was discriminatory.

Mother: Yeah, they had to bring him round [after he had collapsed at a wheelchair games event] but they [hospital staff] just looked at me as if to say, all they could see, because at that stage Stefan was already ... quite a curvature of the spine and he was bent over you know. He was in his wheelchair but he couldn't sit up nice and straight any more, he was quite bent you know, and they, all I could, from my point of view all I could see is ... them looking at this, to me I'm thinking they're just looking at this thing ... lying there you know, and thinking 'well what are we going to do?' you know. But to me it's my *child* it was my, my fourteen year old child that they were sort of looking at. And I am thinking, they asked me, they said 'what do you want me to do?'. And I said 'you save that child's life, you do what *ever* you can to save his life thank you'. You know? And I thought - what the heck, you get all these thoughts in your head thinking well ... they're just looking at ... something you know, because, because he was twisted a bit you know that ... to them. (Int. #8, p.11-12, non-oncology, home/hospital)

Parents of sick children often report their anger and feelings of loss of confidence in professionals when they fail to recognise and affirm the individuality and unique biography of **their** child (Darbyshire 1994). This situation could be said to be exacerbated and heightened where the child is dying, where time is so precious and where there are few 'second chances' for professionals to 'get it right'. The parents describe later how much they would have appreciated nursing and health care support during this palliative care period from staff who were familiar with them and their child and who understood both the nature and particular procedures and practices associated with Paediatric palliative care.

2.3 Juggling Family Needs

Caring for a dying child was extremely time consuming and often required parents to make significant changes in their lives. The two most significant issues in relation to family, other children, friends and social networks which parents raised were the impact of illness on other children in the family and the parents' capacity to remain in paid work.

2.3.1 *Brothers and Sisters*

Of the ten participating families, the number of children in each ranged from one to eight. Thus all but one of the children who were the focus of this study had one or more siblings. Parents related that brothers' and sisters' reactions to and acceptance of the family's situation varied. Some found it difficult to watch their brother or sister deteriorate while others actively involved themselves in the care of the sick child. One had twice donated bone marrow in an effort to cure his sick brother and some took on the role of surrogate parents to younger siblings while their parents' attention was consumed by the needs of the dying child.

The majority of parents did not raise the issue how or if they prepared siblings for the death of their brother or sister. Jenny's mother however did mention that she had tried to prepare her daughter Lucy each time that they thought Jenny might die. Because of the number of times that Jenny had reached a critical point but subsequently recovered, Lucy became quite "fed up".

Mother: I tried to prepare Lucy every time that, you know Jenny was really sick and she might die, and [after a few false alarms] she stood there, she stomped the floor with her hands on her ... on her hip and said, 'Well just when is she going to die? (Laughter). She was quite fed up that we kept preparing her all the time (laughing) and then she wouldn't die. (Int. # 1, p.8, non-oncology/home)

When Jenny did die, Lucy said:

Mother: 'Are you sure?' and I said 'Yes her heart's stopped beating'. 'Well I'm going to check!' You know having had the experience before that every time we told her she was going to die and she didn't. So she ran away and got my stethoscope and had a listen, she said 'I can't hear her heart beating' and I said 'No, her heart's stopped now.' 'Oh well, she must be dead' she said (laughter) quite matter of fact.

AH: And how did you feel at the time?

Mother: Oh, Lucy could always give you a laugh. (Laughter) But like, she had to make sure for herself 'cos she wasn't gonna listen to what anybody else said. Yeah. I mean the only thing that stuck in Lucy's mind and that worried her about ... the whole thing was just the ugly sort of bruises and that that were on ... Jenny's legs and that. I mean the fact that she was dead and that didn't ... you know, because we'd prepared her ... so much and ... you know, I told her what dead people look like and ... they're very, very pale and they don't open their eyes and they ... eventually get cold and basically you know, reinforcing over and over. And all the time like the previous six months of trying to tell her that it wasn't going to be long (laughter) and that. And so the fact that she died didn't seem to bother her too much, but the thing that she remembers to this *day* is ... all the ugly bruises over ... Jenny's legs and that. (Int. #1, p.33-34, non-oncology/home)

Accounts such as this seem to indicate that younger children such as Lucy did not appear to approach the death of their brother or sister with the same degree of trepidation or anticipatory grief that their parents did. Oliver's sister Rachel had been staying with her grandparents so that the parents "could devote their entire attention to looking after Oliver". On the day of Oliver's death the grandparents and Rachel went to the family home, however Rachel's general behaviour and inability to fully comprehend what was happening was disconcerting for her parents who fully appreciated the seriousness of the situation.

Mother: My Mum and Dad had come over and they'd brought Rachel. So ... yes ... so they were here with us and Rachel was here. She got to say goodbye to him.

Father: Like he, he had, basically he didn't say much at all, for most of the time, except for ... you know ... drink please or ... whatever. Didn't really have much to say to her or whatever but then, in the middle of the afternoon sometime he just said, 'Oh Rachel, you can kiss me goodnight now'. And then she responded to that and then she went off and she was ... you know, just playing around the place ... and then when he really ... started labouring for breath, well I think faster and then slowed down or something didn't he? whatever ... but his breathing changed dramatically ... and Josephine's mum was here and she had been a nurse and she probably saw what happening ... realised what was happening before we did. Certainly before I did anyway ... she sort of asked ... her husband to take Rachael, just take her out for a little bit ... which he did so she was ...

Mother: She was dancing around and ... showing off to everybody and ...

Father: She was having wonderful time, so not quite the right ...

AH: Being a five and a half/six year old.

Father: Yeah.

Mother: Yeah it, it was just a bit difficult you know, having a yeah ... I mean she ... I guess she, she knew what was happening but ... the reality of it ... you know, didn't sink in so ... yeah her behaviour wasn't really appropriate and it just ... so ... [it was] just good for her to go out just for that little while. (Int. #6, p.34-36, oncology/home)

Stefan had two younger siblings with the same medical condition and as such, the prospect of an untimely death was also expected for them. With this in mind, their mother was concerned about how they would react to Stefan's death.

Mother: I always used to think - well, how is it going to affect, like Peter and Bronwyn with the same condition. Are they gonna think well, Stefan's not here you know, when is it gonna happen to me. And I am sure that did enter their mind you know. Bronwyn being very ... lot younger ... she must have been four. She being so little and very innocent and, she came out with some really, really good things you know at times because Stefan had a ... lap top computer ... lent to him by [a service provider] and of course that had to go back because it is for *that* person only and when that person does not need it for whatever reason it goes back and of course they wanted it back.

But Peter at this stage could have done with one. So the school thought - well, we'll hang on to it, ask [the service provider] whether Peter can have it. 'No he can't have it, it's got to come back, we've got to go through all the paperwork and blah, blah, blah, and see whether he can have one'. So it sat at the school for months and months and months and then they came back and said 'yes, he can have it now' you know, and Bronwyn thought - it came back and it was Peter's now. She said 'Oh, does that mean when Peter dies I get it?' (laughter)

Such an innocent thing and she came out with lots of things like that and you, you just got to laugh at them because it was so ... classic you know. I mean it hit her terribly too. I mean she was old enough to understand what was going on. She used to walk around with the Stefan's photo ... dancing around here to the music and kissing him and saying 'Oh Stefan, why did you die, why did you die'. And you'd see it and it [would] break you to pieces but ... that was a, a way of coping you know. (Int. # 9, p.27, 30-31, non-oncology/home)

Her eldest son coped differently however.

Mother: Jack, who was our oldest, he, he didn't come [to the hospital when Stefan died]. (...) He actually

disappeared ... after Stefan had ... like I said they had just walked in through the door when Stefan had passed out ... at home here and he actually ... went out when, after we'd gone in the ambulance, he'd actually gone and I thought 'heck where has he gone?' and I was worried the whole time in the hospital, I was worried 'Where's Jack? What's he doing?'. But he just had to go. Went for a walk. And he's a drummer. He's actually in a band and he was a drummer then and he came home and he just bashed the heck out of his drums (laughter) to get it out of his system. But he wouldn't come to the hospital. No. He thought no, I just want to remember him ... the way he was. (Int. #9, p.23-24 non-oncology/home)

For one young boy, seeing his unconscious sister having seizures was something that he wished he had not seen.

Mother: Patricia [nurse] suggested that Bradley come to meet us at ... they have a little airstrip halfway between here and [nearby town]. Well I hadn't even thought of that because if she'd died Bradley wouldn't have got to see her and a friend of mine brought him down to meet us at the airport which ... was really hard because she was fitting quite badly and ... he ... well he saw her and ... sort of took him away because ... I mean he'd sort of been there through her whole illness and saw lot of awful things happen to her and ... just got her to the hospital and ... got her settled in and ... we brought him back and you know he'd, he'd spend, spent some time with her but when she started fitting all the time sort of, he didn't, he said 'Mum, I wish I hadn't seen that' He didn't wanna see that. (...) He found it hard. He'd come into the hospital in the morning about, round about 11 o'clock and he'd spend a couple of hours with her and ... you know, he'd just talk to her and hold her hand ... [be] with her. I think she, I don't know whether, you don't know whether she could hear or not but he just did that and ... he'd go off and then come back at three and ... then spend the rest of his time ... there. But to keep him there all day long was, was too much for him and it was too much for us. (Int. #2, p.31-32 oncology/hospital)

Six of the ten participating families had two children each. Some parents had help from family and friends both in providing respite care with the sick child and by caring for other children in the family. Some juggled looking after both children by taking turns with each child. When in hospital, the logistics of doing this was greatly assisted by the availability of play rooms which were attached to the ward. It made a significant difference for one family whose son Malcolm, spent the last two weeks of his life as an inpatient. Malcolm was concerned about picking up 'germs' from his sister and was therefore not inclined to have her in his room. His

mother would then spend time with the him in his hospital room and with his sister in the playroom.

Mother: I'd go and pick Kristie up from school and we would go straight back in [to the hospital] and then wait for Daddy to come from work. The playroom's most helpful because Malcolm wouldn't let her go in his room in case she had germs. So having somewhere where she could go and be happy rather than feel ostracised or unwelcomed [was good] she'd have better fun in the play room than she would've if she was in Malcolm's room. That was certainly very helpful, and I used to go and spend some time in there. (...) Without the playroom I wouldn't have been able to bring her in and she wouldn't have seen much of Malcolm. (Int. #5, p.44-45, oncology/hospital)

George's parents were keen to enable his brother to pursue the usual interests and activities associated with a 'normal' childhood such as involvement in sport. This meant that his mother spent more time caring for George while his father cared for his brother.

Mother: I spent most of the time with George so that Garry could take Louie out. Because we also didn't ever want to stop Louie doing the things that he wanted to do. I mean that was the last thing we ever wanted because Louie found it very difficult having George as he was. And I think from a young age he learned that he never knew if we were going to be home or not because of how George was being rushed off to hospital or rushed interstate and things like that. So Garry, really you took over taking Louie to soccer practice and cubs and athletics and all those things and I spent a lot more time with George during the week. It served it well because at least Louie grew up with a reasonably normal sort of upbringing doing things he wanted to do. (Int. 9, p.30, non-oncology/hospital)

Dividing parental attention between brothers and sisters was not however, always possible. The parents of one child who had seven siblings, were simply unable to give the other children the attention they believed they needed. Following their sick child's death their mother was preparing to "get back on deck" again only to find that in the intervening time, her other child had "grown up" and now felt that he did not need her as much.

Mother: And I was, I didn't know, for me it's almost a relief when she'd gone because she was suffering. That last fortnight, I think, well she, she was, she wasn't suffering too badly. She only, she got a tremendous grip on life. I mean she didn't want to let go. But that last fortnight she, (inaudible) she was tired, so, in that way I guess I was grieving before, and, and also because you've

then got time to try and give all the other kids some time. *They, they were* good in that they knew ... the rest of the family had to sort of give way to Louise's needs and they did, they (inaudible) anything like that, but, I think we were both aware at the time that we hadn't given them the time and attention that they should've had and they needed. And of course it was quite funny once we'd, once we got back on deck again it was, I thought I really must give David more attention. He was going to his dad saying 'I wish mum wouldn't give me all this attention, I've done without it', you know, 'I don't need mothering now, I've grown up!' (laughter) So I had to learn to back off again. (laughter) (Int. #10, p.39-40, non-oncology/home)

2.3.2 *Parents Work and Careers*

The impact of having a very sick child affected all areas of parents' lives. They described it, using a range of metaphors of destabilisation and powerlessness as, "losing control of our lives", "putting your life on hold" and 'having the rug just pulled out from under your feet'. One family found it necessary to relocate themselves closer to their child's hospital while another built a new home so that the hospital-style bed their daughter used could be moved easily throughout all areas of the home. Parents' employment was also often put on hold or adapted to suit their caregiving schedules. Some mothers and fathers were able to retain their employment by taking combinations of long service leave, annual leave and leave without pay. For two families, their place of residence was also their work site. One mother described how this was not the convenience that may initially be imagined.

Mother: I was doing a lot of work in the enlarger room at that time 'cos we did photographs and most, most my work now is done on a machine but at that stage it was all done in the dark room. But even now, if someone wants an enlargement done, well they can wait, and they can wait, and they can wait (laughter) and they have to practically push me in the dark room and nail the doors and get on with it, because I just hate being in the dark room. I just can not stand being on my own, *with my thoughts*, you know, because there were, there was a lot of, you'd think about it, and you'd think about it over and over again and it, it was, it was depressing yes, but, at the same time you've got all these other things to do, like a business to run, kids to look after and the only time you could actually think about it was while you were working because in the dark there was lots of time to think. Because we had a, three or four kids, we've got two younger children than Louise and we had, five older ones? So eight altogether. So I did most of my crying in

the dark room (laughter) (Int. #10, p.38-39, non-oncology/home)

Two mothers and one father left their place of employment to care for their child. Another father initially reduced his weekly working hours by taking intermittent annual leave but eventually had to resign.

Father: I had six weeks off and then I was working ... I was working. Well I had to work but Susan was much more important than work. So I worked it out with my employer that I'd have Mondays off as an annual leave day. I'd have ... Tuesday I'd work, Wednesday I'd have off as an annual leave day. Thursday I'd work. Friday I'd have off as a annual, err ... as a day off because I'd work every Saturday. So I worked Thursday, err ... Tuesday, Thursday and Saturday. So I don't know about most people, but if you're only working those funny days you're really not too enthused about work at the best of time let alone worrying about ... if anything was happening at home. And the reason I chose those days was because it was Monday, Wednesday, Friday was our treatment days so, it worked out pretty good. (...) And yeah, it was a month after that she relapsed and that was more devastating than the first time by a long mile. (...)

Mother: The worst. That was the worst.

Father: Ten times worse than being told the first time. Because from the time we were told the first time, all the way through for that seven months we were always winning. From almost day one we were winning because the Chemo [cancer] cells got less and less and then there was none, and then there was none for six months. So we were always winning. But then ... when she relapsed for the first time ... we were losing. And I guess we both knew that if we started to lose ... the chances of losing more is ... greater all the time. So that was ... a hundred times worse that ... when the first time being told.

Mother: Mm. So I just quit work. I just went and told them what had happened and said I'm just, just not coming back.

Father: I didn't come back.

Mother: You didn't go back.

Father: No. (Int. #3, p.35-38, oncology/home)

One mother who was able to continue working said her workplace was very accommodating of her periodic need to be absent but in doing so she never actually took leave to enjoy a holiday.

AH: How many weeks annual leave did you have with your job?

Mother: Theoretically four and I never ever, ever had any for a holiday because I took it off any time George

was sick or if, if there was something going on well then I would take my annual leave to be with him. So I, I never, never had holidays and I never had sick leave as such it was all, all in, in George's care. Mostly when he was in hospital being, really sick and I was really lucky because work accommodated that. I had to work pretty hard to, to keep that up but they gave me a lot of time off on full pay as well and I guess it showed at George's funeral because an awful lot of the company was there at the time but they were extremely good. I was fortunate and Garry, they were very good with you too really weren't they?

Father: I never had any problems at the time. (Int. #9, p.31 non-oncology/hospital)

Another mother also managed to continue working in her part-time position however, she related how, over the long term, recurrent trips to hospital made it difficult.

Mother: Yeah like you know there is one day that ... I got in there about two o'clock in the afternoon ... and I was still there at 10 pm that night in the Emergency Department. She still hadn't been admitted onto a ward yet. And I was supposed to be at work at 10:30. I admittedly, seeing I was still sitting there and knew that it was going to be hours at 7 pm and I rang up and said 'Look I don't think I'll be able to make it to work tonight, I'm still sitting in the emergency department'.

But ... I mean when, when people have got other kids in their family, and they've got other things they have to do you, you know ... it's a big chunk out of your life. Admittedly when they're sick as well in between time it's not like ... most other kids, you know they have a an acute illness, they go in there you expect to wait and you know you come home and they'll get over what ever it is they've got or they get admitted and it's not sort of going to be a constant thing throughout your life, whereas this is. You know it's, that there's always going to be reasons why they're going to be sick. There's, there's not a sudden *something* at the beginning which is say like an accident or something where they, you know, become brain damaged and then there's that vegetative *long* vegetative state. This is always, you know that they're going to progress towards death and it's not going to be just *something* happens and then like ... two years down the track *death*, and they're well in between time or stable in between time. But you know there's ... going to be periods where they're going to be sick and probably ... progressively get sicker. It's not like you can just go in and you've got time to wait *ten* hours while they sort themselves out. (Int. #1, p.49-50 non-oncology/home)

2.4 Experiencing the Child's Death and Dying

Mother: I guess the whole ... whole system no one, no one talks about death do they. I mean it's not a thing that you talk about or get trained on. So ... when it happens no one really knows how to ... cope with the ... death and ... the following on from ... from that. (Int. #3, p.64)

Death and dying in contemporary times are life events which have been confined predominantly to hospitals and hospices. As such, these are stages of life which many people have not had the opportunity to observe, know, and learn about other than perhaps from dramatised accounts viewed through media such as films and television. Dying at home, once a common occurrence in the earlier part of this century, is an option which is becoming increasingly popular, especially for children who are terminally ill. Section 2.1.4 of this report identifies the reasons why some of the participating parents in this study and their children, preferred to be at home rather than in an institution at this time.

Although the death of a child was traumatic for all parents regardless of the place of death, the experiences and challenges which parents encountered in the different settings varied. This section begins with parents' accounts of their prior experience of death and dying as this seemed to impact significantly on how parents coped.

2.4.1 *Previous Understandings and Experience of Death and Dying*

Of the seventeen participating parents two mothers had prior experience of caring for the dying, both through their professional work as a nurses. None of the seven fathers interviewed mentioned having been with or caring for a dying person prior to their child. In two families the child's grandmothers, who had once 'worked with elderly people' and 'had been a nurse' respectively, had previously encountered death.

Two families had experienced the prior death of a child, one at birth and one in infancy. One mother, whose daughter Mary died at birth found that experience 'very traumatic' but qualitatively different from the death of her fourteen year old son Stefan because they had not come to know Mary as an individual, whereas with Stefan, as the mother explained, he was "a person you know, and you've lived with [him] for all that time". For this reason, she found Stefan's death much harder to accept saying that "you never get over it, it just eases a little bit that's all". The very early death of Mary also meant that this mother's experience of death did not include a 'hands on' knowledge which would be gained by providing care over a period of time.

The other mother, whose infant child Alice died while in hospital, found that this experience significantly influenced how she approached Jenny's

death which in turn, has influenced her how she has prepared for the death of the dying child she is currently caring for.

Mother: As I said you know, he [doctor] took her [Alice's body] *away* and on reflection now I wasn't ready ... to give her up. And as I said, having had Jenny die at home and having all those hours with her was, was much better. Like I always regretted not holding her [Alice] longer. So this time [in preparation of the third death of a child] I sort of ... I said 'practice makes perfect'. You sort of decide what's important ... beforehand and then ... hopefully you get a chance to actually tell people before it actually gets to that ... stage so that they know what your wishes are. (Int. #1, p.62, non-oncology/home)

Jenny's mother had both previous experience of her own child's death and the experience she had gained in a professional context. However, she found that caring for her own dying child was uniquely different, an experience that professional knowledge and experience seemed ill-equipped to prepare one for.

Mother: But for me, once it's sort of ... once it's, when it's your own kid it's always a bigger deal than ... it is for somebody else that you're nursing. Just for the strength ... of your emotions and it's something that ... you know, I probably wasn't quite as prepared for this. Because you cope with things in a more detached way at work but when it's home it's a bit different. (Int. #1, P.55, non-oncology/home)

Overall, parents' unfamiliarity with death was a major issue for them. For the majority of parents in the study, the death of their child was an utterly new and alien experience and unlike Jenny's mother, they did not have the 'benefit' of prior learning and experience.

Mother: We'd never experienced ... death ... only grandparents and, and they were a, a good age, and we didn't see them actually die, and that was hard to lose grandparents and Isobel's death is the first death of both families. Tossed us *so hard* ... *ahh very hard*. (Int. #7, p.39, oncology/hospice)

Father: I guess the whole ... system no one, no one talks about death do they? I mean, it's not a thing that you talk about or get trained on so ... when it happens no one really knows how to cope with the ... death and ... the following on from ... from that. (Int. #3, p.122, oncology/home)

The majority of parents described how death was largely unknown and fearful to them. Moreover, some described their great distress because they

felt that the death of their child was untimely and out of sequence with their expectation of the 'natural' course of events. As Roy (1996) noted, "the dying of children scrambles the whole order of human time". According to Roy, a natural and almost compulsive reaction is to pretend that the imminent death of a child is not a reality therefore causing everyone "to turn away from that horizon [of the evening sky and] to make-believe and to act as though the morning has hardly begun" (Roy 1996). For parents the 'make believe' was enmeshed with hope for their child's survival.

2.4.2 *Maintaining Hope: 'You don't want to believe your child is dying'*

In the sections of the parents' accounts where they discussed hope, two salient aspects stood out. Firstly, they did not want to believe that their child was dying and secondly, they felt unprepared to face such a journey with their child. The nuances of the former appeared to significantly impact on the latter. Being told that their child was dying and that there was nothing further that could be done to save his or her life did not automatically lead to parents accepting the child's death as inevitable. Parents did not give up easily the hope that their child would survive. Here, parents describe this:

Mother: Well that ... It was probably in our case, we just didn't ... even think about that. [funeral arrangements] We just put that side of it out of our mind because ...

Father: But I think that's just natural.

Mother: ... whenever we were in Malcolm's presence we didn't feel as though he was going to die. I mean he was so much living ... (Int. #5, p.38, oncology/hospital)

Mother: In my mind and in Ken's mind ahh ... something was telling us.. she's not dying. You don't want to believe your child is dying and right up until the time that she died, we didn't think that she was dead. We thought that she was asleep. (...)

Father: [When Isobel was admitted to the hospice] the doctors ... said well she's ... 'be prepared that, that, that she might not even see the night out' and sort of hit us like a sledge hammer that ahh ... Wow! You know, we didn't ... weren't prepared for this at all ahh ... (...)

Mother: But nobody can prepare you for that anyway, you don't want to believe it. And if somebody said ... she's not gonna live ... we wouldn't, well you wouldn't accept it, well I wouldn't have accepted it anyway.

Father: I was just ... just sitting there [at Isobel's bedside] ... transfixed I suppose and ... trying to cope with the whole, with everything that was happening and all I wanted her to do was ... start breathing again and, and get better and ... get up out of bed and, and come home with us. And ... I didn't even want to accept the fact that ... she wasn't going to. And when she finally took her

last breath ... even then ... and after then well we, we, it was just so hard to get used to. (Int. #7, p.32, 36, 38-39, oncology/hospice)

Some parents did not come to accept the inevitability of death until the final hours or minutes of their child's life. For two families acceptance was expressed in terms of giving their child 'permission' to die and 'letting them go'. In both of the instances related below, acceptance was coupled with the realisation that their child's condition was unquestionably terminal and prolonging life or even simply wishing for it to continue, was equated with prolonging the suffering, for both the child and the parents.

Mother: We, in the end we just said, Mummy and Daddy want you to go (crying) and once we gave her permission she just took ... took her breath and ... and she left you could feel her, her, she, you could feel her going ... (Int. #3, p.107, oncology/home)

Mother: On Sunday he had [developed] pneumonia ... and the doctor said that ... (crying) that 'he can't take any more'. So we just let him go. (Int. #5, p.14 oncology/hospital)

For the mothers above, the time between their absolute realisation that their child was going to die and the child's death was relatively short with both children dying the same day. A longer time frame between the acceptance of death and actual death, coupled with the perceived futility of their child's life in the face of suffering, led Jenny and Gloria's mothers to think about euthanasia. Gloria's mother felt that "when it gets to that stage when there's absolutely nothing left except suffering" that euthanasia should be an option. However she also acknowledged that being theoretically or philosophically in favour of euthanasia is not the same as putting euthanasia into practice with one's own child. But, as a parent sitting at the child's bedside 'waiting' for death and watching the struggle, the child's suffering and the parent's suffering become almost inseparable.

Mother: It's very hard and when you think afterwards maybe you shouldn't ... shouldn't ... think like that you know. I'm saying now I believe in it [euthanasia] but ... in some ways when you do it ... I don't know. I think we all just get ... when there's just absolutely no hope and they're just ... you know, really, you know like they're ... not even breathing properly you know, struggling to ... they have ... they get that sort of death breathing ... that was pretty awful stuff ... to watch. (crying) (Int. #2, p.36, non-oncology/hospital)

Ways in which parents' hope for their child's survival seemed to affect their potential to look ahead and make plans for after the death of their child are discussed more fully in Section 2.4.5. The following Section focuses in part, upon how this phenomena may also have restrained parents from wanting to know and also inhibited them from asking about what happens when a

person dies. Parents also described how the health care system seemingly failed to adequately prepare them for the process of their child's dying. A lack of preparedness was most noticeable among the parents who cared for their children at home. It was in this setting, with only intermittent assistance from professionals, that parents were most acutely in need of information and practical advice.

2.4.3 *Death Dying at Home: 'No one told us that ... she would get so cold so quickly'*

The experiences of parents whose children died at home differed according to how death occurred, the types of support which parents had and the extent of their confidence and knowledge. A sense of being unprepared and not knowing were common themes. Not being prepared emotionally was one aspect which Isobel's mother felt "that nobody could prepare you for anyway". Other areas of being unprepared related to practical concerns such as identifying the different stages of dying and knowing what happens to their body when a person has died. Parents described feeling inadequately supported by health professionals, both at the time of discharge from hospital and when visiting health professionals 'provided support' in the home. The following accounts illustrate the nature of this unpreparedness and the anguish which parents believed could have been lessened if not prevented. For some, such as Susan's parents, this distress remains long after the death of their child, compounding their grief.

Mother: I suppose the other thing that ... no-one really told, well ... they did because Greg asked our GP, was what to expect when Susan died. And I was too scared to touch ... her body once she had ... gone because I'd watched too many TV programs where bones, arms and legs fall off and things like that. No one told us that ... she would get so cold so quickly ... and her skin actually started changing.

Father: I guess ... because I asked the GP that the day before she died. But I guess it was one of ... I, I look at it as one of those things that you really don't want to know. But you obviously don't.

Mother: No, I did, no. I needed to know because I do have ... regrets that I didn't ... hold onto her after she'd gone.

Father: You held her hand didn't you.

Mother: I held her hand but I was too scared to ... (crying) to touch her. And even when Greg [Susan's father] ... I remember the Funeral Directors came, when Greg put her in a ... a bassinette, it was horrible, had to put her in a bassinette. But I was scared that he was gonna break her. No one told me that ... they don't break. And no one told me that, I mean it's pretty common sense now that I know but ... I remember ... we were looking at her nappy and, and obviously when

people die it just ... everything comes out ... and her nappy was full and I was just so ... I was just ... like ... how, you know, she can't go off with a dirty nappy like that. And they did tell us 'just leave it, we'll change her', like the Funeral Directors do. And Greg's mum actually said, 'no that's what happens'.

Father: Yeah.

Mother: Because she's worked with ... elderly people before. But her legs. I mean that's one thing I can't get out of my mind. She was lying down but her legs were actually ... sort of open a bit ... when she died so ... no one told me to put the legs together because that's the way they were gonna be. And that's the way they were when we went to, when we had the viewing, the legs were ... outward. I mean just those things *I needed to know*. I needed to know. As much as I didn't wanna ... believe that she was gonna die ... I needed to know that. (Int. #3, p.101-102, oncology/home)

Mother: As soon as she passed away, within ... seconds ... she had this beautiful smile on her face, her lips were pink, her lips weren't pink before, her lips were pink and I remember screaming out and saying 'look at her face!' And I said to her, I turned to Greg and said 'she's there already'. It didn't take very long. And then a few minutes later she had no expression at all did she?

Father: No.

Mother: Pink lips had gone, and I'm gonna live with that thought forever, the fact that she smiled and I know she's, I know she's in Heaven, I know she's with God, and I know she's being looked after ... and I know she's with us but ... it was like well, what do we do now? We didn't know what to do. (Int. #3, p.49, oncology/home)

For health professionals and other readers whose child is not facing death, this account, with its horrific images of a disintegrating body may seem hard to understand, but for most parents there is very little about their child's dying and death which is "common sense" or 'obvious', especially at the very time when their child is taking their dying breaths and parents are facing their last moments in this world with their son or daughter. Although Susan's mother and father were told something about what to expect, this information was only given to them the day before she died and only then because Susan's father had made a point of asking.

Mother: See that was the other thing no one told us that breathing changes. I've never seen a dying person before ... and ... no one told us *that* and her breathing was going [to be] funny. *I was* panicking 'cos I didn't know what was gonna happen and *that was* I mean, another thing too, once Philip [Medical Consultant] told us to go home ... I thought she was gonna die the next day. No one told

me that it was gonna take ... a ... you know, a time frame. And then when it was happening ... no one said that her breathing was going to change. I mean she'd breathe and then she wouldn't and then she'd breathe and then she wouldn't ... and then took that last breath and like you're waiting ... for the next one, and there wasn't a next one. But she passed away. (Int. #3, p.106, oncology/home)

These parents' experiences call on professionals who care for dying children and their families to consider how best to ensure that parents have the knowledge, information and support which will enable them to help both their child and themselves at this time. We need to ask 'Who is best placed to give this information and support?' (for the two are surely inextricably linked) and also 'what are the best approaches to take in order that this can be done most sensitively and successfully?'

Where Paediatric palliative care is home-based, the GP would often be suggested as the most appropriate person to fulfil this role. However, the GP may lack the detailed knowledge of paediatric palliative care and the child's and family's biographies which parents in this study identified as being so important for them. A recent study into the nature, extent and evaluation of adult palliative care in South Australian nursing homes found that general practitioners spend very little time with dying people. They may occasionally be present in the very last moments of a person's life but generally their contact is intermittent. One GP stated that 'I can only just pat them on the head and say goodbye, but I don't actually see them [die]' (Clare and De Bellis 1996)

This general lack of experience in actually being with dying people could be one reason why Susan's GP was unable to prepare to her parents for what could be called 'the practicalities' of dying and death. Another explanation was raised by Susan's mother, that these aspects of death are 'common knowledge'. To those familiar with providing care to the dying and dead, changes in skin colour and body temperature, 'death breathing', Cheyne-Stokes respirations, rigor mortis, incontinence and the (in)flexibility of the human body after death do become "common knowledge" and shared practices develop which enable professionals to "notice, understand and act" (MacLeod 1996) on these. Those unfamiliar with dying and death are however, unaware of these seemingly obvious facets of death. Another possible explanation for why parents seem not to be informed of the 'practicalities' of their child's dying may be that professionals assume that parents' knowledge is more global than specific. Throughout their experience, Susan's parents had become very knowledgeable in relation to the diagnosis and treatment of her condition. This may have led the family GP to mistakenly assume that their knowledge also extended to the process of death and dying, but as Susan's mother explained, she had never seen a dying person before and because of that, she needed to be told what to expect.

A similar situation of "panic" and "not knowing what to do" may have occurred for Alexander's parents if it weren't for what they termed, "divine intervention or something". They felt extremely lucky that on the day when

Alexander died, a nurse with considerable paediatric palliative care experience, with whom they had developed a friendship while Alexander was in hospital, had come to the family home for an unofficial visit.

Mother: Oh the girls were good like the, the nursing sisters that we got to know because we'd been down there *so* long.

Father: Occasionally they'd come up here socially and spend a weekend here. And actually, the weekend he died Julie [nurse/friend] was going to go home on the Friday night.

Mother: No, on the Saturday, she came Friday night to stay.

Father: Oh, that's right. And she was going to go home Saturday morning.

Mother: She had to leave by 2 o'clock. Alexander asked her, he said 'what time do you got to go home'. And she said 'I've got to go home at 2 o'clock because I've got a dinner party tomorrow night'. And he said 'oh yeah okay'. And he'd been staying in bed, because he was a bit of a night owl ... he used to ... stay in bed all day, and he was gradually longer in bed you know, the week before [he died]. Like he'd only get up by 5 o'clock in the afternoon and come out and watch a bit of TV and stuff and then ... be in bed by about 10 o'clock and you know, sleep all day. And then on the Saturday that, that he died Julie was here and he'd asked her the night before ... 'what time do you got to go home?'. He got up at half past 12 ... at lunch time which I was a bit shocked about actually. And he walked out, he actually walked himself from the bedroom into the lounge room which is fair distance ... and sat on the lounge and ... I gave him his medication and Julie said 'I'll sit with him'. And ahh, he died at ten to one. I'm sure, not consciously obviously, but something in him, well you know, like if I'm gonna die, die while she's here and then she can sort it out and ... [he would have] felt more secure that way.

Father: The kids [his brother & girlfriend] had just left for tennis. And he knew that they'd gone to tennis. Sam and Kathy and ... it's, it's all part of a plan like ... when your body relaxes I guess that what happens, his body was relaxed and everything was going normal, I was up here working, Joanne was down there doing ...

Mother: Getting your lunch.

Father: Getting my lunch. Julie was there and she then stayed the following night, she cancelled her dinner appointment.

Mother: Oh, her husband must be very understanding she, as soon as he died, you know, like, Lew carried him into his bed. [Julie said] 'where do you want him put?' She just sort of ... it was just calm for us because ... there was no panic. Like Julie said 'there's no panic you know'

... and she sort of took out his nasogastric feeding tubes and all of that and, and sorted him out on his bed and ... he looked like, oh, he looked better than he had for weeks and ahh ... you know, the, Sam and Kathy were at tennis and they were about half an hour to three quarters of an hour away. And she said 'Well, I'll go and get them for you if you really want', but she said 'There's no, he doesn't, you don't have to, like, Alexander doesn't have to go straight away, he can wait until ... they come home, you can keep him here'.

So we did that, we, whereas if you're on your own you might have panicked and, and got the undertaker in to take him away straight away but, we didn't and, and the friend of mine that we stayed, I stayed with at Richmond, she became like a surrogate mother. When I couldn't be with Alexander at the hospital Colleen would be there. In fact sometimes I think he preferred her than me but, and so I rang them on the Saturday morning and said 'I think you'd better come up if you', you know, [want to see him before he dies] and they missed him by a couple of hours but they were here as well. So Alexander was still here ... and that was good for them. Ahh, then the kids came home from tennis and then you know, then he went after that. But that wouldn't have happened that way if Julie hadn't been here.

Father: It's just luck, that it worked out that that was the weekend she was coming up.

Mother: Oh, well. Divine intervention or something I don't know but ...

Father: Whatever it is ...

AH So having somebody like Julie here made a difference to you?

Father: Oh, *huge* difference.

Mother: *Oh. yes*

Father: 'Cos you would have panicked otherwise. Having not been through a system like this or a set up like that before, you just panic.

Mother: You just don't know what to do you know.

Father: What do I do now, who do I ring, what do I do, you know. (Int. #4, p.36-41, oncology/home)

Mother: Yes, so that was a Godsend having Julie here. I guess you'd cope but I don't think you would cope as calmly or as well. I don't think that we would have done anyway. (Int. #4, p.44, oncology/home)

The value of Julie's presence was both as a guide and practical helper. In laying Alexander's body out and removing the evidence of illness, such as his nasogastric tube, she was able to make him 'look better than he had for weeks' enabling the parents' last images of him to be positive. She informed the parents of their options and without taking over, allowed the parents to make choices. Had Julie not been with them, it is difficult to

know who would have answered these parents questions; What do I do now, who do I ring, what do I do?.

Themes of panic and not coping were common for all but one family who cared for their child at home. Louise's parents were among those who did panic. What they wanted in the event that Louise should die while she was in hospital Monday through Friday each week had been discussed with staff. It was decided that they "would not prolong it for her", and she would not be resuscitated. The possibility of her dying while she was at home, Friday evening to Sunday however, was not discussed. When she did 'unexpectedly' die at home her father reacted by attempting mouth to mouth resuscitation and by calling for an ambulance whose crew then attempted defibrillation because 'they had no instructions not to'. Retrospectively, her mother observed that 'I don't know what we were doing, we certainly weren't thinking'.

AH: Did you have help at the time that Louise died at home, was somebody rostered on here?

Father: No, it was me. I had to cover about four, six or eight hours that day. So I started about seven in the morning, she died at night. She didn't wake up from the, the night before. But she was very cold. (...) So I covered her up and suddenly heard, heard her rattle you know ...

Mother: Went rushing over to her ...

Father: Got the ambulance over but ...

Mother: It's funny, you make all these decisions like, what are we going to do you know, if there is a crises you know, we'd thought well, we're not going to prolong it for her and we're, we're going to, if she goes, then she goes and leave it at that. And, and this was all in place at the hospital so that they knew if she died to leave it. And yet, when she died here we rang for an ambulance! (Laughter)

Father: (inaudible - laughter)

Mother: But no, she did die.

AH: What did the ambulance people do?

Father: Oh they tried, heart, they, they tried those machines you know with the heart massage and everything ...

AH: They tried to resuscitate her?

Mother: Yeah.

Father: Yeah, because they had no instructions not to.

AH: Right.

Father: And, I must admit I tried ...

Mother: *But we were here ...*

Father: *I tried mouth to mouth* and everything else and we couldn't get her going. And she got ...

Mother: It was pretty futile when you think about it, I don't know what we were doing, we certainly weren't thinking. But the boys were here. David and Terry were

here. (...) But, *yeah it was, it was a surprise*, I wouldn't say surprise, it sounds like something happy.

Father: It wasn't expected.

Mother: Even though you know ... it's on the cards. I mean she was as frail as could be. She had got over so many illnesses and so many ... set backs when we *thought* she was going to die. We sort of thought oh, she's invincible you know. She's never going to go and then, when she did go it, it was most unspectacular. She just seemed to stop breathing and ... the care worker what was with her ... had got, she'd, she'd been ...

Father: She'd been on over night.

Mother: ... what do you call it? Cheyne, Cheyne-Stokes or something? Breathing all night, really rapidly most of the night. And ... she left a note to the effect that, that Louise's breathing was very noisy, and Dave [father] described it to me afterwards and I thought 'Oh'. I know from the animals, once they start that, that that, they're on their way out. But the care worker didn't know, she didn't have that information to say, 'oh look, her breathing's really bad and that it's Cheyne-Stokes and, and that'. I could [have] be more aware of what was going on. But, and Dave certainly wasn't aware of it either.

Father: She didn't seem to be making that noise when I got ... took over. She was ...

Mother: She was noisy and rattles ...

Father: No, that was at the end, only at the end ...

Mother: Right.

Father: ... she was all right from seven o'clock till about nine and then ... suddenly I heard the rattles [demonstrates] I've got an attack on ...

Mother: That was just the last breath ...

Father: Yeah, and that's really all it was. She was breathing reasonably well up to then but she was *cold*, and I was so surprised so ... that's why I tucked her hands and everything in because she was cold ... but she was obviously ...

Mother: She was under a mountain of blankets.

Father: Oh yeah. No it was unusual, because usually she's not, couldn't believe it myself but, it's only when you look back you can see it [understand what happened] (Int. #10, p.50-56, non-oncology/home)

This account highlights again the difficulty in assuming that dealing with the dying and death of your own child is merely a series of natural events to be planned and managed as if they were a project. Your own child's death is no planning or management exercise but a crisis of scarcely comprehensible proportion. Louise's parents did what a great many other parents describe doing even in lesser crises such as following their child's accidental injury - they **panic**, and almost as instinctively as breathing, they try to prolong their child's life so that they may have them in their world for

that little bit longer. The care worker who had been rostered on the night before was not a trained nurse and possibly had never worked with dying people before. Her lack of experience meant that she did not recognise the signs of Cheyne-Stokes breathing and was therefore unable to inform Louise's parents of 'what was going on'.

2.4.4 *Death and Dying in Hospital and Hospice: 'The waiting was pretty hard'*

Caring in hospital was marked by the amount of time spent keeping a vigil at the bedside rather than in providing, practical care. This seemingly passive waiting and watching was difficult for parents. Gloria's mother described the anguish that she and her husband felt during the last few days of Gloria's life as all that was their daughter seemed to be transformed by pain and deterioration into "nothing except suffering".

Mother: The ... waiting was pretty hard. They talk about euthanasia well ... if, if you know we were allowed to have the, have it here ... I would have done it. I would have had it done because it just ... seemed like you know ... when she died I said, 'Oh ... I'm so relieved, she's out of pain'. And after I felt really guilty, I thought I shouldn't have said that. You know we might have had her for a little bit longer ... a few more days or whatever but ... you just sort of wish you could take their pain away and ... the waiting it was awful. You don't want them to die but you don't want to see them ... suffer, especially when they are having fits and things you know, they can't ... you know, she never drank or ate in the end ... it's pretty awful. I think ... you know, it should have been [an option] when it gets to that stage where there's absolutely nothing except ... except suffering ... because you don't know what pain they are in. [Gloria had been unconscious for a few days] (Int. #2, p.35, oncology/hospital)

Mother: I think we'd been waiting like ... this is eight months of ... wondering when and how and ... you know, we would wait every day that she got sick, is this the day that everything suddenly? ... you never knew ... it's just a build up. Yeah I, I feel guilty that I should have said that because I think well ... I don't know it's silly I suppose. I just couldn't stand to see her like it any longer. And she would've hated it. She'd hated when ... you know, she couldn't be like all the other kids. (Int. #2, p.36-7, oncology/hospital)

Gloria's impending death and the death of one other child who also died in hospital was not openly acknowledged between the parents and the child. This second family felt that their son might have known but that he never

raised the matter because 'he knew that I [mother] would cry'. Gloria's mother however felt that she was always waiting for Gloria to 'ask us a question' but she never did. Gloria's mother in particular struggled with the dilemma of 'do you tell her or don't you?'. One reason given by Gloria's mother for not telling her, was that they did not want to take away her hope. Gloria's mother believed that not telling meant that 'she always had hope'. Another reason was because of Gloria's perceived fear of the word cancer. Keeping Gloria's impending death a secret for a period of eight months required the reluctant compliance of the hospital staff:

Mother: Every time a doctor came in we had everyone worked out not to say anything in front of her about dying or anything like that, even [mention] the word cancer to her. It might sound silly but my father died of cancer as well and the word cancer to her, she got very, very frightened. So we talked about tumours all the time, we hadn't talked about cancer, it was a tumour. (Int. #2, p.13, oncology/hospital)

The professionals working with this family did not agree with the parents' decision 'not to tell' however, they did, after a period of trying to persuade them otherwise, respect their wishes. While the obvious tensions in this situation have not been explored in depth, it is possible that this concealment may have contributed to rather than alleviated the parents' anxieties at this time.

George's parents, in response to a question about what was traumatic or difficult for them while providing care for him in hospital, raised a number of issues. The first related to an occasion when staff, unannounced, were "saying goodbye" to George but in doing so, they seemed to have presented a formal acknowledgment of his imminent death. George's parents had both accepted the inevitability of his death, however they felt that the action of saying goodbye had been "sprung upon them" without adequate forewarning. From the parents' perspective, this was an event which unsettled and 'threw' them. They felt that they would have appreciated having been consulted or involved in this event, especially since its implied message regarding George's imminent death was so profound. This seemingly 'minor' incident also highlights how disarming it can be for parents to find themselves in a position of powerlessness in relation to their child and how easily parents can come to feel 'outside' of the circle of consultation and control.

Father: That was one, I didn't like the way that was handled that day, personally. Of saying goodbye to George.

AH: What happened?

Father: Well I didn't realise that's what we were going to do. And so I didn't, I didn't really take much time, I was just sort of sitting there. I didn't, wasn't ...

AH: You didn't feel comfortable with what was happening?

Father: *If I'd have known before hand and sort of thought about it, maybe. (...)*

Mother: Ah, but I can't remember how that day actually even came around.

Father: No, it was sort of sprung upon us. Or it [was] *sprung upon me I don't know* if it was on Penny [George's mother].

AH: So you feel it was a situation that wasn't, that ... you weren't in control of?

Father: Mm. *Well I, it was, I mean as it turned out it was all right 'cos I just didn't, I didn't really say much and I just talked to George by myself afterwards, which was what I wanted to do.*

AH: Nobody had consulted you before hand.

Father: Mm. That's right. (Int. #9, p.46-47)

Pain relief and the administration and effects of morphine were also major concerns for George's parents. George had received morphine for pain which his parents believed had affected George's personality saying that 'he was just not George' however, it was not 'killing the pain or anything like that'. In response to discussion about increasing his morphine dosage, George believed that this would hasten his death, and in a moment which would shake any parent, George told his parents that, "you're going to kill me". This was obviously distressing for his mother who found herself in the dilemma which confronts many parents in relation to their child's pain control. She did not want her son to die but part of her wanted this very much because she could see that while George's life was fading, his pain and suffering were not. His parents described this:

Mother: We'd gone through four or five days where he really, don't know how you'd quite describe it, he was, he was just not George was he?

Father: Mm.

Mother: The morphine was really taking an effect although it wasn't killing the pain or anything like that. And ah we had extremely awful days and nights where he'd just leapt out of bed and all sorts of things and it was really very difficult and when we brought the dog in I don't think any of us were expecting afterwards that he would have been how he was 'cos he was actually chatting away.

Father: Mm.

Mother: It's, probably what (crying) hurts most is that, when we were talking, we knew that we'd have to increase his Morphine and he said 'You're going to kill me!' (crying) I mean it really was right. That was exactly what, and we knew that was, what was happening anyway. You know that, that he was slowly dying anyway. That was very hard when he said that ... because that was really the first time that he'd ever, ever made a statement like that to us and all that I could say was well you know, 'I just don't want you to die George'.

'Cos I didn't, but I did. I knew that there was nothing else that was gonna happen anyway because he was always, he only had a couple of days left.

Father: Mm

AH: Was he complaining of being in pain a lot?

Father: Oh yeah.

Mother: He was, he was in constant pain. (Int. #9, p.36-38, non-oncology/hospital)

Mother: George understood everything about his illness and he understood everything about his treatment. He always had to know what things were going to do so ... he fully understood what morphine would do in his situation because you know, his lungs were just absolutely chock a block. We couldn't clear the mucus out, nothing would come out at all.

AH: Yes.

Father: And the fluid had built up around his heart so he really, he wasn't any, there wasn't anything left for him, there, there was nothing that we could do. We could just try to make him more comfortable and certainly from that point on, I mean he really, after that, that was it. It was sort of, maybe it was his last statement.

Father: No. I talked to him after that.

Mother: We, we certainly said other times you know, how much we loved him and that. But, yeah it was, that was a difficult, a difficult part but at the same time we certainly had to, to say our goodbyes probably that afternoon, because we wouldn't have had much opportunity after that, after that day, 'cos that was about the Monday I think that that happened.

Father: Mm. I thought it was earlier than that. I reckon it was it was about the Friday. (Int. #9, p.39-40, non-oncology/hospital)

The above incident occurred on an afternoon which had been George's only lucid moment for days. The morphine dosage was increased and George spent the next three days in an unconscious state while his parents waited at his bedside. The fact that he was unaware of what was happening was a relief for his parents because his demise "would've been the most undignified thing he would ever have imagined". Additionally, his unawareness made his last few days of life "not so bad" for his parents.

Father: Certainly those, the last days were, they were just really waiting days the last couple of days where you thought that he'd go but he didn't but, you just, it, prepare yourself for the, 'cos the next day would come ...

Father: Yeah 'cos I reckon, I reckon the Monday was that day when he was bringing stuff up non stop and Tuesday and Wednesday just sitting around waiting.

Mother: Yeah

Father: So it was probably about the Sunday that he went on the infusion.

AH: Did the infusion then adequately, give him adequate pain relief until ... ?

Father: Oh presumably. He was unconscious, he was out 'cos he had a sleeping, sleeping things and so on.

AH: Right. What was that like, for you as parents?

Mother: While he was peaceful it wasn't so bad but before he sort of slipped into that, I mean it was, it was, he didn't have a pleasant time it was just about what, was it almost a day?

Father: Mm.

Mother: And I think we'd gone for weeks and not been able to, to lift the mucus at all, and it just flowed out of him.

Father: Yeah it was ...

Mother: It was the most revolting thing you've ever seen.

Father: Yeah well first, as his heart was failing, it was filling his lungs with fluid and that was washing all the mucus out.

Mother: It was absolutely horrible.

Father: Yeah

Mother: I mean I'm glad that there was no way knowing he knew what was happening because for him it would've been the most undignified thing he would ever have imagined. It was just, if anybody had told me that you had to go through that I would never have believed them I don't think. I mean I'd read about it, 'cos that book that was made into a film about this little girl with CF and that was the way that they described her dying and I thought it was just fiction. It wasn't. It was quite horrible.

AH: Were staff supportive?

Mother: Extremely supportive. They cleaned him up all the time, and kept him nice.

Father: I think they were just as, just as shocked as we were.

Mother: I think so. Because I don't think they'd had, the other children who had sort of died around at that time hadn't had that particular kind of death did they?

Father: No.

Mother: So yeah, they were, they were very good. We had a, we had a room next to George's that we could go and have a sleep in. I think they had Louie [George's brother] in there as well. He wanted to be there. They continually came round, even the physios that had, had to give up treating George, still came around three or four times a day to see us [and] to talk to George and everybody was, was extremely good, make us tea and talk to us and at the same time they would, would tend

to George even though there was nothing really that he needed done. (Int. #9, p.56-58, non-oncology/hospital)

2.4.5 *Planning for After the Child's Death: 'Doing your homework' and 'Saying goodbye'*

What happens after a child's death? This question was largely unasked by and unanswered for parents prior to their child dying. Determining if, how and where parents wanted to spend time with their child's body, learning how to lay out the body at home and preparing for funeral arrangements were predominantly unplanned and undiscussed.

Many parents, not unnaturally, did not want to believe that their child was dying and for some, this seemed to deter them from asking questions about death and dying or from making decisions about funeral arrangements. This reluctance seemed to be shared by professionals who likewise did not seem to initiate discussion in this area. Occasions when health professionals were involved in giving this type of information to the parents occurred only when either parent asked directly or only after the child's death.

Malcolm's father felt completely unprepared for his post death arrangements. Within an hour of Malcolm's death his parents were asked to make arrangements for the funeral director to collect his body from the hospital. Neither parents had 'done their homework' and so finding out about funeral directors and making decisions at this time was difficult for them. Malcolm's father felt that the staff were remiss in not addressing the issue with them beforehand and were subsequently insensitive to their situation.

Father: I suppose it's the job of a social worker would've, should've been that, knowing that the child's on palliative care that 'hey, you've got to get your act together sometime, and this is what, this is the ground rules'. But we weren't told the ground rules so I suppose the social worker hadn't done their job. (...)

You can't assume that we've already ... you've already done your homework on working out which one [funeral director] you want because you know that ... the end in near but you don't want it ... but so ...

Mother: You don't admit it until it does.

Father: But then ... if you were ... sort of told that ... like, at this stage, now you've gotta sort of start getting yourself organised for, for the, when it [death] happens. But we weren't really pre-warned on that side of the picture. And yeah, it was a bit sudden ... on the same day. I mean. if it was the next day well, you could ... you know, you could handle it but not sort of then right [after he has died]. But it, that might be normal practice, but I mean I think being pre-warned, well a procedure of how

to, once a child's in palliative care that you need to really start to get you affairs together. You know I, maybe they were, they might have assumed we knew, I don't think ... the sensitivity of ... checking of whether we did. But we had own problem with the fact that, you know, what the outcome might be ... (...)

Mother: But you felt a bit, put on the spot.

Father: Especially something like ...

Mother: Like an hour after something's [death] happened.

Father: Yeah. They could ... a person's died ... right, next you do this. It's not like you know, it was the next day or, or half a day later. But not you know, it's like saying ... [his body] hasn't even got cold. That's a bit, bit harsh. (Int. #5, p.31, 33-34, 39-40, oncology / hospital)

While Malcolm's father did not want to fully acknowledge the future need for a funeral director, he suggested that staff could have checked sensitively whether he and his wife had had made any preparations and if not, encouraged them in that direction well before the actual need arose. After they had made their initial calls and had left the hospital, Malcolm's parents went home. Instead being able to spend time with the friends who had gathered at their home to support and comfort them, they had to ask them to wait while they spent 'the next hour or so' making funeral arrangements.

Sitting here, the house was full of friends who have come round to support you and here you are sitting talking about funerals and ... you know, just say 'look' you know, 'we have to do this' and it probably took an hour or so ... to do it all. And I think, I mean, certainly they're friends that understand but ... it was ... it wasn't easy. So I mean it's ... more probably our fault than anything but we didn't think about it but when you haven't done it before ... (Int. #5, p.40, oncology / hospital)

A recurring theme in this study was parents' tendency to blame themselves when their knowledge and experience was insufficient to help them through difficult situations directly related to the practices of caring for their children. Malcolm's mother was no exception in this respect in that she believed that not understanding about funeral arrangements was their "fault". When parents are grieving the death of their child there are often undertones, or indeed explicit articulations of self-reproach, guilt and the 'if only' nagging questions. An essential component of paediatric palliative care practice should, it seems, be the ability to raise 'difficult' issues such as the practicalities of funeral arrangements with parents with the tact and sensitivity required to enable the parents to learn and understand at their pace and in their terms.

Susan's parents had decided on the funeral company they wished to use, however how or when to make a booking was something that they did not understand. Fortunately, their parents were knowledgeable and supportive and through them they were able to obtain the necessary information.

Father: But I mean, a lot of people don't have a lot of family ... once they lose their child well ... what do you do? What, do you ring the funeral director two days before and book them or? You know, sounds bizarre ...

Mother: Well we hadn't even thought ...

Father: ... but I said to Dad a couple of days before [Susan died], we'd decided we were gonna use White Ladies, well Dad, do we ring them now and ... like make a booking for two days? or, or do you wait until they go? [die] What happens if they're busy and all these ... ?

Mother: Unknowns.

Father: ... but Dad knew ...

Mother: Yeah.

Father: ... but, I didn't know. We'd never rang a funeral director before, and I didn't even know that ...

Mother: You don't think about it, I didn't ...

Father: ... if I rang them today and they say 'well we're really busy, we'll we come around tomorrow'. Well I mean you just don't, you just don't know what they, what they do so ... (Int. #3, p.108-9, oncology/home)

Do you need to make a booking? Do you wait until they die? What happens if the Funeral Directors are busy? These are very real concerns which are not at all bizarre for those with little or no experience of death. As Susan's father asked, 'what happens for parents who have not received information from service providers and who do not have family who can help them at times such as this?'. In addition to family support, these same parents also talked about the help which they received from a good friend who among other things knew that a doctor would need to be notified of the child's death.

Mother: ... Daniel, our brother-in-law now, he was wonderful. (...) [He] rang them [funeral director] and explained how to get here, explained the situation, warned them that it was a child and things like that. We didn't have to do any of that.

Father: It guess it was just to have someone here that ... like as Anita said, for the last ... I guess, Anita's parents, my parents, and brothers and sisters had lived here basically ... but Daniel was an ... outsider from the family and that was really good ... to have someone that ...

Mother: At the time he wasn't a relation was he?

Father: ... yeah that wasn't related. I mean he was a very good friend, but ... he could sort of take over that "being in charge role" and ... and be a little bit distant from it so ...

Mother: So that was good, but, but no one told us, yeah ... that's what you had to do. I mean if, like Greg said, if we didn't have family and friends to do that ...

Father: Yeah. I mean we didn't have that problem but I could see a lot people that, that would have. Wouldn't know what to do, or who to ring or ...

Mother: I mean and then at, by the time White Ladies got here it, it had been a few hours. The Priest had come to talk to us. Oh with, with the doctor, I mean that was another thing, we didn't know we had to ring the doctor. Luckily Daniel did. I mean he knew or someone knew. (Int #3, p.110-112, oncology/home)

An unfortunate outcome for parents who live in isolated rural areas, geographically distanced from their primary treatment hospital and using additional services such as the local general practitioner and visiting nurses, is that gaps in services can occur more easily. This was particularly noticeable for those parents who did not receive coordinated, specialist palliative care services where an individual, often a nurse, had responsibility for liaison between parents and service providers.

"We didn't know" and "we weren't told" were key phrases which parents often used to describe the uncertainty and at times the helplessness which they felt as they sought to make their child's last hours and minutes comfortable. Sometimes parents simply did not have time to fully explore what their options were because they were immersed in providing care or because the child's death came much sooner than initially predicted. When Oliver's parents first made the decision to take him home to die they were told that he had two or three months to live and that palliative care services would be organised. However, when the promised services failed to materialise the parents "contacted them because we wanted to go out and do a couple of things [and] we wanted a wheelchair". This first, and as it turned out, only visit, was an introductory meeting and the parents were given the wheelchair, information leaflets and a contact phone number.

A discussion of parents' understanding of what they knew and what they were told is illustrative of an important aspect of our qualitative research values. We have no wish to undertake a "hermeneutic of suspicion" (Dreyfus 1991) which would seek to 'expose' either professionals' lack of communication or conversely to undercut parents' accounts by 'explaining' that parents would have been given information but that this may have been forgotten⁴. What seems a more fruitful issue for professionals involved in paediatric palliative care is the parents' **perceptions** of their lack of knowledge and preparedness.

Within a short space of time Oliver returned to the hospital because he had developed new problems which required review. Following this Oliver was once again discharged. He died three days later and before his parents had been reviewed by the palliative care service. His parents believed that there may have been services available that would have helped but felt that 'they

⁴ In Darbyshire's study (1994) and indeed in many others, parents described a phenomena of what they called "going into shutdown" which will be familiar to both parents and professionals. Here, parents described how after hearing 'bad news' or the word 'cancer', that they "shut down" and remember nothing else about the consultation and conversation.

were too deeply immersed in providing the care to really sort of go chasing around to tie things up'. Without the adequate needs assessment and subsequent service provision which took into account their rural location and the speed of Oliver's demise, all that these parents could do was struggle on and hypothesise later.

Mother: ... and then at the end he was really labouring for breath and I ... Mum said to me, 'Oh perhaps he'd be more comfortable in hospital with some oxygen' but that, that stage lasted for ... such a short time that ... if we had decided to take him down there [to the local hospital] he would have been dead before, before we got there but ... you know, even just well, if we'd had something to prop under him or something just to sit him up a bit he might have been a bit more comfortable but, as I said it was really ... it, it seemed like for ever but I guess it was probably only ten or fifteen minutes. But you know it's just very difficult watching and not being we able to do anything. I don't know whether, you see, there may be other things available that, that would have helped us but because we don't know, you know, what they are ... [it's difficult to know what to ask for] (Int. #6, p.47-48, oncology/home)

Despite difficulties such as these, this family did seem to find valuable help after Oliver's death. As the following account indicates, their contact with the funeral director and his flexibility were valued and they were able to keep Oliver's body with them overnight, for fifteen to sixteen hours, without any problems.

Father: It was, a person that we knew [the undertaker] and I found that, well on one hand it was sort of thing, oh should we or shouldn't we ... because you know, we know them ... that might be difficult. But on the other hand it was ... very useful. I mean, I found it very ... relaxing or ... easy ... with that contact, so ...

Mother: Yeah. I mean he, he arrived up here the next morning and gave us a big hug and ... love from his wife and ... later on it was love from the kids and you know, things like that so it was, it was very personal. But he just, yeah, he was quite happy you know, for us to do what we wanted and ... just gave us a couple of instructions the night before ... like on the night that he died. So I mean it's, as I said before, there is nothing that you can do to make it easy ... I said to him ... you know, that we'd be (ironic laughter) never be ready for him to, to take ... Oliver away but you've got to let go don't ya? (Int. #6, p.51-52, oncology/home)

Some parents had preconceived notions in relation to what they believed they were 'allowed' to do which deterred them from asking. One example of this was described by Stefan's mother. Stefan had been taken, by

ambulance, from home to hospital after having a cardiac arrest at home. Although the ambulance personnel were able to regain his pulse, his condition was such that the hospital's receiving staff, in consultation with the parents, did not persist with resuscitation attempts. Thus Stefan's death occurred at the same time as his 'admission' to the hospital. His mother said that she would have liked to have taken his body home for a period of mourning but her beliefs that "you just can't do that" and "he had to stay at the hospital" deterred her from asking.

Mother: Of course eventually you have to leave, you've got to leave him there you know, and that was the hardest thing. To actually *leave him in the hospital* and I thought well, that was the same ... feeling as other times where I had to put him down, and I said 'Well, where am I going to put him?' And they said 'Put him here and we'll take care of it'. And I thought well, 'Is he going to be all right here?', you know, as if he's still around. And you're thinking well, 'you be careful of him, don't you hurt him' you know, 'look after him'. But I was almost dragged away because I just couldn't leave him you know. (...) We'd been there for hours and I mean, it comes to a time where you just can't ... you know, I wanted to bring him home but you can't do that, it's just not ... the way you do it you know, he had to stay at the hospital. Stefan had to stay there. And ... and until ... he goes to ... well wherever, you know, funeral place or ... no it was just, it was just my husband and I left there in the end *but* it was just the fact that ... neither of us wanted to go but you've just, you've got to go eventually and it's just both of you pulling at each other saying come on we've got to go you know. (Int. #8, p.25-26, non-oncology, home/hospital)

Because of the chronic nature of Stefan's condition, it was unlikely that an autopsy, or any other procedures which relate to deaths occurring in hospitals within twenty-four hours of admission, would have been necessary. It may then, have been possible for his parents to take his body home and thus avoid the distressing process of being 'almost dragged away' and 'having to leave him in the hospital'. However, as many of the parents explained, it is very difficult to express clear preferences and wishes when in the domain and presence of professionals at the best of times and doubly so when you have just watched your child die. Being able to grieve the loss of a child in a place you feel comfortable is very important for parents. Health care facilities whose policies and staff are flexible and sensitive enough to accommodate parents' individual wishes in this regard can facilitate parents being able to stay with and leave their child in ways which are most helpful to them.

A participant mother who is currently expecting the death of a third child felt very strongly that if this child's condition necessitated her to be in hospital at the time of death, as opposed to home which is her first choice, she would also like to be able take her child's body home. In order to

facilitate this process, this mother, in collaboration with her child's Medical Consultant, has devised a 'Palliative Care Plan' which clearly expresses her wishes and acknowledges her Medical Consultant's support. This plan has been placed in the front of the child's case notes 'where everyone can see it' so that nothing is left to chance. If, in the meantime the parents change their mind about any aspect of their wishes, they may amend the plan accordingly. [See Appendix 5, for copy of this plan]

The parents whose children died in hospital or in a hospice were generally satisfied with the care received after their child had died. Parents were given choices about helping to prepare their child's body after death (although none elected to) and all felt that they were able to spend as much time with their child's body as they needed.

Mother: At the time she [Gloria] died ... there was ... Roger [Gloria's father], myself and my sister. Roger's two sisters and Bradley [Gloria's brother] were here [home] and when she actually died ... we got the ... the doctor down but ... like the nurses wanted to ring, you know, ring here straight away and we just needed a couple of minutes to ourselves and I said to my sister (inaudible) we'd said goodbye to her that many times over the last few days that we just spent ... a few minutes with her and ... say goodbye to her. When we ... they [nurses] rang here and ... it was probably all in a matter of five minutes. (Int. #2, p.40-41 oncology/hospital)

George's parents found that being in hospital at the time of his death did not impede them from doing the things that they had planned to do.

Mother: Well we did the things that, that what we'd said [we'd do] because the whole family was there at the end, and some of the staff were there and we had, we had probably a quarter of an hour with him by ourselves because he want, Garry remembered that he wanted us to hold him. And then we came out while they, they went in and cleaned him up and took his tubes out. We were invited in to do that but we chose not to. They cleaned him all up and bathed him and, and then we, we went in to see him. And then they helped us to make all the phone calls and everything. And then we all sat down in a room there and had coffee and, and sat and talked for what about an hour until we were ready to go. (Int. #9, p.61, non-oncology/hospital)

Spending time with their child's body after death was a valued opportunity for parents, brothers and sisters and other relatives and friends which enabled them to begin 'letting go' by saying goodbye to the child. Gloria's mother particularly appreciated the peace and privacy offered at the Funeral Director's.

We went and spent ... some time with her at the funeral directors as well, the day before the funeral, and ... I spent some time with her and actually it was ... I was really frightened [at first] but it turned out, it was really good, it was really peaceful. Just the three of us, [mother, father and brother] and we spent some time together ... at the funeral directors and there was just the three of us and it was quite peaceful and we all said goodbye again ... (Mother 2, p. 42, oncology/hospital)

It is perhaps in this section dealing with the child's actual death that we should mention one of the most obvious omissions in all of the participants' accounts. Parents scarcely mentioned or described any systematic bereavement care services which they received following their child's death, although Childhood Cancer's support workers were clearly valued by the parents who mentioned them. We raise this issue, aware that few specific questions concerning bereavement care were asked during the interviews. However, parents discussed several salient and meaningful aspects of their experiences here which were not prompted by direct questions. It is possible, and thus at least potentially a matter of real concern that parents did not describe bereavement counselling and support because they had received little or none, or because it had made little or no impression on their lives following their child's death.

2.5 Parents' Perceptions of Services and Support

Mother: But yeah, the one thing I would say is there's gotta be some sort of services to enable you to ... look after the kids when they are *extremely* sick, right at the end because ... I don't know ... because there doesn't seem to be a lot on offer at the time. (Int. #1, p.9)

The types of services and supports used by parents varied according to the nature of their child's condition, what was offered and/or available and what parents were able to locate for themselves. These included visits from the Royal District Nursing Society (RDNS), Domiciliary Care, care attendants, volunteer workers, social workers, the local GP and for some rural parents, their local hospital. Other assistance came from foster parents, family members and friends. For parents who cared for their child at home, the availability of services and support was a critical issue. Leaving the safety and security of a institutional environment to care for a dying child was, as participants have stated, a tremendous undertaking for all parents. The uncertainties and fears for an unknowable and often unthinkable future compounded to make the practical aspects of carrying out their child's Palliative care even more daunting.

Additionally, parents were sometimes concerned as to how, on a personal level, they would be able to respond to and meet the needs of their child. As George's mother highlighted, the last thing parents wanted was to not give their children what they needed. Thus, leaving the institution was

coupled with the expectation and understanding that there would be adequate support for their child and themselves as carers. In relation to services and supports, the child's needs and the parents' needs were closely related.

2.5.1 *Valued Services and Supports: 'the door was always open'*

Nurses were the most frequent service providers visiting the home. Dressings, drawing up of and administration of intravenous injectables, needs assessments, provision of equipment and liaison between treatment centres, local doctors and parents were the most common reasons for visits. While parents clearly valued nurses' technical and practical expertise at this time, it was also clear that the 'how' of nurses' practice, the caring stance which conveyed their availability and approachability, was as important for parents as the 'what'.

Mother: ... and Samantha (nurse) ... especially, it wasn't just for Isobel, she seemed to be [here] for the rest of us as well you know. Sometimes she could be here for an hour or so. (Laughter) Pick her brains about things that she would tell us, little things that perhaps we could do or ... you know, perhaps she might ring [if] she couldn't come ... if she was gonna be here at a certain time, if she couldn't she would always ring and tell us and ... but ... it was, she was just wonderful. (Int. #7, p.55-56, oncology/hospice)

Mother: Oh he had a central line. So yeah, there was a dressing sort of on his ribs there and ... that needed to be changed once a week and then ... she [nurse] was coming every day ... to ... make up the morphine syringes ... for him ... just for the last few days.

Father: Mmm. Yeah, and to see how we're going and, you know, basically answer any questions or ... give guidance, whatever. Yeah, she would come here at about 9 o'clock in the morning or 9.30 or something and spend ... a bit of time here ... half an hour, or an hour or whatever. Perhaps longer a couple of times ... I can't remember. (Int. #6, p.62, oncology/home)

Parents described similar understandings of the hospital nurses whom they found to be valuable and supportive towards their caring for their child. While in hospital with a sick child, parents become almost hyper-attentive in relation to nurses and indeed other professionals (Darbyshire 1994). Parents in this study too described how they "learnt quickly" who were "good nurses". As this father recalled:

Father: But you learnt quickly, you learnt after about ten days in hospital, (laughter) you learn ah ... I guess you learn what nurses are good and what aren't. And after

two weeks you learn whether the nurses are doing it right or wrong because we're there for 24 hours a day in this room and it certainly doesn't take you long to ... get the gist of what, of what's going on. (Int. #3, p.18)

As was the case in their own homes, parents were wary of hospital staff caring for their child whom they perceived not to have the clinical expertise necessary to understand and work safely with technology and pharmacology related to their child's condition. In this respect, agency nursing staff tended to be perceived by parents as possessing less specialist skills as these parents observed:

Father: (...) specialised nurses should certainly be in the Oncology Ward or the Renal Ward or Heart Ward (...) In those ones, that certainly should have specialised nurses. Whereas some other ones ... that's with the agency and should go ... because a lot of them had never, I mean they knew how to ... most of them knew how to take a temperature. But they never knew anything about chemo or any of those. Or side effects or whatever because I guess they've never come into contact with it before.

Mother: And we, because we're there all the time and we knew more, they used to give us the agency nurses. Because they knew that we'd say something and was ... In the end we just requested not ... we would request ... as soon as the change in nursing came on [request not to have agency nurses]. (Int. #3, p.12, oncology/home)

It was also important for parents to feel that they were viewed by professionals an integral and essential part of their child's care.

AH: What sort of things did you actually appreciate about the staff. What kinds of caring?

Mother: Well I guess firstly you felt appreciated for being there. And they appreciated us being there. It's a very busy ward and they don't, they don't have the time to spend with the children and ... you know, if I wasn't there it would have taken them awhile for the pans to come and so on. So all those things were appreciated by, by the patient and by the nurse. It took a load off them. But also ... you know, some of them were ... were interested to, to talk to you and, and just remind you that you're still in a world rather than ... stuck away in a box, in a room, but ... you know, could joke around or ... be a part, be, you know, because it was like home after awhile, we spent so much time there, that you felt ... at home. (Int. #5, p.16, oncology/hospital)

One family who lived 'in the country' did have a different sense however, in that they felt "inconvenient" to some staff. This seemed to be inconvenient

in the sense of being 'out of the way' and 'out of the ordinary' rather than being 'in the way'.

Mother: That was the other thing, sometimes I felt as if it was our fault that they were here, the district nurses. Like they made us feel it was, we were inconvenient.

Father: And especially when it ...

AH: An inconvenience?

Mother: An inconvenience, yeah.

Father: *Oh yeah.* And especially 'cos it was something different. It wasn't a sponge bath or whatever they ... do. It was something ... 'Oh, I don't know how to do it'.

Mother: But the palliative care nurses never made us feel that way. (Int. #3, p.99, oncology/home)

Some doctors were were a source of support for parents at home. As the following accounts indicate, spending time with parents, especially on a 'busy day', were valued. Caring practices by professionals, such as spending time with parents (even if they "didn't do anything") or simply being available by phone for assistance, advice and/or reassurance were of enormous comfort and benefit to parents.

Mother: [the doctor] called in. Like after we got home, he called in that day didn't? the first day.

Father: Yeah.

Mother: And he called in every day ... to see us. And one day on the weekend he, he sat here for ... an hour or an hour and a half I think ... and just chatting and answering questions and ... then he told us what he had been doing. You know it was Saturday, and he'd delivered a baby and set a broken leg and done this and that.

Father: Attended a motorbike rally where he, you know, had to be the doctor for a rally.

Mother: And you know he'd sat here and we were sort of thinking oh ... it's sort of one of those things like he had nothing to do (laughs) except sit here with us and as he was leaving he sort of just gave us a hint of how, how busy his day had been but it was ...

Father: So he, that was good. (Int. #6, p.22-23, oncology/home)

Mother: It was made very clear to us that the staff down here at the hospital cared about us and about Oliver and that (...) the door was always open if we wanted to come back at any time you know, if we weren't coping or just didn't feel comfortable at home.

Father: Didn't even have to come home.

Mother: No.

Father: If we didn't want to. (...) If we felt that we needed to come back we could have come back at any time or simply rung up or whatever for advice or

someone, a shoulder to cry on sort of thing or whatever. (...) and we also had the facility here [local rural hospital] which they said 'there's a room there if we needed to ... we could shift down there'. And one of the senior nurses there [local hospital] said look, she lives in the town, 'if we needed something during the night or day or wanted a shoulder to cry on or someone to ask questions, here's, you know, my phone number is in the book' (laughter) sort of thing. (...) I was very happy that whatever, if we needed to find out something or [needed] some help or something, support with something or facilities or resource, it was there, we just had to sort of say 'Help!' and help was on its way. (Int. #6, p.38-39, oncology/home)

Occasionally special relationships were forged between visiting nurses and the children. Isobel's parents described such a relationship:

Father: Yes, she [nurse] was a bubbly, effervescent sort of person and, and that's what Isobel really needed I think, was to, she didn't need anybody that was gonna be depressed or gloomy around her she, she, Samantha was exactly the opposite and it was almost ... you know because Isobel was so ... down that, that it was, it was funny that Samantha could come in and be light and bright and cheerful. That was what Isobel needed really and it took her mind off things and, and she really appreciated that. (Int. #7, p.55-56, oncology/hospice)

While we do acknowledge that parents were generally critical of visiting nursing support, the family who discussed District Nursing support at greatest length, did appreciate those whom they described as "the District Nurses which are the different District Nurses (...) the palliative care nurses". Once again it seemed that having specialist palliative care skills and understandings was the deciding factor in how valuable this service was for parents. As this father observed:

Father: I'd had experience with District Nurses before and I didn't *really*, especially at that stage of our lives, we didn't *want* any other hassles ... and they were great ... the two ladies, they were different ladies, they were fantastic. (Int. #3, p.43, oncology/home)

A further aspect of professional services and support which seemed very important for parents at this time was that the staff with whom they had shared so much in the previous weeks, months or years did not appear to 'forget about them' after their child's death. A child does not simply die and disappear without trace. They leave behind memories, possessions, stories and recollections, all of which can assume near iconic importance for the parents and families left behind. Parents were extremely appreciative of staff who acknowledged the child's memory and their relationship with the family by the most seemingly simple, yet profoundly important gestures of

sending a card, telephoning occasionally to ask how the family were doing, remembering the child's birthday ... These were the gestures which helped create a community of memory and which prevented the parents from feeling that they were, after all, 'just another case on the books' whose file had closed with their child's death. These parents describe the importance of these 'little things', which are of course, far from little:

Mother: Things that we ... appreciated afterwards were ... a couple of the nurses and the ward ... clerk was ... the ward ... sent us some sympathy cards and ... Doctor Simpson and one of the other nurses attended Oliver's funeral. And we had a card from chap, from the palliative care, ... the chap that had called in. I mean, he was here half an hour, hardly felt like you know, that we knew him but he cared enough to send, you know, a card to us which was I thought was nice. (Int. #6, p.41, oncology/home)

Mother: You lose that as well you know you're ... you lose your child but you also lose that [relationships with hospital staff].

Father: Well, people that you spent a lot of your last nine months with (laughs). A lot of your, for the last nine months, all the stresses and strains and the highs and the lows of the previous nine months. As you thought were going well and ... then you get devastating news and think things have picked up and the miracle's happened and then you get devastating news and ... you know, the people that you have been around at that time ... have been there to help you ... and all of a sudden, (laughs) they're not there. You're apart again. (...)

Mother: All I meant to say, you know, about that was that ... you know, it was really nice to hear from people [at the hospital] and ... because ... we sort of, we'd seen so much of them and felt quite close to them and ... you know just to know that they ... were still thinking of us (laughs) ... you know was really nice. Got a letter too didn't we, from Dr. Porter. (Int. #6, p.42-43, oncology/home)

Another mother and father described the wrench of leaving the hospital and the "security" and relationships which they had formed there. The wrench here was not only about leaving though. What was more difficult was entertaining the possibility that the valuable relationships which had helped sustain the parents could possibly be chimerical, and that in fact the doctors and nurses who had been such valuable friends may only be "just good actors doing their job". These parents also highlighted the importance of their child being remembered, for example by having their photograph displayed. In ways such as this, the community of memory was created and maintained. For while death may be the physical annihilation of a child, the forgetting or refusal to mention or acknowledge the child's existence

seemed to be an equally painful form of annihilation. As these parents recalled:

Father: I guess when we left, probably the sort of big one I'm onto now but yeah ... leaving that hospital ... knowing you're not coming back and not hearing from them again.

Mother: The hospital was our home, I mean ...

Father: ... certainly pretty hard for me.

Mother: ... apart from this place, it was our home ... And it's the only place we felt safe, apart from here. In fact safer there than here really.

Father: Yeah and it's a funny feeling, 'cos you, you know these people for thirteen months ... and *they are your friends*, umm ... I mean, I know that they're doing their job *but* there is a few of them that we certainly became friends with and they certainly are friends with you ... even though they're doing their job. But then suddenly ... that's it. You don't hear anything from them. And then you start to think - Mm ... were they our friends, or were they just good actors doing their job. - And certainly for a long time I felt like we'd lost this group of friends ... and then you get to the stage well ... maybe they weren't friends, maybe they were just nurses, or just doctors, or whatever you know.

Mother: And then when you go back and visit and they ...

Father: Yeah I know.

Mother: ... greet you and they ... know exactly what your doing because they've asked about you from other people, and they've still got Susan's photos up and ...

Father: And I actually asked one of them once, 'Do you ... forget us?' and, and they said well, and she was really honest, she said, 'new kids come on all the time, but umm ... she doesn't forget, she might forget your names, but she certainly would never forget ... the people. Yeah, so I felt really good. Yeah. (Crying) (Int. #3, p.62, oncology/home)

This was not only an issue concerning professionals, for friends, family and relatives too could inadvertently feel that by not mentioning the dead child, that they were somehow sparing the parents distress. As these parents stated however, this refusal to mention or acknowledge the child's life had the opposite effect:

Mother: And people that talk about it, I mean we talk about it all the time, there's not a day go by that we haven't spoken, yeah Greg and I.

Father: Oh yeah we do, yeah

Mother: And it just upsets us so much that people don't talk about her ...

Father: Yeah

Mother: ... and ... you know last Christmas ... no one mentioned her name. Not one family member mentioned her name and that hurt me so much. (Int. #3, p.63, oncology/home)

2.5.2 *Unhelpful and Alienating Services: 'they had no idea'*

Rather than being supportive, some parents' experiences of their encounters with health professionals were distressing and unsettling for both themselves and their children. Parents described both the helpful and unhelpful in a range of professionals - nurses, doctors, social workers etc. In each case where parents described negative experiences with nurses, they believed that the nurses had not adhered to fundamental practices such as hand washing before commencing procedures, or that they were unfamiliar with equipment and/or treatment modalities. Additionally, it became apparent to parents that the majority of nurses who visited their homes had neither experience or training in palliative. This was often compounded by the professionals' professed unfamiliarity with children and their special needs and often a similar unfamiliarity with current paediatric therapies.

After losing confidence in a succession of visiting nurses, Susan's parents did eventually have one that they were very happy with however, by this stage they had taken on all of the care tasks that the visiting nurse would have usually be responsible for. This did not mean that they had no need for nursing support, and described how much they valued this contact

Mother: One of the (...) nurses kept in contact, she kept

...

Father: Oh she was lovely.

Mother: ... visiting, she just visited, she never did anything, she just visited and she was *wonderful*.

Father: She was really, she did her job really well.

Mother: Yeah. She came to, she came the day ... leading up to Susan's death, and the day she died she just *happened* to come to see how we were and ...

Father: Well she came a few times in the last two weeks but she knew things were really bad.

Mother: Yeah. But she happened to come that, that day.

Father: She was standing at the doorstep half hour after Susan died. It was just ...

Mother: And she said, 'Oh, I can't come in'. I really wanted her to so I said 'No, you come'. She sat with us. She gave me a foot massage once during that time and she came to Susan's funeral.

Father: She was just really lovely, yeah.

Mother: I see her now in the street and we talk. It's just really, *she ... did her job* and the others though, I can't say one good thing about them.

Father: She did her, beyond her job and the other people certainly were below their job. (Int. #3, p.58-60, oncology/home)

Staff at these parents' local (rural) hospital were similarly unfamiliar with some aspects of their child's care. Susan's parents continued to describe how the nurse that they were happy with tended to be more of a 'friend' however, they made it clear that the relationship was able to develop in this supportive manner because they believed that she knew what she was doing from a professional viewpoint and that was why they "were happy to talk to her".

The primary source of 'in home' help for one family was assistance from care workers whose training was minimal - "not necessarily nurses, they're just help". Problems experienced by these parents included staff not turning up for shifts, unwillingness of staff to continue to provide care because the job was too demanding, staff injury, and inexperienced staff's lack of knowledge. One other situation included a 'nurse' who was removed from the home care environment by her supervisor because she was "becoming *too* involved". This was not however the perception of the parents. They had confidence in this worker's ability and were able to leave their child in her care, confident that she would appropriately manage any difficulty which arose. The following lengthy extracts describe the difficulties encountered by Louise and her parents as Louise moved between hospital and home, often on a daily basis.

Father: The hospital wouldn't let her home unless we had someone here as well.

Mother: There had to be somebody with her 24 hours a day. So when she was home for the weekend we'd have somebody around the clock. So all our time, extra help we got, was sort of bundled into that ... weekend slot. (...)

AH: That was nursing assistance?

Father: No, just ... not necessarily nurses, they're just, just help. Minders.

AH: Care Attendants?

Father: Yes, care. Just so that they could be there 'cos we had, one of us had to be there with them as well 'cos quite often she needed two people. It wasn't just one person, you couldn't, I was about the only one who could manage her on my own, no one else could. She put so many people into hospital but ...

Mother: Oh, she put a lot of people in hospital with injuries.

Father: With the hands and that 'cos the spasms were ... *real* spasms.

Mother: They claimed workers compensation for the damage that she had done ...

Father: That was at hospital. That was at this hospital.

Mother: ... you know, with the wrists and the hands and the backs and that sort of thing.

Father: (inaudible) and there were two or three of them at the [hospital] with their backs and that 'cos she was ...

Mother: Yeah, at least eight that we know of that put claims in. (Int. #10, p.40-42, non-oncology/home)

Mother: You needed a large pool of care givers because if you just relied on one or two ...

Father: They're worn out within a day or two.

Mother: ... the *stress* was enormous and they were worn out. The bigger the pool, the more people you had to *teach*, and of course you'd get a fairly big drop-out rate 'cos they'd feel ... well, this isn't for us.

Father: The couldn't handle it. Mm.

Mother: They couldn't handle it and so it was a ... a really, it was a difficult situation for everyone wasn't it? There was another nurse who used to get on very well with Louise, who was becoming *too* involved ...

Father: The hospital moved her.

Mother: ... So the hospital had to move her, and I don't think that was ...

Father: Tricky

Mother: ... *yeah, I could see the reason behind it*, but on the other hand it was stability that she didn't need moving away from ... because she died within three months of that didn't she? Two or three months?

Father: Oh, around about five, five months yeah ...

Mother: Yeah

Father: But *she was very good with her* 'cos she was ... strong hands and she could, [was] used to walking dogs, she could handle Louise's spasms better than most of the others. But she ...

Mother: But the more you worked with her the more you could anticipate her needs, and you knew what she was asking for. Louise herself used to become quite frustrated when she got new people on that didn't know what to do or what, what was the problem. I think she was tired out when (inaudible) (laughter).

Father: She knew they were kids. She knew they were learners 'cos she, the effort she had to put in to try and make them understand something.

Mother: In fact the last thing she said was Timothy, where's Timothy?

Father: No Timothy [nurse], she, because he was out in the nurses' desk and he, she had an incompetent nurse in with her ...

Mother: She was just new.

Father: ... and, and, and she didn't know what to do with her.

Mother: She needed to go to the toilet and Louise was signing [uses sign language] she needed to go to the toilet and this nurse couldn't understand her ...

Father: And, and she managed to get hold of the ...

Mother: ... and she screamed out Timothy! Timothy!

Father: ... and he came running ...

Mother: ... Timothy came running and he realised what was the matter immediately ...

Father: It was the first time that she'd spoken in three months, she needed to get that word out.

Mother: Yeah. It's the last thing she ever said, yeah so ... it was a tremendous effort though.

AH: Mm. In relation to the nurse that was withdrawn because she'd become too involved ...

Father: Oh 'cos she, well she was attached to Louise from the point of view ...

Mother: I don't think she was emotionally attached, she was ...

Father: ... treated her like a daughter you know, she was ...

Mother: Yeah.

Father: ... you ...

Mother: ... she was sort of a substitute mother and I think ... I was quite happy to leave her in Barbara's care knowing that Barbara *knew* all the problems ... and that if anything ... untoward did happen, or if there were any problems Barbara was there and Barbara could cope with it, ahh ... whereas, I guess I could relax the, the, the parent side of things, and the worrying and the mother, *being* the mother and because I knew Barbara was there. I think Julia [Barbara's supervisor] may have sort of picked up that if we weren't careful Barbara was going to become the mother, and I might lose ... the position of being mother you see so.

Father: I doubt whether it would've happened.

Mother: I can't, I can't see that myself.

AH: So that wasn't your concern then?

Father: No, no. We weren't concerned at all.

Mother: Well I wasn't happy about it, but I wasn't ... desperately upset about it, I, I felt ...

Father: I wasn't concerned for sure ... because ...

Mother: ... yeah, I felt it was a bit rough on Barbara 'cos all she'd done was do her job.

Father: She was looking after her very, very well.

Mother: And she was looking after her well, and she, she was involved in her yeah. She'd bring her flowers and things like this and ... and she would, and she did some sewing with her and ...

Father: (inaudible)

Mother: ... yeah, she was, she did more than just nurse her I suppose yeah and, and I wasn't against that at all. I think the only thing Barbara did that I, I wasn't happy with was, was the fact that she was, concerned about Louise's teeth all the time.

Father: Mm. (Int. #10, p.68-73, non-oncology/home)

Mother: Overall (inaudible) everyone tried their best. If there were any ... stuff ups it, it was generally accidental.

Father: Oh, I mean, someone mightn't have turned up (inaudible) you expect that *occasionally*.

AH: Somebody might?

Mother: Not turn up for a shift.

AH: Not turn up.

Father: I mean we, we had it once or twice at home yeah. [most likely an understatement in light of the number of instances mentioned during the interview] I was doing, sometimes eight, ten hours when we were supposed to have someone else on but, I mean, it didn't worry me, but I mean ...

Mother: Some of the care groups weren't very well organised. There was one particular group they seemed to sort of leave the carers to organise themselves and that led to a few problems where nobody turned up, each one thinking the other was going to come.

AH: Mm. Were you given contact numbers (...) for people that you could ring in that event that that sort of thing happened.

Father: Oh you did, but see, I mean, if they've got no one else available at that stage, then there's no one else available. It's, (laughing) and not only that, you'd wait half an hour or an hour just to see if they do turn up. But by then you say ... don't worry ... and sort it out. (Int. #10, p.88-90, non-oncology/home)

While nurses provided the majority of home care assistance for families in the oncological category, those in the non-oncological category were more likely to use a wider variety of services and to have a longer period of care. They were also the group who encountered the most difficulty in obtaining home assistance and maintaining continuity of care as illustrated above by Louise's parents who managed her care between hospital, hospice and home.

Parents were acutely aware of when professionals seemed not to respect their position as the child's parents or where they failed to respect the child as a person. For example, one mother recalled her fraught relationship with a social worker and described her sense that her daughter was being merely 'used' by a doctor:

Mother: We had a social worker, from [a hospital] and he umm ... forgot to say anything, I think, maybe they need to have a bit more training, he, he umm ... he didn't help us at all, he was very tactless, he was very thoughtless, that's the only thing I could say, this, this is a Social Worker that goes, you know, through the wards in [the hospital] umm ... I've had umm ... some contact with the social worker from Childhood Cancer and she's very good. . But umm ... this, he was a, he was a young fellow and umm ... I mean we would talk some personal

things to him ahh ... and he would just come in when we had visitors and just start talking about anything with us and we've got a ... you know, people and visitors and things and we said to him ... 'ewe don't want to discuss, you know, private things in front of visitors' and umm ... and we had to tell him a couple of times and in the end we just said to the ward sister 'forget about it' because he wasn't, wasn't helping us (inaudible) more a problem if anything, because we never knew when he was going to walk in and umm ... say things umm ... (Int. #2, p.4, oncology/hospital)

Mother: We did that lots of times [the child having repeated medical examinations] lots of times and she had to go through ... quite a few doctors coming in and saying ... like she had to touch her nose and touch her finger, these sort of things. She had to do that a lot which at the time (inaudible) but I guess you've got to do it to make sure ... that she [is okay]. (...) There was one [doctor] ... he just came in and I mean it was, that day she didn't need to have extra ... touch fingers, do this, touch that you know, she just didn't need it ... 'cos he was just doing some sort of study on, actually I don't think he asked the nursing staff if he could do it.

AH: And he hadn't asked you?

Mother: No he just came in and did it. (Int. #2, p.52,-53, oncology/hospital)

2.5.3 *The Financial Costs of Caring*

The costs to families of caring for a child with a chronic or life-threatening illness are well known, both in relation to direct care costs of equipment, supplies, transport, parking, etc. and in the more indirect costs of parents' career interruption or inhibition. Parents in this study discussed the costs of palliative care mainly in relation to both general hospital and care services funding and in connection to their own particular work/financial situations.

Parents expressed concerns that palliative care services were not a particular priority item within health care. There was a general perception that pressures to cut costs and a prioritising of acute and adult-oriented services led to palliative care services for children being underfunded. This was evident for participants when, for example, there were temporary ward closures or when parents could not obtain the one-to-one specialist nursing care at home which they felt that their child's condition demanded. As this mother commented:

Mother: But with budget cuts and everything it's sort of a luxury. I mean palliative care seems to be one of the things that's sort of ... *off* to the side you know (...) palliative care doesn't seem to attract a lot of huge

research funds. Well not that you hear anyway ... in the media that umm ... and I guess it's because ... part of society's put a taboo on death and dying. (Int. #1, p.53-54, non-oncology/home)

This mother's account of the difficulties that she faced in obtaining coordinated care was illustrative here. These parents had organised relief care with foster parents, a volunteer from a hospice and a baby sitter (occasional use only) whom she had taught some of the more technical aspects of her daughter's care. She used hospital services only whenever her child developed an acute medical problem. The foster parent arrangement worked well for this mother up until the final stage of her child's illness. At this time the mother felt that her daughter was too ill to move back and forth from the family home to the foster parent's home. The volunteer worker, a seventy year-old woman, provided minimal relief because she was unable to do the more technical aspects of the child's care such as suctioning. Nor were professional nurses a viable option, primarily because the mother needed more than a short daily visit (which may have been available through the RDNS) and also because of the prohibitive costs of employing a nurse privately. The mother explained:

Mother: ... and then the last sort of ... week and a half it was like she kept coming out with more and more bruises and ... before we got quite to this stage Gordon [Medical Consultant] had made ... a lot of enquires about ... sort of getting some help at home. Because I wanted to keep her at home, I didn't want her to sort of ... go into hospital and even ... like the hospices they weren't ... geared up for doing short term respite for babies. Not, not at her age you know sort of thing ... older people, kids and that but ... not babies and even with private health cover ... getting, like a District Nurse or somebody in, well we worked out that within two days I would have used up my total years (laughter) allowance.

So I mean, it was just crazy, there was just nothing that you could get to actually come in ... like overnight, to give you rest because she was really irritable ... I would say the last few months and ... it was rarely sometimes I would be in bed before 2.00 am, 3.00 am. in the morning. (...) So I would ring Gordon again and he'd say 'give her another lot'. And, and she was also on Vallergan at night. Just nothing would knock her out basically. And so you know, often it sort of ... that sort of ... you need someone that could come in, well I would have *liked* to have had someone who could come in overnight so wouldn't have to stay up all night with her until she settled ... to get her off to bed.

Like you know, I could have had, we worked out ... I had enough in my private health cover to cover you for two nights and (laughter) that's (inaudible) used up ... the allowance. Because it is normally like, for District Nursing to come in for an hour to do ... like ... you know,

activities of daily living type of stuff [bathing, dressing etc]. There's nothing sort of set up for ... those sorts of facilities [overnight relief]. That would be good to have something like that. (Int. #1, p.10-12, non-oncology/home)

Another child's care alternated between home and hospital. Both of his parents were in paid employment and remaining so was "really important" for them as they were "conscious of preparing for life after George" knowing that it would be very difficult. Paradoxically, however it was not only parents who had lost an income or incomes, but parents who managed to maintain their jobs who found it extremely difficult, if not impossible to obtain the services which they believed to be essential for their child's palliative care. George's parents found that their employment status hindered the amount of assistance that they were able to receive. Normal avenues of care, such as child care centres, were unsuitable and little help was available from extended family.

AH: Did you have any hired help from any (...) agency on those weekends? [When George was at home]

Mother and father: No.

Mother: That was the one thing we could not get. We, we couldn't get that anywhere we, we tried desperately to get just additional assistance and the best we got was probably for a couple of months he was able to go to a day centre place which was totally unsuitable because it was for, mainly for children with management problems and it was unsuited to George but it was all that we could, could do and in the end we just couldn't let him go. I mean it just wasn't fair [on George] and all, all the types of assistance that we thought that we could get we just didn't get anything. Nothing at all.

AH: Which avenues did you try and find unsuccessful?

Mother: We had the, the social work people looking into things like home help ... visitors coming in just for an hour or so just to give us a bit of a break or the only thing we had was district nurses during the week if he happened to be home during the week. We had those twice a day. We had those for years. (...) But they [social workers] tried different service groups, Domiciliary Care, some of those and they couldn't get any thing for us. It was difficult because we were both working and that seemed to hinder what services you could get hold of because we were both working. Now what income has to do with assistance I have no idea but this seems to be, well there seemed to be a bit of mentality out there that you didn't need the normal sorts of services if you could afford it which was ridiculous. So we never had any and we didn't have family help either unfortunately. I think towards the end both lots of our families just found it too difficult to handle. I mean it was hard enough for them

but they found it very difficult so we didn't get any help at all. (Int. #9, p.20-22, non-oncology/hospital)

Other parents described the financial difficulties associated with one or both of the parents giving up work to care for their child:

Mother: I stopped work. I was doing family day care and I couldn't look after the children any more ... umm ... so, yeah we lost that income. Just a couple of hundred a week but ... made a difference. (Int. #5, p.50-51, oncology/hospital)

Mother: The [parents'] business went into receivership and, and in order to pay, we did, well we didn't have the income after that to pay the mortgage on the house which had to be mortgaged up to the hilt to try to save the business from previous years so we really had not much option but to sell the house. (Int. #10, p.58, non-oncology/home)

5.4 *Relatives, Brothers and Sisters and Friends*

For the majority of participants, family, friends and siblings were an important source of additional support. Their supportive practices ranged through caring for the ill child's siblings, assisting with direct care to the ill child, relieving parents for short periods and of course undergoing bone marrow biopsies and donating bone marrow where the brother or sister was a good 'match'. These mothers' comments were typical here:

Mother: They (older siblings) were staying home to help, while they could. Ainslie in particular was a big help 'cos he's a big lad. He's six foot and he's very, quite strong. So he helped a lot with nursing Louise. Just lifting her around and breaking spasms and things like that. (Int. #10, p.40, non-oncology/home)

Mother: Sam his brother took him out of hospital, got permission to take him out of hospital, took him to the super cross motor bikes at the Entertainment Centre and then took him back again. (Int. #4, p.67)

One of Alexander's school friends provided valuable companionship and support when he was in hospital and at home. Likewise, his brother Sam also assisted with Alexander's care.

Mother: Kevin (Alexander's friend) would go down, his mother would take him down on a Saturday afternoon and he would sit with Alexander for a couple of hours. She'd go off and do something and come back and pick him up. And he was that good a friend that ... you know,

like he'd hold the vomit bowl for him or he used to help the nurses hold the platelet bags if he needed platelets. He even stayed *over* at the hospital one night, they let him stay over.

Father: Which was good.

Mother: Well, that was all right. (...) He shouldn't have really been there but he was caring for Alexander. He was taking my place. And he came and *actually stayed* with him in his bedroom, when he knew Alexander was dying. I reckon that's pretty brave for a 14 year old. 'Cos he could have woken up the next morning and Alexander could have been dead. And he was here (at family home) all the time, he was just excellent. It was just no, no trouble for Kevin to go and he'd just sit, if Alexander was ... asleep or ... didn't want to talk ... Kevin would just sit and ahh ... but if he wanted to play a game or build something then Kevin would build something. Amazing child for that age you know. (...)

Mother: Sam his brother took him out of hospital, got permission, to take him out of hospital, take him to the super cross motor bikes at the Entertainment Centre and then took him back again.

Father: And then Kevin stayed the night.

Mother: And then Kevin stayed the night. (M & F: laughing)

Father: But those things are good because it keeps them relaxed and their friends, it keeps them involved. (Int. #4, p.65-67, oncology/home)

Further support was also available for this family when they took Alexander home for the last time.

Mother: We had my, well Sam his brother was still living here then. He's married now. And his now wife, his girlfriend then, she was also living here at the time and she was a great help ... as he, and he [Alexander] trusted her. So if I wasn't capable of doing it [his care] ... then he would let her do it. (Int. #4, p.34, oncology/home)

Support from relatives was not always available to families. Sometimes the child's medical condition was simply too overwhelming. For other participants, close relatives lived interstate. Timing of family support was also a significant factor for one mother. In the final few days of her daughter's life, this mother felt that there was a fine line between having adequate family support and too much:

Mother: At this stage it was basically my sister and Roger's [husband's] sister. (...) We didn't get a lot of support throughout from Roger's family but it got to the stage where all of a sudden people were ringing and it was at such a critical time for us ... well that was our last

time to spend with her so we told the rest of the family to keep away because it was too hard, it was just too hard having people come you know, people coming in and out when she was so ill. (Int. #2, p.28-29, oncology/hospital)
5

5.5 Volunteers: 'more than just looking after her and cuddling her'

Some families had received assistance from the voluntary sector. Only one family in the non-oncological category mentioned having help from a volunteer who, in this instance, was associated with a hospice. Unfortunately, this elderly volunteer was unable to provide the type of help which the mother actually wanted and needed as she could not provide total care for the child, including suctioning and other technical practices. Thus, this mother was unable to be sufficiently relieved of her caring duties for longer than the time required to do the family shopping. While the volunteer did provide support such that the mother felt that "it was better than nothing", what she would have preferred was someone who was capable of providing all aspects of her daughter's care and who could have been available overnight when the mother's need for rest and sleep were paramount in order that she could undertake next day(s) of caring. As the mother explained:

Mother: What I would have liked was if there had been some sort of *hospice in the home care* (laughter). I mean for, for me it would have needed to be someone who was trained ... because it was more than just sort of ... you know just sort, you know, looking after her and cuddling her and, and those sorts of things. So I mean ... that would have been nice. Just, just to have a break. Particularly overnight too. Because you tend to cope and keep ... going on through the day but sort of, when you get night after night of ... very little sleep, it sort of just ... a ... someone to sort of come in say from ... nine pm at night and leave at seven o'clock in the morning or whatever, would have been nice. (Int. #1, P.20, 21, non-oncology/home)

Wished for services, such as a "hospice in the home" program were, for this mother, the optimal solution for her very difficult situation which caused her to become "so exhausted". Her emotional and physical exhaustion was echoed by other parents in both the non-oncological and oncological categories. For many parents, the intensity of care which their child required meant that feelings of exhaustion arose only days after discharge

5 Similar sentiments were expressed by parents in Darbyshire's (1994) study, when they described how their energies could be drained and their focus on their sick child diffused by feeling the need to keep parents, family and friends supported and informed in relation to the child's hospitalisation.

from hospital.⁶ Some families tried to overcome this by alternating 'shifts'. That is, one member provided care while the other tried to get some sleep. But this was not always possible, as Oliver's parents illustrated. He was "vomiting all the time" and needed frequent trips to the toilet. He was so weak "he couldn't hold his head up" and needed one person to support his head and hold the vomit bowl while the other lifted and manoeuvred him onto the toilet.

Father: Yes. That [managing Oliver's vomiting] was getting harder and harder to, when I think ... by sort of ... the middle of Sunday I think, well, we had managed pretty well just the two of us ... well, you know it was within our range, our limits to handle sort of thing ... the first few days. But by Sunday morning or afternoon ... as he deteriorated ... and he, he really deteriorated quite quickly in the end ... I was beginning to think that you know this more that what just two, two of us can handle we, we really needed to have three people virtually. (...) If one of you is sleeping, I thought well you know, I really couldn't see that, we, we needed more ... people than what, if Sunday night was gonna ... you know, if we were still caring Sunday night ... we had to have change what we did ... have more people there or perhaps maybe consider ... I was beginning to think well maybe you know, do we need go to the local hospital or wherever. We needed to do more.

Mother: If it had gone on, we couldn't have coped. (Int. #6, p.32-34 oncology/home)

Oliver's vomiting did not settle down, nor did they get extra help. His death, which followed soon after, was the reason why their difficult situation did not continue. Not having adequate help in the home at times like these was the primary motivation causing these and other parents to consider hospital/hospice options.

All parents in the oncological category mentioned that they had varying forms of assistance from the Childhood Cancer Association and/or Camp Quality. For some, this included volunteers who either supported the parents and other family members directly or established 'buddy' relationships with their sick child. For all parents, this type of assistance was valued. One characteristic of this type of help which was especially appreciated by parents was that the support persons assigned to them had an understanding of what they and their child were going through.

Mother: Actually we've had phone calls and visits from sort of assigned support worker from the Childhood Cancer Association, you know we've had several phone calls and visits from Josephine who was the lady that had kept in contact with us and also from another lady too

⁶ See (Hunt and Burne 1995) for an account of the exceptionally difficult medical and nursing problems which children with neurodegenerative disorders can pose.

who she wasn't actually assigned but she just fell in love with Oliver and sort of assigned herself (laughter) didn't she?

Father: Yeah.

Mother: Yes so that's, that's been nice because I mean particularly Josephine has you know, she has been through, she didn't lose her daughter but yes she has certainly been through the treatment with her and ... so I guess she has a better understanding of what ahh ... of what its like. (Int. #6, p.57, oncology/home)

Volunteer support for one mother was valued because it enabled her to engage in activities which she equated with a normal existence.

Mother: We're still in close contact with the, our support worker with Childhood Cancer. She's still friendly with us ... in fact we speak every week and we're quite close. It almost seems as though she knows we are not having a bad day 'cos she'll ring. I didn't really want that support at the beginning but now it's very important. And it's important too I think, that she knew Malcolm before ... he died. I took the support actually as respite (...) someone for Malcolm, someone additional that would take ... spend some time with him so I could do things around the house to make me feel normal. Like, do the washing and clean out the cupboard or do the shopping or something. Rather than have someone do that and [me] spend more with Malcolm I felt it important to be still be a part of the world and the way it all works so she used to take him to the pictures or just come and watch videos with him or ... depending on how he felt or ... take him for a drive or play cards or something so ... that was important. (...) I think also she being a nurse, Malcolm felt comfortable, being with her 'cos he knew ... knowing that she would know what to do if something went wrong. He was always conscious of the fact that he wasn't well, even though he didn't want, he didn't show it to anybody else, I could see that ... these little bits of security, he was setting up. (Int. #5, p.27-28, oncology/hospital)

The importance of having someone who would "know what to do" in a crisis was important for both Malcolm and his mother. This afforded both of them comfort in the knowledge that the mother's absence for a time would not precipitate disaster. It is notable that 'normal life' for the above mother concerned activities which were a component of her usual unpaid work such as cleaning out cupboards, doing the washing and the family shopping. This mother, like other parents, tended to use relief support in order to keep on top of the practicalities of family life. None of the participating parents in this study mentioned relief care or support which was abundant enough to enable them to undertake other aspects of 'normal life' such as reading, gardening, meeting with friends or pursuing sporting

activities. For some, leisure was a concept of the past as the focus of their lives now revolved around their sick child and other parenting responsibilities. The extent of this was illustrated by another mother who, following her son's death, noted that:

Mother: We [parents] just looked at one another and thought, now what do we do? You know, because my day had been so full ... looking after *him*. It's just suddenly empty. (Int. #4, p.36 oncology/home)

The death of their son for this family meant that they needed to redefine and readjust their lives. Another mother said that their son's illness essentially meant that they had to put their lives 'on hold' for two and a half years.

3 Executive Summary

3.1 *Background to the Study*

In early 1996 Professor Philip Darbyshire collaborated with Sara Fleming, Unit Nursing Head of Ronald McDonald House in developing and submitting a research grant application to the South Australian Health Commission: Palliative Care Program - Statewide Projects in order to study the experiences of parents who had been involved in the palliative care of their dying child. The proposal was successful, \$23,488 was awarded and the project commenced in September 1996 when Amanda Haller joined as the project's Research Assistant. In the latter stages of the study, The Department of Clinical Haematology and Oncology at WCH also contributed \$3,896.88 towards the funding of the study.

The study was a qualitative exploratory investigation which involved interviewing seventeen parents from ten two-parent families who had cared for their dying child within the last five years. Of the ten families, four lived in rural locations and the remainder lived within a 25km radius of central Adelaide. All parents chose to be interviewed in their own homes.

The interviews with parents were intended to be focused but roomy in that the palliative care period was of central interest, but clearly, parents needed to be allowed to tell their story in ways which were most appropriate and meaningful for them. Each interview lasted between 45 and 180 minutes. Interviews were transcribed verbatim and then checked to ensure accuracy of transcription.

Interpretation of the interview data involved a close, line by line analysis where the researchers were looking for themes, commonalities, practices, and even absences which would illuminate the parents' experiences. The major interpretive themes within the report are presented in Section 2 under the following headings: 'The Meaning of Palliation'; 'The Nature of Parents' Caring Practices'; 'Juggling Family Needs'; 'Experiencing the Child's Death'; and 'Parents' Perceptions of Services and Support'.

In this Executive Summary, we highlight the salient themes which emerged from this analysis and suggest possible implications for clinical practice.

3.2 *The Meaning of Palliation*

3.2.1 The Commencement of Palliative Care - 'Finding out'

Most parents were able to identify a clear episode or point at which palliative care began, which was usually the point at which they were told that further treatment was likely to be unsuccessful. For most parents there was a significant time span between diagnosis and the commencement of palliative care which helped parents to adjust to the receiving of the 'worst possible news'.

3.2.2 The Child's Life Expectancy - 'How long have we got?'

This was the parents' major question and at a time of such great uncertainty, this was the hardest uncertainty to bear. Knowing, at least approximately, how long their child was going to live helped parents to prepare for and to make plans for their child's dying.

3.2.3 Parents' Understandings of Palliative Care - 'What does it mean?'

Parents had a range of understandings and perceptions surrounding palliative care, but for most of the parents, the period of palliative care was a time for trying to maintain and sustain a sense of normality in family life in the face of the most abnormal of circumstances. Parents also saw the period of palliative care, not as a time when 'nothing could be done' but as a time for fostering the child's quality of life while acknowledging its diminishing quantity. Closely related to this was parents' focus during the palliative care period on evaluating and carefully choosing any active or symptomatic treatment for their child. Such interventions were now judged and balanced against a range of other priorities.

3.2.4 The Location of Palliative Care - 'Choosing where our child will die'

The parents' children died in various settings, not always at home as was planned but seven of the ten children died in the 'planned' place. Parents tried to balance many factors in deciding on the child's place of death, such as the child's own wishes, their own preferences, their perceived strength and ability to cope in relation to the child's care needs and their own positive or negative perceptions of health care settings.

3.2.5 Transitions - 'The hospital was our home'

The journey from the treatment phase of an acute or chronic illness to palliative care was both a physical/locational as well as an existential transition for parents. They described a range of uncertainties, anxieties, isolations and losses that they felt on leaving hospital for home. Parents expressed the sense of a concomitant loss - the impending loss of their child and the additional loss of the friends, familiarity and security associated with the hospital.

3.3. Parents' Caring Practices

3.3.1 Equipment and Supplies - 'Gearing up'

Five of the families provided end-stage care for their child solely at home, while others cared for their child at home more intermittently. 'Gearing up' for the move from hospital to home was unforgettable for parents, particularly for the sheer quantity of equipment needed in order that they might care for their child at home. Parents described setting up what seemed like a 'mini-hospital' in the home, with most moving the child between their bedroom and a main family room or lounge where the child could be at the centre of the home and family. This 'Gearing up' with equipment seemed more physically and emotionally taxing for parents of non-oncology children whose palliative care period tended to be much longer. Rural parents also described particular logistic difficulties in obtaining equipment and equipment-related support.

3.3.2 Technical Aspects of Palliative Care - 'Nurse things'

Parents readily took on aspects of care for their child that would traditionally be performed by nurses, eg maintaining intravenous infusions, giving injections etc. They did this to enable themselves to provide care for their child at home. Parents felt it essential that they learn these skills in order to be able to maintain their child's palliative care and treatment at home. Parents also believed that community and other support nursing services would have been unavailable to undertake such intensive care and would be unavailable at the unpredictable and unsocial hours when such care was required. Some parents also preferred to give all of their child's care when their confidence and trust in visiting or community nurses had been shaken, possibly through professionals' expressed unfamiliarity with children and paediatric palliative care or through a perceived laxness in asepsis and infection awareness.

3.3.3 Parents' Multiple Roles - 'Me the mum, and me the nurse'

It was not easy for parents to be both their child's mother and their nurse. This is not simply a matter of taking on an extra role, ie as a nurse, but of making a significant alteration to the fundamental nature of being a parent. Some parents expressed difficulty in reconciling the practices of being a caring parent who soothes away pain and distress, with the newly acquired practices of administering possibly painful injections, or urging the swallowing of vile-tasting medicines. Parents also described vividly the exhaustion which they often felt as they tried to be both parent and nurse to their dying child, in addition to their panoply of other responsibilities which did not disappear during this time.

3.3.4 Pursuing Normality - 'Having a life'

Parents were acutely aware of the importance of 'having a life', even in the midst of dying. They worked towards creating a home and family where their child would experience what they judged to be a good quality of life, even although they were dying. They wanted their child to 'have a life', which was as life-affirming as their condition would allow. Parents were acutely aware of when their child's conceptual balance of Quality of Life moved into the negative. This was often in the very last few days before death when increasing pain and suffering outweighed the child's capacity for pleasure, comfort and enjoyment. At this point in the child's descent towards death, parents often felt that they 'had no life'.

3.4 *Juggling Family Needs*

3.4.1 Brothers and Sisters

All but one of the children in this study had one or more brothers or sisters. Parents described a range of sibling reactions to the family's situation and to their dying brother or sister. Some found it extremely difficult to even watch their deterioration while others actively involved themselves in their care. Parents did not discuss how or if they prepared brothers and sisters for the child's death. Paradoxically, parents reported how siblings, especially younger brothers or sisters often provided a valuable 'light relief' at such a desperate time by making the kinds of comments or asking the questions that perhaps only young children can be forgiven for asking.

3.4.2 Work and Careers

Parents described the elaborate and demanding logistics of trying to hold down jobs and focus conscientiously on work while also trying to be there for their child during hospital stays, clinic visits, etc. Being in two places at once both physically and existentially was impossible and many of the parents either gave up jobs or took extended periods of leave, including periods of leave without pay.

3.4 Experiencing the Child's Death

3.4.1 Parents' Previous Understandings of Death and Dying - "When it's your own, it's always a bigger deal"

Parents were largely unfamiliar with death and dying, finding these to be fearful concepts. Some parents had had previous experience of caring for dying people professionally, but reported that this experience was no real preparation when it came to their own child's dying and death. It is debatable as to whether any amount of knowledge could prepare a parent for their child's death, but the parents caring for their child at home described the negative impact and consequences of their lack of knowledge concerning some of the practicalities of dying and death, eg, not recognising Cheyne-Stokes breathing, and thinking that their dead baby's limbs would break off if they held them.

3.4.2 Maintaining Hope - "You don't want to believe that your child is dying"

Being told that their child was dying and that nothing further could be done to save their lives, did not lead automatically to parents' acceptance of death as being inevitable. Some parents did not accept the inevitability of death until the final hours or minutes of their child's life. At this time the focus of parents' hope changed from hope for recovery to hope described by parents as "what they did *not* want to see", which was invariably their child's pain and suffering.

3.4.3 Death and Dying at Home - "No-one told us that she would get so cold so quickly"

While the experiences of parents whose child died at home were different, there were recurrent themes within their accounts which have implications for paediatric palliative care. Being unprepared

for death and not knowing about a range of practical issues as opposed to philosophical or theological issues were common recollections. From the perspective of experienced professional practice, many parents' concerns or knowledge deficits seem almost absurd, but there was little absurd about the distress caused, for example, to the mother who felt unable to hold or touch her dead daughter for fear that her limbs would break or fall off and whose abiding memory of her child when laid out was that her legs were awkwardly open because she had not understood the need to place them together at the time of death. Parents generally described a pattern of receiving inadequate detailed, practical information about the actual time of death, its immediate antecedents and what they needed to do following their child's death. Even parents who would be considered to be experts in every area of their child's disorder and treatment, could not be assumed to know what was required in caring for the dying and dead child, and some parents described vividly their panic at this time.

3.4.4 Death and Dying in Hospital and Hospice - 'The waiting was pretty hard'

Parents' caring in hospital was marked by the considerable time spent in vigil at the bedside. This was not a benign passive waiting, but a 'waiting and watching' which was laden with anxiety, dread and often horror as parents watched their child's final deterioration and indignities. For parents in hospital, other dimensions of 'Parenting in Public' (Darbyshire 1994) arose, for example sensing a loss of power and control over important aspects of their child's life and death. One family described their unease when staff came to their son's bed to say goodbye to him. While this may have been intended as a caring and well meaning gesture, the parents felt that this had been sprung on them without consultation.

3.5. *Parents' Perceptions of Services and Support*

3.5.1 Valued Services and Supports: 'the door was always open'

Services and supports used by parents were both professional and personal and varied according to the child's condition, what was offered or available and what parents could find for themselves. Parents understood the magnitude of the commitment involved in opting to care for their dying child at home while facing a future which was both unknowable and unthinkable. They expected that there would be adequate support available to help them fulfil the overarching imperative - that they must meet all of their child's needs.

Nurses were the most frequent service providers who visited the child at home and their value for some parents transcended their instrumental functions as injectors, wound dressers or equipment providers. Parents had a very clear recollection and appreciation of the professionals whose caring practices enabled and supported them during this time. Often, this was the professionals who were perceived as going that extra mile for the child and parents. Parents valued professionals who took time to spend with them, even when they were clearly busy, who made it clear that they were really approachable and available to parents and who made parents feel that the door was always open and who were not depressed or gloomy around the child.

3.5.2 Unhelpful and Alienating Services

Some home visits were not supportive or enabling for parents. In each instance where parents described negative experiences with visiting nurses, it was clear that the parents' confidence and trust had been shaken by the nurse's failure to adhere to care practices which parents deemed to be vital for their child's well being, for example by failing to wash hands, or by professing an ignorance of the particular needs of children or of their child's particular equipment or treatment modality. For some parents, what they perceived as the need for them to manage, assess, teach and monitor a pool of visiting nurses and assorted carers changed the meaning of such help from support to an additional burden. In this situation, there could be no real relationship development between parents and nurse(s) which would enable the trust and professional friendship to develop which was deemed important if parents were actually to derive a benefit from having nurses visit them at home. The complexity of the issue of involvement and the associated limits and boundaries was highlighted by different parents who described the unhelpfulness of each end of the involvement spectrum, from professionals who seemed cold, aloof and uninterested to those who seemed close to 'taking over' the parents' roles and their children.

Parents were similarly concerned when medical services and particular doctors seemed to lack the specialist knowledge or the involved caring stance which parents described as being so essential. Parents generally described how they would try always to deal with their child's consultant or specialist as they could find it frustrating and unproductive to go through less experienced junior doctors in hospital or to deal with local GPs.

3.5.3 The Financial Costs of Caring

Unsurprisingly perhaps, parents described a range of costs and financial implications of caring for their child at this time. These ranged from

seemingly 'minor' items such as petrol and parking costs (remembering of course that minor items multiplied soon become major) to parents' seeing their business go into liquidation because they could not devote the time necessary to it and to their child. Parents tried hard to keep jobs and care for their child at the same time but for some, it was simply impossible 'to be in two places at once'. Something had to give, and this could never be the child's welfare. It was not only parents who had lost an income (or incomes) who found the costs of caring for their child to be high, or beyond their reach. Parents who were in employment found that their income excluded them from accessing services, yet their income and insurance were hopelessly insufficient for them to 'buy' the services which they required, for example, specialist nursing care during the night to allow them some sleep.

3.5.4 Relatives, Brothers and Sisters and Friends

Simply having an extended family, neighbours and friends was no guarantee that such a network would be a *ësUPPORTÍ* network. Parents described how support from family and friends was not always available, could be difficult to ask for and could not be absolutely relied on. Parents explained the delicate social balancing which took place as they tried to mediate this vexed question of *ësUPPORTÍ*. For example, there were times when parents would ask for and gratefully receive help, but there were also times when parents tried to keep family away, not through malice or selfishness, but as one parent explained, "because that was our last time to spend with her (...) and she was so ill." Most parents described family, friends and older brothers and sisters as a huge help, both in assisting with direct care and in supporting and helping with the parents' other children.

4 Recommendations

All qualitative researchers are wary of presenting recommendations from small-scale studies in a didactic manner, however, this exploratory study has highlighted several important issues for paediatric palliative care provision.

Despite the increasing acceptability of discussion surrounding death and dying, parents still seemed to be in the dark concerning a great many important aspects of their child's dying and death. Professionals cannot assume that parents will have the necessary knowledge of death, even although they are otherwise experts in relation to their child's care. Parents may seem to be functioning as nurses, but they rarely have the experience or knowledge of death at close hand. Parents needed direct and unambiguous information, not dancing around the topic. Parents were also very clear that they valued the expertise and specialist knowledge of health professionals who had specific paediatric knowledge and current clinical experience.

Parents were hugely appreciative of the assistance and support given from visiting nurses, but only when the nurse was clearly experienced in working with children and when she had knowledge and experience of paediatric palliative care which could be shared. Paradoxically, nursing or medical help from professionals who did not have this experience or knowledge was often perceived as being more stressful than helpful.

While the parents' accounts do indicate that some extremely valuable services are being provided, there is a sense that this may be more fortuitous than designed. What seems clear from these parents' experiences as described is that services and support during this period tended to be fragmented and often difficult for parents to access unless they were "lucky" enough to have very good connections and relationships with specialist health services personnel.

Fragmentation of services and the difficulties involved in accessing appropriate services is sadly no new phenomena in health care, as many parents and families will attest. However, paediatric palliative care provision should have an advantage over other areas of child health service provision such as asthma or diabetes care in that in South Australia at any given time, there will be far fewer children requiring palliative care services.

In the light of this study's explication of parents' perspectives and experiences regarding their child's palliative care we would suggest that paediatric palliative care service providers give urgent consideration to the establishment of a specialist Paediatric Palliative Care Co-ordinator position. This should be a senior Nursing position which would reflect the advanced level of

educational, clinical and managerial capabilities which such a post holder would require in order to initiate, develop, implement and evaluate such an innovative service development. It will also be clear from the parents' accounts presented in this study that this person should be contracted on a flexible rather than on a '9 to 4' basis which will enable them to both coordinate and provide support and care at the times when parents and families require them. A further obvious consideration is that the post holder would certainly require the exclusive twenty-four hour use of a suitable car which would be able to transport both people and equipment at any time of day or night.

This is now the time to take the provision of a coordinated, specialist paediatric palliative care service from out of the 'too-hard' and into the 'can-do' basket.

5 References

- Alderson, P. (1993). Children's Consent to Surgery. Buckingham, Open University Press.
- Amenta, M. (1994). "Terminally Ill Children in Hospice Care." Home Healthcare Nurse 12(4): 66-67.
- Arnold, J. and P. Gemma (1994). A Child Dies: A portrait of family grief. Philadelphia, The Charles Press.
- Ashby, M., R. Kosky, H. Laver, and E. Sims. (1989). Report of the Subcommittee on the Management of Dying Children and Their Families, Report to Adelaide Children's Hospital.
- Attig, T. (1996). "Beyond Pain: The Existential Suffering of Children." Journal of Palliative Care 12(3): 20-23.
- Baum, F. (1996). Research to support health promotion based on community development approaches. Health Research in Practice Vol. 2. Colquhoun, D and Kellehear, A. (Eds.). London, Chapman & Hall.
- Bernheimer, L. (1986). "The use of qualitative methodology in child health research." Children's Health Care 14(4): 224-231.
- Clare, J. and A. De Bellis (1996). The Nature, Extent and Evaluation of Palliative Care in South Australian Nursing Homes. Adelaide, Australian Institute of Nursing Research, SA.
- Clark, D. (1997). "What is qualitative research and what can it contribute to palliative care?" Palliative Medicine 11(2): 159-166.
- Darbyshire, P. (1994). Living With a Sick Child in Hospital: The Experiences of Parents and Nurses. London, Chapman & Hall.
- Davies, B. and R. Steele (1996). "Challenges in Identifying Children for Palliative Care." Journal of Palliative Care 12(3): 5-8.
- Dreyfus, H. (1991). Being-in-the-World: A Commentary on Heidegger's Being and Time, Division 1. Cambridge, Mass., MIT Press.
- Fitzpatrick, R. and M. Boulton (1994). "Qualitative methods for assessing health care." Quality in Health Care 3(2): 107-113.
- Fragar, G. (1996). "Pediatric Palliative Care: Building the Model, Bridging the Gaps." Journal of Palliative Care 12(3): 9-12.
- Goldman, A. (1996). "Home Care of the Dying Child." Journal of Palliative Care 12(3): 16-19.
- Hunt, A. and R. Burne (1995). "Medical and nursing problems of children with neurodegenerative disease." Palliative Medicine 9(1): 19-26.
- International Work Group on Death, Dying and Bereavement/Workgroup on Palliative Care for Children. (1993). "Palliative Care for Children." Death Studies 17: 277-280.
- Jacob, S. and S. Scandrett-Hibdon (1994). "Mothers grieving the death of a child: case reports of maternal grief." Nurse Practitioner 19(7): 50-55.

- Judd, D. (1995). Give Sorrow Words: Working with a dying child. London, Whurr.
- Liben, S. (1996). "Pediatric Palliative Medicine: Obstacles to Overcome." Journal of Palliative Care 12(3): 24-28.
- MacLeod, M. (1996). Practising Nursing - Becoming Experienced. New York, Churchill Livingstone.
- Rando, T., Ed. (1986). Parental Loss of a Child. Champaign, Research Press Company.
- Roy, D. (1996). "When Children Have to Die." Journal of Palliative Care 12(3): 3-4.
- South Australian Health Commission (1995). Report to Parliament on the Care of People Who Are Dying in South Australia, South Australian Health Commission.
- Thomas, J. (1994). Parents. Caring for Dying Children and Their Families. L. Hill. London, Chapman & Hall: 43-66.

6 Appendices