

ACKNOWLEDGEMENTS

The author gratefully acknowledges the financial support of Queensland Health Central Zone Management Unit and the Centre for Palliative Care Research and Education in the development of this resource.

Enormous thanks for this booklet must also go to Dr Judith Murray for giving permission to use a number of her original works and for her constant support.

Acknowledgement is also given to the staff at the Royal Children's Hospital for their cooperation and assistance with ideas and chapters for this booklet.

DISCLAIMER

The information and views expressed in this resource are those of the author. It is not the responsibility of, nor does it necessarily reflect the views of, the organisations to which individual team members may be affiliated or that of the Centre for Palliative Care Research and Education.

The information in this resource is provided in good faith without any express or implied warranty. Although the author has attempted to make the information as correct as possible, no guarantee is given regarding accuracy—it may contain technical inaccuracies or typographical errors.

Any links offered to resources are provided for the interest of readers. Provision of these links does not constitute endorsement or support for the information, products, services, or persons associated with the related resources.

COPYRIGHT STATEMENT

© The State of Queensland, Queensland Health, 2006.

Copyright protects this publication. However, Queensland Health has no objection to this material being reproduced with acknowledgment, except for commercial purposes. Permission to reproduce for commercial purposes should be sought from the Policy and Quality Officer, Queensland Health, GPO Box 48, Brisbane Q 4001.

■ CONTENTS

ACKNOWLEDGEMENTS	1
Disclaimer	1
Copyright statement.....	1
CONTENTS	2
LIST OF FIGURES	4
PREFACE	5
INTRODUCTION	7
What is the purpose of this booklet?	7
Who is it for?	7
How can it be used?	8
Is there a role for 'others' in parental bereavement?	8
Why do we need to understand and study bereavement?	8
Who can do bereavement work?	9
Definition of terms.....	9
AN OVERVIEW OF THEORETICAL MODELS OF BEREAVEMENT AND HOW THEY RELATE TO PARENTAL BEREAVEMENT	10
Traditional 'popular' grief theorists.....	10
Towards a new model of grief	10
New theories of parental grief based on 'continuing bonds'	11
CHILDREN WHO DIE FOLLOWING AN ILLNESS	12
Cancer and leukaemia—the oncological conditions	12
Life-threatening conditions.....	12
Life-limiting conditions.....	12
WHAT IS SO UNIQUE ABOUT THE DEATH OF A CHILD?	14
The parent–child attachment bond	14
What is so profound about the death of a child for a parent?.....	14
When children and parents are separated through death	15
Parental bereavement as an individual experience	16
WHEN DOES BEREAVEMENT START?	17
Commencing Bereavement Work	17

How can we assist the child and their family to commence bereavement work?.....	17
Can parents prepare for the death?.....	18
Can there be sudden death within palliative care centres?	19
WHAT CAN PARENTS EXPECT TO EXPERIENCE IN BEREAVEMENT?	20
What does 'normal' bereavement look like?.....	20
HOW LONG WILL THIS GRIEF LAST?	22
Answering Questions About Duration	22
Those at particular risk of 'complicated grief'	22
PHYSICAL AND PSYCHOSOCIAL IMPLICATIONS OF BEREAVEMENT FOR A PARENT	23
Physical health.....	23
Financial impact.....	23
Employment.....	24
Social isolation	24
Marital impact.....	24
Bereavement and divorce—is it a myth?.....	25
Gender differences in coping with bereavement.....	25
IMPLICATIONS FOR PROFESSIONALS WHEN WORKING WITH BEREAVED PARENTS	27
What parents reported as helpful in their bereavement.....	27
CONSTRUCTIVE TASKS PROFESSIONALS CAN UNDERTAKE WITH PARENTS IN BEREAVEMENT	29
What we can advise parents about the first year.....	29
Further implications for grief therapy practice	30
CONCLUSION	31
SUGGESTED READINGS FOR PARENTS	33
USEFUL ORGANISATIONS IN QUEENSLAND	34
Organisations that offer counselling.....	34
Support Groups.....	34
REFERENCES	36

■ LIST OF FIGURES

Figure 1: Principles associated with theories of parental grief based on the concept of continuing bonds	11
Figure 2: Parental experiences following the death of a child.....	20
Figure 3. Summary of research findings on gender differences in coping with bereavement.....	26

■ PREFACE

In 1998, the Royal Children's Hospital and Health Services District (RCH and HSD) in Brisbane, Queensland, Australia, initiated a paediatric palliative care project. Funded by Queensland Health, this initial project sought to identify the needs of health professionals and families caring for children with progressive malignant disease. A handbook written for health professionals and titled 'A Practical Guide to Paediatric Oncology Palliative Care' was developed as a result of this project. A follow-up book for parents and families was later developed.

In 1999, a more extensive needs analysis of the requirements of families with children suffering from non-malignant, life-limiting illnesses—"The State-wide Paediatric Palliative Care Education and Community Awareness Project"—was commissioned by Queensland Health. As project leader, I worked with a steering committee from the RCH and HSD comprising Dr Helen Irving, Dr Jim McGill, Tim Rogers and Michele Noyes, to complete the project in 2000. As key recommendations for action, the project report highlighted education and training for health care professionals, particularly regarding working with children with life-limiting conditions in the area of loss, grief and bereavement. This became one of the strategic priorities for RCH and HSD staff.

In August 2003, a three-day paediatric loss and grief training workshop was held in Bundaberg, Queensland, for professionals involved in the support of children with life-limiting illness and their families. Dr Judith Murray, a well-respected leader in the area of loss and grief, and I collaborated to develop an innovative program. The workshop was well attended by representatives from health, education, disability, and pastoral care sectors. At the end of the workshop participants were asked to identify key areas of loss and grief thought to be essential for inclusion in an educational resource. The booklet, 'When Children have a Life-Limiting Illness: Questions and Answers around Loss and Grief', written by Liz Crowe was the result. With the support of staff from the Centre for Palliative Care Research and Education (CPCRE), an educational resource for professionals and/or parents caring for children with life-limiting illness was subsequently developed.

The next step was to address the area of bereavement, where resources and education for parents and health care professionals are minimal. This booklet, 'When a Child Dies—A Guide to Working with Bereaved Parents after the Death of a Child from Illness', has been written to address this gap. Each section in this booklet could have been a booklet in itself. While there are several issues I would have liked to have addressed or expanded upon, these were not within the scope of this project.

I am also well aware that this booklet can give only minimal recognition of the very personal impact on the practitioner when working with families in the intense, and very intimate, experience of bereavement following the death of a child. Working with bereaved families can be as rewarding as it can be frightening and isolating. Having good supervision or someone with whom to discuss the struggles and highlights of such work is essential.

The booklet is limited in that much of the existing loss, grief and bereavement literature on parental bereavement has a bias towards the 'elite subgroup of couples with a stronger bond, better communication or coping skills, less intense grief or other adaptive characteristics.'¹ It is hard to find bereaved couples to interview outside those seeking assistance, from either a support group or therapy. Hence, the parents being interviewed and represented in the literature rarely include single parents, parents from a lower socio-economic background, or parents from different cultural backgrounds. This needs to be considered when reading the booklet because, as any person working in palliative care can testify, illness does not have a bias when choosing its victim; it happens to people from all walks of life.

It is my hope that this small booklet may provide some guidance to people's interactions with families following a child's death after illness. At the least, I hope it provides assurance that all the excellent work that is being done has a sound theoretical foundation.

Liz Crowe

■ INTRODUCTION

Working with a parent or parents after their child has died can be a confronting and daunting task. It can be difficult to ascertain what 'normal' grief is and when to involve other specialised health care professionals such as psychiatrists. Parents may want to talk about the same issues over and over, or they may just spend a lot of time crying—which may leave those in the caring role wondering if they are doing the 'right' thing or are even being helpful. People who are working with bereaved parents can be unsure about how much information parents will find useful and what information they may require. Those who have a busy workload that may include working with either a number of bereaved people or being confronted as a 'one off' with a bereaved parent can find it difficult to keep abreast of all the current literature and research into parental bereavement. This booklet aims to give a concise overview of current research and literature with practical advice on how to work with a bereaved parent. There is also an extensive bibliography and list of additional resources at the back of the booklet.

WHAT IS THE PURPOSE OF THIS BOOKLET?

This booklet has been designed for anyone who seeks to understand the grief processes experienced by parents and the extended family following a child's death after prolonged illness. It aims to inform practice by providing a succinct summary of the latest research in this area. Information is one of the most powerful tools we can contribute to bereaved families and this booklet aims to assist us in this task.

WHO IS IT FOR?

This booklet has been designed for health care professionals, teachers, respite care workers, chaplains, emergency workers and anyone who works, or is in contact, with children who die following a prolonged illness and is interested in working with the family in bereavement. Studies demonstrate that while there are many similarities experienced in bereavement between parents who have a child die after a life-threatening illness and other forms of death (e.g. acute illness, suicide, tragedy) there are also differences.² This booklet focuses on the issues for families who have had children die from either:

- an oncological disease—cancer or leukaemia
- other life-limiting conditions—such as cystic fibrosis, organ failure, muscular dystrophy, metabolic disease or haematological disease.

Within this booklet the word 'child' is used to refer to someone who has died in childhood before the age of 18 years.

This booklet is intended as a guide to current literature and research regarding the issues of childhood bereavement. It is also a resource to accompany other books or journals on the topic, or to add to the expertise of organisations who work with these families.

HOW CAN IT BE USED?

This booklet is designed to answer the most common and troubling questions about childhood bereavement. These may be questions that workers ask themselves or are frequently asked by families and communities following the death of a child. As busy clinicians, teachers and pastoral care workers it can be difficult to review the most current literature and information regarding all aspects of our work. This booklet aims to bring you information on parental bereavement in an easy-to-read and understand format. Small sections of this booklet may be photocopied to give to parents or others who need information about bereavement following the death of a child from illness.

IS THERE A ROLE FOR 'OTHERS' IN PARENTAL BEREAVEMENT?

For parents who have had a child die the road can be long, hard and often lonely. There will be days when parents will be 'crazy' with grief, and other times when they may feel quite at peace. There will be days when they may experience both these feelings within the same day or even hour. They may feel unknown and abandoned by friends, family and strangers alike. So is there a role for 'others'—doctors, nurses, social workers, psychologists, chaplains, teachers, guidance counsellors, pastors, friends, extended family, neighbours, priests and sometimes strangers in the form of other bereaved parents, funeral directors or support groups? The answer is YES. All of these people can play some role, maybe even a vital or profound role. It may not be 'intense therapy' that these families need but assurance, information, safety, having someone who listens without judgement or advice and, very importantly, the opportunity for laughter, love and friendship. Research demonstrates that formal therapy is only required when grief becomes extremely complicated and prolonged.⁸ When therapy is offered outside of complicated grief the evidence suggests that therapy may sometimes do more harm than good.⁸

Parents need to hear from others that they can survive this experience and survive it well, that their surviving children will adjust long-term, and that even marriages can endure the strain and grief.

WHY DO WE NEED TO UNDERSTAND AND STUDY BEREAVEMENT?

Good clinical practice should have its foundations in clinically proven theory and research—working with bereaved parents is no exception to this rule.

As people who will be supporting or working with bereaved families we need to have a sense of what the journey of parental bereavement may be like. We need to understand the commonalities for parents so we can offer assurance to them that they are not going crazy, that they are not alone. We can encourage everyone affected by the death of a child to communicate openly and honestly as a major first step of the grief process.

WHO CAN DO BEREAVEMENT WORK?

Bereavement work does not necessarily mean or require intense therapy. Good bereavement work can simply mean:

- keeping the bereaved family involved with their local community
- listening and respecting the family's wishes
- ensuring the family have choices
- making sure the school is ready and equipped to help siblings return to school after the death
- coordinating support for families, for example by ensuring the family doesn't get too many lasagnes
- simple and humble acts of kindness
- accepting the family without judgement
- giving parents the opportunity to talk and cry about the child who has died.

DEFINITION OF TERMS

- **Loss** can be described as that sense that all is not well. It 'is produced by an event which is perceived to be negative by the individuals involved and results in long-term changes to one's social situations, relationships, or cognitions.'³
- **Grief** refers to the reaction to loss—the emotional response to loss: the complex amalgam of painful effects including sadness, anger, helplessness, guilt, despair.⁴ It incorporates diverse psychological (cognitive, social-behavioural) and physical (physiological-somatic) manifestations.⁵ Grief can be the result of any change that requires a person to give up or let go of what they have enjoyed or loved or found meaningful.⁶
- **Mourning** describes the psychological processes that occur in bereavement; the processes whereby the bereaved person gradually undoes the psychological bonds that bound him or her to the deceased.⁴ This is the slow process of recognising what has been lost and how our lives will now be different without that person.
- **Suffering** refers to the width of the gap between the reality of 'what is' and 'what is desired'.
- **Bereavement** is the objective situation of having lost someone significant;⁵ the reaction to the loss of a close relationship.⁴ The origin of the term bereavement means "the state of being deprived." Bereavement deprives us of the living presence of someone we love or care about.⁷



AN OVERVIEW OF THEORETICAL MODELS OF BEREAVEMENT AND HOW THEY RELATE TO PARENTAL BEREAVEMENT

Grief and mourning are the processes that move a bereaved parent from a state of denial and disorganisation to a position where they can continue on with their life. There are several major theories and models regarding loss and grief, but no one broadly applicable working model.

TRADITIONAL 'POPULAR' GRIEF THEORISTS

In 1917, Freud wrote the article 'Mourning and Melancholia' and described mourning as a task to detach the survivor's memories and hopes from the dead. He believed grief work is accomplished when a bereaved individual is able to withdraw attachments from the deceased and live contentedly in a restructured lifestyle.⁹ In 1944, Lindemann felt that bereavement was aimed at conscious expression of feelings and confronting the reality of loss, with the goal of therapeutic intervention being the successful resolution of grief. He developed the concept of 'normal', as well as 'abnormal' grief.⁹ In 1961, Bowlby classified stages of grief, similar to his theories on attachment, whereby successful resolution of grief involved acceptance of loss and detachment.⁹

Kübler-Ross developed the idea that work on death and dying and mourning unfolded in predetermined phases. This theory became accepted as the truth and was adopted universally; it would still be the most well-known grief theory in the community.⁸ In 1982, Worden described the four tasks of grieving as (a) accepting the reality of the loss, (b) working through the pain of grieving, (c) adjusting to an environment in which the deceased is missing, and (d) withdrawing emotional energy and reinvesting in another relationship.

TOWARDS A NEW MODEL OF GRIEF

The purpose of grief has been defined for most of the 20th century as to break an attachment.¹⁰ From the 1980s onward there has been increasing recognition that dominant traditional theoretical perspectives do not accurately reflect the unique experiences of parental grief.

More recent theorists see the traditional definitions of unresolved or abnormal grief as the 'normal' reactions of parental grief, arguing that traditional theories have not been able to explain the complex and multidimensional nature of grief.¹¹ Modern theories based on a growing body of empirical work with bereaved parents have thus evolved to recognise the intensity and the special and unique features surrounding the loss of a child.⁹ These theories suggest that bereaved parents do not detach from their child. The new emphasis on parental bereavement is the concept of 'continuing bonds' with their deceased child.¹⁰ This concept of continuing bonds challenges the dominant assumption that resolution of grief is achieved through severing bonds with the deceased.⁹

NEW THEORIES OF PARENTAL GRIEF BASED ON 'CONTINUING BONDS'

A summary of some of the principles described in more recent theories of parental grief that are based on the concept of continuing bonds is shown in Figure 1.

Figure 1: Principles associated with theories of parental grief based on the concept of continuing bonds

Grief work is not essential to enable the bereaved to come to terms with their loss. ⁹
The dead child becomes central to the conversational life of parents. ¹²
The purpose or goal of grief is the construction of a 'durable biography' so they may integrate their memory into their continuing lives. ¹³
Families make changes and adjustment dependent on their relationship with self and others in the wider social world. Parents report how their deceased child continues to have an influence on their thoughts and feelings. ¹⁴
A multidimensional approach to bereavement is needed. ¹⁵
Through writing, establishing memorials, rituals and prayer, parents maintain a healing connection with their dead child. ⁹

Consistent with the assumptions inherent in these new theories of grief, many recent scholars and clinicians argue that the narrative story¹⁶ helps to organise and make meaning of the survivor's life after the death, as well as the life of the person who has died. This can be achieved by the process of active interaction within a community in which the death is recognised, the deceased person is mourned, and the continuing bond with the dead person is validated and shared.⁸

Similarly, other writers describe the important roles that dead people fulfil for the living as being:

- a continuing role model
- someone with whom survivors may check out personal values and priorities
- a guide and mentor
- a significant other whose views of the world and of the bereaved people continue to be an influence.⁹



■ CHILDREN WHO DIE FOLLOWING AN ILLNESS

For parents who have had a child die following illness the losses are great. The death may be the secondary loss in a series of losses.

There are essentially two major groups of parents who will have a child die following a prolonged illness:

- those who will have a child die from an oncological condition such as cancer or a form of leukaemia
- those who will have a child die from either a life-limiting or a life-threatening condition.

CANCER AND LEUKAEMIA—THE ONCOLOGICAL CONDITIONS

The general public immediately think of the loss affecting the parents when they hear of a child who has died following an illness. Throughout the duration of the illness most families with an oncological condition will be focusing on treatment and full recovery. The statistics for childhood cancers are promising, with a 70% survival rate. Between 20 and 30 children die from cancer in Queensland each year. Cancer remains the main medical cause of death, and the second greatest cause of death, second only to accidents, in Australia.¹⁷ Children who die from cancer are in the minority. The death of a child is difficult for everyone in the Oncology Unit, parents and staff.

LIFE-THREATENING CONDITIONS

Life-threatening conditions that may lead to the death of a child include:

- acquired brain injury—an injury to the brain that is so severe it will eventually cause death, for example in the case of near-drowning or motor vehicle accidents.
- meningitis
- encephalitis
- premature birth
- severe, prolonged or chronic illness e.g. chronic asthma.

LIFE-LIMITING CONDITIONS

There are many other conditions that can lead to the death of children. These life-limiting conditions are usually genetic in nature and often diagnosed in the first two years of life. For these parents and families the death of the child may mean not only the loss of their precious child but also the loss of their perceived roles as parents and as a family within the community.

Examples of life-limiting conditions include:

- cystic fibrosis
- muscular disorders (e.g. muscular dystrophy or muscular atrophies)
- congenital abnormalities
- neurodegenerative and neurological conditions
- metabolic conditions (e.g. mucopolysaccharidoses)
- organ failure (e.g. kidney or heart disease)
- severe multiple disabilities.

Some of these diseases are diagnosed in children sometime between birth and two years of age. Many of these parents will not remember a time when the disease or illness was not a major and driving force in their lives and family. Many of these disorders are associated with profound physical and intellectual disabilities, which have required 24 hour care from the family. The family has already had to grieve the loss of a 'normal' child.

Understanding the nature of these illnesses and pre-bereavement experiences for parents is important for a number of reasons. For example, Cook suggested that the mother-child bond strengthens during the child's illness, thereby creating more intense grief for the mother when the child dies.¹⁸ Mothers in particular have described the extraordinary 'special bond' they had with their child, particularly if the child was nonverbal. Their perception was that this child 'needed them more, was more vulnerable, and the care given was more intensive' so they felt that the gap in their lives was larger.¹⁹

Other writers have described how many parents who have had a child die from a prolonged illness—either life-limiting, life-threatening or in some cases an oncological diagnosis where the child has had multiple remissions and relapses—experience a 'chronic sorrow', which can be a complicating factor in bereavement.

Chronic sorrow is described as a long-term sadness that accompanies ongoing loss and that sometimes comes to the fore, and sometimes will sit on the periphery of consciousness.²⁰ Put simply, chronic sorrow exists when people have long-term involvement with a loved one who is chronically ill or disabled and the situation continually causes periods of sadness and loss, as well as joy and satisfaction.



■ WHAT IS SO UNIQUE ABOUT THE DEATH OF A CHILD?

THE PARENT–CHILD ATTACHMENT BOND

Parents and children share an intimacy and strength of bond. There is something sacred and indescribable about the love between a parent and a child. Several theorists describe how parents experience a distinctive connection and closeness with their children, an attachment unparalleled in most other relationships.^{21,40,51} Indeed, as Raphael described:

A child is many things to a parent:

- a part of the self
- a part of the loved partner
- a representation of the generations past
- the genes of the forebears; the hope of the future
- a source of love, pleasure, even narcissistic delight
- a tie or a burden
- and sometimes a symbol of the worst parts of the self and others.⁴

WHAT IS SO PROFOUND ABOUT THE DEATH OF A CHILD FOR A PARENT?

Parental grief is generally considered one of the most severe, enduring and debilitating forms of bereavement.¹ For many parents, the bond with their child is 'the most significant interactive relationship they have' in their lifetime.²² The death of a child and the subsequent bereavement for parents has been shown as being associated with more overwhelming reactions and severe adjustment disorders than other forms of bereavement.⁵ While the death of a spouse is often associated with a two-year intense mourning period, it is suggested that parents of deceased children maintain very close ties with their child even after 13 years of bereavement.¹⁵

With the death of their child, parents lose their hopes and dreams for the future. The bond between parent and each individual child is considered by some to be irreplaceable or, 'sacred'.²³ This bond between parent and child 'cannot be broken by lack of interaction because they are not contingent upon changes in the behaviour of the other'.²² The death of a child can threaten the identity and role of parents. Consequently, bereaved parents may face intense feelings of guilt, impotence and worthlessness.¹ Parents do not expect to outlive their child; it goes against the natural order and justice of the universe.¹

WHEN CHILDREN AND PARENTS ARE SEPARATED THROUGH DEATH

When a child has been ill for any length of time the journey for the parent and child is shared. When a child is seriously ill their lives become much more enmeshed with that of their parents than of that of their well peers. Depending on the age and development of the child, the amount of time they are forced (and sometimes want) to spend with their parents is unusually long and often intense. For example, children who are ill in their adolescence will be very dependent on their parents, sometimes even for toileting and showering, at a time when most other children their age would be demanding privacy and solitude.

Death is the ultimate split in this journey and connectedness. Something that parent and child have been working for, and often fighting for together, is over. Parents will now take a new journey on their own. For many parents the journey their child is taking is unknown. Even for those families who have a strong sense of faith there is still no definitive answer about what lies ahead for their child. No one can advise them with absolute confidence that they know where their precious child is. The isolative journey the parent is embarking on is as equally unknown and frightening, one that many parents will question their ability to make.

Human beings are diverse and complicated, whether they are born to the same family, gender, race, religion or are complete strangers. Bereavement, grief reactions and emotions mirror our differences as human beings.

PARENTAL BEREAVEMENT AS AN INDIVIDUAL EXPERIENCE

How a person feels and reacts on becoming bereaved depends on many aspects related to the individual, the death and the circumstances of the loss. It is important for those who work with the bereaved to understand that reactions are varied and influenced by many factors, such as:

- gender
- culture
- age of the parents—younger parents seem to adapt better¹⁵
- developmentally older parents appear less resilient and less able to emerge from the severe dislocation of loss of a child¹⁶
- cause of death
- social support systems
- family support and relations
- number of children in the family
- the age of the child at death appears to be irrelevant to the grief process, but rather that treatment may vary according to age²⁴
- length of time since death
- length of time with a support group
- subsequent deaths in the family
- subsequent divorce
- involvement with religion²⁵
- relationship to the bereaved (not just biological but also the essence of the relationship)
- meaning that is assigned to the loss.⁸



■ WHEN DOES BEREAVEMENT START?

COMMENCING BEREAVEMENT WORK

Technically, bereavement work commences from when the child dies. However, if we want the bereavement process to 'go as well as possible', the good work in loss and grief needs to start at the point of diagnosis for the child. For example, the way that parents received the news that their child was diagnosed with a serious life-threatening or life-limiting illness can be the possible starting point of an uncomplicated grief.

In order for parents to eventually get to a space where they can integrate the death of their child successfully into a life that is once again fulfilling, they need:

- to feel a sense of no regrets
- to feel that all that could be said and done was achieved
- to know that they were, and had the opportunity to be, the parents they wanted and needed to be to that child
- to feel that they were kept informed
- to feel confident that they maintained a sense of control and power over the things they could
- to know that they had a loving, open and uncomplicated relationship with the child who died.

HOW CAN WE ASSIST THE CHILD AND THEIR FAMILY TO COMMENCE BEREAVEMENT WORK?

A number of principles can be identified in the literature to support the family and child and ensure that the bereavement goes 'as well as possible'. These include:

- keep the family and child informed
- assist and assure the parents in their discussions with other children
- ask and advise the family about where the child can die—at home, at home with domiciliary support, or the hospital
- find out what the family fears regarding the death; can these be resolved?
- ensure that the family is aware of pain management that can be offered and organised
- ask the parents if they would like video footage, photos, handprints or hair from their child before the child dies or before they are buried or cremated
- ask the parents if they have thought about the funeral
- inform the parents that their child can stay with them as long as they like after the death

- prepare the family for what they may physically see, smell, hear and feel at the time of death
- assure parents that we are all flexible and able to work in with their needs.

In moments of distress, parents may not know what questions to ask, so we can gently suggest things to them so their options remain open.

Remember that parents and siblings will cope well with most things if they have prior INFORMATION.

If you have only met the family since the death of the child you will need to get a thorough sense (assessment) of what has happened for them as a family, and as individuals, with regards to the child who has died, and maybe beyond this, to support them in their journey of bereavement.

CAN PARENTS PREPARE FOR THE DEATH?

Deaths that are anticipated occur as a consequence of illness, aging, or occasionally when a person has been seriously injured and remained critically ill or impaired for some time. People who love this person and are usually aware that death is imminent, may have the opportunity to prepare for, and come to terms with, the closeness of death and probability of loss.⁴ Anticipatory grief is defined as the progression through the phases of grief prior to the loss of a loved one.²⁶

There are two conflicting theories in relation to anticipatory grief:

- that it assists in bereavement because it gives parents time to prepare and say goodbye
- that it complicates bereavement.

Either situation can occur, depending on a range of other variables impacting on the child and the family. Results from studies have been largely inconsistent when attempting to discover if there is a difference between the grief reactions of those who have had prior warning about impending death (long-term illness) and those with a sudden death.¹ Many studies suggest that there can be positive aspects associated with experiencing anticipatory grief. For example, studies have concluded that compared with parents who experience a sudden death, parents who experience a more expected death:

- have often been found to experience somewhat less severe grief¹
- may be provided with the opportunity to do all they can for the dying child
- may be better socialised into the bereavement role²⁷
- may manage better long-term because of the preparatory phase, and having a chance to say goodbye

- cope better with the certainty of death rather than the constant uncertainty of everything (especially the case for men)²⁸
- may be less confused post-bereavement, more likely to accept the reality of their loss, and markedly less likely to express feelings of guilt and anger²⁹
- are more likely to have endured the erosive stress of caring for a chronically or terminally ill child.¹

However, not all anticipatory grieving has positive outcomes for parents. Studies report negative anticipatory grief can arise when:

- parents have been heavily invested in the care of their child during illness and disability—they are more likely to be left with a loss of identity and worthlessness
- members of the community assume that there was a 'burden of care' and the family will be 'better off' now that the child has died
- activities of the family revolve around the illness, such as in palliative care; when death occurs, the impact of loss and feelings of disorganisation and meaninglessness are likely to be more acutely experienced²⁹
- extended terminal illnesses are present; these can be significantly associated with a higher percentage of intense grief reactions.³⁰

At this time there appears not to be any definitive, empirically validated answer regarding the impact of anticipatory grief on eventual adjustment.²⁶ One common theme, however, is that for parents who do experience anticipatory grief an important aspect for bereavement to go well is being able to say 'Goodbye'.⁴ Moreover, regardless of whether anticipatory grief has positive or negative effects on parents, there is no evidence to suggest that anticipatory grief has an effect on marital outcome.¹

CAN THERE BE SUDDEN DEATH WITHIN PALLIATIVE CARE CENTRES?

Yes—there can still be unexpected or sudden deaths within palliative care centres as deaths can happen 'out of turn'. A sudden death in this situation can leave families and staff ill-prepared and has the potential to complicate the bereavement process.



WHAT CAN PARENTS EXPECT TO EXPERIENCE IN BEREAVEMENT?

WHAT DOES 'NORMAL' BEREAVEMENT LOOK LIKE?

For parents, the death of a child is the single most catastrophic event imaginable. The death of a child is commonly held in the literature to be the most devastating, intense, traumatising and difficult-to-process loss of all.²⁴

'Grieving is hard work. Grieving is the work of coming to terms with the fact that the person we loved is dead. The person who loved us back, whose needs gave shape and focus to our days, is dead. No longer here. We will never have them back. What we most want we cannot have'.²⁸

'Am I going crazy?' 'Can I survive this?' 'Is this normal?' 'How long will I feel this bad?'

These are some of the most common questions we are asked in our work with bereaved parents and they can be hard to answer. A summary of what the literature tells us about parental experiences following the death of a child is presented in Figure 2.

Figure 2: Parental experiences following the death of a child³¹

Feelings	The most intense grief and overwhelming for humans ²²	Bereaved parents had a preoccupation with thoughts of the child ²²
	Produces the widest range of reactions ²² —regret, sense of loss, anger, feelings of hopelessness, loneliness	The loss of a child impacts not only upon the individual parent but the parental relationship, family system and society itself ⁵
	Parents endure grief of a dead child and then undergo severe family crises. A bereaved couple is jolted by another loss—the loss of illusion about each other ³²	Parents are 'tortured' by their feelings of guilt, as they have failed to 'protect' their child from illness. ³² Guilt overrides logic
	Fear of further death; fears they are 'going mad or crazy'	Numbness: a period where people may feel disconnected from the reality of their feelings and the situation. Feelings of emptiness
	Denial: this is people's way of protecting themselves from a reality too painful to bear. Reported feelings of worthlessness—no longer having value in their lives and communities	Wishing to believe that the bereaved child is still alive; a preoccupation with the image and memories of the dead child

Physical symptoms	Anxiety and fearfulness	Lethargy and tiredness
	Depression	Tension
	Difficulty in sleeping	Somatic distress
	Mental disorganisation—an inability to do things sequentially	Pain of grief—often physiological; feeling physically ill, nauseated, phantom pains throughout the body, headaches etc
Behaviours	Loss of usual habits and patterns	Activity: using activity as a means of distraction
	Imitation of the deceased's behaviour	Searching: people may find they are constantly restless
	Hostility	Increased dependence on others
	Feeling overwhelmed: by their own feelings, by people, by their loss	Passive distraction: sitting in front of the TV to avoid thinking
	Avoidance and exposure: either completely avoiding anything that reminds them of their child (eg school, hospital) or completely immersing themselves in the old routines of their child as constant reminder	Over-indulgence
Positive aspects	Positive feelings: feeling that this is now the start of a new phase in their lives; that their child will have peace and freedom at last	Altered perspectives: believing that they no longer know what the world is about. Feeling that everything has changed about them, their values, their faith, their friends. Placing importance on different things now
	Relief: maybe relief that the child has died and will no longer suffer	

The reactions summarised in Figure 2 are 'normal' and expected. Yet when parents grieve they may experience all or none of these feelings. These emotions will not happen in 'stages'—parents can not finish with one emotion or experience and move to the next. Grieving is fluid. It is important to assure parents that these reactions serve to protect the bereaved person, to help them gather strength and move towards healing and an ability to gradually integrate the death into their lives.²⁸

These emotions are the essential hard work of grieving. It is work that bereaved parents will have to face, day-by-day, memory-by-memory—the new awful reality that their beautiful, important and loved child is gone.²⁸

■ HOW LONG WILL THIS GRIEF LAST?

ANSWERING QUESTIONS ABOUT DURATION

For a parent, the duration of the acute phase of grief will be affected by many variables. Some of these variables are:

- the facts surrounding the child's death
- the parent's relationship with the child
- the quality and strength of other relationships
- the life history of these parents.

While much of the research describes the acute phase of grief as lasting 6–8 weeks this is grossly inadequate for the death of a child.³³ Parents may report a 'shift' in their grief around four to six months after the death, where the every-minute intensity of their grief is replaced by the grief coming in waves.²⁸ Marica Kraft Goin suggests that not only do many people maintain a 'timeless' emotional involvement with the deceased, but this attachment often represents a healthy adaptation to the loss of a loved one.⁵ Answering questions about 'how long' is enormously challenging. Many conventional models of grief indirectly disempower both the bereaved person and the 'would be carer' by implying grieving people must passively negotiate a sequence of psychological transitions forced on them by external events.⁸

THOSE AT PARTICULAR RISK OF 'COMPLICATED GRIEF'

Considering that 'grief is nearly always complicated'³⁴ there are certain individuals and situations with a higher risk or greater vulnerability to experiencing grief that could be identified as complicated.⁴ The indicators for parents at higher risk for complicated grief include:

- a history of mental health problems
- a history of depression
- parents who are already marginalised in society
- parents who are socially isolated⁴
- parents whose support networks become ineffective in the face of death⁴
- those who may be discouraged from expressing their grief or have no opportunity to do so²⁹
- those who perceive the death as sudden and untimely
- parents with concurrent stresses (financial, marital etc)
- parents who were ambivalent about the relationship with the deceased
- low level of education, which is associated with adjustment difficulties among bereaved³⁵
- the identification of absence of grief and delayed grief reactions.³⁵

PHYSICAL AND PSYCHOSOCIAL IMPLICATIONS OF BEREAVEMENT FOR A PARENT

PHYSICAL HEALTH

Physiological research has demonstrated that bereavement may impact on the 'immune system, lead to changes in the autonomic nervous, and cardiovascular systems, and account for increased vulnerability to external agents'.⁵ This research also suggests that bereaved persons visit and consult their health care professionals with psychological symptoms more frequently,²⁹ and that the bereaved suffer increased mortality when compared with the expected incidence for non-bereaved members of the population (widowhood).²⁹ However, research in this area is fraught with methodological limitations. Definitive conclusions on the health consequences of bereavement, especially in relation to mortality, are difficult to make.

FINANCIAL IMPACT

There can be enormous financial consequences for families when they care long-term for children with a life-threatening illness before their death. Families with a disabled or chronically ill child often face increased expenses and generally have lower incomes than families with non-disabled and well children.³⁶ The impact of having a child with a life-limiting illness for more than several months impacts financially for a number of reasons. For example, the parents:

- may become dependent on the welfare system
- may no longer be emotionally or physically capable of paid employment, due to 'high needs' or in the palliative phase of their child's illness
- may experience financial burdens and stresses of the accumulated debt even after the child's death
- can face many out-of-pocket expenses associated with hospitalisation (public or private)—such as the costs of eating outside the home, transport to and from hospital, car parking, medicines, wheelchairs, nappies, tubing, bandages and other equipment
- must meet funeral expenses
- can sometimes face reductions or cuts in social security payments on the death of a child.

Studies have described families' concerns of creating 'second generational poverty', as debt incurred while caring for their ill child does not allow them to care for their surviving children in the future.³⁷ Some studies also suggest that couples can come near financial ruin after the death as they indulge themselves in spending as comfort and distraction. Parents can become 'trapped' in buying cars and clothes, eating out and spoiling the other children—all in an attempt to heal and feel 'better'.³²

EMPLOYMENT

The effect of a child's illness and death on parental employment can also be significant. When they are primary caregivers, mothers may be forced out of the workforce. Studies have also reported that fathers may be marginalised at work due to fatigue, demands of caring at home, and being distracted by the situation at home.³⁷

SOCIAL ISOLATION

Social support following the loss of a loved person has been suggested as one of the key factors buffering the bereaved from the detrimental effects of the loss.³ However, feelings of social isolation are common among bereaved parents. This can be because:

- many parents report that their social system undergoes a breakdown¹⁰
- friends and colleagues may be uncomfortable with the death and do not know how to support the parent; 'People just didn't know how to deal with it'³⁸
- parents sometimes feel others can't understand their loss¹¹
- parents may no longer want to socialise in the environment they used to share with the child e.g. school functions
- parents may feel that enjoyment is a betrayal of the child who has died.³²

MARITAL IMPACT

Studies report that during the first months and years of bereavement the couple and family relationships bear much of the individual parent's emotional reaction to loss.²⁴ Some theorists suggest that this can result in the death of a child contributing to a deterioration of the marital relationship, while others argue that it has little negative impact, and can even improve the relationship.¹ The majority of bereavement research has, however, focused only on mothers.¹

Research describing some of the difficulties experienced by marital partners following the death of a child has reported the following:

- some individuals believe that it is impossible to give comfort to your partner when you feel an equal grief and that sharing of grief is blocked by 'mutual protectiveness'³²
- the death of a child can precipitate increased friction within the marital relationship, and an increase in arguments, general conflict, hostility and irritability; bereaved couples are susceptible to breakdowns in communication³⁹
- a 'conspiracy of silence' where neither parent talks of the child³⁹
- one partner often believes they should not enjoy themselves out of respect for their grief³²
- different religious beliefs between partners can also be a source of conflict³²

- the death of a child can have serious sexual repercussions for bereaved parents¹
- most couples abstain from sex for some time; their lack of sexual desire results mostly from being engulfed with grief and constant exhaustion.¹

Research in this field has also identified a number of variables that may affect marital outcomes following the death of a child. These include:

- grief variables—mothers and fathers may grieve differently
- family/couple dynamics
- anticipatory grief
- cause and type of death e.g. suicide, murder, accidents or illnesses are associated with more intense grief⁴⁰
- stability of the relationship prior to the child being diagnosed or becoming ill
- effects of attending a support group or therapy/counselling
- the specific nature of the parent-child relationship
- previous grief experiences
- availability of social supports
- number of children
- the age of parents
- length of the relationship
- socio-economic status of the bereaved parents
- religious faith, which often provides grieving parents with hope and meaning.^{41,42}

BEREAVEMENT AND DIVORCE—IS IT A MYTH?

It is estimated that 75 to 90 per cent of bereaved couples experience severe marital distress.^{32,43} However, there is little empirical support for such high estimates. Schwab (1992) found that the death of a child can be catastrophic for marriages, with increased conflict, severe withdrawal and breakdowns in communication, sexual difficulties and other problems.³⁹ One longitudinal study found that a third of all couples experienced some sort of marital disruption following their child's death.⁴¹

However, despite findings suggesting that the death of a child can disrupt the marital relationship, there is also much evidence for resiliency in couples, with current research suggesting the majority of marriages survive the loss of a child.¹ Bereaved couples need to be informed and reassured that relationships can and do survive after a child's death.²⁴

GENDER DIFFERENCES IN COPING WITH BEREAVEMENT

Parents endure grief following a child's death and may undergo a severe relationship crisis.

The bereaved couple may be jolted by another loss—‘the loss of illusion about each other’.³² Researchers have sought to investigate whether there are masculine and feminine styles of communicating at this time. In interpreting the findings from this research, it is important not to generalise about men and women—remember that some men do cry and some women can read road maps! Indeed, research in this field has presented many conflicting results. A summary of recent studies is presented in Figure 3.

Figure 3. Summary of research findings on gender differences in coping with bereavement

Parents grieve at different times, express grief in different ways, or cope with loss differently. ²²	Father used work as a means of ‘escapism’ or to ensure exhaustion and sleep at the end of the day. ³²
As time passes, men feel more anger and women feel more guilt associated with the death of their child. ²²	Fathers were more concerned and frustrated about their wives’ grief, whereas wives were angry over their husbands not sharing their grief. ⁴⁴
Women have less difficulty in expressing grief and other emotions but may need help in rethinking, restructuring and finding fresh meanings in their life. ⁴⁵	In response to the disability and the death of their children, fathers wanted to find something to do. They wanted to take action and keep busy with tasks. ³⁸
Mothers had a higher level of past grief and fathers had a higher level of present grief. ⁴⁶	Fathers stated they could manage their strong emotions in their work and home lives but while they were alone in their cars the feelings would break through. ³⁸
Mothers were also found to cry and reflect about the dead child more than fathers, but appeared to shed their grief over time. ¹	Men may resist being helped due to their inclination towards independence. Men may associate ‘needing help’ with being ‘weak’. ⁶
	Guilt was a less prevalent experience among fathers although they do use the word ‘responsibility’ more. ³⁸
	The fathers rejected the idea that they grieved less, just differently to their wives; ³⁸ men grieve for their wives. ³⁸
	Men tend to be less verbal about their grief; ⁶ they often respond more cognitively to their loss. ⁶

It’s important to recognise that while the literature may reflect some gender differences in the way men and women respond to grief and bereavement, these differences and styles are just as valid as any other, and can still be healing.⁶

IMPLICATIONS FOR PROFESSIONALS WHEN WORKING WITH BEREAVED PARENTS

The most current research on grief therapy leaves us with the conclusion that grief therapy should be engaged in selectively—for those bereaved persons whose grief is traumatic or prolonged. We need to respectfully witness the self-help efforts of those who do not require our well-meaning involvement—and might even be harmed by it. When grief therapy is offered it must attend to the profound challenges to clients' (inter)personal systems of meanings brought about by tragic loss, and facilitate the survivors' own struggle to find significance both in the death and in their ongoing lives.⁸

A multidimensional approach to the understanding and intervention of bereavement is suggested. This could include:

- individual work
- couple work
- family work
- encouragement and resources of self-help
- facilitation and support of support groups and linking families together
- community education and development.¹⁵

WHAT PARENTS REPORTED AS HELPFUL IN THEIR BEREAVEMENT

Studies have found that parents report a number of things help them in bereavement, including:

- having a sense of control, which helped reduce feelings of helplessness and powerlessness; regaining control is also important in rebuilding the assumptive world²⁴
- being asked opinions and others actually listening to them⁴⁷
- being given information; 'over protectiveness' in professionals actually disempowers parents⁴⁸
- linking objects to the child which assists parents in their adjustment by helping them stay connected to the child as they move forward in their lives¹²
- the attempt to make sense out of the death and find meaning in it¹¹

WHAT PARENTS REPORTED AS HELPFUL IN THEIR BEREAVEMENT CONT...

- talking with other parents who had experienced the same thing—this was the most helpful way of coping with the deaths of their children¹¹
- helping others and 'contributing' to society through working with children, the homeless, returning to school or changing careers in order to benefit others¹¹
- creating memorials or scholarships in their child's name¹¹
- engaging in creative pursuits including journal writing, sculpting, pottery and gardening as well as therapy and seeking support from their spouses and children¹¹
- advising parents to expect difficult times and situations; some of the most difficult times can be:
 - when asked the question 'how many children do you have?'
 - special occasions, due to their children's absence from and inability to participate in weddings, birthdays and holidays¹¹
 - insensitive comments and behaviours among family and friends about the child's death¹¹
 - the first year and all the milestones that brings—the first Christmas, birthday, Mothers Day without the child are particularly painful and dreaded by the bereaved parents.



CONSTRUCTIVE TASKS PROFESSIONALS CAN UNDERTAKE WITH PARENTS IN BEREAVEMENT

There are a number of important actions that professionals can take to help parents who are bereaved. Some of the key tasks are as follows:

- listen to parents
- construct conversation around remembering the child who has died
- help parents construct a durable biography of their child
- encourage parents to write their child's biography
- establish memorials
- honour and remember their child
- enable parents with others in their social world to remember the child
- recognise that many parents experience social isolation and intense loneliness
- recognise the importance of putting parents in contact with other parents who have experienced the death of a child
- advise parents of support groups⁹
- helping the parents to know what to expect in their grief.¹

Most bereaved persons cope with their grief with the help of family, friends and neighbourhood supports. Some seek aid from mutual help organisations; others need the support of grief counselling—that is facilitation with 'uncomplicated or normal grief to a healthy completion of tasks of grieving within a reasonable time frame'. A small minority require grief therapy—'those specialised techniques...which are used to help people with abnormal or complicated reactions'.⁵

WHAT WE CAN ADVISE PARENTS ABOUT THE FIRST YEAR

There are a number of key points that you may wish to advise parents about as you support them in their journey. Some advice you can give parents includes:

- it's important to know that you won't always feel like this
- it's important to connect with other people—you can't do it on your own
- assume that you will have to educate other people
- keep the lines of communication open with your partner and other children
- allow your feelings to emerge
- realise that you cannot always help or 'save' your partner and other children
- expect an emotional roller coaster

- take care of yourself physically
- offer yourself some pleasures
- seek spiritual support
- expect setbacks and detours
- respect the rhythm of your own grieving.²⁸

FURTHER IMPLICATIONS FOR GRIEF THERAPY PRACTICE

For those individuals who may require more intensive and professional support, a number of key assumptions that underpin grief therapy have been identified in the literature. These include:

- Recognising the varied ways people grieve, support techniques need to range from the casual to the highly structured.⁵
- Grieving persons cope with their grief in complex and diverse ways. Any one person may respond to different losses in very different ways and may have very different support requirements at different points in time.⁵
- Self-help interventions fulfil a critical function in that they supplement professional services and have the potential advantage of avoiding the costs of formal therapy.⁵
- A quest for meaning plays a prominent role in grieving. When a client is struggling for significance in the loss, the counsellor would be well advised to facilitate this process.⁸
- Counsellors should be cautious about instigating a search for meaning in the minority of cases in which clients do not spontaneously undertake such a search, as these individuals might well be coping adaptively using pragmatic rather than philosophic strategies.⁸
- Counsellors need to remember that meaning-making is more an activity than an 'achievement', as the provisional meaning of the death tends to be revisited as the reality of living with loss raises new questions and undermines old answers.⁸
- Those with a masculine style of grieving may choose to say nothing. If there is silence, join in the quiet. If the person speaks, be an effective listener—don't interrupt with questions or comments, and show interest and give verbal cues. Validate the feelings and let them know they are normal and healthy. Remember, a lack of expression is not necessarily a lack of feelings.⁶
- It is a humbling experience to be invited into someone else's grief; treat this with respect.
- The most meaningful and spiritual moments occur in very common and unexpected settings.⁶ Always be respectful and prepared to invite and hear them.

■ CONCLUSION

It is consistent throughout the literature on grief work that the death of a child is recognised as the most severe, enduring and debilitating form of bereavement within the context of human relationships.^{1,24,30,49} 'As workers within this field we may often be forced to fulfil a certain role with sensitivity and at the same time, cope with our own emotions of sadness, injustice, anger and sometimes revulsion. Tears should be for their pain and suffering, not ours'.⁵⁰ It can be difficult and painful to fulfil all of these roles. It is comforting to know that it is okay to cry with parents and their families, as long as the tears are not for yourself. It is also important to remind yourself that you are only involved with such an intimate and raw experience because you are actively trying to assist and offer comfort, practical advice and information. You are not passive in this role. It is good to recognise the longevity and intensity of parental bereavement—some report that it can be 13 years intense grief¹⁵—and that parents will incorporate the child into their ongoing lives and will go from loving in the presence, to loving in the absence.⁸

It is important to appreciate the need for parents to incorporate the dead child into their lives in order to make sense and meaning of the loss.⁸ We, as people who care and work with bereaved parents, need to normalise the many and varied ways that parents can grieve their child—from conversations, visualisations, fatigue, crying, shock and the numerous other examples.^{4,5,28} We need to educate and advocate for these parents amongst their families, communities and the medical organisations for recognition of their loss.

Parents need to speak openly about their child and to feel supported.⁹ Parents need to have validation that their child lived and died and remains an active presence within the family even in death.⁸

It is rare that the only loss that the bereaved parent will suffer is the loss of their child. It is important to acknowledge that the loss of their child will not exist in isolation. Bereaved parents usually also experience a 'social death', with many parents reporting that their social system undergoes a breakdown.¹⁰ There are the enormous financial costs associated with having a child being chronically ill and then dying.³⁶ Financial problems may be exacerbated by the impact on one or both of the parents' employment situations.³⁷ The physiological health of the bereaved parent can also be compromised.⁵

The impact on the relationship of the parents will be profound, with literature finding both positive and negative changes.⁹ Despite findings suggesting that the death of a child can disrupt the marital relationship, there is also much evidence of resiliency in couples, with current research suggesting the majority of marriages survive the loss of a child.¹ Bereaved couples need to be informed and reassured that relationships can and do survive after a child's death.²⁴

Working with bereaved parents is a humbling and intimate experience that can be frightening, rewarding, spiritual, lonely and heart-warming. Always respect each family's individual way of coping with the loss of their child and feel privileged to be invited in to share it with the family. In the darkest moments of your work remember the words of the wise Dr Judith Murray—'as hard as it is to work in this area it is a lot harder to die and to be left behind.'

On behalf of the families you are working with, thank you for your powerful and important contribution. Never underestimate the significant role you may be playing in the lives of bereaved parents.

■ SUGGESTED READINGS FOR PARENTS

GENDER AND GRIEF

Golden T, Miller JE. *A Man You Know Is Grieving—12 Ideas for Helping Him Heal from Loss/When a Man Faces Grief—12 Practical Ideas to Help You Heal from Loss*. Indiana: Willow Green Publishing. 1998.

THE DEATH OF A CHILD

Rosof BD. *The Worst Loss: How Families Heal from the Death of a Child*. New York: Henry Holt and Company. 1994.

Sarnoff Schiff H. *The Bereaved Parent*. New York: Penguin Books. 1977.

■ USEFUL ORGANISATIONS IN QUEENSLAND

ORGANISATIONS THAT OFFER COUNSELLING

Queensland Health organisations which offer free counselling services with a Social Worker or Psychologist can be found in each region, though there may be a waiting list.

- Community Health—usually found under 'Queensland Health';
- Your local hospital

The following services offer counselling, usually on a sliding pay scale (e.g. what is affordable)

- Lifeline: includes a 24 hour crisis line (Phone 13 11 14);
- Centacare: (Ph: 07 3250 4305; cfcsc@centacarebrisbane.net.au);
- Kinnections: (Freecall: 1800 600 636 or 07 3435 4300).

SUPPORT GROUPS

Cystic Fibrosis Queensland

Rainbow House

31 Kate Street, Kedron Queensland 4031

Ph: 07 3359 8000

Fax: 07 3359 3380

Freecall: 1800 670 990

Email: admin@cysticfibrosisqld.org.au

Muscular Dystrophy Association Queensland

Level 1, 147 Wharf Street, Spring Hill Queensland 4000

Ph: 07 3016 1800

Fax: 07 3831 2666

Freecall: 1800 676 364

Queensland Clinical Genetics Service

Royal Children's Hospital, Herston Queensland 4029

Ph: 07 3636 1686

MPS: Mucopolysaccharidoses and Related Diseases Society Australia

30 Paringa Place, Bangor, New South Wales 2234

Ph: 02 9543 9003

SIDS : Sudden Infant Death Syndrome

68 Creek Road, Mt Gravatt Queensland 4122

Ph: 07 3849 7122

Fax: 07 3849 7121

Email: Brisbane@sidsaustralia.org.au

SANDS Inc : Sudden and Neonatal Death Syndrome

PO BOX 49, Royal Brisbane Hospital, Herston Queensland 4029

Ph: 07 3252 2865

Compassionate Friends (support for bereaved parents)

PO Box 218, Springwood Queensland 4127

Ph: 07 3254 2657

Email: tcfqld@powerup.com.au

Website: <http://www.uq.net.au/tcfbrisbane>

Childhood Cancer Support

PO Box 295, Red Hill Queensland 4059

11 Bramston Tce, Herston Queensland 4006

Ph: 07 3252 4719

Fax: 07 3852 2350

Email: info@clcs.org.au

Website: www.clcs.org.au

CANTEEN—Australian Organisation for Young People Living with Cancer

11 Tufton Street, Bowen Hills Queensland 4006

Ph: 07 3252 5188

Website: www.canteen.org.au

Leukaemia Foundation of Queensland

Level 4, Mincom Central, 193 Turbot Street, Brisbane Queensland 4000

Ph: 07 3318 4418

Support Services Ph: 07 3840 3844

Email: lfq@leukaemia.com

REFERENCES

1. Oliver L. Effect of a child's death on the marital relationship: A review. *Omega—Journal of Death and Dying* 1999;39(3):197–227.
2. Matthews L, Marwit S. Examining the assumptive world views of parents bereaved by accident, murder and illness. *Omega—Journal of Death and Dying* 2004;48(2):115–136.
3. Miller ED, Omarzu J. 'New Directions in Loss Research' in Harvey JH, ed. *Perspectives on Loss: A Sourcebook*. Washington, DC: Taylor & Francis, 1998;3–20.
4. Raphael B. *The Anatomy of Bereavement: A Handbook for the Caring Professions*. London: Hutchinson. 1984.
5. Stroebe MS, Stroebe W, Hansson RO, eds. *Handbook of Bereavement Research: Theory, Research and Intervention*. New York: Cambridge University Press. 1993.
6. Golden T, Miller JE. *A Man You Know Is Grieving—12 Ideas for Helping Him Heal from Loss/ When A Man Faces Grief—12 Practical Ideas to Help You Heal from Loss*. Indiana: Willow Green Publishing. 1998.
7. Attig T. 'Relearning the World: Making and Finding Meanings' in *Meaning Reconstruction and the Experience of Loss*. Washington, DC: American Psychological Association. 2000, p.36.
8. Neimeyer RA, ed. *Meaning Reconstruction and the Experience of Loss*. Washington, DC: American Psychological Association. 2000.
9. Davies R. New understandings of parental grief: Literature review. *Journal of Advanced Nursing* 2004;46(5):506–513.
10. Klass D. 'The Inner Representation of the Dead Child in the Psychic and Social Narratives of Bereaved Parents' in Neimeyer RA, ed. *Meaning Reconstruction and the Experience of Loss*. Washington, DC: American Psychological Association. 2000.
11. Coyle B. *Restoring Meaning and Purpose After the Death of a Child: A Qualitative Psychological Study*. Doctoral dissertation. *Dissertation Abstracts International* 1998;59(3-B):1363.
12. Klass D. 'Spirituality, Protestantism, and Death' in Doka K, Morgan J eds. *Death and Spirituality*. Amityville, NY: Baywood. 1993.
13. Walter T. A new model of grief: Bereavement and biography. *Mortality* 1996;1(10):7-25.
14. Riches G, Dawson P. *An Intimate Loneliness: Supporting Bereaved Parents and Siblings*. Philadelphia, PA: OpenUniversity Press. 2000.
15. Rubin SS. 'The Death of a Child is Forever: The Life Course Impact of Child Loss' in Stroebe MS, Stroebe W, Hansson RO, eds. *Handbook of Bereavement Research: Theory, Research and Intervention*. New York: Cambridge University Press. 1993.
16. Neimeyer RA, Stewart AE. Trauma, healing, and the narrative emplotment of loss. *Families in Society* 1996;77:360-375.
17. Dr Helen Irving, Oncologist, Royal Children's Hospital, Brisbane, Australia; personal communication.
18. Cook J. A death in the family: Parental bereavement in the first year. *Suicide and Life Threatening Behaviour* 1983;31(1):42-61.
19. Milo E. Maternal responses to the life and death of a child with a developmental disability: A story of hope. *Death Studies* 1997;Sep/Oct 21(5):443–477.
20. Olshansky S. Chronic sorrow: A response to having a mentally defective child. *Social Casework* 1962;43(4):190-193.
21. Bowlby J. 'Attachment and Loss' in *Sadness and Depression* (vol 3). NY: Basic Books. 1980.
22. Klass D, Marwit S in Sidmore K. Parental bereavement: Levels of grief as affected by gender issues. *Omega—Journal of Death and Dying* 2000;40(2):351–374.
23. Klass D, Marwit S. Toward a model of parental grief. *Omega—Journal of Death and Dying* 1988–89;19(1):31-50.
24. Rando TA in Janzen L, Cadell S, Westhues A. From death notification through the funeral: Bereaved parents' experiences and their advice to professionals. *Omega—Journal of Death and Dying* 2004;48(2):149–164.
25. Worden J W. *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*. New York: Springer. 1991.

26. Lindemann 1944 in Sprang G, McNeil J. *The Many Faces of Bereavement: The Nature and Treatment of Natural, Traumatic and Stigmatized Grief*. New York: Brunner/Mazel. 1995.
27. Gerber I. 'Anticipatory Bereavement' in Schoenberg B, Carr AC, Kutscher AH, Peretz D, Goldberg IK, eds. *Anticipatory Grief*. New York: Columbia University Press. 1974:26–31.
28. Rosof BD. *The Worst Loss: How Families Heal from the Death of a Child*. New York: Henry Holt and Company. 1994.
29. Parkes 1975 in Smith CA. *Social Work with the Dying and Bereaved*. London: Macmillan. 1982.
30. Schwab RA. Child's death and divorce: Dispelling the myth. *Death Studies* 1998; Jul-Aug, 22(5):445–465.
31. Burnett P, Middleton W, Raphael B, Dunne M, Moylan A, Marinek N. Concepts of normal bereavement. *Journal of Traumatic Stress* 1994;7:123–134.
32. Sarnoff Schiff H. *The Bereaved Parent*. New York: Penguin Books. 1977.
33. Rando TA. *Treatment of Complicated Mourning*. Champaign, IL: Research Press. 1993.
34. Attig T. 'Stories of Grieving' in *How we Grieve: Relearning the World*. New York: Oxford University Press. 1996.
35. Roskin 1984 in Ginzburg K, Geron Y, Solomon Z. Patterns of complicated grief. *Omega—Journal of Death and Dying* 2002;45(2):133–147.
36. Corden A, Sloper P, Sainsbury R. Financial effects for families after the death of a disabled or chronically ill child: A neglected dimension of bereavement. *Child Care Health & Development* 2001;28(3):199–204.
37. Crowe E. [Unpublished] Queensland Health Report: Statewide Paediatric Palliative Care Education and Community Awareness Project June 1999–July 2000.
38. Wood J, Milo E. Fathers' grief when a disabled child dies. *Death Studies* 2001;25:635–661.
39. Schwab R. Effects of a child's death on the marital relationship: A preliminary study. *Death Studies* 1992;16:141–154.
40. Sanders C. *Grief: The Mourning After*. New York: John Wiley & Sons. 1989.
41. Bohannon J. Grief response of parents to neonatal death and parent participation in deciding care. *Omega—Journal of Death and Dying*, 1990–1991;22:109–121.
42. Schwab R. Paternal and maternal coping with the tragedy of a death. *Death Studies* 1990;14:407–422.
43. Simpson M. *Dying, Death, and Grief: A Critically Annotated Bibliography and Source Book of Thanatology and Terminal Care*. NY: Plenum Press. 1979.
44. Schwab R. A child's death and divorce: Dispelling the myth. *Death Studies* 1998; Jul-Aug, 22(5):445–465.
45. Rubenstein G. Locus of control and helplessness: Gender differences among bereaved parents. *Death Studies* 2004;28:211–233.
46. Seecharan G, Andresen E, Norris K, Toce S. Parents' assessment of quality of care and grief following a child's death. *Archives of Pediatrics & Adolescent Medicine* June 2004;158(6):515–521.
47. Kavanaugh K, Robertson P. Recurrent perinatal loss: A case study. *Omega—Journal of Death and Dying* 1999;39:133–147.
48. Gyulay JE. Grief responses. *Issues Compr Pediatr Nurs* 1989;12(1):1–31.
49. Klass D. *Parental Grief: Solace and Resolution*. New York: Springer. 1988.
50. Stewart A, Dent A. *At a Loss: Bereavement Care When a Baby Dies*. London: Bailliere Tindall. 1994.
51. Rando T, ed. *Parental Loss of a Child*. Champaign IL: Research Press. 1986.