

*Journeys: Palliative care for children and teenagers* is available in hard copy free of charge.

## Journeys order form

name: .....

address: .....

.....

..... postcode: .....

telephone: .....

email: .....

number of copies:

Return this form to Palliative Care Australia.

fax 02 6232 4434

email [pcainc@palliativecare.org.au](mailto:pcainc@palliativecare.org.au)

post PO Box 24  
Deakin West ACT 2600

NMM code: P1083



Palliative  
Care  
Australia

PO Box 24  
Deakin West ACT 2600

t: 02 6232 4433  
f: 02 6232 4434

e: [pcainc@palliativecare.org.au](mailto:pcainc@palliativecare.org.au)  
w: [www.palliativecare.org.au](http://www.palliativecare.org.au)



For some families, their journey takes them to a place where they must confront issues concerning dying, death and bereavement.

This section includes chapters on bereavement support, making memories, and celebrating anniversaries. It contains:

- suggestions for talking to children about dying and death
- information on end-of-life decisions you should consider
- a description of the dying process
- detailed information about what to do when your child dies
- options for funerals.



## 4 – THE NEXT LEG

‘We mostly felt torn—hoping for the best while preparing for the worst.’

‘Our ultimate goal became to help our daughter die well and to help our son survive as a ‘whole’ person.’

‘How do you know when the time comes?’



## SECTION 4 – CONTENTS

### Chapter 21 – Talking to children about dying and death ..... 103

Key points ..... 103

Preparing your children ..... 103

### Chapter 22 – End-of-life decisions ..... 106

Key points ..... 106

Choices for you to consider ..... 106

Resuscitation planning ..... 107

Memory making ..... 108

### Chapter 23 – Funeral planning ..... 109

Key points ..... 109

Planning your child's funeral ..... 109

### Chapter 24 – The dying process ..... 114

Key points ..... 114

The signs of death ..... 114

When your child dies ..... 115

How to help your other children at this time ..... 118

### Chapter 25 – What to expect in the first weeks and months of bereavement ..... 119

Key points ..... 119

Dealing with practical issues ..... 119

How your body responds ..... 120

How your child's death affects different family members ..... 120

Loss and grief ..... 121



**Chapter 26 – Bereavement support ..... 123**

Key points ..... 123

Understanding bereavement ..... 123

Returning to work ..... 124

Using resources ..... 126

**Chapter 27 – Remembering your child ..... 128**

Key points ..... 128

Making memories and marking occasions ..... 128

**Chapter 28 – Deciding on another baby ..... 131**

Key points ..... 131

Another baby? ..... 131

The road ahead ..... 133

**Tools**

Tool 6—Selecting a funeral director ..... 134

Tool 7—Some common symptoms of grief ..... 135  
(Tool for family members)

Tool 8—Tips to help you through your grief ..... 137  
(Tool for parents and grandparents)

Tool 9—How to support someone who is grieving the loss of their child ..... 138  
(Tool for family and friends)

Tool 10—Ten healing rights for grieving children ..... 140  
(Tool for siblings, parents and teachers)

Tool 11—Notes for grieving children and teenagers ..... 141

Tool 12—Dealing with grieving students in your class ..... 142  
(Tool for teachers)

Tool 13—Help for special events ..... 144

**Thank you ..... 148**

## 21 – TALKING TO CHILDREN ABOUT DYING AND DEATH

### Key points

- Many parents struggle with the question ‘Should we tell our child they are dying?’
- Your decision to talk with your child about dying and death may be guided by your own instincts, your child’s condition, your knowledge of your child, and your cultural and spiritual beliefs.
- You can ask members of your care team for advice and support.
- Children have varying thoughts and concepts of death according to their age, developmental level, and life experiences.
- Children who know they are dying can have time to prepare, time to share and create memories, time to plan, and time to say goodbye.
- It is important to prepare brothers or sisters as much as possible according to their age and personalities.
- Make sure your care team, family, and friends are aware of your decision about what your children actually know.

### Preparing your children

Many parents wonder whether they should talk to their children about dying and death, how much they should tell them, and what impact it will have. There are no easy answers and your decisions should be guided by your own instincts, your child’s condition, your knowledge of your children, and your cultural and spiritual beliefs. This can be a confronting and difficult decision to make and at times, parents may disagree on the approach they wish to take.

Families who have been able to talk to their children about dying and death have found many benefits, including:

- providing reassurance to children through open and honest communication—children do not feel alone because they can share their questions and fears with their parents
- opening opportunities for families to say the things that need to be said
- providing an opportunity to complete unfinished business and to create memories for the whole family.

*‘Hannah (5 yrs) knew that Gabby was very sick—there were no secrets about her illness and treatments, but it took a long time to tell her that Gabby was dying. Before we could tell Hannah we first had to accept this ourselves.’*



'We didn't tell our daughter she was dying, but we managed to have many meaningful conversations about life and death within a loving and gentle context that felt right for us.'

'Josh (4 1/2 years) had a pet mouse named Tommy who had died recently. We used Tommy's story to talk to Josh about dying, death and heaven when Kessia was getting worse. We told him how Tommy had been too sick for his body to work anymore and that was why Tommy died. We told him that Tommy's spirit was alive in mouse heaven where he was very happy, had lots of little mouse friends to play with and all the cheese he could eat.'

You may wish to seek the advice of trusted friends, pastoral carers, or counsellors when making this decision. Asking someone from your care team to explain to your child what is happening with their illness can also help. Talking with children can often be a matter of right time, right place, right person.

When you talk to your children, you should be aware of what they are capable of understanding at their age. Children's concepts of death vary and are described briefly below, in terms of age.

- Children 2 years or younger cannot comprehend what death means. However, they do have a sense of someone significant being absent. They react to disruption in their normal routine and are sensitive to non-verbal cues and will pick up on the emotional atmosphere around them.
- Children aged 3 to 5 years usually see death as temporary, a condition from which you can return.
- Children aged 6 to 10 years are much more curious about death, and tend to ask many questions. They have the ability to understand that death is forever.
- Children aged 11 years and older have a more sophisticated and realistic view of death. They realise it is final but they also appreciate that those left behind need to grieve, find meaning, and remember.

Children's understanding of death will also be influenced by:

- their personality
- prior experience of death
- family norms and rituals
- film, television and books
- the experiences of their peers.

Books, DVDs, and other resources can be useful tools to help when talking about dying and death. They can provide a safe space to share feelings and thoughts. They can also be a trigger for discussing difficult issues and may provide your children with a better understanding of the journey ahead. See the resource list for information sources.

### *Preparing your unwell child*

Children are usually much more aware of what is happening to them and those around them than people may realise. Many parents worry that children who know they are dying might 'give up'. However, many children who know they are dying choose to live life to the fullest and make every moment count. Being able to tell your child that they will die gives them time to prepare, time to share and create memories, time to plan and time to say goodbye.



See Journeys Resource List

Books

If your child does ask questions, try to answer honestly. This allows important things to be said and may relieve some of the emotional burden your child may have been experiencing. Make sure everyone who is in contact with your children is fully aware of what your children have been told.

Remember you are not alone. Your care team can help answer questions your child may have about their condition and care. A pastoral carer can help with spiritual questions or questions children have that seek to find meaning in what is happening to them.

### *Your other children*

As your child comes closer to death, it's important to prepare their brothers and/or sisters as much as possible. Ideally, older children should know from you that their sibling is dying. They need accurate and honest information about what is happening and an opportunity to spend time with their brother or sister. With younger children, it may be wise to wait until the last few days before telling them what lies ahead.

*'After several months of chemotherapy, surgery and intensive radiotherapy, he went into remission. But after 10 weeks of remission, his cancer returned. We knew there was no hope. This was the beginning of the end. His father and I were so afraid for Andrew (aged 16 years), but we didn't want him to know his prognosis. We were concerned how he would react. But with the gentle and persistent persuasion of our oncologist and the team, we realised Andrew had to know. What really turned it all around was that I didn't want Andrew to die alone and frightened.*

*So when we decided to tell Andrew, with the help of the team, his whole demeanour changed. Where previously he'd been angry and aggressive, now calmness enveloped him, he told us 'I'm glad I know'. He only had a short time left and he wasn't going to waste it.*

*Andrew's rationale about knowing and being prepared was that this gave him the opportunity to say his goodbyes and say the things he needed to say.*

*He told me on March 20, he was going to die, I asked him if he was ready to go. He nodded 'Yes'... I couldn't believe this was happening, but I was relieved and in a way, happy that Andrew was aware and accepting of his fate. His bravery and courage was inspirational.'*

*'We thought it really important that our older son knew that his brother (aged 17 months) was going to die. Telling him the truth was the least we could do for him. He could participate in the process of saying goodbye to our young son. Our older son wrote letters to our younger son in preparation for placing them in the coffin. He helped when we took hand and foot prints of our younger son we could remember him by (he still keeps them in his room many years later). He would spend time playing with him and reading him stories. We made sure we had lots of photos. We knew this would help later and it did.'*

Sometimes adolescent brothers and sisters cope by spending time out of the house. Peer support may be important to them as well as an escape to a 'normal' environment. You can still make special efforts to include them in the caring—this may reduce feelings of guilt and regret later.

It may be helpful to ask a trusted adult to pay particular attention to brothers and sisters and to be available to them to talk about their concerns and fears if they want to.



## 22 – END-OF-LIFE DECISIONS

'Andrew became unwell in February and told us he wanted to die at home. Hospitals depressed him so much. I was a little apprehensive as Andrew was on copious amounts of drugs and I was concerned I wouldn't be able to manage his pain efficiently or care for him properly. The local community palliative care team assisted us alongside the team from the hospital. I found nursing Andrew a privilege and a joy as I was able to help my darling son live his final months at home in the warmth and love of our family.'

'We wanted Gabby to die at home—she had spent so much of her two short years in hospital, we needed her with us without tubes or machines—just surrounded by family.'

'We made the choice to care for our son at home, but when the time came to go to hospital to reduce the trauma on our other children. This decision was made with the view that we were always with him and the hospital was like a second home—he was in so often, knew all the staff in the cardiac ward, and they loved him a lot.'

### Key points

- Acknowledging that your child will die does not mean you have given up on them. Your love, hope, and strength can help prepare them and your family for what lies ahead.
- Many families discuss end-of-life care and find comfort in the fact their child will not suffer unnecessary treatments to prolong life.
- Having to make difficult decisions in a time of crisis and distress may be avoided by planning ahead.

### Choices for you to consider

Over the course of your journey, from the initial shock, confusion, and grief of your child's diagnosis and through their illness, there will have been times you have thought about your child's death.

Parents speak of needing to find the strength to lead their family so they feel they did everything they wanted and needed to do—for their dying child, their other children, and for themselves. You may have heard that one of the most important goals of this time together is to 'minimise regrets'.

Sometimes planning can help reduce the fear of the unknown. One way to achieve this is to be aware of the choices you may need to consider and to make plans to help guide your family. This chapter explores some of these sensitive issues.

#### *Planning care*

It takes courage to plan for care at the end stages of life. If you are able, it will help ease the burden when the time comes. Many families find comfort in the fact their child will not have to be subjected to unnecessary treatments. Planning ahead can also mean you don't have to make difficult decisions at a time of crisis and distress.

Wherever possible, if you feel your child is old enough and capable, they should be involved in these discussions. For example, they may have strong views on where they wish to die and who they want present. Think about and discuss where you would like to be and who you would like present at the time of your child's death.

## Resuscitation planning

Your child's doctor or a member of the care team will discuss with you several actions that can be done in the event your child's condition deteriorates. These are called 'Allow natural death' or 'Do Not Resuscitate Orders'.

### About resuscitation planning

Resuscitation is the act of reviving someone whose heart or breathing is stopping or has stopped. Resuscitation might involve CPR (chest compression and manual mask breathing), or full intubation and ventilation on a machine. It may also include such considerations as dialysis, intravenous fluids, and heart starter drugs. Resuscitation may not be successful.

Resuscitation planning means deciding ahead of time what to do if your child's breathing or heartbeat stop.

Remember that these decisions can always be reviewed and changed at any time.

If your child is old enough, you may want to ask their views about resuscitation.

Your doctor will describe resuscitation procedures and ask you what treatment preferences you want for your child. As part of these treatment preferences, you may be asked to confirm your decision and document it in an 'Allow natural death' (AND) or 'Do Not Resuscitate Order' (DNR).

These orders inform healthcare professionals that certain medical actions should not be performed. The order can prevent unnecessary or unwanted invasive treatment at the end of life.

These orders do NOT mean 'do not treat'. Treatment for infections or other treatable conditions, intravenous feeding and fluids, pain management, and comfort care can still be provided for your child.

Once you have made a decision, hospital staff will record your wishes in medical notes. Your decisions should also be noted on your care plan.

You should discuss your wishes with your general practitioner and care team members if your child is being cared for at home.

### Considering organ donation

Some families have expressed a desire to have information about organ or tissue donation. This may well be possible despite a long history of illness. If you are interested, discuss this with your care team.



See [Journeys Resource List](#)

[End-of-Life decisions](#)



'The last few days had been shattering and we knew Zach didn't have much time left. Although it seemed selfish at first, we got two nights of nursing care so that we could get some sleep. As it turned out, on the third day, Zach died. It was another gruelling day and in hindsight, I think we were better able to get through it because we weren't completely exhausted.'

## When parents disagree

The choices you are being asked to consider are very emotive and confronting. It can be difficult for both parents to share the same feelings and reach an agreement. If this happens, you are not alone. Many parents, whether together or separated and sharing the care of their child, feel in conflict at times. Get help with this issue early by discussing it with a care team member and asking for support.

## Other planning

It can be an exhausting time as a child approaches death. Often, parents keep a bedside vigil because they are concerned their child may die in their sleep. It can be a great help if you have plans in place to help you during this time. You might think about the following options:

- In-home nursing—your care team can advise how you can access this service. Knowing someone is caring for your child and will be there to wake you should anything happen may be enough to help you get some much needed sleep.
- Asking a trusted family member or friend to take on the night watch—knowing someone is watching over your child and will wake you if needed can be of great help.

## Memory making

It's important to make memories and record special times and things about your child and family. Some parents have suggested:

- keeping a diary or journal
- having a professional photographer or friend take photographs of you as a family
- recording home movies, especially for siblings or future siblings
- making family handprints and footprints.

Sometimes memory making activities don't quite go as planned – but it won't matter in the end if it's not perfect.



See Journeys  
Resource List

Remembering your child

'My daughter (7 years) would wake in the middle of the night and we would have the most incredibly deep conversations. They were some of the most special times we shared during her illness. I wish with all my heart that I had thought to keep a diary to help me remember what we had said.'

## 23 – FUNERAL PLANNING

### Key points

- A funeral is a time to acknowledge your child and the meaning your child's life holds for you and your family.
- Some families find comfort in planning their child's funeral before their child dies. Others feel it is something they cannot think about until after the event.
- If your child is old enough and knows and understands that they are dying, they may find it a positive experience to help plan their own funeral.
- Siblings can be involved and included as much as they would like in the funeral arrangements.
- Planning helps you understand funeral costs and what services are provided. Obtain several quotes and ask questions before deciding what is right for you. Financial assistance may be available.
- After your child dies, you can generally choose to keep their body in your own home or at the funeral home.
- Take the time you need to plan your child's funeral and make it as personal as you would like.
- The funeral does not have to happen straight away.

### Planning your child's funeral

Planning your child's funeral can be another of the difficult tasks you find hard to contemplate. However, over time you may find it is something you want to do well, and plan for in advance. It can relieve significant burden and stress at the time of your child's death.

Many children and adolescents have helped plan their own funeral, choosing favourite songs, who they wish to be involved, and where they would like to be buried or have their ashes placed. Your child may welcome this opportunity; many see it as a celebration of their life and a special goodbye.

When your child dies, it is not uncommon for well meaning family and friends to take over in an effort to help you out. It may be difficult for you to think straight and you may find yourself agreeing to others' suggestions. This is why some parents have found it helpful to discuss their wishes in advance.



'Before our son (17 months) died we arranged his funeral. That may sound awful to some but we found it helped prepare us for his death. Neither my husband or I are religious but our son was baptised in the Catholic Church. We wanted the priest to meet our son before he died, to know what he looked like, to know him, to know why we chose the music and prayers we did. The priest was great and the funeral had special meaning for all of us, including him.'

### Some considerations when planning a funeral

- Some parents feel able to talk about funeral plans only after their child has died. This is okay; the important thing is to choose what's best for you and your family.
- Occasionally, some parents decide they do not wish to use a funeral director and choose to take on all arrangements themselves. There is no legal requirement that a funeral director be involved.
- Others have found value in handing over funeral arrangements to a trusted family member or friend.

The most important thing to remember is to take time in making your decisions and to do what is right for you and your family.

### Selecting a funeral director

Your circumstances and wishes will influence your choice of funeral director. You may want to ask family, friends, or a pastoral carer to recommend a funeral director, or you may want to 'shop around' for someone you feel will understand your needs and help you arrange the service your way.

Tool 6 is a checklist of questions to ask when choosing a funeral director. You may want to copy this sheet and take it with you when meeting with them.



See Tool 6

Selecting a funeral director

Page 134

### Funeral costs

When arranging the funeral, be sure that you understand what costs you must pay. Ask for itemised quotes for the funeral director's service costs, and cemetery and crematorium costs. For some services, an up-front payment may be required. You may want to get two or three different quotes. You can also ask about a payment plan.

Be prepared for miscellaneous costs to cover such things as flowers, the celebrant, and death and funeral notices in the newspaper. You may be eligible for financial support for funeral costs. You can seek advice from Centrelink (or have a friend ask for you). Some charitable agencies also contribute to funeral costs. You may also be eligible to claim the cost of the funeral against your superannuation scheme.

'Andrew (16 years) wrote a will and letter for us to open after he'd gone. He planned his funeral, he picked the church, his resting-place, his pallbearers, songs, and special things he wanted placed in his casket. He asked that the journey from the church to the cemetery be taken via the sea route. He also asked for two doves to be released at the ceremony to represent that his spirit had been set free.

We dressed Andrew and did his hair. He told us he wanted to look good. The four of us placed him in the casket and arranged everything the way we knew he wanted it. I found this very comforting to be able to care for him until the end.'

### Planning the funeral: things to consider

#### Involve your child

Your child may have ideas for their own funeral. Some children choose music and special songs, the clothes they wish to be buried in, or where to hold the service.

#### Involve your other children

Include your other children—they may have special wishes, tributes and contributions to make to the service, or they may not want to participate at all. Listen to what they want and respect their choices. Prepare them also for what to expect before, during and after the funeral if they attend. Ensure there is another adult to look out for them.

#### Involve grandparents and significant others

Grandparents are often keen to be included in these arrangements. Whenever possible, it is helpful to acknowledge the special grief and loss of grandparents.

#### Cultural and religious beliefs

Different cultures and faiths have their own traditions relating to death and funerals. Talk to family and religious leaders about what you need to consider.

#### Burial or cremation

This is an individual choice and is often a decision informed by cultural, religious, or personal beliefs.

If you are considering burial, you may want to ask about family plots, plaques, and headstones. Many families who visited the cemetery before the funeral felt more prepared for the burial. It can also give brothers and sisters a chance to see where the coffin will be placed.

If you are considering cremation, you may want to know what is involved, the cost and when you will receive your child's ashes.

#### Where to hold the service

Some families choose a place that has special significance: at home, in a church, garden, or park. Others choose the funeral home, crematorium, or gravesite.

#### Who to invite

You may choose to hold a private service or burial.

#### Who will conduct the service

You may choose a family member, friend, minister, chaplain, or celebrant to conduct your service.

#### Who will speak at the service

You may want to ask your other children, grandparents, or significant others to speak at the service.



'After my daughter (7 years) died, I asked if we could keep her body at home until the funeral. No-one seemed to know, but our GP found out we could. The day after she died, her body was taken for a few hours to the funeral parlour and then we had her at home for five days before the funeral.

We borrowed a large air conditioner to keep the room cold and lay her on her bed dressed in her favourite fairy pyjamas. Looking back, it was one of the best things we did. It gave Joshua (5 years) a chance to ask lots of questions about death and to see for himself that his sister's body wasn't working anymore. He was able to spend time with her and say goodbye in his own way—decorating her with stickers, cuddling her and having time to cry with her.

It helped all of us. We could still see her, touch her, kiss her. Family and close friends took turns sitting with her, saying goodbye intimately and privately. It was a very peaceful time.'

## Funeral home or own home

### Things to consider

#### Funeral home

Following discussions with your funeral director, when you are ready, you can choose to drive your child to the funeral home or have the funeral director come to your home, hospital or hospice. Funeral directors are usually very flexible and will come to your home at whatever time suits you. (You may need to check if there are additional costs for work outside normal hours.)

You should discuss with the funeral director what they will do before they come to your home so you can be prepared. You can also ask for other things, like having your child's blanket placed over them, or having a favourite toy accompany them. You can collect these things afterwards.

When the time comes for you to give your child to the funeral director you may be overwhelmed with emotions. Having the support of loved ones around you at this time may help.

#### Your own home

It is becoming more common for families to keep their child at home in the days leading to the funeral. Discuss with your funeral director if there are any special requirements to keep your child at home, for example, your child's body may need to be embalmed (embalming is a treatment of the body with antiseptics and preservatives) if you wish to keep them home for a few days.

If embalming is necessary, the funeral director will arrange to collect your child's body for a few hours. It does not need to be on the day your child dies, but will need to happen soon after. In summer you may need to keep the room chilled.

Arrangements to collect your child's body for the funeral will need to be made. Again, discuss your wishes with the funeral director and be clear about what will happen. You could also drive the coffin there yourself.

## Personalising your child's funeral

Your child's funeral service can be a very special family occasion. Some ideas and suggestions for personalising the service in honour of your child include:

- favourite songs and music

The choice of songs and music is an easy way to reflect your child's personality.

- photographs or slideshows

If you have access to a large screen and projector, you may want to include slideshows of favourite photographs during the service.

- flowers, balloons, candles and other tributes

You may have definite ideas about what kind of flowers you want or if you don't want any at all. Instead, you may want bunches of helium balloons to be released after the service, or candles or incense to create an uplifting atmosphere. You may want to request donations for a favourite charity or toys for a local hospital. You might place special stickers on their coffin.

- coffin

You can choose a special colour and decorate a coffin to suit your child.

- service booklet

You may want to create a personal booklet for the service with photos and drawings by your child.

- friends and the school community

Involve your child's friends to read, sing, or play an instrument. Your child's school may want to participate in some way (should you wish), perhaps by providing a choir or a guard of honour.

- record the service

Video or audio record the service, or ask those who spoke to give you a copy of what was said. This can be very helpful for young siblings who may have trouble remembering the day in years to come.

- remembrance book

It is not uncommon for parents to have little recollection of the service or who was there. You may want people who attend to sign a remembrance book. Your funeral director can arrange this for you.



See Journeys  
Resource List

Remembering  
your child

'Leigh's service was a real celebration of her life. Her girl cousins wore fairy costumes and we all proceeded into the church with her open coffin, to one of her favourite fairy songs. We held brightly coloured bunches of helium balloons, her teddy bear and a big basket of all her favourite goodies. We had slideshows during the service, asked friends to sing special songs, and felt we really captured her personality and vitality.'

'When Randall (5½ years) passed away, his younger brother Baden was 2¾. We explained to Baden that Randall was too sick to come home and would be living in the sky where he would be happy and no longer sick. He would travel in his magic blue Thomas box (coffin) into the ground and 'magic' out of his box up into the sky. Baden now seems to have a simple understanding as to why we always refer to Randall as being in the sky and not at the cemetery. We like to refer to the cemetery as 'Randall's Special Place', as it just sounds more child friendly.'



## 24 – THE DYING PROCESS

### Key points

- As people come closer to death, their bodies begin to shut down gently with less circulation of blood, and slowing of breathing and brain function.
- You can never be completely ready for your child's death. This will be a time of intense emotion for your family.
- Take as much time as you need to say goodbye to your child. This is a time for all the family to express love and sorrow.
- Whether your child dies at home, hospital, or hospice there are only two legal requirements to fulfil—obtaining the death certificate and registering your child's death.
- If your child died unexpectedly or shortly after an operation or procedure in hospital, a Coroner's notification may be necessary, with a possible post-mortem.

### The signs of death

As people come closer to death, their bodies shut down gently with less circulation of blood, and slowing of breathing and brain function. There are a number of particular physical signs that might be seen or felt by carers such as:

- changes in body colour with pale/bluish hands, feet, and lips, and possibly a mottled colour in arms and legs
- cooling of hands and feet
- interrupted and very irregular breathing (called Cheyne-Stokes breathing)
- restlessness or unsettled behaviour
- loss of wakefulness
- decreased appetite and thirst, non-absorption of feeds
- noisy breathing as the person is unable to swallow their saliva
- incontinence or strong urine
- eye changes such as looking a little sunken or glazed.

It is reassuring to know that the child does not suffer from these signs. These signs can be unpleasant to watch, but they may help the family to prepare for death.

Spiritually, some parents also sense that their child's death is near and they feel the need to be very close. Parents may not wish to share their child with too many people and may also feel quite restless themselves.

Caring for your child at this time will generally require more advice and support from your care team, but this need not intrude on your need for privacy. A calm, peaceful environment is the most important thing at this stage.

Despite a loss of wakefulness, we know that people in this stage can still hear and feel touch, so you may choose to play your child's favourite music and have familiar voices talking to them. You may also like to use aromatherapy or soft lighting to create a calm environment.

Your child may need sedative medications if they are restless or agitated. Noisy secretions can be simply managed by laying your child on their side or by administering some drying-up medication (your doctor can advise you on this).

Wherever your child is being cared for, make space so you can cuddle with them if you want—maybe a double bed, lounge, or mattress on the floor. You may also choose to involve other family members at this time.

### *How will your child look after they die?*

You may wish to prepare your other children for how their sibling will look once they have died.

When a person dies, the body changes occur over a period of hours. Your child will gradually feel cool and even a little clammy to touch. Their skin colour also changes as they become pale. Blood pools in different areas under the skin and can look like bruises. Due to the pooling of blood, their body will also become stiff (rigor mortis)—this stiffness reverses later. You can still touch your child as much as you like.

At the time of death, some muscles in the body also relax and there may be loss from the bladder or bowel. There may also be some ooze from the mouth and nose. This can occur when you move your child for washing or undressing. Also, air may escape from mouth or nose, and facial features change as muscles relax. Being aware of this will help you be prepared for these changes.

## **When your child dies**

This is a challenging and difficult time and there are some things you need to prepare for to make it easier. Preparation will also allow you to think about what is 'right' for your child and your family.

*'We knew Leigh was close to dying for a few days. By then she had developed pneumonia and was struggling to breathe. She was in and out of consciousness. Morphine eased her breathing and restlessness, allowing us some quiet time to read to her and massage her with strawberry scented oils.'*



'I really wish we'd thought about taking prints of her hands and measured how tall she was. It sounds strange, but I wish I could remember how tall she was and not forget things like that. I see other girls now and wonder—was she that height or a bit bigger? I also wish we'd taken a lock of her hair and clay mould of her hands and feet. I've heard other parents say how nice it is to have something physical to touch—and she had such cute feet too.'

Wherever your child dies (e.g. home, hospice, hospital), there is nothing that needs to be done in a hurry. This is your personal time to be with your child and to say goodbye. You can take as long as you need. Sometimes, a person's religious, cultural, or spiritual beliefs will influence how they wish to spend this time.

It is a time for you, your other children, and maybe also grandparents and friends to express love and sorrow. You might like to think about how private or shared you would like this time to be. You may choose to do this in many different ways. Here are some examples of how other families have chosen to spend this time:

- listening to their favourite music while cuddling or talking to their child
- sleeping with their child one last time
- washing their child and dressing them in a favourite outfit
- taking family photos
- taking ink or paint prints of their child's feet or hands—this can also be done as a family collage to include parents' and siblings' handprints or footprints
- making clay imprints of their child's feet or hands—many parents have found this a good way to remember the size, shape, and feel of their child's hands or feet
- cutting a lock of hair to keep
- recording their child's height, weight and any other details you want to remember.

### *What to do if your child dies at home*

Families sometimes worry about what they 'have to do' when their child dies. This is usually what needs to occur:

- When you and your family are ready, you will need to phone your care team doctor to let them know your child has died—they will then lead you through the next steps, according to the day of the week and time of day.
- In all probability, the police will not need to be called.
- Your doctor will check your child and sign a death certificate and a cremation certificate if cremation is being considered, and give this to you or forward it to your funeral director.
- You will need to contact a funeral director. Many families choose a funeral director before their child dies.
- You can keep your child's body at the funeral home or choose to keep your child's body at your own home.



See Journeys  
Resource List

End-of-Life decisions

There are a few circumstances when a healthcare professional is obliged to refer a death to the Coroner. Not all notifications to the Coroner become Coroner's investigations. A Coroner's investigation is carried out solely to establish the cause of death if it is unclear, and may include a post-mortem.

The Registrar of Births, Deaths and Marriages is responsible for issuing a formal death certificate. The funeral director usually notifies the Registrar of your child's death and can apply, on your behalf, for a formal death certificate from the Registrar a few weeks after the death.

### *Post mortems and autopsies*

In the rare situation where a Coroner's post-mortem is required, the Coroner does not have to seek your consent. However, you are able to lodge an objection to a post-mortem. The Coroner's office and your care team can advise of the appropriate process for this, and answer any questions you may have. Your written consent is required for retention of any organ or tissue.

You may request a post-mortem or biopsies if you feel it would be helpful to your understanding of your child's condition and cause of death. You may also be asked by your clinical team to consent to a post-mortem for research or teaching purposes. This is strictly your choice.

Remember, if you are unclear about what you need to do or the decisions you need to make, talk to a member of your care team.

### *What to do if your child dies in a hospital or hospice*

If your child dies in a hospital or hospice, you can take as much time as you need to say goodbye. You can invite other family members and friends to see your child to say their own goodbyes.

It may be possible to donate organs or tissue for research if there is no Coroner's requirement. If this is something you would like to explore, ask a member of your care team for more information.

If there is no Coroner's investigation, a doctor will issue a death certificate. You need to take this to the funeral director. You have the option of taking your child home—either for a last visit or to stay at home until the funeral. Staff can help you arrange this.

If you do not wish to take your child home, now is the time to contact your funeral director and arrange for them to collect your child's body from the hospital or hospice. If you have not chosen a funeral director, your child can remain in the care of the hospital or hospice until a funeral director has been arranged. Leaving without your child can be a very emotional time for the whole family. Staff will be there to support you.

If you wish to take your child home for a last visit, you can arrange for the funeral director to collect your child's body from your home later on. If you wish to take your child home until the funeral, there are a few things you should know. Chapter 23 on funeral planning contains more information.

'Leon and I knew that Brianna was very close to death for about the last two weeks, every night I would lie next to her and tell her that it was okay, she didn't have to stay here with mummy and daddy, that we loved her immensely and she was a very brave little girl. On the night that she died I had just finished telling her this and got up to get a nappy to change her and put her into bed. As I sat down with her again, I knew at that moment that she had gone. Very peacefully, no struggling for breath.

Leon picked her up and we sat on the couch together and kissed and cuddled her before ringing anyone. I will never regret those last few moments that Leon and I had with our daughter; I think she had held on all day until the moment that she had her mum and dad to herself.

As it was 10.30 at night, I rang family and my best friend and they all came out to say goodbye. Our local care nurse left the hospital and came to our house, she guided us through it all. A beautiful lavender bubble bath and then dressing Brianna in her best pretty pink dress. When it was time, Leon and I drove Brianna into town to the funeral parlour ourselves as we didn't want the memory of Brianna 'taken away' in a hearse. As we drove back home a huge lightning and thunder storm was starting and I felt it was significant to us as it was exactly how I was feeling.'



See Journeys Resource List

Helping your partner or children

'Over the next days and weeks, we talked openly about how we were feeling, said it was good to cry and feel sad, and we tried to make sure our son was surrounded with love and security—from us or other family and friends when we weren't up to giving him the attention he needed.'

'When my son Bwembya died I was able to manage my grief, but providing emotional support for my children is what almost drove me over the edge. After caring for a sick child for so many years, I was emotionally drained. When my oldest daughter became depressed it took all I had to keep sane. The crisis passed after counselling and taking time off to spend days with the girls.'

## How to help your other children at this time

Breaking the news to brothers and sisters about their sibling's death should, where possible, be done by parents. Siblings should be given an opportunity to say their own goodbyes and to be involved as much as possible and as their age allows. Use truthful, plain words when talking to your children. Some vague explanations can leave too much to the imagination and may trigger unnecessary fears.

Children's reactions to death will vary greatly depending on their age and stage of development, their relationship with their brother or sister, and whether they have had any previous experience of death.

Here are some suggestions based on the experiences of other families:

- Try not to have particular expectations of how your children may react or grieve, but rather offer encouragement and support to help them respond in their own way.
- Give your children a chance to say goodbye. Being able to spend quiet undisturbed time with their brother or sister is an opportunity that is very special. They may wish to write or draw a goodbye note, or give their sibling a favourite toy 'to keep'.
- It will help sometime in the next few days to talk with your children about what will happen and what to expect at the funeral service. Offering the choice to be involved and included is important.
- Be prepared for questions your child may ask such as: 'What will happen to their body?', 'Why is he put into the ground?', 'Can she feel anything?', 'What if he's not dead?', 'What is cremation?' and 'What will his ashes look like?'. These questions need honest, simple, accurate, and sometimes repeated answers given in a caring and nurturing atmosphere.
- As you will be dealing with your own grief at this time, it may be helpful to ask a trusted relative or friend who the children know to spend special time with them too.

## 25 – WHAT TO EXPECT IN THE FIRST WEEKS AND MONTHS OF BEREAVEMENT

### Key points

- Your child's death will affect you, your other children, and your family members in different ways.
- Bereaved parents often talk of 'surviving' rather than 'coping' with the death of their child.
- Your body acts to protect you in the first 4–6 weeks following your child's death by producing hormones which may have a numbing effect.
- As the hormones start to wear off, feelings of loss and grief can become stronger.
- At the same time, those who supported you during your child's illness may start to return to their normal lives, leaving you feeling vulnerable and alone.
- There may be other losses you did not anticipate, such as separating from the bonds you formed with your health care team and other parents.
- It is helpful to know the common grief reactions to loss and recognise when you may need professional help.

### Dealing with practical issues

There are often a lot of 'practical' things to do when someone has died. You may want to arrange for a family member or friend to help you do this. Some of the services you may need to cancel and people you may need to notify include:

- family doctor
- Medicare/private health fund
- recreational clubs, sporting groups and libraries
- any agency or service where you may receive a reminder for check up or review
- other health professionals, for example, dentist
- school
- religious or social organisations
- bank.

If you are receiving any type of Centrelink payment you will need to notify them about the death of your child. You may also be eligible for a special bereavement payment. See the resource list for information on Centrelink.

*'In the first few weeks after Gabrielle's death we closed the world off and just concentrated on the three of us. Friends and family brought food and made quick phone calls but largely we were on our own 'softening the fall' for each other. We were free to talk about how we felt and remember the special times. The world ceased to exist until we were ready to join in again.'*



## How your body responds

'After we buried Brianna I felt a massive hole was in my chest, I didn't feel like a real person anymore. Acting like a zombie half the time, just going through the motions, trying to hold it together for the boys.'

You may have noticed or heard that many people demonstrate an amazing capacity to 'cope' with death and all that needs to be done in the short space of time afterwards. This response is facilitated by the release of hormones in the body called endorphins. Endorphins are often released when someone is very upset at the death of someone close.

Even if we know that someone is going to die, it is still a shock. As the endorphins start to wear off, the pain of the grief begins to come through. This is the time when a bereaved person starts to feel worse. This can be a scary experience, as grievers often expect they should be 'starting to feel better'. Many parents have said they felt as though they were going mad. These are very normal feelings in an abnormal situation.<sup>5</sup>

## How your child's death affects different family members

### Parents

Parents expect to die before their children—when a child dies it seems to be against the natural life cycle. Parents have the difficult task of developing a new life without the physical presence of their child. The expectations and hopes of future events and milestones are lost, for example, school, marriage, grandchildren.

### Grandparents

Coping with the death of a grandchild can seem like a double loss because grandparents are not only experiencing the loss of a grandchild, but also witnessing the suffering and distress of their own child. Grandparents may feel guilty, thinking it should have been them because they have lived a long life. Grandparents may need to seek support whilst working through this grief experience.

### Siblings

It is important to remember that siblings have unique relationships with one another. Siblings need their own time to grieve and may even need their own special person to debrief with, as they often feel they don't want to give their parents any more to worry about.

Some things to keep in mind include:

- The death of a sibling can create a specific kind of aloneness.
- Siblings will often postpone their grief whilst they care for other family members.



See Tool 8

Tips to help you through your grief  
Page 137

<sup>5</sup> Drew, D. 2005, *Paediatric palliative care: Caring for your child at home*, Sydney Children's Hospital Randwick.

- Siblings can also say things they don't mean—with their sadness occurring at a later time, often triggered by another event.
- The death of a sibling will change the position of children in the family.
- The grief for a sibling may re-occur as they face new life experiences, for example, graduation, marriage, birth of children.
- Siblings experience the same range of emotions and feelings as adults but will often express them in different ways, perhaps through behaviour and play.<sup>6</sup>



See Journeys  
Resource List  
Books

## Loss and grief

*'Bereavement is what happens to you, grief is what you feel, and mourning is what you do.'* Celia Hindmarsh.

As endorphins in your body start to wear off, you will begin to feel your pain and grief more strongly. Grieving (also called mourning) describes the feelings and reactions you have following a significant loss. It is an essential part of healing. Some parents describe grieving as 'being lost in a maze of conflicting emotions' or a sense of losing control. Many speak of it as an emotional roller-coaster.

*'No words can describe the feeling of loss or grief, it was so individual for all of us, as we all had a different relationship with him.'*

### Some common grief reactions to loss

#### Psychological responses

shock, numbness, denial, sorrow, loneliness, guilt, regret, fear, depression, relief, panic, helplessness, anger, feeling out of control, confusion, lack of emotions

#### Physical response

lethargy, fatigue, can't concentrate, trembling, shaking, headaches and body aches, dizziness, sweating, nausea, chest pains

#### Behavioural responses

crying, social withdrawal, lack of energy, searching for things to do, loss of appetite, over eating, insomnia, don't want to get out of bed

#### Social responses

lack of interest in other people and usual activities, avoidance of others, needing to be with others, feeling alienated or detached

#### Spiritual response

loss of meaning and purpose, questioning faith and beliefs, feeling a sense of emptiness, loss of joyfulness, loss of direction

<sup>6</sup> Drew, D. 2005, *Paediatric palliative care: Caring for your child at home*, Sydney Children's Hospital Randwick.



There is no right way to grieve and grieving can last a long time. Everyone will grieve in a different way and at a different pace. For many, grieving never fully comes to an end. It may help to know that your grief will become less raw over time. You will never forget your child but in time, you can get better at living with the loss.

### *Coping or surviving?*

You may find that a common question asked of you is 'How are you coping?' Many bereaved parents feel that the word 'coping' isn't strong enough to describe how they are feeling after their child's death. They feel they are 'barely surviving' and speak of 'keeping their heads above water' or 'just enduring' the pain. They wonder how they will ever survive the death of their child and what meaning life will hold.

If you are feeling this way, you are not alone. These can be very normal reactions. A list of common grief symptoms is provided at the end of this section to help you identify what are 'normal' responses and what are 'irrational' or 'abnormal' responses. Being aware of the difference can help you know when to seek professional support and guidance from a bereavement counsellor, your general practitioner, or other health professional.

### *Other separations which can cause feelings of loss and grief*

Feelings of loss can result from separating from:

- your hospital or hospice care team
- your health care team that helped care for your child at home, sharing intimate, vulnerable, and challenging times together
- other parents you shared part of your journey with and who provided you with support and understanding
- the routine and life that you had caring for your child.

Other potential losses:

- As people around you return to their own lives, they may stop dropping around or calling. You may have feelings of being abandoned when you most need support.
- Practical support such as help with meals, groceries, or cleaning stops.
- Breakdowns in relationships and friendships may occur as you begin to redefine your life and feel those around you are unable to meet your needs.

As with other parts of your journey, you do not need to walk this path alone. The information on bereavement support in Chapter 26 can help you find support as you move through your grief.



See Chapter 26  
Bereavement support  
Page 123

## 26 – BEREAVEMENT SUPPORT

### Key points

- Bereavement support is help with the process of grieving.
- There are many people, support groups, and other resources which can help you in your bereavement.

### Understanding bereavement

'Bereavement' is the process of grieving and mourning accompanied by intense feelings of loss and sadness brought about by death. It describes the process where we begin to live with the physical loss of a loved one.

Acknowledging loss and finding ways of accepting the reality of their child's death helps bereaved parents express their painful feelings and allows them to grieve for their child. With time, help, and support there is a way of living with loss.

With the loss of a child or a sibling it is common to find that nobody can actually relate to how you feel. Bereavement support provides an opportunity to share feelings with others who know exactly how you feel.

#### *Bereavement support for parents*

Many parents wonder how they will ever cope with the demands of every day living. Partners, relatives and friends may experience or express grief differently and may seem unsympathetic. Some may wonder if they will ever feel positive or happy again.

Parents naturally look to their partner for support. However, they are grieving too and may have less capacity to give you the comfort you need. Grieving is individual but close friends and family can help provide support and reassurance during this time. If you feel you need more from them, Tool 9 contains ideas for how they can better support you.

There is also a wide range of supports that can help:

- professional counsellors
- community based support groups
- pastoral carers and church-based support groups
- hospital-based support groups
- internet-based bereavement support groups.

*'I finally realised in looking back that while I will always be a bereaved parent, the season of my bereavement has finished. It took me a long time but I understand now that I don't have to feel guilty about coming back into life; I wasn't dishonouring my daughter.'*



See Tool 9

How to support someone who is grieving the loss of their child  
Page 138



See Journeys Resource List

Books  
Bereavement, loss and grief



'I can understand why the percentage of marriage break-ups is so high when a child dies. Leon and I have dealt with Brianna's death very differently. It was Sara, the palliative care nurse who kept telling me that 'mums and dads deal with death differently, don't try to make him talk about it or make him face the little things that you do, let him grieve in his own way and you may get moments together where you can grieve as a couple.'



See Tool 9

How to support someone who is grieving the loss of their child  
Page 148

See Journeys Resource List  
Books

See Tool 8  
Tips to help you through your grief  
Page 137

Many parents have also found value in reading books about grieving and stories from other bereaved families about their experiences. They can help reassure you that what you are feeling is normal and provide connections to your own experiences.

## Returning to work

It can be difficult to go back to work. Think about having a talk with your manager, and decide how you share information about your loss with the people you work alongside. You may like to have your care team assist you with these discussions and to help you think about the following points:

- how many hours a week to start back
- what to do on a bad day when you can't stay at work
- what to tell people about approaching you
- negotiating flexible work hours
- investigate options to work from home
- your financial needs.

Sometimes work can be an escape, a place where things are normal.

### *Bereavement support for grandparents*

Many of the supports available to parents are also available to grandparents. You may wish to read through this information and the resource list to give you some ideas of what may help you during this time. There are also many books written especially for grandparents.

### *Bereavement support for siblings*

As parents grieve, bereaved siblings will need support in their own grief. When we listen to bereaved children and teenagers, they tell us what their needs are:

- for there to be adults around them who they can turn to and trust
- for them to have their feelings received without judgement or criticism (they will already feel vulnerable and helpless)
- for tears to be allowed to flow (it is not helpful for them to be encouraged to be brave)
- for acceptance, when tears don't flow easily
- for a secure setting and acceptable safe ways in which anger and other feelings can be expressed.

Some practical ideas for providing these safe ways are: allowing lots of physical exercise or shouting and noisy play, steering them towards cushions or a punch bag (if you have one), going for walks, playing sport, or allowing a very messy painting session!

### Practical things that may help grieving children and teenagers

Take time before changing things that are familiar and include everyone in the family in making these decisions. Children and adults need time with things that belonged to the dead child. It is helpful for children to choose belongings that they can treasure. These memories are what help us get in touch with our feelings.

Touch is important. Pets can give children something to love and cuddle, or take on walks. Equally, a favourite soft toy can be very comforting. Many children like to be stroked or given a gentle massage and a cuddle. Listening together to relaxing music, or a story or relaxation CD can sometimes be very helpful, especially if getting to sleep is difficult.

It may help children to meet other children who have been bereaved so they know they're not alone. However, children's bereavement groups are few and far between. You can ask your general practitioner, hospital, hospice, or care team if they have someone trained in supporting children.

Reading books and watching DVDs about grieving can help open discussions.

Encourage children to write about and draw their thoughts and feelings about the death and their memories. Perhaps ask your child to write down what they would have liked to say to their sibling, tie their message to a balloon, and say goodbye; a simple ceremony to help share some of the hurt and pain and begin to let it go.

Other ways of remembering are creating scrapbooks of times spent together or filling a 'memory box' with special things associated with their sibling (sometimes possessions that smell of the person may be very precious).

It can be helpful to make time for 'special days' like anniversaries, birthdays, or mother's and father's days. This is discussed in chapter 27 on remembering your child.

Children and teenagers may need to look again at the details surrounding their sibling's death as they grow older. Feelings they had when they were eight will be very different several years on. This is not unresolved grief but the experience of different feelings at a later stage in life.

For those who have been bereaved a long time ago, it can still be helpful to find out details surrounding the death years later. Although this can be painful, it can also be a healing and comforting thing to do.



See Chapter 27  
Remembering  
your child  
Page 128

'After Gabrielle died Hannah (7yrs) refused to speak of her for some time (she told us later it was because we cried when we spoke about her). Gradually she would speak about Gabby but only to Kym and me but with time, support, and love she started to talk of Gabrielle to other family and friends. The important thing was Hannah was allowed to grieve and remember in her own special and unique way. We were there to provide a 'soft place' for her and to ensure that she was not pushed into anything that she was not comfortable with. Hannah now speaks freely to most people about her 'special' sister.'



'When our son died, we got counselling for the girls at the Hills Family Centre. Counselling helped the girls deal with all the issues they had and move on with their lives. My older daughter took two and a half years to deal with her loss and my younger daughter went to about ten counselling sessions and she was able to deal normally with her loss.'

So, for children, what helps is to be:

- reassured that they will still be loved and cared for
- encouraged to participate in simple rituals
- assured that whatever they feel is all right
- helped to feel and express emotions
- told it's all right to enjoy themselves
- encouraged to look forward to a time when they won't forget their brother or sister, but will remember without such hurt.

If we listen to children, they will tell us what they need. There is clear evidence that children will survive the pain of loss, providing they are loved and cared for.

## Using resources

There is a large and growing body of books for child and adolescent readers about issues related to dying, death, and bereavement. Here are some useful guidelines that may help when selecting appropriate material.

### Guidelines for selecting resources

#### Evaluate the book first

It is not enough to find just any book on loss or grief; you need to be comfortable with the information it contains and the attitudes that it conveys.

Select titles, topics and approaches that suit your child

Think about what you hope your child will gain from a book and then search for titles that meet those needs.

#### Be prepared to cope with limitations

You may need to decide whether a book is of sufficient value to be useful, or whether you can be creative in adapting it to your purposes.

Match materials to the capacities and concerns of your individual child

Often, this requires little more than matching a book to your child's interests and reading abilities.

#### Whenever possible, read the book along with your child

Reading a book together about death and grief can sometimes make it possible for you both to support each other in coping with loss and sadness.

Adapted from: Doka, K. (ed) 2000, Living with grief: Children, adolescents and loss, Hospice Foundation of America, USA.

Places to find books and other resources include:

- members of your care team
- hospital and community health centre libraries
- public libraries
- community-based health care support organisations
- national telephone support services
- some internet sites
- other families who have had similar experiences.



[See Journeys](#)

[Resource List](#)  
[Books](#)



## 27 – REMEMBERING YOUR CHILD

### Key points

- There are no rules about dealing with anniversaries, birthdays and special days.
- Whatever you decide, do not expect too much of yourself, but do whatever is helpful and meaningful for you.

### Making memories and marking occasions

Your child will never be far from your heart or thoughts. However you choose to remember your child and to mark special occasions, it will be important to do whatever you find helpful and meaningful for you and your family.

'Each anniversary of Leigh's death we have a picnic out at the cemetery with family. We play her favourite music, eat her favourite foods and do things like write messages to her on helium balloons and release them to the skies.'

#### *Creating memories*

Some suggestions from other families include:

- Keep a journal and record your thoughts, feelings, and memories about your child—happy moments, funny things they said or did, special things they shared with their brothers and sisters.
- Write the story of your child's birth, life, illness journey, death, funeral – using photos. This can be significant for young siblings or children born after the death.
- Make a photograph album or memory album with your child's details, photos, special certificates.
- Create a memory box to put all your special keepsakes such as clothes, toys, cards you received, letters you have written to your child.
- Compile memories of your child from family and friends.
- Plant a special tree or perhaps a plant that flowers on the anniversary of your child's birth or death.
- Create a special garden or corner where you can spend time and reflect.
- Adopt a star in honour of your child.
- Preserve some flowers from the funeral.
- Display favourite photos and keepsakes of your child.

- Make a quilt with patches created by special family and friends to share their thoughts with you and preserve your loving memories. The process itself can be comforting as people sit down to work together on the project.
- Frame a special sketch done by your other children of the family.

### Marking anniversaries and important milestones

There are many special family days, anniversaries and milestones which can be painful reminders of your child's absence. It may help to know that bereaved parents often find that the time leading up to these special occasions can be more difficult than the occasion itself.

Birthdays and holidays such as Christmas, new year and Easter can all bring back feelings of grief as you remember sharing these celebrations with your child. You may find that your support network is particularly sensitive in supporting you during these times. However, there are other anniversaries and milestones which only the bereaved family are aware of, or other significant days they are not prepared for, such as:

- date of diagnosis
- date of relapse/s
- date of death
- mother's day and father's day
- future milestones which your child will never meet, for example starting school, graduation day.

There are no rules about how (or even whether) to mark anniversaries, birthdays and special days. Whatever you decide, do not expect too much of yourself, but do whatever is helpful and meaningful for you.

Here are some ways that families have chosen to mark important dates and remember their child:

- Visit the grave with balloons and a picnic—invite family and friends to join you.
- Hold a special memorial service—at a church, a park, or wherever you choose.
- Place a message in your local newspapers to mark the occasion. Or write messages to your child on helium balloons and release them to the skies.
- Write a poem, song, or letter to your child. You may wish to keep this private or share with family. Some parents have talked about writing a letter to their child and then burning it, the smoke carrying their message to their child wherever they may be.
- Add a special plant to your garden or at the gravesite.
- Make a special Christmas decoration each year.



See Journeys  
Resource List

Remembering  
your child

'At Randall's funeral a candle was lit which was given to us afterwards. We started lighting it on special days and now light it every night for dinner. Before this one burnt to the bottom we purchased a new one, and used the first candle to light the replacement. We do this every time the candle is nearly finished and in doing so we now have our own special 'eternal flame'.'



See Tool 13

Help for special  
events

Page 144

- Get together with family members and browse through a photo album or watch a DVD of your child.
- Make or buy celebration candles, which you can light on each anniversary.
- Some parents like to carry a physical reminder of their child with them, such as a grief pin, angel pin, ring, or even a tattoo.

## 28 – DECIDING ON ANOTHER BABY

### Key points

- When you have a child with a life-limiting illness or following the loss of your child, you may find that your previous thoughts and plans about having another child will be affected. You may be wondering when, or whether, you should have another child.
- You and your partner may feel differently about having another child.
- There is no right or wrong decision, only what is right for you.
- Genetic counselling is a service which can help you decide whether to have a child if you are concerned about the risks of passing on a genetic disease.

'Geoff and I oscillated about having another baby for about a year after Kessia died. We did the classic pros and cons list, convinced ourselves we were getting too old, and that financially, it would be easier with just the three of us. But we kept coming back to the fact that we just wanted another little person to love.'

### Another baby?

Every child is unique and special, and your love and memories will always remain—another child will not diminish these. Many parents are frightened about having another baby after one of their children has died. These doubts and uncertainties are not unusual. It is also normal to have a strong desire to have another child.

#### *Having another child*

It can take courage to contemplate having another baby after a child has died. You may have some uncertainties:

- Will this baby be all right?
- Can I handle something going wrong?
- How will I sleep at night?
- Will I be able to love another child?
- Is it worth the risk?

If you decide to have another child, there are some special issues to keep in mind.



See Journeys  
Resource List

Deciding on  
another child



'After lots of genetic and reproductive counselling, Leon and I decided to have another baby. Getting pregnant was the easy bit—the genetic testing was horrible, but something we felt we had to do. I did not want to see another child suffer like Brianna did. Now we have Lucy (6 months old) and every day I see her big sister in her and the best word for it has to be bittersweet. Wonderful and painful rolled together. Lucy will one day know about her big sister Brianna and we will always consider her as a big part of our lives.'

### Special issues for parents

It may take time to agree on whether to have another child.

It will be important to discuss your feelings openly and honestly.

After the death of a child, fathers may feel a sense of guilt or failure in their role of 'family protector', and regret wasted opportunities such as returning to work.

Fathers tend to receive less emotional support from their peers and may face a longer struggle in coping with their grief before being able to consider another child.

Mothers may have a very powerful urge to have another baby.

### Special issues for siblings

It is natural for siblings to have thoughts and fears about another pregnancy and they may ask direct questions about whether this next child will die too.

Respect and acknowledge their feelings openly and honestly.

Include your children in the birth and care of the new baby so they don't feel excluded.

Help your new child feel a bond with their brother or sister who died. Photos, belongings, and DVDs provide opportunities to talk about their sibling and help them feel a connection.

For a whole range of reasons it may be that this isn't the right time for you to have another baby: you may feel your life is too unsettled or you may have too many other demands.

### Genetic counselling

Genetic counselling is a service, available at many large hospitals, which can help bereaved parents in the following circumstances:

- they have had one child with a genetic disease and are worried that any future children may have the same disease
- they have had two or more miscarriages, a stillbirth or an early infant death
- they are in their mid thirties or older and want to have another child.

By asking questions about family history, a genetics service can estimate the risk of developing an inherited disorder, or of passing one on. In some cases there are tests to find out if you are carrying a genetic disorder. More information about genetic counselling and other services available can be found in the resource list.

## The road ahead

The loss of a child is like no other. Your journey from here will continue as you find a pathway through your grief. Through grieving we learn how to experience loss while investing in life. How well we manage this affects our quality of life, and how we relate emotionally to others throughout our lives.

Many bereaved parents shared their treasured memories and stories from their personal journeys to help put this book together. You are your best guide on information you find helpful. Listen to yourself. Learn what works for you.

*'I am fearful wounded, yet not mortal slain. I will allow myself to rest awhile, and rise to fight again.'* Anon



See Journeys  
Resource List

Deciding on  
another child

*'We read as many books on grieving as we could. It helped us realise early on that we were faced with a choice: Do we say 'yes' to life and live as best we could, or do we let our grief and loss define us as a family and forever remain broken people?*

*It didn't take us long to know what we wanted. We wanted to come out of this whole; we wanted to give our young son the best life we could, we wanted to honour our daughter's life and memory, and be the best family we could be.*

*Our motto became 'take one day at a time'. It was an old cliché, but boy, it really helped us get through a lot of dark days. Three years on, we feel we continue to heal and that our love for her keeps us on track.'*



## TOOL 6 – SELECTING A FUNERAL DIRECTOR

A funeral director is there to help carry out your wishes. The list of questions below may help you decide what to ask when choosing a funeral director. You might ask a trusted family member or friend to help with this.

- If I want to see my child (viewings), can we have as many viewings as our family needs? Do we need to make appointments?
- Can we have our child's body at home?
- If I want to, can I be involved in washing, dressing and caring for my child's body prior to their body being placed in the coffin?
- What kinds of expenses are involved? Funeral costs vary considerably. It is important to know what services you will receive and how much each part will cost. You might want to contact a number of funeral directors to obtain written itemised quotes. Ask if they have a payment plan.
- What is embalming? Is it necessary? What's involved? Why would I need to think about that?
- Do you routinely use makeup? Some parents have been unhappy that makeup has been used on their child without their permission.
- What styles of coffins are available? Can I choose a special colour or decorate the coffin?
- What about flowers, balloons, or doves? Are we able to organise these if we want?
- I have some cultural and religious beliefs I would like taken into consideration—is the funeral director able to respect my needs?
- What's involved with either burial or cremation?
- How soon can I have my child's ashes at home with me?
- Should we involve our other children? How might we involve them?

## TOOL 7 – SOME COMMON SYMPTOMS OF GRIEF

Grief comes with a mix of feelings, sensations, thoughts and behaviours. As you read through this list keep in mind:

- you may experience all of these symptoms or only a few
- they can occur in any order on any day
- how long each symptom lasts can vary
- if these symptoms are too intense, extreme or last for lengthy periods, seek professional help
- there is no time limit to how long your grief will last—most bereaved parents say that it doesn't ever fully go away, but you learn to deal with it better.

Tool for family  
members

### Feelings — *the experience of loss*

Sadness—a deep emotional response

Shock—a sense of disbelief

Loneliness—emptiness and isolation

Denial—difficulty accepting the loss

Anxiety—frustration, blaming, agitation

Numbness—initially the body goes on autopilot

Guilt—a sense of not doing enough

Acceptance—the path of healing and new meaning

### Sensations — *the physical response*

Pain—chest, stomach, headache

Dizziness—at any time

Tiredness—a deep sense of fatigue

Sensitivity—to noise and light

Muscle weakness or shakes

Changed digestion

Difficulty swallowing

Dry mouth



## Thoughts — *the mental impact*

Confusion—muddled and disordered

Poor concentration—distraction, absent mindedness

Obsession—preoccupation with what happened

## Behaviours — *the grief expression*

Eating—more or less appetite

Overactivity—restlessness, needing to be busy

Withdrawal—inability to socialize

Dreaming—about who died and what happened

Difficulty sleeping—also wishing to sleep more

Seeking—the reason for illness and death

Remember grief is a natural response to loss but the impact of the loss of a child can mean the experience of mourning will be very intense and overwhelming. Be gentle with yourself and let someone else know when you are feeling like you are unable to cope. It is normal to need extra supports at times. These times are not always at the beginning of your loss and can be some months or years later.

## TOOL 8 – TIPS TO HELP YOU THROUGH YOUR GRIEF

- Take one day at a time.
- Be aware that everyone involved will react differently.
- Surround yourself with family and friends and those who will support you.
- Share your feelings with others. Find a trusted person to talk to about your child or grandchild.
- Try to be active and exercise.
- Avoid medications such as sedatives—they can be useful for providing needed relief for short periods but should not be taken to avoid your grief entirely.
- Try to resist being rushed into big decisions, such as moving or changing jobs.
- Try to avoid activities you don't feel ready for if well meaning friends try to help you 'feel better'.
- Set goals for yourself, consider volunteer work for a charity or develop new interests.
- Maintain hope. You may find hope and comfort from those who have experienced a similar loss. Knowing some things that helped them, and realising that they have recovered and time does help may give you hope that sometime in the future your grief will be less raw and painful.
- Don't underestimate the healing effects of small pleasures as you are ready. Sunsets, a walk in the bush, a favourite food—all are small steps toward regaining your pleasure in life itself.
- Permission to backslide. Sometimes, after a period of feeling good, we find ourselves back in the old feelings of extreme sadness, despair or anger. This is often the nature of grief, up and down, and it may happen over and over for a time. It happens because, as humans, we cannot take in all of the pain and the meaning of death at once. So we let it in a little at a time.
- There is no time limit on grieving.
- Seek professional support if your grief becomes too intense.

Tool for parents  
and grandparents



Tool for family  
and friends

## TOOL 9 – HOW TO SUPPORT SOMEONE WHO IS GRIEVING THE LOSS OF THEIR CHILD

A family member, friend, or colleague has lost a child and you don't know what to say or do to help them. It's a hard time for everyone and you find yourself scared of saying or doing the wrong thing. No one can take away the pain and sadness of grief, but knowing that people care is comforting and healing for grieving people.

### *Suggestions for things that might help*

- Allow them to talk and express their loss as much as they are able—but realise that sometimes they don't want to talk.
- Tell the family how sorry you are about the child's death and about the pain they must be feeling.
- Be available to listen, to run errands, to help with the other children, or whatever else seems needed at the time.
- Encourage them to be patient with themselves and not to expect too much of themselves.
- Give special attention at the funeral and in the months to come to the child's brothers and sisters, grandparents, and family (they are often in need of attention which parents may not be able to give).
- Let your genuine concern and caring show. Tell them how much you care—'I can't begin to imagine how you feel'.
- Recognise that grieving has no time limit and varies from individual to individual. Continue to support them beyond the first few months.
- Talk about your memories of the deceased child and the special qualities that made the child endearing, and remember to say the child's name.
- Acknowledge the death through visits, phone calls, sympathy cards, donations, and flowers.
- Remember important days which may be difficult for the bereaved, such as birthdays, the death anniversary, mother's day, father's day, and other significant days.
- Create opportunities for partners to have time together and time out.
- Keep calling, always leave a message and ring back. Appreciate that your bereaved relative or friend doesn't always return phone calls right away.
- Expect your relationship with the bereaved to change and grow.

### *Some things that may not be helpful*

- Changing the subject when the family mention their child.
- Avoiding them because you are uncomfortable—being avoided by friends adds pain to an already painful experience.
- Making any comments which in any way suggest that their loss was their fault.
- Pointing out that at least they have their other children—children are not interchangeable; they cannot replace each other.
- Saying ‘You should be coping or feeling better by now’ or anything else which may seem judgmental about their progress in grieving.
- Saying that you know how they feel.
- Telling them not to cry. It hurts us to see them cry and makes us sad. But, by telling them not to cry, we are trying to take their grief away.
- Thinking that good news—family wedding, pregnancy, job promotion—cancels out grief.
- Having expectations for what bereaved parents should or should not be doing at different times in their grief.
- Waiting until you know the perfect thing to say. Just say whatever is in your heart or say nothing at all. Sometimes just being there is comfort enough.
- Finding yourself saying any of the following:
  - It was God’s will—it was meant to be. Now you will have an angel in heaven.
  - He’s in a better place now.
  - Time heals all wounds.
  - You are still young enough to have more children. At least you have other children.
  - It was for the best. It could have been worse...
  - It’s been \_\_\_\_\_ (amount of time) and you have to get on with your life.
  - Everything happens for a reason.



## TOOL 10 – TEN HEALING RIGHTS FOR GRIEVING CHILDREN

Tool for siblings,  
parents and teachers

Your brother or sister has died. You are probably having many hurtful and scary thoughts and feelings right now. Together, those thoughts and feelings are called grief, which is a normal (though really difficult) thing everyone goes through after someone they love has died.

The following ten rights will help you understand your grief and eventually feel better about life again. Use the ideas that make sense to you. You can put this list on your bedroom door or wall. Re-reading it often will help you stay on track as you start to heal and feel better. You might also ask the grown-ups in your life to read this list so they will remember to help you in the best way they can.

1. I have the right to have my own unique feelings about my brother or sister's death. I may feel mad, sad or lonely. I may feel scared or relieved. I may feel numb or sometimes not anything at all. No-one will feel exactly like I do.
2. I have the right to talk about my grief whenever I feel like talking. When I need to talk, I will find someone who will listen to me and love me. When I don't want to talk about it, that's okay too.
3. I have the right to show my feelings of grief in my own way. When they are hurting, some kids like to play so they'll feel better for awhile. I can play or laugh, too. I might also get mad and scream. This does not mean I'm bad, it just means I have scary feelings that I need help with.
4. I have the right to need other people to help me with my grief, especially grown-ups who care about me. Mostly I need them to pay attention to what I'm feeling and saying, and to love me no matter what.
5. I have the right to get upset about normal, everyday problems. I might feel grumpy and have trouble getting along with others sometimes.
6. I have the right to have 'grief-bursts'. Grief-bursts are sudden, unexpected feelings of sadness that just hit me sometimes even long after the death. These feelings can be very strong and even scary. When this happens, I might feel afraid to be alone.
7. I have the right to use my beliefs about my god to help me deal with my feelings of grief. Praying might make me feel better and somehow closer to my brother or sister who died.
8. I have the right to try to figure out why my brother or sister died. But it's okay if I don't find an answer. 'Why?' Questions about life and death are the hardest questions in the world.
9. I have the right to think and talk about my memories of my brother or sister. Sometimes those memories will be happy and sometimes they might be sad. Either way, these memories help me keep alive my love for them.
10. I have the right to move forward and feel my grief and, over time, to heal. I'll go on to live a happy life, but the life and death of my brother or sister will always be a part of me. I'll always miss them.

Adapted from: Wolfelt, A.D. 2006, *My grief rights: Ten healing rights for grieving children*, Centre for Loss and Life Transition.

## TOOL 11 – NOTES FOR GRIEVING CHILDREN AND TEENAGERS

### *It's okay to:*

- cry and feel low and depressed—you've lost a great deal
- feel angry, embarrassed and not want to talk about your feelings
- copy some of the activities and interests your brother or sister had before they died, but you need to retain your own life too
- 'live in the past' for a while—it can help you to keep alive the memory of your brother or sister, but try not to let life pass you by
- have fun and enjoy life, to laugh again and forget for a while, forgive yourself for the fights and arguments and nasty things you might have said to your brother or sister who died
- go on living.

### *It's not okay to:*

- use drugs or excessive alcohol to dull your senses—this can only act as an escape and hide the pain, it doesn't help to heal it and it will then take longer to accept the hurt
- act out your frustration with reckless driving or skipping school
- do things with your anger that can hurt other people because you are hurting yourself
- experiment casually with sex, just to get close to someone
- hide your feelings and avoid talking about what is bothering you to protect your parents or siblings
- act as the scapegoat or bad guy to appear tough.

### *Signs you might need to seek extra help:*

- prolonged deterioration in relationships with family and friends
- risk taking behaviour such as drug and alcohol abuse, fighting and sexual experimentation
- lack of interest in school and poor academic performance
- signs of chronic depression, sleeping difficulties and low self esteem
- dropping the activities that once meant so much to you.



## TOOL 12 – DEALING WITH GRIEVING STUDENTS IN YOUR CLASS

### Tool for teachers

You have been given this sheet because a child in your class is grieving the loss of their brother or sister.

### *Steps for supporting grieving students*

The following steps help support the grieving student as well as prepare your class for making the grieving student feel comfortable and supported.

1. Talk with the bereaved student before they return.

Ask them what they want the class to know about their sibling, the death, funeral arrangements, or other matters. If possible, call the family prior to the student's return to school so you can let the student know you are thinking of them and want to help make their return to school as supportive as possible.

2. Talk to your class about how grief affects people and encourage them to share how they feel.

One way to do this is to discuss what other types of losses or deaths the students in your class have experienced, and what helped them cope.

3. Discuss how difficult it may be for their classmate to return to school, and how they may be of help.

You can ask your class for ideas about how they would like others to treat them if they were returning to school after a death, pointing out differences in preferences. Some students might like to be left alone; others want the circumstances discussed freely. Most grieving students say that they want everyone to treat them the same way they treated them before. In general, they don't like people being 'extra nice'. While students usually say they don't want to be in the spotlight, they also don't want people acting like nothing happened.

4. Provide a way for your class to reach out to the grieving classmate and his or her family.

One of the ways students can reach out is by sending cards or pictures to the child and family, letting them know the class is thinking of them. If students in your class knew the child who died, they could share memories of that child.

5. Provide flexibility and support to your grieving student upon his or her return to class.

Recognize that your student will have difficulty concentrating and focusing on school work. Allow the bereaved student to leave the class when she needs some quiet or alone time. Make sure that the student has a person available to talk with, such as a school counsellor.

**Do:**

- listen—grieving students need a safe, trusted adult who will listen to them.
- follow routines—routines provide a sense of safety which is very comforting to the grieving student.
- set limits—just because students are grieving, doesn't mean the rules don't apply. When grieving, students may experience lapses in concentration or exhibit risk taking behaviour. Setting clear limits provides a more secure and safer environment for everyone under these circumstances.

**Don't:**

- suggest the student has grieved long enough.
- indicate the student should get over it and move on.
- act as if nothing has happened.
- say things like:
  - It could be worse. You still have one brother.
  - I know how you feel.
  - You'll be stronger because of this.
- expect the student to complete all assignments on a timely basis.

As a teacher, you have the opportunity to touch children's lives in a very special way. Your actions have a lifelong impact. When a death influences the lives of your students, you and your school can make a life-long difference by creating an environment for healing and support.



## TOOL 13 – HELP FOR SPECIAL EVENTS

Holidays can be hard times for grieving families. They are filled with family get-togethers and festive events which can be sad reminders of your child's loss and absence. Surrounded by holiday cheer, the pain of loss can seem overwhelming. Sometimes, a simple 'Happy New Year!' or 'Merry Christmas!' from a well-meaning friend can send you into a tailspin. It's hard to put on a happy face when you're grieving inside.

Whether your grief is new or old, there are ways you can make the holidays more bearable and less tiring for you and your children. You may also discover ways to honour the memory of your child and to begin new meaningful traditions in the family.

Here are some suggestions. Take what is helpful for you.

### Some suggestions

#### Accept your limitations

Grief can be all-consuming, no matter what time of year it is. Special events place additional stresses and demands on our lives. You may not be able to do all the things you've always done. Lower your expectations and allow yourself time and space to grieve.

#### Plan ahead

Decide ahead of time what you can and cannot do and let your friends and family know. You may want to make a list of all the things you usually do—greeting cards, baking, shopping, decorations, parties, dinners—and decide what you most want to do. Talk with your children about plans and allow them to be involved in deciding how the family spends the holiday. They will appreciate being included.

#### Ask for help if you need it

You may want to continue certain traditions around the holidays, but feel you can't do it alone. Involve others. People enjoy supporting others in concrete ways, such as cleaning, cooking and baking.

#### Allow for rest

These times can be physically and emotionally draining for us all. Grieving is tiring too. Naps, walks, quiet times and other forms of relaxation—even for a short stretch of time—can be revitalising. Encourage children to have times of rest and quiet play as well.

### Some suggestions

#### Eliminate unnecessary stress

Of course we can't entirely remove stress from the holidays. But we can set limits! For example, we all know how exhausting shopping can be, especially as we get closer to the events. If you plan to buy gifts, consider shopping early or buying from catalogues or over the internet.

#### Acknowledge your child's life

There are many creative ways to honour your child's memory during special events. You may wish to do so by carrying on your family traditions or by creating new ones. Here are some ideas.

- Buy or make a memorial candle to light during the evening throughout the season.
- Observe a moment of silence or prayer before a meal (or at another appropriate time) in honour of your child.
- Make a special toast or share memories of your child.
- Buy a gift in honour of your child.
- Make a donation to a charity in the name of your child, or help a family in need by making a meal for them or sending presents to their children.

---

Remember: there is no right or wrong way to handle a holiday. Some may wish to keep family traditions while others choose to change them. Everyone grieves differently. Honour your child, yourself and your grieving and have a peaceful holiday.







## THANK YOU...

Thank you,  
for changing our lives  
and becoming a special part of our family.  
For being our son,  
big brother and little mother hen.

Thank you,  
for the silliness, smirks and big cheesy grins,  
your mischievous sense of humour,  
your endless chatter  
and funny little sayings.

Thank you,  
for the way you  
hopped, jumped, skipped and danced.  
For running tiptoed through the house,  
for surrounding us  
with your boundless energy.

Thank you,  
for the muddy clothes  
and muddy feet, hands and face.  
The sticky fingers.  
The holes in the garden  
and clutter through the house.

Thank you,  
for the missing tools,  
disappearing pegs  
and tangled sticky tape.  
For showing me  
the snails and worms,  
chimneys and smoke,  
diggers and cement mixers.

Thank you,  
for the handpicked flowers  
and precious little stones.  
For sharing your lollies  
and half-eaten chocolates.

Thank you,  
for the kisses and cuddles;  
our special times together.  
For your unconditional love  
on offer to everyone.

Thank you,  
for being a devoted big brother,  
for caring and sharing  
and showing the way.

Thank you,  
for your stubbornness,  
changing moods and determination,  
and for using these traits  
in fighting your battle.

Thank you,  
for the privilege  
to share in your courage.  
To be the one  
to hold your hand or cuddle you  
in times of distress.  
For your trust and patience  
in us and your caregivers.

Thank you,  
for teaching us how to live,  
how to fight,  
how to die.  
For the reassurance  
that you are still around us.

Thank you for showing us  
the power of love.  
An indestructible force.  
An unbreakable bond so special,  
it will carry us through our lifetime  
and beyond.  
We thank you for just being you.  
Randall Northey

## ACKNOWLEDGEMENTS

This project brought together many extraordinary parents, health professionals, family members and carers who shared a common wish—to help other people by sharing details of their own personal journeys. Their advice and contributions have driven the information in this book.

Most of all, we acknowledge the children and teenagers whose living we learn from and whose lives we honour in this work.

2nd edition

*Content editors*

Sara Fleming – Children’s, Youth, Women’s Health Service, SA

Sandra Coombs – Sydney Children’s Hospital, NSW

Marianne Phillips – Princess Margaret Hospital for Children, WA

1st edition

*Carers reference group members*

Denise Chang, in honour of her daughter (Kessia, 7)

Alison Donhardt, in honour of her daughter (Gabrielle, 2)

Fiona and Royce Jenkins, and Jared, Blake and Tait, in honour of their daughter and sister (Bridgitte, 4)

Patricia Kasengele, in honour of her son (Bwembya, 16)

Malinda Martin, in honour of her son (Joshua, 5)

Michelle and Shane Northey in honour of their son (Randall, 5)

Nicci Parkin, in honour of her son (Lewis, 16)

Susan Walter, in honour of her son (Steven, 19)

Amanda and Leon Wardle, in honour of their daughter (Brianna, 2)

*Clinical reference group members*

Sara Fleming – Women’s and Children’s Hospital, SA

Dominique Baldock – Bear Cottage, NSW

Alison Donhardt – Carers’ representative

Donna Drew – Sydney Children’s Hospital, NSW

Judy Frost – The Children’s Hospital, Westmead, NSW

Robyn Hayles – Royal Children’s Hospital, VIC

Fran McArdle – Carers Australia

Andrea Murphy – Very Special Kids, VIC

Carol Quayle – Royal Children’s Hospital, VIC

Nigel Stewart – Port Augusta Hospital, SA

Susan Trethewie – Sydney Children’s Hospital, NSW

*Australian Government Department of Health and Ageing*

Rita Evans, Katy Robinson, Glenda Wadsley

*Palliative Care Australia*

Donna Daniell, Denise Chang, Bernadette Allen, Sara Jones

*Authors 1st edition:* Denise Chang, Sara Fleming