



After the Loss of a Child

A resource for parents of children in palliative care

Contents

Introduction 3

Before the Death..... 3

Talking to Your Child..... 3

Talking to Your Child's Siblings ... 4

Talking to Friends and Family 5

Anxiety and Worry 6

After the Death..... 7

What Happens When
My Child Has Died? 7

The Funeral 8

Financial Issues 9

Practical Considerations 10

Grief..... 11

About Grief..... 11

Everybody Grieves Differently... 12

Grief and Identity..... 12

Grief and the Body..... 12

Grief and Sleep 14

Grief and Guilt..... 15

Grief and Relationships 16

Different Ways of Grieving..... 16

Grief and Intimacy 17

Communication..... 17

New Relationships 17

Parenting After the Loss of a Child 18

Grief and Children 18

Grief and Adolescents 20

When to Seek Help 21

Grief Over Time 22

Grief Doesn't Have a Timeline ... 22

Looking Toward the Future..... 22

Other Losses 23

Managing Anniversaries,
Milestones and Significant
Occasions 23

Remembering..... 24

Self-Care 25

Seeking Help 26

It's Never Too Late to Seek Help... 26

Where Can I Find Help? 26

Useful Online Resources 27

Useful Books..... 28

Useful Bereavement
Organisations (Victoria)..... 29

Introduction

No parent expects to outlive their child. It is the news that every parent dreads – news that feels horrible, unnatural, unfair and unbearable. Having to contemplate caring for your sick child, yourself and your family, and to face a future without your child in it, can feel terrifying and completely overwhelming.

We understand that during these times, there can be a lot of information to take in. This resource has been developed in order to help parents through this difficult time. It is designed for parents of children in palliative care, but is also a useful resource for any parent who experiences the loss of a child. *After the Loss of a Child* looks at common issues and processes occurring both before and after the death, and provides information and helpful tips for navigating your own and your family's grief experience both immediately and in the long term. It also includes a list of helpful organisations, websites and information resources that you may like to access if you need further information or help.

This resource is divided into sections, so that it can be referenced as needed, rather than read all at once. It has been written as support guide, but please be aware that it in no way replaces seeking advice from professionals along your grief journey. You will need support from many sources along the way. Don't be hesitant to seek it.

The Australian Centre for Grief and Bereavement would like to thank everyone who has been involved in putting this resource together. In particular, Alison Boughey; the Paediatric Palliative Care Project Steering Committee; the clinicians and bereaved individuals who reviewed the resource and provided their feedback; and the Victorian Department of Health who provided funding and support for this important project.





Before the Death

Talking to Your Child

Among the most challenging situations a parent can face is when their child asks a direct question about their illness, including questions such as ‘will I die?’ Parents often immediately feel a need to protect their child from difficult information and may try to deflect this question. Some children may not want to talk about the seriousness of their illness, but there are others who do, and if they feel unable to ask questions or talk to those they trust most, they can feel isolated and worried. What to tell a sick child about their illness depends on so many factors and there can be no ‘one size fits all’ approach. There are some things however, that parents may like to consider when responding, in addition to their intimate knowledge of their child’s personality and coping style.

Children are intuitive

Children are acutely aware of the emotions of others – they know when those around them are sad or frightened. They also gather information from a range of sources (e.g. snippets of overheard conversations, other children with the same illness, changes in their body). Indeed, they generally know a lot more than we think and if we deflect their questions, they learn that it is not okay to talk about such things, and this can leave them alone with ideas that are wrong or damaging. Younger children for example, often think that their illness is a punishment for bad behaviour.

Children see things differently

Keep in mind is that young children in particular, do not think about dying in the same way an adult does. Their worries may be quite different to what one might expect. Common concerns include being worried that they will be alone, that they have done something wrong, that no one will feed the dog, that their parents might break up, or that they will be in pain. These are all things that parents can reassure their children about.



Creating a safe space

It may be helpful not to think of this as a question of whether or not to 'tell'. It may be better to focus on creating a space where your child knows they can ask a question and receive an honest answer, rather than telling them information they don't want or need. Many parents will need help and support in having these sorts of conversations. This might come from someone in the family or friendship group who has a special relationship with the child, or it may be from a trusted health professional. These individuals may be able to guide you through the process, sit with you as you talk with your child or have the conversation themselves.

Encourage your child to ask questions and try to respond clearly, honestly and as age appropriately as you can. Be aware that you may need to revisit this conversation a number of times, responding to the same questions, as children often take time to process and understand the information. For this reason, it is important to remain clear and consistent in your responses so as to avoid confusion.

Your child will likely be very scared – scared of dying, scared of being separated or abandoned from you, scared of being in pain, or scared of being alone in hospital. Try to reassure them regularly that you will keep them safe, and perhaps look at coming up with a plan for sharing the support, both between parents, and with other family members if needed, so that your child isn't alone too often. Reassure and continually remind your child that if they are in pain, they need to let someone know, so that the doctors and nurses can help alleviate it.

What happens after death?

Your child may have questions about what happens after death. The answer to this question will depend on your own faiths and beliefs, as well as what your child may already believe in. Once again, they may have already formed their own opinion and it may differ to your own beliefs as a parent. How you respond is entirely up to you, however be aware that trying to convince them of your beliefs when they have their own, may do more harm than good. If your child has not formed their own opinion and you are unsure around what to say, or if you and your partner have differing beliefs, you might like to talk with your child about a range of different beliefs that people have and let them make up their own mind.

Seek extra support

Talking to your child about death can be difficult and confronting. It can also bring your own issues around death and dying to the surface. It can be really helpful to have a chat to your doctor, nurse, palliative care support staff or a social worker about having these conversations with your child. It may also help for you to have them present to help with the conversation if needed, especially if your child has questions around what will physically happen to them when they die. When making decisions around end of life care (e.g. hospital, hospice, home) if possible, involve your child in this conversation, as they may have a preference.



Talking to Your Child's Siblings

Although it is natural to want to protect children from hurt or upset, it is important that you take the time to talk and listen to your child's siblings, both before and after the death.

Preparing your children

When your child has a life-limiting illness, it is important that you have preliminary conversations with their siblings about what might happen. Start by asking them if they know what is going on and if they have any questions. Try to answer their questions honestly and don't be afraid to acknowledge when you don't know the answer. If they ask you if their sibling is going to die and you say no, then afterwards they may be resentful and even more confused. They may have a lot of questions or be frightened that they might die as well. Answer all their questions as honestly and as age appropriately as possible, reassuring them that there is nothing they have done to cause the illness, that both you and they are well, and that they are not going to die too. Be prepared to revisit the conversation numerous times if needed.

Clear and honest explanations

After the death, you will need to explain what has happened to them as soon as possible. It is important that you tell them the facts in a simple and age-appropriate way, e.g. 'Your brother/sister has died and will not return'. Young children often take things literally and saying things like 'Your brother/sister has gone to sleep', or 'Your brother/sister went to hospital and isn't coming home', can be confusing and lead to unnecessary fears, e.g. they may become afraid of going to sleep or visiting hospital.

It is also important to explain why their brother or sister has died, e.g. 'Your brother/sister died because his/her body stopped working, this means they can no longer breathe, eat or feel hot or cold'. This will reassure children that the death wasn't a result of anything they said or did.

Be prepared to answer their questions

Children often ask a lot of questions in order to process information. They may even keep asking the same, or similar questions, because they do not yet understand. Whilst it can be hard, try to be patient, and do your best to answer their questions about death in an honest and consistent way, without glossing over the truth or minimising the impact of what has happened by saying that 'everything is fine'.



Talking to Friends and Family

Family and friends can be a much needed support network, so it is wise to let them know what is happening and give them a chance to say goodbye to your child if they wish to. Depending on how big your network is, it may help to enlist the help of a friend or family member to act as a communications point in order to reduce the burden on you.

Talking about death and grief can be hard

Talking about death is never easy and often people feel uncomfortable and don't know what to say. As a result, it is common for friends and family members to say things that may unintentionally cause hurt or offence. It is normal that you would be feeling very sensitive at this time and it's okay to let people know if they have upset you. Be honest with them – let them know that it's nothing personal, but you are very sensitive at the moment and that the things they are saying are not providing comfort. Let them know that nothing they say will make you feel any better or 'fix' the situation and that this is okay.

Let them know if you need their help

If you need your family and friends to support you in a certain way, whether it be in a practical sense (e.g. helping with childcare), in a physical sense (e.g. hugs) or in an emotional sense (e.g. someone to listen) then let them know. More often than not they will be relieved to be able to help in a way that is useful to you.

Anticipatory grief

When your child has a life limiting illness, it is common to experience grief both before and after the death. When we find out that a loved one is dying, we often begin grieving for them, even though they are still with us. We grieve the impending loss, not just of them physically, but also the loss of their presence within our lives — loss of their dreams, their future. This is sometimes called 'Anticipatory Grief' and is very normal. You may find it helpful to talk to someone at this time, whether it is a family member, a friend, a social worker or counsellor. Some parents (not all) may also find some comfort in beginning funeral preparations prior to the death.



Anxiety and Worry

Anxiety and worry may occur when caring for a child with a life limiting illness. You may become worried about whether they are comfortable or in pain, whether they are scared or anxious, or whether they might die when you're not there. You may feel anxiety around changes in their appearance, changing roles in the family, or about financial pressures. These feelings are to be expected, and are all very normal concerns, but they can nonetheless be debilitating and leave you feeling helpless, exhausted, angry and frustrated.

Common symptoms of anxiety

Symptoms of anxiety may include:

- feelings of distress, panic, apprehension, dread and uneasiness
- tightening of the chest, or chest pain
- racing heartbeat
- hot and cold flushes
- constant and repetitive worrying
- obsessive thinking, e.g. having the same thoughts over and over again
- compulsive behavior
- changes in eating habits
- shifts in breathing.

What can help?

You may find the following helpful:

- Talking to a friend or family member about what you are thinking or feeling.
- Writing things down or journaling.
- Relaxation activities e.g. sleeping, listening to music, massage, meditation.
- Breathing exercises – e.g. try deep, slow and focused breathing, especially into the lower abdomen, as this can refocus the energy of the anxiety and ground you back into your body.
- Maintaining a healthy lifestyle where possible.
- Reducing the amount and frequency of stimulants such as caffeine, alcohol and tobacco.
- Seeking help from a support worker, GP, counsellor and/or mental health practitioner.
- Finding out more about your child's illness and what to expect.
- Increasing your understanding of anxiety and acknowledging that it's a very normal response. This can help increase your sense of control.

For further information on anxiety, visit www.beyondblue.org.au



After the Death

What Happens When My Child Has Died?

At a hospital/hospice

When a child dies in hospital or in a hospice, medical and support staff will be on hand to help guide you through the next steps. A member of the medical team will confirm the death and document this accordingly. Hospital staff should endeavour to provide you and your family with as much privacy as possible. Don't let anyone rush you in saying goodbye and performing any rituals and if you would like to be part of the preparation of the body (e.g. washing and dressing), don't be hesitant in asking staff to include you in this process. When you are ready, hospital staff will discuss your options around contacting a funeral director to collect your child's body and will have conversations around organ and tissue donation (if requested) and coronial examination/autopsy (if required).

At home

In many cases (where possible), parents wish for their dying child to be cared for at home, in a familiar environment. At home community palliative care support can be arranged through your local hospital or palliative care agency to help you do this and to make sure your child is comfortable and not in any pain. When your child has died, you will need to contact your local GP or a community palliative care nurse to arrange a home visit in order for them to confirm the death and document this accordingly. Palliative care support staff can help you with this if needed. You can then call the funeral director of your choice and arrange a time for your child's body to be collected. Be aware that you don't need to rush this – the funeral director can provide advice around timeframes and can be flexible around pick up times so as to accommodate goodbyes and so that you can perform any rituals.



Saying goodbye

Following the death of your child, it is important that you take your time in saying goodbye – don't let anybody rush you in this. Often parents find comfort in helping bathe the body one last time, performing religious or cultural rituals and verbally and physically saying goodbye. You may also wish to keep a lock of your child's hair, or dress them in a particular outfit. Remember this is a deeply personal moment and you need to do whatever is right for you.

The Funeral

Planning the funeral

Funerals are individual and personal. Some elements of the planning may be distressing or overwhelming, whereas others may provide comfort and recall memories. Whilst for some, it might seem easier to pass over the organisation to someone else, many parents find that organising the funeral gives them a sense of control in an otherwise chaotic and distressing situation. A funeral director can help you plan and organise the funeral you want for your child, or in cases of older children, the funeral that your child wanted. You may like to talk to a few funeral directors before you select the one that's right for you. Take your time in planning and if you need support during this time from family, friends or support staff, don't be afraid to ask for it. You may also find it helpful once you have decided what you want, to delegate certain aspects of preparations to family and friends, for example, writing the death notice, arranging the flowers, calling back people who ring, etc.

Should siblings/young children attend the funeral?

If they are old enough to have a conversation, give your children the choice as to whether or not they would like to participate in the funeral, viewing or any other mourning rituals and/or religious/cultural services. Make sure you explain to them exactly what is going to happen, so that if they do choose to participate, they are not frightened or confused by the experience, e.g. at the viewing, let them know that their sibling will not be moving, may look a bit different and feel cold to touch; and at the funeral people will be very sad and crying, because they loved their sibling very much and miss them. It may be useful to ask a trusted friend or relative to help support your child/children if they attend, in case you become too overwhelmed to do so, or if they change their mind on arrival about attending.

Financial Issues

Having a seriously ill child can be extremely draining financially and it is not uncommon for families to struggle financially when it comes time for the funeral. It can be difficult to ask for financial help, however you shouldn't be afraid to ask, as you may regret not doing so in the future.

Possible assistance options

- Family and friends are often desperate to help in some way following the death of a loved one. If you have a close support network, talk to them about your situation, as they may be able to help.
- Talking with a social worker. If your child has been in hospital at some point, you would likely have had contact with a social worker. Consider giving them a call, as they are well placed to be able to look into your options for you.
- Hospital and community services often have access to funeral funds.
- Organisations like Bereavement Assistance (www.bereavementassistance.org.au) may be helpful. Bereavement Assistance is a not-for-profit funeral director that provides low-cost funeral services for victims of fire and natural disasters, for those on social security, for people with no family or friends and those who are experiencing poverty and distress. They can be contacted on (03) 9564 7778.

You may also find yourself struggling with large accumulated debts (loans, bills, credit cards etc.) as a result of the costs associated with the provision of care and support for your child. When you are ready, it is a good idea to meet with a financial advisor, so as to discuss and plan for repayments and avoid increasing the debt further.





Practical Considerations

What to do with your child's belongings

You will find that many people have an opinion about what you should do with your child's belongings after they have died, i.e. when to pack up their room, clothes, toys, etc. This can be a very personal and difficult decision to make, so try not to let others dictate when or how you should do this. Take your time and hang onto things for as long as you need.

People's needs are individual and unique. For some bereaved people, belongings are a comfort, a symbol that links them to their loved one. For others, they can be a painful reminder of what they have lost. What you do with your child's belongings, and when, is completely up to you. Be aware though, that often people clear away or throw out possessions too soon after the death and come to regret it at a later time. If you are thinking of throwing things out or giving them away, perhaps consider boxing them up for now and reconsidering your feelings in 6–12 months.

Making major decisions

Try to defer making decisions around significant changes that cannot be reversed (e.g. large purchases, selling of assets, relationship changes, disposal of belongings etc.) for at least 6–12 months following the loss of your child. In the early weeks and months of grief, people often liken their experience to walking around in the fog. Grief can cloud and inhibit your ability to think rationally, so be careful not to commit to anything that you may not be able to follow through with, or that you may come to regret. If you feel however, that a significant decision needs to be made sooner rather than later, consider seeking assistance and/or guidance from family, friends or a professional before proceeding.



Grief

About Grief

Grief is our response to loss. It is the normal, natural and inevitable response to loss and it can affect every part of life, including our thoughts, behaviours, beliefs, feelings, sense of identity, physical health and our relationships with others. No parent expects to outlive their child, and as a result, the grief experienced can be very difficult.

With the support of family and friends, many people adapt to loss well and may not experience intense and persistent feelings; however, for some, the experience of grief can be overwhelming and further support may be helpful.

Common grief responses

Grief responses may include:

- sadness
- anger
- anxiety
- disbelief
- panic
- mood swings
- relief
- fear
- irritability
- numbness
- guilt
- emptiness.

It is a common myth that people ‘get over’ grief after a certain amount of time has passed. This simply isn’t true. The reality is that a part of you will always grieve the loss of your child. With time, the pain will lessen, but the sorrow you feel will always be a part of you. There is no ‘return to normal’ but, rather, we learn to live around a new kind of normal.



Everybody Grieves Differently

Grief is an individual experience

Everyone's grief journey is different. Your grief is unique to you and as long as you are not causing harm to yourself or those around you, there are no 'right' or 'wrong' ways to grieve. Grief is individual and personal, and it's important to respect each other's way of grieving, even if we don't necessarily understand it.

Grief can make people very sensitive and they may react or respond in unexpected ways. Grief can be likened to having an open wound and it can be easy for others to inadvertently 'touch a nerve' or say or do the wrong thing. There is no formula for what helps and what doesn't. What one person finds helpful, another person may not.

If you are concerned about your grief responses, or someone else's, the following questions may be helpful in better understanding the situation:

- What is the context of the behaviour?
- Is it safe?
- What is the meaning of the behaviour to you/the bereaved person?
- Does it provide comfort?

If you are still concerned, don't be afraid to seek further advice from a health professional.

Grief and Identity

Often parents describe feeling 'lost' after the death of a child and this feeling often relates to a loss of their sense of identity, their role and their purpose. How do you learn to accept the unacceptable reality of losing a child? Feelings around loss of identity can be particularly acute when parents lose an only child. It can also extend beyond parenting, to feeling unsettled in social circles, work, faith and in society as a whole. When a child has received ongoing healthcare, or has been in palliative care environment for a period of time, there is also a sense of loss for the hospital and community staff who have provided support (sometimes over many years) and loss for the way of life and routines associated with being a carer.

When people grieve they are coming to terms with what has changed in their lives and unfortunately, there is no 'return to normal'. Rather, over time, we learn a new kind of normal and create a new identity for ourselves – essentially, re-learning the world and re-learning ourselves within it.



Grief and the Body

We know that grief affects our emotions, but what many people aren't aware of is that grief can also have a big impact on our physical health and wellbeing. It is common and very normal to experience a variety of physical symptoms and ill health after the loss of a child. The body and mind are connected and when we grieve, it's not just our mind that grieves, but our entire self.

Common physical responses

Physical responses to grief may include:

- lack of strength/physical exhaustion
- sleeping difficulties
- crying
- feelings of heaviness and numbness
- dietary problems and stomach upsets
- weakened immune system/frequently getting sick, e.g. colds and flu
- aches and pains
- heart palpitations
- loss of appetite
- headaches
- high blood pressure
- shortness of breath
- disrupted menstruation
- restlessness and agitation
- weight loss or gain
- skin conditions
- flare-ups of existing conditions
- confusion or being unable to concentrate.

Your energy needs

When grieving, your body requires and uses greater amounts of energy. Things that were basic and everyday before, e.g. eating, sleeping and exercising, become increasingly important; but at the same time, feel much harder to achieve.

When grieving it may help to modify or adapt your usual patterns and routines in order to get the energy your body requires. For example, it might be easier for you to eat small meals at regular intervals, rather than have three large ones each day; you may need to take a short nap during the day; or you might find it more practical to go for a walk instead of going to the gym.



Grief and Sleep

It is normal and extremely common for sleeping patterns to be disturbed when grieving.

Insomnia

Insomnia (being unable to sleep) is a normal and common physical reaction in those who are grieving. Insomnia can affect your concentration, memory and mood, and can also increase your risk of accidents or injury.

Tips for managing insomnia

- The idea of a 'good night's sleep' will differ widely from person to person. Try to stop expecting a specific amount of sleep each night – it's okay to fall short of the ideal.
- Avoid stimulants such as tea, coffee, tobacco and caffeinated drinks before bed.
- If you can't sleep, get up and do something else until you feel sleepy again.
- Do something relaxing before bed, e.g. take a warm bath, listen to relaxing music.
- Minimise stress and anxiety where possible – writing things down, journaling or talking to someone can be helpful.
- When you are in bed, mindful breathing into your lower abdomen can be helpful, as it is a way of distracting the brain from racing thoughts and can help to relax your body, making it easier to fall asleep.
- Warm and soothing drinks such as herbal tea or warm milk before bed may be helpful.
- If considering natural and/or over-the-counter remedies, seek advice from a pharmacist or health professional before using.

Oversleeping

Some people respond to grief by oversleeping. They have trouble getting up in the morning and feel constantly tired.

Tips for managing oversleeping

- Try to maintain normal sleeping hours where possible.
- Set a time that you will go to bed and a time you will get up each day.
- In the mornings, try using events such as going to work, catching up with someone or going to an appointment to motivate you to get up at the appointed time.



Grief and Guilt

Guilt is a very common feeling following the loss of a child. Parents may feel guilty that they weren't able to prevent the death, or that they have survived when their child hasn't. Some parents feel guilty that they weren't able to give their child a full life, or that they didn't spend enough time with their child, and in some cases, parents may feel guilty if they weren't able to be there when their child died.

Guilt is a very normal grief reaction

It's important to understand that whilst difficult, guilt is a very normal grief reaction, one that will be experienced by most grieving people in some shape or form.

Guilt can manifest in many ways. It can bring sadness, regret, shame, doubt, heaviness and anxiety, as well as feelings of failure, inadequacy and unworthiness. It can also impact on our physical health.

Guilt isn't always logical, or satisfied with reasonable explanations. Often grieving people say they know their guilt isn't rational but this doesn't make the feelings go away.

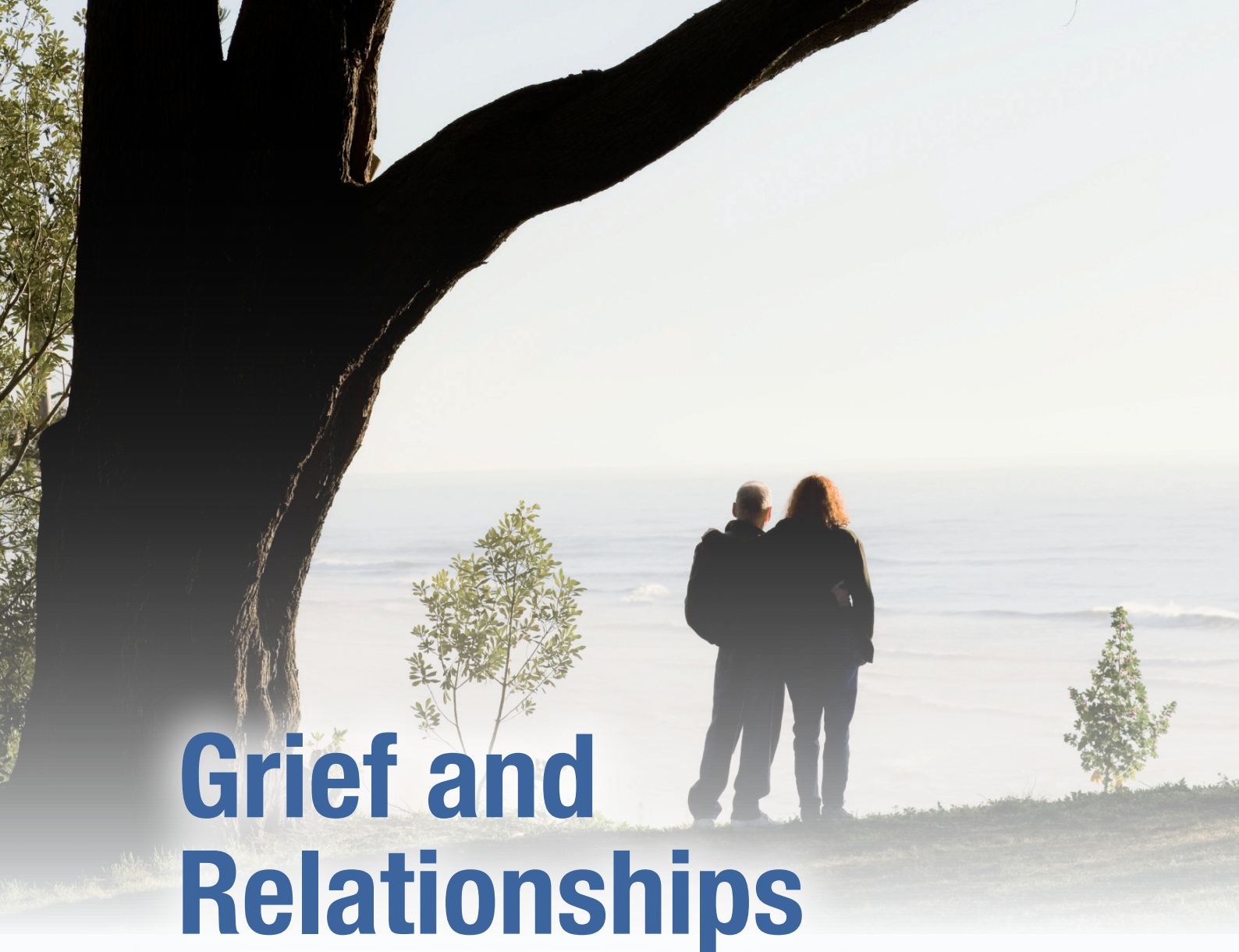
Managing feelings of guilt

Whilst guilt isn't something we can necessarily just 'get rid of', what we can do, is acknowledge that it's okay for it to be there. Normalising these feelings, and accepting that it's okay to have them, is perhaps the first step in starting to move towards a place where things can become bearable again.

With guilt there isn't a simple on/off switch, and like grief itself, there is no timeline for how long we will carry feelings of guilt. Below however, are some tips that may help you to manage and tolerate your guilt.

Tips for managing your guilt

- Recognise that you are human. Nobody is perfect. We all make mistakes and we all have regrets.
- Normalise your guilt: The more you make your feelings of guilt 'wrong' the longer they will stay. Try to work with your guilt, rather than against it.
- Consider: If your child were still here – what would they say to you about how you are feeling?
- What would you say to a friend who was feeling this way? Can you say that to yourself?
- Try to remember the good memories, as well as the hard ones.
- Ask your child for forgiveness, either out loud, in your mind or on paper. You won't receive an answer, but the process of asking can be healing.
- Talk to a close friend, family member or a counsellor about how you are feeling. Saying things out loud and talking them through can go a long way to helping you to process and work through your emotions.



Grief and Relationships

In many ways, the sustained love and support of family and friends can be very helpful following the loss of a loved one. Grief, however, can also cause great strain on relationships between partners, family and friends. If your grief is affecting your relationships, it's a good idea to talk to someone about it, whether it is with the person involved, a supportive friend/family member or a health professional.

Different Ways of Grieving

Grief is very individual. For example, some people are open and expressive with their grief, crying, and wanting to talk, whilst others are more private, may be reluctant to talk and prefer to keep busy. Indeed, there are a range of factors that can influence the way we grieve, such as culture, gender, age, relationship to the deceased and belief systems. It is quite common for two people in a relationship, or for members of the same family, to grieve very differently and this can sometimes cause resentment or misunderstandings.

Grief is personal, and as long as you are not causing harm to yourself or those around you, there are no 'right' or 'wrong' ways to grieve. It's important to try to respect each other's way of grieving, even if we don't necessarily relate to it or understand it. It is common for partners to grieve differently and this does not mean that your relationship will break down. If you are concerned with the way in which your partner or loved one is grieving, talk to them about it.



Grief and Intimacy

Grief can affect our desire for sex and intimacy. For some, grief can cause a decrease in desire for intimacy, whereas for others it can create an increased desire. Having sex and being intimate with a loved one ideally makes us feel good and the idea of this can sometimes leave us feeling guilty, e.g. how can I enjoy myself when my child has died? It is perfectly normal to feel this way. Try to keep in mind however, that happiness and sadness can co-exist and that alongside pleasure, intimacy can also provide comfort and connection.

Sometimes with partners, our sexual needs/wants do not align, which can cause frustration in a relationship. If your needs aren't aligning, then it may help to talk to your partner, a trusted friend or a GP/health professional.

Communication

The key to any healthy relationship, regardless of the nature of the relationship, is good communication. We communicate not just by talking and listening, but also through body language, touch, our actions and by being understanding. Try to keep in mind that not everyone is prepared to talk about their grief and that this is okay. If you are having problems communicating with someone close to you, or if you feel they are reluctant to communicate with you around how they are feeling, try to think of other ways that you can communicate with them, e.g. writing a letter, doing something thoughtful or helpful, or even simply giving them a hug.

New Relationships

Seeking out new relationships, e.g. new friends, a new partner, a new community or a new workplace, can occur after the death of a loved one. Significant life events can lead us to question what is missing in our lives and sometimes we may feel the people in our current relationships don't understand us or aren't able to give us what we need. Often people find it difficult to connect with others who may not have shared a similar experience and may find greater solace connecting with or attending a support group for others who have experienced a similar loss. This can be a useful way of increasing your network, but keep in mind that you don't have to choose between old and new. You can have the best of both — preserving and working on existing relationships whilst forming new ones.



Parenting After the Loss of a Child

Grief and Children

It is natural for parents to want to protect their children from hurt or upset. It can be very difficult to watch your children experience grief and to accept that you cannot simply ‘fix’ things for them. Like adults, children experience, express and process grief in a variety of ways depending on their age, stage of development, personality, family culture, understanding of death, past experiences of loss and the context of their bereavement. When considering how best to provide support, the child’s unique grieving needs should also be considered.

Common grief responses in children

Children, like adults, will vary in their responses to death and dying; however, there are some common factors that may affect them.

Common signs of grief in pre-school-aged children

Pre-school-aged children (i.e. ages five and under) may:

- be affected by emotions of those around them that they don’t understand
- grieve in doses, alternating between displaying grief and playing as if nothing has happened
- have a matter-of-fact curiosity about death, asking confronting questions
- become fussy, irritable, withdrawn, or show signs of insecurity
- have distressing dreams and nightmares
- experience restless sleep
- have difficulty concentrating or making choices
- feel guilty or responsible for their sibling’s death
- act or behave in ways that are younger than they are, e.g. bed wetting or clinging behaviour
- feel bewildered and physically search for their loved one who has died.

Common signs of grief in primary-school-aged children

Children of primary school age (i.e. ages 6–12) may:

- experience a difficult transition period, want to see death as reversible and believe death only happens to other people
- be very curious about death and burial rituals and ask detailed questions
- imagine death as a bogeyman or ghost
- play games pretending to die
- be angry over the death and focus their anger at certain people or at anyone involved with the death, e.g. doctors, parents
- take time to absorb the reality of what has happened and might not appear to be immediately affected by the death
- be quick to blame themselves
- feel guilty that they survived when their sibling did not
- experience disturbed sleep, decreased appetite, poor school performance or have physical reactions, e.g. headaches, stomach upsets
- worry about who will look after them if a parent or other caregiver dies
- take on a parenting role to younger siblings
- ‘act out’ feelings rather than talk about them
- be concerned about what their peers think and might be anxious about being seen as ‘different’
- feel isolated, because no-one else has had a similar experience

Helping children navigate their grief

Listen and talk with them

Children need time and to feel safe in order to express how they are feeling. Be prepared to revisit conversations a number of times, as children need time to process information. Be patient, open, honest and consistent with your responses. Reassure them that grief is normal, and that it’s okay to be upset about what has happened.

Include them

Include children in decision-making when appropriate; for example, give your child the choice as to whether or not they would like to participate in the funeral or any other mourning rituals. Rather than making suggestions, speak with them about their ideas of ways they would like to remember their sibling.

Provide safety and security

Death can threaten a child’s sense of safety and control. It is vital that the child’s physical and emotional needs are met to support them in adapting to the loss. Try to maintain routines and firm, but fair, boundaries as much as possible.

Provide opportunities for expression

Many children respond well to creative outlets, and there are a range of activities that you can do with children to encourage them to process and express their grief, including:

- drawing and painting
- reading and storytelling
- writing poetry or letters to the person who has died
- craft activities, e.g. making a memory box or collage
- music and dance.



Grief and Adolescents

It's difficult to bear witness to the pain of young people. As bystanders, we may want to take away or fix the pain of adolescents who are grieving and, as a result, we may try to avoid talking about the loss or the person who has died, modify information about their death, or try to accelerate the adolescent through their grief. While these responses may ease our discomfort, they can result in the adolescent concealing their grief, withdrawing from loved ones, or expressing their feelings in destructive ways.

Grief is not always visible

Grief comprises the many thoughts and feelings experienced following a loss. As adolescents are in the process of becoming more independent of their parents and other central figures in their lives, they can feel reluctant to outwardly express their grief, as it reinforces a sense of dependence and vulnerability. Even so, all adolescents grieve when someone they love dies.

Common grief responses in adolescents

Like adults, every teenager is different, however there are some common factors that may affect them.

Adolescents may:

- grieve in doses, breaking up their grief into bearable amounts, however this can often manifest in intense outbursts
- experience a multitude of emotions that can come and go in waves
- feel guilty that were unable to save their sibling or guilty that they survived when their sibling did not
- seem out of character and unpredictable
- not want to talk about their grief
- have problems sleeping, or oversleeping
- feel alienated from their peers.

Be aware of danger signs such as chronic depression, violence, drug and alcohol abuse or dramatic changes in personality, and seek professional support if necessary.



Helping adolescents navigate their grief

Be available

It is when we are truly listened to that we feel most understood. Provide adolescents with an accepting, open, communicative environment in which to grieve. Convey to them that it is okay to feel the emotions that they feel, and that you will be there for them if they need to talk.

Peer support

Adolescents often look to their peers for support when times are tough. Encourage them to connect with their friends in a safe environment where you can.

Talk about the loss

Invite adolescents to talk about their loss and/or their sibling, however should they not want to talk, you need to respect their choice. Let them know that you are available and ready to listen when they are ready and check in from time to time to see if they are. When discussing the death and their grief, ask specific questions and answer their questions honestly and clearly. Don't tell half-truths, and if you don't know the answer to something, say so. Share your memories, thoughts and beliefs with them without pressuring them to adopt your perspective.

Model healthy grief

Like all of us, adolescents learn from the behaviour they sense and observe. The more they observe healthy communication and the normal and natural expression of the many feelings associated with loss, the more likely they will understand and accept the breadth of emotions they may be feeling. Be aware however, that your own grieving style may look very different to your adolescent's. Finding out how they express their grief and reassuring them that it's okay to have different ways of grieving, will help them to feel more supported.

Support yourself

You won't be in any position to provide support to if you don't first take care of yourself, both physically and emotionally. If you are struggling, don't be afraid to ask for help, whether that be through family, friends or a health professional.

When to Seek Help

With good information, love and support, children and adolescents can learn to understand and work with their grief. However, if you are concerned by their behavior, or feel that they need more assistance than you can provide, then don't hesitate to seek further help from a health professional.



Grief Over Time

Grief Doesn't Have a Timeline

Grief doesn't have a timeline, nor does it have an expiry date. The truth is that you will always grieve the loss of your child. With time, the degree of pain will lessen, however it will never go away completely. Feelings of grief can be triggered at any time – sometimes at times when we least expect it. Grief isn't something you just 'get over'. Rather, over time, we learn to live around our loss and to adapt to a changed world – a world that can never be the same again.

Keep in mind that it's okay to admit you are struggling with your grief, whether it be weeks, months, years or even decades after the death. It's never too late to seek support if you need it.

Looking Toward the Future

In the immediacy of bereavement, it can be difficult, upsetting and even frightening to think about how the future might now look. When you lose a child, you not only grieve their presence in our lives, but also the future you should have had with them. Plans and goals previously made are forced to change and this can be very confronting.

Often parents are saddened or feel guilty when they start to construct a future without their child in it. The reality is however, that life does continue. With time, life can find meaning again as you start to rebuild and relearn this changed world around you. Try to keep in mind that looking toward the future doesn't mean that you have forgotten your child, or are dishonouring their memory in any way. You will always carry a part of them with you, no matter what the future brings, or how life evolves.



Other Losses

Other losses experienced, either before or after the loss of your child, whether they be additional bereavements, loss of possessions, relationships, employment, etc., can be particularly strong grief triggers. They can take us back to the time of the initial bereavement, or exacerbate the feelings associated with it.

It can sometimes be hard to figure out if your response to the new loss is a grief response, a separate response, or a combination. It may help to step back and ask yourself – before the loss of my child, would I have responded to this situation in a similar way?

Managing Anniversaries, Milestones and Significant Occasions

Anniversaries and significant events

Birthdays, holidays, Christmas, anniversaries... For the bereaved parent, the list of significant events that can trigger grief responses can be endless.

While our responses will change over time, the sorrow and pain as these occasions come and go can be draining and emotionally exhausting, and the lead up to such events can often feel worse than the day itself. It is important to recognise the impact anniversaries and other significant occasions can have and to take good care of yourself during these times.

Milestones

Milestones, those gained and those missed, can also be painful and difficult when grieving. It is normal and natural to feel sadness when milestones occur. When a child dies, we don't just grieve the loss of them physically, but also the loss of their dreams, their future and their presence within our lives.

Milestones may include:

- those relating to the death, e.g. yearly anniversaries
- occasions that they never got to experience, e.g. first day of school, graduations, weddings, having children
- personal life transitions or events that you wish they were there for.

Tips for managing anniversaries, milestones and significant occasions

Below are a variety of ideas that may help you to better navigate anniversaries, milestones and other significant occasions.

Beforehand

- Look at your diary and make a note of events and milestones that may be difficult for you. Start to think about what you can do during these times to look after yourself.
- Consider spending time with someone who understands the significance of the occasion.
- Think about how to answer certain greetings in advance. For example, when someone wishes you 'happy holidays', you may respond with 'thank you', 'I'll do my best', or 'best wishes to you too'.
- Keep a journal in the lead up to, and after, the significant occasion – make note of things that were particularly difficult so that you can better navigate them next time.

On the day

- Free yourself from the expectations of yourself and others and give yourself permission to 'not be okay'.
- You might like to come up with rituals to honour and acknowledge your loss, e.g. writing a letter to your child, visiting a landmark, or arranging to meet up with friends and family.
- Talk to other people about your memories of your child and ask them about theirs.
- Do something you wouldn't normally do in their memory, e.g. make a donation in their name, plant a tree, sign up for a class in something you've always wanted to do or volunteer to help a charity.
- Do something that makes you feel good. It may be as simple as reading your favourite magazine, going for a walk, listening to music, getting a massage or enjoying a good cup of coffee.

Remembering

Significant occasions, milestones and other grief triggers often bring back a wide range of memories. Initially these memories may be painful, however, with time, memories that initially upset you may instead provide comfort.

The love you have for your child does not end because they have died. Death ends a life, but not necessarily a relationship. Remembering can help you to feel close to your child, even though they are gone. Below are a range of activities that may help you to establish rituals around remembering.

Rituals and remembering

- Tell your story: talk to family and friends about your child and the memories you have of them.
- Create a memorial that has meaning to you.
- Create a photo album or collage.
- Explore creative outlets, e.g. poetry, writing, song, dance, painting, art.
- Put together a memory book or scrapbook.
- Talk to your child: people often talk to their loved ones after they have passed away. Often we miss being able to converse with them or tell them about our day. Verbalising what we wish we could say to them can provide comfort and help us to remember them.

Self-Care

Supporting yourself

Self-care means you looking after you. When we are grieving and/or supporting someone who is grieving, it can be all too easy to neglect our own physical and emotional health and wellbeing. Acknowledging the significance of your experience and taking the time to look after yourself however, can make a big difference in your ability to function on a day-to-day basis, especially in the long term.

Tips around self-care

Self-care may take the form of:

- rest and relaxation, e.g. sleep, massage, meditation
- physical activity, e.g. walking, cycling, gardening, team sports
- eating a healthy and balanced diet
- social interaction, e.g. engaging with friends, family, colleagues, local community
- talking about your grief, e.g. with family, friends, a counsellor or other health professional
- putting yourself first – this is one instance where making yourself a priority is important
- setting aside time just for you
- doing activities that bring you pleasure, e.g. hobbies, music, reading, going to the movies
- asking for help – don't be afraid or ashamed to seek help if you need it.

Supporting others

The reality of life is that often when we are at our lowest, there may still be others around us that need our support, e.g. other children, partners, family, friends, community, ageing parents or even pets. It can be all too easy to overlook your own wellbeing when supporting those around you, so it is important to be aware of your own needs, boundaries and limitations.

Some things to consider:

- Put yourself first. Look after yourself and then support those around you if needed.
- Be aware of your own limitations and be realistic in your commitments. You're not a superhero and nobody expects you to be one.
- Support can be a two-way street. Talk to the person/people you are supporting about how you can all help to support each other.
- Consider what you can delegate to others, particularly around day-to-day tasks, e.g. dropping kids at school, walking the dog, cooking dinner.
- Try to remember yourself in this picture – you need to be fair to both yourself and the person/people who need your support. Model good self-care to those you are supporting.
- Listen to your body. It is a good indicator of whether you are taking care of yourself.
- Don't ignore or stifle your emotions, e.g. feeling sad, angry, upset. These feelings are normal and natural grief responses and it's okay to experience them.



Seeking Help

It's Never Too Late to Seek Help

Grief doesn't have a timeline. It's okay to admit you are struggling with your grief, whether it be weeks, months, years or even decades after the death. There is nothing shameful about asking for help. You don't have to tough this one out alone.

Although grief can be very painful, most people (85–90%) find that with the support of their family and friends and their own resources, they gradually find ways to learn to live with their loss and do not need to seek professional help.

Sometimes however, the circumstances of the death may have been particularly distressing, or there may be circumstances in your life that make your grief particularly acute or complicated. If you are finding it difficult to manage on a day-to-day basis, or you are concerned by your behaviours or responses, it may be helpful to see a counsellor or other health professional.

Where Can I Find Help?

If you are concerned about the way in which you are grieving, it is important to find out more. Help can come from a variety of sources, including (but not limited to):

- friends and family
- GP and/or health professionals
- community health services
- counselling or a support group
- telephone helplines, e.g. Lifeline 13 11 14.



Useful Online Resources

Below is a brief list of useful online resources. In addition to these, you may also find it worthwhile searching for blogs or forums relating to the loss of a child, as many people find it helpful to read about other parents' experiences.

Palliative care resources

Royal Children's Hospital
www.rch.org.au/rch_palliative

Palliative Care Victoria
www.pallcarevic.org.au

Perinatal Palliative Care
www.pnpc.org.au

Very Special Kids
www.vsk.org.au

Caresearch
www.caresearch.com.au

Bereavement resources (Australia)

Australian Child and Adolescent Loss and Grief Trauma Network
www.earlytraumagrief.anu.edu.au

Australian Centre for Grief and Bereavement
www.grief.org.au

The Compassionate Friends Victoria
www.compassionatefriendsvic.org.au

SIDs and Kids
www.sidsandkids.org.au

Very Special Kids
www.vsk.org.au

Bereavement resources (international)

Dougy Centre (USA)
www.dougy.org

Cruse Bereavement Care (UK)
www.cruse.org.uk

Winstons Wish (UK – for children)
www.winstonswish.org.uk

Skylight (NZ)
www.skylight.org.nz

Financial/legal resources

Births, Deaths and Marriages Victoria
www.bdm.vic.gov.au

Centrelink
www.humanservices.gov.au/centrelink
Search for 'Bereavement Payment' to access information around available bereavement allowances.

Bereavement Assistance (funeral financial support)
www.bereavementassistance.org.au



Useful Books

The following selection of books are available for purchase through the Australian Centre for Grief and Bereavement (www.grief.org.au).

Books for children

What Does Dead Mean? A Book for Young Children to Help Explain Death and Dying

Caroline Jay and Jenni Thomas

The Children Who Lived: Using Harry Potter and Other Fictional Characters to Help Grieving Children and Adolescents

Kathryn A. Markell & Marc A. Markell

35 Ways to Help a Grieving Child

The Dougy Center, USA

Beginnings and Endings With Lifetimes in Between

Bryan Mellonie & Robert Ingpen

Books for adolescents

The Grief Book: Strategies for Young People

Elizabeth Vercoe (with Kerry Abramowski)

Sometimes Life Sucks: When Someone You Love Dies

Molly Carlile

Helping Teens Cope With Death

The Dougy Centre, USA

Books for adults

Coping With Grief, 4th Edition

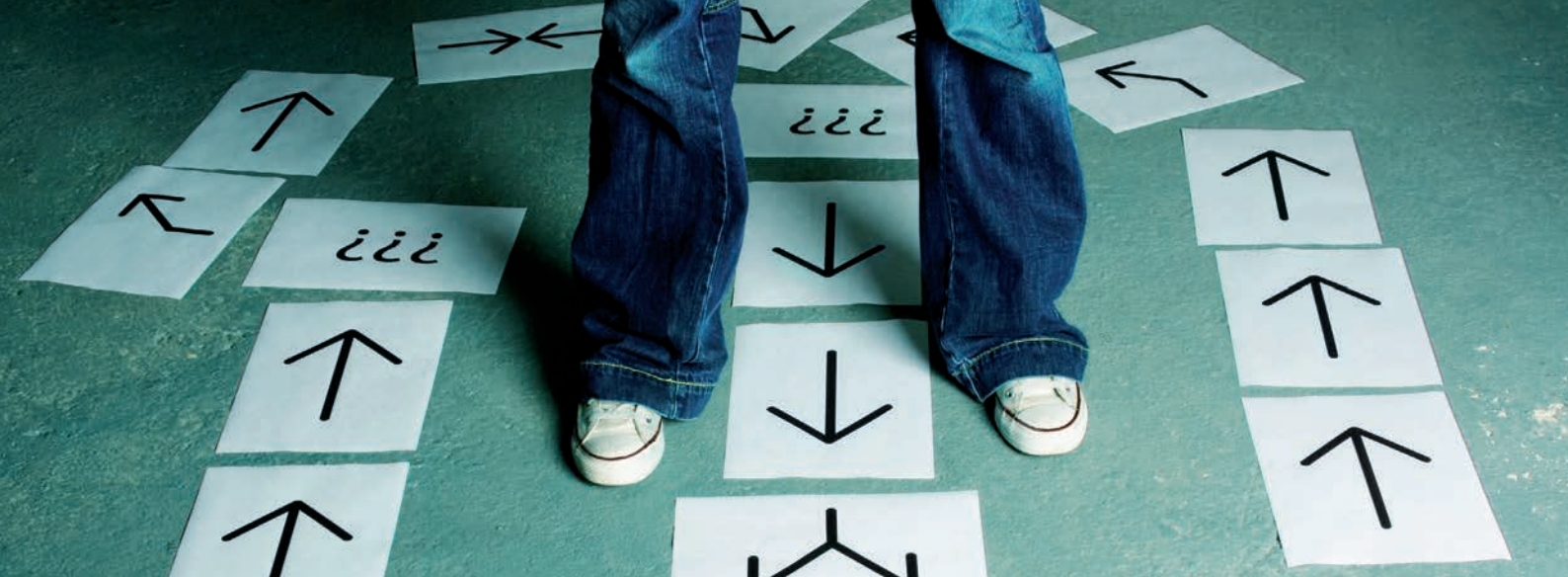
Mal McKissock & Dianne McKissock

Beyond Words: Grieving When Your Child Has Died

Skylight, NZ

The Essential Guide to Life After Bereavement: Beyond Tomorrow

Judy Carole Kauffmann & Mary Jordan



Useful Bereavement Support Services (Victoria)

Please note: Whilst this resource has been developed with a Victorian focus, many of the sites listed below provide services interstate as well.

Australian Centre for Grief and Bereavement

Services: Bereavement counselling, support groups, information, education and training for bereaved adults, adolescents, children and families.

Website: www.grief.org.au

Phone: (03) 9265 2100 or 1800 642 066

Email: counselling@grief.org.au

The Compassionate Friends Victoria

Services: Support groups, peer support and information for bereaved parents and siblings.

Website: www.compassionatefriendsvictoria.org.au

Phone: (03) 9888 4944 or 1800 641 091

Email: support@compassionatefriendsvictoria.org.au

Royal Children's Hospital

Services: Bereavement program for parents, grandparents and siblings

Website: www.rch.org.au

Phone: (03) 9345 6111

SIDS and Kids East Coast (NSW & VIC)

Services: Counselling and support services, support groups, online forum, information and 24-hour bereavement support line for families who experience the loss of a child up to the age of 6.

Website: www.sidsandkidseastcoast.org

Phone: (03) 8888 1600 (VIC office) or 1300 308 307 (24-hour support line)

Email: melbourne@sidsandkidseastcoast.org

Very Special Kids

Services: Bereavement support program for families inclusive of counselling support, events and information.

Website: www.vsk.org.au

Phone: (03) 9804 6222 or 1800 888 875

Email: mail@vsk.org.au



The Australian Centre for Grief and Bereavement is a not for profit organisation established to provide a range of education, counselling, research and clinical services for those working in, and affected by, grief and bereavement.

**Australian Centre
for Grief and Bereavement**

253 Wellington Road
Mulgrave VIC 3170

(03) 9265 2100

Freecall: 1800 642 066
Fax: (03) 9265 2150

Website: www.grief.org.au

ABN: 22 038 903 478
ACN: 159 297 444



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