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JOURNEYS
Palliative care for children and teenagers
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Palliative care for children and teenagers
Journeys: Palliative care for children and teenagers

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SUMMARY OF CONTENTS

This book is divided into four sections. Each section contains information on one stage of the journey. You are encouraged to read this book at your own pace—to read it as you feel ready to explore different parts of the journey of living with your child.

Section 1 – Introduction

The introduction outlines the purpose of this book and encourages you to adapt the information to suit your own needs.

This section includes special notes for:

- families living in rural and remote areas
- families from culturally diverse backgrounds
- Indigenous families.

This section also includes definitions of words you may come across during your journey.

Section 2 – Getting ready

When your child is diagnosed with a suspected life-limiting condition, your search for answers and information begins.

This section:

- looks at the early information needs many families have
- outlines palliative care and what kind of care you can expect to receive
- describes the roles of the different health professionals you may come across
- provides hints on how to find reliable health information about your child’s condition and possible treatment options
- includes information about your rights and responsibilities
- provides information on accessing financial support.
Section 3 – On the road

As your journey continues, you will see changes in your child’s health and wellbeing.

This section helps you find the best way forward by:

• exploring the options and choices available in caring for your child
• providing tips on care planning and managing the symptoms of your child’s condition.

This section also focuses on emotional support for your family by:

• describing the feelings of loss and grief that family members may experience
• providing suggestions for recording special moments with your family
• looking at ways for you to support yourself, your children, your partner and other family members
• suggesting ways to seek support from those around you
• exploring spiritual issues.

Section 4 – The next leg

For some families, their journey takes them to a place where they must confront issues concerning dying, death and bereavement. This section explores these issues and guides families along this unknown path.

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.
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This section includes special notes for:

- families living in rural and remote areas
- families from culturally diverse backgrounds
- Indigenous families.

This section also includes definitions of words you may come across during your journey.

1 – INTRODUCTION

“We felt as long as we had some sense of control, we could handle most things.”

“...endless nights of thinking, how are we ever going to get through this?”

“We knew when something felt right for us.”
SECTION 1 – CONTENTS

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1 – ABOUT THIS BOOK

The beginning of a journey

This book aims to better equip you for the many situations and issues you may face as you live with your child’s illness. It has been developed by people who have been on this journey and their shared wisdom is found in these pages. It includes a lift-out Journeys Resource List containing information on a range of topics such as sources of quality information, support services, and resources to help care for your child, other family members and yourself.

The words ‘palliative care’ may have been mentioned to you. Palliative care is not only about end-of-life care. Palliative care is holistic care that aims to relieve symptoms and improve quality of life by addressing physical as well as emotional, cultural, spiritual and social needs. Importantly, it includes care for family and friends. Some children receive palliative care for only a short time; other children may receive palliative care for many years.

Who is this book for?

This book is mainly designed for parents and carers of children and teenagers with a life-limiting illness but may also be useful for extended family, friends or your support network.

The information seeks to support parents and carers in their role as advocates for their child. It also provides information for teenagers who have a life-limiting illness, particularly as they begin to explore their own independence and autonomy.

What tools are provided?

Sections two, three and four contain a number of tools. Tools include forms, checklists and information sheets covering different subjects that may be of use. These tools can be photocopied and shared. You can also download electronic versions of the tools at www.palliativecare.org.au.

What topics or issues are covered?

Each section of this book reflects the information needs you may have at different stages of your child’s illness.

Section 1: Introduction

This is the section you are reading now. It includes definitions of common words used in the book as well as words you may hear when discussing your child’s illness. There is also information on the approach different cultures might take to care.
Section 2: Getting ready—diagnosis and early information needs

You will most likely have many questions following your child’s diagnosis. This section explains:

- paediatric palliative care
- the role of the different health professionals who may be involved in your child’s care
- how you might find reliable health information about your child’s condition and treatment options
- your rights and responsibilities
- how to access financial supports.

Section 3: On the road—managing the illness and its impact

This section focuses on caring for your sick child, particularly if you are caring for your child at home. It also includes chapters on emotional and spiritual support for yourself, your children, and other family members. Advice about interacting with or seeking support from extended family and friends, your child’s school or your work colleagues is also included here.

Section 4: The next leg—on dying, death and beyond

This section contains material concerning dying, death and bereavement. It explores choices available to parents and carers, such as talking to your children about dying and death, and making funeral plans. It also includes chapters dealing with bereavement support for yourself and your children, as well as suggestions for making memories.

You may not need all the information contained in this book or you may wish to revisit it at different points along your journey.

Where can I find more information and resources?

The pocket in the back cover of this book contains a lift-out Journeys Resource List with further information about:

- books you might find helpful
- online resources and websites containing further information
- services and facilities you may require through your journey.

The items in this booklet were selected because they provide current, high quality, accurate information, and will support your needs for more detailed information and advice. The resource list is reviewed and updated regularly and new versions can be found at www.palliativecare.org.au.
How do I use this book?

This book is the starting point as you begin to look for information and support that best meets your needs. In your own time, read the information provided. Some sections of this book may cover topics you don’t need or aren’t ready for yet. This book is designed with space for you to record your questions and thoughts in the margins or at the end of each section.

The information in this book can help you:

• find information and support
• raise questions about your child and their care
• communicate your needs to people around you
• care for yourself
• gently explore some of the difficult issues you may have to face in the future.

A compass symbol is used throughout this book to direct you to other sections or chapters where further information can be found.

2 – CARE

Different needs

All children and families are special, and no illness, child, family, or situation is the same. Palliative care is individualised, catering to the unique physical, emotional, spiritual, social, and cultural needs of the child, their family and carers.

Families in rural and remote areas

If your family lives in a rural or remote location, caring for a child with a life-limiting illness can have its own challenges. Some things for you to think about might include:

• Do you have to travel to specialist treatment centres for care?
• Will your family be separated or move from home to the city for long periods of treatment?
• Will your family experience financial burdens? Travel and accommodation costs, additional medical costs, double grocery bills for family at home and family in the city, and loss of employment can be significant. Services such as transport assistance schemes are an example of assistance available.
Do you have ready access to equipment and medications?

How will you keep up the close relationships formed with other parents and healthcare staff while at city hospitals?

How will your privacy, confidentiality and distress issues be minimised in a small community?

How might you and your family have access to options such as respite choices?

The resource list has more information on support that may be available.

Culture and care

Every culture has customs and beliefs which may shape the way you wish your child to be treated, or how you manage the care of your child. Sharing your customs, beliefs, language and traditions with your care team will help them provide more sensitive care. Being able to use a professional interpreter service has benefits such as translation of complex medical information, and protection of your privacy.

Some areas that you may have certain attitudes or beliefs about include:

- how you think about illness, pain and disease
- attitudes to medications and nutrition
- your understanding of dying and death
- customs surrounding death, burial or cremation, and bereavement
- spiritual matters, as well as religious issues, including rituals.

Be sure to discuss these issues with your care team. Your care team will try to respect culturally specific customs and attitudes that are important to your family. Your care team may also be able to provide information on social support networks that can provide understanding, support and comfort.

Aboriginal and Torres Strait Islander families

If you identify as Aboriginal or Torres Strait Islander, traditional beliefs and culture can have a big impact on the way you want your child to be cared for. You may feel there are cultural barriers to receiving care for your child in the way you want. There are many things you might want to think about and discuss with your care team. It is important you feel comfortable with your care team and able to talk to them about anything that worries you.
Things to talk through and choices to make

- Indigenous health worker/Aboriginal health worker/Indigenous liaison officer

  Would you like a specialised health worker on your care team? Some centres have specially trained palliative care health workers who may help you communicate better with your care team. There may be an Aboriginal or Torres Strait Islander medical service near you that can help.

- Place of care

  Are you reluctant to use hospitals or other health institutions? If so, it may be possible for your care team to come to your home or a smaller health clinic.

  Do you want to take your child to your traditional land to be cared for? If so, you should think about their health and make plans to take them back while they can travel.

- Elders and kin

  Are there special family or community members you need to talk to when making important decisions about your child's care? If so, do they live near you and can you ask them to visit in case you have to make decisions suddenly and need to have them close by? It may be possible for your care team and your community to arrange a family meeting (through teleconference or video conference).

- Traditional medicine

  Do you want to use traditional medicine or a traditional healer as part of your child's treatment? Discuss this with your care team. They will respect your wishes and, wherever possible, will include them as a part of the care your child receives.

- Ceremony

  Do you need to plan special ceremonies with your family and community to celebrate your child's life?
## 3 - WORDS AND MEANINGS

You may hear words or terms that are confusing. Here are some helpful definitions for words you might hear or see in this book.

<table>
<thead>
<tr>
<th>Words</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>acute condition or acute illness</td>
<td>A medical condition of short duration that often starts quickly and may only change the person’s ability to function for a short period of time. This is different to a chronic condition (see below).</td>
</tr>
<tr>
<td>allied health workers</td>
<td>Health professionals including psychologists, physiotherapists, pharmacists, social workers and occupational therapists. See chapter 4 for more information on different health professionals.</td>
</tr>
<tr>
<td>bereavement</td>
<td>Bereavement is the response to a loss and includes the process of ‘recovery’ or healing from loss. Each person will grieve and ‘recover’ in their own way.</td>
</tr>
<tr>
<td>care-oriented treatment or comfort-oriented treatment</td>
<td>Terms to describe care that is focused on ensuring the person has the best possible quality of life. Care and cure-oriented treatments can work together.</td>
</tr>
<tr>
<td>carer</td>
<td>A carer is generally a family member or close friend who provides for the needs of the patient.</td>
</tr>
<tr>
<td>chronic condition or illness</td>
<td>A medical condition which has persisted for a long period of time.</td>
</tr>
<tr>
<td>complementary or traditional therapies</td>
<td>Complementary therapies can be used in conjunction with conventional therapies and include a broad range of treatments including vitamins, minerals, nutritional and herbal supplements, massage, aromatherapy, music therapy and homoeopathic medications. The term traditional in this context, refers to the treatments that have been recognised by different cultural groups and peoples.</td>
</tr>
<tr>
<td>Words</td>
<td>Meaning</td>
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</tr>
<tr>
<td>conventional treatment</td>
<td>The range of treatments prescribed or practiced by medical health care providers.</td>
</tr>
<tr>
<td>coroner</td>
<td>A government officer who investigates, by way of an inquest, any death not clearly due to natural causes. The work of the coroner is determined by laws and officers are therefore required to request such activities as autopsies in certain circumstances.</td>
</tr>
<tr>
<td>diagnosis</td>
<td>The process of identifying a disease by its signs or symptoms through the use of various diagnostic procedures, such as reviewing patient history, physical examination, scans, and laboratory tests. Not all illnesses have a complete diagnosis.</td>
</tr>
<tr>
<td>end-of-life care</td>
<td>The end stage of palliative care where the patient is very close to death. Palliative care does not begin at the end of life but is involved from the time a person is diagnosed with a life-limiting illness. See palliative care.</td>
</tr>
<tr>
<td>evaluation criteria</td>
<td>A set of questions used to test that something is able to deliver what it promises.</td>
</tr>
<tr>
<td>family</td>
<td>Relatives, friends and key people who are identified by an individual as being part of their family. They are not necessarily a blood relative.</td>
</tr>
<tr>
<td>health professionals</td>
<td>Doctors, specialists, nurses and allied health workers who are specially trained and also recognised by an appropriate registering body.</td>
</tr>
<tr>
<td>holistic needs</td>
<td>The physical, emotional, spiritual, social, and cultural aspects of a person’s needs.</td>
</tr>
<tr>
<td>hospice</td>
<td>A special place set up to care for people with life-limiting illnesses. A hospice provides coordinated holistic care in a home-like environment.</td>
</tr>
<tr>
<td>Words</td>
<td>Meaning</td>
</tr>
<tr>
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</tr>
<tr>
<td>key coordinator</td>
<td>A person who works with you to plan, coordinate and communicate the care provided by the different members of the care team.</td>
</tr>
<tr>
<td>life-limiting illness</td>
<td>An illness where it is expected that death, before adulthood, will be a direct consequence of the illness and therefore is expected to shorten the child’s life.</td>
</tr>
<tr>
<td>medication</td>
<td>A range of drugs used to address symptoms.</td>
</tr>
<tr>
<td>medicine</td>
<td>Drugs taken by mouth used for the treatment of an illness.</td>
</tr>
<tr>
<td>multidisciplinary team</td>
<td>A team of health professionals who work together to develop and implement a plan of care. Membership varies depending on the services required by the person.</td>
</tr>
<tr>
<td>paediatric palliative care</td>
<td>Care to maximise the comfort, wellbeing and quality of life of children with life-limiting illnesses, and of their families and carers.</td>
</tr>
<tr>
<td>palliative care</td>
<td>Specialist care provided for a person living with a life-limiting illness. The primary goal is quality of life.</td>
</tr>
<tr>
<td>palliative care team</td>
<td>A multidisciplinary team which may include nurses, doctors, social workers, volunteers, chaplains, allied health workers and other complementary health therapists.</td>
</tr>
<tr>
<td>pastoral care</td>
<td>Care provided by a person trained in providing spiritual support for a child, their family and carers.</td>
</tr>
<tr>
<td>post-mortem</td>
<td>A medical examination to determine the exact cause of death.</td>
</tr>
</tbody>
</table>
| primary carer               | A person who provides the primary support role for the patient. When the patient is a child, the primary carer may be the mother, father, a carer or a combination of these.}
<table>
<thead>
<tr>
<th>Words</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>prognosis</td>
<td>Prognosis refers to the doctor's expectation of how a patient's disease will progress. This judgement is based on their knowledge and experience with patients with similar medical conditions.</td>
</tr>
<tr>
<td>respite care</td>
<td>A service which provides temporary care for the patient. Respite can be in a hospital, hospice or the home.</td>
</tr>
<tr>
<td>resuscitation</td>
<td>A medical action aimed at returning someone to life when their heart or breathing has stopped. Resuscitation may or may not be successful.</td>
</tr>
<tr>
<td>sick child/ seriously ill child</td>
<td>These terms are used in this book to indicate a child who has a life-limiting illness.</td>
</tr>
<tr>
<td>specialist palliative care provider</td>
<td>A health professional who is trained as an expert in assessing and addressing the needs of a person with a life-limiting illness, and of their family and carers.</td>
</tr>
<tr>
<td>symptoms</td>
<td>Symptoms are signs of an illness and include such things as pain, fever, nausea, fatigue and breathing difficulties.</td>
</tr>
<tr>
<td>team-oriented approach</td>
<td>Health professionals with a range of training and skills, working together as part of a multidisciplinary team.</td>
</tr>
<tr>
<td>treatment</td>
<td>A term that describes a broad range of activities to improve health or comfort, and includes medications, tests, surgery, counselling or massage therapy.</td>
</tr>
</tbody>
</table>
4 – WHAT DO PEOPLE DO?

Depending on need, there are many different types of healthcare workers who may be involved in the care of your child.

**Medical staff**

Medical staff include general practitioners, palliative medicine physicians, other medical specialists (such as oncologists and cardiologists), and nurses. Their tasks often involve:

* symptom control—such as pain, nausea, or constipation
* arranging meetings to develop your child’s care plan
* providing advice to local services involved in care of children with life-limiting illnesses.

**Specialist palliative care nurses**

Specialist palliative care nurses have advanced training in caring for people with a life-limiting illness. They provide care, advice and support for children and their families and carers, including:

* direct care in the home, hospital or hospice
* linking families with support services
* helping determine what respite care services are available if required
* assisting with accessing equipment and supplies required for care at home
* advocating for children and families who require palliative care.

**Physiotherapists**

Physiotherapists provide support to children and families by:

* assessing and monitoring muscle strength and mobility, and providing programs to help children maintain their physical abilities
* providing splints, gait retraining, walking aids and rehabilitation to maximise a child’s potential
* conducting a respiratory assessment and developing a care plan to help your child breathe as easily as possible
* providing education and support to parents and carers in the physical tasks that may be required to deliver care at home
* teaching techniques to enhance pain management.
**Clinical psychologists**

Clinical psychologists provide a range of services that can help parents understand the nature of their child’s illness and identify meaning and hope in their own situations. They can:

- encourage families to understand the unique experience of the child, parents, carers, and siblings within the family’s unique cultural background
- help families adjust, cope and learn new parenting strategies
- help families to accept and manage their feelings as well as spiritual issues
- communicate with local services on your behalf if you choose.

**Occupational therapists**

Occupational therapists can help children realise their full potential. Within the palliative care context, occupational therapists work to maintain the quality of life experienced by the child by:

- encouraging and maximising independence and participation in everyday activities
- facilitating age-appropriate play skills
- maintaining comfort and support
- helping with the supply of equipment
- assisting with home management strategies.

**Play therapists**

Play therapists are skilled in child development and can assist children and families with palliative care needs in many ways:

- in hospital, during admission, or appointments
- provide support in relation to adjustment to hospital
- assist with recreation activities
- prepare children for medical procedures
- teach coping strategies for pain management
- in the home
- support the child and family in the home environment by teaching coping strategies for pain management
- assisting with recreation activities.
Social workers

Social workers provide support and a range of interventions to help children and families. A social worker can provide emotional and practical support which may involve referral to community services, educational and practical assistance, and grief and loss counselling. Social workers can offer support groups for siblings and parents. Social workers may be able to provide information on financial support, home support programs, and information on accommodation for parents while children are in hospital.

Pastoral care workers

Pastoral care workers bring a caring presence into the lives of children and families, working alongside the other health professions to provide spiritual and emotional care as an integral part of treatment. They bring a willingness to listen, respecting at all times, who you are and what is happening for you. Pastoral care workers can include counsellors, chaplains, and other religious ministers or elders. They work to offer hope and comfort, and if requested, may offer prayers and other religious rites or rituals, depending on individual needs.
When your child is diagnosed with a suspected life-limiting condition, your journey begins.

This section:
- looks at the early information needs many families have
- outlines palliative care and what kind of care you can expect to receive
- describes the roles of the different health professionals you may come across
- provides hints on how to find reliable health information about your child’s condition and possible treatment options
- includes information about your rights and responsibilities
- provides information on accessing financial support.

2 – GETTING READY

‘I wish we had understood palliative care better—we would’ve used them more if we knew then what we know now.’

‘Our first thought was: Who’s going to help us?’

‘You don’t get information unless you know the right questions to ask.’
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5 – WHAT IS PALLIATIVE CARE?

Key points

- Palliative care is care for people who have a life-limiting illness for whom the primary treatment goal is to maximise quality of life.
- A life-limiting illness is an illness that is expected to result in early death.
- Palliative care incorporates a ‘whole-person’ approach to caring—managing physical pain and other symptoms, together with emotional, spiritual, social, and cultural care of the person, their family and carers.
- Palliative care can be provided in many care settings including hospitals, hospices and with the right support—your home.

About palliative care

The focus of palliative care is on improving the quality of life of the patient and their family and carers. It is also about maximising care choices.

Palliative Care:

- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help children live as actively as possible until death
- will enhance quality of life and may positively influence the course of an illness
- provides relief from pain and other distressing symptoms
- can be introduced early in the course of an illness alongside cure-oriented treatment or treatments that are intended to prolong life - this may include chemotherapy or radiation therapy, and investigations needed to better understand and manage distressing clinical complications
- offers a support system to help the family cope during the child’s illness and in their own bereavement
- uses a team approach to address the needs of children and their families, including bereavement counselling if required.1

---

About palliative care for children and teenagers

The national standards for palliative care are the same for all Australians. However, palliative care for children and teenagers is slightly different from palliative care for adults because of the need to provide care that:

- embraces the whole family as well as the child
- involves health professionals with specialised skills in the care of children
- supports families as they care for their sick child and their other children
- understands the different responses by children to symptoms and their treatments.

Because there is often uncertainty about the child’s prognosis, palliative care may require an approach that combines palliative care with cure-oriented treatment. The delivery of palliative care seeks to ensure the best quality of life and a ‘hope for the best, prepare for the worst’ approach.

The timing of referral to a palliative care team is your choice, but starting the relationship early can mean better preparation and support. Palliative care for children and teenagers is about maximising choice — choice about the care your child and your family receive. You will be supported by your care team in making decisions about the care of your child. Having choices and making decisions may also help you feel more involved and in control.

The diagram below illustrates the palliative care model and how the child, their family, and community are the centre of care regardless of where the care is provided and who is involved in providing this care.

Palliative care for children and teenagers


Palliative Care Australia, 2005, Standards for providing quality palliative care for all Australians, Canberra.
6 – WHO PROVIDES PALLIATIVE CARE?

Key points

- Palliative care is provided by a number of people working together as a team with a shared goal to meet your needs when and where you need it.
- Your team may include nurses, doctors, social workers, volunteers, pastoral care workers, and allied health practitioners.
- You and your child are the most important members of the care team.
- Identify a key coordinator (e.g. general practitioner, clinical nurse consultant) to work with you to plan, coordinate and communicate all the care provided by the different members of the care team.

Care providers

Care providers may be based in a hospital or in the community. They may visit you at home, at school or in hospital. A multidisciplinary team has members from different areas of expertise in health care who work together.

Your care team

The members of a care team will depend on your child’s and your family’s needs. The aim of the care team is to provide the best continuous care, even though the actual members of the care team may change over time.

You are the primary carer and the care team is there to provide guidance, education and support for you and your child. Open and honest communication between you and your care team will help make this happen.

A typical care team includes:

- care providers from your local community e.g. district or community nurse, general practitioner, local pharmacist
- specialised medical consultants e.g. paediatrician, palliative care nurse
- allied health professionals e.g. social worker, physiotherapist, occupational therapist
- pastoral carers e.g. priest, chaplain, rabbi
- complementary therapists e.g. massage therapist, music therapist.
Roles of people involved in the care team

- general practitioners
- medical specialists
- physiotherapists
- pharmacists
- complementary therapists
- social workers
- pastoral carers
- bereavement counsellors
- volunteers
- clinical nurse coordinators
- nurses
- community nurses
- key coordinator

Your key coordinator is the person from your care team who has the role to plan, coordinate and communicate, to all care team members, the current care arrangements for your child. The key coordinator ensures the whole team is working well together on your behalf. Identify who your key coordinator is and make sure you have their contact details so you can ask for assistance if new issues or problems arise.

Your key coordinator will also help you and your family prepare and learn new skills in caring for your child.

Other support groups

A wide range of other services are available to your child and family. Being able to use some of these services may depend on where you live. See the resource list at the end of this book for more information on:

- palliative care organisations
- community support organisations
- voluntary organisations
- pastoral care services.
Knowledge about what might happen and how to respond will help you and your family to make choices and plans.

The best source of health information can be your child’s care team.

Reliability and appropriateness are important considerations when searching for health information.

Do not be afraid to ask questions. Your care team is used to hearing and responding to all types of questions. Asking the same questions again is okay too.

Sometimes your questions may not have any answers. Sometimes questions cannot be answered with absolute certainty.

Finding reliable information

You may feel a need to find out more about your child’s condition, including treatment options and disease details and supports.

Knowledge about what might happen and how to respond will also help you to be more informed and give you a greater sense of control.

This chapter will help you find sources of information about your child’s illness.

Ask your care team

The best source of health information can be your child’s care team. Don’t be afraid to ask for more information. You are entitled to have access to the most reliable information possible. Chapter 9 has further information on your rights and responsibilities.

Sometimes, your questions may not be answered with absolute certainty. A child can have a set of life-limiting symptoms but not a complete diagnosis of what the causes or illness are. However, you can expect to have your questions answered honestly by your care team.
Asking questions

Write down questions or concerns that are important to you and ask members of your care team.

After attending meetings or important decision-making sessions, it may be helpful to ask for a written summary from your key coordinator.

Take a support person with you. It would help if it was the same person each time.

If possible, plan on talking about sensitive issues while your young child is not present.

Take notes in a diary or journal. This is the best way to keep track of what was said and when.

It’s all right to ask the same question a few times if you don’t understand something.

Your care team members are used to hearing all sorts of questions and answering questions is part of their job — just ask.

Ask your key coordinator how you can get answers to other questions you may think of later.

Ask for advice on where to get more information, including written information.

Ask to reschedule meetings if significant family members are unable to be present.

Adapted from: Hudson, P. 2004, Supporting a person who needs palliative care: A guide for families, Palliative Care Victoria.

Some general questions for you to consider are:

- What can be done to keep my child comfortable?
- What can I expect as my child’s condition progresses?
- What can we expect from this treatment or procedure?
- How are services provided after hours?
- How and where can my child receive short-term in-patient or respite care?
- Are there any new treatment options we can try?

Don’t forget to ask the questions that nag at you in the early hours of the morning.
Assessing sources of health information

Seeking out further information on your own is something that many parents do. It can give you a better understanding of your child’s disease, progression and impact. It can also give you a greater sense of control over your situation and the choices available. However, seeking out information on your own is a personal choice and not for everyone.

Not all information is wholly accurate. When looking for health information, the reliability and appropriateness of the information are always the most important things to consider. You can share the information you have found with your care team so that they can work with you. The following checklist may also help.

Questions to ask about health information

<table>
<thead>
<tr>
<th>Question</th>
</tr>
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<tbody>
<tr>
<td>Who is providing the information?</td>
</tr>
<tr>
<td>When was this information published? How up to date is it?</td>
</tr>
<tr>
<td>Do you understand the information or is it full of medical jargon?</td>
</tr>
<tr>
<td>Does this resource provide links to other reputable resources?</td>
</tr>
<tr>
<td>Does this person or company have a commercial reason to promote a particular product?</td>
</tr>
<tr>
<td>Does the resource discuss the risks as well as the benefits of a particular approach?</td>
</tr>
</tbody>
</table>

8 – TREATMENT OPTIONS

Key points

- There may be many treatment options available for your child.
- All treatments require careful consideration on what is involved, the possible benefits and whether the benefits outweigh the possible risks or side effects.
- Conventional medicine involves treatments practiced by medical doctors and by other health professionals.
- Complementary therapies are treatments that may be used together with conventional treatments.
- Gather as much information as you need, in writing if you prefer, and take time to be certain about treatment options before making a decision.
- Your care team is a good source of information about treatment options.

Thinking about treatment options

As your child’s illness and symptoms change, so may treatment. This can be a challenging time as parents and care providers are required to make decisions about treatments in the best interests of the child. There can be a difference between what someone can do and what someone should do.

All treatments, whether conventional, complementary or alternative, require careful consideration. The potential benefits need to be balanced with a clear view of the risks and whether the risks are worth the possible improvements. It is helpful to get as much information as you need and take as much time as your situation allows before making a decision about treatments.

Each child is different and each illness is different and can behave differently in each body. It is important to learn, with the help of your care team, about your child’s illness and how it affects your child. Sometimes, you may find that certain treatments are not the best option for your child.

Knowing exactly what is involved in the possible treatment will help everyone involved have a clearer picture about what to expect.

A list of useful questions you might use when considering different treatment options is included later in this chapter. Your care team is a good source of information about possible treatments and you can discuss the various options with them.
Conventional medicine

Conventional medicine involves treatments that are practised by medical doctors and by other health professionals, such as physiotherapists, psychologists and registered nurses.

It is usually through conventional medicine, such as scans, blood tests and x-rays, that families find out about their child’s illness. Life-limiting illnesses can be complex and conventional medicine cannot always provide a clear diagnosis or promise a cure. However, at all times, the care team will use all its skills to ensure the children in their care live the most comfortable and active lives possible. Doctors and nurses who have experience with your child’s illness will help you work out which medications and therapies will best help your child.

Monitoring your child’s condition may involve ongoing medical tests, and visits with your care team will allow you to discuss how well your child’s treatments are going and when changes are required.

Complementary treatments

Complementary treatments can also be known as traditional treatments. The term traditional, in this context, refers to the treatments that have been recognised by different cultural groups and indigenous peoples. Examples of complementary treatments include vitamins, minerals, nutritional and herbal supplements, massage, aromatherapy, music therapy and homoeopathic remedies.

Although usually not evidence-based, care teams generally recognise certain complementary therapies can be an important part of your child’s medical care, particularly when they improve general wellbeing.

Most palliative care professionals will be sympathetic if you choose to explore complementary treatments. Your care team may warn against any they believe are harmful, but you will always have the right to choose treatment options without this changing in any way your right to the best care from your care team. You may like to review Chapter 9 on your rights and responsibilities in palliative care and Chapter 7 on reliable health information.
Questions to help guide you

The box below contains questions to think about when considering different treatment options.

<table>
<thead>
<tr>
<th>Questions about treatments, therapies or products</th>
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</thead>
<tbody>
<tr>
<td>Is it safe? What are the expected or possible side effects?</td>
</tr>
<tr>
<td>Do the benefits outweigh the risks?</td>
</tr>
<tr>
<td>Will it interfere with the amount of quality time you have left with your child?</td>
</tr>
<tr>
<td>Is it intended for the same condition your child has? And for the same age?</td>
</tr>
<tr>
<td>How does it work? Is there any proof that it works?</td>
</tr>
<tr>
<td>Can you get a second opinion?</td>
</tr>
<tr>
<td>Is it compatible with medications your child may be taking? Are you allowed to continue with your current medications on this treatment?</td>
</tr>
<tr>
<td>Do care team members know about the complementary therapy you are considering?</td>
</tr>
<tr>
<td>What does it cost?</td>
</tr>
<tr>
<td>What’s involved? Will it be uncomfortable for your child?</td>
</tr>
<tr>
<td>Is the person giving the therapy qualified or experienced? Are they an accredited member of a professional society or similar group?</td>
</tr>
<tr>
<td>If you are worried or not satisfied, will you be able to say so?</td>
</tr>
<tr>
<td>At what point do you review the treatment and how do you measure if it has worked?</td>
</tr>
</tbody>
</table>

Tool 2 contains more information on making decisions about your child’s treatment and care.
You, as primary carer for your child, have a number of important rights as well as responsibilities. Knowing these rights and responsibilities will help you communicate with your care team and ensure the best care for your child.

If your child is under 16, or you are the legally appointed guardian of your child, you have the legal responsibility to make decisions in the best interests of your child.

At age 16, a child is legally able to make their own decisions, independent of your views. However, in practice, this will depend on many factors such as their intellectual, health and communication abilities.

Decisions are not set in stone — you and your child have the right to change decisions at any time.

In caring for their ill child, parents and primary carers have the most important role. However, this can also be a difficult role. They are their child’s voice and are required to ‘stand up for’ or advocate for their child’s wishes when decisions about care are made.

‘Having a non-verbal, intellectually disabled teenager did impact on our responsibilities. We were ultimately responsible for ensuring his rights first and then our rights as carers.’
Your palliative care rights as parents and carers for children and teenagers

### Your right to be informed
- to have any question answered as honestly and as fully as possible
- to be given information in a way and form that you can fully understand and use
- to seek further information or a second opinion before making a decision - including understanding the benefits, risks and side effects of all treatment options
- to have access to other organisations and government services that may be helpful, for example bereavement support.

### Your right to be involved in decision making
- to participate in all decisions about the care options for your child — including the decision to refuse treatment to the extent permitted by law
- to say no at any time you and your family are not comfortable
- to choose someone else to make the decisions on behalf of you and your family
- to have access to a professional mediator.

### Your right to change your mind
- to change your mind about your child’s treatment or care at any time — even if the treatment has started.

### Your right to be heard
- to have your opinions heard and respected
- to be able to say no to things that you do not feel comfortable doing, including participating in research projects
- to have any issues or complaints about the care being provided to your child discussed.

### Your right to receive compassionate, supportive care that respects your child’s and your family’s needs, regardless of beliefs, religion, lifestyle, social or economic background
- to have access to respite or other care as required.
### Your palliative care rights as parents and carers for children and teenagers

<table>
<thead>
<tr>
<th>Your right to receive care in a professional, safe environment</th>
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</thead>
<tbody>
<tr>
<td>• to have all care provided in a competent and professional manner</td>
</tr>
<tr>
<td>• to know the professional qualifications of all people involved as members of your care team.</td>
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<table>
<thead>
<tr>
<th>Your right to confidentiality of your child’s personal records</th>
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<tbody>
<tr>
<td>• to have your child’s records only given to those persons directly involved in the care of your child</td>
</tr>
<tr>
<td>• to have your privacy respected at all times.</td>
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</table>

<table>
<thead>
<tr>
<th>Your right to decide the role you play in the care of your child</th>
</tr>
</thead>
<tbody>
<tr>
<td>• to decide the role you wish to play in your child’s direct care without the pressure to choose any specific option</td>
</tr>
<tr>
<td>• to change your mind, and be able to access other care setting options at any time.</td>
</tr>
</tbody>
</table>

Adapted from: Palliative Care Australia, 2005, Standards for providing quality palliative care for all Australians: Patient rights and responsibilities, Canberra.

If your child is under age 16, or you are the legally appointed guardian of your older child, you are required to be the decision maker in your child’s care. At age 16, a child is legally able to make their own decisions about their care. However, this can present many significant challenges. The child needs to be fully informed and able to make decisions based on this information. When a child is sick, there are many situations where this may not be possible, for example when the teenager no longer has the capacity to communicate. Every child is different and as this aspect of decision making can result in conflict, it should be carefully discussed with everyone involved.

### Understanding your responsibilities

As the key member of your child’s care team, you have a number of responsibilities. Your care team is there to help you with these responsibilities.

‘Because Lewis was 16, I assumed he had rights to decide his treatment, although it was never made explicit. I respected the choices he made because it gave him some control over his life, but it was hard for me. For instance, when he was in the hospice and very weak, he was given the option of taking another course of chemo. He wanted it, because he was so optimistic, but I felt it was futile and probably harming him more. However, I let him do it because he needed to affirm that for himself.’
Your palliative care responsibilities as parents and carers for children and teenagers

Your responsibility to keep well informed
- to ask all your questions and find answers, with guidance from your care team
- to find out the benefits, risks and side effects of all treatment options being considered.

Your responsibility to be actively involved in treatment and care decisions
- to be involved or to choose someone to be involved and make decisions on your behalf
- to try to make decisions based on reliable accurate information from trusted sources
- to seek advice from your care team and others to help make decisions.

Your responsibility to communicate openly and honestly with all members of your care team
- to provide all relevant information to the care team. Your team can only provide the most appropriate care if they know all the necessary information about your child. This includes many issues such as use of alternate treatments that you sense may not be agreed with.
- to answer questions honestly
- to always tell the care team if you have issues or complaints with the care being provided.

Your responsibility to look after yourself and your other family members
- to encourage yourself and your family to practice self-care activities to reduce stress and promote wellbeing
- to give each other permission to take time out to reenergise and rest, so that everyone is able to provide the best care for the child.

Health complaints

It is important that you communicate clearly with your care team about your experiences, expectations and issues. Feedback that you provide to your care team is very helpful for making improvements to services provided.

There may be times where you feel it is important to lodge a formal complaint. Complaints are best lodged, in the first instance, with the complaints officer or other relevant person at the service with which there is a problem. Complaints can also be lodged with the Health Ombudsman or medical and nursing registration boards in your state or territory. See the resource list for contact details.
10 – FINANCIAL SUPPORT

Key points

- A number of government and non-government services and charities can help with the costs of caring for your child.
- Ask your key coordinator about which member of your care team can help you gain access to these services.
- The Australian Government, through Centrelink, provides a number of support payments. These payments can cover support for carers and may extend up to 12 weeks after the death of your child. Establishing a single person as your contact with a Centrelink office will help you access all the benefits you are entitled to.
- Your doctor will often be required to complete certain forms to confirm your child’s condition.
- The Australian Government under Medicare subsidises healthcare costs through the Medicare and Pharmaceutical Benefit Scheme safety nets.
- Other financial support services include equipment programs, accommodation services and travel services.

Financial support options

The resource list at the end of this book includes information and contact points for financial assistance you may be able to access.

Accessing services may require completion of forms and paperwork. Don’t hesitate to ask for assistance from your key coordinator and social worker to help complete these forms.
The following types of programs should help reduce the financial burden on this journey. Your care team can provide more information.

**Types of support**

<table>
<thead>
<tr>
<th>Income support</th>
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<tbody>
<tr>
<td>Parents and carers may need income support to help them during their child’s illness if they are not working. This support may include the Carer Payment and the Carer Allowance. The amount of the allowance will depend on your personal circumstances. It is helpful to locate a single contact person within Centrelink to help you access all the benefits you require.</td>
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<tr>
<th>Subsidised healthcare costs</th>
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<tbody>
<tr>
<td>Your child is likely to have care provided in a range of care settings. Every Australian is entitled to access public hospitals at no cost. If relevant, you may wish to check your entitlements with your private health fund and identify any gap payments with your provider.</td>
</tr>
<tr>
<td>When your child is in the care of your GP, x-rays and blood tests are covered by Medicare, while medications are covered by the Pharmaceutical Benefits Scheme. It is helpful to speak with your doctor, pharmacist and Medicare to ensure you are obtaining all the benefits you are entitled to. Centrelink may provide you with a Health Care Card which will further reduce the health care costs for medications and doctors’ visits.</td>
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<tr>
<th>Equipment programs</th>
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<tbody>
<tr>
<td>Specialised equipment such as oxygen pumps and syringe drivers may be important to help you care for your child at home. A number of programs can loan equipment or help cover the costs.</td>
</tr>
<tr>
<td>In the case of long-term home care, you may qualify for modifications of your home to help make it safer and easier to care for your child.</td>
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<thead>
<tr>
<th>Respite and accommodation services</th>
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<tbody>
<tr>
<td>Accommodation may be required for times when you travel to a distant hospital or when your child spends time in a respite home. There are a number of options that may suit your and your child’s needs.</td>
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<table>
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<tr>
<th>Travel support</th>
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<tbody>
<tr>
<td>Your child and your family may have to travel long distances to receive the required care. There are government schemes which contribute to the cost of travel.</td>
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<tr>
<th>Home help services</th>
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<tr>
<td>Help with shopping, gardening, general chores and child care support may also be available.</td>
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</table>
**TOOL 1 – CARE TEAM CONTACT LIST**

It is helpful to keep a list of your care team members with you. Include their location/address, phone and pager numbers, and role to identify who they are—for example, key coordinator/team coordinator, doctor, nurse, general practitioner.

<table>
<thead>
<tr>
<th>Name:</th>
<th>Location:</th>
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<tbody>
<tr>
<td>Contact #:</td>
<td>Role: <strong>key coordinator</strong></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Name:</th>
<th>Location:</th>
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</thead>
<tbody>
<tr>
<td>Contact #:</td>
<td>Role:</td>
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</table>

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<tr>
<th>Name:</th>
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<td>Contact #:</td>
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<tr>
<td>Contact #:</td>
<td>Role:</td>
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TOOL 2 – DECISION MAKING

Making decisions and planning care

While there are many things we cannot control, there are important choices that can be made about the care of a child with a life-threatening illness. Parents share the difficult task of making these decisions with the help of doctors, nurses, and other health professionals. Parents know their children better than anyone else. Doctors and the rest of the care team bring experience and specialist knowledge.

It is often helpful to think about and discuss what the best approach would be if your child were to deteriorate suddenly. This is called advance care planning. Sometimes doctors and parents are unsure how to raise the question of decision making. Signaling to your child’s doctor that you are ready to talk about some of the more difficult aspects of the illness and its treatment can help facilitate important discussions.

What decisions will I be asked to make?

What is the overall goal of care?

When a child cannot be cured of their illness, or when a cure is extremely unlikely, the focus of care may shift. This may involve attempting to prolong the child’s life for as long as possible, or to ensuring the time that remains is as full of life and happiness as it can possibly be. Sometimes there is a choice to be made between length of life and quality of life.

Prolonging life or pursuing a cure when this is unlikely nearly always comes at a cost, and parents can find themselves torn. Do you leave no stone unturned in the search for a cure or do you ensure your child does not suffer? These can seem impossible choices and different families may make different decisions when faced with identical circumstances.

It is important to know that palliative care, including the management of pain and other symptoms, can be combined with ongoing efforts to cure your child’s disease or prolong their life, if such efforts are considered to be in the best interests of the child.

What treatments are and are not appropriate?

There may be many treatments that are possible. But distinguishing between what could be done and what should be done is important. What are the benefits and burdens of the various treatments? Only the individual child or those who know and love them can know what is a burden and what is a benefit to them. For example, some children feel frightened and distressed when they are in hospital, while others feel safe and may even enjoy the activities on offer there.
The process of decision making

The key word here is ‘process’. Where circumstances allow, take time to seek information, to think, and to talk with experts and with friends and relatives.

Gather as much information as you can

Meet with the health professionals involved in your child’s care and ask questions. You may need to ask the same question a few times to fully understand the answers. It may also be helpful for you to see blood test results or scans.

Ask yourself some key questions

• What are the most important things to you and to your child?
  It can be hard to distinguish between what you may want for your child and what they might want for themselves. Even if your child is very young, it may be helpful to think what they might say if they could speak for themselves.

• If time was limited, what would make this time the best it could possibly be?

• Ask your child some key questions. An older child may not be able to participate fully in decision making but may be able to offer a perspective on how they experience their illness and treatment.

  What is most important to them?
  What are their hopes?
  What are their worries?

Talk together as parents. You may not always see things the same way at the outset so it is important to respect each other’s views and continue talking.

Seek support from family, friends, and from your spiritual or cultural community. There may be key individuals who are of special value. It’s okay to ask if they can be included in discussions with the care team.

Once a decision is made

Once important decisions are made, it’s crucial that everyone involved or likely to be involved in your child’s care is informed. Many hospitals and palliative care services have documents where these decisions are recorded. This does not necessarily mean the decision is legally binding. Decisions will need to be reviewed as your child’s condition changes.

A word on hope

Even in circumstances where there seems to be no hope for a child’s survival, many parents find they simply cannot accept it. In their head they understand, but in their heart hope remains. This is okay and hoping for the best while preparing for the worst may be a helpful way to approach the situation. Hope can also be refocused on goals such as going home, comfort, or time.
Notes
Notes
As your journey continues, you will see changes in your child’s health and wellbeing.

This section helps you find the best way forward by:

- exploring the options and choices available in caring for your child
- providing tips on care planning and managing the symptoms of your child’s condition.

This section also focuses on emotional support for your family by:

- describing the feelings of loss and grief that family members may experience
- providing suggestions for recording special moments with your family
- looking at ways for you to support yourself, your children, your partner and other family members
- suggesting ways to seek support from those around you
- exploring spiritual issues.

3 – ON THE ROAD

‘Can we care for her at home? What will we need to do?’

‘How can we best support our other children?’

‘I felt hurt that some family and friends weren’t there to support me.’
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    (Tool for family and friends)
11 – PLACES TO CARE FOR YOUR CHILD

Key points

- Depending on your child’s illness and situation, there are choices about where you look after them.
- As the illness progresses, your child may spend time in more than one place of care. Regardless of the place of care, your care team aims to make arrangements so care is provided according to your choices.
- Knowing about the different places of care will help you make choices.
- Decisions about places of care can be changed at any time.

Care settings

Children can be cared for in their home, in hospital, or if appropriate, in a hospice. While many families choose to remain at home, sometimes the condition of the child, difficulty of care, availability of support, or family needs may mean another place of care is better.

Regardless of which you choose, you are able to move between care settings as needs change. Remember you can always return to the hospital or hospice for extended periods or for the remainder of your child’s care. Taking time to consider care options will help you plan and get organised.

Caring for your child in a hospital or hospice

Families whose child has a life-limiting illness are likely to be familiar with the hospital environment and the types of care provided. A hospice is a specialised care setting dedicated to patients with palliative care needs. Both hospitals and hospices provide full-time care for your child and on-site access to expertise. There are hospices dedicated to the palliative care needs of babies, children, and teenagers in New South Wales and Victoria.

Each hospital and hospice has its own set of arrangements and special programs for children in palliative care. You may like to talk to your care team about these. Whether in a hospital or hospice, be encouraged to express your wishes and be creative in personalising this environment to meet the needs of your family.

‘It was very calm at the hospice and Lewis (16 yrs) felt very safe there. I had to shift my idea of ‘home’. The hospice was home for us, that’s what it’s designed for after all. I brought some home things in for the room and lived there the whole time he was in. I was lucky I was able to just do that.’
Caring for your child at home

Often in the early stages of palliative care, children are quite active and have little discomfort. They are likely to be at home, attending school, and participating in family activities. As your child's illness progresses and symptoms develop, your care team will provide help with ongoing assessment and management.

Benefits of home care

Some of the benefits of home care are:

- the family is together and parents may feel better able to provide support and reassurance to all their children
- privacy and comfort is enhanced in a familiar environment
- siblings can be included and made to feel an important part of what is happening in the family - siblings may feel good about helping their sick brother or sister
- children are usually happier at home among their toys, pets, family members, and friends
- parents may feel more in control over their child's care, and experience a sense of achievement and pride in providing that care.

Getting ready for home care

Parents may fear taking their child home, yet for many the experience is a very positive one. You’ll have many questions about your child's care, particularly as your child’s condition changes. You can discuss these questions with your key coordinator. Your key coordinator can show you how to:

- bathe/shower your child
- get around the house and community
- feed your child
- give and store medications safely
- toilet safely and use portable systems such as urine bottles and commode chairs
- entertain your child
- communicate with your child
- care for your child’s skin
- store equipment such as dressings and tubes.

Families who have been through this experience say that being organised and prepared is a good idea.


**Tips**

- Write everything down — set up a daily journal, diary, or notepad.
- Ask for help to set up a medications chart to record when and how to give medications.
- Use a calendar to record appointments and expected visitors.
- Have easy access to the numbers to call for help.

**Privacy**

You may need strategies to cope with the flow of visitors and to make sure you have special time with your child – especially as your child’s condition deteriorates. There are ways to maintain your privacy, including:

- limiting visitors and callers—‘Can you please ring between 9 and 10am?’
- consider putting a sign on your front door asking visitors to come at another time
- restricting the length of visits—even 15 minutes can be a long time
- asking one or two friends to act as contacts if a lot of people are ringing for updates
- setting up a blog for family and friends as an easy way to keep them updated
- telling people how to be comfortable with you and your child
- not fretting about how the house looks, your housekeeping is not on show
- setting up an answering machine to screen calls without promising to call back
- using your answering machine to provide an update.3

**Help with home care**

Home care can be made easier with the right help, including the support of your care team, community services, and other assistance.

Your key coordinator will liaise with your general practitioner, paediatrician, community nurse, and other services to support you at home during the palliative care phase. A social worker can also provide support and advice about many issues.

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The type of help available includes:

- support with nursing care (such as administering medications and changing catheters) from community or palliative care nurses, and their assistance in teaching parents how to do these things themselves
- help with running the home (cleaning, meal preparation, transportation) from family, friends, volunteers or service groups
- assistance with financial issues
- support in providing personal care (hygiene, feeding) and managing your child’s symptoms and nutritional needs
- counselling and emotional support
- equipment aids to make functioning at home easier, such as an electric hospital bed, oxygen, bedpans and soft mattresses
- respite care services to allow carers to take a break
- home visits and 24-hour phone availability to advise on care management
- vehicle modifications to help wheelchair transport and access.

**Respite care**

Taking regular breaks from caring can be a helpful way to care for yourself, your children and your partner. Examples of respite care assistance include:

- support workers come to your home to care for your child while you are taking a break
- admission for short stays to a hospital, hospice, disability care home, or residential home
- programs for sibling respite.

Things for you to think about when planning a short break include:

- Can the palliative care service arrange a volunteer or paid carer to be with your child while you take a break? You might be able to ask a family member or friend to do the same.
- Can the palliative care service arrange night care? Rest at night is important for everyone. Night care may be accessed through Commonwealth Carer Respite Centres and other community agencies.
- Do you have insurance that may help pay for a carer or home nurse? If you have private health insurance, it may help fund respite nursing shifts.
- What if you need a longer break? If you decide you need a longer break your care team may be able to arrange respite care for your child in a hospital or palliative care unit. Children’s hospices can be used by children and their families for respite care, transitional care between hospital and home, and end-of-life care.
12 – CARE PLANNING

Key points

- A care plan explains how you and your care team work together to provide the best care for your child.
- A care plan contains information on your choices in caring for your child.
- Care planning should involve your child (to the extent that their ability allows), your family, and your care team.
- While it may seem difficult to raise some issues when your child is well, it is generally helpful to plan care in advance to avoid making decisions in a crisis.
- The care plan is revised regularly to reflect the changing needs of your child and your family.

What is a care plan?

When you and your care team have discussed what works best for your child, your choices and decisions can be recorded in a care plan. The care plan communicates your choices to those who are caring for your child, including family members, paid carers, and medical staff.

Your care plan might include:

- instructions regarding playing, feeding, comforting and sleeping—try using diagrams and photographs, for example, to show your child’s preferred lying or seating positions
- helpful hints for solving specific problems
- what to do and who to contact in case of emergencies
- basic medical history to help communication with new care team members
- instructions for regular medications, including those used for symptom control
- your decisions regarding resuscitation or other critical events.

You may want to have more than one care plan if your child is cared for in different settings—a home care plan, hospital/hospice care plan, or respite care plan.
care plan. Or you may decide to take your care plan everywhere with your child. You may wish to give a copy of your care plan to the hospital if your child is admitted through the emergency department.

If possible, use a computer to record your care plan so you can update it easily.

## Developing a care plan

Developing a care plan with your care team will take time. Good communication is needed to make sure everyone understands and agrees on the goals of care. The care plan is based on:

- your child’s condition (physical, emotional, spiritual, social, and cultural) and its impact on their health, and changes to your family’s lifestyle
- where you would like to care for your child, and where your child would prefer to be cared for
- the needs of your family as individuals and as a unit.

As your journey continues, you will need to revisit and update your care plan to reflect your changing needs. Your key coordinator should anticipate and coordinate these changes for you.

An example of a care plan is included at the end of this section—this shows the types of information to consider when planning care.
13 – SYMPTOM MANAGEMENT

Key points

- Care plans contain important information about managing your child’s symptoms.
- With the right support, symptoms can be well managed in a home care environment.
- Knowing when and who to call with questions will help with home care.

Recognising symptoms

You know your child, but you will also need to know how to recognise signs of problems. When preparing your child’s care plan, your care team will help you understand:

- things to expect with your child and what to look for
- what you should do if problems arise
- what to do to make your child feel better
- how to use medications correctly and safely
- who to call if you are concerned or unsure.

It’s all right to contact your care team if the treatments do not seem to work and your child continues to experience symptoms, or if you just feel unsure. It’s important that you feel confident and supported. The following section discusses some basic areas of symptom management.

Tips for symptom management

Feeding and nutrition

This is a very emotional area. Parents may feel a strong obligation to nourish their child but most serious illness makes this difficult in one way or another.

If swallowing becomes difficult (with times of choking, gagging, coughing or hesitation with mouthfuls), talk with your care team about your child’s body positioning, food textures and the availability of expert assistance.
If your child becomes unable to take food and fluids it will be time to discuss other options with your care team. This may include discussion about feeding tubes such as nasogastric tubes or gastrostomies. These decisions are made in the best interests of your child.

**Skin care and comfort**

Illness can affect the condition of your child’s skin because of decreased activity, poor circulation, weight loss, or other illness related causes. Protecting the skin with cushioning, moisturising, massage, and pressure area care is the best way to avoid problems.

This means making sure your child changes position regularly during the day and night, and using padding such as a sheepskin, soft mattress overlay, or special cushion.

**Pain**

Most parents worry about their child suffering pain. You will know if your child is in pain by their reactions. These include:

- looking tense or stiff
- frowning, moaning or crying
- not feeling like eating
- not feeling like joining in an activity
- being unusually quiet, cranky or irritated.

The key to controlling pain is making sure you have the medications and tools to use when needed. This will mean having medications at hand, understanding when and how to use them, and having a reliable way to give them to your child.

There are also non-medication measures for controlling pain including adequate rest, positioning, using warmth and cold, distraction, and massage.

The amount of pain is not always constant and can vary from day to day. You’ll need to know how long the medications will take to work, and how long they will likely work to control pain. Your care team can help with this. Make sure your care plan has a ‘plan B’ if the first approach doesn’t work. Recording the time and amounts of medications given is important to help your care team work out the correct medications and their timing. See Tool 3 and Tool 4 where you will find a medications chart or just use your own diary.

Using medication may mean you need to learn new skills. It is also important that you know the common side effects of the medications, for example constipation, and whether you may need to manage these symptoms early.

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Nausea and vomiting

The causes of nausea and vomiting are often difficult to identify and you will need your care team’s help to find out if there might be a cause which requires more treatment.

There are many medications to help control nausea and your care team can work with you to find the right one for your child. Also, practical things to help your child include: keeping smells down, providing fresh air (or a fan), emptying bowls quickly, mouth rinses, cool face washes, aromatherapy, and distraction.

Constipation

Constipation is often an underestimated symptom which can cause extreme discomfort, nausea and behaviour changes. Constipation can be caused by:

- medications such as codeine and morphine
- lack of physical activity
- poor fluid and fibre intake
- illness that causes slow bowel action.

Use of laxatives is important. The trick with most children is finding what they will swallow and making sure you keep giving the laxatives to prevent constipation. At times an enema or suppository may be needed to clear a blockage.

It’s usually a good idea to keep a record of your child’s bowel movements and give them extra fluids if possible. Gentle clockwise stomach masses may also help. Make sure your child is as comfortable as possible on the toilet or bedpan; a padded seat, pillow to hug, or a footstool to rest the feet on can all help.

Breathing problems

Changes in breathing may be an expected, but unwanted part of illness. This may also be a symptom of deterioration.

Changes in breathing may not actually make the child uncomfortable, but they can be difficult to watch. When the focus is on the child’s comfort, many families have found oxygen may not be helpful. Some children don’t like the oxygen mask or nasal prongs. If oxygen is required, particularly in chronic situations, your care team will help with supply, delivery and education.

Other suggestions your care team might discuss include:

- sitting the child up at a 45 degree angle
- freshening air with an open window or fan
- managing saliva secretions with a drying agent medication or gentle suction

‘We managed the symptoms very well with the help of our team. When Bwembya started having respiratory problems we were taught to try to manage the home ventilation on our own with a large supply of oxygen for the severe attacks.’
• gentle chest physiotherapy
• helping the child relax with soothing routines such as massage, music, stories, and distraction
• giving smaller meals to decrease full stomach pressure under lungs
• soothing a cough with cough lozenges, mixture, or puffers.

Fitting
A child with a neurological disorder, brain tumour or existing epilepsy may be at risk of seizures or fitting. They may already be on medications to prevent these. If your child could have a fit or seizure, you should have special medication on hand ready to use. Talk with your team about this. Know the first aid steps to protect your child if they have a seizure.

When to call for help about a symptom
Call your team whenever you feel unsure, unsafe or uncomfortable about your child’s wellbeing. It’s important to trust your instincts. Your care plan will include information on who to contact and how to contact them, at any time. Have this information handy and visible.

Remember no question is a silly question—sometimes it is helpful just to have confirmation that you are doing all the right things for your child.

You may want an immediate response to a rapidly worsening or frightening symptom and decide to call an ambulance. Your child may settle before the ambulance arrives. If this happens, you may decide to stay at home or go to the hospital. Be clear with the attending ambulance officers what you want to do.

It is helpful for you to give your care plan to the ambulance officers or the emergency staff. This may be valuable if you have resuscitation plans—so the communication is very clear, without you having to answer many questions. Your care plan can speak for you at this time. However, ambulance officers may have to follow their own rules.
14 – FEELINGS OF LOSS AND GRIEF

Key points

- Children who understand their diagnosis and the limitations it places on them will experience feelings of loss and grief.
- Each family member experiences feelings of loss—parents, children, brothers or sisters—from the point of diagnosis and throughout their journey.
- Grief is a normal part of living with a child with a life-limiting illness.
- While there is no right or wrong way to grieve these ‘early losses’, it helps to know what is and isn’t a normal reaction to loss, so that you can recognise when you or other family members may need professional counselling and support.

Understanding early loss and grief

In addition to struggling with the meaning of the diagnosis and the many changes this brings, families experience the loss of hopes and dreams for the future. This is often described as ‘early grief’, ‘anticipatory grief’ or ‘pre-emptive grief’.

It’s important to understand that this is a normal part of living with a child with a life-limiting illness. These feelings can surface at any time and it may be helpful to understand how different people express their feelings of loss.

Normal feelings of loss

For the sick child
- the loss of a healthy self and being able to do things they enjoy
- the loss of a ‘normal’ life—going out with friends, playing sports, attending school, and doing other activities
- the loss of independence
- the loss of hopes and dreams for the future.

See Tool 7
Some common symptoms of grief
Page 135
For siblings

- the losses of living with the reality of a brother or sister’s illness, for example, the loss of time to just have fun
- the loss of a healthy playmate and friend
- the loss of parents’ time and attention
- the loss of family normality.

For parents

- the loss of being able to be a ‘normal’ parent and not having to worry about medications, treatment, understanding medical jargon, and all the other changes.
- missing out on important milestones, such as starting school, graduating, getting married
- difficulties parenting other children.

When to seek help

There is no right or wrong way to react, and grieving is a natural and healthy response to loss. Responses to grief may include:

- crying and sadness
- anger, guilt or remorse
- insomnia or general restlessness
- poor concentration or inability to make decisions.

Sometimes, help coping with grief might be needed. Some signs that professional help might be required include:

- emotions and feelings that are too intense or severe to cope with
- continued fears or anxieties about your wellbeing or thoughts of self-harm
- intense emotion, obsessional thoughts, or behaviours that make functioning difficult.

Children’s reactions to loss and grief

Like adults, children will have many reactions to their own illness or the illness of their brother or sister. When faced with loss, children may feel anxious, angry, afraid, and sad. Children may not have the language or maturity to understand where their feelings are coming from.

Non-verbal or developmentally impaired children may also experience loss and grief in a different way from their older peers. Your care team will be able to provide ideas to help them communicate and share their feelings.
### Immediate reactions to loss and grief

<table>
<thead>
<tr>
<th>Shock and disbelief</th>
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<tbody>
<tr>
<td>Some children may pretend everything is normal or replace the reality of what is happening with fantasy or imaginary tales.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Distress and protest</th>
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</thead>
<tbody>
<tr>
<td>They may be upset and distressed, cry and need comforting. They may become unusually attached to their parents or other people who make them feel secure.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Continue as if nothing has happened</th>
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<tbody>
<tr>
<td>They may seem to be uninterested in what is happening and want life to continue as usual.</td>
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</tbody>
</table>

### Later common reactions

<table>
<thead>
<tr>
<th>Anxiety</th>
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<tbody>
<tr>
<td>They may fear change in all aspects of their lives and generally lose confidence.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Sleep disturbance</th>
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</thead>
<tbody>
<tr>
<td>They may have night terrors, nightmares, find it difficult to go to sleep, or want to sleep with someone.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sadness and longing</th>
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</thead>
<tbody>
<tr>
<td>They want life to return to how things were before, or talk a lot about the past.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Anger and acting out</th>
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</thead>
<tbody>
<tr>
<td>If children are feeling awful or don’t understand the cause of their pain or what to do about it, they may revert to anger and misbehaviour. They will need your support and patience to work through their feelings. If it becomes a problem, it may help to seek counselling with a person experienced in these issues.</td>
</tr>
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<table>
<thead>
<tr>
<th>Guilt and blame</th>
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</thead>
<tbody>
<tr>
<td>Children can often feel they have somehow contributed to the situation, for example, if they had at one time felt jealous of a sibling. It is important to tell them it’s no-one’s fault.</td>
</tr>
</tbody>
</table>
Later common reactions

Problems at school
- Their friendships or ability to concentrate on study may be affected.

Physical complaints
- They may seek comfort and nurturing through physical complaints, both real and imaginary. It is their way of seeking attention.

Bedwetting
- In times of stress, crisis or uncertainty, bedwetting can reappear in children. This is a sign of anxiety and again, patience and understanding is needed.

Clinging to parents and family
- They may feel anxious that something could happen to you and become clingy or demanding. They may grow very attached and always want to be with you. Younger children may revert to babyish behaviour. Remember this is their way of seeking reassurance.

Adapted from: Crowe, L. 2003, When children have a life-limiting illness: Questions and answers around loss and grief, Centre for Palliative Care Research and Education, Queensland.

Counselling may be available from a social worker, palliative care worker or general practitioner. Your general practitioner can refer you to a psychologist for professional support. This may be subsided by Medicare. You may also speak to a professional loss and bereavement counsellor.
Coping or survival strategies are the collections of things we do to help us get through difficult situations.

Each person has their own way of coping and everyone needs to feel accepted and supported.

General coping strategies include taking one day at a time, sharing your feelings and fears, and taking a break or asking for help.

Looking after yourself is important and will help you maintain a level of energy and resilience.

Caring for yourself

Coping or survival strategies are the things we do to help us get through difficult situations. Every person will have, or learn, their own coping strategies. Finding out that a child has a life-limiting illness, combined with the task of caring for that child is a difficult journey for everyone involved.

Looking after yourself can be hard, but it’s important. Taking time to look after your own needs can give you more energy, capacity, and reserve to care for your sick child and your family. Caring for yourself helps relieve stress, avoid illness, and may help you feel happier at home.

There are many reasons parents don’t seek help for themselves, including: feeling their child’s needs are more important, their care team is too busy, not trusting another carer, or simply wanting to stay close to their child.

Tips for caring for yourself

Accept help from others—talk with people who are willing to help you, trust them to do some practical things to take the load off you. Keep a list of people and things they can do.

Find outlets for your feelings, such as physical activity, music, gardening.

Eat well and exercise regularly to maintain your energy. You can use simple stretching and relaxation tapes or on-screen exercise guides if you don’t want to leave home.

‘Due to lack of rest, my husband David had a physical breakdown — he had raging pneumonia and was very ill. In actual fact I nearly lost David and Joshua in the one week. They were both hospitalised at the same time. So I would advise everyone to try to look after yourself and remember to seek respite before it’s too late.’
Tips for caring for yourself

Get enough sleep. It is common for parents to have trouble sleeping but if you are finding it hard to sleep on a regular basis, speak to your doctor.

If you are working, negotiate an easier time schedule and workload.

Talk with your key coordinator about respite options.

Share your feelings. Join a support group, talk regularly with a friend, or write your feelings in a journal.

Take time out to do things you enjoy.

Go outdoors—nature can be a wondrous healer.

Use relaxation tools in the home such as aromatherapy, soothing music, warm baths, meditation or yoga.

Make time to be with your partner.

Taking care of yourself — a checklist

Do I have someone I trust to talk to about how I'm feeling?

Am I trying to get some regular exercise?

Am I trying to get enough rest and sleep?

Am I trying to eat regular meals?

Do I get enough breaks from caring?

Do I have regular times for relaxation?

Emotional support

There are a number of people who can provide emotional support for you and your family, and offer suggestions and practical assistance to help you look after yourself.

The needs of families will change throughout their child’s illness. Emotional support and counselling can help families from the time of diagnosis and through the many ups and downs of the journey.

Communication

It’s important you feel your views and feelings about your child’s care are being heard by your care team. You may find it difficult to initiate a discussion about things that are concerning you, particularly when you’re sharing personal feelings and emotions. Be encouraged to express your questions and feelings with members of the care team.

If language is a barrier to understanding, you can access professional interpreters. Ask a member of your care team about this.

Who provides emotional support?

Emotional support and understanding can come from different people—family and friends, your care team, community groups, and pastoral carers. Emotional support can be as simple as having the right person in the right place at the right time for you to share your thoughts.

Other parents of children with life-limiting illnesses can be a valuable source of support. They can provide a shared sense of understanding and a feeling that you are not alone. Your child’s hospital or care team may be able to put you in contact with a parents’ support group. There are also many community groups who can provide support.
16 – HELPING YOUR CHILDREN

Key points

• Good communication with children occurs when children feel included, respected and listened to.

• It’s important to respond honestly with the right words for the child’s age and listen to their verbal and non-verbal responses.

• Your care team can help you build your confidence to talk with your children about difficult subjects.

• It’s better for your children to hear directly from you, in a safe and supportive environment, what is happening to them, their brother, or sister.

• Children experience similar feelings to adults—they may feel anger, fear, confusion, sadness, and depression.

• Providing each of your children with an extra support person (a trusted family friend, or teacher) can be a great help to them.

• Keeping your children entertained and stimulated helps distract them from constantly focusing on their or their sibling’s illness.

• What you tell your child about their illness is a personal choice, but honesty in answering questions and providing explanations is always very important.

• Talking with children can often be a matter of right time, right place, right person.

• Be prepared for a conversation when and where your child chooses to talk.

Communicating with your children

Parents often express concerns about how to talk to their children about the illness. While there are many things to think about when working out how to discuss illness with children, it is known that good communication with children occurs where children feel included, respected and listened to.

Your care team may talk to you about the importance of having open conversations with your children: talking about what is happening to them, their brother or sister or close relative. If you feel uncomfortable about this, they can help build your confidence with skills and knowledge. You are the best person to support your children, to work out what they need, and how to provide it.
When you talk with your children, remember that every child is different and will have their own unique ways of hearing and processing information. Children will express their feelings and thoughts in many different ways.

The age of your child makes a difference to what they can understand and how they will respond to significant events. While their birth age can be used as a general guide, it is more important to be aware of your child’s developmental age or maturity level when talking with them. As your child’s parent, you are the best person to judge where your child is at, what they need, and how to help them get it.

Children do not always have the words to talk about their thoughts and feelings and may communicate through play, behaviour, and drawing. Be aware of both their verbal and non-verbal cues and respond honestly, using appropriate words for your child’s age.

**What do I tell my children?**

This is a very common question for parents struggling with what to tell their sick child and other children about the illness and what it means. You may want to ‘protect them’ by not telling them, but this good intention can actually exclude them from sharing in a family experience and might make things more difficult later on. You may decide that you will let your child lead you in conversation and, while being ready for questions, you’ll wait to be asked.

It is better for your children to hear what is happening from you directly in a safe and supportive environment. It may give them the opportunity to share things with you and identify things they would like to do. Children may fill in the gaps with their own stories. These stories can be far more frightening than the reality. As a guide, when telling children about the illness, it is important to use the proper medical name of the diagnosis. This can avoid later confusion. For example, a parent might say to a young sibling:

‘Your brother has Duchenne Muscular Dystrophy which will affect the muscles in his body as he grows. He will need to go into a wheelchair one day because the muscles in his legs won’t be able to hold him up to walk.’

Using the right words stops your other children from worrying that they can ‘catch’ things from their sibling. It may also make it easier for them to explain their brother or sister’s illness to other children and adults.

Children mostly get their cues from their parents. If you encourage an open attitude by sharing your feelings and fears, they will feel able to do the same. If you adopt a code of secrecy, children may hide their anxiety, sadness, and distress. They may repress their feelings and not tell you things, such as if they are having nightmares. They may also want to protect you.
How should you talk to your children?

Keep it simple and honest. Answer their questions but don’t overwhelm them with extra details.

Talk to your children in a direct, open, clear, gentle, and loving way. Let them know there are no wrong questions, that you are always available to talk.

Reassure children that the situation is not their fault and they have done nothing to cause it.

Give information gradually over time rather than in one big session. It’s better to keep children informed of gradual developments or changes in the illness rather than waiting for the situation to become more serious.

Repeat explanations as needed.

It’s important to keep siblings updated with important things that are happening with their sick brother or sister.

Children’s understanding of a situation can change over time and they may need to re-explore earlier issues.

Emotional support

This section explores the emotional needs of your sick child or adolescent, and how you can support your other children as they cope with the issue of having a sibling with a life-limiting illness.

Emotional support for your sick child

Children can be very resilient and are often able to adapt to their situation better than most adults might imagine. They live for the present but will also adjust their goals for the future in relation to what is happening.

It can be difficult to know how to initiate a conversation with your child about their illness. It can help to remember that many children, particularly when they are young, have short attention spans and will only briefly wish to talk about their illness. Don’t expect too much from any one conversation.

Your children will benefit if they sense that you are willing to listen and talk about their thoughts and feelings. Finding opportunities to join with your child in play may stimulate sharing of experiences. The physical effects of illness may make it hard to touch and cuddle. Work with your care team to make this possible.
Children like to think they are able to protect members of their family. Your children may also be protective of you and hesitate to worry you with their thoughts. It can be helpful to have someone else they feel comfortable talking with. This could be a relative, close family friend, or teacher.

**Emotional support for your sick teenager**

Teenagers are faced with different challenges as they start to develop a sense of independence. This is often complicated by the restrictions of their condition. Teenagers also have a greater sense of the future and perhaps have already started to plan what their life may have looked like. They may experience a sense of further loss as they remain dependent on their parents for care and supervision. This is also a very physically conscious stage of development and the effects of illness on appearance may be very difficult.

The role of peer support in the life of an adolescent is crucial. As teenagers, they may have developed some close friendships and may feel more comfortable confiding in trusted friends. Although you may feel excluded, these peer supports will be very important to your child. Acknowledging friendships can also help them maintain a sense of normality. For some young people this may include exploring their sexuality and relationships. There is a range of peer support groups that can be an avenue for young people to meet and share experiences with their peers.

Adolescents may seek to make meaning out of what is happening in their lives and what the future may be for them and their families. They may wish to talk about after life issues and plan their funeral. Providing them with space and opportunities to express feelings, fears, regrets, and hopes is important. For example, music therapy can be a good outlet for creative expression.

With teenagers, an honest, adult approach and respect for their privacy is likely to be appreciated. It is important to include them in all decisions regarding their care, including informing them of any adverse effects of suggested treatments. This will allow them to make informed choices about their care and help them feel more in control.

**Emotional support for siblings**

Finding the time and energy to support your other children can be hard. Siblings will also have their own needs during this time. If possible, involve them in what is happening and allow them space to ask questions and process the information in their own time and way. Even very young children will sense when things are different in the family and may express this through their behaviour.

Children benefit from routine and consistency. This can be a challenging time and the support of family, friends, and community can be helpful. Recognising the unique relationships between all siblings and providing opportunities to encourage quality time for them will be appreciated.

*Jo’s father turned up from interstate and that was really hard... he had been out of our lives and now he was back. Jo didn’t want to see him but I knew how important it was for his dad to spend some time and I tried to negotiate their contact. How would I feel if I were his dad? This was really hard because I wanted to give Jo choices and control about who he spent time with. In the end it was a compromise.*
Siblings may often feel like they are no longer the focus of attention and may feel overlooked. They are also going through a similar range of emotions to you around loss, fear, and grief. They may benefit from counselling or other support from school or community groups. Social support from existing relationships will be very important at this time.

Some suggestions for supporting your other children include:

- talk to your children and keep them well informed about what is happening
- involve your children in caring for their sibling by giving them a role they enjoy
- try and find some quiet one-on-one time to focus on each child
- reassure your children that it is all right to feel the way they do and share some of your feelings with them
- identify someone amongst your family or friends who can specifically support each of your children, someone who can give them special time and attention
- contact their day centre, preschool or school, inform them of what is happening, and ask what support they can provide.

**Entertainment and activities**

Engaging with your child and keeping them active, mentally if not physically, will continue to be important. There are many avenues you can explore to keep your child entertained at home—only limited by your imagination. A few suggestions include:

- music and play provide a creative outlet and an opportunity to express how they are feeling
- redecorate their room
- websites can provide children with education, entertainment and even online support groups—suggest computer projects they may like to do, such as creating slideshows of their favourite photos
- libraries, including toy libraries, can provide a brief outing as well as new books, audio books, and toys to keep them interested for a few hours—reading to your child can be a special way of sharing time together
- home schooling or distance education can provide academic stimulation—talk to your school about fun home activities and projects
- computer games, board games, and craft projects can be a good way to spend time together and have fun
- set up the ‘bed bound’ child in the family room so they feel in the middle of things
- your occupational therapist or play therapist may have some ideas.
Pets

Most children love animals. If you don’t already have a family pet and would like to explore pet therapy for your child, someone in your care team may know of a contact.

Holidays, thrills, and spills

Enjoy your time with your child and go for a holiday. This might be a simple trip to a charity-funded holiday house or a big adventure funded by a charity organisation. When planning for a holiday:

- engage your sick child in careful discussion about what they want
- talk with your care team about what is possible—don’t overcommit yourself
- plan for ‘what if’ and go prepared
- be excited, enjoy and record!
17 – HELPING YOUR PARTNER

Key points

- Make every effort to communicate honestly and openly. Each of you should feel able to share your feelings, thoughts, and concerns without fear or blame, or of overwhelming your partner.
- Explore solutions together and try to be patient
- Make time for each other.

How illness might affect your relationship

During your journey, being able to share the load and feel supported by your partner will be invaluable. Any traumatic experience can have a significant strain on a relationship. Some parents and carers have found the experience of having a child with a serious illness brings them closer together, although it is common for couples to find this experience overwhelming. Many couples struggle in their relationship during and after caring for a child with a life-limiting illness.

Common relationship issues

Caring for a seriously ill child can place significant strain on a relationship. By recognising and overcoming common relationship issues, couples can work towards supporting each other better. This chapter describes some ways parents respond to having a child with a life-limiting illness, and some hints and tips to help you understand and support your partner.

Anger

It is common for a parent of a child with a life-limiting illness to feel angry. Sometimes, this anger can become misplaced and is taken out on those closest.

Understand:
- anger is often a reaction to the loss, or impending loss, of the child
- people express anger with those they feel safe and secure with
- anger is an expression of frustration and helplessness.
When feeling angry:

- think about what you say before you say it
- ‘hear past the anger’ and focus on the underlying feelings; you may be able to work towards pulling together rather than apart.

**Unmet expectations**

One partner may feel they are carrying the load and caring for their child alone. They may feel that the other ‘just can’t deal’ with a seriously ill child. They may feel overburdened or abandoned, for example, if their partner works long hours. Some strategies for addressing these feelings include:

- communicate what you need from your partner
- try to respect each other’s differences and coping strategies
- seek professional counselling to explore issues
- accept support from family and friends.

**Intimacy**

Many couples express concern over their sexual relationship. The emotional pulls and physical demands of caring for a seriously ill child over an extended period often impact on a couple’s desire or ability to maintain an intimate relationship. Exhaustion can greatly affect libido. Sometimes, just recognising that this is a common reaction to particularly stressful situations can help.

Try to understand you will have different intimacy and sexual needs during times of stress. Discuss these differences so that you don’t interpret the actions of your partner as uncaring or rejection. Share intimate moments by simply touching, holding hands or talking about personal issues.

**Emotional support**

It is natural to look to your partner for comfort and emotional support:

- try to remember that both of you are hurting and have limited energy to comfort each other
- family, friends, pastoral carers, counsellors, or other parents can be an alternative source of support and care during this stressful time.
18 – HELP FROM FAMILY AND FRIENDS

Key points

- Many family members and friends will provide reliable, constant, and strong support to you and your family.
- How family and friends react to your situation is not always predictable and may surprise you.
- Some family or close friends may not know what to do or fear saying the wrong thing.
- Talk to family and friends about your needs. With guidance and direction, they may be able to support you.

Extended family and friends

Many family members and friends will provide good support, both practical and emotional, while others may need guidance in learning how they can support you better.

Friends and family members will have different ways of responding to your child’s illness. Some may keep themselves busy to avoid facing your child’s illness, while others may isolate themselves. Although this behaviour can cause misunderstandings and hurt feelings, it is important to understand that this is often a response to their feelings of distress for you, and an inability to know how to talk to you or help.

Emotional support

While the child, parents and siblings are the ones most obviously in need of emotional support, other members of the family and even close friends need support as well.

Grandparents have special needs. They experience a ‘double blow’ of seeing their own child in turmoil as well as trying to make sense of their grandchild’s illness. Grandparents’ hopes and dreams for the future are questioned, as is the natural order of life. This can be very difficult and feelings of guilt are not uncommon. They often feel they have had a long and satisfying life, and see the unfairness that it is their grandchild and not themselves who is seriously ill.

See Journeys Resource List
Books
It may be beneficial for those around you to seek emotional support. By seeking emotional support, extended family and friends can better cope with their own range of emotions—emotions from seeing their son, daughter, brother, sister, niece, nephew or dear friend undergoing such difficulty—and allows them to reenergise to continue in their supporting role.

**Providing direction**

Some family and close friends may need guidance and direction to better support you. Sometimes, people may:

- not know what to do so avoid contact with you, or assume you want to be left alone
- not want to watch you suffer and fear they will say the wrong thing and upset you
- feel guilty about their own healthy children
- feel uncomfortable when you cry, and avoid talking about what is happening so they don’t have to confront difficult situations.

Sometimes, their reactions can be hard, perhaps making you feel disappointed, alone and isolated. Even though your family and friends may not be doing the things you want, they probably have good intentions. Some of the suggestions below may help them be more supportive.

You may also be overwhelmed by expressions of care and concern. If this is the case, you will need to kindly communicate this and ask for space or a more organised approach.

### How you can help family and friends understand what you need

Contact them and let them know what it is you need. Lots of people can cope with practical tasks and may welcome being given a job and feeling helpful.

Be specific about what you and your family do need and want. For example, ‘We have enough food thanks—but I’d love an hour to go for a walk with my husband. Could you please watch the kids?’

Tell them you are upset, but that what they do or say is not responsible for your sadness. Let them know it is very hard to know what the ‘right’ thing to say is and that you don’t expect them to solve your problems or fix your feelings and emotions.

Give them some printed material on your child’s condition, on suggestions for helping, or whatever it is you would like them to learn about. This can be done in a way that is tactful and helpful. This gives them the power to read it in their own time and space.
How you can help family and friends understand what you need

Tell them about your fears and anxieties. Let them know what will be a crisis for you (for example, the first admission to hospital, the next MRI or blood tests) so that when these events happen, they have the chance to be there for you.

Tell them you are still the same person and it’s important to you that they recognise this. You’re not just a parent of a child with a life-limiting illness—remind them you still need a laugh, a beer with a friend, a coffee and chat, and that you still want to do these things with them or at least be asked.

Adapted from: Crowe, L. 2003, When children have a life-limiting illness: Questions and answers around loss and grief, Centre for Palliative Care Research and Education, Queensland.

Most family and friends do want to help; they just may need some guidance and direction from you. You can copy Tool 5 and give it to family and friends.
19 – YOUR COMMUNITY

Key points

School

- School is more than a place of learning. It can provide important relationships and support for sick children, their parents and siblings.
- School provides a reassuring routine and a sense of normality.
- Having an open and informed relationship with your child’s school will benefit you and your child. Arrange to meet with your child’s teachers and keep the school updated on developments in your child’s health and care needs. Ask your care team about support for the school.

Employers and work colleagues

- Most parents find continuing to work a challenge. Your workplace will most likely be understanding and flexible if you need to reduce your hours or take leave.
- Your social worker can help you provide supporting documentation, and also help with accessing financial advice and assistance.

Your child’s school

Deciding what role your child’s schooling will play is one you and your child need to make through discussions with your care team and your child’s teachers. Continuing to attend school in some capacity for as long as possible provides benefits for children and families:

- keeping routines as consistent as possible, providing your child with a sense of security and another focus beyond their illness
- having the benefits of play and maintaining contact with their friends as well as continuing their education.
- allowing your child to feel a sense of achievement by continuing to study.

Your child has a right to attend school, even if it is only going to their favourite lesson once a week or meeting with their friends at lunch time.

Having an open and informed relationship with your child’s school will benefit you and your child. It is important your school is aware of the difficulties you are facing and the impact they may have.
Suggestions for dealing with school issues

Talk to your child and ask what they want to do about school. Think about schooling options such as shorter days or attending a few days each week, and develop a plan.

Set up a meeting with your child’s teacher and school principal. Consider including the teachers of your other children – they also need to be aware of what is going on. Discuss:

- your child’s illness and family situation (as much as you are comfortable) so they have a good understanding of what is happening
- what you want the other students/families to know about your child’s illness
- ways of helping your child stay in touch with their classmates
- how you can contact your other children at school quickly if needed
- how you can best keep the school updated.

If you need help with the school or explaining your child’s health, talk to a member of your care team to get advice. Consider asking them to come along with you.

Find out what additional emotional and educational support the school can provide for all your children. Schools may have support services available or be able to provide you with some home activities and resources.

When it is no longer possible for a child to attend school, their education may continue through various home tuition support services or hospital schools for as long as the child is well enough and enjoying the learning experience. Some schools are able to link home and school through internet webcam technology.
Employers and work colleagues

Most parents find continuing to work a challenge. Your workplace will most likely be very understanding and flexible if you need to reduce your hours or take leave. Your social worker can help you provide supporting documentation, and also help with accessing financial advice and assistance.

If you are continuing at work, you may feel particularly vulnerable about your family’s situation and it’s your choice whether you share this information with your employer and work colleagues. Some parents choose to keep this information private, partly because their workplace is an ‘escape’ where life continues as ‘normal’ and where they feel they are treated as ‘normal’. Others may choose to confide their family’s situation to their employer and close work colleagues, particularly since they may be in need of understanding and support in the workplace.

Some employers offer employees and their families free access to a confidential counselling service (often referred to as an employee assistance program). This service is usually made available for personal or work-related issues and gives you an opportunity to explore how you are feeling about work, your family or anything else you wish to discuss.

If you are having any difficulties, discuss this with your care team and they may be able to help you.
A common response to life changing events is to search for meaning and understanding, including questioning your current beliefs.

Spirituality is about how you experience your world. It is possible to have spiritual needs independently of religious needs.

The spiritual needs of children are as real and important as those of the adults who surround them.

Provide opportunities for everyone to explore their own sense of spirituality.

What is spiritual care?

When people are confronted by serious illness and life changing events, a common response is to search for meaning and understanding. Spirituality is about how people experience the world they find themselves in. This may or may not include a god figure or a religious faith. It is about how we try to find meaning in the world and how we react within it. It is possible to have spiritual needs independently of religious needs.

Spiritual care is about responding to the uniqueness of your situation. Everyone is different in how they deal with their doubts, beliefs and values. Some people can find a spiritual connection in a ritual, such as listening to a piece of music or by spending time in a special place. Connecting with nature can provide a sense of peace or balance, even if only for a short time. Whatever a person’s interpretation of spirituality, it should be respected and validated throughout their journey.

Maintaining a sense of hope for the future is important for many families; it underpins our expectations. Hope can be strongly connected with our spiritual beliefs. What children and families hope for may change over time. People can experience various transformations of hope: hope for cure, for comfort, for dignity, for effective treatment, to be free of pain, and to cope as a family and as an individual.

You may feel a sense of distress about familiar beliefs because of your child’s diagnosis. It’s normal to have anger and doubts but at the same time, wish to seek reassurances. It’s important to explore these complex feelings with someone you trust.
Children and spirituality

The spiritual needs of children are as real and important as those of the adults who surround them. It is important to provide opportunities for everyone to explore their own sense of spirituality. Children often have a very clear view of their doubts, beliefs and values and may wish to discuss these. It’s helpful if you can give your child the opportunity and time to talk about these issues or, if the child prefers, you can find someone from your care team who can help you.

‘Talking with your child about this part of their life can be difficult. Resources such as children’s story books and programs can be helpful in initiating conversations. However, often these discussions will be spontaneous and may catch you by surprise. What is important is to provide space to explore with children what they perceive is happening in their world and what it could mean for them and their family.’

‘The chaplain at the hospital was really good, he just kept coming and saying hi, that’s all. One day he was on the ward and I grabbed him and introduced him to Lewis. I told Lewis he was an expert in spiritual matters and did he have anything he wanted to talk about? Lewis signed ‘death’. It was really poignant. I did most of the talking because I needed to have that talk with Lewis and the chaplain just stayed with us and allowed it to happen. Having him there made it possible. It was like permission.’
**TOOL 3 – SAMPLE CARE PLAN**

| Name |  
| Weight | 35kg | DOB | 15/06/05 | Age | 5 years |
| ID Numbers (Medicare/hospital) | xxxxxxxxxx | xxxxxxxxxx |
| Allergies | penicillin |
| Diagnosis (if known) or main illness | muscular dystrophy |
| Key Coordinator |  
| Contact details |  

**Specific instructions (Area to record specific instructions for the care of your child)**

**IF this happens**

- Temperature above 38 degrees for longer than 6 hours.

**THEN follow these instructions**

- Contact key coordinator for advice.
- Increase fluids intake.

**Care goals**

<table>
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<tr>
<th>Skin care</th>
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</table>

**Care actions**

- inspect skin all over each day
- apply moisturiser each day
- change wound dressing as ordered.
- decrease pressure/irritation to skin:
  - fleece pad
  - egg crate mattress
  - keep skin clean and dry
  - gently massage pressure points with lotion
- turn and reposition twice a day
- keep nails short

**Results**

- 15/11/10 – After 2 weeks skin has improved. No further signs of redness.
- Scratch on arm while playing covered with dressing.
## TOOL 3 – CARE PLAN

### Date:

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<th>Name</th>
<th>Weight</th>
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<th>Age</th>
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<th>ID Numbers (Medicare/hospital)</th>
<th>Allergies</th>
<th>Diagnosis (if known) or main illness</th>
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<th>Key Coordinator</th>
<th>Contact details</th>
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**Specific instructions (Area to record specific instructions for the care of your child)**

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<th>IF this happens</th>
<th>THEN follow these instructions</th>
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<td>Care goals</td>
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<td>Skin care</td>
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<td>Mouth care</td>
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<td>Bowel care</td>
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<td>Entertainment</td>
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**Tool 4 – Sample Medications Chart**

*Keep the medications list up to date* by crossing out any medications stopped and adding new ones.

*Take it with you* each time you visit your child’s doctor, hospital, pharmacist, and care team.

*Keep it with you* at all times in case of an emergency.

<table>
<thead>
<tr>
<th>Name</th>
<th>Weight</th>
<th>DOB</th>
<th>Age</th>
<th>Allergies</th>
<th>Contact name</th>
<th>Contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>35kg</td>
<td>15/06/05</td>
<td>5 years</td>
<td>penicillin</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of medication</th>
<th>Strength/form/route</th>
<th>What is medication for?</th>
<th>How much to use and when</th>
<th>Special Instructions</th>
<th>When to start/when to review</th>
<th>Possible side effects</th>
<th>Discuss with care team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amoxicillin</td>
<td>125mg syrup by mouth</td>
<td>urine infection</td>
<td>5ml, 3 times a day</td>
<td>- give every 8 hours approximately - use syringe measure</td>
<td>1 Nov 2010 review in 2 weeks</td>
<td>diarrhoea mouth thrush</td>
<td></td>
</tr>
</tbody>
</table>

*List all medications currently used* including: prescription medications, over-the-counter medications, and herbal and natural treatments.

*Medications come in different forms*: tablets, liquids, capsules, inhalers, drops, patches, creams, suppositories, injections, drips.

Adapted from: *National Prescribing Service Medicines List — get to know your medicines.*

<table>
<thead>
<tr>
<th>Name</th>
<th>Tick or sign when medication has been given.</th>
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<table>
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<tr>
<th>Name of medication (brand or generic name)</th>
<th>Strength/form/route</th>
<th>How much to use and when</th>
<th>Special Instructions</th>
<th>Time</th>
<th>Date</th>
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<tbody>
<tr>
<td>Amoxicillin</td>
<td>125mg/ml syrup</td>
<td>5ml, 3 times a day</td>
<td>Give every 8 hours approx, use syringe measure</td>
<td>7am</td>
<td>✓</td>
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<td>3pm</td>
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<td>10pm</td>
<td>✓</td>
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### TOOL 4 – MEDICATIONS CHART

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<th>Weight</th>
<th>DOB</th>
<th>Age</th>
<th>Allergies</th>
<th>Contact name</th>
<th>Contact details</th>
<th>Name of medication Brand or generic name</th>
<th>Strength/form/route</th>
<th>What is medication for?</th>
<th>How much to use and when?</th>
<th>Special Instructions</th>
<th>When to start/when to review</th>
<th>Possible side effects</th>
<th>Discuss with care team</th>
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When a friend or family member is caring for a seriously ill child, you may not know what to say or do. Your genuine concern and desire to help will be of comfort. Think about some of the following suggestions.

**Offer**
Support can be offered in practical ways, such as bringing a meal to your friend’s house or running errands. Give your friend an idea of what you are able to do.

**Respect**
When entering your friend’s home, be respectful of the family, their routine, and need for privacy. Be prepared that it might not be a good day for visitors.

**Follow**
Your friend will sometimes need to talk about his or her experience, and other times will choose not to. Watch for signs, or ask them whether they want to discuss their experience, be distracted, or just to be quiet.

**Ask**
When in doubt, ask your friend how you can best offer your help and support. Try to keep on task when providing help and be mindful they may be too exhausted and busy to talk.

**Comfort**
Sometimes simple gestures like a well chosen card, small posy of flowers, baking, or a basket of treats is a way of showing that you care.

**Consider**
Be aware of the child’s health condition. If you are unwell or have been near another sick person, don’t visit.

Remember siblings—if you take a present for the sick child, try to give some special attention or a small gift to the siblings as well.

Help the family maintain their routine whenever possible by providing transport and babysitting.
Provide

Provide ways for the children to keep in contact with their friends or peers. Find out if there is a roster for home help, meals and transport, or offer to coordinate or set one up. Help to share with others what the family like to eat, and what everyone is cooking. Deliver food for dinner by 5pm and aim for provision of a complete meal that is easy to heat and serve.

Help with general household tasks, such as:

- washing clothes or dishes
- cleaning and tidying up around the house
- walking the dog
- answering the phone or helping answer correspondence
- driving your friend or family member to places they need to go
- mowing the lawn or taking care of the garden
- grocery shopping
- picking up medications or supplies.

Remember—your aim is to support your friend and the key is to provide help which is dependable, sensitive and easy for them to accept.
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?”
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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.
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.
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.’

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.
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.

**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
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.
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 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.
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.

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.

‘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.’

‘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

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<tr>
<th><strong>Involve your child</strong></th>
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<tr>
<td>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.</td>
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<tr>
<th><strong>Involve your other children</strong></th>
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<tr>
<td>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.</td>
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<tr>
<th><strong>Involve grandparents and significant others</strong></th>
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<tr>
<td>Grandparents are often keen to be included in these arrangements. Whenever possible, it is helpful to acknowledge the special grief and loss of grandparents.</td>
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<tr>
<th><strong>Cultural and religious beliefs</strong></th>
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<tr>
<td>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.</td>
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<tr>
<th><strong>Burial or cremation</strong></th>
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<tr>
<td>This is an individual choice and is often a decision informed by cultural, religious, or personal beliefs.</td>
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<tr>
<td>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.</td>
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<tr>
<td>If you are considering cremation, you may want to know what is involved, the cost and when you will receive your child’s ashes.</td>
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<th><strong>Where to hold the service</strong></th>
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<td>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.</td>
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<th><strong>Who to invite</strong></th>
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<tr>
<td>You may choose to hold a private service or burial.</td>
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<th><strong>Who will conduct the service</strong></th>
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<tr>
<td>You may choose a family member, friend, minister, chaplain, or celebrant to conduct your service.</td>
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<tr>
<th><strong>Who will speak at the service</strong></th>
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<tbody>
<tr>
<td>You may want to ask your other children, grandparents, or significant others to speak at the service.</td>
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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.

‘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.’
**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.

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"When Randall (5½ years) passed away, his younger brother Baden was 2½. 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."

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"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."
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.

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

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.5

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.

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5 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.6

**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.

**Some common grief reactions to loss**

<table>
<thead>
<tr>
<th>Psychological responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>shock, numbness, denial, sorrow, loneliness, guilt, regret, fear, depression, relief, panic, helplessness, anger, feeling out of control, confusion, lack of emotions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physical response</th>
</tr>
</thead>
<tbody>
<tr>
<td>lethargy, fatigue, can’t concentrate, trembling, shaking, headaches and body aches, dizziness, sweating, nausea, chest pains</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behavioural responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>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</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>lack of interest in other people and usual activities, avoidance of others, needing to be with others, feeling alienated or detached</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Spiritual response</th>
</tr>
</thead>
<tbody>
<tr>
<td>loss of meaning and purpose, questioning faith and beliefs, feeling a sense of emptiness, loss of joyfulness, loss of direction</td>
</tr>
</tbody>
</table>

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***See Journeys Resource List Books***

‘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.’
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.
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
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.

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.

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’.”
• 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.
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.

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.
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?

Adapted from: Drew, D. 2005, Paediatric palliative care: Caring for your child at home, Sydney Children’s Hospital, Randwick.
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.

**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.

Adapted from: Today’s Health, American Medical Association.
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.

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.

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.

Adapted from: Child Bereavement Charity, What’s OK and not OK, www.childbereavement.org.uk.
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.

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**

<table>
<thead>
<tr>
<th>Accept your limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Plan ahead</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ask for help if you need it</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Allow for rest</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
</tr>
</tbody>
</table>
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

© Michelle Northey, Christmas Day 2004
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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.

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