

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

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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.



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.”



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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.



See Chapter 5

What is palliative care?
Page 29

'Our son, Joshua taught me to believe in myself and to never give up. No matter how tough things got, we never gave up hope.'

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.

'I can remember thinking when the doctors first gave us Gabrielle's prognosis, 'They have the wrong child' and I waited for them to come back and apologise... but they didn't come back.'

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.



See Journeys Resource List

Accommodation
Travel and transport



See Chapter 10

Financial support

Page 43

- 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?



See Journeys
Resource List

Aboriginal and
Torres Strait Islander
information and
support

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.

Words	Meaning
acute condition or acute illness	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).
allied health workers	Health professionals including psychologists, physiotherapists, pharmacists, social workers and occupational therapists. See chapter 4 for more information on different health professionals.
bereavement	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.
care-oriented treatment or comfort-oriented treatment	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.
carer	A carer is generally a family member or close friend who provides for the needs of the patient.
chronic condition or illness	A medical condition which has persisted for a long period of time.
complementary or traditional therapies	<p>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.</p> <p>The term traditional in this context, refers to the treatments that have been recognised by different cultural groups and peoples.</p>

Words	Meaning
conventional treatment	The range of treatments prescribed or practiced by medical health care providers.
coroner	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.
diagnosis	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.
end-of-life care	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.
evaluation criteria	A set of questions used to test that something is able to deliver what it promises.
family	Relatives, friends and key people who are identified by an individual as being part of their family. They are not necessarily a blood relative.
health professionals	Doctors, specialists, nurses and allied health workers who are specially trained and also recognised by an appropriate registering body.
holistic needs	The physical, emotional, spiritual, social, and cultural aspects of a person's needs.
hospice	A special place set up to care for people with life-limiting illnesses. A hospice provides coordinated holistic care in a home-like environment.

Words	Meaning
key coordinator	A person who works with you to plan, coordinate and communicate the care provided by the different members of the care team.
life-limiting illness	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.
medication	A range of drugs used to address symptoms.
medicine	Drugs taken by mouth used for the treatment of an illness.
multidisciplinary team	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.
paediatric palliative care	Care to maximise the comfort, wellbeing and quality of life of children with life-limiting illnesses, and of their families and carers.
palliative care	Specialist care provided for a person living with a life-limiting illness. The primary goal is quality of life.
palliative care team	A multidisciplinary team which may include nurses, doctors, social workers, volunteers, chaplains, allied health workers and other complementary health therapists.
pastoral care	Care provided by a person trained in providing spiritual support for a child, their family and carers.
post-mortem	A medical examination to determine the exact cause of death.
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.

Words	Meaning
prognosis	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.
respite care	A service which provides temporary care for the patient. Respite can be in a hospital, hospice or the home.
resuscitation	A medical action aimed at returning someone to life when their heart or breathing has stopped. Resuscitation may or may not be successful.
sick child/ seriously ill child	These terms are used in this book to indicate a child who has a life-limiting illness.
specialist palliative care provider (including nurses, doctors, counsellors)	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.
symptoms	Symptoms are signs of an illness and include such things as pain, fever, nausea, fatigue and breathing difficulties.
team-oriented approach	Health professionals with a range of training and skills, working together as part of a multidisciplinary team.
treatment	A term that describes a broad range of activities to improve health or comfort, and includes medications, tests, surgery, counselling or massage therapy.

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.

