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1 — OVERVIEW

THE BEGINNING OF A JOURNEY

You have been given this folder because there is an indication that your child may have a life limiting condition. You and your family may begin a journey during which you will need information and support. When a child needs palliative care, a whole new world opens — one that you have not chosen to enter.

Palliative care is not just about symptom management or end of life care. For some, palliative treatment can last several years while for others it may be for a shorter time. However long the time, palliative care aims to enhance all aspects of the life for the sick child, as well as their family, friends and communities.

Many families who have accessed palliative care for their child have found that one of their most immediate and consistent need was for information — what are our options, where can I get help, what do we tell our children?

This folder aims to better prepare and equip you for the many situations and issues you may need to face as you navigate through living with your child's illness. It directs you to quality information, support services and resources to help care for your child, other family members and yourself.

Importantly, this folder has been developed by people who have been on this journey and their shared wisdom is found in these pages.

WHO IS THIS FOLDER FOR?

This folder is mainly designed for parents and carers of children and teenagers with life limiting illnesses.

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

Another important purpose of this folder is to provide information for extended family, friends, carers, teachers and others in your social and support network.

See Chapter 4
'What is
palliative
care?'






CARER'S QUOTE

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.

WHAT RESOURCES ARE LISTED?

Each section of the folder contains a list of resources which include:

- books and videos 
- online resources and websites 
- services and facilities. 

The resources were selected because they contain current, high quality and accurate information. They will support your needs for more detailed information and advice.

Resources will be reviewed and updated regularly and can be found at www.pallcare.org.au

WHAT TOOLS ARE PROVIDED?

Sections 2, 3 and 4 contain a number of tools covering different subject areas. These tools can be photocopied and shared.

WHAT TOPICS OR ISSUES ARE COVERED?

This folder seeks to supply you with information about many practical and sensitive issues.

You may not need all the information contained here or you may wish to revisit the folder at different points along your journey.

This folder has 27 chapters divided into four sections. Each section aims to reflect the information needs you may have at different stages of your child's illness.

SECTION 1: INTRODUCTION

This is the section you are now reading. It includes definitions of common words used in the folder as well as words you may hear when discussing your child's illness. Additional notes for families living in rural and remote areas, families from culturally diverse backgrounds, and Indigenous families, are also included to acknowledge and focus on some unique needs of these special groups.

SECTION 2: GETTING READY — DIAGNOSIS AND EARLY INFORMATION NEEDS

You will most likely have many questions following your child's diagnosis. This section aims to explain what paediatric palliative care offers, outlines the role of different health professionals who may be involved in your child's care, and provides hints on how to find reliable health information about your child's condition and treatment options. It also includes information about your rights and responsibilities and how to access financial support.

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 death and dying, and making funeral plans. It also includes chapters dealing with bereavement support for yourself and your children, as well as suggestions for making memories.

HOW TO USE THIS FOLDER

This folder aims to be a starting point in knowing where to look or who to go to for specific information and support which best meets your needs.

In your own time read the information provided. Some sections of this folder may cover topics you don't need or are not ready for yet. You may like to think about how the information provided applies to you and your child. The folder is designed with space for you to record questions and thoughts in the margins or at a special page at the end of each section.

Ways you can use this folder include:

- to help you find information and support
- to help you raise questions about your child and their care
- to help ensure that you and your child receive the best support and care available
- to help the people around you understand what you need
- to help you care for yourself
- to connect you with other people who have had similar experiences
- to help you gently explore some of the difficult issues you may have to face in the future.

This folder is also designed to allow you to remove sections easily to photocopy or pass to those you wish to share and discuss this information with.

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

CARER'S QUOTE

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 — ADDITIONAL NOTES FOR FAMILIES

DIFFERENT NEEDS

While all children and families are special, no illness, child, family or situation is the same. The following notes aim to highlight certain issues relevant to certain family groups that may have different needs.

RURAL AND REMOTE FAMILIES

If your family lives in a rural or remote location, caring for a child with a life limiting illness can have its own challenges. Considering some of these issues and the resources may help you care for your child.

Some issues for you to think about 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 medicines?
- How will you keep in contact with 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?

Please see the Resources list at the end of this section for information on available support.

CULTURALLY DIVERSE FAMILIES

If your family is from a culturally diverse background, there are many customs or 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.

Some issues for you to think about include:

- Do you feel that you can communicate with your child's care team? You may feel suddenly dependent on other people who communicate for you. This may be especially frustrating when trying to understand the complex issues about your child's health and treatment.
 - Being able to use a professional interpreter service may have benefits such as:
 - being able to translate complex medical information
 - protecting your privacy if you feel uncomfortable about sharing personal and intimate details with other family and friends
 - protecting family and friends who are emotionally attached.
- Do you feel that the care team respects your attitudes to illness and care? People from different backgrounds will often have different attitudes about illness. It is important for you to recognise these differences and have them explained to everyone involved in your child's care. Having a family member, friend or interpreter help you with this could be a good idea. You may also find that a hospital social worker has experience in helping to bridge cultural differences between families and health care teams.
- Some areas that you may have certain attitudes or beliefs about include:
 - how you think about illness, pain and disease
 - attitudes to medicines and nutrition
 - your understanding of death and dying
 - customs surrounding death, burial or cremation, and bereavement
 - spiritual matters, as well as religious issues, including rituals.

You should think about these issues and be sure to discuss them with your care team with the help of your chosen support person. Your care team will try to respect culturally specific customs and attitudes that are important to your family.

- Do you have a family or social support network? If you have resettled in Australia and have no family or social support network, you might feel very isolated and alone. There may be special groups you can connect with who may be able to provide understanding, support and comfort.

Please see the Resources list at the end of this section for information on available support.



See Chapter 9
— Financial
Support

INDIGENOUS FAMILIES

If your family has an Aboriginal or Torres Strait Islander background, traditional beliefs and culture can have a big impact on the way you want your child to be cared for.

If you identify as an Aboriginal or Torres Strait Islander, regardless of where you live, you may feel there are cultural barriers to receiving care for your child in the way you want.

Some issues for you to think about include:

- Do you feel comfortable talking to your child’s care team? Working together with your care team will benefit your child. Don’t be afraid to ask questions — doctors are used to being asked all sorts of questions and it is their job to give you answers. Chapter Six, **Reliable Health Information**, gives tips on what sorts of questions to ask.
- Do you want a specialised Indigenous health worker on your care team? Some centres have specially trained palliative care Indigenous health workers. Is there an Aboriginal Medical Service near you that you can get help from? An Indigenous health worker may help you communicate better with your care team.
- Do you feel reluctance about using 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.
- 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?
- 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.
- Do you want to use traditional medicine or a traditional healer as part of your child’s treatment? If yes, discuss this with your child’s care team. They will respect your wishes and wherever possible, will include them as a part of the care your child receives.
- Do you need to plan special ceremonies with your family and community to celebrate your child’s life?

It is important for you to feel comfortable with your care team and to be able to talk to them about anything that worries you.

Please see the Resources list at the end of this section for information on available support.

3 — WORDS AND MEANINGS

This chapter describes the meaning of certain health words used in this folder.

Words	Meaning
acute condition or acute illness	A medical condition of short duration that starts quickly, has severe symptoms, but only changes the person’s ability to function for a short period of time. This is different to a chronic condition (see below).
allied health workers	Medical professionals who are not medical doctors and include psychologists, physiotherapists, pharmacists, social workers and occupational therapists.
alternative treatments	See complementary treatments.
bereavement	Bereavement is the process of grieving and mourning, accompanied by intense feelings of loss and sadness, brought about by death.
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 and is used when the focus is shifting away from cure oriented treatment. Comfort and cure oriented treatments can work together.
caregiver	A caregiver is generally a family member or close friend who provides for the needs of the patient and may take on additional tasks of a technical nature to provide ongoing care for the patient, for example, the administration of medicines.
chronic condition or illness	A medical condition which has persisted for a long period of time causing ongoing disruption to a person’s ‘normal’ life.
clinical stage	Certain medical conditions or illnesses progress through known stages called clinical stages. These stages are a way for health professionals to gather and share evidence about the treatments that have been proven to be most effective at certain stages.
complementary/ traditional/alternative treatments	These terms are used to describe a broad range of treatments that are seen as outside conventional treatments. Examples include vitamins, minerals, nutritional and herbal supplements, massage, aromatherapy, music therapy and homoeopathic medicines. The term traditional in this context, refers to the treatments that have been recognised by different cultural groups and indigenous peoples.
conventional treatment	The range of treatments prescribed or practiced by medical doctors and allied health professionals.




Words	Meaning
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 definition for 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 spiritual, physical, cultural, social and emotional aspects of a persons needs.
hospice	A special place set up to care for people with life limiting illnesses. A hospice provides coordinated holistic care (medical, emotional and spiritual support services) in a home-like environment.
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 condition	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.
multidisciplinary team	A team of health care providers 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, their families and carers.
palliative care	Care provided to patients with a life limiting illness. It aims to maximise the quality of life of the patient, their family and caregivers.

Words	Meaning
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 caregivers.
post-mortem	A medical examination to determine the exact cause of death.
primary caregiver	A person that provides the primary support role for the patient at all levels of need. When the patient is a child, the primary caregiver may be the mother, father or carer or a combination of these.
prognosis	Prognosis refers to the doctor's expectation of how a patient's disease will progress, based on their knowledge and experience with patients with a similar medical conditions.
resources	People, tools or materials that you can use as a source of help or information. The resources included in this folder include existing literature (books, brochures, etc.), information found on the internet (websites), and support groups and community organisations (people) as well as how to access services.
respite care	A service which provides temporary care for the patient. Respite can be in a hospital or hospice or it can mean a change in the caregivers in the home.
resuscitation	The act of reviving someone whose heartbeat or breathing has stopped.
sick child/seriously ill child	These terms are used in this folder 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 manager in assessing a person with a life limiting illness, their family and care needs and taking action to ensure that such needs are met, through the coordination of a care team.
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.
traditional medicine	See complementary treatments.
treatment	A term that describes a broad range of activities to improve health or comfort, and includes medicines, tests, surgery, counselling or massage therapy.

RESOURCE SET

SECTION 1 — INTRODUCTION

Welcome to the resource set for Section 1 of *Journeys — Palliative Care for Children and Teenagers*. In this set you will find a list of resources which includes reading material titles, organisation names and contact details, and other information.

The aim is to make it much easier for you to find additional information and support. The symbols    are used to illustrate whether the resource is found by phone, book or website/email.

It is important that this information is current. You may like to check with your care team that this is the most current version available. If not, an updated version can easily be provided.

The resources listed here are those which are generally available across Australia. Space has been allocated for you to record other resources and contact details, particularly those available in your local area. Again, your care team will help you with a specific resource set for your state or territory if one is available.

WHERE CAN I PURCHASE OR BORROW THE BOOKS LISTED HERE?

All of the books listed in this resource set are readily available.

Library — the listing includes the full title, author and ISBN number. This is all the information the library or bookshop will need to find this book for you.

Hospital/Health Care centre — check with your care team. There are many collections of books and reading materials available for loan.

Internet purchasing — again, each of these books are currently available for online purchasing at any major online bookstore.

RESOURCES

The following information is relevant to all families, including those residing in rural and remote areas.



Accommodation support

Your care team will be able to provide information about the options for family accommodation support which will assist you to stay close to your child while attending hospitals and medical checks.

Ronald McDonald House Charities work to improve the health and wellbeing of seriously ill children. Their work includes the Ronald McDonald Houses. Ronald McDonald Houses are attached to major women's or children's hospitals and provide a 'home-away-from-home' for seriously ill children and their families. Access criteria apply.

Ronald McDonald House Charities
PO Box 392
Pennant Hills NSW 1715
T: 02 9875 6666
F: 02 9875 6588
E: rmhc@rmhc.org.au
www.rmhc.org.au

Transport assistance schemes

Angel Flight Australia is a charity that co-ordinates non emergency flights for financially and medically needy people. All flights are free and may involve patients or compassionate carers travelling to or from medical facilities anywhere in Australia.

Angel Flight Australia
T: 1300 726 567 (toll free)
T: 07 3852 3300
F: 07 3852 6646
E: mail@angelflight.org.au
www.angelflight.org.au

Each State and Territory provides travel assistance programs for families who are required to travel long distances while attending to their health care needs.

Ask your care team (specifically your social worker) for information on how best to access these schemes.

A number of charitable organisations have travel assistance programs for families.

Ask your care team (specifically your social worker) for information on how best to approach these organisations.

Financial support

Centrelink provides information on how best to access a range of Australian Government programs for financial support. As a carer, you may be eligible for a number of payments and services.

Centrelink
T: 13 10 21 (for your nearest office)
www.centrelink.gov.au

Information on carers payments and support
www.centrelink.gov.au/internet/internet.nsf/individuals/carers_index.htm

Medicare Australia and the **Pharmaceutical Benefits Scheme (PBS)** provide access to subsidised health care programs for all Australians. Medicare Australia provides access to general practice, specialists, radiology, pathology and optometrists services. The PBS provides access to prescription medicines. Both programs have a Safety Net system to increase the financial benefits as soon as a certain threshold of health expenditure has been reached. Talk with your doctor and pharmacist to be certain you and your family are fully registered and ready to receive these benefits.

When you are entitled to a Health Care Card under Centrelink arrangements, additional subsidies for health costs apply.

Medicare Australia
www.medicare.gov.au

Medicare Public Enquiries Line
T: 132 011 (during business hours)
E: medicare@medicareaustralia.gov.au

Pharmaceutical Benefits Scheme Enquiries Line
T: 1800 020 613

Location of closest Medicare Australia Claiming Office or facility
T: 132 011
www.medicareaustralia.gov.au/yourhealth/where_to_find_us/mol.htm



RESOURCES

Services for people with additional needs

All TTY (Telephone Type Writer) enquiries
T: 1800 552 152 (free call)
or

Translating/Interpreting Service
T: 131 450 (local call rate)
T: 1800 552 152

Aboriginal and Torres Strait Islander Access Line
T: 1800 556 955

If you have **private health insurance**, the fund may provide reimbursement for certain health care costs, depending on the level and type of private health insurance.

Contact your private health fund directly to be fully aware of the services you are entitled to claim.

The **Commonwealth Carer Resource Centres** are operated by Carers Associations in each state and territory of Australia and provide a range of free information and services, including:

- practical written information about support services, home help, financial entitlements, legal matters, respite care, health and wellbeing, and dealing with grief
- counselling, through the National Carer Counselling Program
- referrals to community and government services
- emotional support
- education and training opportunities.

A free Carer Support Kit is available in English and 13 other languages. In addition to general information, it includes information on taking care of yourself, managing health care and medications, and emergency care. An Indigenous Kit is also available.

Commonwealth Carer Resource Centres
T: 1800 242 636

The **Commonwealth Carelink Centres** provide a single point, nationally, for anyone to access information on community-based care and services in their local area.

Commonwealth Carelink Centres
T: 1800 052 222
TTY: 1800 555 677 and ask for 1800 052 222
Speech-to-Speech Relay: 1800 555 727 and ask for 1800 052 222
Interpreter assist: 13 14 50

Equipment hire

Each state and territory provides assistance for families who require access to a range of equipment to help them care for their child at home. In some states the programs are called PADP (Program of Appliances for Disabled People).

These programs will also be able to advise on services including home and care modifications and access to a specialist child occupational therapist.

Ask your care team (specifically your social worker) for information on how best to access these schemes.

The **National Independent Living Centre** provides access to information and advice on medical equipment and consumables available through the Independent Living Centre network. Local centres are able to advise on programs for funding support.

National Independent Living Centre
T: 1300 885 886 (for your local centre)
www.ilcaustralia.org.au

Australian Capital Territory
T: 1300 885 886
T: 02 6205 1900
F: 02 6205 1906
E: ILCACT@act.gov.au
www.health.act.gov.au/ilc

New South Wales
T: 1300 885 886
T: 02 9890 0940
F: 02 9890 0966
E: help@ilcnsw.asn.au
www.ilcnsw.asn.au



RESOURCES

RESOURCES

Queensland

T: 07 3397 1224
 T: 1300 885 886
 F: 07 3394 1013
 E: enquiries@ilcql.org.au
 www.ilcql.org.au

South Australia

T: 1300 885 886
 T: 08 8266 5260
 F: 08 8266 5263
 E: ilcsa@ilc.asn.au

Tasmania

T: 1300 885 886
 T: 03 6334 5899
 F: 03 6334 0045
 E: ilc@ilctas.asn.au
 www.ilctas.asn.au

Victoria

Brooklyn Vic 3025
 T: 1300 885 886
 T: 03 9362 6111
 F: 03 9314 9825
 E: ilc@yooralla.com.au
 http://deis.vic.gov.au/

Western Australia

Independent Living Centre of Western
 Australia
 T: 1300 885 886
 T: 08 9381 0600
 F: 08 9381 0611
 E: enquiries@ilc.com.au
 www.ilc.com.au

Respite care

Your care team will be able to provide advice and information on options for respite care in your area.

The **Commonwealth Carer Respite Centres** provide a single point of contact for carers seeking information and advice about centres for respite services and support available. These centres are run by a wide variety of community organisations across Australia.

T: 1800 050 059

Social support links**Community support organisations**

A range of community support organisations and illness specific support groups are established across Australia. These groups can often be a great source of information and networking with families experiencing similar journeys. To find whether they may meet your needs:

- talk with your care team members
- contact the carer resource centre (below)
- look in your local Telstra supplied phone directory or under white pages on the <http://telstra.com> web site.

The Commonwealth Carer Resource

Centres, operated by Carers Associations in each state and territory, are able to provide information on support services, counselling and community services.

Commonwealth Carer Resource Centres
 T: 1800 242 636

Resources for culturally diverse families**General support**

Social workers are able to connect families with interpreter, financial, community and other services. You may like to ask your care team to arrange for a social worker to meet with you.

Interpreter Services (National)

Provides 24 hour a day access to interpreter services

Translating and Interpreting Service

T: 131 450

Palliative Care Victoria has produced a number of publications in different languages on palliative care.

Palliative Care Victoria

Suite 3C, 182 Victoria Street
 East Melbourne VIC 3002
 T: 03 9662 9644
 F: 03 9662 9722
 www.pallcarevic.asn.au

Carer Support Kits are available in English and 13 other languages from the **Commonwealth Carer Resource Centres**.

Commonwealth Carer Resource Centres
 T: 1800 242 636

The **NSW Multicultural Health Communication Service** produces brochures on palliative care in 20 languages.

NSW Multicultural Health Communication Service
 PO Box 58
 Gladesville NSW 2111
 T: 02 9816 0347
 F: 02 9816 0302
 E: mhcs@sesiahs.health.nsw.gov.au
 http://mhcs.health.gov.au

Centrelink Multicultural Services can help if you need information in your own language, including free interpreter services for interviews and free translation of documents relating to Centrelink business.

Centrelink Multicultural Services
 T: 13 12 02

Community Support

Cancer Information and Support Services run a cancer helpline which is staffed by both enquiries officers and nurse counsellors who are registered nurses with oncology qualifications and experience. The **Cancer Helpline** can provide callers with links to cancer support groups and other community resources. The Cancer Helpline is available in languages other than English through the Multilingual Cancer Information Line.

Cancer Information and Support Services**Cancer Helpline**

T: 13 11 20
 www.cancervic.org.au/cancer1/patients/support

Peak body for migrant and community health centres

Social workers are able to connect families with interpreter, financial, community and other services. You may like to ask your care team to arrange for a social worker to meet with you.

Multicultural Development Association — Multicultural Health Network
 T: 02 3394 9300

Resources for Indigenous families**General support**

Indigenous Palliative Care — addressing cultural needs website

The purpose of this site is to assist palliative care professionals in providing culturally appropriate palliative care services to Indigenous peoples and communities.

Indigenous Palliative Care — addressing cultural needs website
 http://www.indpac.org.au

