



# Paediatric Palliative care

NATIONAL ACTION PLAN PROJECT

## DISCUSSION PAPER

### Paediatric Palliative Care in Australia

CONSUMERS



Paediatric  
Palliative Care  
AUSTRALIA & NEW ZEALAND



PalliativeCare  
AUSTRALIA

This project received grant funding from the Australian Government

### Support services for consumers

Palliative Care Australia thanks you for bringing your experiences to this important process. If reading the material in this Discussion Paper or sharing your story has raised any issues for you, we encourage you to please contact the Australian Centre for Grief and Bereavement for free telephone support on 1800 642 066.

## Introduction

Palliative Care Australia (PCA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ) are working together to improve the palliative care experience for infants, children and young people and their families and carers.

In 2020, our organisations were funded by the Australian Government to work together to bring forward the first ever Paediatric Palliative Care National Action Plan for Australia. This presents a unique opportunity to review and build the capacity of the Australian health care system to better serve the needs of infants, children and young people living with life-limiting conditions and their families and carers.

To achieve this, we need to understand the views of everyone engaged in their care as well as understand the experiences of children, young people, and their families and carers. This is an opportunity for you to shape the direction of paediatric palliative care services into the future.

Hearing the experiences of children and young people, as well as those of their family and carers experiences, is critical to this process. You can tell us what genuinely supports your quality of life and your confidence in caring for your child. We need to hear when this has been achieved and what is needed to ensure the best possible care is achieved for all children, young people, and their families and carers.

We also wish to capture the views of those working in our health system to identify what works well and what could be improved for staff and consumers. We are interested in views of those working in specialist palliative care, and wish to understand the journey to, or with, specialist palliative care, and the barriers that exist. Equally the voices of those delivering generalist palliative care to paediatric consumers through primary care and other medical specialties; those providing allied health; and those delivering NDIS-funded services, can all inform the picture of paediatric palliative care nationally.

On behalf of our organisations, we thank you for your contribution.

Thank you and kind regards,



**Meera Agar**  
Chair  
Palliative Care Australia



**Sara Fleming**  
Chair  
Paediatric Palliative Care Australia  
and New Zealand



# Contents

Introduction	3
Background	6
Responding to this Discussion Paper	7
1 Improving quality of services in the community and acute care	8
2 Improving access to services	10
3 Improving skills of the workforce, parents and carers	12
4 Improving knowledge of palliative care across the community	14
5 Improving collaboration between States/Territories Governments and the Commonwealth Government	16
6 Improving research and data collection	18
7 Improving uptake of advanced care planning	20
8 Improving dissemination of information	22

## Terms used in this Discussion Paper

### Paediatric Palliative Care

PCA adopts the definition of palliative care for children with life-limiting conditions as an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on the enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of short breaks, and care through death and bereavement\*.

### Family

The term family includes siblings, parents (including separated parents), step-parents, grandparents, and other carers.

### Age Groups

Paediatric palliative care services are provided from the perinatal period, through to age 18 years, noting a period of transition to adult services can also be supported where required up to the age of 25.

### Health Consumer

Health Consumers New South Wales defines a health consumer as people who use health services, as well as their family and carers. This includes people who have used a health service in the past or who could potentially use the service in the future.

\* Together for Short Lives, Information – Children’s palliative care definitions, available: <https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/>

# Background

The **Paediatric Palliative Care National Action Plan** is part of a three-year project - *The Paediatric Palliative Care - National Action Plan project*. This project is part of the *Supporting children with life threatening medical conditions and their families 2019 Election Commitment*.

There are 10 activities within the *Paediatric Palliative Care - National Action Plan project*. Further information on the project can be found [here](#).

We have completed a literature review which has highlighted the available evidence to build a picture of what paediatric palliative care is in Australia.

## The literature review examined eight key areas, including improvement of:

- 1 quality of services in the community and acute care
- 2 access to services
- 3 skills of the workforce, parents, and carers
- 4 knowledge of palliative care across the community
- 5 collaboration between States/Territories and the Commonwealth
- 6 research and data collection
- 7 uptake of advanced care planning
- 8 dissemination of information.

These eight areas form the sections of this Discussion Paper. The literature review can be found [here](#).

# Responding to this Discussion Paper



## Response period

Responses to this Discussion Paper will be open for a two-month period to 5pm on 30 August 2021.

Responses outside these dates will not be considered.

You **do not** need to respond to all of the questions.

## How will the information be used?

Responses to questions in the Discussion Paper will be compiled with evidence from the Literature Review and other feedback from consultations/focus groups to inform the development of a Paediatric Palliative Care National Action Plan.

Demographic information will be used to support the analysis of the responses only.

## Support services for families – consumers and carers

PCA and PaPCANZ thank you for bringing your experiences to this important process.

If reading the material in this Discussion Paper or sharing your story has raised any issues for you, please contact the Australian Centre for Grief and Bereavement on **1800 642 066**. This **free confidential telephone support** has been made available for consumer participants taking part in this process.



## Demographics

To assist in analysing responses to the Discussion Paper, please complete the following questions:

### Are you:

a young person with a life-limiting illness who has received or are receiving palliative care?

a carer/family member of a child or young person who has a life-limiting illness who has received or are receiving paediatric palliative care?

a consumer from a disease specific or consumer organisation?

a clinician? If so, in what sector?

### What is your residential postcode?

What is the main reason you are contributing to this Discussion Paper consultation?

Do you have any further comments?

# Improving quality of services in the community and acute care



Sometimes, infants, children and young people experience illnesses that are likely to shorten their lives. It is important they and their families and carers receive support to live as well as they possibly can.

Palliative care services can provide an important part of this support, whether the infant, children or young person is at home, in the community, in hospital or in a children's hospice. Specialists in children's palliative care often need to work together with the infant, children or young person general practitioner, other paediatricians, nurses, and a range of other professionals and community support to deliver care.

The important elements of care that we have identified from the existing research include:

- » making sure that the family is at the centre of all care provided
- » allowing families and carers to have access to (or at least know about) palliative care early
- » making sure treatments aimed at curing or prolonging life can sit alongside treatments aimed at improving quality of life
- » making sure that the child and family, where required, are supported by a multidisciplinary team meeting their individualised needs
- » having guidelines for care which can be adapted to suit a specific age group, such as infants through to young people.

## What are your thoughts on the following?

How can palliative care for infants, children and young people be improved?



How can the various services and individuals involved in providing palliative care to infants, children and young people work better together?



# Improving access to services



## What are your thoughts on the following?

Paediatric palliative care services can be delivered at home, in the community, in hospital or in a hospice. Care needs to be provided in whichever setting meets the current needs of the infant, child or young person and their family and carers.

All the major children's hospitals in Australia provide specialist paediatric palliative care services. (one each in Queensland, Western Australia, South Australia, and Victoria and three in New South Wales). There are three children's hospices across the country including Very Special Kids (Victoria), Bear Cottage (New South Wales) and Hummingbird House (Queensland).


In regional, rural and some metropolitan areas local health professionals, such as general practitioners, often provide care collaboratively with, or supported by, the specialist paediatric palliative care services. This can occur by phone and telehealth.

It is also important that health services and health professionals provide care that meets the cultural and spiritual needs of families and carers, such as those from Aboriginal and Torres Strait Islander background and culturally and linguistically diverse populations.

The important elements of care that we have identified from the existing research include:

- » the ability to access palliative care services from the time of diagnosis
- » making sure infants, children and young people can be cared for wherever feels right for the child and family
- » allowing children and families to have flexibility and choice in their preferred place of care
- » supporting children, families and carers to change their preferred place of care in response to a change in care needs
- » ensuring the preferred place of care can meet the families' cultural and spiritual needs
- » having access to services when they are needed, such as an after-hours telephone support service.

How can we make sure that infants, children and young people who need palliative care get it when they need it?



How can we avoid a situation where some people receive better support than others?



## Improving skills of the workforce, parents and carers



Specialist paediatric palliative care services provide direct care to infants, children and young people with complex palliative care needs. The services vary in their constitution but draw on a range of disciplines including specialist medical, nursing and allied health staff.

Pastoral care through multi-faith chaplains and spiritual advisors may also be included in the specialist team. Accredited interpreters and additional support services should also be included as needed.

Where children, young people, families and carers are unable to access face to face specialist paediatric palliative care services, the service can provide support and advice and can educate other health professionals such as general practitioners and those working in community settings who are providing care.

Families and carers need information and training on the practical aspects of home and hospital-based care including symptom management, medication administration and nursing care. Improving the skills of caregivers will enhance their confidence and the quality and scope of care they can provide in the home.

The important elements that we have identified from the existing research include:

- » specialist health professionals who provide paediatric palliative care should have more advanced skills and knowledge
- » there is an expectation that health professionals frequently involved in caring for children with life-limiting conditions have a foundational level of paediatric palliative care knowledge and skills
- » core competencies in a palliative approach to care could be required for undergraduate clinicians and qualified paediatric care providers.
- » parents and carers must have access to training to support them in caring for their infant, child or young person in the home.

### What are your thoughts on the following?

What do you think doctors, nurses and other health professionals need to know more about when it comes to looking after infants, children or young people with illnesses that may cause them to die at a young age?



How can health professionals better understand and include an infant, child or young person's family (parents, step-parents, siblings, grandparents and other key figures) in care?



## Improving knowledge of palliative care across the community

# 4

### What are your thoughts on the following?

Generally, there is a reluctance in the community to discuss death and dying. The community also have a limited understanding of what palliative care is and what palliative care services can offer.

Further, there is a limited understanding that palliative care services can be accessed from the time of diagnosis of a life-limiting condition and how palliative care can be provided alongside curative treatment.

Depending upon their diagnosis, Infants, children and young people can receive palliative care for many years. Palliative care needs in infants, children and young people can also vary, from times of increased need during acute illness, the ongoing management of the condition, and end-of-life care..

Some of the important elements that we have identified from the existing research include:

- » the community are more likely to accept paediatric palliative care once they understand that it focusses on relieving symptoms and enhancing quality of life
- » the need to improve comfort in discussions about death and dying
- » the need for enhanced understanding that palliative care can be provided alongside curative treatment
- » the importance of providing education to community groups who interact with the child or young person and their family on understanding palliative care

What would you like the general population to better understand about palliative care for infants, children and young people?





# 5

## Improving collaboration between States/Territories Governments and the Commonwealth Government

In Australia, Federal and State or Territory governments all have a role in the development, funding, and provision of paediatric palliative care. Areas include policy and evidence guidance, workforce, program delivery and data collection.

At the national level, a number of best practice guidelines have been developed to ensure that state-based services are developed in line with these guidelines. Best practice guidelines include a National Consensus Statement on Paediatric End-of-Life Care<sup>1</sup> (Australian Commission on Safety and Quality in Health Care), and a Paediatric Addendum to the Palliative Care Service Development Guidelines<sup>2</sup>, (Palliative Care Australia).

Collaboration across jurisdictions is facilitated through PaPCANZ. This network of specialist health professionals aims to lead the development of paediatric palliative care by sharing information and resources, advocating for this patient group, facilitating education and training, and contributing to the development of standards, guidelines and research.

Some of the important elements that we have identified from the existing research include:

- » National policies and practices that ensure a shared vision for paediatric palliative care and consistency across jurisdictions in working to achieve this vision
- » Federal governments facilitating collaboration across jurisdictions by supporting national level data collection on children with life-limiting conditions and paediatric palliative care service provision.

### What are your thoughts on the following?

What advice would you have for the State and Federal governments about working together to help infants, children and young people who need palliative care?



1. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and highquality paediatric end-of-life care. Sydney: ACSQHC, 2016.  
2. Palliative Care Australia 2018, Paediatric Addendum - Palliative Care Service Development Guidelines, PCA, Canberra. Prepared by Aspex Consulting, Melbourne.

# Improving research and data collection

# 6

What are your thoughts on the following?

To date there have been many projects undertaken that identified priorities for research in paediatric palliative care. Most often these have identified clinicians' research priorities, but there have also been attempts to understand the research priorities from the perspective of infants, children, young people and their families and carers.

CareSearch (the Australian palliative care knowledge network) includes paediatric palliative care as part of its collection of systematic reviews. CareSearch increases awareness of current research activities by maintaining a register of Australian research projects and studies in palliative care. CareSearch also provides access to a research data management system that supports data collection and reporting.

It is challenging to estimate the current and future demand of children living with life-limiting conditions and the number of children and their families who would benefit from paediatric palliative care service involvement. Estimates from overseas have involved complex processes for data collection<sup>3</sup>. However, the ability to collect and analyse data has the potential to support current and future paediatric palliative care service delivery.

There are a number of key focuses for research in paediatric palliative care which include:

- » the prevalence of infants, children, young people with life-limiting conditions in Australia
- » to inform workforce planning
- » to support and inform continuous demonstrate quality improvement
- » to demonstrate quality indicators<sup>4</sup>

The important elements that we have identified from the research include:

- » enhancing routine data collection
- » promoting research in recognised areas of importance
- » ensuring all key stakeholders are represented in research activities.

What would help to improve research in paediatric palliative care?



3. Palliative Care Australia 2018, Paediatric Addendum - Palliative Care Service Development Guidelines, PCA, Canberra. Prepared by Aspex Consulting, Melbourne.  
4. Palliative Care Australia 2018, Paediatric Addendum - Palliative Care Service Development Guidelines, PCA, Canberra. Prepared by Aspex Consulting, Melbourne.

# Improving uptake of advanced care planning



Families and carers, children (where appropriate), together with the care team, share the challenge of making decisions and planning care for the infant, children and young person. These choices are individual and are different for every infant, child or young person, and may need revision if the child's condition changes.

Advanced care planning is a process of discussion between families, carers and health care providers about goals and preferences for care in the context of the patient's current and anticipated future health. The objective is to determine the overall goal of medical care, and the interventions that should and should not be provided. This will guide current treatment, as well as future treatment in the event of a deterioration in the child's condition. In most cases these are discussions that evolve and progress over time<sup>5</sup>.

Advance care planning should begin by talking about what the family understands about their situation, what is important to them, their hopes and goals, as well as their fears.


Advance care planning for infants, children and young people with life-limiting conditions has the potential to improve care for them and their families and carers, provide the opportunity to make timely decisions based on clear information, before acute deterioration, and avoid non-beneficial clinical interventions at the end-of-life.

The important elements that we have identified from the research include:

- » infants, children and young people with life-limiting conditions who are likely to benefit from advanced care planning either do not receive it or receive it close to the end of their life when its usefulness can be limited
- » the uptake of advanced care planning can be enhanced through population and system level interventions, patient and family focused interventions and training for clinicians.

## What are your thoughts on the following?

How do you think we can help children, young people and families and carers share their goals, values, hopes, and fears about care with the doctors, nurses and others who care for them?



5. The Royal Children's Hospital Melbourne, Advanced Care Planning available at <https://www.rch.org.au/advancecareplanning/>

# Improving dissemination of information

## 8

### What are your thoughts on the following?

An essential component of high-quality paediatric palliative care is effective communication between children and young people living with a life-limiting condition, family members, and health professionals, underpinned by access to educational and informational resources.

Families and caregivers should receive information that enables them to make informed decisions about the care, and to relay the needs of the child, young person, and family to others, including schools, NDIS, care providers and support workers, as well as other family members, friends and the wider community.

Families and carers need information and training on practical aspects of home-based care including symptom management, medication administration and physical care. It is also important that discussions are held, and information is provided about the infant, child or young persons clinical condition, their prognosis and the goals of care.

To support collaborative decision-making, information provided to children, young people and their families and carers should be:

- » specific to the child and young persons' individual circumstances
- » clearly explained and understandable (including for the child or young person)
- » provided at the appropriate time
- » culturally appropriate
- » consistent
- » up to date
- » provided verbally and in writing.

Family meetings between health professionals and families are an essential tool in paediatric palliative care to inform, deliberate, clarify, make decisions and set goals for future care. These discussions should also be communicated to the wider care team such as general practitioners and other networks relevant to the individual infant, child, young person and their family.

The important elements that we have identified from the research include:

- » promoting patient- and family-centred care, to ensure the expertise and preferences of patients and families and carers inform care
- » managing dissemination of information through care coordination
- » fostering partnerships across a range of healthcare professions and care settings
- » improving documentation of information.

What is the best way for doctors, nurses, and other health professionals to share information about an infant, child or young person's care?





**Paediatric**  
Palliative care

NATIONAL ACTION PLAN PROJECT