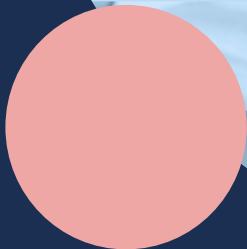




**Paediatric
Palliative care**
NATIONAL ACTION PLAN PROJECT

Paediatric Palliative Care National Action Plan



DECEMBER 2022


**Paediatric
Palliative Care**
AUSTRALIA & NEW ZEALAND


PalliativeCare
AUSTRALIA

Acknowledgements

The consumer voice has directly influenced the Paediatric Palliative Care National Action Plan and the priorities within it. Palliative Care Australia and Paediatric Palliative Care Australia and New Zealand are very grateful for the commitment of time and the preparedness of consumers to share their experiences about living with a child or young person with a life-limiting condition. These stories and insights have brought into sharp focus the many elements of the paediatric palliative care system that are both valued and working well and have also highlighted the deficits and areas for improvement.

The Plan has benefited from a comprehensive and rigorous literature review by the research team from Queensland University of Technology.

We acknowledge and appreciate the knowledge and experience of healthcare providers from all areas of the paediatric palliative care service system who contributed to this Paediatric Palliative Care National Action Plan. This included paediatric palliative care services and organisations, including Non-Government Organisations and peak bodies, as well as government representatives from states and territories. We look forward to working collaboratively with all the individuals and organisations who contributed to this Plan in its future implementation.

This project was funded by the Australian Government.

Images on the front cover and on the next page represent the diverse stakeholders who developed the Paediatric Palliative Care National Action Plan.

Acknowledgement of Country

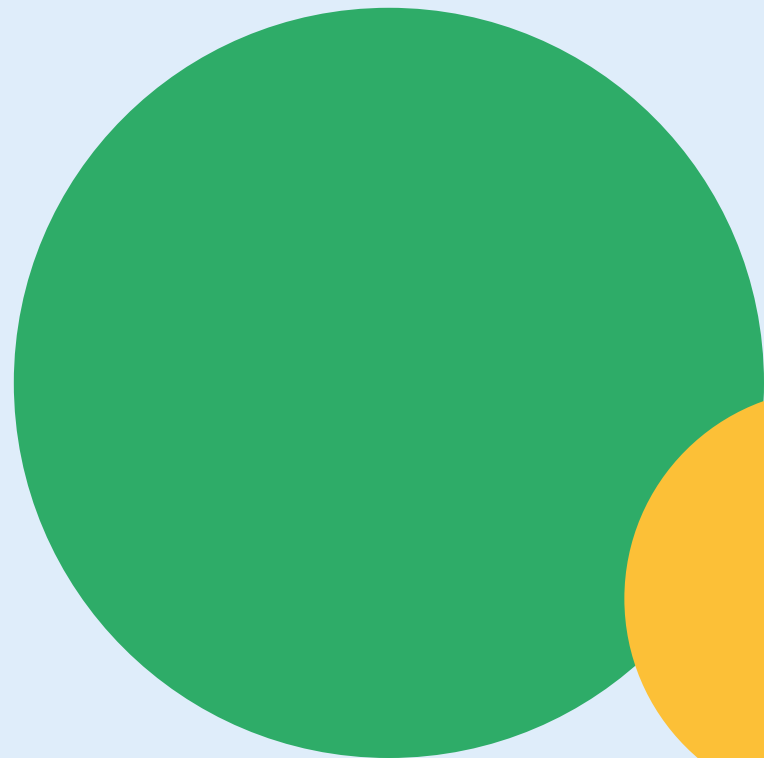
Palliative Care Australia (PCA) is in Canberra on the land of the Ngunnawal People. PCA wishes to acknowledge the traditional owners of this land, the Ngunnawal People and their elders past and present. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region.

Disclaimer

Aspex Consulting were contracted to undertake consultations with a wide range of stakeholders and developed a draft Paediatric Palliative Care National Action Plan for PCA to consider and amend. The PCA would like to thank Aspex Consulting for their contribution to development of the Paediatric Palliative Care National Action Plan.

List of abbreviations

| | |
|----------------|---|
| ACSQHC | Australian Commission for Safety and Quality in Healthcare |
| LGBTQI | Lesbian, Gay, Bi-Sexual, Trans, Questioning/Queer, and Intersex |
| PaPCANZ | Paediatric Palliative Care Australia and New Zealand |
| PCA | Palliative Care Australia |
| PCOC | Palliative Care Outcomes Collaborative |
| QuoCCA | Quality of Care Collaborative Australia |



Foreword

On behalf of Palliative Care Australia (PCA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ) we would like to thank the many individuals and groups who have contributed to the development of the Paediatric Palliative Care National Action Plan (the Plan).

The Plan was prepared by PCA with funding support from the Australian Government Department of Health and Aged Care.

The rigorous research base and broad consultation process has ensured that this Plan forms a valuable addition to the existing body of knowledge about paediatric palliative care in Australia. The Plan is closely aligned to the Palliative Care Service Development Guidelines 2018- Paediatric Addendum, the National Palliative Care Strategy, 2018 and the Australian Commission on Safety and Quality in Health Care's National Consensus Statement: essential elements for safe and high quality paediatric end-of-life care, 2016 (with an update expected in 2022).

This Plan is intended for policy makers and those in system and service design including Commonwealth, state and territory governments, and all other organisations involved in the paediatric palliative care service system.

The Plan provides guidance on key priorities and proposed actions to improve outcomes for children, young people and their families living with a life-limiting condition as informed by input by consumers and other key stakeholders.

As a document published by PCA, the Plan does not reflect commitments by and across governments - though it may inform future government efforts to strengthen paediatric palliative care. It has been written to reflect the diversity of funding, policy and service delivery arrangements already in place across jurisdictions and in the regions. Implementation of any recommended actions from the Plan will remain a decision for each jurisdiction.

In acknowledging the sheer diversity of issues and concerns that are often part of the journey for children and young people with a life-limiting condition and their families, the Plan aims to promote direct and positive outcomes. PCA and PaPCANZ look forward to continuing to work with and support paediatric palliative care services and the children and families accessing them.

We commend this document to you to inform future paediatric palliative care service design and development. PCA encourages all government and non government stakeholders to take use of the goodwill and momentum apparent through the development of the Plan.



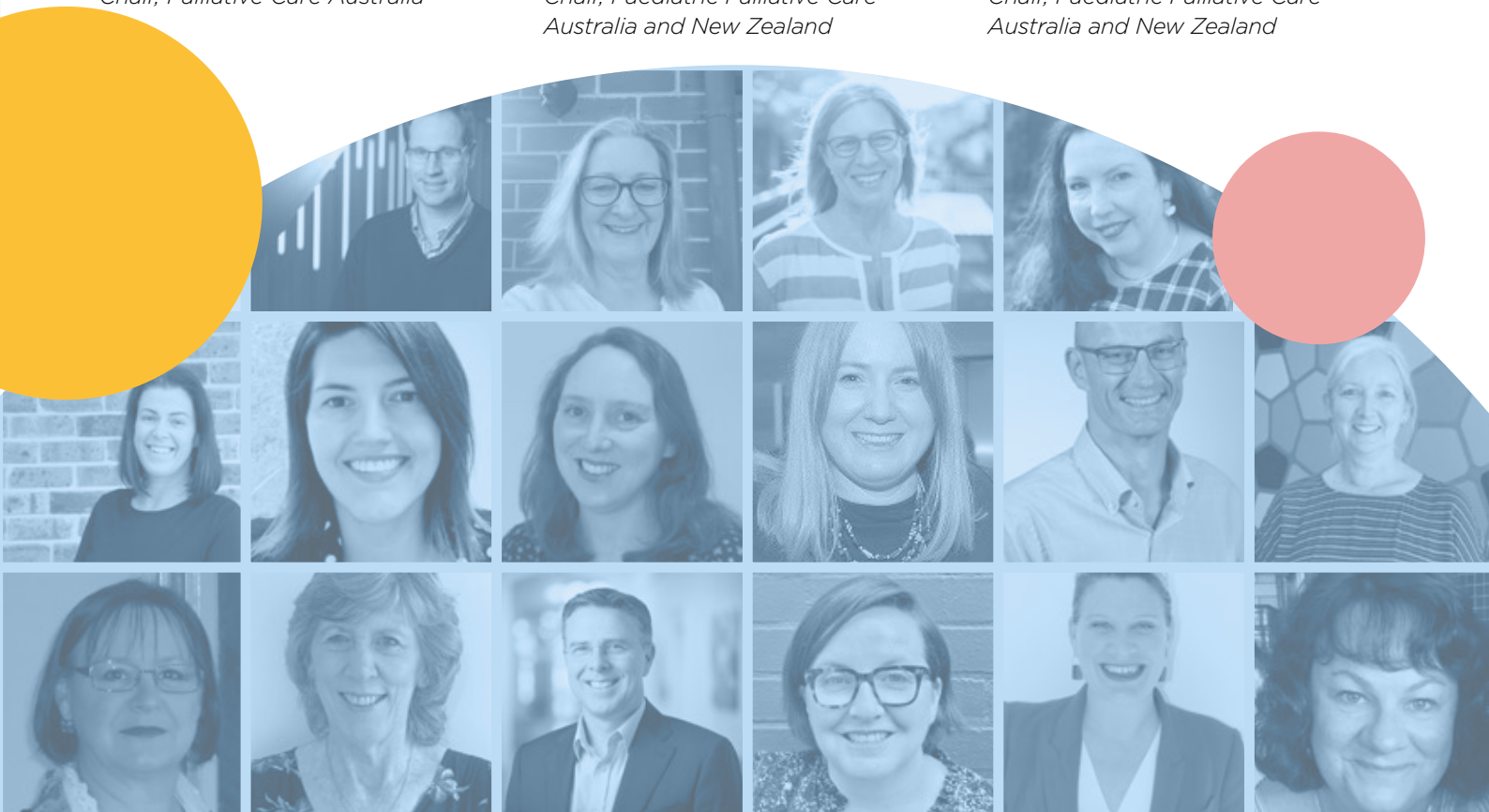
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Consumer Foreword

For many of us, the decision to participate in sharing our experiences and insight for the Paediatric Palliative Care National Action Plan was an easy one.

We are drawn to this space by the legacy of our children. The ability to play a small part and contribute to this project means that our child's death meant something. In sharing our stories, we are contributing to ensuring that others walking the path behind and beside us are cradled and carried through the journey safely and with care.

As a parent it is your core role to love and protect your child; When your child becomes ill you lose your bearings. You need a team of dedicated, caring and highly skilled health professionals to help you navigate this new way of living. No parent should ever have to bury their child, but if they do then having the right care and support around them can mean that their child can live and die with dignity and love. And all of our children deserve this.

As consumers we had the opportunity to collaboratively and openly discuss ways the Australian healthcare system can learn from our experiences, in order to develop and improve all paediatric palliative care services and ensure no family in need goes without. Throughout this process, we have felt totally supported. Our thoughts and views have been listened to and respected. We valued the open discussions. This has been a true demonstration of a very valued partnership between consumers and the Project team. This plan is thoughtful, respectful and reflective of the real lived experience. This is what we need, this is what will work.

The voices of consumers being so uniquely weaved through the Paediatric Palliative Care National Action Plan is what makes this plan so different. Until you have been told that your child is going to die- to wake each morning wondering if this will be their last, to hold them in your arms as their heart stops beating - you can never understand what it means to live the paediatric palliative care journey.

The consumer voice highlights the uniqueness of paediatric palliative care and the significant role that families play in this important area of health care.

We can look at the action plan through a lens that can't be understood from a textbook or from professional experience; We provide practical insight from the rollercoaster that is loving a child with a life-limiting condition, through every stage of the journey.

We have seen what paediatric palliative care can be and the impact it can have. It is a sentiment echoed by many of the families who contributed to this plan, that we wish we had understood the true and life-changing impact of paediatric palliative care earlier on in our journey. In its truest essence, paediatric

“The voices of consumers being so uniquely weaved through the Paediatric Palliative Care National Action Plan is what makes this plan so different.”

palliative care is about living, supporting, empowering and embracing the child and family.

We believe that the Paediatric Palliative Care National Action Plan will be life-changing for many families. It is hoped that changes can be made in order to break down the barriers and fear attached to the term 'palliative care' and to understand that paediatric palliative care isn't just about dying, it's about living. We hope the Action Plan will establish a uniform, consistent and transparent approach to paediatric palliative care, so that all families in Australia who have a child with a life-limiting condition will be able to access palliative care services, in the most appropriate, informative, supportive and compassionate way.

Penned by Bec, Lyn, Preeti, Simon, and Tara, on behalf of the consumer team contributing to the Paediatric Palliative Care National Action Plan.

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Vision and priority areas



Vision

The Paediatric Palliative Care National Action Plan is a roadmap for a national approach to prioritise and work towards common goals and objectives for paediatric palliative care. This is to ensure that children with life-limiting conditions and their families are supported and receive the information and care they need.

The Paediatric Palliative Care National Action Plan has been developed as a stand-alone document; however, it is closely aligned to the National Palliative Care Strategy, 2018¹ the Palliative Care Service Development Guidelines Paediatric Addendum, 2018² and the current Australian Commission on Safety and Quality in Health Care - National Consensus Statement: essential elements for safe and high-quality paediatric end-of-life care, 2016.³

The Australian Charter of Healthcare Rights, 2019⁴ which applies to all people in all places where health care is provided also underpins the approach we have taken in the development of the Paediatric Palliative Care National Plan.

Terminology

For this Paediatric Palliative Care National Action Plan, the words 'children and young people' refers to everyone under 18 years old. This includes neonates and infants.

The term 'family' refers to siblings, grandparents and other people with a significant relationship to the child or young person. It is acknowledged the family, particularly for Aboriginal and Torres Strait Islander people, extends to community and other key decision makers.

Underrepresented groups refer to culturally and linguistically diverse groups (CALD), Aboriginal and Torres Strait Islander, LGBTIQ+, those experiencing homelessness or living in out of home care.

Intended audience

The intended audience for the Paediatric Palliative Care National Action Plan is policy makers and those responsible for system and service design, healthcare and disability services, non-government organisations, researchers, and research funders. It brings the voices of health professionals, service users and diverse consumer groups directly to these change makers.

Implementation

The Paediatric Palliative Care National Action Plan provides guidance and direction on key priorities and actions to improve outcomes for children, young people and their families living with a life-limiting condition, as informed by consumers and other key stakeholders.

Implementation of the recommended actions of this Paediatric Palliative Care National Action Plan is a decision for each jurisdiction.

Effective implementation will require active partnerships across governments, service providers, researchers, peak organisations, and diverse consumer groups.

Acknowledging the importance of co-design, this Paediatric Palliative Care National Action Plan requires partnering with people with lived experience from the outset and throughout the process of implementation, to ensure needs and preferences are appropriately reflected in implementation solutions.

The co-design approach recommended for implementation of the Actions in the Paediatric Palliative Care National Action Plan is supported by the work of Australian Commission on Safety and Quality in Health Care - Partnering with Consumers Standard⁵ where systems are designed and used to support patients, carers, families and consumers to be partners in healthcare planning, design, measurement and evaluation.

The plan on a page

Implementation of the recommended actions of this Plan is a decision for each jurisdiction. Effective implementation will require co-design and active partnerships across government, service providers, researchers, peak organisations and diverse consumer groups.



Quality

- 1.1 Facilitate active involvement of the child, young person, family and community (or decision makers) in care planning and care provision through guidelines, supported by health professional training and education.
- 1.2 Designate a care coordinator to support children, young people and families (noting this may change throughout the care continuum) to receive integrated care from healthcare and other support services.
- 1.3 Support healthcare providers through structured communication training to initiate advance care planning discussions with empathy and compassion and enable regular opportunities for these discussions over time.
- 1.4 Promote and support alignment with the current Australian Commission on Safety and Quality in Health Care end of life guidance.
- 1.5 Develop and implement guidelines for health care workers who are providing non specialist paediatric palliative care in the community, to support best practice, holistic paediatric palliative care.

Access

- 2.1 Develop and implement an optimum paediatric palliative care pathway including a transition pathway between paediatric and adult palliative care services.
- 2.2 Develop community led, culturally safe and responsive care pathways for paediatric palliative care of Aboriginal and Torres Strait Islander people.
- 2.3 Develop culturally diverse and responsive care pathways for paediatric palliative care of underrepresented groups.
- 2.4 Develop a National Paediatric Palliative Care Workforce Strategy.
- 2.5 Deliver comprehensive and multidisciplinary specialist paediatric palliative care across all jurisdictions.
- 2.6 Expand community-based paediatric palliative care capability and capacity.
- 2.7 Embed an outreach education model to support access to care for children and families in rural, regional, and remote areas through upskilling and training health professionals to deliver sustainable paediatric palliative care education.

Information sharing and collaboration

- 3.1 Routinely assess and discuss with children, young people, families and communities (or relevant decision makers) their information needs at all stages of palliative care and facilitate access to information tailored to need.
- 3.2 Develop a targeted community awareness strategy that can build knowledge about key issues relevant to supporting children, young people and families who need paediatric palliative care.
- 3.3 Collaborate with key stakeholders to enable implementation of the Paediatric Palliative Care National Action Plan.

Data and research

- 4.1 Undertake a prevalence study.
- 4.2 Develop outcome measures and implement benchmarking for paediatric palliative care.
- 4.3 Establish a national Research Cooperative Group in paediatric palliative care to identify priorities in research and support components of research where a collaborative approach is warranted.

Context

What is paediatric palliative care?

Palliative Care Australia adopts the World Health Organisation (WHO's) definition of palliative care appropriate for children and their families:

- » Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- » It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- » Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- » Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- » It can be provided in tertiary care facilities, in community health centres and even in children's homes.⁶

Palliative Care Australia defines 'specialist paediatric palliative care' as follows:

Specialist paediatric palliative care comprises services provided by clinicians and others who have advanced training in paediatric palliative care. The role of specialist paediatric palliative care services includes provision of direct care to patients with complex palliative care needs, and provision of consultation services to support, advise and educate others who are partnering in palliative care.⁷

The Oxford Textbook of Palliative Care for Children version 3 2021 defines "perinatal palliative care" as:

Perinatal palliative care (PNPC) is a holistic multidisciplinary model of care for both baby and family in the event of a perinatal diagnosis of a life-limiting condition. It aims to provide optimal symptom control and end-of-life care to the baby as well as specialised support to families from diagnosis through to birth, death, and bereavement.



Attributes of paediatric palliative care

In some respects, paediatric palliative care shares similarities with adult palliative care. There is an expectation that care is person-centred, with involvement in care planning by children or young people and their families, and multi-disciplinary models of care.⁸ Spiritual needs are fundamentally important together with a recognition of the importance of culturally safe and responsive care.⁹ However, there are several attributes of paediatric palliative care that differentiate the approach from adult palliative care.¹⁰ The Palliative Care Service Development Guidelines Paediatric Addendum, 2018¹¹ outline these differences:



- » **Care embraces the whole family** and uses a model of child and family-centred care;
- » The family has an increased **role in decision-making** and care for the child;
- » A substantial number of children have **non-malignant conditions**, many of which are specific to childhood;
- » Life-limiting conditions in children can be **extremely rare** and sometimes there is no definitive diagnosis;
- » The child usually always remains under the care of their **primary treating team**, with specialist paediatric palliative care providing support through a consultative model;
- » Perinatal palliative care may be provided **alongside the antenatal care** that a mother receives from the obstetric team;
- » Provision of care across a **wide range of care settings** and healthcare teams can complicate care coordination and communication;
- » Predicting a **prognosis can be difficult** and deterioration can be episodic and unpredictable;
- » The **number of children dying is smaller**; in turn, the lower volumes mean that non-specialist health care providers have less familiarity and experience in palliative care;
- » A **child is learning, growing and developing** along a continuum toward becoming a functional adult which requires social, emotional and spiritual needs;
- » A **child's ability to communicate and understand** varies according to their age or stage of development and underlying condition;
- » The provision of **education and play** is essential;
- » There may be **financial life-changing costs** to families when parents withdraw partially or completely from the workforce to become caregivers;
- » **Siblings are vulnerable**, with parents often providing care for them while providing 24-hour care to a child with a life-limiting condition;
- » **Grandparents are susceptible** to reduced psychological wellbeing through 'doubled worry': worry about the well-being of their grandchild as well as their own child (the child's parent);
- » **Conditions are sometimes familial**. Other children in the family may be conceived with, living with, or have died from, the same condition;
- » There can be **numerous, evolving losses** experienced throughout the illness trajectory requiring grief and bereavement support prior to death; and
- » The death of a child defies what is considered to be the natural order of life; parents do not expect to bury their children and this loss can lead to **prolonged, or even lifelong grieving**.¹²

The breadth of needs in paediatric palliative care is wide and includes considerations distinct to the paediatric context, including physiological and psychological changes associated with a child's or young person's development together with social, recreational, education, family and financial needs and modes of coping with stress.^{13,14,15,16} This expands the breadth of expertise required of the care team to include child life therapists, behavioural specialists, community and social care service support, respite and hospice care, psychosocial and bereavement support to greatly enhance palliative care for children and young people.¹⁷

Throughout a child or young person's illness, their care needs will vary.

Hospital-based care settings provide a key element of the paediatric palliative care service system. This spans neonatal and paediatric hospital wards to the provision of specialist paediatric palliative care services within tertiary paediatric hospitals that are often required for children with life-limiting conditions.

Hospice models are available in some states. Very Special Kids in Victoria has been in operation since 1996,¹⁸ Bear Cottage in New South Wales since 2001,¹⁹ Hummingbird House in Queensland since 2016²⁰ and the Adolescent and Young Adult Hospice in New South Wales in 2023. A project is currently underway to construct Western Australia's first children's hospice, which is anticipated to open in 2023.²¹

Findings from systematic reviews indicate that access to specialist paediatric palliative care is associated with improved quality of life, enhanced symptom control, perceived support, fewer hospitalisations, less invasive treatment, and greater use of advance care plans.^{22,23,24}

Palliative Care Australia and PaPCANZ (Paediatric Palliative Care Australia and New Zealand) expect that planning of specialist paediatric palliative care services by States and Territories will ensure that:

- Every child with a life-limiting condition and their family will have access to at least one specialist paediatric palliative care team, recognising that networked arrangements supported by telehealth and outreach support will be necessary for less populous jurisdictions;
- Specialist paediatric palliative care teams provide networking and palliative care consultative support to other health professionals to enable children and families to have timely and responsive access to paediatric palliative care services, and
- The right care is provided to the right people in the right setting with the right mix of health professionals at the right time.

The PCA Palliative Care Service Development Guidelines Paediatric Addendum 2018, recognise that the specialist paediatric workforce is limited in numbers, yet nonetheless, reinforces the importance of training and expertise in paediatric palliative care for those involved in service provision.²⁵ Pragmatically, these Guidelines also recognise that in regional and remote areas of Australia, access to specialist paediatric palliative care services is limited.

Along with the key role of hospital-based care settings, several studies have identified a key benefit of home-based paediatric palliative care, with children, young

people and families most at ease in a home setting,^{26,27} as well as other benefits relating to quality of life,²⁸ and quality of care.^{29,30}

Most systems of paediatric palliative care seek to integrate care across the continuum, with specialist palliative care providers and health care workers who are providing non- specialist palliative care, noting the management and coordination of care for people living with a life-limiting condition may be undertaken by a wide range of care providers including General Practitioners and other medical specialists such as neonatologists, paediatricians, oncologists, nurses, allied health professionals and pharmacists.

Specialist paediatric palliative care services provide care to inpatients and consultancy support to other services within acute hospital settings such as neonatal or paediatric intensive care units, among others. At the end-of-life stage, the UK NICE guideline is explicit that home-based care should include specialists in paediatric palliative care.³¹ The expectation in Australia, as outlined in the Palliative Care Service Development Guidelines Paediatric Addendum, 2018 is that paediatric palliative care services will be provided in settings to meet the needs of children or young people living with life-limiting conditions, acknowledging that most families prefer to spend as much time as possible at home.³²

Cultural safety and cultural responsiveness

Culturally safe care is an important aspect of paediatric palliative care service provision. Aboriginal and Torres Strait Islander culture is diverse throughout Australia. Factors including cultural assumptions, communication, lived experiences, concepts of health, inter-generational trauma, dispossession and racism need to be acknowledged in ensuring culturally safe care. Paediatric palliative care must align with Aboriginal and Torres Strait Islander values of kinship, culture, and community. Aboriginal and Torres Strait Islander health and wellbeing extend beyond the wellbeing of the individual to the wellbeing of the whole community. Understanding the needs of Aboriginal and Torres Strait Islander communities is essential for health professionals, requiring training, education, and appropriate engagement with community.

Considering the specific needs of culturally and linguistically diverse populations is also important. The World Health Organisation,³³ the Australian Commission for Safety and Quality in Healthcare³⁴ and Palliative Care Australia³⁵ advocate for ensuring capacity in the clinical workforce to accommodate the unique needs of culturally and linguistically diverse populations.

Research also emphasises the importance of ensuring interventions are targeted or adaptable to the needs of specific groups, including, Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse populations.



A snapshot of paediatric palliative care



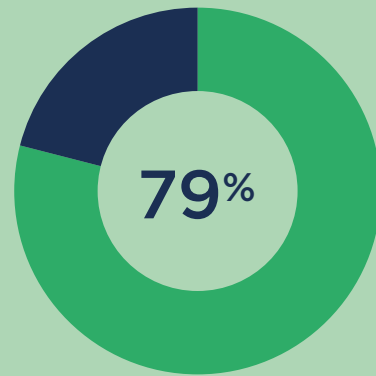
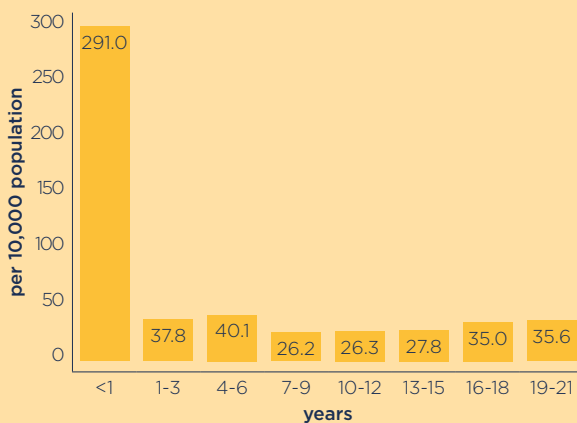
28,976 children and young people (0-21 years)

were estimated to be living with **life-limiting conditions** in Australia in 2021ⁱ

The actual number remains unknown due to a lack of readily available national data.

The evidence to support planning and service delivery is limited.

Prevalence of **life-limiting conditions** by age groupⁱⁱ



of the children under 12 months with **life-limiting conditions** were less than one month oldⁱⁱ

Non-oncological **life-limiting conditions** are more prevalent than oncological conditionsⁱⁱ



Aboriginal and Torres Strait Islander People have higher prevalence of paediatric **life-limiting conditions**^{i*}



*Prevalence per 10,000 population

i. Australian Bureau of Statistics (2021) Census 2021: General community profiles (GCP_C21). Available from: <https://explore.data.abs.gov.au/?pg=0> Accessed August 9, 2022

ii. Bowers A et al. (2020)

The proportion of children with a **life-limiting condition** who have complex needs is estimated to be aboutⁱⁱⁱ

37.5%



Unlike the adult context, **paediatric palliative care** is generally delivered over a longer time frame – on average, about

40%

longer than for adults^{iv}



Categories of life-limiting conditions

| | |
|-------------------|---|
| Category 1 | Life-limiting conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services. |
| Category 2 | Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. |
| Category 3 | Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years. |
| Category 4 | Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. Children can have complex health care needs, a high risk of an unpredictable life-threatening event or episode, health complications and likelihood of premature death. |

Complete citations^{36,37,38,39} for data sources are in the References.

.....
iii. Palliative Care Australia (2018)

iv. Connor SR et al. (2017)

Priority 1: Quality

1

Overview

- » Navigating paediatric palliative care is inherently complex. Timely coordinated and collaborative approaches incorporating clinical and non-clinical support are imperative in providing paediatric palliative care for children and young people with life-limiting conditions.
- » Consumer involvement must be strengthened and is key in the development of policies and procedures to achieve optimal paediatric palliative care.

Benefits

The benefits of implementing the set of actions relating to the priority area of quality include:

- » Empowerment of children, young people and parents to be part of the care team
- » Improved navigation for the family through multiple and complex support pathways
- » Improved insights into and understanding of the care journey
- » Improved experience of care
- » Improved wellbeing for children, young people, parents and health professionals.
- » Improved safety and quality, and
- » Improved workforce capability.

Action 1.1

Involvement in Care

Facilitate active involvement of the child, young person, family and community (or decision makers) in care planning and care provision through guidelines, supported by health professional training and education.

Implementation – Short Term: 1-2 years

- » Develop formal service guidelines to support active engagement of families in the care of their children and young people at all stages of palliative care.
- » Facilitate a process for co-design and consultation with consumers in the development and implementation of policies and procedures.
- » Evaluate the effectiveness of family involvement routinely as part of patient experience of care measures and informally through routine discussions with families and children or young people.

Why is this important?

Empowerment of children, young people and families to be actively involved in care planning recognises their rights for informed shared decision-making. Expertise is needed both to discern a child's or young person's emotional and cognitive development and to communicate in an appropriate manner, to provide the most appropriate amount and kind of information about the illness and to elicit their preferences for care. . Parents and families have insights into their child, or young person's condition and care requirements that means that they can bring relevant experience into care planning and care delivery.

In some cultures, including many First Nations peoples' populations, the community has a significant role in the decision-making process. Unless this is actively recognised, children, young people and families can feel disempowered, leading to dissatisfaction and frustration with the healthcare experience.

Action 1.2

Care Coordination

Designate a care coordinator to support children, young people and families (noting this may change throughout the care continuum) to receive integrated care from healthcare and other support services.

Implementation – Medium Term: 3-5 years

- » Define the role of the care coordinator.
- » Embed processes to identify a care coordinator from the infants', children's, or young persons' care team.
- » Increased resourcing may be required to implement a care coordinator if one is not identified within the children's current care team.
- » Evaluate the effectiveness of the care coordination model as part of patient reported outcomes and experience measures, and informally through routine discussions with families and children or young people.

Why is this important?

Families are often overwhelmed by the large number of healthcare providers involved in the care of their child and this complexity is magnified when there is a requirement for multiple external service providers including disability, education, income support and community-based services.

Coordination of culturally safe care is also essential to meet the needs of Aboriginal and Torres Strait Islander peoples and underrepresented groups. The care coordinator will have a focus on addressing the holistic care and support needs of the child or young person and family.

While the goals of care and needs may vary throughout the care continuum, the designation of a named care coordinator enables a single point of advocacy and care coordination for children, young people and families.

The care coordinator role aims to reduce fragmentation, mitigate barriers, educate, and empower patients and assist in the coordination of care. The expectations of care coordinators are outlined in PCA's Paediatric Addendum – Palliative Care Service Development Guidelines, 2018.⁴⁰

Action 1.3

Advance Care Planning

Support healthcare providers through structured communication training to initiate advance care planning discussions with empathy and compassion and enable regular opportunities for these discussions over time.

Implementation – Short Term: 1-2 years

- » Develop training modules and materials to support healthcare providers who are involved in paediatric palliative care to have challenging and difficult conversations and discuss advance care planning with compassion and empathy.
- » Develop policies which support training in the high-level communication skills required by healthcare providers working in paediatric palliative care to discuss advance care planning with families. Note: Introductory training on advance care planning, primarily in the adult sector, has been developed by Advance Care Planning Australia (<https://www.advancecareplanning.org.au/training-and-education>).
- » Evaluate the effectiveness of advance care planning needs as part of patient reported outcomes and experience of care measures, and informally through routine discussions with children, young people and families.

Why is this important?

Enabling children, young people and families to have timely discussions and access to advance care planning is important as this enables a coordinated approach to be undertaken to describe their preferences in the future for goals of treatment, and where care should be provided amongst other choices.

Given that there may be reticence by healthcare professionals in initiating these conversations, or professional uncertainty as to how best to initiate and undertake advance care planning conversations, there is a role for structured training of healthcare providers in undertaking advance care planning. Consideration should be given to the high-level skills required for paediatric palliative care providers when having advance care planning conversations with families.

Training of healthcare providers should incorporate culturally safe discussions about advance care planning.

Action 1.4

Alignment with the National Consensus Statement

Promote and support alignment with the current Australian Commission on Safety and Quality in Health Care end of life guidance.

Implementation – Short Term: 1-2 years

- » Promote collaboration between ACSQHC, PCA and the palliative care sector to support, advocate for, and promote the essential elements that are required to ensure safe and high-quality care for children and young people who are living with life-limiting illness and/or approaching the end of life.
- » Develop policies which support training in the essential elements for safe and high-quality paediatric end of life care such as End of Life Essentials (www.endoflifeessentials.com.au).

Why is this important?

The Australian Commission on Safety and Quality in Health Care current Consensus Statement⁴¹, 'Essential elements for safe and high-quality paediatric end-of-life care' (National Consensus Statement) describes essential elements that are required in systems to ensure safe and high-quality care for children and young people who are approaching the end of life. The National Consensus Statement 2016 is *mandatory* practice for health services under NSQHS Standards – Action 5.25 and 5.20. This Statement is currently being updated.

The aim of this action is to promote, develop and implement systems that enable care to be delivered in accordance with the essential elements outlined in the end of life guidance, provided as current, by the Australian Commission on Safety and Quality in Health Care.

Action 1.5

Guidelines

Develop and implement guidelines for health care workers who are providing non-specialist paediatric palliative care in the community, to support best practice, holistic paediatric palliative care.

Implementation – Short Term: 1-2 years

- » Develop guidelines for health care workers who are providing non-specialist paediatric palliative care in the community which are built on PCA's National Palliative Care Standards for All Health Professionals and Aged Care Services – for those not working in specialist palliative care.⁴²
- » Ensure the guidelines address all facets of paediatric palliative care from timely assessment and care planning, treatment and support, family and carer support, bereavement support, and transitions of care.
- » Develop a range of educational resources for providers, to support the implementation of these guidelines for those not working in specialist palliative care.

Why is this important?

A large component of paediatric palliative care occurs outside acute care settings, with a substantial part of paediatric palliative care provided by health care workers who are providing non-specialist paediatric palliative care and community nurses.

The PCA National Palliative Care Standards for All Health Professionals and Aged Care Services⁴³ has recently been developed to guide high quality palliative care in non-specialist palliative care settings, and this work should be expanded to specifically reflect how health professionals and services can deliver a high quality and holistic paediatric palliative care approach.



Priority 2: Access



Overview

- » Service planning and the strengthening of resources, education and training underpins access to optimal paediatric palliative care. Building system capacity supports children and young people with life-limiting conditions to receive the care that matches their needs and preferences.
- » Sustainable and mainstream education and training is fundamental to integrate evidence-based quality paediatric palliative care.
- » Gaps exist in access to paediatric palliative care services for underrepresented groups. Service planning requires pathways that are culturally safe and responsive to overcome the unmet needs of vulnerable populations. Underrepresented groups must be involved in co-designing solutions to improve access to paediatric palliative care.
- » Noting that some families' goals will include returning home and to community, specialised skills are required for ensuring a continuum of paediatric palliative care services in these settings. This requires an increase of investment in resources, education, and training to overcome the capacity issues.

Benefits

The benefits of implementing the set of actions relating to the priority area of access include:

- » More timely access to care
- » More culturally safe and responsive care
- » More access to comprehensive, multidisciplinary specialist paediatric palliative care:
 - Across states and territories
 - Across age groups
 - Across life-limiting conditions
 - Across settings including community-based care
- » Enhanced education and support for generalist providers of paediatric palliative care, and
- » A sustainable workforce with the critical mass to meet specialist and generalist palliative care needs.



Action 2.1

Care Pathway

Develop and implement an optimum paediatric palliative care pathway including a transition pathway between paediatric and adult palliative care services.

Implementation - Medium Term: 3-5 years

- » Develop an optimal paediatric palliative care pathway which is informed by evidence, consultation with the sector and co-design with consumers.
- » Disseminate the optimal care pathway.
- » Promote the care pathway through education sessions, webinars, conferences, and other strategies. This is addressed in Action 3 - Information sharing and collaboration.

Why is this important?

A care pathway is not a clinical guideline. Rather it describes the care within each stage from diagnosis or early stage of illness to end of life care that should be considered. An optimal care pathway will provide the opportunity for best care starting from the early stages of recognition of illness and complexity and continuing throughout the illness trajectory.

The first stage of an optimum paediatric palliative care pathway is the diagnosis of the life-limiting condition and recognition of the nature of the disease and its complexity (if this is possible).

Paediatric Palliative Care can be provided concurrently with curative treatment depending on the goals of treatment. There are benefits to children, young people, and families from timely access to palliative care, including quality of life and health outcomes.

Other relevant stages for the care pathway include living with a life-limiting condition; living with disease progression and deterioration; end of life care; care after death; and bereavement support.

The care pathway will also cover the transition from paediatric to young adult palliative care services, since, for many children and young people with life-limiting conditions, the palliative care journey may extend over several years. The approach to palliative care is different between paediatric and adult palliative care teams and there may be a high level of stress and anxiety associated with loss of continuity from the paediatric team for both the young adult and the family. Early planning for the transition from child to adult services is important, and if feasible, both services may be involved for a period of time.

In the absence of systematic use of prompts for referral to paediatric palliative care, there is variation between clinicians' preparedness to discuss palliative care with children, young people and families, and to initiate timely referrals. Timely referral in this context refers to being close to or at the time of diagnosis.

Referrals must be made at an appropriate time which is best for the family.

The process of referral requires care and tailoring to the needs of individual families. It is often helpful for the referring clinician and the palliative care clinician to discuss the best way for a referral to occur.

Action 2.2

Culturally safe and responsive care pathways for Aboriginal and Torres Strait Islander Peoples

Develop community led, culturally safe and responsive care pathways for paediatric palliative care of Aboriginal and Torres Strait Islander people.

Implementation – Medium Term: 3-5 years

- » Develop community led care pathways that seek to enhance culturally safe and responsive care.
- » The care pathways should:
 - interface with community-based service providers including Aboriginal Medical Services and Aboriginal Community Controlled Health Organisations and, the community and family arrangements for decision making and care planning.
 - acknowledge the cultural diversity between the many Aboriginal and Torres Strait Islander peoples and nations and enable access to culturally appropriate information in relevant formats and languages
 - include a process for co-design and consultation with Aboriginal and Torres Strait Islander peoples together with a ratification and review process.
- » Disseminate the care pathway in conjunction with Aboriginal Medical Services and Aboriginal Community Controlled Health Organisations and other relevant community led organisations
- » Promote the care pathway through education sessions, webinars, conferences, and other strategies. This is addressed in *Action 3 - Information sharing and collaboration*.

Why is this important?

Aboriginal and Torres Strait Islander cultures, values and traditions must be respected and included to ensure culturally safe and responsive care pathways for paediatric palliative care.

Developing community led, culturally safe and responsive care pathways which are co-designed with Aboriginal and Torres Strait Islander peoples in your region provides systematic approaches that enable healthcare organisations to deliver care that is relevant to Aboriginal and Torres Strait Islander peoples and is respectful of their needs in relation to culture, kinship and country.

Care pathways need to facilitate Aboriginal and Torres Strait Islander peoples to access culturally responsive paediatric palliative care and support services including the involvement of Aboriginal Health Workers or Liaison Officers, or Aboriginal Community Controlled Healthcare Organisations, if desired.

Where there is respect shown towards cultural safety and responsiveness, there is improved likelihood that paediatric palliative care will be accepted.

Action 2.3

Culturally Diverse and Responsive Care Pathways for underrepresented groups

Develop culturally diverse and responsive care pathways for paediatric palliative care of underrepresented groups.

Implementation – Medium Term: 3-5 years

- » Develop care pathways that seek to enhance culturally diverse and responsive paediatric palliative care.
- » Ensure culturally competent information is accessible to enable appropriate assessment and care for children, young people and their families.
- » The care pathways should include a process for collaboration across jurisdictional boundaries, co-design and consultation with culturally and linguistically diverse people and with other consumers at risk of experiencing access barriers, including due to racial or other discrimination such as LGBTIQ+ people.

Why is this important?

Gaps exist in access to paediatric palliative care services for underrepresented groups.⁴⁴ Cultural competence can enhance access to paediatric palliative care by breaking down barriers. Co-designing culturally diverse and responsive care pathways provides systematic approaches that enable healthcare organisations to deliver care that is relevant to members of the Australian community including culturally and linguistically diverse people, and other people at risk of experiencing access barriers, such as children and young people identifying as LGBTIQ+ and rainbow families.

National Paediatric Palliative Care Workforce Strategy

Develop a National Paediatric Palliative Care Workforce Strategy.

Implementation – Short Term: 1-2 years

It is noted that a National Workforce Strategy is required for the palliative care workforce. This broader Workforce Strategy should include the workforce required to deliver high quality paediatric palliative care

Note: Workforce is a key enabler for many other actions relevant to the Paediatric Palliative Care National Action Plan

- » Develop a workforce strategy which will support the implementation of key actions in the Paediatric Palliative Care National Action Plan including better access to comprehensive and multi-disciplinary specialist paediatric palliative care and community-based palliative care.
- » The workforce strategy must be multi-disciplinary in focus, spanning medical, nursing, allied health disciplines and peer support.
- » The workforce strategy should be developed at a systems level to identify the inter-dependencies and it needs to be relevant to specialist paediatric palliative care, including hospice and respite services workforce and the non-specialist paediatric palliative care workforce.
- » The workforce strategy must be national in focus and its development requires inter-jurisdictional collaboration.
- » The workforce strategy must support the strengthening of the Aboriginal and Torres Strait Islander peoples' workforce as outlined in the National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework 2016–2023⁴⁵ and the 2021 National Medical Workforce Strategy.⁴⁶

Why is this important?

The diversity of life-limiting conditions and the breadth of issues that are relevant to the paediatric context presents complex challenges for paediatric palliative care. As a distinct and relatively recent specialty, the workforce challenges are multi-faceted including optimising scarce specialist resources, ensuring consultancy support to the broader non-specialist workforce, and the promotion of access to best-practice care across a range of settings, including home-based care and diverse regional and remote areas.

One element of the workforce strategy would consider the role of peer support mentors for families. The insights and experiences of peers with a lived experience of paediatric palliative care can provide the non-clinical support valued by parents and families.



Action 2.5

Comprehensive and multidisciplinary paediatric palliative care

Deliver comprehensive and multidisciplinary specialist paediatric palliative across all jurisdictions.

Implementation – Medium Term: 3-5 years

- » Complete a national service audit of each jurisdiction's current service model for paediatric palliative care services, relative to the Service Development Guidelines – Addendum for paediatric palliative care, 2018.⁴⁷
- » Develop a framework for a core multi-disciplinary team in a paediatric palliative care service. This action relies on the prevalence study in *Action 4.1 - Data and Research*.

Why is this important?

The optimal provision of paediatric palliative care is through a multidisciplinary team comprising the disciplines of medical, nursing, and allied health including spiritual care, and grief and bereavement counsellors. Comprehensive paediatric palliative care refers to:

- » Comprehensive across ages, from perinatal to adolescence/young adulthood.
- » Comprehensive across disease categories – this is important given that the prevalence of paediatric palliative care spans a wide range of disease categories including oncological and non-oncological diseases.
- » Comprehensive across settings enabling access to inpatient, consultancy, hospice and respite community-based and home-based services – this is relevant to enable children, young people and families to have choice about their preferred care setting; and
- » Comprehensive across states/territories – whilst there are differences in the population size of Australian states and territories, based on equity it is important that all states and territories have arrangements in place for children, young people and families to have access to multidisciplinary, paediatric palliative care services within their home state or territory. The size and scope of multidisciplinary, paediatric palliative care teams will vary according to population size.
- » The NSQHS Standards⁴⁸ – Action 5.25 and 5.20 require services to provide comprehensive care including end of life care.



Action 2.6

Community based paediatric palliative care

Expand community-based paediatric palliative care capability and capacity.

Implementation – Medium Term: 3-5 years

- » Develop a process to expand community-based palliative care services' paediatric capability, networked with specialist paediatric palliative care providers.
- » Evaluate the process after 12 and 24 months of service to determine cost-effectiveness, measure patient and family experience and improvements in reported health-related quality of life and outcomes.

Why is this important?

Best practice or best outcomes for patients, families, and carers have an expectation that care will be provided in line with the care location goal of the family, noting that most families, children and young people prefer to spend as much time as possible at home.⁴⁹ It is noted that pragmatic challenges such as resourcing, capability, and capacity impact the implementation of community-based paediatric palliative care. Whilst there are similar principles involved in the delivery of palliative care across adult and paediatric settings, there are specific requirements for paediatric palliative care relevant to the needs of children and young people with life-limiting conditions.

Some community palliative care providers may not feel they have sufficient experience or support in the care of children with life-limiting conditions. Efforts to build capacity and provide support to these providers are crucial and best provided by specialist paediatric palliative care teams. Support to local care providers should be as needed and provide advice, management plans and access to a 24hr paediatric palliative care medical advisory service.

Pop-up models such as the QuoCCA model have been demonstrated to be very useful in providing education relating to paediatric palliative care to health professionals caring for children and families.

Multidisciplinary teams should not be limited to community palliative care services and should include community healthcare services.⁵⁰ Models that are tailored to a local context incorporating services such as ambulatory care and pharmacy could also be utilised to expand and deliver community-based care. Establishing this delivery model will build capacity and capability for paediatric palliative care.

In the context of perinatal palliative care, capacity building could allow neonatal/midwifery staff to provide home visits for families who wish to take their infant home to die (rather than being in hospital or hospice). This would allow for continuity of care, continuation of existing relationships, and access to the highly specialised knowledge needed for caring for infants (and families) in the first months of life. This model would be in consultation with specialist paediatric palliative care services.

Action 2.7

Embed the role of an outreach education model

Embed an outreach education model to support access to care for children and families in remote and regional areas through upskilling and training health professionals to deliver sustainable paediatric palliative care education

Implementation – Short Term: 1-2 years

- » Enhance and promote communication and collaboration across jurisdictional boundaries
- » Embed an outreach education model for non- specialist and community palliative care services that supports models of care specific to very remote, remote, and regional communities and integrates with specialist paediatric palliative care providers.

Why is this important?

In consultations for the development of the Paediatric Palliative Care National Action Plan, there was widespread support for the role played by QuoCCA and other state based models in delivering paediatric palliative care education to health professionals in urban, rural, regional, and remote areas to support non-specialist service providers to better meet the needs of children, young people and families with life-limiting conditions.

Note; the QuoCCA project is funded by Department of Health and Ageing National Palliative Care Project until June 2023.

Priority 3: Information sharing and collaboration



Overview

Effective communication and collaboration across teams and settings is pivotal to high quality paediatric palliative care. Strengthening collaboration between providers of care improves both quality and efficiency of paediatric palliative care for all families.

Benefits

The benefits of implementing the set of actions relating to the priority area of information sharing and collaboration include:

- » Improved service collaboration and referral pathways
- » Greater community understanding
- » Increased intersectoral collaboration, and
- » Strengthened communities of practice.

Action 3.1

Assessing information

Routinely assess and discuss with children, young people, families and communities (or relevant decision makers) their information needs at all stages of palliative care and facilitate access to information tailored to need.

Implementation – Short Term: 1-2 years

- » Reinforce with healthcare professionals the importance of actively speaking with children, young people and parents to understand their information needs on a regular basis.
- » Develop policies, procedures and guidelines to ensure that understanding information needs of children, young people and families and responding to those needs is routine practice.
- » Policies should:
 - consider the developmental and health literacy needs of children, young people and families together with the need for interpreters.
 - acknowledge the cultural diversity between the many Aboriginal and Torres Strait Islander peoples and nations and enable access to culturally appropriate information in relevant formats and languages.
 - acknowledge the community and family arrangements for decision making and information sharing.
- » Develop training and access to resources such as those developed by the Australian Commission for Safety and Quality in Healthcare to increase the capabilities of healthcare professionals in communicating with children, young people and families.

Why is this important?

Families sometimes say that they don't know what they don't know. Family and children's need for information will change over time throughout the disease trajectory, as may their health literacy levels. There are multiple challenges. Information requirements will be influenced by the type of health condition and the unique circumstances of every family. For these reasons, information needs of children, young people and families need to be assessed and re-assessed regularly over time.

Action 3.2

Community awareness strategy

Develop a targeted community awareness strategy that can build knowledge about key issues relevant to supporting children, young people and families who need paediatric palliative care.

Implementation – Short Term: 1-2 years

- » Develop a targeted community awareness strategy to increase knowledge and understanding of paediatric palliative care.
- » The targeted community awareness strategy:
 - should adopt a co-design and consultation approach with children, young people and families.
 - requires clarity regarding the communication needs of different population segments and evidence to support the effectiveness of different models of community awareness strategies.
 - should be culturally appropriate and accessible.

Why is this important?

The opportunity for children, young people and families to be supported through social support networks is an important resource that can improve quality of life outcomes.

By normalising conversations about death and dying there is decreased stigma associated with palliative care and greater awareness of the importance of bereavement support. The use of accessible language and case studies that relate to the lived experience of consumers and their community connections, can provide authentic communication valued by families that complements the clinical information they receive and validates their own feelings and experiences.

A community led co-designed approach to developing a targeted community awareness strategy will inform culturally safe communication for underrepresented groups which in turn improves access to services. Culturally safe communication can include yarning, storytelling and language interpreters for Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse communities.

Action 3.3

Implementation of the paediatric palliative care national action plan

Collaborate with key stakeholders to enable implementation of the Paediatric Palliative Care National Action Plan.

Implementation – Medium Term: 3-5 years

- » Collaborate with key stakeholders with appropriate expertise to:
 - maintain the advisory mechanisms, website and resources developed to date through the Paediatric Palliative Care National Action Plan Project (funded between July 2020 – June 2023), and
 - to undertake the work and consultation necessary to scope, develop and identify the detailed requirements for full implementation of the Paediatric Palliative Care National Action Plan.
- » Consumer and key stakeholder co-design is a fundamental component of the implementation of this Plan.

Why is this important?

Implementation of this Paediatric Palliative Care National Action Plan will require action and partnerships across all sectors and levels of the health system, disability services, schools, social care and community support services, non-government organisations, the private sector, researchers and academics, and particularly with the children and families who need paediatric palliative care.

Consumer and key stakeholder co-design is a fundamental component of the collaboration required for implementation of this Plan.

Building networks across states and territories will enable pooling of knowledge and expertise, sharing of innovation, advocacy, and improved capability to support program evolution and communities of practice and implementation of the recommendations of the Paediatric Palliative Care National Action Plan.

Priority 4: Data and research

4

Overview

There is a paucity of data, research, evaluation and benchmarking of paediatric palliative care services. These gaps in data affect policy development, service planning, benchmarking, and quality of paediatric palliative care. Without data-driven planning, it is not possible to ensure that children, young people and family's needs can be fully met. Research in paediatric palliative care must be prioritised to address gaps in evidence-based practice to improve quality of life outcomes for children and young people with life-limiting conditions and their families. Data must be accessible and shared appropriately to support meaningful decisions in policy and service design.

Benefits

The benefits of implementing the set of actions relating to the priority area of data and research include:

- » Nationally consistent and collated data collection
- » Better understanding of population needs
- » Planning and resourcing of services linked to population need
- » Improved collaboration to build research capability and prioritise research
- » Expanded opportunities for paediatric palliative care researchers
- » Stronger partnering with consumers on research
- » A strengthened research base that expands the evidence-base
- » Robust outcome measures and collaborative benchmarking that improve quality and safety, and
- » Translation of research into evidence-based care.

Action 4.1

National Prevalence Study

Undertake a prevalence study.

Implementation – Medium Term: 3-5 years

- » Undertake a prevalence study to enable state, territory and national data to be analysed on a five-yearly basis.
- » A prevalence study would require a national and state and territory data sharing agreement and an organisation to coordinate the data analysis.

Why is this important?

Understanding the prevalence of paediatric palliative care needs is fundamental to ensuring appropriate allocation of resources and service planning by governments and service providers. Beyond prevalence data, an understanding of the unmet needs, diagnoses of the cohort, and the location of these children, young people and families in the community will allow specialist services and community groups to best tailor their services.

Action 4.2

Develop outcome measures

Develop outcome measures and implement benchmarking for paediatric palliative care.

Implementation – Medium Term: 3-5 years

- » Utilise research undertaken to date to establish a National Minimum Data Set and outcome measures for paediatric palliative care.
- » Implement outcome measures and benchmarking using a collaborative approach across sectors to systematically improve patient outcomes in paediatric palliative care.

Why is this important?

Whilst there is a strong commitment to evidence-based service delivery by specialist paediatric palliative care services, further progress is required to develop and collect consistent outcome measures for paediatric palliative care. There is no nationally consistent reporting of paediatric palliative care outcome measures and experience of care measures. This limits the capacity for services to undertake benchmarking and in turn enhance quality and safety.

Action 4.3

Establish Research Cooperative

Establish a national Research Cooperative Group in paediatric palliative care to identify priorities in research and support components of research where a collaborative approach is warranted.

Implementation – Medium Term: 3-5 years

- » Establish a Research Cooperative Group which could be supported by an industry led group. The Research Cooperative Group should include, or work in close collaboration with, consumers, clinical staff, community service staff, academics, and peak body representatives as key stakeholders in identifying research priorities.
- » Undertake a scoping exercise to confirm the scope, objectives, governance, funding and linkages with research organisations and health service providers, nationally and internationally.
- » Ensure governance of the group reflects the breadth of scope anticipated for the group, namely, it should be inter-disciplinary in focus, have cross-jurisdictional representation, and support partnering with consumers, healthcare professionals and peak organisations.

Why is this important?

To achieve high quality, cost-effective paediatric palliative care requires a robust and connected research sector. Further expanding paediatric palliative care research capacity is crucially important in consolidating the evidence-base. Australia has excellent specialist paediatric palliative care services with established researchers. The challenge is that there is a low critical mass of researchers given the smaller size of paediatric palliative care as a discipline and that research networks are not fully developed nor connected, leading to the risk of siloed approaches. This limits the scope for collaboration and partnerships across states/territories and across health and other services.

The rationale for a national Research Cooperative Group is to support structured collaboration across states and territories, building communities of practice across Australia's current research sector in paediatric palliative care and encouraging future coordinated development. The goal of the Research Cooperative Group would be to prioritise research in Australia, collaborate internationally on multi-site trials and research projects, and work towards the translation of research to enhance the safety and quality of care.

The Research Cooperative Group would be inter-disciplinary in focus, have cross-jurisdictional representation and would partner with consumers, healthcare professionals and peak organisations. Combining expertise, the Research Collaborative Group should further enhance clinical outcomes and not increase the workload of already over-committed clinicians. Workforce resource considerations would need to be considered to support the Research Cooperative Group. The Research Cooperative Group would undertake research relevant to outcomes for vulnerable groups in the community and expand the evidence-base across disease groups, including rare conditions, and across service interfaces: hospital to home-based care, specialist to non-specialist palliative care providers, and from paediatric to adult services.

Appendix 1: Background information

Quality

The provision of quality paediatric palliative care can be enhanced through key enablers that include patient and family-centred care, partnerships, integrated care, culturally safe and responsive care, access to advance care planning and the availability of a skilled workforce. These enablers are outlined below and further described in the literature review commissioned for this Paediatric Palliative Care National Action Plan.⁵¹

Family-centred care extends beyond a child or young person's parents or guardians, to include other family members, such as a child or young person's well siblings. Parents are typically the most expert about their children, and their involvement through family-centred care is essential to quality of services.

Fostering partnerships across a range of healthcare professions and care settings is an important component of quality paediatric palliative care. There are a range of advantages of multiple healthcare disciplines contributing to paediatric palliative care, especially in relation to ensuring effective psychological, social, and spiritual care. Such partnerships should extend between specialist paediatric palliative care services and other acute care specialities as well as to a diverse range of community healthcare services, including but not limited to community palliative care.

To support integrated, care, processes need to be in place to support multi-disciplinary care, care coordination and continuity. In Australia, this can be especially important for families living outside major cities. Another approach involves making electronic medical records accessible to a patient's care teams in both hospital and community settings.

Paediatric palliative care concerns must be responsive to the needs of diverse people. In Australia, particular emphasis must be placed on the provision of culturally safe and responsive paediatric palliative care for Aboriginal and Torres Strait Islander people and care that is responsive to the unique needs of culturally and linguistically diverse populations.

Timely provision of advance care planning is another prerequisite for quality care. In spite of the recognised benefits of advance care planning, evidence suggests that many children with life-threatening or life-limiting conditions who are likely to benefit from advance care planning either do not receive this at all or receive it close to the end of their life, when its usefulness can be limited.

Workforce capability has a direct influence on quality

of care and there is a case for building a foundational competence in palliative care among all clinicians. There are also calls for equipping adult palliative care clinicians with the skills they need to provide paediatric palliative care, particularly in areas where specialist paediatric palliative care is not available. A hierarchy of skill levels may be useful for guiding investment in skills training. Understanding unique aspects of care, such as for adolescent and young adult populations, should be incorporated across these levels.

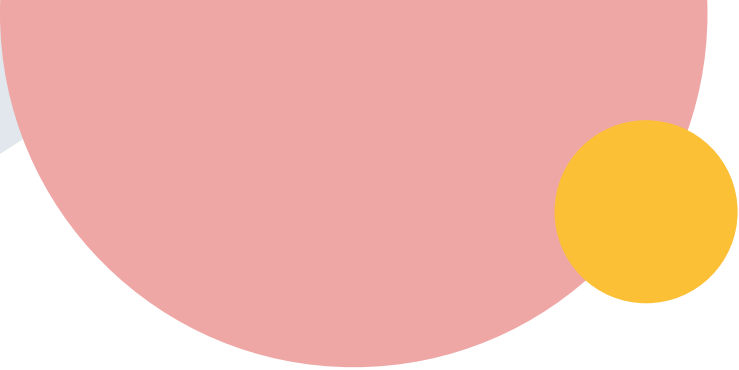
Access

Enhancing access to paediatric palliative care is a key theme explored in the literature review for this Paediatric Palliative Care National Action Plan. Research findings support early integration of paediatric palliative care services and the provision of care in a variety of settings to improve access to paediatric palliative care. The evidence also emphasises the importance of considering the specific needs of Aboriginal and Torres Strait Islander people, culturally and linguistically diverse populations and other underrepresented groups.

Early integration is commonly defined as the concurrent provision of treatment offered with curative and palliative intent. Early integration of paediatric palliative care is recommended by the World Health Organisation,⁵² the Australian Commission for Safety and Quality in Healthcare,⁵³ Palliative Care Australia,⁵⁴ and Paediatric Palliative Care Australia and New Zealand.⁵⁵ The integration of paediatric palliative care can occur as early as antenatal care.

The most common strategy for supporting early integration of paediatric palliative care is through the adoption of one or more 'triggers' to indicate referral to specialist paediatric palliative care. Many different triggers are discussed in the literature. These range from relatively objective triggers, such as diagnosis of a life-threatening condition,^{56,57,58,59} to relatively subjective triggers, such as a clinician's judgement that a patient's death is possible within the next year. Within the scope of the literature review, no evidence was identified suggesting the superiority of any trigger, or triggers, over possible alternatives. With the absence of evidence, there is a recognised need for better referral tools.⁶⁰

A distinctive feature of paediatric palliative care in Australia is that community-based palliative care tends to be provided by adult palliative care teams.^{61,62} This appears to be a pragmatic reflection of the relatively low prevalence of children with life-limiting conditions,



with a large geographic spread, compared to the adult population and resourcing challenges due to a relatively small size of paediatric palliative care workforce.

One of the challenges for adult community palliative care teams is that they may not feel they have the necessary experience and training in paediatric palliative care. Further, families have expressed how important it is to have the involvement of health care providers with specific expertise in paediatric palliative care. This suggests that existing models of care require enhancement to enable greater outreach by specialist paediatric palliative care teams. The aim would be to provide support to both health professionals working in the community and families for palliative care to be provided by healthcare providers who have paediatric palliative care expertise.^{63,64,65,66}

PCA specifies in its Service Development Guidelines that:

- » Paediatric palliative care services will be provided in a wide range of hospital, hospice and community-based settings to meet the needs and preferences of children living with a life-limiting condition and their families. This should include the provision of specialist palliative care via consultancy to support children and their families and local treating teams, regardless of geographic location.⁶⁷
- » In addition to inpatient and outpatient consultations, telehealth technologies increasingly provide opportunities to deliver a variety of care from a distance and to involve those that can provide generalist paediatric palliative care locally, such as general practitioners. Access to care can also be enhanced through an after-hours phone service that connects families with specialist paediatric palliative care.

Education and training

Paediatric palliative care education and training is delivered by various providers. The National QuoCCA project, funded by the Australian Department of Health, is one initiative which aims to deliver paediatric palliative care education to health professionals in urban, rural, regional, and remote areas.⁶⁸ QuoCCA education is coordinated by medical, nursing, and allied health educators based in specialist palliative care teams covering all jurisdictions, including outreach to Tasmania, and the Northern Territory.

The evaluation of the program has shown multiple benefits:

- » Improvement in skill, knowledge, and confidence of health professionals at all levels involved in the delivery of paediatric palliative care, enabling them to provide best practice care for children and families nationally.
- » Improvement in timely and appropriate access to, and quality of, paediatric palliative care in acute and community settings nationally.
- » Improved processes for care planning in local communities; and
- » Increased community and health professional awareness of death and dying as a normal part of life-limiting conditions in childhood and the need for family centred and developmentally and culturally appropriate services.⁶⁹

The literature review undertaken for this Plan identified a paucity of research on training needs among clinicians. The literature review also contained a range of different educational methods for enhancing paediatric palliative care skills across the clinical workforce.

Many stakeholders consulted for this Plan emphasised the need for workforce upskilling to assist health professionals in managing the challenges of working in paediatric palliative care. Despite capacity challenges, there are calls for equipping adult palliative care clinicians with the skills they need to provide paediatric palliative care, particularly in areas where specialist paediatric palliative care is not available.

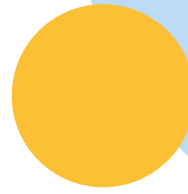
The PCA service development guidelines emphasise that paediatric palliative care is a complex and demanding area of work for health professionals:

“There is an urgent need for more rigorous research to identify how best to support all health professionals providing paediatric palliative care.”⁷⁰

Information sharing

Information sharing with the child, young person and their family improves the uptake of paediatric palliative care service and empowers them to discuss their preferences for care with clinicians. Research outlined in the literature review⁷¹ emphasises the importance of ensuring that communication and interventions are targeted or adaptable to the needs of particular groups, including Aboriginal and Torres Strait Islander people and culturally and linguistically diverse populations. There are further opportunities to improve dissemination of information including managing dissemination of information through care coordination.

Enhancing community knowledge of paediatric palliative care is likely to improve the uptake of services through a greater understanding what is involved in paediatric palliative care. Improving community knowledge of paediatric palliative care aligns with the objective of improving knowledge of adult palliative care. This includes addressing reluctance in society to discuss dying and death and building an understanding about the role and purpose of palliative care, especially how it can be delivered alongside curative care.



Data and research

In the US a national approach to quality improvement through data collation has been established.⁷² The Palliative Care Quality Collaborative is a not-for-profit organisation that houses a national palliative care data registry system, which will capture both program and patient-level quality data. Paediatric palliative care services are feeding into this broader palliative care data collaborative.

In the Australian context, the Palliative Care Outcomes Collaboration (PCOC) is a national palliative care outcomes and benchmarking program. PCOC's primary objective is to systematically improve patient outcomes (including pain and symptom control).

PCOC welcomes the participation of paediatric palliative care services within its remit, however stakeholder feedback from several jurisdictions suggests that PCOC in its current form does not suit the paediatric context – largely because outcome measures from adult palliative care are not transferable to the paediatric context and that more progress should be made towards the development of paediatric-specific outcome measures. King's College in London is developing a paediatric-specific outcome measure, the Children's Palliative Care Outcome Scale or C-POS and this will be important to explore further. Funding will need to be allocated for the development of paediatric-specific outcome measures.

In the US, research cooperative groups have been established in the domain of paediatric palliative care to facilitate collaborative research. Research cooperative groups are a community of paediatric palliative care investigators who seek to support paediatric palliative care through resources including participant registry, quality assurance, caregiver research expertise, measurement expertise, and study closeout support.⁷³ In the UK, the Louis Dundas Centre for Children's Palliative Care plays an active role in collaborative research.⁷⁴ Australia does not have a national research cooperative group for paediatric palliative care.

Appendix 2: What you told us

This Appendix should be read in conjunction with the Thematic Summary of Stakeholder Consultations for the National Action Plan.

Quality

Family involvement in care

- » The caring role of the family should be recognised, supported, appreciated and integrated.

Communication

- » The term 'palliative care' is widely misinterpreted as end-of-life care.
- » Empathetic and compassionate communication is crucial; and
- » Ensuring that each family's views and preferences are understood is important (including from a family/life goals perspective and in the clinical context).

Coordination

- » Coordination is a key role for effective specialist paediatric palliative care; and
- » Where there is more than one service involved in care, such as disability services and health services, there is increased complexity in service coordination.

Advance care planning

- » Advance Care Planning tools are often not suitable for families where the trajectory is unknown; and
- » Consumers who had experienced advance care planning were appreciative.

The importance of that delivery of care cannot be understated, and would best be coordinated through a 'case manager', ...in efforts to optimise patient- and family-centred care.

- Bereaved parent

Access

Care pathways

- » There is fear and stigma about palliative care and its association with end-of-life care.
- » There needs to be increased understanding about what palliative care means.
- » Clinical variation in referral to palliative care needs to be overcome.
- » Palliative care referrals should be timely, at the time of diagnosis, with the goal of palliative care services 'working alongside' curative care and community teams.
- » Timing of referral of children and young people with a rare condition and unknown disease trajectory is difficult; and
- » Invest in a transition pathway between paediatric and adult palliative care services.

Service availability

- » The availability of specialist paediatric palliative care services varies state by state.
- » Specialist services are 'city-centric'; and
- » There is variability in the disciplines available in multi-disciplinary teams.

Resourcing

- » More services and more reliable funding are required to ensure adequate service coverage.
- » Aspects of paediatric palliative care, including community-based palliative care, are not adequately resourced; and
- » It is challenging for services to secure ongoing funding, adversely impacting staff retention.

Care settings

- » Paediatric palliative care is required across all settings including home-based care.
- » QuoCCA is one of the initiatives to upskill community care providers where required; and
- » Availability and awareness of community services is variable.

Equity of access

- » Access to services differs according to different life-limiting conditions; and
- » Services should be provided to families based on need, not based on their own health literacy and self-advocacy.

Responsiveness

- » Cultural safety for Aboriginal and Torres Strait Islander people is fundamental for access to care; and
- » Responsiveness to other vulnerable groups requires a focus on the access needs of culturally and linguistically diverse people, refugees, families where there is an underlying mental health condition, and children in the child protection system.

There's a limited workforce and a limited ability for services to address the needs of paediatric palliative care. All healthcare professionals need to be aware of the needs of children with palliative care needs. It's a basic thing that needs to be embraced regardless of specialty. There's no way the [specialist] workforce is going to be able to encompass all children... palliative care should be a concept we provide to everybody.

- Specialist clinician

Information sharing and collaboration

Information sharing that is responsive to consumers

- » There is variability between service providers in their approach to information sharing with consumers and some lack empathy and compassion.
- » Consumers felt unsupported and lacked understanding of information about planning and expectations for the next stages of their child's life.
- » Empowering families to communicate with multiple services and team members is important; and
- » There are shortcomings in the age-appropriateness of communication by the treatment team in particular for young people.

Effectiveness of information sharing between providers

- » Interagency challenges – Information sharing *within* organisations tends to be much more feasible than sharing between organisations.
- » Within team sharing – team collaboration and communication means ensuring team members' views and perspectives are considered; and
- » Awareness and understanding of the local service context should be promoted.

Community awareness

- » Attitudes about dying and references “palliative” and “palliative care” as care in the last days of life are entrenched and difficult to shift.
- » Families felt let down and excluded by the inability to openly share information about paediatric palliative care in community settings.
- » Peer support mentors have insights and experiences and can provide non-clinical support valued by parents and families. They can provide compassionate listening and non-clinical advice on out-of-hospital support options that have practical benefit. This can improve the wellbeing of parents.
- » Healthcare professionals are not immune from the stigma attached to paediatric palliative care and discussions about death and dying.
- » There is power in storytelling.
- » Conversations about death and dying need to become normalised.
- » Bereavement is challenged by community attitudes that may diminish or ignore family needs.
- » Culturally relevant communication is a key priority; and
- » Knowledge on how to tap into social support systems enable children and families to remain connected.

Cross-jurisdictional collaboration

- » Australia lacks a national coordinating entity to advocate and coordinate policy, program development and research in paediatric palliative care; and
- » There is inconsistency in service and funding models between states and territories.

Other collaborations

- » Other stakeholders include the role of NGOs, sporting clubs and social networks.

Data and research

Data

- » Comprehensive and accurate prevalence data is required to understand what the current needs are for the paediatric palliative care sector in Australia. Currently, best estimates are based on 2016 data from a single jurisdiction, Queensland.
- » Data collection needs to be clinically meaningful, readily extractable, and non-onerous with data management support.
- » Adult data collection methods do not currently have appropriate measures and language for direct transfer to paediatric use.
- » A data collection collaborative which offers individual services benchmarking reports and assistance with quality improvement activities is needed; and
- » Plans for data use, as opposed to just data collection, need to be clear and appropriately resourced.

Research

- » Palliative care specialist services do not have capacity to undertake research and service development which would take away from clinical time and resources.
- » Where targeted research into service development has been trialled, it is often not sustainable as it occurs in silos and is reliant upon project-based funding. States can be restricted in sharing locally developed resources, due to funding being tied to regions; and
- » A national approach is needed to identify and prioritise gaps in research and facilitate collaboration.

A critical enabler of the Action Plan is collaborative governance and leadership. Any national policies and practices to ensure paediatric palliative care is consistent across all jurisdictions must include [input from] people living with a rare disease.

- Bereaved parent

We need national data because without it we can't plan effectively, governments can't budget effectively, and we are failing children who need palliative care.

- Bereaved parent

Appendix 3: Consultations

A number of individuals and organisations participated in the consultations to inform the development of the Paediatric Palliative Care National Action Plan. The consultations included a number of individual consumers and health professionals who are not listed below. We appreciate all the input we received into this important document.

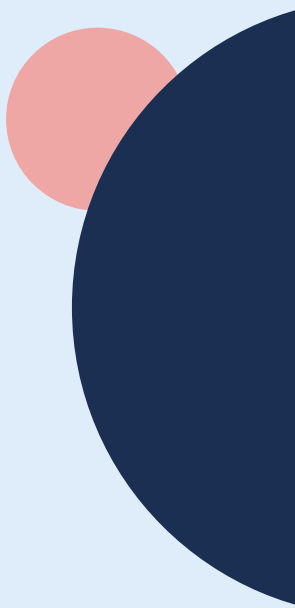
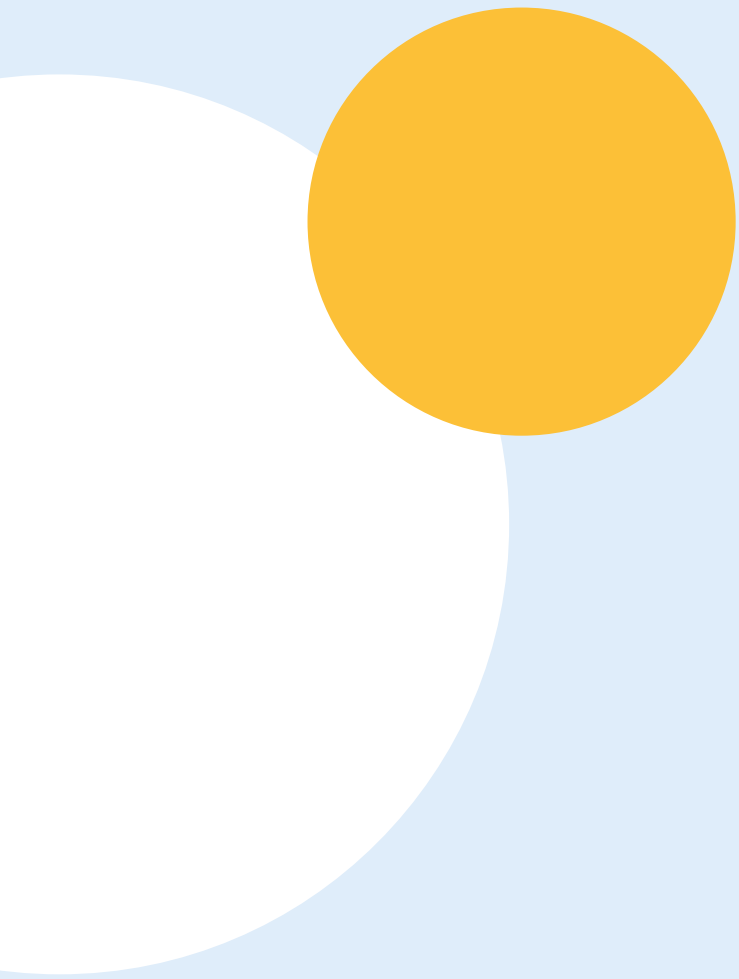
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- » Australian Centre for Grief and Bereavement
- » Australian Commission on Safety and Quality In Health Care
- » Australian Institute of Health and Welfare
- » Cancer Australia
- » Cancer Policy And Services Branch (Federal)
- » Canteen Youth Advisory Committee
- » Canteen
- » Capital Health Network
- » Centenary Hospital for Women and Children
- » Childhood Dementia Initiative
- » Collaboraide - Independent Consultant
- » Cranaplus
- » Department of Health and Aged Care
- » Department For Health and Wellbeing South Australia
- » Department of Health and Human Services (Federal)
- » Department Of Communities and Justice (NSW)
- » Epilepsy Foundation
- » Genetic Alliance Australia
- » Gippsland Primary Health Network
- » Gold Coast Supportive and Specialist Palliative Care
- » Hannah's House
- » HAS foundation
- » Hummingbird House
- » Leukaemia Foundation of Australia
- » Limestone Coast Local Health Network
- » Loddon Mallee Region Palliative Care Consortium
- » Mater Mothers' Hospital
- » National Disability Insurance Agency (NDIA)
- » Northern Territory Health
- » Paediatric Palliative Care Service - Qld Childrens Hospital
- » Paediatric Palliative Care Women's and Children's, Canberra
- » Palliative Care ACT
- » Palliative Care NSW
- » Palliative Care Nurses Australia
- » Palliative Care Queensland
- » Palliative Care South Australia
- » Palliative Care Outcomes Collaboration (PCOC)
- » Perth Children's Hospital - Palliative Oncology
- » Perth Children's Hospital
- » Program of Experience in the Palliative Approach (PEPA)
- » Quality of Care Collaborative Australia (QuoCCA)
- » Queensland University of Technology (QUT)
- » Rare Voices
- » RedKite
- » Royal Children's Hospital Melbourne
- » SA Health
- » Silver Chain Hospice Care Service
- » Silver Chain
- » Southern Metro Palliative Care Consortium
- » Starlight Children's Foundation
- » SWAN Australia
- » Sydney Children's Hospital Network
- » The Children's Hospital at Westmead
- » Top End Health Service
- » Very Special Kids
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