



Paediatric Palliative Care Australia and New Zealand (PaPCANZ)

Pre- Budget Submission to the Federal Budget 2021-22

January 2021

Introduction

Paediatric Palliative Care Australia and New Zealand (PaPCANZ) welcomes the opportunity to make a submission on the Federal Budget 2021-22. In this submission, PaPCANZ supports the recommendations made in Palliative Care Australia's (PCA) pre-budget submission, which calls upon the Australian Government to support funding measures and initiatives that will improve access to palliative care, in particular, for paediatric patients.

PaPCANZ acknowledges the significant contribution of the Australian Government to the *Paediatric Palliative Care National Action Plan Project*. This three-year project, a collaboration between PaPCANZ and Palliative Care Australia (PCA), which commenced in June 2020, will start to build the capacity of the Australian health care system to respond to the specialist needs of children with life limiting conditions. However, more investment is required.

Initiatives in this budget submission to Improve access to palliative care for paediatric patients:

1. Invest in establishing guidelines and standards for bereavement support
2. Invest in the Paediatric Palliative Care Workforce including the development of a National Palliative Care Workforce Strategy
3. Enhancing the experience of families with children with a life limiting condition by:
 - I. Invest in promoting a balance between paediatric palliative care responses for children who have cancer and children experiencing other life limiting conditions
 - II. Invest in a transition pathway between paediatric and adult services
 - III. Invest in increasing awareness and support for the broad social and economic cost in the context of paediatric life-limiting conditions and after the death of a child
4. Commit to palliative care research through dedicated annual funding from the National Health and Medical Research Council (NHMRC) and the Medical Research Futures Fund (MRFF) funding grants. Ensure a percentage of the funding is allocated to Paediatric Palliative Care research specifically.

Rationale

1. Invest in establishing guidelines and standards for bereavement support

Bereavement support in paediatric palliative care is essential, however, it is complex. The “circle of concern” for bereavement support in the paediatric setting includes the child, the family, siblings and carers as well as other support services such as friendship groups, social groups, and the school environments of patients and/or siblings as relevant. A more intensive system of bereavement, and anticipatory grief, supports are often required than is often seen in the adult palliative care settings.

Bereavement support is a recognised component of palliative care and part of a continuum which should span pre-death to post-bereavement care.¹ For families including siblings who have experienced the loss of a child, bereavement support may need to be accessed many years after the loss of a child/sibling.

There is a need for the development of national standards for bereavement service provision in Australia, based on best practice of optimal bereavement interventions. In Ireland the importance of bereavement support in paediatric palliative care is acknowledged through the establishment of [The Irish Childhood Bereavement Network](#). The *Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy (2009)*ⁱⁱ report recommends that bereavement supports for children be developed at appropriate levels and delivered by adequately trained staff to an agreed standard.

Developing national standards for bereavement service provision for paediatric palliative care could be modelled on the Irish experience and tested in the Australian (and New Zealand) context. The model must optimise integration and referral pathways and minimise gaps. The standards and overarching framework would include a strategy for each jurisdiction that:

- Incorporates a plan to support vulnerable groups including Aboriginal and Torres Strait Islander people and people from the full range of culturally and linguistically diverse backgrounds.
- Maps locally accessible grief counsellors and psychologists with specialised grief expertise in paediatric palliative care which is continually updated to assist families and health professionals to know where services are support are available.
- Supports Primary Health Networks (PHNs) building better links and supports for general practice at the local level.
- Brings together State and Territory Governments with local government to coordinates services and build local capacity.
- Improved grief and bereavement education, professional development, and training pathways for health care professionals.

PaPCANZ recommends the development of National Standards and Guidelines for Bereavement Service Provision in Australia

2. Invest in the Paediatric Palliative Care Workforce through the development of a National Palliative Care Workforce Strategy

A National Palliative Care Workforce Strategy is needed to provide guidance on the appropriate staffing mix and numbers that are required to facilitate the delivery of palliative care to all

Australians with a life-limiting illness regardless of age or diagnosis. A National Palliative Care Workforce Strategy should address the workforce needs across all health settings, including tertiary, and community-based care, and ensure appropriate access to consultancy advice from specialised palliative care services. The National Palliative Care Workforce Strategy should address the needs of the Paediatric Palliative Care Workforce.

A National Palliative Care Workforce Strategy that includes the role of GPs, nurses, community pharmacy, allied health, paramedics, and other health professionals in paediatric palliative care should be considered critical. Such a strategy would enable broader workforce issues to also be examined. It should also enable disparities in access to palliative care (for example, across the states and territories and inner city, regional and rural and remote locations) to be identified and addressed.

Currently there are 271 palliative medicine physicians and 3,528 palliative care nurses across Australia (1.0 and 12.2 full-time equivalent per 100,000 population respectively) ⁱⁱⁱ. The number of specialist paediatric palliative care physicians and nurses is a small proportion of this workforce. Specialist skills and knowledge of the adult palliative care workforce is not easily transferrable to the paediatric population.

A substantial number of children accessing paediatric palliative care services 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^{iv}. The complexity of these conditions requires health practitioners to have a wide knowledge base and an understanding of the individual requirement and support required for this patient cohort. An added complexity is that a number of conditions included in the paediatric palliative care diagnosis group includes life-limiting, progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Paediatric palliative care health practitioners, therefore, often have long term relationships with the child and family/carers.

Scholarships would assist and help to ensure that Australia has an appropriate number of qualified Clinical Nurse Specialists, Clinical Nurse Consultants, and Palliative Care Nurse Practitioners to meet the palliative needs of Australians now and into the future, a percentage of these needs to be specifically for paediatric palliative care.

The establishment of a Palliative Care postgraduate scholarship programme could provide funding for successful candidates to undertake postgraduate training in palliative care, for example Graduate Certificate, Diploma or Master of Palliative Care or equivalent, Master of Nursing (Nurse Practitioner) or specific training initiatives contributing to Advanced Training in Palliative Medicine. A stream within the scholarship programme should be available to support the training and upskilling of the Paediatric Palliative Care Workforce.

It is important to acknowledge the need for workforce support to assist health professionals in managing the challenges of working in paediatric palliative care. Paediatric palliative care is a complex and demanding area of work for health professionals.^v

PaPCANZ recommends the development of National Palliative Care Workforce Strategy and palliative care scholarship programme, which includes the Paediatric Palliative Care Workforce.

3. **Enhancing the experience of families with children with a life limiting condition by:**
 - I. **Invest in promoting a balance between paediatric palliative care responses for children who have cancer and children experiencing other life limiting conditions**
 - II. **Invest in a transition pathway between paediatric and adult services**
 - III. **Invest in increasing awareness and support for the broad social and economic cost in the context of paediatric life-limiting conditions and after the death of a child**

The 10 activities included in the *Paediatric Palliative Care National Action Plan Project* funded by the Australian Government represents a unique opportunity to build the capacity of the Australian health care system to respond to the specialist needs of children with life-limiting conditions. This three-year project is a collaboration between PaPCANZ and PCA. However, the project is limited in scope and funding and further work is required.

I.) Invest in promoting a balance between paediatric palliative care responses for children who have cancer and children experiencing other life limiting conditions

A Queensland study *Estimating the prevalence of life-limiting conditions in Queensland for children and young people aged 0–21 years using health administration data*^{vi} reported that in Queensland the non-oncological conditions in paediatric palliative care in 2016 was 38.4 per 10 000 population compared to oncological conditions of 4.9 per 10 000 population.

Although this data is Queensland specific and the fact that there is a lack of reliable Australia wide data, this study highlights the need to undertake further work to scope the resourcing requirements, both current and future, available to oncology paediatric palliative care patients and non–oncology paediatric palliative care patients (Neurology, Haematology, Oncology, Metabolic, Respiratory, Circulatory, Gastrointestinal, Genitourinary, Perinatal, Congenital and other conditions)

The first step in this process will be to undertaking research into the current environment through a scoping study. The scoping study must quantify the resource gaps at the system level, within the workforce and within the not-for-profit sector where non-government organisations (often with limited resources) such as disease specific organisations are providing support to children and families with life limiting conditions.

PaPCANZ recommends commissioning a scoping study to better understand the support available to both the oncology and the non–oncology paediatric palliative care patient cohorts, and to identify strategies to address any gaps.

II.) Invest in a transition pathway between paediatric and adult services

Transition from paediatric to adult palliative care can be complex and fraught with difficulties and occurs in tandem with the transition of multiple other treating teams.^{vii}

The child and family may have been seeing the same group of health professionals for many years and transition to adult services may be a difficult time for children and families. Adult services focus on the young person as the decision maker whereby paediatric services are more family centred. Depending on the diagnosis and the duration of the young person condition, cognitive impairment or learned helplessness may be barriers to them taking complete ownership of their care.

Investment in the development of a Transition Pathway for use nationally should be a priority which includes information for families and young people, training for healthcare professionals in

transition initiation and practical application and for the adult healthcare professionals in working with young adults. Checklists and associated resources should be developed to accompany the Transition Pathway.

Identifying transition issues for non-oncology patients who don't fit the traditional Adult Pall Care referral profiles must be investigated and addressed.

PaPCANZ recommends the development of a Transition Pathway for of children with life limiting conditions (oncology and non-oncology) to adult palliative care services.

III.) Invest in increasing awareness and support for the broad social and economic cost in the context of paediatric life-limiting conditions and after the death of a child

Once a child has a life limiting illness there are financial life-changing costs to families when parents withdraw partially or completely from the workforce to become caregivers.^{viii}

Additional costs occur when families need to access equipment and treatment options for their child. A coordinated approach to providing information and support to minimise the social and economic costs for families should be considered a priority. Families require support in navigating the complex health system, the NDIS and access to support payments through Services Australia.

Research must be commissioned to map and understand the significant social and economic costs families experience whilst caring for a child with a life limiting condition, sometimes for a significant length of time. The findings of results of the research should be used as a basis for future policy decisions.

PaPCANZ recommends commissioning a study on the social and economic costs experienced by families, whilst caring for a child with a life limiting condition, to inform future policy.

4. Commit to palliative care research through dedicated annual funding from the National Health and Medical Research Council (NHMRC) and the Medical Research Futures Fund (MRFF) funding grants. Ensure a percentage of the funding is allocated to Paediatric Palliative Care research specifically.

Australia has benefited from a strategic investment in palliative care projects, which has created a large network of clinicians, academics, researchers and policy makers, and has funded initiatives such as the Palliative Care Outcomes Collaboration (PCOC), CareSearch, and the Palliative Care Clinical Studies Collaborative. The research outcomes from these networks have contributed significantly to the quality of palliative care provided in Australia.

However, to meet the emerging palliative care clinical and policy challenges, a stronger focus on palliative care research priorities and increased investment in research is needed. This will assist in developing the optimal evidence to inform interventions and services.

Research that is specifically focused on palliative care for infants, children, and young adults, must also be a priority. This funding would be in addition to the *National Paediatric Palliative Care National Action Plan* project funding.

Following the inclusion of palliative care as a standalone Field of Research, it is important that grant review panels include the necessary expertise for review of applications on both National Health and Medical Research Council (NHMRC) and Medical Research Futures Fund (MRFF) grant review panels. PaPCANZ calls for sustained targets for palliative care research and in paediatric palliative care research to be included in the 2020-2022 Australian Medical Research and Innovation Priorities.

PCA urges the Australian Government to allocate a minimum amount of funding, per annum, for targeted calls within NHMRC and MRFF research funding grants to palliative care and other end of life care research.

PaPCANZ recommends dedicated funding each year for paediatric palliative care research from the National Health and Medical Research Council (NHMRC) and the Medical Research Futures Fund (MRFF) funding grants.

About PaPCANZ

PaPCANZ is a professional group which aims to build expertise and further develop paediatric palliative care and ensure sustainability and excellence in this dual specialty. PaPCANZ is an incorporated entity. All specialist paediatric palliative care services across Australia are represented by, and contribute to the work of, PaPCANZ.

References

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- ⁱ Department of Health and Children (2010). *Palliative care for children with life limiting conditions -A National Policy in Ireland*. [online] Available at: <https://www.gov.ie/en/publication/ed697f-palliative-care-for-children-with-life-limiting-conditions-in-irelan/> [Accessed 25 Jan. 2021]
- ⁱⁱ Department of Health and Children (2010). *Palliative care for children with life limiting conditions -A National Policy in Ireland*. [online] Available at: <https://www.gov.ie/en/publication/ed697f-palliative-care-for-children-with-life-limiting-conditions-in-irelan/> [Accessed 25 Jan. 2021]
- ⁱⁱⁱ AIHW, September 2020, *Palliative Care Services in Australia*, <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce>
- ^{iv} Palliative Care Australia 2018, Paediatric Addendum – Palliative Care Service Development Guidelines, PCA, Canberra. Prepared by Aspex Consulting, Melbourne (Accessed 25 January 2021).
- ^v Palliative Care Australia 2018, Paediatric Addendum – Palliative Care Service Development Guidelines, PCA, Canberra. Prepared by Aspex Consulting, Melbourne (Accessed 25 January 2021).
- ^{vi} Bowers Alison P., Chan Raymond J., Herbert Anthony, Yates Patsy (2020) Estimating the prevalence of life-limiting conditions in Queensland for children and young people aged 0–21 years using health administration data. *Australian Health Review* 44, 630-636.
- ^{vii} Palliative Care Australia 2018, Paediatric Addendum – Palliative Care Service Development Guidelines, PCA, Canberra. Prepared by Aspex Consulting, Melbourne (Accessed 25 January 2021).
- ^{viii} Palliative Care Australia 2018, Paediatric Addendum – Palliative Care Service Development Guidelines, PCA, Canberra. Prepared by Aspex Consulting, Melbourne (Accessed 25 January 2021).