



A paediatric project focused on improving palliative care for infants, children, and young people

We need your help to improve palliative care for infants, children and young people and their families.

Palliative Care Australia (PCA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ) are working together with an experienced group of professionals to deliver the Paediatric Palliative Care National Action Plan Project.



*Every journey
shared leads to a
brighter path for
others*

Your voice is the key to success

The success of this project relies on hearing what matters to you and your family. Your experiences as a consumer or carer are the best evidence we will have to drive improvement in the quality of, and access to, palliative care throughout Australia.

Your lived experience will provide us with an understanding and a perspective to the project which, when partnered with clinical and academic professionals, will create a holistic approach to improving the provision of paediatric palliative care in the future.

This project is funded by the Australian Government and aims to:

- > increase knowledge of where the gaps are in adequate paediatric palliative care services and where services are needed;
- > improve support and information resources for parents and children with a life limiting condition, workforce in hospitals, hospices, and palliative care providers; and
- > enhance practical assistance for children with high medical needs and life limiting conditions by coordinating a national approach.

You determine how much you contribute and how often

You can determine the extent of your involvement as the opportunities are varied - from a one-off activity through to regular contributions.

The consumer and carer consultations will give a voice to those caring for infants, children or young people with a life-limiting illness, and their family and carers who support them.

The project will conduct 12 consumer and carer consultations over the course of the three-year project.

You can nominate your preferred interests by completing our consumer expression of interest survey. You can nominate to participate in:

- > forums
- > webinars and podcasts
- > providing feedback
- > reviewing documents
- > sharing your experiences
- > surveys
- > website testing

*Genuine
partnerships to
deliver the best
outcomes*

We are here to support you

We understand your participation in consultation activities could be a difficult experience and your wellbeing is our greatest concern. We are committed to providing support should you need it by providing access to a counselling service. The Australian Centre for Grief and Bereavement will be providing this support with the counsellors having an understanding of families who access or have accessed paediatric palliative care services.

You can withdraw from participating in any consultation activity at any time.

How do you register your interest?

To register your interest in contributing to the project we invite you to complete a brief expression of interest survey, found here: palliativecare.org.au/paediatric-palliative-care-consumers

What do we do with the information you provide?

Once you complete the expression of interest survey, we will add your details and preferences to participate to our Paediatric Palliative Care Consumer and Carer Register (Register). The Register is a confidential list of consumers and carers who have indicated their interest in undertaking voluntary opportunities to participate in activities as part of the Paediatric Palliative Care National Action Plan Project.

Your personal information will be securely stored, accessed by the dedicated PCA paediatric project team and will only be used for the purposes of the project. You can view our Privacy Policy on the PCA website at palliativecare.org.au/palliative-care-australia-privacy-policy

What happens after I participate in a consultation?

We are committed to providing feedback to all consumers and carers participating in consultation activities.

A quarterly bulletin will be published providing project updates as well as information on where to access resources we produce throughout the project.

An ongoing opportunity to provide feedback on how the consultation process and support is managed throughout the project will be available through our feedback form which is located on the PCA website at palliativecare.org.au/children/feedback.

Would you like to know more?

If you would like to know more about the project or wish to learn more about the consultation activities, please do not hesitate to contact the PCA paediatric project team at paediatrics@palliativecare.org.au

Working as a Nurse Practitioner in paediatric palliative care I am looking forward to all the great work which will be achieved through the Paediatric Palliative Care National Action Plan Project.

Our work as health care professionals, and therapists will be enriched through new training opportunities, increased access to resources and a raised awareness of our roles in supporting and enhancing the lives of children and families with life limiting conditions.

Sara Fleming

Nurse Practitioner
Clinical Service Director
Paediatric Palliative Care

***Committed
to working
together to
achieve results***

As a Paediatrician working in palliative care, I work with infants, children, young people as well as their families/carers over a range of different stages in the palliative care journey. Every patient is unique, and as health professionals we strive to meet the broad ranging needs of both patients and families.

I am excited that the Paediatric Palliative Care National Action Plan is providing opportunity for consumers (patients, family and carers) to have a voice and provide valuable insights about the challenges faced in these circumstances, as well as examples of what works well for them in hospitals, community and at home.

Listening to consumers/carers will guide the project in the right direction towards a more seamless system, allowing families to focus on what matters most – their child and themselves.

Dr Susan Trethewie

Staff Specialist Paediatric Palliative Care

The consumer voice must be the foundation on which the project is built, and we need your input to make this happen. I became a consumer in 1996 with the birth of my second child Tristan who was diagnosed with a life limiting illness at 12 days of age. I then went on to have a third child, a beautiful baby girl Tiarna after 3 years of genetic counselling. Sadly, at just 8 days of age Tiarna was also diagnosed with the same life limiting illness as Tristan. The experiences that our family had during our children's lives motivated me to get involved as a consumer to ensure that families following in our footsteps had better experiences.

Maria Heaton

Consumer