



# CHILDHOOD DEMENTIA MATTERS

NOVEMBER 2021

**This document provides a summary of the key issues and comments that emerged from the consumer roundtable hosted by Palliative Care Australia and the Childhood Dementia Initiative on 24th November 2021.**

Eight parents of children with dementia from NSW, ACT and SA (including primary carers and bereaved parents) participated in the roundtable event. Staff from the Childhood Dementia Initiative and Palliative Care Australia were also represented. The roundtable provided participants with an opportunity to discuss their perspectives on paediatric palliative care and to highlight their own experiences and challenges. Direct quotes from roundtable participants are presented throughout this summary document.

# Perspectives and Challenges

## → Understanding of childhood dementia

### Parents reported that:

**“No one understands regression”**

They were constantly required to educate health professionals on their child’s condition. The lack of understanding of this progressive, neurodegenerative condition impacted their experiences significantly.

Across all systems supporting their child there is/was little to no understanding of regression and how to support and manage changing dementia symptoms in children.

**“When I did finally confront my fears to visit the nearby children’s hospice I was told that my two terminally ill children had higher needs than they were resourced to cater for and that they would not be able to help”.**

Due to lack of understanding of childhood dementia, parents are constantly advocating for their child and what they need. They find this exhausting.

## → National Disability Insurance Scheme and palliative care services

### Parents reported that:

National Disability Insurance Scheme staff and others working in the disability space have very limited understanding of conditions that are life limiting, degenerative and constantly changing. Families are continually trying to educate professionals in the disability sector about their child’s condition. They constantly battle to get appropriate and timely support that is focused on retaining skills for as long as possible and maintaining a level of stability for this child and their family.

**“I applied for respite this year for my eldest son through the NDIS, I have two sons that are diagnosed. They knocked me back and told me it was my parental responsibility to look after my son.”**

There is a need for more timely and regular assessments, and understanding by the NDIS that more support not less is required as the child’s condition progresses. NDIS Coordinators need to understand what childhood dementia means for a child and their family.

There is no coordination between palliative care and NDIS services and, in fact, they can work against each other. If palliative care is mentioned in an NDIS assessment this can result in the reduction of the NDIS support provided.

**“If the NDIS thinks of my daughter as palliative, what is offered to her will be completely different. The minute you mention the word “palliative”, you risk losing services.”**

**“There is so much work involved with coordinating services that, as parents, it takes up our whole lives.”**

## → Transition to adult services

### Parents reported that:

Children can be well supported by paediatric palliative care services, and then told that they do not have a need for palliative care in the adult system.

There are gaps in transition - a child might be transitioned out of children's services at 16 but some of the adult services may not commence until the child is 18.

**“We are now in the advanced stages of my daughter’s degeneration and we have moved to the adult system. There is nobody coordinating anything in the medical or disability side of things, it all comes down to me and it is overwhelming. We used to be well supported in the children’s hospital but palliative care in the adult’s (hospital) has said they will only step in when my daughter is dying.”**

## → Communication and practice

### Parents reported that:

Health professional communication about what palliative care is and what it can offer is varied. This inconsistency in knowledge and understanding about what support is available means, in the absence of an appropriate care pathway, that parents cannot effectively advocate for a connection to the palliative care team.

**“I couldn’t bring myself to fill out the paperwork because it had “palliative care” on it. Once I did, I realised I had missed years of this wonderful place and people who could have helped us.”**

There is a lack of consistency in the provision of paediatric palliative care services. Referral, access and what services are provided seems to vary depending on:

- Where you are
- Your health professional
- Your child’s diagnosis

The more time and energy spent advocating for their child, the better the levels of service they receive, although this is hugely time consuming and exhausting.

**“The palliative care team were brilliant, but we had to go and ask for it for ourselves”.**

Parents shared their good experiences. Where palliative care and end of life support is provided by the same team that has built a relationship with the child and family members over many months or years, the care and support experience can be extremely positive.

**“We were referred to palliative care 6 months after diagnosis. I am a testament to early integration into palliative care services, it makes a massive difference. The multidisciplinary reviews and support I received were invaluable, it felt like they were the only people who understood what we were going through. My experience has been very positive, but I do feel like my story is one in a million”.**

Some parents, despite their child/ children having a life-limiting diagnosis and being a number of years into their disease progression, have never been referred to nor had a discussion about palliative care with their health practitioner.

**“Coming from the bereaved perspective, having the right care in the last few months and the last few weeks and days, really matters. I’ve supported two mums now who did not have the same support, it was truly traumatic.”**

When asked for one or two things that parents would like to see changed in the health system, they reported:

**“For it to accommodate us and our needs”**

**“Collaboration with community services”**

**“One on one coordinator to assist all”**

**“Continuity and better communication”**

**“Hospital wards with people trained in disability care”**

**“Understanding of childhood dementia”**

**“Compassion”**

**“More resources for transitioning from child to adult services”**

**“Same level of care and understanding taken in adult healthcare settings as in children’s health/hospital care”**

# Background to the roundtable

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.

The Paediatric Palliative Care National Action Plan Project is focused on improving palliative care for infants, children, and young people. As the success of this project relies on hearing what matters to families, the Childhood Dementia Initiative co-hosted a roundtable to hear from consumers impacted by childhood dementia. The experiences shared will help to drive improvement in the quality of, and access to, palliative care throughout Australia through the National Action Plan Project.

Additionally, the Childhood Dementia Initiative is committed to amplifying the voice of families impacted by childhood dementia and will publish outcomes of discussions with families to inform improvements in research, policy and practice.

## **WE WOULD LIKE TO INVITE YOU...**

**To a further discussion on this topic, and other issues key to families impacted by childhood dementia.**

### **PLEASE CONTACT**

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