



childhood
dementia
INITIATIVE

CHILDHOOD DEMENTIA
MATTERS

NUMBER 2

**What families want health professionals and
service providers to know**

OCTOBER 2022



Welcome to *Childhood Dementia Matters 2: What families want health professionals and service providers to know.*

The *Childhood Dementia Matters* series provides insight into various aspects of the lived experience of families who have children with dementia.

This document summarises key themes that emerged during a series of focus groups facilitated by Childhood Dementia Initiative. Twelve parents of children with dementia in Australia participated.

The focus groups invited participants to share their insights on working with health professionals and service providers. Participants shared challenging and positive experiences encountered when accessing support and care, and what they most wanted the professionals working with them to know. Focus groups took place in December 2021, January 2022 and February 2022. Direct quotes from these focus groups are presented in this document.

Childhood Dementia Initiative considers the voices of families as central to improving awareness and understanding of childhood dementia and to creating change. We thank and acknowledge the parents who contributed to this important resource.

CONTENTS

What should health professionals and service providers know about childhood dementia?	3
Can you give an example of a challenging or negative experience?	5
Can you give an example of a helpful or positive experience?	7
If you could share one message, what would it be?	9

What should health professionals and service providers know about childhood dementia?

We understand you won't know everything about our children's conditions. Please be willing to do some research

Parents highlighted the need for professionals to be willing to research their children's specific disorders. This could include reaching out to experts around the world or taking a few minutes to look up a condition. While willingness to undertake some research was highly valued, parents were realistic in their expectations: "We don't expect them to know everything about each individual condition." Demonstrating honesty and humility about knowledge gaps was considered the best approach. Parents quoted professionals who exemplified this approach and who said:

"The more I know, the more I realise I don't know."

"I don't have experience with this, but I can learn alongside you – are you happy with that?"

Understand that childhood dementia results in regression and loss of skills. Use the 'dementia lens' when providing care

"We want you to know that childhood dementia exists. That it's a thing."

The term 'childhood dementia' was considered helpful for both professionals and families: "Those two words help people to understand what the condition is."

Parents noted that viewing their children with a 'dementia lens' fosters consideration of, and planning for, regression and loss of skills. This is a different way of thinking. Existing systems typically focus on building skills and achieving goals and services may be withheld if symptoms are not considered sufficiently severe. Using the dementia lens enables different foci, such as early intervention and maintaining skills.

Our children have complex needs

"We don't fit neatly into boxes."

It is essential to understand and accommodate these children's unique and complex needs. Exceptions need to be made for them. For instance, providing parents with scripts for common, recurring issues in advance rather than requiring them to book an appointment.



Parents are the experts on their children

Listening to and consulting with parents is key to ensuring health professionals provide appropriate care for these children. Not only are parents experts on their child's needs and what's happening for them on a day-to-day basis, they often know a great deal about the disorders affecting their children. Additionally, parents care for their children 24/7, while the professionals they interact with see them for a limited time.

One participant said:

“We have consulted with overseas specialists and shared the information with our daughter's team to make sure she gets the care she needs. We know how she should be cared for. In the hospital, they don't know her, so we need them to use the information we provide to avoid problems.”

Parents and families need respect, care, dignity and kindness

Parents wanted those working with them to understand the importance of being treated with respect, care, dignity and kindness. Of particular note was the need for sensitivity, care and preparation when delivering a diagnosis. Some specific suggestions included:

- Carefully consider and plan for the use of telehealth. Find out if parents will be on their own. Perhaps reconvene to make sure parents are with someone to support them after receiving the news.
- Give information on the next steps and follow-up. Don't underestimate the value families can find in having control of the next steps and in knowing what care and support there is for them.

Parents also wanted health professionals to understand that childhood dementia impacts the whole family: “It's not just about the individual. It's very much about a family.”

Can you give an example of a challenging or negative experience?

The delivery of our child's diagnosis

Parents reported a lack of appropriate support, preparation and sensitivity when they were given their child's devastating diagnosis. A common feature of these negative experiences was a lack of follow-up, information on next steps, or any sense of hope. For example, one parent was told by their doctor that there was no hope and no clinical trials their child could participate in. However, when they contacted people in the USA and UK, they discovered this wasn't the case.

Others reported that their diagnosis 'odyssey' was extended because their requests for tests or their intuition weren't acted on.

A lack of guidance on, or referral to, other professionals and services

"It would be nice if someone would come to me and say, 'this is what we are going to do.'"

Parents need proactive advice and referrals. Otherwise, they are left to figure out who to see themselves. One parent shared that, at the time of diagnosis, "No one suggested we should be seeing a neurologist or other relevant specialists." Beyond a lack of clarity and extra burden on parents, this results in some families missing vital, available, time-critical support. Some reported not being referred to palliative care, or only having access to it during the last few months of their child's life. "We weren't referred to palliative care; we referred ourselves." Referral and transition into the adult system was also a reported pain point.

When professionals added to our burden of care

"Don't put things on us as parents. You can't leave the room if you don't have confidence in the service provider."

Children with dementia have complex and high needs and parents are, in many instances, full-time carers. Rather than relieving their burden of care, some parents experienced service providers or professionals adding to it. For example, one parent shared that a palliative care nurse visited their home expecting the parent to show them how to perform some essential tasks. Others reported service providers and professionals not turning up when booked or not following up with parents as promised, putting the onus on families to chase them.



When the needs of our children weren't accommodated and they didn't receive adequate care

Parents shared a number of experiences where the complex needs of their children were not met and where failures to research or communicate vital information within hospitals and across departments had serious consequences. Here are 2 examples of this:

“Towards the end of our child’s life, he was PEG fed. It needed to be changed regularly. We got to a point where we didn’t want him reclined for the X-ray they needed to do for this procedure. He wasn’t able to communicate that he could not breathe and we were really concerned about leaving him for this. We could not get anyone to understand how to accommodate this request. There were lots of parts of the medical system that understood his condition. X-ray was not one of them. We just could not advocate effectively with them to meet our son’s needs.”

“We had a terrible experience in the hospital with our daughter. Nobody knew what was going on or understood her condition. Nobody knew that temperature spikes were a feature of her condition. It took them 5 days to find out. At one point, they were going to do a lumbar puncture without a general anaesthetic until I told them ‘no’. I wanted doctors to consult with overseas specialists, but they would not.”

When our parenting was called into question

Some parents were referred to parenting courses to manage their children’s behavioural issues. This was despite behaviour and personality changes being symptoms of childhood dementia. Parents were left asking themselves questions like, “What am I doing wrong?”

One said: “There were many times that I came away from appointments and phone calls and began to doubt myself and my own sanity.” They were told to implement the Triple P Parenting Program. Their intuition and insight, however, were that their child’s behavioural issues were occurring because their disease had progressed more aggressively than the health professionals had realised. Understanding childhood dementia helped one parent: “Once I had the terminology of ‘dementia’, I let go of all the parenting strategies. There was a reason they weren’t working!”

Can you give an example of a helpful or positive experience?

Being treated with respect, care, dignity and kindness

“The way that they become part of your inner circle is that genuine level of care.”

Parents valued health professionals demonstrating their respect and empathy by listening. It helps to feel “you are heard and understood as a parent.” Supporting parents to trust themselves and their intuition, rather than calling their opinions into doubt, was also a valued way to demonstrate respect. “You don’t have to have solutions, but you can help parents trust themselves and find the right people to help.”

One parent noted that when health professionals genuinely care about their children and families, “It goes to show how good the experience can be. You just feel like – people that come into your home – it stops being repeated, invasive and like a chore if you consider them part of your inner circle. The way that they become part of your inner circle is through that genuine level of care. They’re not just coming to see a patient. That’s the difference.”

Also shared were experiences where health professionals established credibility by being prepared and responsive. For example, one parent worked with specialists who: “Came knowing the questions we were going to ask and were prepared. They listened and knew what they were talking about.” Another greatly appreciated it when specialists overseas responded to their emails within 24 hours.

When we were connected to support

One parent reported that “our lives changed” when they received help from a support coordinator who was able to refer them to specialists.

Palliative care was also highly valued once accessed for its benefits for children and families. Palliative care teams were considered caring and nurturing. One parent shared that, once they were connected to palliative care, they accessed support from a social worker for the first time. They said palliative care was necessary because: “Palliative care helps your child to live their best life and makes your life better.”



When the impact on the whole family was considered

“When you ask us how we are as a family or as parents, we feel supported, that you are with us on the journey and you care.”

Questions and acknowledgements of the impact of childhood dementia on the whole family were appreciated. “It’s ongoing grieving. It’s continuously new levels of normal and adjusting to something that you hadn’t anticipated.” Beyond acknowledging these challenges, considering the whole family can have a lasting impact: “It is a palliative condition. Every moment counts – we are trying to make memories as well as deal with a chronic condition.”

When health professionals used their knowledge to give appropriate care and accommodate us

Ongoing multidisciplinary support that worked smoothly, and health professionals willing to ask questions and do things differently to accommodate children’s needs, were some of the positive experiences shared. Here are 2 examples of this:

“We found that over time, as we had more contact with the hospital and found out what supports were available at home, we had a profile that meant we navigated the hospital system better because staff knew us. We came across nurses who were prepared to say they didn’t know and ask for direction. Helpful exceptions were made, like being in a single room. Once it was established that we were the exception, the whole thing just moved a lot easier for us.”

“My daughter needed to have her port changed over. There were six children in America that were getting a different kind of port. I went to the neurosurgeon and gave her the email addresses of all the doctors overseas and the pharmaceutical company that made the port. And she was amazing. She actually got in touch with all those doctors overseas and talked to them. I just never expected her to say ‘yes’ to it. And she’s like: ‘yeah, let’s do this’. She did the research, and was very happy to try something new. So that was a good experience for us.”

If you could share one message, what would it be?

We are the experts on our children

“Health professionals are seeing your child for 5 minutes every few months, while you, as a parent, are living and breathing this 24/7.”

“It’s a partnership of bringing medical information together with the expert on their child – their parent.”

“It’s a journey – be on the same page with parents. Trust them, work collaboratively, and don’t come up with your own values or idea of what that life should look like. Parents need to decide how things should look.”

Please do some research to understand more about childhood dementia

“If the professionals don’t know about the disease, we want them to be willing to understand and be open-minded and find out about it – don’t fob us off.”

We need continuity of care

“Continuity of care is really important, as well as having people advocate alongside us. Often we are the best people to advocate for the details of what we need, but to have people within our health support network advocating alongside us is really important.”

“We need someone to support the family, a support nurse or social worker who follows the child’s journey. One main coordinator of information, who passes it on if they leave.”

“Different hospitals do different things. The palliative care team in the children’s hospital did coordinate and was a contact point for us, but in the adult hospital, it’s not the same. It’s very scattered.”



We need to be connected to support

“A caseworker for inpatients and outpatients that are in regular contact would be great. They would help to find the solutions to problems and support us when we are already tired and drained. It would be nice for someone else to take this over for us.”

“Although my child has a life-limiting condition, we have not been referred to palliative care. We need the right people around us.”

“You need to become an expert in the condition, link up to support groups, understand hospital systems and pathways, the pharmaceutical scheme, NDIS, palliative care, community supports, therapists, charities, research projects.

A case manager would be a very helpful support. There’s an enormously complicated ecosystem out here. We’ve stumbled across things by accident that would have been really helpful to know.”

Don’t underestimate the value of having a ‘bedside manner’

“When you speak with patients with a bedside manner and convert things from technical to layman terms: that comfort that you’re able to bring, the level of reassurance, that should never be underestimated.”

Our children are complex and need appropriate care

“Know that our children are complex and that they need to be treated differently to any other patients coming in. It just can’t be treated as a normal surgery or a normal X-ray.”

“Give us confidence that our child is in good hands.”

Is your family impacted by childhood dementia?

We have information and updates for you, as well as opportunities to get involved to affect change, here:

<https://www.childhooddementia.org/for-families>



Are you a health professional?

To learn more and stay up to date on the latest resources and tools to help you work with families impacted by childhood dementia, visit:

<https://www.childhooddementia.org/professionals>

