childhood
dementia
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Childhood Dementia Matters

Family perspectives on the term ‘childhood dementia’

“Whatever terminology you're going to use is going to be confronting .... But using ‘childhood dementia’ would have given me a better path. To know where to go and look for information....”

Parent of child with dementia

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Introduction

Childhood Dementia Initiative is the peak organisation driving world-first action for every child with dementia. Our purpose is to transform research, care and quality of life for children with dementia so they may live long fulfilling lives.

Welcome to Childhood Dementia Matters 3: Family perspectives on the term 'childhood dementia'.

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

This document summarises key insights that emerged during a series of focus groups, discussion and survey responses facilitated by Childhood Dementia Initiative (CDI). Twenty-five individuals from the families of children with dementia participated in total. Family voices and experiences were heard in focus groups, interviews and a short online survey.

Who we heard from

The focus group and interview participants were all recruited from the CDI Family Advocates Program. They were parents of a child or children with a rare genetic condition that causes childhood dementia. Representation in focus groups included:

- Different diagnoses of conditions that cause childhood dementia.
- Residing in different states and territories across Australia, including metro and regional locations.
- Bereaved families
- Families with more than one child with childhood dementia
- Recent diagnosis (within last two years, including during Covid-19 lockdowns)
- Primary carers (mothers and fathers)
- 10 participants (8 families represented)

Representation from survey respondents includes:

- Different diagnoses of conditions that cause childhood dementia.
- Residing in different states and territories across Australia, including ACT, NSW, NT, SA and WA.
- Some respondents reside outside of Australia.
- Bereaved families
- Some respondents identified as Aboriginal and Torres Strait Islander
- Different social relationships including aunts, grandparents and family friends.
- Primary and secondary caring networks.
- 15 respondents.

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 and families who contributed to this important resource.

Background

At present, 2,300 people in Australia are suffering and slowly dying from dementia. These children do not have access to appropriate care or therapies that might help them. It is not a large population, but it is underserved, largely unrecognised and almost entirely ignored, not just in Australia but globally. It is not only these children who are impacted by their dementia. Parents, siblings, extended families, and friends are all affected by the experience of a child living with dementia and given the genetic nature of childhood dementia, many families have more than one child living with the condition. Nearly 9,000 people in Australia are estimated to share a household with a child living with dementia. These disorders lead to severe symptoms, high care needs, extended chronic grief, and poor quality of life for children and their families.

Method

Family voices and experiences were heard in focus groups, interviews and a short online survey. The survey provided participants the opportunity to respond anonymously. We asked families about when they first heard the term “childhood dementia”, their thoughts and feelings around the term and its usage as well as different examples when and how they use the term “childhood dementia.” Families were recruited from Childhood Dementia Initiative’s Family Advocates Program for participation in focus groups and interviews. Additionally, the survey link was shared through CDI social media channels, which provided feedback from a larger cohort of families impacted by childhood dementia. One limitation to this consultation is that families who were involved were connected to Childhood Dementia Initiative either as a Family Advocate or through social media channels. All consultations, survey development and analysis were conducted by CDI staff between October 2022 and March 2023.

What did families share about the term ‘childhood dementia’?

Families shared a range of different experiences about the term ‘childhood dementia’, including how they first came across the term, examples of using the term and their individual thoughts about ‘childhood dementia.’

When did you first hear the term ‘childhood dementia’?

Families reported first hearing of ’childhood dementia’ through different means including internet searches, diagnosing clinicians, post-diagnostic service providers, information resources, patient groups and specific rare disease foundations, and media platforms. Others reported coming across the term in academic research articles when seeking further information about their child’s condition. Other families came across the term in post-diagnosis consultations with additional healthcare clinicians.

Survey respondents reported that they have heard the term ‘childhood dementia’ used by health professionals, in healthcare settings, such as a hospital or clinic, by service providers, by family members and friends. They also reported that they have heard the term used in community groups, in a fundraising opportunity and in raising awareness of children and their families’ experiences of dementia. Some reported only coming across the term ‘childhood dementia’ when they completed our survey, however other families have been using ‘childhood dementia’ for periods of 2 years and 4 years.

“When the clinician did say [childhood dementia] I could grasp what was going on with my child....the pieces sort of flowed together of why she wasn't progressing, why she stopped walking.”

“In the American chat groups, Facebook groups, again, they refer to it as children's Alzheimer's. But I could see I was just in Australia and it was more about dementia. And I think, since doing that, I find it a really easy way to explain what's going on with the boys. People understand dementia, it's a more common term, they get it, they've seen it in elderly people, they can translate that into younger kids.”

“We attended what was called the ‘childhood dementia lab’. And I remember thinking, “okay, so it's not just a symptom, it is actually a form of dementia.” I almost have this kind of ‘A-ha!’ moment and thinking, well, that kind of changes everything.”

What do you think about the term ‘childhood dementia’?

Overall, families reported they thought ‘childhood dementia’ was the best term to explain what their child’s condition was and this term was the most effective term to communicate with all people involved in their network, including family members, healthcare professionals, service providers and community. Some responses included that the term could be shocking, but this did not diminish the efficacy of ‘childhood dementia’ to explain and communicate with both specialised and broad audiences. Families report that they found the term ‘childhood dementia’ confronting initially however this has not stopped them using it.

“‘Childhood dementia’ is a really confronting term to hear and it's horrendous to think that there are children with dementia. But for me, I think it encapsulates what our daughter went through very well and describes in two words her diagnosis quite appropriately.”

“I just think that it makes people understand really what she's going through. It's just been the easiest way to tell her story, I suppose.”

“It was quite confronting upfront. But I think for us it transitioned into quite a good tool to help others understand some of our kids' behaviour. “

“Helps to explain some of my child’s reasons for regression and understand why they had trouble in early days recalling information.

“It's the most succinct way to explain a complex condition in my/ other child/ children. People aren't going to listen if the first bit doesn't grab them.”

“I'm still a little bit divided, because Rett syndrome is probably one of the only conditions where it's not degenerative... But like I said, ‘childhood dementia’ definitely describes what is happening to our children.”

“My husband finds the term confronting; it just sounds upsetting to him. And I said, "I think that's the point”.”

“If we have had a childhood dementia diagnosis at the start, it would have made navigating that path an awful lot easier. Because it would have flagged to the medical team in an emergency that we were a bit complex, and we weren't quite so straightforward. Also, we as parents were not just being overanxious. Thinking back, it would have been a lot more helpful having that terminology earlier.”

Do you use the term ‘childhood dementia’?

Families do use the term ‘childhood dementia’.

All parents in the focus groups reported using the term ‘childhood dementia’, and with different stakeholders in different locations. Most survey respondents also use the term ‘childhood dementia’ and with multiple stakeholder groups across healthcare and accessing services and supports.

Families reported that using the term childhood dementia had revealed a limited understanding of dementia beyond stereotypes of forgetfulness in their broader communities.

“Yes, I definitely do use the term ‘childhood dementia’ purely for the fact nobody knows what Niemann Pick is.”

“I use ‘childhood dementia’ with doctors, with everyone. I've used it quite a bit.”

“I use ‘childhood dementia’ when explaining what happens with Battens disease or discussing the disease.”

“I use it when I am explaining my child’s diagnosis and symptoms to a GP.”

“I use ‘childhood dementia’ when explaining to support workers and carers some of the symptoms of my child’s disease.”

“I use it in the emergency department when I'm having to explain the condition. When you say childhood dementia it has a bit more gravity.”

“Using the term ‘childhood dementia’ makes me realise that there is a limited understanding of dementia in general. Some people will sometimes say things like, “so do they forget things?” And I reply, “yes, like how to talk and how to walk””

Can you give an example of using the term ‘childhood dementia’?

Families shared that they use the term childhood dementia in many different settings, and with positive outcomes for their child or children with dementia, and for themselves as parents, as well as in their role as carer for their child/children and the other people involved. Families provided specific examples of using the term childhood dementia with their occupational therapist, with their National Disability Insurance Scheme planning, in the emergency department of a hospital, as well as during a day surgery procedure..

“‘Childhood dementia’ helped with our recent NDIS review. Being able to use this term helped address one of my big problems with the NDIS, which is they've always given us huge therapy budgets, but not support budgets. Our kids are not kids that are going to respond with therapy because we're trying to maintain skills rather than build them. We need support because it's the adult-rehab-type profile but in a child, and to have that terminology to use helped this enormously.”

“Another place that ‘childhood dementia’ is helpful for me is when we go to hospital; my kids get quite a few respiratory issues. If I say they have Niemann Pick type C, everybody says, “what's that?” I must then explain it in front of the kids, and say, “it's a terminal disease... it's aggressive”, and being mindful that my children are blissfully unaware at the moment that anything is the matter. When I can say ‘childhood dementia” it cuts out a lot of that terminology that I'd otherwise have to use in front of the children and the doctors also understand.”

“Our speech therapist said, “When you started talking about the kids having dementia, it really got me thinking about the techniques that I use with my dementia patients and I tried something different.” They have changed their clinical practice as a result of engaging ‘dementia’ techniques and we cannot believe cannot believe the improved connection and communication that we have seen.”

“We've just had a hospital day-stay procedure for our daughter. Using the term ‘childhood dementia’ proved extremely useful in navigating the process of admission, general anaesthetic, and lobbying and negotiating with the medical staff and admissions staff about the best ways to manage the situation for our child.

For most of the medical team, they were seeing this condition for the first time, and they could then lean on us for guidance on what would work and how we would communicate the process to our daughter. That was a real help and a positive outcome because it meant we got through the day with a lot less stress and a lot less meltdowns and problems.

Using ‘childhood dementia’ to explain her condition helped the team who were seeing her for the first time, without having to spend three hours discussing exactly what else to do, how it works and what had happened? Because, when you're standing just outside the theatre and talking to the anaesthetic nurse, they don't have three hours. I don't know that they'd ever heard the term before, however it was enough for them to just take a step back and go right. How do we do this?

For me, as a parent, I was able to translate what was happening into the kids’ terminology to make it familiar, to make it okay, and no one tried to come over the top of me to make it the other way, and we had a great outcome.”

Families use the term ‘childhood dementia’

“I do say that it's wrong to say this, but I love ‘childhood dementia’. I think it just has helped us so much in explaining things or <u>not</u> having to explain things.”

“The importance of grouping the conditions under ‘childhood dementia‘ and not being so fragmented resonated with me, it just made so much sense. And the comparison was that all childhood cancers are grouped together. We can be more effective and influence policy and treatment.”

“I've seen a profound difference in how people respond to me telling them my kids have childhood dementia, as opposed to, “my kids have Mucopolysaccharidosis 3 type A.” And I wish I had that language in the beginning.”

Using the term ‘childhood dementia’ is helpful for families

Families indicated it would be beneficial if the term ‘childhood dementia’ was used in healthcare settings and by health professionals, including at diagnosis and in literature and resources.

“Think of all the services and things and needs that you would give an elderly dementia patient. This is what I now need for a nine-year-old.”

“The general booklet I have about childhood dementia has been just as, if not more, helpful than information specific to my daughter's disease.”

“’Childhood dementia’ gave our family and extended family some reference points to engage with the case, rather than it just being a long organic chemistry name that means nothing to anybody else.”

“It was helpful because it let me get a grasp of what the diagnosis means and with Battens Disease being so rare. Everyone that I speak to, no one's heard of it. “

“As a mother who embraces the term ‘childhood dementia’, I’m more compassionate. When my child went through her very first steep regression, it allowed me to be more understanding and empathetic towards what she was going through in that regression.”

“Like an older person with dementia, who knows something's wrong or going on, it's the same for my daughter, however she hasn't developed to the same level as an adult with dementia so it's even scarier. Putting her experience in the context of childhood dementia has been more than helpful.”

“For years, I was describing Sanfilippo syndrome to people who were friends or family, and others. I would describe the symptoms and whenever I would describe dementia as one of the symptoms, I certainly got a lot of recognition and understanding.”

The term 'childhood dementia' creates greater understanding within families and friends, community.

Parents and families reported that using the term 'childhood dementia' opens pathways to greater understanding, and enables better access to services, supports, education and resources. The term 'childhood dementia' has given parents and families a greater understanding of the symptoms their child might experience as part of their diagnosis.

"It was quite confronting upfront. But I think for us it transitioned into quite a good tool to help others understand some of our kids' behaviour. "

"[The term 'childhood dementia'] gives some answers and some explanation and some empathy around the behavioural issues that patients, and especially children have, because a lot of the behavioural issues can be seen."

"Even though I didn't want to hear it or like it, it did help us recognise exactly what was going on."

"I think a lot of people have an understanding of how dementia affects the body - especially in adults. So, when explaining a condition like Tay Sachs as being a form of childhood dementia, it helps others relate to how your child goes through regressions and loses skills, as opposed to just saying it's a terminal condition."

"Maybe we were softening it for other people or the group that we were in, so we didn't have to say 'dying', but you can still say it without saying these words and I think 'childhood dementia' works well."

‘Childhood dementia’ is a term that reduces isolation for families.

“We were the rare disease bunch, you know. That separates the general public from us because they go, “well, it's rare, and we'll never have to deal with that,” and they can sit back and separate themselves quite easily.

But when you bring it to a more common term and bring 70 different conditions that come under ‘childhood dementia’, that widens the pool. And suddenly, more people might start to think, well, that could happen to me.”

Next steps

Childhood Dementia Initiative will continue to work alongside families impacted by childhood dementia, and elevate their lived experience and insights to inform our systemic advocacy.

Further research into the use of the term ‘childhood dementia’ and how it is used in larger cohorts of families, with different stakeholder groups and in different settings would provide further evidence to inform language guidelines and policy changes to improve communication, understanding and navigating services and support for families impacted by childhood dementia.

Childhood Dementia Initiative welcomes collaboration in such future research.

This report will be shared with families, healthcare professionals, policy makers, practitioners, researchers, support and service providers, government and community.

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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