Exploring the issues series

Childhood Dementia: Family experiences in Victoria and Tasmania

May 2026

A Childhood Dementia Initiative report

childhood dementia INITIATIVE

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www.childhooddementia.org/getasset/16UAIA

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Acknowledgments

In the spirit of reconciliation, Childhood Dementia Initiative acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respects to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today. This Long Table was held on the lands of the Wurundjeri, Woi-wurrung and Boon Wurrung peoples of the Kulin Nation.

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 grandparents who contributed to this important event.

We thank the Finkel Foundation and CommBank Staff Foundation for making this event possible.

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Executive summary

Dementia is usually only associated with older adults. Tragically, hundreds of thousands of children across the world suffer from dementia, caused by more than 100 life-limiting neurodegenerative disorders, many of which are not yet understood.

In Australia, a baby is born every three days with a childhood dementia disorder from which they will die, most likely before their 18th birthday. Yet most health professionals remain unaware of childhood dementia. Correspondingly, finding care and support is extremely difficult for families. Research is scant and there are currently no cures and very limited treatments.

Childhood Dementia Initiative (CDI) was formed in 2020 to transform this situation. In 2026, CDI conducted a participatory research event in Melbourne – the Long Table – bringing together parents and grandparents of children living with dementia conditions in Victoria and Tasmania. Families shared their experiences of the health system while stakeholders from across health, disability, education and allied health services listened. This report provides a thematic analysis of that discussion, with the intent that it be used as a basis for future systemic improvements.

Key findings

Profound grief and living with the diagnosis

Profound grief accompanied every family's experience, whether newly diagnosed or years into their journey.

- For newly diagnosed families, the grief was raw and immediate, often without any follow-up support.
- For grandparents, the grief was layered – carrying guilt about genetic inheritance alongside fear for their own children and grandchildren.

A prolonged and traumatic diagnostic journey

The path to diagnosis was described by nearly every family as protracted, traumatic and unnecessarily difficult.

- Children were routinely misdiagnosed, sometimes multiple times, before a correct diagnosis was reached.
- Diagnostic results were often delivered in inappropriate ways, including over the phone or without adequate support.

Navigating a fragmented, uncoordinated system

Health systems were siloed and difficult to navigate, leaving families as the sole connective tissue holding their child's care together.

- Parents became the leading experts on their own child's condition, filling gaps left by clinicians with little knowledge of rare disease.

- For families in Tasmania, the absence of specialist services and an unworkable patient transport system compounded every other difficulty.

Systemic failures within the NDIS

The NDIS was a significant source of frustration, confusion and distress for many families.

- Funding was frequently cut for items families considered essential, with the burden of proof falling on already-stretched parents.
- The scheme was not designed for conditions that deteriorate over time or require 24-hour supervision.

An unregulated and inadequate carer workforce

The quality, training and regulation of the carer workforce was identified as a critical, unresolved issue.

- Families went through multiple unsuitable carers before finding one person they could trust.

Fighting and advocating for basic care

Parents described lives structured around advocacy, not as a choice but as a necessity.

- Families with fewer resources and less education were left further behind in a system that rewards those who can fight hardest.

Isolation, loneliness and the toll on families

Isolation was pervasive throughout the Long Table, compounding a severe toll on family relationships, mental health and physical health.

- Marriages had broken down, careers had been abandoned, and physical injury from care-giving was common.

Turning pain into purpose

Despite the magnitude of the challenges described, families were determined to become the change they wanted to see.

- Several families had established foundations to fund research and clinical trials, emphasising that the science exists but funding does not.

Background

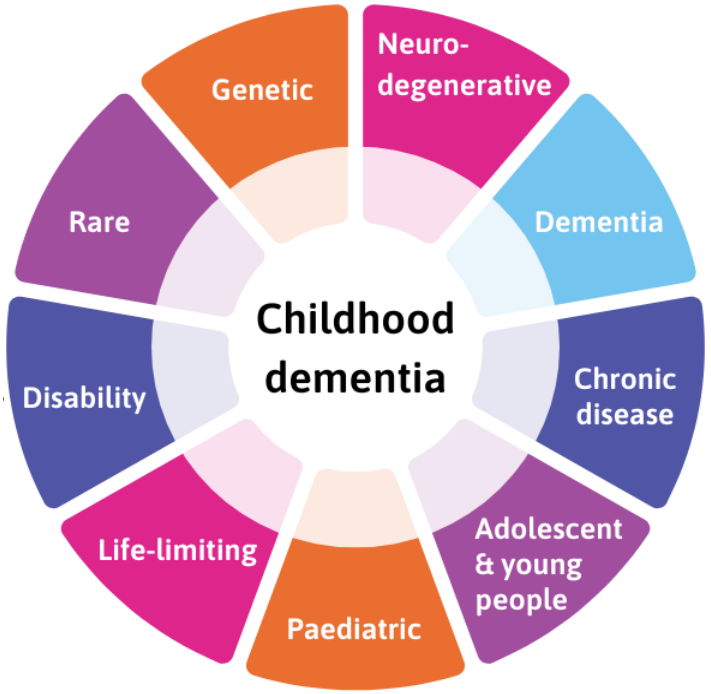
This report explores family experiences of the health and disability support system for children with dementia in Victoria and Tasmania. Through their voices, Childhood Dementia Initiative seeks to communicate how families interact with these systems, and to provide a basis for future improvements.

Childhood dementia is uniquely devastating and severely under-recognised. The condition is unknown to most people, including health professionals. As such, there are tremendous unmet needs in treatment, research and psychosocial support.

Childhood Dementia Initiative commends the professional stakeholders who participated in the research outlined in this report, and their commitment to addressing the needs of families enduring this disease.

About Childhood Dementia

A baby is born every three days in Australia with a childhood dementia disorder from which they will die. Sadly, 50% of these children will die before their 10th birthday and 70% of them before they reach adulthood[1]. Childhood dementia causes 91 deaths in Australia every year. This is a similar number to deaths from childhood cancer for patients aged 0-14 years[2].



Childhood dementia is caused by 100+ neurodegenerative genetic disorders. These conditions have recently been grouped to define this unique and under-recognised cohort. The specific attributes of childhood dementia and the lack of a coordinated approach mean that children with dementia face a uniquely devastating situation in the Australian health system:

- There are no cures for childhood dementia and it is life-limiting for all affected children.
- Children experience chronic, increasingly severe symptoms and their intellectual and physical disabilities progress until they die prematurely. Children suffer from confusion, distress, unhappiness, and pain. The childhood dementia disorders can also cause seizures, loss of vision and hearing, and problems with bones, joints and cardiovascular, respiratory, or digestive systems.
- Due to the lack of awareness, disability, health and education systems don't cater for the unique

needs of children with dementia. This results in heightened carer responsibilities for families. The psychosocial challenges they face are broad, encompassing physical, economic, social, emotional and psychological implications[4].

- Children with dementia are often excluded from essential services due to their dementia symptoms.
- The challenges facing children with dementia are not currently addressed by any national dementia policies globally.
- There is, and has always been, a significant inequity and underinvestment in research. This has resulted in no notable improvement in survivorship for children with dementia[5].
- Childhood dementia disorders are individually rare. Families report struggling to get diagnoses and can subsequently go on to have more than one child without knowing about their genetic risk.

The challenges described by families in this report accumulate and are exponential when there are multiple children with dementia in a family. Given the genetic nature of childhood dementia, this is not uncommon.

Methodology

This report summarises key insights that emerged during a participatory research event in Melbourne – The Long Table for Victoria and Tasmania. The Long Table was developed and hosted by Childhood Dementia Initiative, with this event held as part of CDI's national programme of Long Table events, following earlier events in Western Australia and Queensland.

Parents and grandparents of children with dementia discussed their experiences of health systems and disability services, while stakeholders from those systems and related services listened in silence. The discussion was recorded and transcribed. A thematic analysis of the transcripts was used to generate this report.

For more information on the Long Table methodology, see the Appendix.

Key issues

1. Profound grief and living with the diagnosis

> *"The diagnosis, the disease, is the burden. Actually having a diagnosis is a blessing because you know what you are dealing with."*

The knowledge that a child has a life-limiting condition sits differently for different families. For newly diagnosed parents it was raw and immediate – one mother at this Long Table described waking the morning after diagnosis to a breakdown she could not have predicted, having been sent home from hospital with no follow-up and no one to call. For parents who had been living with that knowledge for years, it had become a thing they managed in silence, held close so they could keep going.

For another family, the grief was compounded by circumstance: their child's diagnosis led to an earlier diagnosis for their sibling, in time for the sibling to receive a life-changing treatment. For a mother who discovered her own carrier status only after her son's diagnosis, the weight of that information was profound – she described feeling simultaneously grateful for the diagnosis and haunted by the inheritance. One father described the experience of having one of his daughters in intensive care in Melbourne while his older daughter died at home in Tasmania. Several families described the particular difficulty of not yet knowing how their child's condition would progress – carrying uncertainty as a permanent companion.

Across the table, families described navigating this knowledge in isolation – without adequate psychological support, without a peer community, and without a system that recognised the weight of what they were carrying. The grief and the logistics had become inseparable.

Grandparents at this Long Table described grief of a particular kind – layered and often invisible. One grandmother described her husband's guilt at the genetic inheritance, and their daughters' fear about their own carrier status. She described the wish to be the fixer without the capacity to fix anything. Another father described his own parents' response – his mother moving to Melbourne to help during a nine-month hospital stay, his father distancing himself, unable to process the situation.

> *"We just needed to be there. Not just as a parent, because you've got a child, but you've also got the mother and the father of this child. No parent should have to go through anything like the people at this table have."*

Alongside living with the grief, some families were channeling it into forward motion. One mother, only months after her son's diagnosis, was already writing a book and researching an ALD conference she hoped to establish in Melbourne. Another family had set up a foundation within the first year of diagnosis, identifying a clinical trial in London and beginning the work of co-funding it. The grief and the determination families experience are not in opposition.

2. A prolonged and traumatic diagnostic journey

> *"It took us seven years to know what she has."*

The journey to diagnosis was described by nearly every family as protracted, traumatic and unnecessarily difficult. The rarity of the conditions, combined with widespread lack of awareness among clinicians, means that children are routinely misdiagnosed – often multiple times – before the correct diagnosis is eventually found. One family described their daughter enduring years of unnecessary invasive testing, including a general anaesthetic for an MRI, when a simple urine test would have given the answer from the start.

Families described years of concerns being dismissed as behavioural or developmental, with parents – particularly mothers – not being believed. Several families recounted experiences of being laughed at or dismissed by specialists, including geneticists, when they raised concerns based on their own careful observations of their child.

> *"I took that information to the hospital and the paediatrician sat there and laughed at me out loud in front of a student doctor. They said, 'Don't be stupid.'"*

The communication of diagnostic results caused additional harm of its own, compounding rather than easing the trauma of diagnosis. Families were routinely told not to Google their child's condition – advice they found both insulting and counterproductive – while being given little or no alternative information or connection to support groups. Diagnoses were frequently delivered in inappropriate ways too: one mother described being told over the phone that her daughter had a fatal neurodegenerative disorder while she was out scootering her other son to the park – alone, with no one to turn to and no follow-up offered.

Several families also experienced the additional trauma of lost biological samples – skin biopsies lost in transit, blood tests that went missing – forcing them to endure the testing process, and the wait for results, multiple times.

> *"At week six I hadn't heard anything. They found out that the sample had been lost in transit to Adelaide. We had to go back down and get another sample done. And then when they tested my other son, I got a call saying his skin biopsy test was in a lab fire."*

Misdiagnosis also caused additional, lasting harm. One parent described receiving a folder at the Royal Children's Hospital with a definitive diagnosis – only to be told a few weeks later it was incorrect, and handed a new diagnosis printed from a Google search.

The repeated experience of being blindsided by the system eroded families' trust in it, leaving them wanting to be prepared for the right conversation rather than ambushed by the wrong one. Once the correct diagnosis was eventually made, families were often still left without meaningful information about the trajectory of their child's condition, what to expect, or where to turn for support.

3. Navigating a fragmented, uncoordinated system

> *"It's frustrating to know that we all live in the one big country, and we don't share the same information across from state to state."*

Parents described health systems that were siloed, difficult to navigate, and ill-equipped to provide care for children with complex, rare conditions. Waitlists were described as excruciatingly long and inflexible. Families waiting for urgent appointments were told to wait months or years, while the window for interventions such as bone marrow transplants – which must be performed before disease progression reaches a threshold – closed.

Across every stage of the journey – from before diagnosis, through the years of care, and into adulthood – families found themselves without adequate information or support, and had to become the leading experts on their own child's condition. The medical professionals responsible for their child's care often knew less than they did. One parent described ringing a London-based professor in the middle of the night to ask whether the treatment path being taken was the right one, because she had no faith in the guidance available at home. Parents described giving their doctors printouts, providing contact details for international specialists, and sourcing clinical guidance themselves, because no one within the system was doing it for them.

The lack of a dedicated care coordinator – a single person families could contact with questions – was a recurring frustration. Families described not knowing which specialist to call with a concern, being discharged from one team without being properly connected to the next, and feeling unable to reach out even with legitimate questions for fear of being a bother.

The transition from paediatric to adult care was described by parents of older children as a cliff edge – a point at which the trusted team who had known their child for years suddenly disappeared, and the family found themselves starting again in an adult health system that had even less awareness of their child's condition.

> *"I fear for anyone at this table who has a child that goes into adulthood, because it's a totally different journey. You feel lost in space because you lose your trusted clinicians."*

For families in Tasmania, these gaps were compounded by geography. The island has no dedicated paediatric specialists for rare neurological conditions, so families must travel to Melbourne for specialist care – and patient transport systems are not equipped for children who could not sit in standard aircraft seating. One parent described their spouse being required to fly alone with their daughter, without any assistance, after being told simply to get on a plane.

> *"Patient transport says, 'Get on a plane.' She can't sit in a normal seat. They made my wife fly alone, without proper assistance. She had to do everything by herself on the plane. After that day, my wife said, 'I'm never flying again. That's just not fair."*

Without adequate assistance for the flight the family has no way to get their daughter to the care she needs.

The disconnect extended across every part of the system – between the NDIS and hospitals, between

paediatric and adult services, between specialists in different states – leaving families as the sole connective tissue, carrying all of the information themselves. One family described nurses attempting to force medication down their daughter's throat because hospital staff had never read the meal plan in her NDIS file, despite her known swallowing issue.

Medication management was a recurring failure point. Parents described essential prescriptions lapsing due to administrative errors, and finding themselves in crisis situations – including at the end of a child's life – without the right equipment or support.

> *"We went home with the wrong equipment that wouldn't fit him. We weren't allowed to get equipment through the NDIS because he was on a discharge plan from the hospital. We had to wait another day for them to trial other equipment that should have been done in the hospital. We exhausted him so much we had to go to hospital the next day. Five days later he died."*

Families also raised the specific failure of the health system to acknowledge fathers and partners as equal participants in their child's care – one parent described letters and clinical records that read as if only the mother existed, despite the father being present and equally involved throughout.

4. Systemic failures within the NDIS

> *"The NDIS thinks the answer to their problems with money is to put people who are already in their own homes and supported by their families into a place to share with three other people. It's not okay."*

The NDIS was a significant source of frustration, confusion and distress for many families. While some families described receiving valuable support, particularly in earlier years, the system's inflexibility, bureaucratic requirements and failure to respond to the complexity of childhood dementia created enormous additional burdens.

Families described having NDIS funding cut for items described as not "reasonable and necessary" – including formula for peg feeds, and stoma replacements for a young person. The cost of gathering the professional evidence required to contest such decisions often exceeded the funding available.

> *"The NDIS came back in a review saying they were cutting his consumables. It wasn't reasonable and necessary to fund his formula for his peg feeds. They were saying they would only fund replacement stomas for two a year. He was going through one every three months because his gut was rotting on the inside."*

The rules preventing families from employing family members as carers were widely criticised, and described as fundamentally at odds with how these children experience trust. For children who struggled to form relationships with strangers, being cared for by an aunt, sibling or grandparent was often the only viable option – a mother who could provide that care better than anyone was, under the scheme's rules, unable to be paid to do so.

The mismatch between NDIS frameworks and the reality of caring for a child with a deteriorating, life-limiting condition was described repeatedly. The NDIS is not designed for conditions that worsen over time, that require 24-hour supervision, or that present complex and unpredictable physical needs.

Ageing parents of adult children with childhood dementia described the particular fear of what happens when they are no longer able to provide care – and the inadequacy of the NDIS's current solutions.

> *"I'm 60 and a single mum, and he's 39 this year. That's one of my biggest fears. If something happens to me, who's going to look after my son?"*

5. An unregulated and inadequate carer workforce

> *"I would rather run myself into the ground than have any of these people care for her."*

The quality, training and regulation of the carer workforce was identified as a critical, unresolved issue. For children with complex, high-intensity needs, the standard of care provided by external carers was frequently inadequate, and the system for recruiting, training and regulating carers provided no assurance of quality.

Families described carers who refused to work with their child, and who lacked the knowledge, skills or motivation to provide genuine engagement and support. Going through multiple carers to find one suitable person added an enormous emotional and practical burden.

> *"It's so unregulated. It's not even just people who don't want to work with particular children – it's people who don't have the capability. You don't even need a certificate. You can just sign up. And that's who we want caring for our most vulnerable children in our society? Not for me."*

Several families described having to accept care arrangements they found deeply unsatisfactory because there were no alternatives, or having to go without support altogether rather than expose their child to carers they did not trust.

Parents also described the financial distortions created by a system in which providers could charge for services not properly delivered. Therapists without adequate training were reported to be signing off on $2,000 reports without having seen the child in over a year – draining funding packages.

6. Fighting and advocating for basic care

> *"Nothing's easy, nothing comes without having to fight. Like we've been down this pathway for so many years, still fighting for the same things."*

Parents described lives structured around advocacy, not as a choice but as a necessity. The exhaustion was not incidental; it was the direct product of a system that provided nothing unless a parent fought for it. Parents were also clear-eyed about the inequity embedded in this fact: families with education, resources

and connections could fight more effectively, while families without were left behind – a dynamic one parent captured by noting how few of the parents at her child's school would have the skills to do what she does, arguing the system shouldn't rely on people like her to tell the experts what's best for their kids.

One parent described emailing an oncologist directly to secure her son's bone marrow transplant, having been sent home by the medical system with nothing more than a referral to the Make-A-Wish charity. Another described spending nights on the phone to specialists in London and the United States because no one in Australia was giving guidance.

Several parents spoke about the particular pressure of being the person who held all the information – the only one who knew the full medical history, the only one who understood the condition, the only one who knew which specialist to call and what to ask. One parent described the pressure of always having to be the voice in the room for their child, while also carrying the knowledge that they did not, and could not, have all the answers. That gap between the role imposed upon parents and the lack of information available was described as its own particular form of suffering.

> *"There's a lot of pressure to be the voice and the lead in the team for your child. At the same time, you don't want to have all the answers – you don't have all the answers. And I think that pressure is in its own league. It is exhausting."*

Families also described a deeply unjust dynamic in which advocating too forcefully for their child risked being penalised. One parent described being told she was "no longer welcome" at the metabolics clinic after asking too many questions – leaving her wondering whether she had in fact been dismissed for asking questions, even as the clinic denied it.

> *"You don't want to advocate too hard for your child, because then you do get turned away."*

7. Isolation, loneliness and the toll on families

> *"It's very suffocating in those early days when you haven't made those links. You just literally feel like you're the only person in the world."*

The sense of isolation and loneliness was pervasive throughout the Long Table. Families described the particular loneliness of carrying an experience that almost no one around them could understand – not extended family, not friends, not neighbours, and not most of the clinicians they encountered.

Grandparents, too, described profound isolation. One grandmother spoke of her social circle shrinking as friends and extended family distanced themselves, either uncomfortable with the situation or unsure what to say. She described the lack of a support group or community specifically for grandparents in this situation, and called for one. Some grandparents distanced themselves from the situation because they could not cope; others became central figures in the care network, at significant personal cost.

> *"Friends die off. I said to my daughter in law yesterday, my circle's shrunk, but I'm okay with that. I feel like we live in a bubble. However, that bubble is okay until it's not."*

Siblings also experienced the shadow of isolation, the sense of their own emotional needs being eclipsed by the demands of caring for their sibling. Parents spoke of feeling guilt about this, while also recognising that siblings developed particular capacities for empathy and resilience.

Finding even one other person who shared their diagnosis and truly understood their experience was described as transformative. Multiple families described the process of locating other families – through Facebook groups, international disease foundations, or chance encounters – as a turning point.

> *"Relationships are strained. We are so close to not being good, me and my husband. It's because he exists in this happy world that everything is okay until it's not okay. That leaves a very, very heavy burden on your shoulders."*

That isolation compounded a heavier toll on family relationships, mental health and physical health, which ran throughout the discussion. Marriages had broken down. Parents had left careers. Physical injury from caregiving was common. Sleep deprivation was endemic and unacknowledged by the health system.

The mental health impact on families was severe, particularly at the point of diagnosis; families described being sent home without any support structure. One parent described calling triple zero the morning after her child's diagnosis because she had no one else to call, having been discharged the previous day with a folder containing a diagnosis and no follow-up plan. The absence of routine psychosocial support at diagnosis was not unusual; it was the norm. Sleep deprivation was a thread that ran through many stories – one parent described her son not sleeping from birth until he was 32 years old, with no response from the health system. Where new parents with sleepless newborns had access to sleep consultants and maternal health support, families of children with complex needs had nothing: not acknowledged, not resourced, not considered.

For families caring for adult children, the physical demands of care had become unsustainable. One parent described the years she and her husband had spent providing two-person lifts for their adult son – at significant physical cost – and the difficult journey to finding a housing arrangement that worked for the whole family.

> *"I've got a lot of back issues from all of the lifting. Nothing is great, nothing is ideal. But I want head space so I can actually make really good decisions for my son too. And I don't think I could do that when I was all-encompassed in it."*

8. Turning pain into purpose

> *"If we can help other families in any way, then that gives us a little bit of peace along what is a really tough journey."*

Despite the magnitude of the challenges described, the Long Table was also marked by an extraordinary determination; a sense that families had no choice but to become the change they wanted to see. Many parents spoke of new purposes: establishing foundations, funding clinical trials, advocating to the government, writing books, creating Facebook communities and connecting families with each other.

Several families at this Long Table had gone beyond individual advocacy to set up disease-specific foundations, with the explicit goal of funding research and clinical trials. The science, they emphasised, was available – what was missing was funding.

> *"The science is there. I don't think people and clinicians realise the science is actually there. It's the funding, a lot of the time, that is a huge barrier."*

Parents who had come further in their journey were acutely aware of what they wished they had known earlier – and were determined to be that resource for families just entering this space. The sense of solidarity and responsibility to one another was palpable.

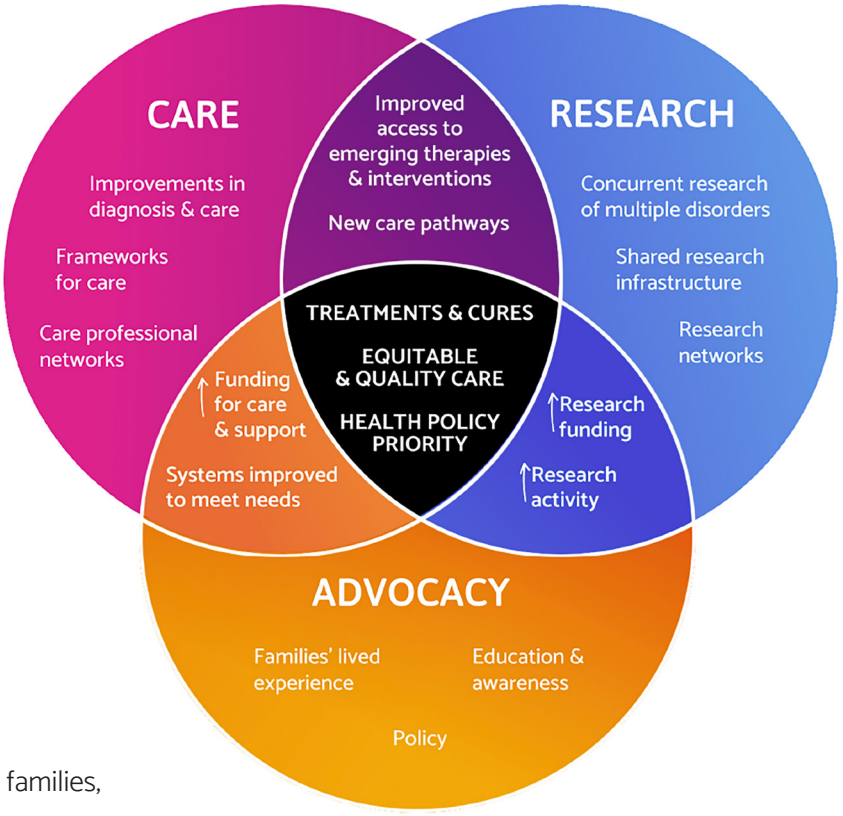
> *"I am forever grateful for the people who forged ahead of me. Not years – I'm talking about the two or three years before I got our diagnosis. I'm forever grateful for those parents in our rare disease space who fought and pushed and didn't accept that there's nothing that we can do."*

Childhood Dementia Initiative

Childhood Dementia Initiative is driving world-first action for every child with dementia, bringing all the genetic conditions that cause dementia in childhood together under a single umbrella.

Childhood Dementia Initiative works to ensure that Australian children and their families can access the treatments and support they need. CDI's work is informed by the Framework for Childhood Dementia Systems Change and underpinned by the key principles of evidence, people and co-design. The framework aligns with the National Strategic Action Plan for Rare Diseases.

Framework for Childhood Dementia Systems Change



Established in 2020, Childhood Dementia Initiative drives vital change by:

- Building evidence that is validated by families, experts and empirical data.
- Building networks, bringing cross-disciplinary experts together to enable change, including families, researchers, health professionals and service providers, and policymakers.
- Enabling partnerships, collaborations and co-design, to ensure sustainable, effective solutions are implemented.
- Advocating for enablers, including investment, policy and practice changes, as well as greater awareness.

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Appendix 1: The Long Table Methodology

"Amazing methodology, one of the most powerful and profound events I have attended in my 40-year career in children's health care services. – Health system stakeholder, WA Long Table"

The Long Table is a method of consultation that enables participants to contribute perspectives and ideas freely and fully in conversation. It was devised in 2003 by US artist and academic Lois Weaver, who calls it 'an informal format for serious conversation'6. Weaver considers it especially suited to inviting community knowledge around difficult conversations, breaking down institutional barriers to knowledge, and cultivating community. It has since been adapted and delivered across the world by diverse groups.

Participants are invited to take a seat at the table and talk with each other about a designated topic, with no hierarchy among the speakers. No one is formally introduced. They can move between speaking at the table and returning to a seat on the outside to spectate. A host is available to welcome and answer any questions, but does not act as a moderator or facilitator. There is no agenda to follow. Everyone has the power to shift the conversation's direction. The format focuses on deep listening[7].

Weaver has promoted the format as open source, encouraging others to freely borrow and adapt[8].

CDI's Adaptation of the Long Table

The voices of parents underpin CDI's work for better care, research and policy. Stakeholders were invited out of their comfort zones to a dedicated venue to hear parents and grandparents talk about how the health and disability support system works for families living with childhood dementia in Victoria and Tasmania.

For CDI's Long Table events, the format is adapted so that:

- Only invited 'context experts' – parents and grandparents of children with dementia – are seated at the table and invited to speak.
- Significant stakeholders – clinicians, researchers, policymakers and other decision-makers – are seated in the outer circle, invited to listen deeply without interjection or questions.
- There is no question-and-answer segment.
- The discussion is audio recorded and transcribed, and used to generate a report and open-access research papers.
- There is an explicit intent to follow up, inviting all stakeholders to a subsequent round table to identify solutions and actions.

'Classic' Long Table	CDI Long Table, Melbourne
Anyone who attends the event can take a seat at the table.	Only invited 'context experts' (families) are invited to speak.
The resulting mix of people at the table can include those with power to make change and those without.	People with the power to make change are invited to listen for an extended period without any interruptions.
There is no moderator, but a host is available to assist if required.	This element was unchanged.
There is no time limit on the discussion.	The discussion ran for 90 minutes before the host brought it to a natural close. Everyone attending was given a notebook and pencil so they could record their own observations.
There is no record of the discussion, beyond any notes written on the table.	The discussion was recorded (audio only). The transcript was used to generate a report outlining the issues and themes discussed.
There is no intent to follow up.	There is an explicit intent to follow up and invite all stakeholders who participated to a subsequent roundtable discussion to identify solutions and actions to achieve them.

This adaptation ensures that parents are heard in real time, collectively, without having to repeat and re-traumatise themselves. Stakeholders are invited out of their usual roles to listen without filtering, challenging or problem-solving – often a profound experience for them.

Speakers and Stakeholders

This Long Table brought together parents and grandparents of children living with dementia conditions across Victoria and Tasmania, including conditions such as Sanfilippo syndrome (MPS III), Niemann-Pick C disease, metachromatic leukodystrophy (MLD), alpha-mannosidosis, adrenoleukodystrophy (ALD), and other neurodegenerative genetic disorders. Families included those who were newly diagnosed, those caring for adolescents and adults, and those who had experienced bereavement.

Seated around the table were stakeholders from across health, disability, education and allied health services, who observed and listened in silence throughout the discussion.

Appendix 2: Long Table Event Guides

Participants and spectators at the Victoria and Tasmania Long Table were provided with the following guides, adapted from CDI's standard Long Table materials.

Long Table Participant Etiquette Guide

This is a collaboration of conversation and discussion about childhood dementia.

- Anyone seated at the table is an expert in their child, their family and their experiences of childhood dementia.
- Family voice and experience is the only course.
- No one will moderate, but a host may assist you.
- It is a democracy and everyone shall be heard.
- To participate, simply take an empty seat at the table.
- If you leave the table you can come back again and again.
- Feel free to write your comments on the tablecloth.
- There can be silence. There might be awkwardness. There might be sadness or tears. There could be laughter.
- There is an end, but no conclusion.

This Long Table was held on the lands of the Wurundjeri, Woi-wurrung and Boon Wurrung peoples of the Kulin Nation. We thank the Finkel Foundation and CommBank Staff Foundation for making this event possible.

Long Table Spectator Etiquette Guide

As a spectator, you are invited to watch, observe and participate through deep listening to the discussion and conversation at the Long Table.

The people at the table are parents and grandparents of children with dementia conditions. They are experts in their child, their child's condition, their family and their experiences of the health and disability support system. There is no question-and-answer segment or time to ask questions during the Long Table.

A long table was set with a white tablecloth and marker pens, to help document the conversation and produce a physical record of the event, with surrounding chairs for spectators placed around the Long Table.

Appendix 2

Long Table participant etiquette guide

Etiquette

The Long Table: Exploring the Issues in Health for Childhood Dementia

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But a host may assist you.

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Feel free to write your comments on the tablecloth.

There can be silence.

There might be awkwardness.

There might be sadness or tears.

There could be laughter.

There is an end, but no conclusion.

We respectfully acknowledge that this Long Table is on the lands of the Wurundjeri, Woi-wurrung and Boon Wurrung peoples of the Kulin and pay our respects to their Elders past and present.

We thank the Finkel Foundation and CommBank Staff Foundation for making this event possible.

Long table spectator etiquette guide

Coming to the Long Table

What is a Long Table?

The Long Table is a format for discussion that uses the setting of a table conversation as a means to generate public discussion and new knowledge. Conceived in 2003 by Lois Weaver in response to the divided nature of conventional panel discussions, the Long Table allows voices to be heard equally, disrupting hierarchical notions of 'expertise'.

The Long Table has been set at institutions and festivals worldwide, and invited hundreds of people to sit and share their views and experiences on a myriad of topics.

What to expect

Setting the table
The Long Table is an event; people participating in the discussion have been invited to be seated at the table, and people have been invited to spectate by watching and listening from seating outside of the table.

A Long Table
A long table will be set with a white tablecloth and marker pens to help document the conversation and produce a physical record of the event.

Surrounding chairs for spectators will be placed around the Long Table.

A host and etiquette
The Table will moderate itself, and there is no need for anyone to 'tie up loose ends' at the end. However, a host can ensure everyone follows Long Table etiquette and close the conversation at the set time.

Your role

As a spectator, you are invited to watch, observe and participate through deep listening to the discussion and conversation at the Long Table.

The people at the table are parents of children and young people with dementia conditions. They are experts in their child, their child's condition, their family and their experiences of the health system. There will not be any 'Q&A' or time to ask questions during the Long Table. We encourage you to document
what questions you would like to ask, and share these with us after the event as part of our evaluation. Additionally, there will be a Round Table consultation in late 2026 in Melbourne providing you an opportunity to bring your questions and insights from the Long Table.

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Schedule

Arrival 9.30 am

Introductions 9.45 am

The Long Table commences at 10.00 am

Lunch will be served from 12.15 pm

Finish 1.00 pm

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