Exploring the issues series

Childhood Dementia: Family experiences in Western Australia

July 2024

A Childhood Dementia Initiative report

childhood
dementia
INITIATIVE

Childhood Dementia Initiative (2024). Childhood Dementia: Family experiences in Western Australia

https://www.childhooddementia.org/getasset/A5RLME

July 2024 Sydney, Australia.

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.

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.

Thank you to the Rare Care Centre at Perth Children's Hospital for partnering with CDI on this research and supporting families impacted by childhood dementia.

Contents

Executive summary

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

In Australia, a baby is born every 2 days with a childhood dementia disorder from which they will die, most likely before their 18th birthday. Before they die, they live with chronic, increasingly severe symptoms. Childhood dementia causes a similar number of deaths in Australia to childhood cancer for patients aged 0-14 years. Yet most health professionals are unaware of childhood dementia. Correspondingly, finding care and support is extremely difficult for families. Additionally, research is scant and there are no cures or treatments.

Childhood Dementia Initiative (CDI) was formed in 2020 to transform this situation. Listening to families is at the heart of CDI's approach. In 2023, CDI conducted a participatory research event in Perth called The Long Table. Parents of children with dementia discussed their experiences with health systems in Western Australia (WA), while stakeholders from related systems and services listened. This report provides a thematic analysis of the discussion, with the intent that it be used as a basis for future improvements.

Key findings

Profound ongoing loss and anticipatory grief
Profound grief and experiences of trauma were woven through every story.

- Caring for their children as they progressively deteriorate, and with the knowledge that they will die, is uniquely devastating for this cohort of families.
- The unpredictability of ever-looming multiple losses is particularly stressful, especially as parents endeavour to build memories.

Lack of information and support
Both before diagnosis, and as their children's symptoms progressed, families were without adequate information or support.

- The onus falls on parents to proactively research their child's condition and hunt down specialists worldwide who could advise on care.
- Parents often hold greater knowledge than the specialists within health services.
- The effort involved in searching for someone who understands and can help is overwhelming.

Isolation and loneliness
Families shared feeling alone and isolated and yearning for connection.

- The lack of information and support is a key contributor to feelings of isolation and loneliness. Having so many clinicians unfamiliar with their child's disease made parents feel abnormal.

- Connecting with other parents facing childhood dementia was vital.
- Siblings also felt lonely as a result of their parents' focus on the progressively sick child.

Challenges with health systems and services

Parents painted a picture of health systems that failed to provide timely or comprehensive care for their child's needs.

- Health systems were described as uncoordinated, fragmented, rigid and difficult to navigate.
- The inflexibility of scheduling and waitlists are experienced as particularly dehumanising and illogical.
- Access to support and essential medications is sometimes disrupted by bureaucratic hurdles, poor communication, and transitions from paediatric to adult services.

Fighting and advocating

The time and energy parents spent fighting and advocating for their children was one of the most persistent themes. This spanned nearly every domain of life, from healthcare to education to social supports.

- Parents considered it unjust that already overwhelmed families have to become full-time advocates to access basic services.
- Some parents had to undertake their own fundraising for transport and equipment costs, or take legal action to access supports.

Inequity and difficulties accessing clinical trials

Clinical trials were considered vitally important, but families were unsupported in their efforts to access them.

- The process of trying to find trials can be complex and disappointing, and participation can be extremely disruptive.
- Despite the immense challenges, families expressed and demonstrated a willingness to do all they could to participate in trials, including travelling great distances.

Turning pain into purpose

Many parents spoke about a drive to help others and create positive change for the childhood dementia community.

- Parents spoke of honouring their children through activities like advocacy, fundraising for research or supporting other families.
- The effort involved in doing this work, on top of their other informational and emotional burdens, was significant but worthwhile.

Background

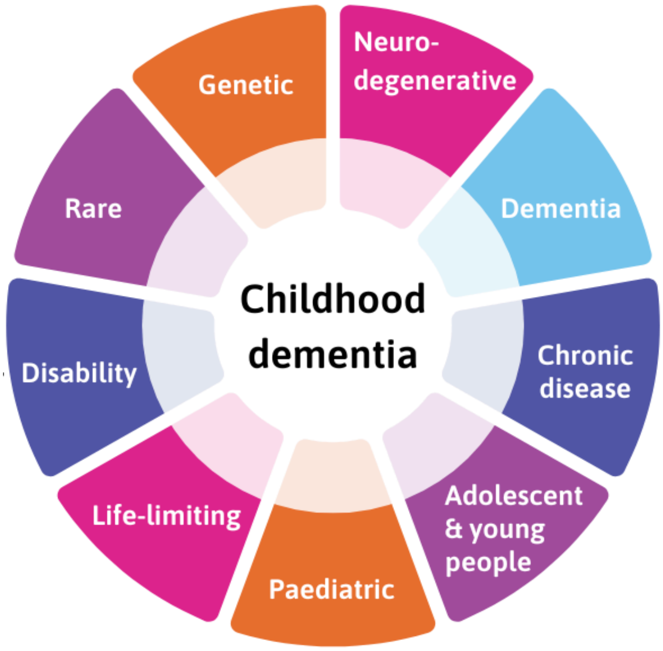
This report explores family experiences of the health system for children with dementia in Western Australia (WA). Through their voices, Childhood Dementia Initiative seeks to communicate how families interact with the health systems in WA, and to provide a basis for future improvements.

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 2 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 means the 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 complex 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 complete 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[3] [4] 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 Perth called The Long Table. Held in March, 2024, the Long Table was developed and hosted by Childhood Dementia Initiative in partnership with the Rare Care Centre at Perth Children's Hospital. Parents of children with dementia discussed their experiences of health systems across Western Australia (WA), while stakeholders from those systems and related services listened.

Seven parents of children with dementia spoke about their experiences when seeking health care and support for their children. Present were mothers and fathers, some couples and some individual parents. They were seated together at a table in the centre of a room. Seated around them were stakeholders who were invited to deeply listen and observe without interjection or questions. For more information on the methodology, see Appendix 1.

Key findings

Profound ongoing loss and anticipatory grief

"The cloud of we know what's going to happen to our children. I mean, I can talk about it. But I keep the lid on that box of emotion, because I have to."

Profound grief and experiences of trauma were woven through every story. Parents faced the devastating knowledge that their children had life-limiting conditions characterised by progressive deterioration and loss of abilities. The emotional weight of this was staggering. They spoke of feeling like they were grieving their children while still caring for them.

The hardest part for many was the unpredictability – they didn't know if or when they would lose the ability to walk, talk, eat or breathe independently. Enjoying each moment was bittersweet when the threat of loss loomed so large. One father spoke about it feeling like "a slow car crash you cannot come back from".

Parents had to compartmentalise their own fears and sorrows to stay present and positive for their children. They described focusing on the joys and milestones of each day. But the pain of it was always there, even if often unspoken.

Some found comfort in connecting with adults with the same condition as their child, who defied dire prognoses. But many also had to rewrite their visions of the future and grapple with profound existential questions about fate, fairness and finding meaning.

For parents of children who had lost abilities like walking and talking, there was a particular anguish in trying not to compare them to their prior selves. **The discussion revealed a group of families quietly carrying immense emotional burdens that often went unrecognised by the wider world.**

Lack of information and support

"Sometimes you do feel apprehensive to take the medical advice from whoever it is, whatever department you're seeing … I think they know very little about it – probably looked at journal articles, and have actually indicated that they know nothing … They're caring for my child. But I don't know if I can trust what they're saying is actually best practice. I think that's why we go to the United Kingdom."

"It took us 7 years to know what she has."

Families found themselves without adequate information or support before and after diagnosis. They had to become experts in their children's rare conditions because medical professionals often knew little about them.

Many spent long stretches of time not even knowing of another individual with the same condition. Basic information on what to expect or how to manage care was lacking.

One parent recalled a doctor admitting that the stack of information she had amassed about her daughter's disease was far more than what he knew. Others described giving doctors printouts and contact information for international experts because local clinicians were at a loss.

The onus fell on parents to proactively research their child's condition and hunt down specialists worldwide who could advise on care. While some eventually connected with knowledgeable researchers and clinicians, it took immense persistence and resourcefulness. Families had to travel vast distances to access information and support. Some travelled from regional and remote locations to access services and support in metropolitan centres. Others travelled to the UK or USA to access specific clinics or explore potential clinical trials. Enabling this travel required that families fundraise or refinance the family home.

Beyond the diagnosis, families struggled to get information as their child aged and symptoms progressed. The lack of a centralised resource compounded the challenges, especially for non-English speakers or those without pre-existing scientific knowledge.

Parents felt largely left to fend for themselves informationally. While some forged strong partnerships with certain clinicians, overwhelmingly they felt unsupported in their hunt for knowledge and expertise.

“I'm still looking. I'm not saying people don't care, but I'm looking for that person who goes, ‘This piques my interest here; I want to know more.’ I want to find those researchers or people in Australia, or even the Southern Hemisphere or anywhere in the world."

“We need medical professionals to take an interest in rare diseases. We need to feel heard, acknowledged and supported. We need to be able to trust that medical decisions are being made by professionals who spend time educating themselves regarding their patient's diagnosis and seek to deliver best practice in the context of the diagnosis.”

Isolation and loneliness

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

The sense of isolation and loneliness was pervasive throughout the discussion. Parents often felt profoundly alone in their struggles caring for a child with dementia, with one participant stating, “It’s a lonely, lonely spot.”

The rarity of the individual conditions meant that most people, including medical professionals, had never encountered them before, which heightened feelings of isolation. Many participants spoke about the transformative power of connecting with other families facing childhood dementia. Finding even just one other person who truly understood their experiences was like a lifeline.

However, forging those connections often took a lot of effort and time. Multiple parents described finding Facebook groups or travelling internationally to attend family conferences to connect with others who shared their diagnosis. While online connections were valued, the opportunity to bond in person was particularly treasured.

The hunger for community underscored how acutely alone these families felt. The isolation also extended to siblings, who grew up in the shadow of their brother or sister’s illness. Some parents worried that they neglected the emotional needs of their healthy children because the affected child's needs were so all-consuming. However, there was also a sense that siblings developed unique strengths, like empathy and resilience, from those experiences.

Feelings of isolation were also experienced with extended family and friends who struggled to understand the realities of their lives. The burden of constantly having to explain and advocate was immense: "There's nothing more exhausting than having to retell your story."

Challenges with health systems and services

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

"…no multidisciplinary team approach between the departments."

Parents described health systems that were siloed, difficult to navigate, and ill-equipped to provide comprehensive and timely care for their child's needs.

Many children needed to see a wide array of specialists, but care was fragmented and uncoordinated. Parents had to become the sole locus of information, responsible for updating different departments and doctors on their child's full medical picture. They described a "disjointed and inflexible" process of "silos that don't talk to each other".

Waitlists were excruciatingly long, with one parent noting it took over two years to get an appointment which they were told would happen in six months. Scheduling was rigid and dehumanising, with families having to just "take what you get" even if appointment times upended work, school and family needs. The journey to diagnosis was long and illogical for many – one family waited four years to access genetic testing that ultimately gave them an answer.

Transitioning from paediatric to adult care was another point of significant disruption, with established supports suddenly evaporating.

Medication management was yet another battle, with children's essential prescriptions sometimes lapsing due to bureaucratic hurdles and poor communication.

Overall, families felt like they were constantly running up against brick walls trying to cobble together care in systems that weren't set up to support the complexity of their needs. While individual clinicians could be wonderful, systemically the experience was one of frustration, rigidity, long waits and poor coordination.

Fighting and Advocating

“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."

“I guess change can't happen unless you make noise and get up and fight, which is what we do every day just to get basic needs met ."

One of the most persistent themes was the inordinate amount of time and energy parents had to spend fighting and advocating for their children. This spanned nearly every domain of life, from healthcare to education to social supports. They had to battle to get diagnoses, timely appointments, essential therapies, medications, adaptive equipment, suitable school placements, and respite care.

The participants were united in their frustration at systems that put the onus on parents to push for every necessary support and for appropriate care. Parents considered it unjust that already overwhelmed families had to become full-time advocates just to access basic services.

For non-English speakers or recent immigrants, the barriers were even higher.

Some parents had to take legal action to access essential supports. Others had to fundraise incessantly to cover the costs of travel and equipment that their children needed. The seemingly perpetual battle left many feeling depleted and demoralised.

While they were fiercely determined to get the best for their children, they resented having to fight so hard for basic rights. Many also felt that their other children missed out on attention because the affected child’s needs were so consuming. The toll on marriages, careers and family life was profound.

“We shouldn't have to do this day in and day out. It's not okay."

Inequity and difficulties accessing clinical trials

Every family spoke of the importance of accessing clinical trials. Timely access to clinical trials is the only possible pathway for any kind of treatment for children and young people with dementia conditions. Parents shared different experiences and knowledge of how to access clinical trials, and awareness of how to seek potential access. Those who had the ‘insider’ knowledge from participating in clinical trials were forthcoming in providing this information with other parents who were still ‘outsiders’ to access potential trials for their child.

Despite their critical importance, families carry the burden of locating and trying to access trials, as well as managing parental and ethical considerations of participation in clinical trials. They can also face not being eligible for or accepted into trials. This can follow complex processes including diagnostic screening. Age limits for participation were barriers that parents discussed.

“If anyone in Australia is interested in researching DNA repair disorders, I don't know where to find that information.”

“Our daughter has had approximately 96 lumbar punctures over the last 5 years.”

“Clinical trials in the childhood dementia space have the ability to change the face of the medical landscape, because it will be cutting edge technology. And no one else is going to put their children forward to do it. But we parents will, and we do, and we have [put our children forward]."

Families need to travel large distances regularly to participate in clinical trials. Additionally, family life is significantly disrupted by this necessary travel.

“We moved our life over there [to the USA] for 10 months And now we go back every 6 months.”

“We've been travelling from Perth to Melbourne every fortnight for 6 years.”

Turning Pain into Purpose

“… you know, 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, I guess.”

Amidst the struggles, many parents spoke about channelling their pain into purpose. They described a drive to help others and create positive change for the childhood dementia community.

This sense of purpose took many forms – participating in studies, fundraising for research, promoting genetic screening, contributing to patient registries, advocating to streamline diagnosis and access to therapies, creating parent guides, and linking families for peer support. Some took on public speaking to raise awareness or participated in media interviews. Others volunteered with rare disease organisations or started their own initiatives.

There was a sense that families had no choice but to become the change they wanted to see. While it was an immense burden to carry when they were already so stretched, many also spoke of the drive to honour their children. They didn’t want other families to suffer alone like they had, so they were determined to light the path and “make noise” for change. At the same time, some wrestled with how much to put their child forward as a public face of the disease. They worried about protecting their privacy and right to be seen as a whole person, not just a diagnosis.

Overall, there was a powerful sense of solidarity, that in coming together they could create a world where people with childhood dementia can live fuller, longer, better supported lives.

“I am forever grateful for the people who forged ahead of me. And I'm not talking about years; I'm talking about the 2 or 3 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.

Framework for Childhood Dementia Systems Change

Childhood Dementia Initiative works to ensure that Australian children and their families can access the treatments and support they need. This will change the lives of thousands of Australians now as well as the lives of future generations. Childhood Dementia Initiative'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, which recognises the need for research into rare diseases to be collaborative, person-centred and systematically address gaps.

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

- Building evidence that is validated by families, experts and empirical data.
- Building networks. We bring cross-disciplinary experts together to enable change. This includes families, researchers, health professionals and service providers, and policymakers.
- Enabling partnerships, collaborations and co-design. This ensures sustainable, effective solutions are implemented.
- Advocating for enablers. This includes investment, policy and practice changes, as well as greater awareness. Shifts in funding, policy and awareness are already having an impact.

References

1. Elvidge K, Christodoulou J, Farrar M, et al. “The Collective Burden of Childhood Dementia: A Scoping Review.” *Brain*, vol. 146, no. 11, 20 July 2023, https://doi.org/10.1093/brain/awad242.

2. Australian Institute of Health and Welfare. Australia’s children: Cancer incidence and survival. Updated 25 February 2022. Accessed 2 December 2022. https://www.aihw.gov.au/reports/children-youth/australias-children/contents/health/cancerincidence-survival

3. Djafar JV, Smith NJ, Johnson AM, et al. “Characterizing Common Phenotypes Across the Childhood Dementia Disorders: A Cross-sectional Study From Two Australian Centers.” *Pediatric Neurology*, vol. 149, 1 Dec. 2023, pp. 75–83, https://doi.org/10.1016/j.pediatrneurol.2023.09.006. Accessed 2 Apr. 2024.

4. Nevin SM, McGill BC, Kelada L, et al. “The Psychosocial Impact of Childhood Dementia on Children and Their Parents: A Systematic Review.” *Orphanet Journal of Rare Diseases*, vol. 18, no. 1, 7 Sept. 2023, https://doi.org/10.1186/s13023-023-02859-3.

5. Childhood Dementia Initiative (March 2024). “Childhood Dementia Global Clinical Trial Landscape Analysis.” https://www.childhooddementia.org/getasset/LZPRVX

6. “Long Table on Live Art and Feminism with Lois Weaver.” *LADA Live Art Development Agency*, www.thisisliveart.co.uk/projects/long-table-on-live-art-and-feminism-with-lois-weaver/. Accessed 25 March 2024

7. Ungunmerr, M. “Dadirri: Inner Deep Listening and Still Quiet Awareness.” *Miriam Rose Foundation*, 1988. Accessed 25 March 2024 https://www.miriamrosefoundation.org.au/dadirri/

8. Split Britches. “Long Table.” Accessed 25 February 2024. https://www.split-britches.com/long-table

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.” - WA health system stakeholder

For complex and highly emotive topics, it can be challenging to create an environment where participants feel comfortable enough to openly share rich, unfiltered accounts of their experiences.

In March 2023, Childhood Dementia Initiative (CDI) partnered with the Rare Care Centre at Perth Children’s Hospital to deliver The Long Table. At this event, key stakeholders ranging from researchers to those working across paediatric and adult settings, the NDIS, education, allied health, clinical nursing and palliative care listened silently to a group of parents whose children have dementia. With no questions to structure their conversation, and without trying to solve any problems, the parents talked about what it was like to engage with the state’s health services as they sought treatment and care for their child.

What is The Long Table?

The Long Table is a method of consultation that enables participants to contribute perspectives and ideas freely and fully in conversation.

The Long Table 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 they do not act as a moderator or facilitator. There is no agenda to follow or agreed time to finish up. Everyone has the power to shift the conversation’s direction, to embrace silences or break them. The format focuses on deep listening[7].

Weaver has promoted the format as open source, encouraging others to freely borrow and adapt[8]. She suggests this blend of theatrical spectacle and domestic familiarity is especially suited to inviting community knowledge around difficult conversations, breaking down institutional barriers to knowledge, and cultivating community.

From ‘lived experience’ to ‘context expertise’: adapting the methodology for Childhood Dementia Initiative

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 talk about how the health system works for families living with childhood dementia.

The Long Table format was adapted for this session:

- Parents stayed at the table and spoke, and stakeholders stayed seated in the outer circle to listen and observe. This was done so that:
    - Parents could focus on each other during conversation.
    - If stakeholders reacted with strong emotions, it was less obvious to the speakers.
    - Stakeholders were able to focus on listening without needing to respond or provide their professional opinion or expertise.
- Significant stakeholders were invited so that parents were heard in real time, collectively, without having to repeat and re-traumatise themselves.
- There was no question-and-answer segment where stakeholders could challenge parents or assert their professional opinions or expertise.

‘Classic’ Long Table	CDI Long Table, Perth
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.	After approximately two hours, the host identified a natural lull in the discussion and gently brought it to a close.
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.

	Everyone attending was given a notebook and pencil so they could record their own observations.
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.

Speakers and stakeholders

There were clear and specific roles, for speakers (parents of children with dementia conditions) and for spectators (stakeholders including clinicians, researchers, policymakers and other decision-makers). All attendees received email correspondence before the Long Table, reminding them of the event's purpose and roles, with a corresponding etiquette guide (see Appendix 2).

While all speakers were parents of children with dementia, their situations and experiences were very different. Almost all of their children had different conditions causing their dementia. None of the parents had met before.

Attendees were sent a feedback survey.

Observations from feedback survey from both parents and stakeholders

100% of participating parents and stakeholders agreed or strongly agreed that:

- The format of The Long Table was easy to understand
- The Long Table method was appropriate for the audience
- The Long Table had given them a greater understanding of families' experiences of childhood dementia.
- They wanted to be kept updated on future events.

Attendees were invited to share their most significant reflections or learnings from The Long Table:

"The methodology was fascinating and moving."

"I think the parents who attended were mindful of letting all the parents have their voices heard. The host did not need to guide hardly at all. I imagine different parents on another occasion may generate a different experience."

“I think the parents who attended were mindful of letting all the parents have their voices heard. The host did not need to guide hardly at all. I imagine different parents on another occasion may generate a different experience.”

“A comment one of the parents said really resonated with me: 'Make the easy things easy so we can fight the hard'.”

“Was to be able to reach out and meet new people that are now going through what we have been doing for the past 17 years and not to feel so alone anymore.”

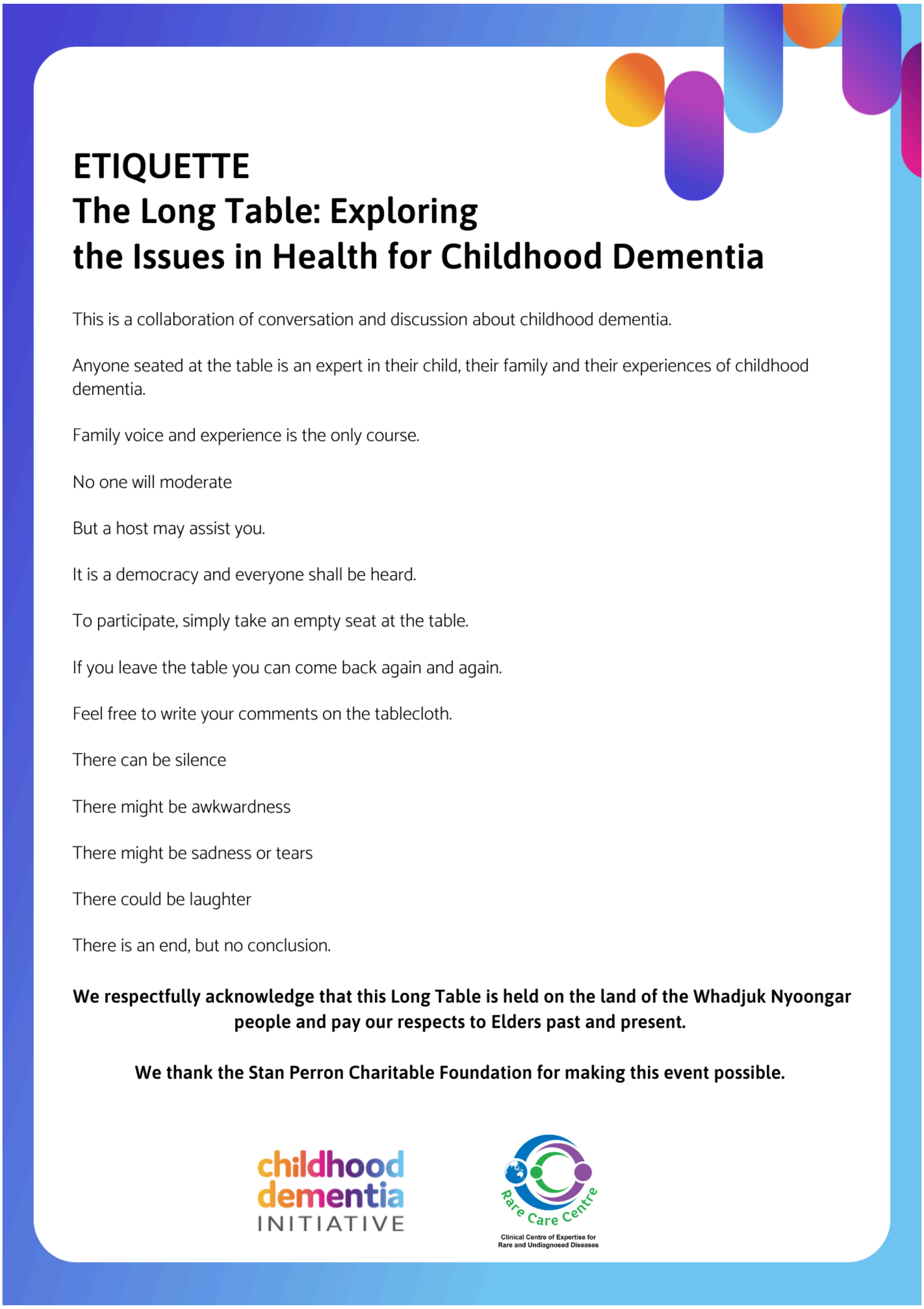
“The empowerment given to the parents who attended, to speak openly, freely and respectfully as they also listened to each other. The parents not being interrupted, or asked to clarify, by the stakeholders who remained silently, listening hard, was energising.”

“… it has prompted me to understand more about RD (rare disease) impacts in general, including wellbeing impact, loneliness, lack of connection to other families, difficulties navigating and accessing information, lack of inclusion criteria for multiple sectors/agencies supports and access to therapy and clinical trials.”

“Placing families at the forefront and professionals in the background changes the experience from the usual consumer feedback methodologies, as families are in the driving seat, allowing them to tell their story honestly and openly in their own way and in their own time. The feedback is richer and more meaningful and is, therefore, more powerful in its impact. It gave me ideas of how we need to target and focus future strategies to better support families.”

Appendix 2

Long Table participant etiquette guide



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

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.

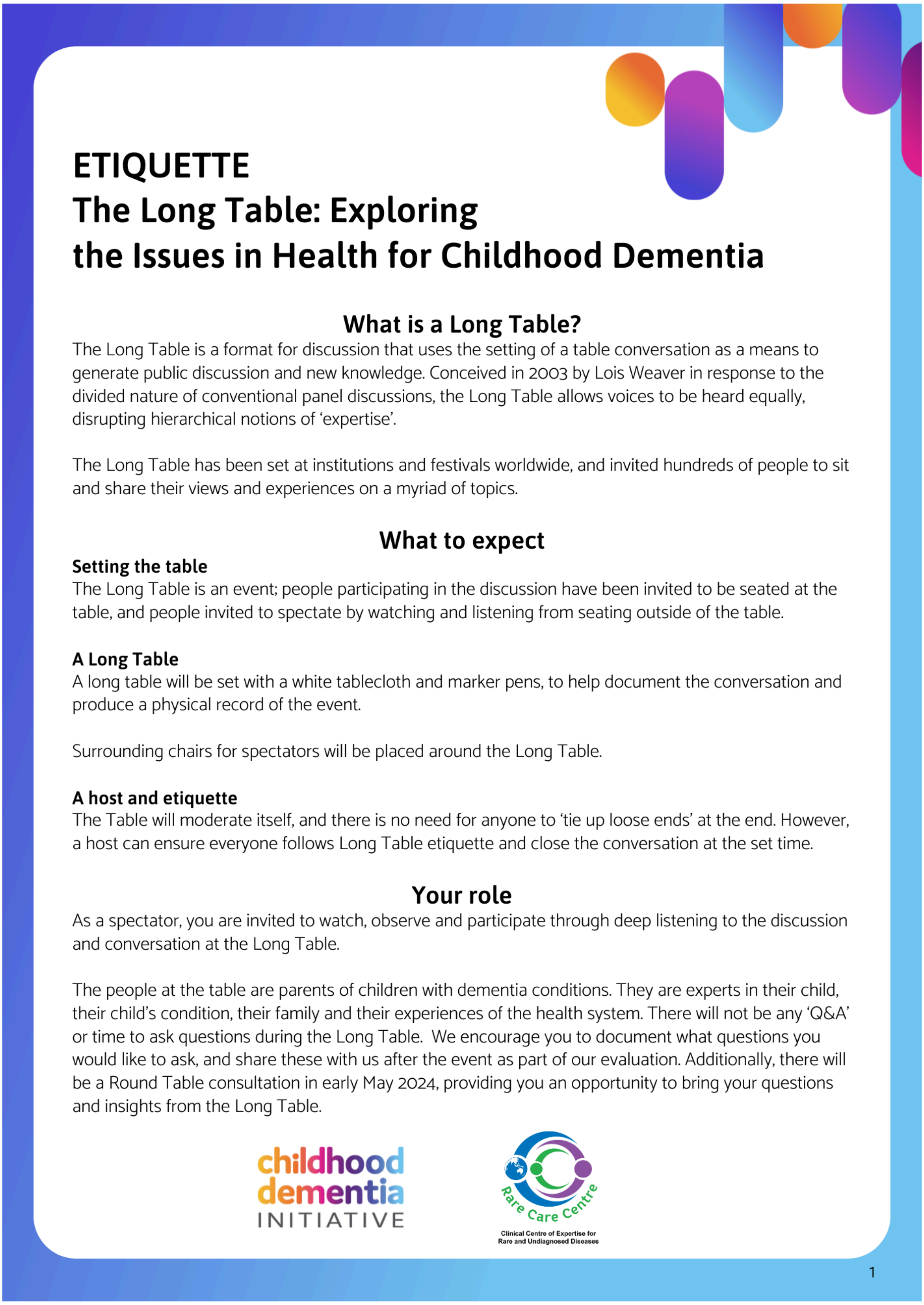
We respectfully acknowledge that this Long Table is held on the land of the Whadjuk Nyoongar people and pay our respects to Elders past and present.

We thank the Stan Perron Charitable Foundation for making this event possible.

childhood
dementia
INITIATIVE

Rare Care Centre
Clinical Centre of Expertise for
Rare and Undiagnosed Diseases

Long table spectator etiquette guide



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

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 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.

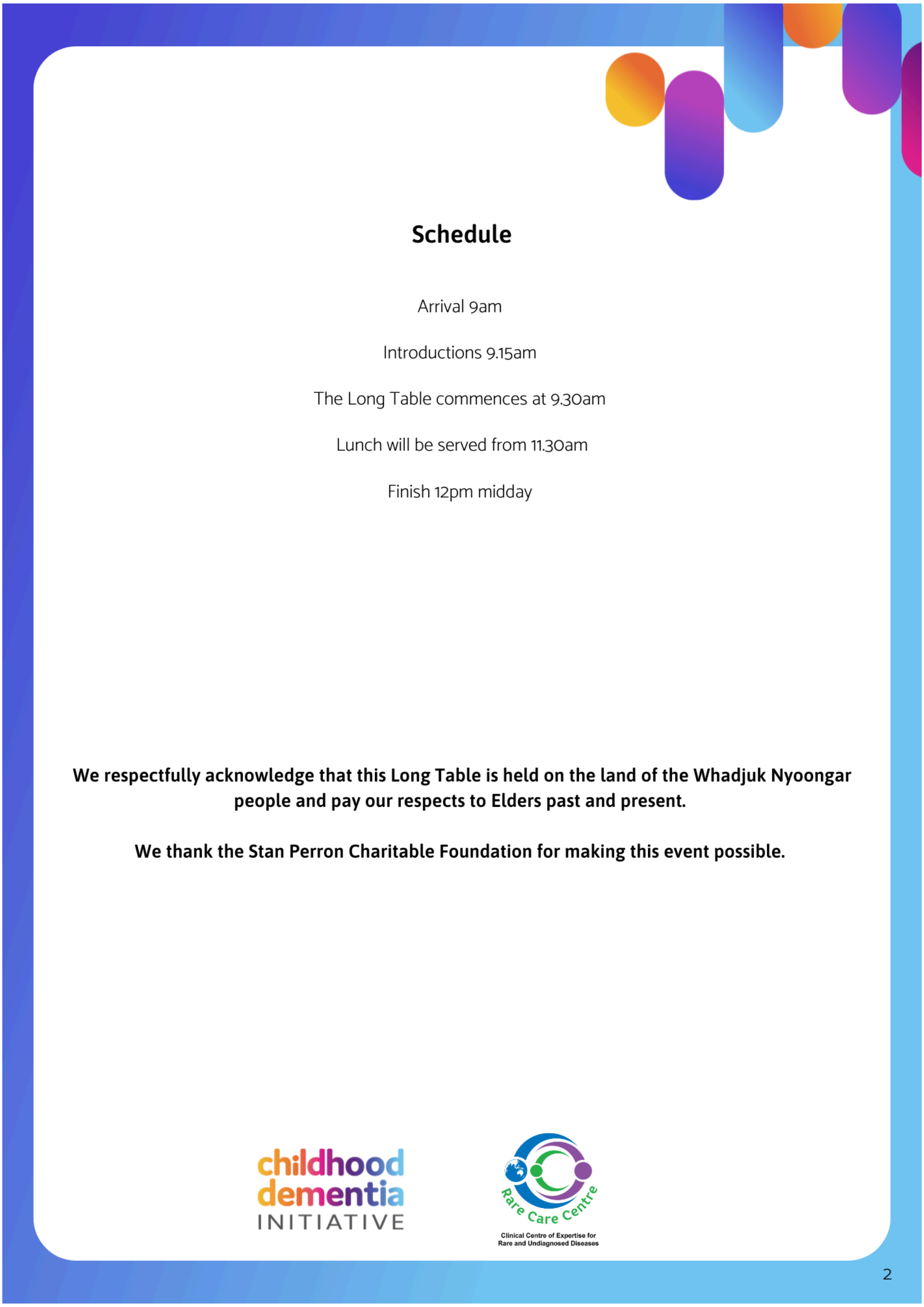
A host and etiquette
The Table will moderate itself, and there is no need for anyone to 'tie up loose ends' at the end. However, a host can ensure everyone follows Long Table etiquette and close the conversation at the set time.

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 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 early May 2024, providing you an opportunity to bring your questions and insights from the Long Table.

1



Schedule

Arrival 9am

Introductions 9.15am

The Long Table commences at 9.30am

Lunch will be served from 11.30am

Finish 12pm midday

We respectfully acknowledge that this Long Table is held on the land of the Whadjuk Nyoongar people and pay our respects to Elders past and present.

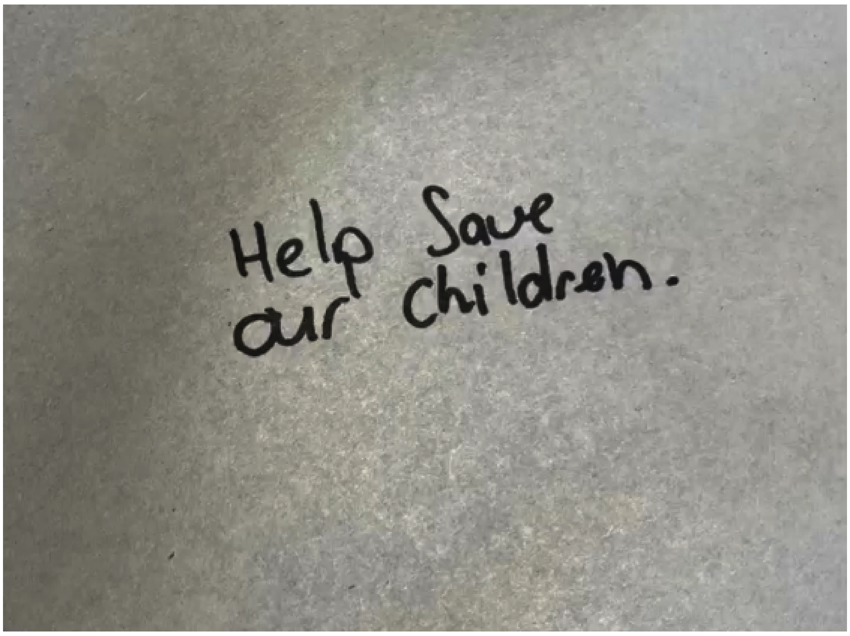
We thank the Stan Perron Charitable Foundation for making this event possible.

childhood dementia INITIATIVE

Rare Care Centre
Clinical Centre of Expertise for Rare and Undiagnosed Diseases

2

Message written on the tablecloth



This message was written on the paper tablecloth of the Long Table.