Round Table Report

Next Steps for Childhood Dementia Care in Queensland

October 2026

A Childhood Dementia Initiative report

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Round Table report Queensland

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Executive summary

This report summarises the outcomes of the Round Table on 'Next Steps for Childhood Dementia Care in Queensland', which brought together 15 stakeholders from health, palliative care, disability, research and community sectors to address the critical issues facing children with childhood dementia and their families in Queensland. The consultation aimed to build consensus on these issues and develop prioritised recommendations for meaningful change.

The Round Table identified 4 priority areas for action:

1. Prevention and carrier screening
2. A national model of care, delivered in Queensland
3. Health and professional education
4. Improved communication

For each priority area, stakeholders identified the current challenges, desired future state and specific recommendations for improvement. Key themes that emerged across the priority areas included the need for:

- Building on existing Queensland strengths, particularly the Queensland Lifespan Metabolic Medicine Service
- Evidence-based advocacy that draws on existing research such as Mackenzie's Mission
- Cross-sector collaboration and family-centred approaches
- Integration with Queensland Health, starting with Queensland-specific implementation of national standards
- Recognising the economic benefits of prevention and early intervention
- Equity of access for every child, regardless of where they live

There was clear consensus among the professionals in attendance that action is needed. Participants emphasised that while the 4 priority areas are urgent priorities, they do not cover every issue facing families.

This report outlines the discussions that took place, analyses the opportunities identified and presents recommendations for improving care and support for children with childhood dementia and their families in Queensland. It will inform discussions with the Queensland health sector and policymakers, and will contribute to the evidence base for systemic change.

Background and context

Dementia is usually only associated with older adults. Tragically, hundreds of thousands of children across the world live with dementia. It is caused by more than 145 genetic conditions that cause progressive cognitive decline, many of which are not yet well understood. In Australia, a baby is born every three days with a condition that causes childhood dementia 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 to 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 and very limited treatments.

The Round Table was organised in response to insights gathered from families in Queensland through the Brisbane Long Table held on 14 May 2025, documented in the pre-reading materials 'Childhood Dementia: Family experiences in Queensland' (draft executive summary) and 'What Matters Most: Priority Actions' published in January 2025. The event aimed to build on the knowledge gained by witnessing these collective family experiences, and to harness the expertise of professionals across sectors to shape meaningful change.

Methodology

The Round Table was conducted at the Centre for Children's Health Research in South Brisbane on 11 November 2025 and followed a structured format:

1. Welcome and framing
2. Identifying issues
3. Recommendations development
4. Shared understanding and refinement
5. Close and next steps

Participants were asked to review pre-reading materials and consider priority issues based on these readings, their professional experience and, for those who attended, what they heard at the Long Table. The discussion followed a consensus-building approach, with participants working in small groups and then sharing insights with the whole group.

Participants represented community organisations, hospice care, paediatric palliative care, metabolic medicine, rare disease advocacy and research institutions. Most had attended the Brisbane Long Table, with additional experts joining to broaden the professional perspective. Four small groups shared their priority issues with the whole group, and dot voting was used to select 4 priority areas. Each group then developed recommendations for one priority area, considering the current state, desired state, key stakeholders, timelines, expected impact for families, barriers and what success would look like. Groups rotated so that every participant could add to each priority area before the recommendations were presented back and refined together.

Queensland context: the Queensland Lifespan Metabolic Medicine Service

Queensland has established infrastructure and expertise that provide a strong foundation for improving childhood dementia care. Participants referred to the Queensland Lifespan Metabolic Medicine Service as an exemplar of the coordinated, holistic care they want available to every child with dementia.

> *"We recognise the Queensland metabolic lifespan service as a brilliant service, and one that perhaps we should be modelling off."*

About the service

The Queensland Lifespan Metabolic Medicine Service is a joint public health service run by Queensland Health and Mater Health Services Brisbane. It treats people with inborn errors of metabolism, including those with mitochondrial diseases, across their lifespan, working across Queensland Children's Hospital and Mater Hospital Brisbane. It is unique in Queensland in managing care across both children's and adult hospitals, so families do not lose their team when a child reaches adulthood. Its multidisciplinary team includes medical specialists, nurses, dietitians, social workers, genetic counsellors and psychologists.

Many conditions that cause childhood dementia are inborn errors of metabolism. Queensland families affected by these causes of childhood dementia are already connected to this service. Its practice offers an example of what good care for children with dementia can look like.

What makes it a model

Participants from the service described practices that reflect what families have asked for:

- **Care at diagnosis.** Recognising the significance of diagnosis, with allocated time, social work and nursing staff in the room when a diagnosis is given, and dedicated pathways for follow-up. Genetic counselling has recently been added, and families have regular contact with the team in the 1 to 2 weeks after diagnosis.
- **Early connection to wider supports.** Working closely with Hummingbird House and paediatric palliative care services and referring early.
- **Care across the lifespan**. One service that follows people from childhood into adulthood, reducing the loss of support at transition that families describe elsewhere.
- **Family-wide support**. Seeing couples identified as carriers from pregnancy, discussing the natural history of the condition with them alongside genetic counsellors and offering testing to siblings so they have informed choices about their own future.

Building on Queensland's strengths

The service shows that comprehensive, coordinated care is achievable within Queensland's existing health system. Alongside it, Queensland's research infrastructure, including the Centre for Children's Health Research, and its existing networks in genomics, paediatric palliative care and rare diseases, provide building blocks that can be leveraged and expanded. The recommendations in this report build on these strengths rather than proposing entirely new systems.

Participants also noted an important limitation. Not every child with dementia is cared for through metabolic medicine. Children with conditions such as Rett syndrome, leukodystrophies and other neurological conditions may be cared for in neurology, general paediatrics or other services, where these supports are not in place. The aim is to make this standard of care available to every child with dementia, wherever they receive care.

Key issues identified

Participants identified a wide range of issues affecting children with childhood dementia and their families in Queensland, spanning health systems, disability support, education and community services. These included:

- Complex, fragmented systems. Families must navigate health and NDIS systems described as 'foreign and complex spaces', becoming project managers and unpaid advocates during already traumatic times.
- The moment of diagnosis. How diagnosis is delivered shapes what follows, yet the time, skills and supports needed are not consistently available.
- Parents as experts. Parents' expertise in their child's care is not always respected, while at the same time families carry the burden of educating professionals and making difficult decisions alone.
- Suffering, loss and grief. Families experience types of suffering that are not resolved by symptom management or an NDIS package.
- Workforce knowledge and confidence. Many health professionals lack confidence and access to current, evidence-based information about childhood dementia.
- Equity of access. Families in rural and remote areas, and culturally and linguistically diverse families, including those from refugee and trauma backgrounds, face additional barriers.

Through dot voting, participants selected 4 priority areas for focused attention:

1. Prevention and carrier screening
2. A national model of care, delivered in Queensland
3. Health and professional education
4. Improved communication

They emphasised that these are strategic starting points, and that the broader issues remain important and will require ongoing advocacy and system development. The issues are explored in more depth followed by the recommendations for change.

1. Prevention and carrier screening

Participants identified reproductive genetic carrier screening as offering the potential to prevent childhood dementia while giving families informed reproductive choices. This priority emerged from recognition that significant research evidence already exists and that successful models operate internationally.

Medicare currently funds reproductive carrier screening for 3 conditions: cystic fibrosis, spinal muscular atrophy and fragile X syndrome. None of these cause childhood dementia. Broader screening panels of around 1,300 genes are available, but only to those who can pay for them.

> *"That's great, it's a good start. But people are generally, or they should be offered broader screening than that, which could be universally free."*

Current tests create inequitable access based on families' financial capacity rather than medical need. Participants also noted that many pregnancies are unplanned, which makes broad awareness of carrier status in the community, and education about the options available, all the more important.

Participants highlighted that robust research already supports expanded carrier screening. The Mackenzie's Mission study[1] provided comprehensive evidence and economic modelling, though the government response has been limited.

> *"There was data and options for expanding that. The research exists."*

There are compelling economic arguments: the long-term costs of caring for children with complex, progressive conditions far exceed the investment required for preventive screening. Participants considered screening before pregnancy preferable to relying on genomic newborn screening, which often comes too late to offer meaningful options for many of these conditions. One participant described how the Jewish community has used couple screening for decades:

> *"The Jewish community has been doing couple screening for 20, 30 years... they use the genetic information to match-make couples so they avoid having children with those affected."*

Participants acknowledged the sensitivity of discussing prevention with affected families. They emphasised that screening is about informed choice, not devaluing children living with dementia now. Cultural and religious considerations were raised, with participants stressing that families deserve to know their options and to make informed decisions with whoever is appropriate for them. A participant from the rare disease sector cautioned that the word 'prevention' caused discomfort in national rare disease consultations, and asked whether the childhood dementia community has been asked about its views. Participants agreed that support services for carrier couples are essential:

> *"When you're looking at prevention and you have a diagnosis that I'm a carrier for whatever it is, you mourn the loss of this projected future."*

2. National model of care

Participants envisioned comprehensive, coordinated care networks that ensure equity of access for every child with childhood dementia.

> *"The desired state is to have network centres for childhood dementia… they're holistic, they bring together absolutely everybody… it would mean that we have equity of care for every child, basically."*

This model would bring together health services, allied health, disability support, palliative care, community programs, education, research opportunities, carer support and day-to-day practical help. Central to it is 'a care coordinator, fully resourced and funded as a role bringing all of that together', supported by agreed standards of care, which participants described as an absolute priority. The model was strongly influenced by the Queensland Lifespan Metabolic Medicine Service (see Queensland context).

Participants noted that coordination should extend beyond health professionals to the 'circles of care' around each family, including community services and schools. Existing networks such as Project ECHO already connect health professionals and could be broadened. Some improvements could be made now within individual services, without extra funding, while others will require targeted investment, such as giving clinicians more time in appointments to speak with parents without the child present.

Participants recognised the need for national coordination, with delivery at state level. They stressed that a national model of care will only work if states are resourced to deliver it, and that governments 'need to actually be accountable and actually provide the resources for the state to deliver'. Workforce training would also be critical for success. Including children with dementia in state-based dementia plans and genomics work was seen as an important step.

Key barriers identified by participants included funding, government support and buy-in, and reluctance of services to work together, which participants candidly described as 'territory wars and egos'.

3. Health and professional education

Rather than expecting every health professional to become a childhood dementia specialist, participants prioritised accessible, high-quality education resources that enable appropriate care and referral when needed. The discussion revealed significant awareness gaps, even among paediatric specialists.

> *"It wasn't until I worked at Hummingbird House, when I was like 45 years old, after being a paediatric nurse since I was 18, that I first heard of… the first child I ever looked after with childhood dementia."*

Participants also acknowledged practical limits: 'there are so many conditions under an umbrella… you can't teach everything', with more than 450 life-limiting conditions in children. Instead, the desired state is:

> *"Knowing where the specialist education is. It's readily available and accessible, so that when clinicians come across a child and family with the diagnosis, they know exactly where to go for that information."*

Participants suggested building on existing high-quality resources and bringing them together in 'one place… very similar to how Palliative Care Australia have done it', so that professionals are not 'fumbling around trying to glean information off Wikipedia'.

Participants distinguished between specialists working regularly with childhood dementia, who need mandatory, accredited training, and generalists, who need ready access to quality resources. This is particularly important in rural and remote areas, where a clinician 'may see a child and then not see another one for maybe 5 or 10 years'. NDIS staff were highlighted as needing targeted education:

> *"NDIS particularly need lots of education… they just see a name on a piece of paper, and that's it."*

4. Improved communication

Participants identified improved communication by health professionals as fundamental to transforming family experiences. Families' current experiences were described as 'hit and miss' and dependent on individual clinicians, with communication that can 'feel like good luck, rather than good management'.

Barriers include judgement, paternalism and professional bias, a lack of knowledge and exposure to childhood dementia, limited funding for education and health professionals' capacity, capability and confidence.

The desired state is consistent, effective and positive communication, with active listening and families feeling heard. Difficult conversations, especially at diagnosis and when a child's abilities change, should happen with the 'right person, right time, right way, right place'. Participants recommended starting with Queensland Health:

> *"Compulsory, standardised communication training for all health professionals during onboarding in Queensland Health, because we thought we'd start local."*

Practical suggestions included a patient passport, described as 'what you need to know about my child', so that staff have a quick reference when a child presents to an emergency department. Participants also proposed:

- minimum requirements for difficult conversations
- better communication between teams
- self-reflective practice
- equipping professionals to communicate with the child as appropriate
- helping the community around families to know how to communicate with and support them

Resources would be tiered: universal resources for the whole community, targeted resources for key supporters around the family, and specialist resources for clinicians and service providers. Expected impacts included better experiences for children, families and clinicians, increased safety, reduced isolation, improved trust and 'childhood dementia on the map in politicians' minds for improved access and funding'.

Opportunities and recommendations

Participants explored each of the 4 priority areas to build a desired future state and recommendations on how to achieve it.

1. Expanded reproductive carrier screening

Recommendation: Advocate for publicly funded reproductive genetic carrier screening that includes childhood dementia conditions, building on existing research evidence and successful international models.

Current state: Medicare funds screening for 3 conditions, none of which cause childhood dementia. Broader panels are available only to those who can pay, creating inequitable access. Community and professional awareness of carrier screening is low.

Desired state:

- Equitable access to broad carrier screening panels.
- Screening integrated into routine preconception care.
- Comprehensive genetic counselling and support for couples identified as carriers.
- Childhood dementia conditions included in funded screening.
- Families are given information and can make informed choices about their reproductive options.

Key stakeholders: Genetic Health Queensland and other genetic services, reproductive and maternal health providers, GPs, Queensland Health, federal health policymakers, medical colleges, Childhood Dementia Initiative, Human Genetics Society of Australasia (HGSA) and Australasian Society for Inborn Errors of Metabolism (ASIEM), genetic counselling services, family support organisations and research partners.

Timeline considerations:

- **0 to 6 months:** compile Queensland-specific economic modelling building on Mackenzie's Mission, and engage genetic services, maternal health providers and consumer groups.
- **6 to 12 months:** work with Queensland genetic services to design a pilot, including counselling protocols, support pathways and evaluation.
- **12 to 24 months:** implement the pilot and use the results to advocate for expanded Medicare funding.

Potential impact for families:

- Information before conception, enabling informed reproductive choices.
- Reduced incidence of childhood dementia through informed family planning.
- Access to genetic and psychological counselling and support when carrier status is identified.

Required investment/resources: Economic modelling and pilot development, genetic counsellor capacity, information systems to track uptake and outcomes, and community engagement and communication resources.

Success measures:

- Increased number of couples accessing comprehensive carrier screening.
- Reduced wait times for genetic counselling.
- Improved professional awareness and referral.
- Policy change enabling Medicare funding for broader screening panels.

Implementation considerations:

- Engage the childhood dementia community about prevention, recognising that the topic can be painful for families.
- Frame screening is an informed choice that does not devalue the lives of children living with dementia.
- Respect cultural and religious considerations, and provide information in ways that support decisions with the people families choose.
- Raise community awareness, recognising that many pregnancies are unplanned.

2. A national model of care with Queensland delivery

Recommendation: Develop a coordinated childhood dementia care network in Queensland, modelled on the Queensland Lifespan Metabolic Medicine Service, while advocating for national coordination and standards of care.

Current state: Children with dementia receive fragmented care across multiple providers, without dedicated coordination or clear pathways. Queensland has proven models of coordinated care, but these are not available to all children with dementia.

Desired state: Network centres for childhood dementia that integrate health, allied health, disability, palliative care, education, community support and research.

- A fully resourced and funded care coordinator for every family, from diagnosis onwards.
- Clear standards of care, with equity of care regardless of location or condition.
- Coordination that extends to the circles of care around families, including schools and community services.

Key stakeholders: Queensland Health and Children's Health Queensland, the Queensland Lifespan Metabolic Medicine Service, specialist paediatric, palliative care, disability and mental health services, Hummingbird House, Childhood Dementia Initiative and rare disease organisations, research partners and NDIA.

Timeline considerations:

- **Now:** improvements individual services can make without extra funding, and mapping of existing services and care pathways.
- **Short term:** adapting the Queensland Lifespan Metabolic Medicine Service model, developing Queensland care standards and piloting coordinated care in South East Queensland.
- **Medium term:** extending coordinated care to regional Queensland through telehealth and regional hubs.
- **Long term:** national standards of care, funding and legislation.

Potential impact for families

- A complete change to the family experience, with reduced burden of care.
- Improved quality of life for children and families.
- Consistent, coordinated care regardless of postcode or condition.
- Required investment/resources: Funded care coordinator roles, standards of care, information systems for shared care planning, telehealth capability, and more clinician time in appointments.

Success measures:

- Equity of good care for every child with dementia.
- Families reporting improved coordination and reduced burden.
- Reduced trauma for health professionals who repeatedly hear the same stories.
- Economic benefits from coordinated rather than reactive care.

Implementation considerations:

- Address barriers including funding, government buy-in and reluctance of services to work together.
- Make sure national commitments come with resources for states to deliver.
- Include children with dementia in Queensland's dementia planning and genomics work.
- Make sure the model reaches children cared for outside metabolic medicine.

3. Accessible education and resource hub

Recommendation: Create a centralised education and resource hub that gives professionals, families and communities immediate access to high-quality childhood dementia information, with Queensland-specific pathways.

Current state: High-quality resources exist across many organisations but are dispersed and hard to find. Professionals, especially in rural and remote areas, may rarely encounter childhood dementia and lack quick access to reliable information.

Desired state:

- One place where all resources can be found, similar to Palliative Care Australia's approach.
- Information that is contemporary, rigorous and relevant, developed with specialist services.
- Mandatory, accredited training for specialists working regularly with childhood dementia.
- Just-in-time resources for generalists, allied health and NDIS staff.
- Family, peer-to-peer and community education, including public awareness.

Key stakeholders: Medical colleges, health services, the education sector, NDIS, Childhood Dementia Initiative, NORD, Palliative Care Australia, rare disease organisations and family advisory groups.

Timeline considerations: Participants considered it reasonable to develop systems and platforms within a year, as many resources already exist. Learning is lifelong, so the hub will need ongoing review.

Potential impact for families:

- Families meet professionals who know where to find accurate information.
- Less pressure on families to educate their care providers.
- Accessible resources for families that remain relevant.
- Required investment/resources: Platform development, content curation and review, discipline-specific modules and integration with Queensland Health professional development.

Success measures:

- Families say it is 'a move in the right direction' and 'much better than when I had this experience'.
- Improved confidence among health professionals.
- Increased use of resources across Queensland health services.

Implementation considerations:

- Build on existing resources rather than duplicating them.
- Tier content for specialists, generalists, allied health, NDIS staff and families.
- Consider including childhood dementia in undergraduate paediatric education.

4. Queensland Health communication standards

Recommendation: Introduce compulsory, standardised communication training for all health professionals at onboarding in Queensland Health, with specialist training and tools for staff who work regularly with children with dementia and their families.

Current state: Communication is 'hit and miss' and clinician dependent. Barriers include judgement, paternalism and professional bias, limited knowledge and exposure, funding and professionals' capacity, capability and confidence.

Desired state:

- Consistent, effective and positive communication, with active listening.
- Right person, right time, right way, right place' for difficult conversations.
- Minimum requirements for difficult conversations at diagnosis and when a child's abilities change.
- Good communication between teams caring for the child and family.
- Children involved in conversations as appropriate.

Key stakeholders: Hospital and state health leadership, families and consumers, peak bodies, the Department of Education and NDIS professionals.

Timeline considerations:

Participants recommended starting locally with Queensland Health onboarding.

Potential impact for families:

- Improved child, family and clinician experiences.
- Better understanding and accessibility of services.
- Increased safety and reduced isolation.
- Improved trust and confidence in clinicians.

Required investment/resources: Communication training at onboarding, resources and workshops, a patient passport, and self-reflective practice opportunities.

Success measures:

- Increased family capacity and effective communication
- Improved trust and confidence in clinicians.
- Increased attendance at appointments and reduced burden.
- Childhood dementia on the map in politicians' minds for improved access and funding.

Implementation considerations:

- Tier resources: universal for the community, targeted for supporters around the family, and specialist for clinicians and service providers.
- Help the community around families to know how to communicate with them and support them.
- Consider the voice of carers, including paid lived experience roles.

Next steps and conclusion

The Round Table on Next Steps for Childhood Dementia Care in Queensland brought together valuable expertise and perspectives from across health, palliative care, disability, research and community sectors. The discussions resulted in 4 priority areas and actionable recommendations: expanded reproductive carrier screening, a national model of care with Queensland delivery, an accessible education and resource hub, and Queensland Health communication standards.

Our immediate next steps focus on sharing these findings with decision-makers, and securing commitments from key stakeholders to lead specific initiatives. Critical actions include:

- Presenting this report, together with 'Childhood Dementia: Family experiences in Queensland', to the Queensland Minister for Health and other key decision-makers, so that professional recommendations are read alongside family experiences.
- Engaging Queensland Health and Children's Health Queensland to explore how the Queensland Lifespan Metabolic Medicine Service model could be extended to all children with dementia.
- Advocating for children with dementia to be included in Queensland's dementia planning, consistent with the National Dementia Action Plan, which recognises children as a priority population.
- Continuing national advocacy for a national model of care and standards of care, with resources for states to deliver them.
- Advocating for publicly funded reproductive carrier screening that includes childhood dementia conditions.
- Building ongoing engagement with politicians and policymakers, with this report forming part of the wider evidence base Childhood Dementia Initiative has gathered with families and professionals.

The discussions highlighted the complexity of challenges facing children with childhood dementia and their families, but also identified significant opportunities to build on what already works in Queensland. Participants recognised that change will be ongoing. As one participant said: 'learning is lifelong... it's not a one-off, it's an ongoing thing.'

Participants described success as the day families at a future Long Table say things are 'a move in the right direction' and 'much better than when I had this experience'. The engagement and collaboration evident throughout the Round Table provides a strong foundation for implementing these recommendations, and for creating lasting, positive change for children with childhood dementia and their families across Queensland.

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