HealthConsult

Childhood Dementia Initiative

# Childhood Dementia Care and Support Landscape

## Pathway Toward Report

29 October 2024

*Better thinking. Better advice.*

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# Contents

# Abbreviations

| | |
|---|---|
| ACT | Australian Capital Territory |
| AIHW | Australian Institute of Health and Welfare |
| AYA | Adolescent and young adult |
| CALD | Culturally and Linguistically Diverse |
| CDI | Childhood Dementia Initiative |
| CF | Cystic fibrosis |
| CNC | Clinical nurse consultants |
| CoE | Centres of Excellence |
| CPD | Continuing professional development |
| DMD | Duchenne muscular dystrophy |
| GP | General practitioner |
| IVF | In vitro fertilisation |
| KPI | Key performance indicators |
| MASS | Medical Aids Subsidy Scheme |
| MBS | Medicare Benefits Schedule |
| MDT | Multidisciplinary team |
| MRFF | Medical Research Future Fund |
| MSAC | Medical Services Advisory Committee |
| NDIS | National Disability Insurance Scheme |
| NORD | National Organization for Rare Disorders |
| NSW | New South Wales |
| PBS | Pharmaceutical Benefits Scheme |
| QLD | Queensland |
| RCC | Rare Care Centre at the Perth Children's Hospital |
| UNSW | University of New South Wales |
| VA&EP | Victorian Aids and Equipment Program |
| VSK | Very Special Kids |
| WA | Western Australia |

# Executive summary

## Overview

Childhood dementia encompasses 145+ individual genetic conditions[1] that cause significant damage to the brain and nervous system in children. Like adult dementia, affected children progressively lose cognitive and physical abilities, and with a scarcity of effective and available treatments, most die in childhood. The complexity and severity of these conditions pose numerous challenges for families, who often struggle to navigate a fragmented care system.

Childhood Dementia Initiative (CDI) engaged HealthConsult to identify the gaps and issues with the existing childhood dementia national care and support landscape. This **Pathway Toward Report** consolidates findings on available care and support services for children, parents and families impacted by childhood dementia. It includes principle-based considerations for improving care and support available to these families.

## Methodology

HealthConsult used a mixed-method approach to triangulate key findings. The project began with a rapid literature review on PubMed that identified 58 articles on childhood dementia, dating back to 1984. This was supplemented with a review of CDI reports (e.g. family experience reports, childhood dementia burden analysis, global clinical trials landscape, and the "Childhood Dementia Matters" series) and rare disease/dementia plans from states and territories. More than 110 stakeholders, including healthcare professionals and peak bodies, participated in virtual interviews and focus groups. In addition, an online survey was completed by nursing staff, specialists, and allied health professionals.

Two limitations of the engagement approach used were: (1) that most stakeholders were from CDI's existing pool, so many had some familiarity with childhood dementia; (2) the stakeholders consulted did not include primary care physicians or laboratory-based researchers, and only included limited stakeholders working in the disability and education sectors.

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[1] Elvidge et al Brain, The collective burden of childhood dementia: a scoping review.

# Key findings on the care and support landscape

Table 1 highlights the gaps and key future considerations derived from the **ten themes** that were identified by our methodology about the current care and support landscape for childhood dementia. These themes are aligned with the Chapters in this report.

**Table 1: Summary of key findings across childhood dementia care and support landscape**

| Theme | Need | Current gaps | Potential Actions |
|---|---|---|---|
| **Healthcare professional awareness and training** (Chapter 3) | Knowledge development and sharing of resources on childhood dementia, both for the diagnosis stage (common symptoms, tests to order, things to consider, case studies) as well as disease progression, management, and ongoing care needs. Childhood dementia should be integrated into relevant professional training programs. | General lack of awareness of childhood dementia among healthcare professionals. Absence of targeted training programs. Childhood dementia has almost no representation in professional training curricula. | **Launch training initiatives:** Develop comprehensive training programs for healthcare professionals.<br>**Collaborate with educational institutions:** Integrate childhood dementia into medical school curricula and professional development.<br>**Telehealth and e-learning:** Ensure training programs are accessible in rural/remote areas via e-learning and telehealth solutions. |
| **Diagnostic pathways** (Chapter 4) | Shorten the diagnostic odyssey so children can access appropriate care, and emerging treatments including clinical trials. | Delays in diagnosis due to lack of awareness, protracted referrals, and inconsistent diagnostic pathways. Insufficient access to genetic testing and counselling services. | **Educate healthcare providers:** Increase awareness of childhood dementia's early signs.<br>**Streamline diagnostic pathways:** Implement a red flag system for childhood dementia and develop appropriate referral pathways to centre of expertise. Expand access to genetic testing and reduce turnaround times.<br>**Cascade testing and genetic counselling:** Improve access to cascade testing for reproductive partners to assess carrier status, as well as access to genetic counselling for families. |

| Theme | Need | Current gaps | Potential Actions |
|---|---|---|---|
| **Care coordination** (Chapter 5) | Comprehensive care coordination through social workers or case managers to assist families in accessing day-to-day care and services. | Fragmented integration between health and disability services. No centralised navigation support. Inconsistent care coordination across states and territories. | **Centralise care coordination:** Develop a national, accessible navigation and support service.<br>**Hospital-based coordinators:** Improve linkage between clinical and community services via hospital-based coordinators.<br>**Care coordinator roles:** Ensure roles are sustainable, well-resourced, and that ongoing training is provided. |
| **Health services** (Chapter 6) | Coordinated medical care, including primary, secondary and tertiary healthcare services, to address childhood dementia needs. | Fragmented care services, particularly in rural and remote areas. Lack of standardised models of care across states. Administrative and resourcing barriers limit multidisciplinary teams (MDTs). | **Standardise care models:** Develop nationally accepted care models based on the commonality of childhood dementia needs.<br>**Support MDTs:** Create consistent MDTs to provide interdisciplinary care pathways and better care coordination.<br>**Virtual care and telehealth:** Expand modes of delivery to better support all families including regional, rural and remote. |
| **NDIS and disability services** (Chapter 7) | Support in navigating the NDIS to manage progressive disability needs and ensure equitable support across the cohort. | Difficulty navigating NDIS processes, especially as disease progresses. Limited understanding of childhood dementia among NDIS staff. Geographic disparities in service availability. Tension between disability and life limiting conditions / palliative care. | **NDIS training:** Increase disability workforce understanding of rare, progressive conditions like childhood dementia.<br>**NDIS flexibility:** Increase NDIS staff understanding that progressive conditions such as childhood dementia may change patient needs rapidly. Hence, flexibility in the application process and ongoing management is required. Investigate potential red flag system for NDIS to indicate a severe, degenerative life limiting condition is involved.<br>**Barriers with palliative care:** Better coordination needed between NDIS and palliative care, to ensure that families aren't excluded from services or fall through the gaps. |
| **Psychosocial support** (Chapter 8) | Continuous emotional, psychological, and social support for children with dementia and their families. This should begin | Inconsistent access to formal peer support networks and counselling, particularly in regional areas. Lack of specialised | **Ensure early psychosocial support:** Implement psychosocial support at diagnosis and extend it throughout the disease journey and beyond, for children with dementia, their parents and families. |

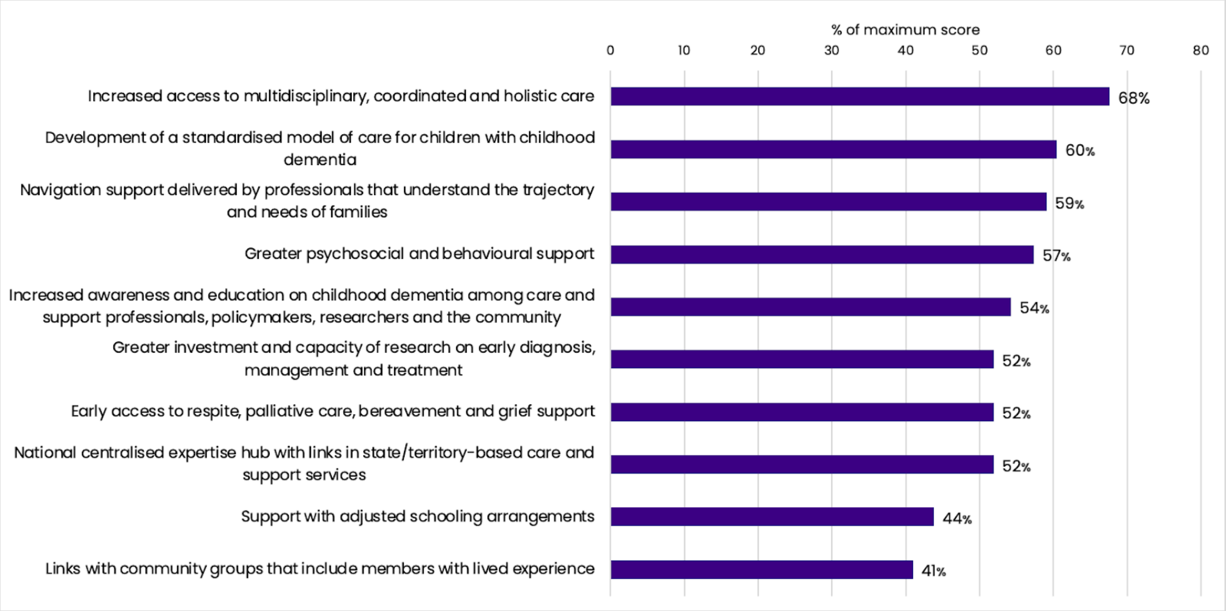
| Theme | Need | Current gaps | Potential Actions |
|---|---|---|---|
| | at diagnosis and continue through to end-of-life care and beyond. | psychological support, including grief and bereavement support. | **Expand grief, loss and bereavement support services:** Establish tailored grief and bereavement supports, including addressing anticipatory grief and the ongoing loss experienced by children and their families.<br>**Virtual care and telehealth:** Expand modes of delivery to better support all families, including regional, rural and remote. |
| **Education support** (Chapter 9) | Access to appropriate educational resources so children with dementia can continue to attend school and maintain social connections. | Lack of awareness and resources to support children with childhood dementia in educational settings. | **Develop educational resources:** Provide materials and support to educators and the school community to better understand the needs of children with dementia.<br>**Collaborate with treating clinicians and care coordinator:** Ensure education plans are coordinated with healthcare services. |
| **Palliative care** (Chapter 10) | Timely access to palliative care services, including symptom management and psychosocial support. | Misconceptions around palliative care led to inconsistent referral timings. Limited access to specialised paediatric palliative care, especially in remote areas. | **Promote early referral systems:** Increase awareness of early referral benefits for palliative care.<br>**Expand paediatric palliative care:** Ensure equitable access to specialised palliative care services for all children. Where local paediatric palliative services are not available, provide training for those working in adult palliative care and/or provide a consultative service to support them.<br>**Integrate palliative care into the future care model:** Any work to standardise care models should consider including palliative care in the model, including explicit criteria about palliative care as quality of life and end of life care. |
| **Hospice and respite care** (Chapter 11) | Fit for purpose respite and hospice care that supports both children and families no matter what stage of the disease journey. | Limited availability of hospice and respite services, including barriers to access such as behavioural challenges and prioritisation based on end of life. | **Increase hospice and respite care capacity:** Expand facilities and staff to ensure one-on-one care is available when needed and that service is accessible for families living in remote and regional areas.<br>**Investigate models of respite provision that include hospice in the home.** |
| **Research** (Chapter 12) | Access to the latest research and clinical trials | Lack of infrastructure and funding for clinical trials and research. Clinicians often | **Establish research networks:** Facilitate collaborations between research institutions, hospital sites and clinical care. |

| Theme | Need | Current gaps | Potential Actions |
|---|---|---|---|
|  | to improve treatment options. | lack the capacity to contribute to new research initiatives. | **Secure funding:** Increased government and private sector investment in childhood dementia research.<br>**Identify research priorities:** Systematically determine key areas of focus to guide research efforts and resource allocation.<br>**Prioritise translational research:** Focus on bridging the gap between basic science discoveries and clinical applications to accelerate the development of new treatments and interventions.<br>**Establish a patient registry:** A patient registry would help quantify the number of patients and families living with a childhood dementia condition in Australia and may provide insightful data on demographics, available services, clinical outcomes and it could support attracting relevant clinical trials to Australia. |

Source: HealthConsult (2024) based on the triangulation of thematic analysis of stakeholder consultations and grey and peer reviewed literature

When asked to rank the opportunities to improve the childhood dementia care and support landscape, health professionals responded through the survey with **'increased access to multidisciplinary, coordinated and holistic care' as the highest prioritised opportunity** and **'development of a standardised model of care for children with childhood dementia' as the second highest prioritised opportunity (Figure 1).**

**Figure 1: Priority opportunities for improving the care and support landscape for childhood dementia**



Source: HealthConsult (2024) Healthcare professionals survey developed for CDI (n=42)

'% of maximum score' was calculated by weighting answers indicated as the greatest opportunity out of the options given as 10, answers indicated as the second biggest opportunity as nine and so on. Weighted scores were then added for each opportunity option to give a total value, this was then divided by the maximum possible weighted score (i.e. all 44 respondents choosing the same option as the biggest opportunity, the score for which would be 44 x 10 = 440) to give a percentage.

# Conclusions

This report reveals systematic challenges faced by children with childhood dementia and their families across the care and support landscape. These challenges include **navigating a complex diagnostic pathway, accessing appropriate services** and **coordinating care**. Our **fragmented system** burdens families, who must manage **disjointed support structures.**

A major concern is **the limited awareness and understanding** of childhood dementia among **healthcare professionals**, which **contributes to delays in diagnosis and inconsistent care**. Families also experience **significant barriers** in **accessing essential services. In rural and remote areas**, geographic disparities further compound the difficulties of securing appropriate care.

Families face significant **emotional strain** with inadequate psychosocial and emotional support throughout the disease journey. The current system is also **not agile enough** to meet the **rapidly changing needs of children with progressive conditions** like childhood dementia. **Insufficient funding for dedicated childhood dementia research and limited access to clinical trials** further restricts **treatment advancements**.

**This report highlights the need for a cohesive, national approach** to integrate health, disability, psychosocial services and education, ensuring seamless and equitable support. Coordinated action is essential to address these gaps and improve outcomes for children with dementia and their families. Coordinated efforts across sectors are essential to close these gaps and improve outcomes for children with dementia. Addressing these shortcomings will require strong collaboration across the system, with changes becoming evident over time.

# Next steps

CDI is committed to raising awareness of childhood dementia, accelerating therapeutic research, and improving care and quality of life for children with dementia and their families. The next step suggested for CDI involves co-designing scalable, adaptable solutions across diverse regions and settings in Australia, in collaboration with people with lived experience and healthcare professionals. Chapter 13 outlines a series of co-design workshops aimed at validating the current gaps and determining appropriate actions with these stakeholders. The workshops should focus on identifying challenges, developing actionable solutions, and creating a detailed implementation strategy for priority areas. This approach ensures that future solutions are deeply informed by lived experience, aligning with CDI’s strategic goals and enhancing the effectiveness of care strategies.

# 1. Introduction

## 1.1. Context

Childhood dementia, encompassing 145+ individual genetic conditions, is defined as:

*"Progressive neurocognitive decline, presenting before 18 years of age; characterised by multiple losses of previously attained development skills in the context of generalised (i.e. not focally restricted) brain dysfunction, secondary to disease of monogenic aetiology".*[2]

Australia is the first country in the world to begin considering the collective group of childhood dementia disorders in a system-wide approach. **Recognising childhood dementia as a collective group of disorders achieves** several important outcomes:

**Outcome 1:** It emphasises shared symptoms and impacts, streamlining diagnosis and enabling more consistent treatment approaches.

**Outcome 2:** It enables economies of scale in research and care, pooling resources and knowledge to accelerate treatment discoveries and improve access to comprehensive, coordinated care.

**Outcome 3:** It enhances public and clinical understanding, raising awareness of the collective impact of these disorders, leading to earlier recognition, better support, and informed healthcare practices.

Founded in 2020, Childhood Dementia Initiative (CDI) is leading this collective effort, advocating for systemic changes so that children with dementia receive the treatments, support, and inclusion they urgently need. To build on existing research on the current landscape of care and support for this cohort, CDI engaged HealthConsult on 17 April 2024 to:

1. Identify gaps and issues with the current national childhood dementia care and support landscape, including services available for children, parents, families and carers.
2. Engage with a wide range of stakeholders including medical, psychological, care and assistance, community care and policy professionals to inform the identified gaps and issues with the current care and services available to children with childhood dementia and their families.

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[2] Elvidge et al 2023.Brain, The collective burden of childhood dementia: a scoping review.

3. Develop a 'Pathway Toward' Report (this report) that outlines areas for improvement in the care and support landscape and provides a basis for future action in the form of key areas for improvement.

## 1.2. Project methodology

The **Pathway Toward Report** has been informed by the following steps:

- **Situation analysis**, that included a rapid literature review and consultations with CDI staff and advisory groups, consisting of both professional and lived experience perspectives.
- Development of **data collection tools**, including consultation guides and an online survey, used to gather stakeholder input on the current care and support landscape for childhood dementia in Australia.
- Development of a **Stakeholder Summary Report** which presented the triangulated findings from the analysis of the broad stakeholder engagement conducted with over 110 stakeholders representing various healthcare professionals, and the rapid literature review on the current care and support landscape for childhood dementia.
- Development of this **'Pathway Toward' Report** (this report) that outlines areas for improvement in the care and support landscape and provides a basis for future action in the form of key areas for improvement.

Further details of the project methodology are described in Appendix B.

## 1.3. Structure of this report

The structure of the remainder of the report is as follows:

- **Chapter 2: About childhood dementia.** Describes the prevalence and incidence of childhood dementia in Australia, the challenges it presents, its limited recognition in state and national plans, and the care and support services required across different stages of the disease.
- **Chapter 3 to Chapter 12:** Each Chapter explores the current challenges, what care and support services currently exist, and the gaps identified.
- **Chapter 14: Conclusions and next steps.** Summarises the key considerations proposed by healthcare professionals under each care and support theme.
- **Appendices.** Provides examples of models of care from other health conditions and an overview of the project methodology.

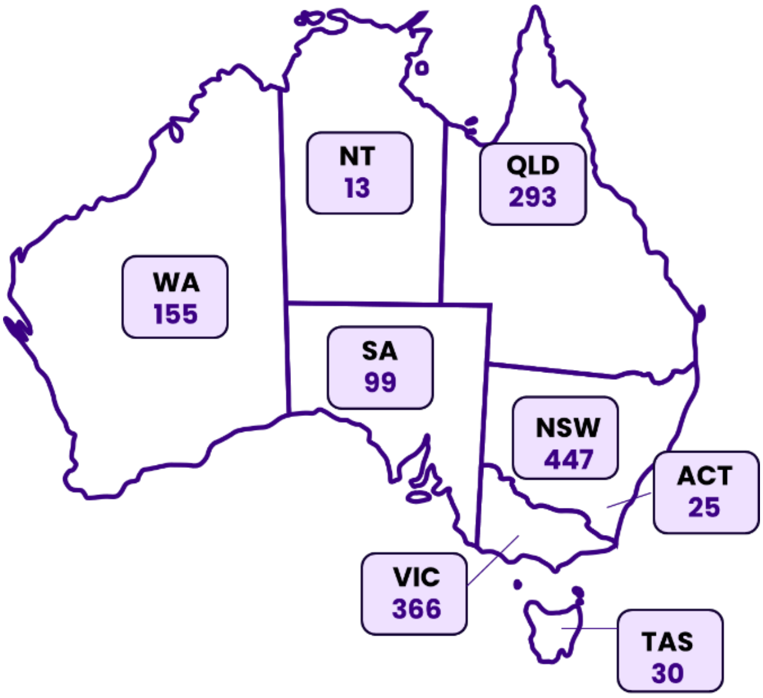
# 2. About childhood dementia

This Chapter describes the prevalence and the incidence rate of childhood dementia in Australia; the unique challenges it presents; the limited recognition available in state and national plans; the stages of the disease and the care and support services required across different stages of the disease.

## 2.1. Prevalence and incidence rate

In 2023, childhood dementia was estimated to have an incidence of 34.5 per 100,000 (affecting 1 in 2900 births).[3] Half of all children with dementia die before the age of 10, and 70% of them will die before they reach adulthood. In Australia, childhood dementia claims approximately 91 lives annually, a similar number to childhood cancer (in children aged 0-14 years).[4] Since many of the affected children don't live long, it was estimated that 1,394 individuals were living with childhood dementia in Australia in 2021.[5] Figure 2 shows the estimated number of affected children living in Australian states and territories in 2024.

**Figure 2: Estimated prevalence of childhood dementia in Australia in 2024 (n=1,428)**



Source: Estimated number of children living with childhood dementia in 2024 is calculated by CDI based on the 2021 incidence rate by Elvidge et al. 2023

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[3] Elvidge et al 2023. Brain, The collective burden of childhood dementia: a scoping review.

[4] Elvidge et al 2023. Brain, The collective burden of childhood dementia: a scoping review.

[5] Elvidge et al 2023. Brain, The collective burden of childhood dementia: a scoping review.

## 2.2. What makes childhood dementia unique?

Childhood dementia is genetic, progressive and life-limiting. Children with dementia have complex care needs that often don't fit within established health and social care services. Parents and carers face immense difficulty finding appropriate care and endure ongoing grief as their child loses their abilities. Due to the limited recognition, awareness, and a lengthy diagnostic process (also referred as *diagnostic odyssey*), these children and their families face significant unmet needs.

The experiences of children and their families are detailed in the 'We don't fit' report.[6]

The childhood dementia conditions share the following characteristics:

- **Progressive and terminal:** Childhood dementia severely affects cognitive functions, leading to progressive neurological decline, ongoing loss of skills and physical abilities and ultimately, premature death.
- **Emotional and psychological impact:** The regression in cognitive abilities is profoundly distressing for families, as they not only witness the loss of previously mastered skills and changed personalities, but also face the added challenges of managing severe behavioural issues and disrupted sleep patterns, further compounding the emotional toll.[7,8]
- **Burden of care:** The burden on families is significant and enduring, with one in three parents giving up their careers to care for their child.[9]
- **Multiple children within the family unit:** Due to the genetic nature of the conditions, 15-20% of families may have more than one child impacted, compounding the complexity and trauma. Without timely diagnosis, parents are unable to understand their risk for future pregnancies.

In contrast to other childhood diseases, there has been no significant improvement in survival rates for children with dementia. There is also a gross inequity in research investment and a scarcity of effective and available treatments.[10]

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[6] Nous Group, March 2023, 'We don't fit' The lived experience of families affected by childhood dementia and their interactions with care and support services report, accessible at: https://d1iap1m2kaw9nt.cloudfront.net/4296899de7646ce5d193bc96d8a49a31.pdf

[7] Childhood Dementia Initiative. Childhood Dementia: Family experiences of Health Systems in New South Wales. March 2024. https://d1iap1m2kaw9nt.cloudfront.net/9fbdfb11363dac2de5c61c7e21277655.pdf

[8] Djafar et al, 2023. Paediatric Neurology. Characterizing Common Phenotypes Across the Childhood Dementia Disorders: A Cross-sectional Study From Two Australian Centers accessible via https://pubmed.ncbi.nlm.nih.gov/37806042/

[9] Nevin, SM. An In-Depth, Mixed Methods Study Investigating Quality of Life, Psychological and Healthcare Needs of Children with Dementia and Their Families: Interim Findings.; (personal communication, 2024).

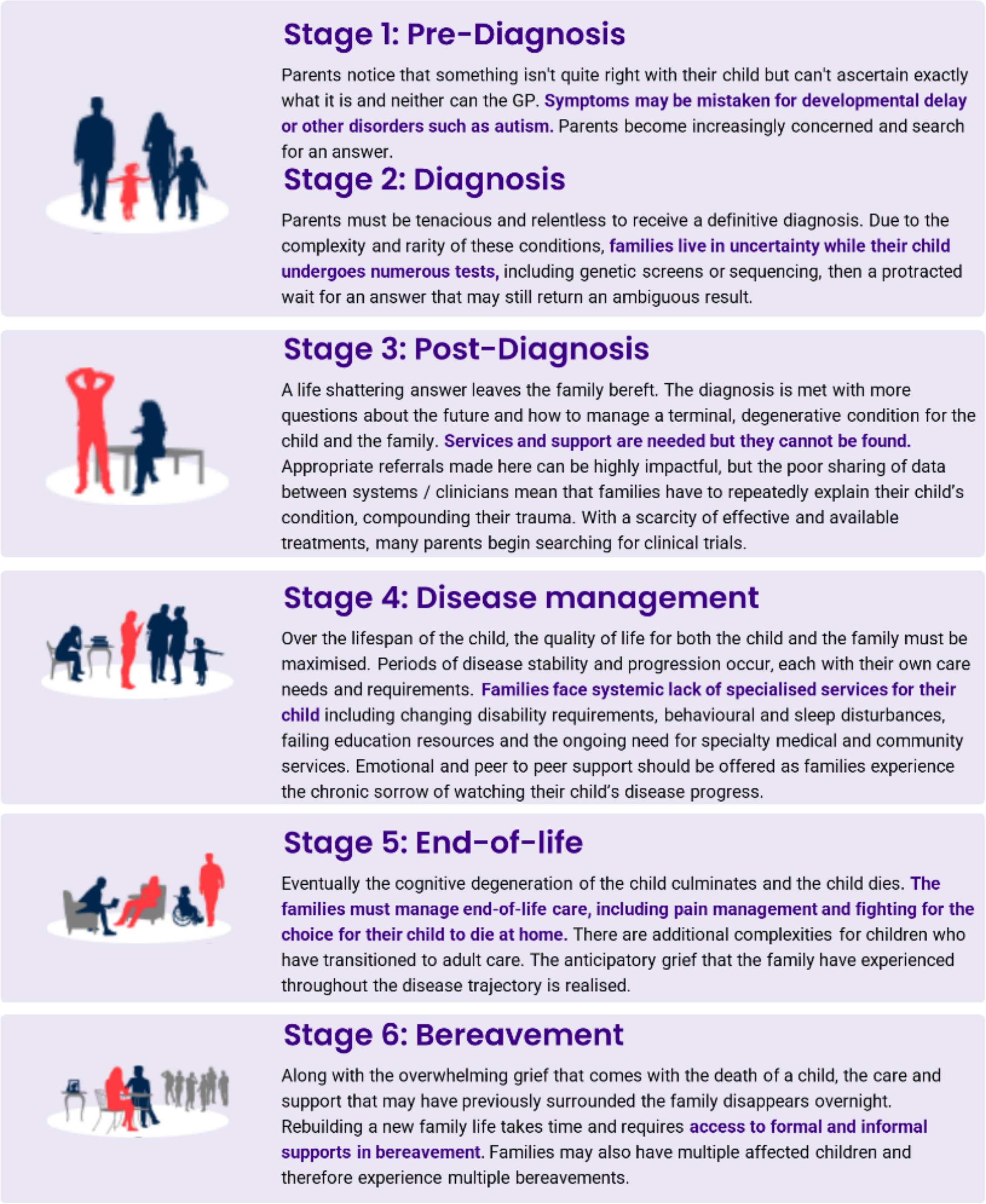
[10] Childhood Dementia Initiative: Report reveals research inequity

## 2.3. Childhood dementia disease stages

The childhood dementia journey unfolds in **six distinct phases**, each requiring tailored support strategies to meet the evolving needs of the child and their family (Figure 3).

A typical journey begins with concerns about a child's development, moves through diagnosis and management, and ends with bereavement support for the family.

Figure 3: The childhood dementia disease stages



## Stage 1: Pre-Diagnosis

Parents notice that something isn't quite right with their child but can't ascertain exactly what it is and neither can the GP. **Symptoms may be mistaken for developmental delay or other disorders such as autism.** Parents become increasingly concerned and search for an answer.

## Stage 2: Diagnosis

Parents must be tenacious and relentless to receive a definitive diagnosis. Due to the complexity and rarity of these conditions, **families live in uncertainty while their child undergoes numerous tests,** including genetic screens or sequencing, then a protracted wait for an answer that may still return an ambiguous result.

## Stage 3: Post-Diagnosis

A life shattering answer leaves the family bereft. The diagnosis is met with more questions about the future and how to manage a terminal, degenerative condition for the child and the family. **Services and support are needed but they cannot be found.** Appropriate referrals made here can be highly impactful, but the poor sharing of data between systems / clinicians mean that families have to repeatedly explain their child's condition, compounding their trauma. With a scarcity of effective and available treatments, many parents begin searching for clinical trials.

## Stage 4: Disease management

Over the lifespan of the child, the quality of life for both the child and the family must be maximised. Periods of disease stability and progression occur, each with their own care needs and requirements. **Families face systemic lack of specialised services for their child** including changing disability requirements, behavioural and sleep disturbances, failing education resources and the ongoing need for specialty medical and community services. Emotional and peer to peer support should be offered as families experience the chronic sorrow of watching their child's disease progress.

## Stage 5: End-of-life

Eventually the cognitive degeneration of the child culminates and the child dies. **The families must manage end-of-life care, including pain management and fighting for the choice for their child to die at home.** There are additional complexities for children who have transitioned to adult care. The anticipatory grief that the family have experienced throughout the disease trajectory is realised.

## Stage 6: Bereavement

Along with the overwhelming grief that comes with the death of a child, the care and support that may have previously surrounded the family disappears overnight. Rebuilding a new family life takes time and requires **access to formal and informal supports in bereavement.** Families may also have multiple affected children and therefore experience multiple bereavements.

Source: HealthConsult in consultation with CDI (2024), based on Nous Group: We Don't Fit report[11]

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[11] Nous Group 2023. 'We don't fit': The lived experience of families affected by childhood dementia and their interactions with care and support services report

## 2.4. Limited recognition and awareness

Despite its severity, childhood dementia **lacks specific recognition in national action plans** for dementia,[12,13,14] paediatric palliative care,[15] and other health care policies. While a rare disease action plan exists and provides an important framework,[16] its broad scope means it cannot address the unique needs of conditions like childhood dementia. Recognising childhood dementia as a subgroup of rare diseases offers a more targeted approach to ensuring that specific needs are met effectively.

This gap in targeted policy reflects a broader issue of **under-recognition across health, disability, education and social/community support systems,** which worsens the challenges families face in **securing timely and appropriate care**.

Without national guidelines or specialised expertise within the health and care systems, the quality of care children receive depends largely on their families' ability to advocate and their level of health literacy. This creates inequities and, more alarmingly, risks the safety of these children.

Healthcare professionals report that children with dementia often present with symptoms resembling more common conditions like autism or developmental delays, leading to misdiagnosis and steering families through a **fragmented care system**. As a result, these children fall through the gaps between health, disability, and palliative care services, where their needs are neither fully understood nor prioritised by the clinical and non-clinical professionals involved.

The lack of structured support intensifies the emotional and logistical burdens on families, as highlighted by this direct quote:

> “We become reluctant experts on our children’s diseases, often knowing more than the medical professionals we encounter. We don’t fit into the systems we need to access daily, systems that were not set up with any conception that a child could need this level of support.”
>
> Parent of a child with dementia

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[12] Australian Department of Health and Aged Care, National Framework for Action on Dementia 2015 – 2019 and consultation paper for the development of the National Dementia Action Plan 2023-2033.

[13] Action on Dementia discusses younger-onset dementia, which refers to people under the age of 65 (and under 50 for Aboriginal and Torres Strait Islander people)[13]. This Framework acknowledged the difficulties younger people and their families face in accessing appropriate services, managing employment or increased family responsibilities. However, action plans developed by states and territories such as those developed by New South Wales, South Australia, Queensland, Western Australia and Tasmania also lacked recognition of childhood dementia

[14] On another note, Dementia-Friendly Central Coast Framework acknowledges the challenges faced by children whose parents were diagnosed with dementia, including coping with family dynamics. This finding is aligned with reports on the impact of childhood dementia on siblings, who are often neglected or isolated as parents focus on managing the needs of the child with dementia. Siblings were also reported to grieve without formal support.

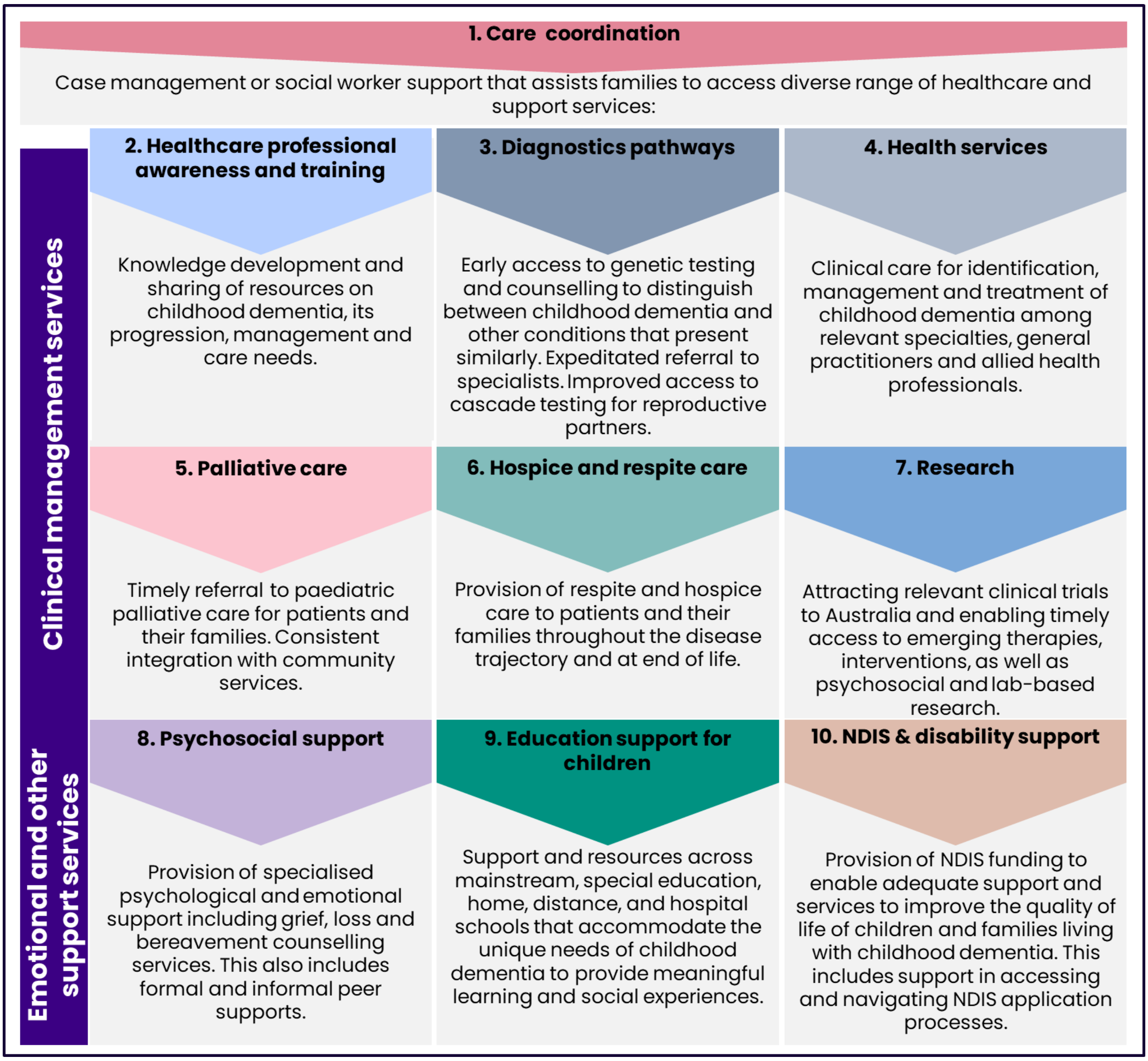
[15] Paediatric Palliative Care, Paediatric Palliative Care National Action Plan

[16] Australian Department of Health and Aged Care, National Strategic Action Plan for Rare Diseases 2020

## 2.5. Care and support services

Effective support for children with childhood dementia requires coordination between healthcare providers, disability services, educational institutions, community organisations, and families. An integrated and collaborative approach would ensure continuous, accessible care that adapts to the increasing needs of both the children and their families, improving their overall quality of life. By triangulating the information gathered throughout this project, HealthConsult have identified **ten essential care and support services**, as shown in Figure 4. Figure 5 illustrates when and how these care and support services are needed by the children and their families throughout the different stages of the disease.

**Figure 4: Essential care and support services required for childhood dementia**



**1. Care coordination**

Case management or social worker support that assists families to access diverse range of healthcare and support services:

**2. Healthcare professional awareness and training**

Knowledge development and sharing of resources on childhood dementia, its progression, management and care needs.

**3. Diagnostics pathways**

Early access to genetic testing and counselling to distinguish between childhood dementia and other conditions that present similarly. Expeditated referral to specialists. Improved access to cascade testing for reproductive partners.

**4. Health services**

Clinical care for identification, management and treatment of childhood dementia among relevant specialties, general practitioners and allied health professionals.

**5. Palliative care**

Timely referral to paediatric palliative care for patients and their families. Consistent integration with community services.

**6. Hospice and respite care**

Provision of respite and hospice care to patients and their families throughout the disease trajectory and at end of life.

**7. Research**

Attracting relevant clinical trials to Australia and enabling timely access to emerging therapies, interventions, as well as psychosocial and lab-based research.

**8. Psychosocial support**

Provision of specialised psychological and emotional support including grief, loss and bereavement counselling services. This also includes formal and informal peer supports.

**9. Education support for children**

Support and resources across mainstream, special education, home, distance, and hospital schools that accommodate the unique needs of childhood dementia to provide meaningful learning and social experiences.

**10. NDIS & disability support**

Provision of NDIS funding to enable adequate support and services to improve the quality of life of children and families living with childhood dementia. This includes support in accessing and navigating NDIS application processes.

Source: HealthConsult (2024) based on this project methodology

Families of children with childhood dementia often begin their journey seeking answers for undiagnosed symptoms, only to **face a complex, fragmented system**. They encounter long waits, limited awareness from healthcare providers, and ambiguous test results. Some may experience several different diagnoses before receiving the correct diagnosis.

Even before diagnosis, children may be referred to allied health services, but once diagnosed, the **need for continuous, coordinated care** becomes critical.

Families require **dedicated support navigating** the healthcare system, accessing psychosocial and educational resources, and managing referrals for clinical trials, palliative care, and NDIS support.

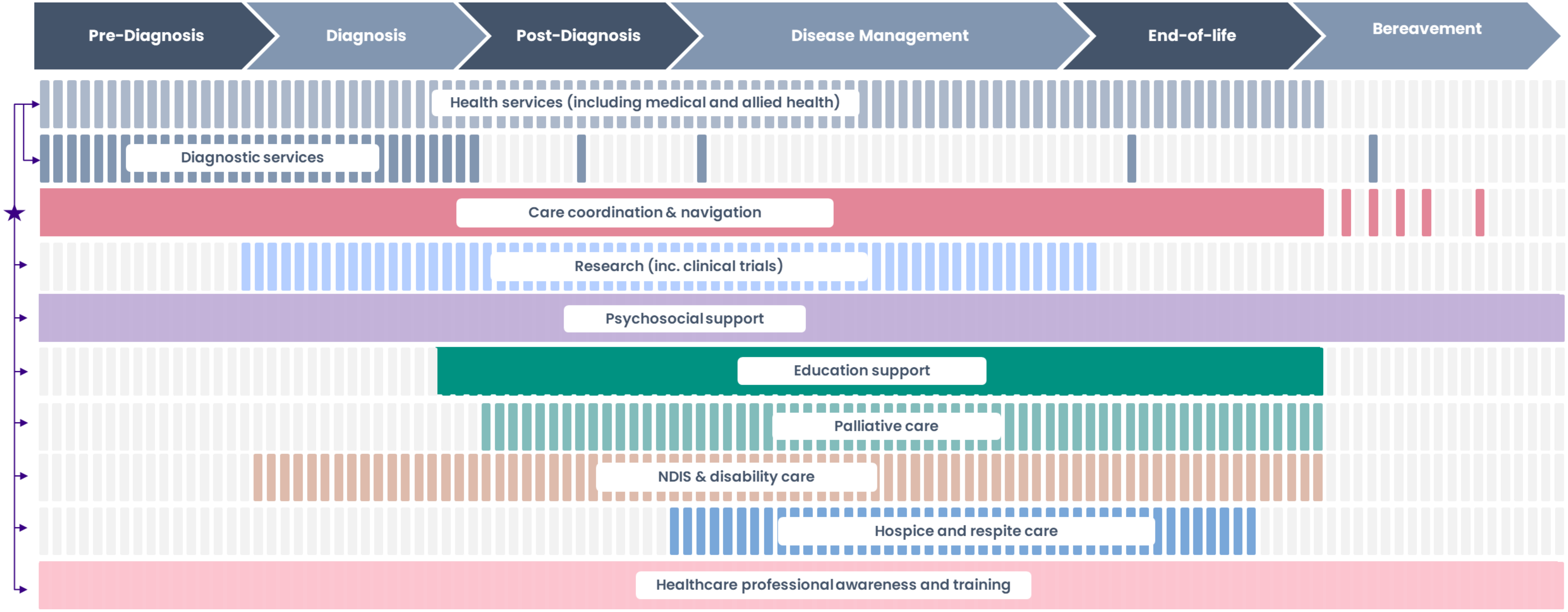
Clinicians consulted by the HealthConsult team stress the **importance of care coordinators** in **easing the burden** on parents and ensuring children receive the services they need. **A multidisciplinary team (MDT) approach, involving specialists, allied health and psychosocial support, is essential for addressing the complex medical, emotional, and developmental needs unique to childhood dementia.**

Our analysis highlighted **the need for continuous learning and training opportunities for healthcare professionals** to better support affected children and their families.

**Figure 5 Key:**

- **Continuous boxes** indicate the need for continuity of care throughout the disease stages between families and relevant staff members.
- **Broken boxes** indicate that families may be seen periodically by different treatment staff. There is a need for shared access to patient information, including proper handover of notes to reduce the requirement for families to repeatedly recount distressing events and information.
- **The arrows** on the left side show how most children begin their journey by seeking health services (including medical services and allied health), which then leads to referrals for diagnostic tests. Once childhood dementia is confirmed, there is broad consensus among health professionals and families (based on previous work) that care coordination services will significantly improve the quality of life for children with dementia and their families. A single point of contact can be instrumental in providing family centred support, tailoring assistance to individual family circumstances, and developing support options both in hospitals and the community.

Figure 5: The care and support requirements across the childhood dementia disease trajectory



Source: HealthConsult (2024) based on this project methodology.

Chapters 3 to 12 delve deeper into each identified care and support theme discussing current challenges recognised by healthcare professionals, what services currently exist, what is needed and the gaps that should be addressed. These Chapters aim to provide a comprehensive understanding of how to enhance care strategies and make them more effective for families affected by childhood dementia.

The Chapters are aligned closely to disease stage trajectory: **Chapter 3:** Healthcare professional awareness and training, **Chapter 4:** Diagnostic pathways, **Chapter 5:** Care coordination, **Chapter 6:** Health services, **Chapter 7:** NDIS and disability services, **Chapter 8:** Psychosocial support, **Chapter 9:** Education support, **Chapter 10:** Palliative care, **Chapter 11:** Hospice and respite care, and **Chapter 12:** Research.

# 3. Healthcare professional awareness and training

**Greater awareness and training** for healthcare professionals on childhood dementia is essential to **improve diagnosis and management**. Effective training ensures symptom recognition, accurate diagnoses, and timely support for affected children and their families. The lack of structured, widely available education, limited integration of childhood dementia into existing clinical curricula, and the absence of specialised clinics and clear referral pathways exacerbate these challenges, hindering the quality of care and outcomes for children with childhood dementia.

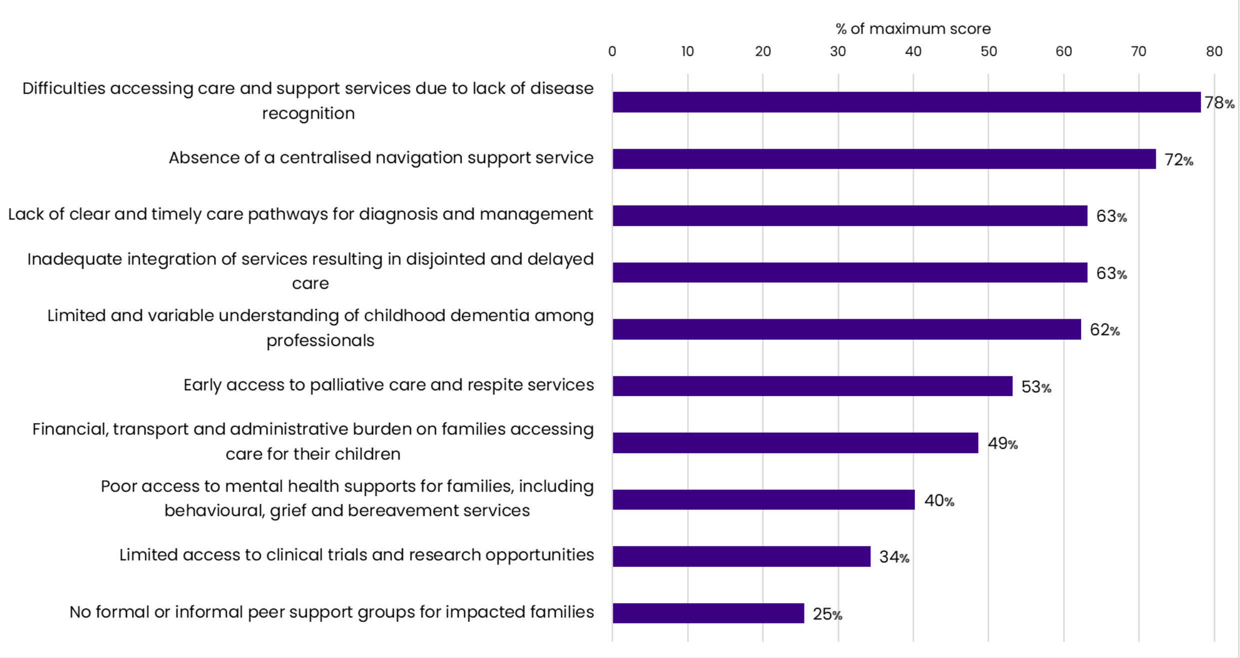
## 3.1. Current challenges

Stakeholders highlighted a **lack of awareness of childhood dementia among healthcare professionals,** with many stakeholders reporting their colleagues were **unaware of childhood dementia and the unique care needs**. Very few were aware of, or had participated in, any kind of tailored childhood dementia training content specific to their profession.

Our discussions with healthcare professionals identified that this knowledge gap affects diagnosis timelines including genetic testing (as discussed in Chapter 4), access to medical and allied health services (discussed in Chapter 6), psychosocial support (discussed in Chapter 8), palliative care (discussed in Chapter 10), and eligibility to clinical trials (discussed in Chapter 12). As such, **challenges related to a lack of disease awareness are manifold and interrelated,** having a significant effect on the care and outcomes of a child with childhood dementia and their family.

**Healthcare professional survey respondents noted *"Limited and variable understanding of childhood dementia among professionals"* as the fifth biggest challenge in relation to childhood dementia care and support** as experienced by families (Figure 6).

Figure 6: Ranking of the main challenges for childhood dementia care and support services



Source: HealthConsult (2024) Healthcare professionals survey developed for CDI (n=44).

'% of maximum score' was calculated by weighting answers indicated as the highest challenge out of the options given as 10, answers indicated as the second highest challenge as nine and so on. Weighted scores were then added for each challenge option to give a total value, this was then divided by the maximum possible weighted score (i.e. all 44 respondents choosing the same option as the first or largest challenge, the score for which would be 44 x 10 = 440) to give a percentage.

## 3.2. What exists currently for healthcare professional awareness and training?

**There is a lack of structured, widely available educational programs specifically focused on childhood dementia for healthcare professionals** with only one instance of childhood dementia specific course content noted by a stakeholder (for a Diploma of Dementia Care in Tasmania). Some disease-specific training is available to healthcare professionals on mitochondrial disease[17], although it is targeted at General Practitioners and primary care health professionals, and addresses the full age range of mitochondrial patients rather than addressing the specific needs of children impacted. There is also the rare disease training content provided by Rare Voices Australia, which is not specific to childhood dementia (although includes some genetic conditions which come under the childhood dementia umbrella).[18] As one stakeholder reported, the available content is limited in scope and reach, emphasising the need for more comprehensive, widely available and easily accessible resources. Notably, existing rare genetic disease training programs often overlook or provide minimal coverage on childhood dementia and rather focus on the

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[17] https://www.mito.org.au/for-health-professionals/

[18] Access to RVA's online education portal available online at; https://rarevoices.org.au/education/

collective of all rare genetic diseases[64], rather than the commonality of symptoms and needs that the childhood dementia cohort shares.

## 3.3. What is needed?

Due to the **absence of structured education** on childhood dementia, healthcare professionals reported having to **rely on informal networks and opportunistic training** to gain information where possible. This knowledge deficit can result in delayed diagnoses, inadequate management and treatment of symptoms, insufficient support for families, and limited understanding of the various types of regression experienced, an experience that was conveyed to CDI throughout consultation with families.[19] These gaps highlight the urgent need for more comprehensive and accessible educational resources tailored to healthcare providers across various specialties and disciplines.

Professional training needs and suggestions made by consulted stakeholders also include:

- The development of comprehensive childhood dementia training programs **integrated into continual professional development** obligations for healthcare professionals of a variety of disciplines including medical, primary and allied health.
- Inclusion of childhood dementia specific course content into existing rare disease training programs/content and medical school courses.
- **Creation of a centralised repository for childhood dementia education and training resources,** best practice, diagnostic tools, and management strategies to support healthcare providers in caring for a child with childhood dementia and their families.
- **Stakeholders** noted that the establishment of **specialised clinics or 'centres of expertise' for childhood dementia would help to increase healthcare professional and public awareness of childhood dementia** and improve quality of care**.**
- **The development of clear and published referral pathways and guidelines for healthcare professionals** to streamline the diagnosis and treatment process for childhood dementia even in an absence of disease recognition by individual clinicians (this is also linked with Chapter 4 and 12).

> *"We have this idea that specialists are health literate and that consumers need to be taught health literacy, and actually I think both of those are a bit fallacious. There are very health literate consumers and there are specialists who are only literate in their very narrow field of expertise."*
>
> Psychosocial researcher

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[19] Childhood Dementia Initiative. Childhood Dementia: Family experiences of health systems in New South Wales report, March 2024. Available online at; https://www.childhooddementia.org/news/nswhealth

*"I often get information from parents because they're in contact with more information groups and things like that, and they often are more aware of things, and I rely on it because with some illnesses which are very rare, you know, it's just not in the medical literature."*

Paediatric neurologist

**Potential areas for action:**

- There is a lack of targeted training programs specifically focused on childhood dementia for healthcare professionals, with existing rare disease programs and medical courses failing to include this critical content.
- Healthcare professionals treating children with childhood dementia lack online, easily accessible resources.
- Insufficient awareness and understanding of childhood dementia among clinicians, policymakers, and the general public perpetuates stigma and delays condition recognition.

**Implementation considerations:**

- Any targeted training programs for childhood dementia should align with existing professional development and accreditation requirements in Australia, including medical schools, continuing professional development (CPD) programs, and specialty colleges (e.g. Royal Australian College of General Practitioners, Australian Medical Association).

- The healthcare workforce's capacity to absorb and implement new training, especially in rural and remote areas, must be considered. Tailored solutions may be required for different settings, including leveraging telehealth, "on-demand" education and e-learning platforms to ensure equitable access.

- Innovative training approaches are needed to address the fact that knowledge about childhood dementia includes information that does not currently exist in the literature. One possible solution could be the establishment of a Community of Practice, which CDI are undertaking in 2025.

- Developing mechanisms to monitor the uptake, effectiveness, and impact of the training and awareness programs will be essential. Regular evaluations and feedback from healthcare professionals and families can help ensure continuous improvement.

# 4. Diagnostic pathways

**Diagnosing childhood dementia** is a **challenging and complex** process. It often starts when parents notice their child's development slowing **(i.e. developmental delay)** or regressing **(i.e. loss of skills)**. These signs are sometimes mistaken for conditions like autism. Without clear answers, the families' general practitioner (GP) is likely to refer the family to specialists in paediatrics, neurology, genetics, or metabolic medicine. Families then face a long **period of uncertainty** as their child undergoes various tests, including genetic screening and/or sequencing, to reach a definitive diagnosis.

## 4.1. Current challenges

The **disorders that cause childhood dementia are rare**, and as outlined in Chapter 2, this likely **leads to low clinician awareness,** often resulting in **delayed diagnoses** for families. The **average delay in diagnosing childhood dementia is 2 years** from the onset of symptoms, with some conditions having an even longer median time to diagnosis.[20] A survey of NSW families found that **over 50% of children with dementia saw more than 15 healthcare practitioners before receiving an accurate diagnosis,** and for 30%, the process took more than five years.[21]

Parents often report that their **early concerns about their child's development were overlooked by healthcare professionals,**[22] as the initial symptoms were non-specific and easily mistaken for more common neurodevelopmental disorders. This highlights the interrelation of challenges faced by families of children with childhood dementia, as discussed elsewhere in this report. For example, **lack of education and training on childhood dementia for health professionals** (as discussed in Chapter 3), particularly GPs, can delay referrals for specialist testing, impacting clinical trial eligibility (discussed in Chapter 12) and access to potential treatments.

A paediatric neurologist reported that the progressive nature of childhood dementia is not often clear at first, with some conditions seeming static, until the disease worsens. This complicates diagnosis. This neurologist also added that **epilepsy and other neurological conditions can cause cognitive regression,** which may be a cause of misdiagnosis for those with childhood dementia.

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[20] Elvidge KL, Christodoulou J, Farrar MA, et al. The collective burden of childhood dementia: a scoping review. *Brain J Neurol*. 2023;146(11):4446-4455. doi:10.1093/brain/awad242

[21] Childhood Dementia Initiative. Family experiences of health systems in New South Wales. Published online 2024. Available at ; https://d1iap1m2kaw9nt.cloudfront.net/9fbdfb11363dac2de5c61c7e21277655.pdf

[22] Childhood Dementia Initiative: We don't fit. Childhood Dementia Initiative. March 2023. https:// www.childhooddementia.org/news/we-dont-fit

Tragically, families consulted by CDI echoed what we heard from clinicians, that specialist referrals often occur only after noticeable skill regression, at which point valuable intervention time has been lost. They also highlighted long, location-dependent **wait times to see specialists,** leading to significant emotional and practical strain on families.[23]

A significant number of children with childhood dementia **have treatment options that could improve their life, both quantity and quality, if diagnosed and treated early.**[24] Unfortunately, the limited treatment options are often ineffective due to **late diagnosis.**[25] Once neurodegeneration starts, halting or slowing it is extremely difficult, and brain damage currently cannot be repaired. As such, early diagnosis is vital for accessing treatments including clinical trials as soon as possible, when available.

Early diagnosis also **helps families assess the risk** of childhood dementia **for future pregnancies and plan, accordingly**, including the use of IVF techniques to reduce their risk. Healthcare professionals consulted recommended offering cascade testing of family members, especially parents, and providing **genetic counselling immediately after diagnosis.** Also, **swift interpretation of results is crucial given the psychological burden on families.** Delays in diagnostic testing can be significant. For example, one family waited four years to access genetic testing to receive an answer.[26]

In summary, **early diagnosis of childhood dementia is invaluable, even without treatment options.** It reduces parents' **stressful search for a diagnosis,** ensures earlier care and support, helps families plan future pregnancies as well as their finances and housing requirements, and enables more timely interventions to preserve the child's skills, like occupational and speech therapy.[27]

## 4.2. What diagnostic pathways and services exist currently?

GPs typically provide initial assessments upon presentation of symptoms and referrals to specialist care. **Specialists in metabolic medicine, paediatrics, neurology and/or genetics offer more in-depth medical assessments and diagnostic testing**, including genetic and genomic testing. A triage system based on genetic test results could support specialists to distinguish childhood dementia from developmental delay, autism, or other disorders which

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[23] Childhood Dementia Initiative (2024). Early diagnosis of childhood dementia: challenges, importance, and opportunities for improvement https://www.childhooddementia.org/xxxxx September 2024 Sydney, Australia. (forthcoming)

[24] Childhood Dementia Initiative (2024). Early diagnosis of childhood dementia: challenges, importance, and opportunities for improvement https://www.childhooddementia.org/xxxxx September 2024 Sydney, Australia.

[25] Sevin C, Deiva K. Clinical Trials for Gene Therapy in Lysosomal Diseases With CNS Involvement. Front Mol Biosci. 2021;8:624988. doi:10.3389/fmolb.2021.624988

[26] Childhood Dementia Initiative. Childhood Dementia: Family experiences in Western Australia. Published online July 2024. https://d1iap1m2kaw9nt.cloudfront.net/e66b1b6265cd7f7a8869d2c660a31638.pdf

[27] Childhood Dementia Initiative (2024). Early diagnosis of childhood dementia: challenges, importance, and opportunities for improvement https://www.childhooddementia.org/xxxxx September 2024 Sydney, Australia. (forthcoming)

present similarly would provide children with dementia with earlier access to care and support. A genetic specialist noted that **access to gene arrays and the number of tested mutations has increased over recent years**. However, many of the specialists consulted highlighted the challenge of interpreting genetic testing results, with uncertain results, causing more stress for both families and doctors as they attempt to confirm the diagnosis.

Since 2020, Medicare funded genomic testing has been available in Australia for children under the age of 10 with intellectual disability or global developmental delay of at least moderate severity.[28] In November 2023, a new Medicare item was added for patients with suspected mitochondrial disease, some of whom may develop childhood dementia.[29] However, in the past year this item number has only been utilised around 40 times, indicating underutilisation of this test when compared to the estimated prevalence. For certain conditions, MRI imaging and/or biochemical tests on blood or urine can be strongly suggestive of a particular childhood dementia condition, but confirmatory genetic tests are then performed. For many, whole genome sequencing is required to reach a definitive diagnosis; however, interpretation of the results requires specialised skills and patients experience significant wait times.

## 4.3. What is needed?

**Referral processes:** The majority of consulted stakeholders agreed that there is a need for improved pathways to **accelerate diagnosis**. Inconsistent referrals due to a lack of awareness among clinicians often result in delayed diagnoses for families and long wait times for results of diagnostic tests.[30] One of the **top three challenges** relating to care and support services for childhood dementia by healthcare professionals in the survey **was the** "**lack of clear and timely care pathways for diagnosis and management**" (Figure 6).

**Genetic testing and counselling:** Stakeholders reported that extended waits both to accessing genetic testing and for the results to come through, sometimes taking up to a year, delays diagnosis and specialist care. It was reported by a clinical geneticist stakeholder that some families and hospitals cover the costs of urgent private tests to expedite diagnosis when childhood dementia is strongly suspected. A consulted clinical geneticist suggested doubling public genetics services to reduce these delays.

> *"Every single public genetics service in Australia probably needs to double their FTE."*
>
> *Clinical geneticist*

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[28] MBS Online - May 2020 News

[29] MBS Online - November 2023 News

[30] Childhood Dementia Initiative (2024). Early diagnosis of childhood dementia: challenges, importance, and opportunities for improvement https://www.childhooddementia.org/xxxxx September 2024 Sydney, Australia.(forthcoming)

Stakeholders advised that due to the genetic nature of childhood dementia, **cascade testing for other family members,** including siblings, **should be offered immediately after diagnosis.** However, they noted that families often must push hard for access to testing. They emphasised that **early access to cascade testing** is essential for **timely diagnosis** of siblings and to **help restore reproductive confidence for extended family members.** They highlighted the need to improve the availability and accessibility of this testing as a priority.

> "Some [clinicians] are reluctant to order genetic testing because they're worried about the complexities involved; genetic counselling and challenges of delivering results and so on."
>
> Clinical geneticist and researcher

Stakeholders repeatedly noted that access to genetic counsellors is often limited, with some healthcare providers admitting that they have had to counsel families themselves without proper training, leading to inadequate support for families.

**Newborn screening:** There is work ongoing by the Australian Government to expand newborn screening which may result in some additional childhood dementia disorders being included in the test. This has the potential to give children with these disorders the opportunity to access treatments prior to symptoms developing.

A highlighted issue that was that by current screening policy, conditions can only be included if there is an intervention, meaning almost all childhood dementia conditions are excluded. However, this information may be very important both to families' planning, and for drugs in the development pipeline to enable recruitment of patients within the therapeutic window to clinical trials.

Concern was expressed by one stakeholder (a paediatric metabolic clinician) that **1)** Newborn screening can sometimes result in false positives or false negatives, with some genetic or biochemical markers being difficult to interpret, and **2)** Following up with asymptomatic individuals places a burden on healthcare systems, which are often underfunded. Expansion of newborn screening must be underpinned by well-resourced clinical services that have the capacity to support newly diagnosed families and deliver timely access to available treatments and clinical trials.

**Potential areas for action:**

- A lack of disease awareness and recognition among GPs and specialists, combined with insufficient education and training on childhood dementia for healthcare professionals, delays diagnosis and care.
- There is no standardised diagnostic protocol for childhood dementia across healthcare settings, leading to inconsistent and prolonged diagnostic journeys for families.

- The lack of a red flag system and standardised referral pathways to expert teams contributes to delays in diagnosis, as inconsistent triage protocols across the healthcare system hinder timely and accurate identification of childhood dementia. Implementing these measures could streamline diagnosis and ensure more consistent care.
- Genetic testing services have long turnaround times for results. There is likely a need for workforce improvements, and better access to timely cascade testing for family members to support reproductive confidence.

**Implementation considerations:**

- Developing standardised diagnostic protocols requires collaboration between healthcare providers, government bodies, and patient advocacy groups to ensure consistent pathways across all jurisdictions. Introducing such protocols will necessitate additional funding and resources for infrastructure, staff training, and diagnostic tools across hospitals and primary care settings.
- Expanding the genetic services workforce will require long-term workforce planning, including the training of additional clinical geneticists and counsellors. Collaboration with universities and training institutions to increase capacity for medical genetics programs will be essential.
- Increased government funding could support new genetic services or current service expansion, including new equipment, lab space, and staff. Funding must also account for equitable access to these services, particularly in underserved regions.
- Expanding telehealth services to provide genetic counselling and testing in rural and remote areas can help address access issues, but it will require infrastructure improvements and regulatory considerations for secure data sharing.
- The “Reforming Pathology Service” reform outlined in the 2024-25 Budget highlights the government's commitment to ensuring pathology services remain clinically appropriate, cost-effective, and responsive to technological advancements. This reform cited ongoing benefits from automation and economies of scale in the Genetics service group.[31]
- Whole genome sequencing is considered gold standard and considered an approach to reduce diagnostic odyssey. New technologies such as long-read sequencing and multi-omics offer advanced diagnostic capabilities but require significant infrastructure and trained professionals. Challenges include ensuring systems can handle the complexity of data sharing and interpretation.
- Expanding newborn screening to include more childhood dementia conditions offers early diagnostic potential. Adequate resources and properly resourced clinical services are essential to manage screening outcomes and provide timely access to interventions.

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[31] https://www.health.gov.au/resources/publications/budget-2024-25-reforming-pathology-services?language=en

# 5. Care coordination

**Care coordination** for children with dementia would involve an **integrated system that seamlessly connects healthcare, disability, community, and education services,** ensuring that families have a **central point of contact** to manage all aspects of their child's care. **It would alleviate the burden on families** by providing support for **navigating complex systems, facilitating communication** between different service providers, and ensuring **timely access to needed** care and resources**.**

> *"There is a lack of complex care coordination. There is a lack of integration between government supports in health and disability. More clinical centres of expertise with integrated translational research capacity are needed. More understanding of diagnostic pathways and when to refer for diagnostic pathways is needed. Ongoing mental health and psychosocial support is needed."*
>
> Advocacy worker

## 5.1. Current challenges

**Healthcare professionals reported that the lack of access to care coordination services has a significant impact on the wellbeing of the entire family. Families are consistently tasked with 'project managing' their child's care, which places an undue burden on them.**[32]

Families are expected to possess a high level of health literacy and knowledge of how services are structured, leading to inequity, especially for Culturally and Linguistically Diverse (CALD) families and those with lower health literacy, as noted in CDI consultations with families.[33] Healthcare professionals also acknowledged the challenge families face in managing interactions across multiple sectors, including health, disability, community services, and education.

**Stakeholders reported that families affected by childhood dementia would benefit from care coordination. The "absence of a centralised navigation support service" and "inadequate integration of services, resulting in disjointed and delayed care" were ranked as the second and fourth most significant challenges in the childhood dementia care and support landscape, respectively** (Figure 6).

Other areas of concern identified by health professionals include:

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[32] Nous Group 2023. '<u>We don't fit</u>': The lived experience of families affected by childhood dementia and their interactions with care and support services report

[33] Childhood Dementia Initiative. Childhood Dementia: Family experiences of health systems in New South Wales report, March 2024. Available online at; https://www.childhooddementia.org/news/nswhealth

- **High variability and inconsistency of services across states and territories**, with many lacking formalised care coordination or support services.
- **Inconsistent communication flow between fragmented services and care streams** (e.g. medical, allied health, community care, disability), placing the onus on parents to frequently pass on complicated and comprehensive medical information.
- Hospital staff, including social workers, often **lack the resources and capacity** to **consistently connect with community-based services.**
- **High staff turnover among social work professionals makes it difficult for families to build trust and rapport.**

## 5.2. What care coordination exists currently?

Currently, care coordination for childhood dementia is limited. Two large children's hospitals in Sydney and Perth offer complex care navigation, but the **eligibility criteria often exclude children with childhood dementia,**[34,35] as their condition may remain stable for long periods**.** Some **paediatricians, social workers, or clinical nurse consultants (CNC)** stated they informally take on a care coordinators role within an MDT model, but this is not specialised for childhood dementia and is only funded in tertiary settings.

> *"What tends to happen is the subspecialist becomes the default [medical care] coordinator and provider of care because people can't afford to go and spend $500 to see a paediatrician…I think the paediatricians, because of their general skills, do work very well as the main coordinator of information. If you have subspecialists doing that, particularly neurologists, then it gets more fragmented."*
>
> Clinician

The Rare Care Centre based in the Perth Children's hospital provides a model for rare diseases care coordination.[36] This service supports eligible children with diagnosed or undiagnosed rare diseases to access acute and community-based services. However, the service operates on a drop-in, drop-out basis, where children are discharged once their care needs are perceived to have been met and it therefore does not provide the continuity of support required to effectively address the needs of children with progressive conditions (the model of care for the Rare Care Centre is outlined in Appendix A).

Stakeholders involved in palliative care and respite care services noted the need for continuity and better communication between acute and community-based services, but

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[34] All referrals to Kids GPS Care Coordination are assessed against the following eligibility criteria: 1. The child/young person is a patient of SCHN or has been referred to SCHN for tertiary level care or advice. 2. The patient has a chronic and complex condition, involving multiple health care providers. 3. There is not a designated key person coordinating the patient's care within a multidisciplinary team 4. There is potential to facilitate a more coordinated approach to the patient's healthcare needs, in particular for patients who frequently utilise hospital services over a twelve month period demonstrating one or more of the following: more than 4 Emergency Department presentations, or, more than 14 days length of stay for hospital admission/s, or, greater than ten outpatient appointments, or, infants identified as being at risk of significant future hospital utilisation.

[35] Referrals to the Perth based Clinical Centre of Expertise for Rare and Undiagnosed Diseases (Rare Care Centre) are assessed against the following eligibility criteria: The patient 1. has a RUD (including undiagnosed patients with high probability of RD), and has an identified current gap in service needs (clinical and/or cross-sector) according to Rare Care Interventions, AND is receiving ongoing paediatric care from either a PCH Team, a Paediatrician at CDS or a private paediatrician.

[36] Information available online at https://pch.health.wa.gov.au/Our-services/Rare-Care-Centre

noted these services are under-resourced. Some suggested that paediatricians, CNCs, or community-based peer navigators with lived experience could serve as effective care coordinators, but barriers like cost and inconsistent accountability remain challenges for families seeking comprehensive care. **Advocates from childhood dementia disease specific groups noted that the care coordination role needs to be filled by someone with the patients' best interests in mind.**

## 5.3. What is needed?

**Children and their families would benefit from holistic, standardised and accessible care coordination services to bridge the gap between health services, community-based care, education, and the NDIS.** Such a service needs to **cater to the unique needs of children with childhood dementia and their families**, ensuring **equitable access** regardless of location or specific condition.

**Continuity of care (maintaining the same MDT and care coordinator) is essential** to ensuring families do not need to repeatedly explain their child's condition at each new appointment. Families have reported this is both time consuming and distressing.[37]

A care coordinator would also provide emotional support to families, providing a **'hand holding' mechanism** between appointments to check in with families.

> *"Families don't understand what is happening, especially those from vulnerable backgrounds. They need a 'hand holding' mechanism between appointments – where a coordinator finds out how the appointment went and how they can support the family."*
>
> Paediatrician

For CALD families, there may be cultural barriers for putting themselves forward to advocate for care. Care coordinators could potentially improve equity of access to high quality care by vulnerable populations.

**Potential areas for action:**

- Healthcare professionals agreed that hospital-based coordinators could fundamentally improve how hospital care is linked with community services.
- There was broad consensus between healthcare professionals, patient advocates, stakeholders involved in research and policy that embedding care coordinators is considered a positive step to providing continuous, consistent support that is

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[37] Childhood Dementia Initiative. Childhood Dementia: Family experiences of health systems in New South Wales report, March 2024. Available online at; https://www.childhooddementia.org/news/nswhealth

sensitive to the evolving needs associated with childhood dementia and it could alleviate the administrative burden on families.

- The role of care coordinators for childhood dementia may be similar to other proven models, such as the McGrath Breast Cancer[38] or childhood cancer care coordination models detailed in Appendix A.
- The use of digital tools to support coordination could be considered.

**Implementation considerations:**

- Healthcare professionals are stretched beyond capacity, highlighting the need for mechanisms to strengthen collaboration and ensure integrated care planning between acute and community-based services.
- Ensuring any roles aimed at improving care coordination are accessible and sustainable is crucial, with attention to funding and availability for all families.
- There is a need for specialised ongoing training to equip those in care coordination roles with the skills and knowledge to address the unique challenges of childhood dementia and provide comprehensive support to families.
- Implementing a care coordination framework that integrates medical, disability, and community services can ensure more holistic support for families. This requires establishing clear roles across medical, psychosocial support services, and disability care providers.

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[38] Information available online at; https://www.mcgrathfoundation.com.au/?gclid=Cj0KCQjw9Km3BhDjARIsAGUb4nxg65VPOeSR3Eq6D50h6gy3AbXKT5CpcN770mfAGpg_h36buPlexAgaAp7kEALw_wcB

# 6. Health services

Health services for the children with dementia and their families are discussed in two sections: **1)** Medical services, and **2)** Allied health services. While diagnostics, palliative care, hospice and respite care, and psychosocial support are essential parts of health services, these have significant needs and are addressed in separate Chapters. This Chapter also highlights the importance of an integrated care model and team-based approach to ensure high quality care delivery.

## 6.1. Medical services

The provision of medical services, which includes GPs, specialist care, and some community care services for children with childhood dementia faces significant challenges and gaps partly due to **the lack of a standardised model of care for this cohort.** The **absence of a model of care results in fragmentation of patient care and inequity in service provision. Consecutively, families often struggle to access coordinated and appropriate services for their child.**

### 6.1.1. Current challenges

**Healthcare professionals repeatedly agreed that there is a pressing need for greater integration of medical services for childhood dementia including specialists, GPs and community care.** Stakeholders, particularly paediatrics, metabolic medicine and genetics, frequently raised the need for MDTs. Currently families consulted by CDI describe medical care as being ‘cobbled together’ across disciplines, geographies and the public/private sector.[39]

> *“There are no MDT clinics for childhood dementia in our service. In the ideal world it would be great to have an MDT clinic… because [childhood dementia] is multidisciplinary, a whole-body disorder. So it's not just dementia, it's many other things as well, which involves many systems of the body and needs a lot of input from multiple teams.”*
>
> Metabolic physician

Stakeholders emphasised that **an integrated childhood dementia model of care does not exist and should include clear pathways for diagnosis and disease management across relevant medical specialties** including GPs, care coordinators, allied health and community health services. Although a specific childhood dementia model of care was not identified,

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[39] Childhood Dementia Initiative. Childhood Dementia: Family experiences of health systems in New South Wales report, March 2024. Available online at; https://www.childhooddementia.org/news/nswhealth

there are disease specific guidelines (global consensus clinical guildelines for Sanfilippo Syndrome[40] and international primary care guidelines for Rett syndrome[41]), as well as rare disease recommendations (National Recommendations for Rare Disease Health Care[42]), however **a rare disease model of care would not address the specific needs of children with dementia, and it would be both resource-intensive and challenging to create and implement models of care for each separate childhood dementia condition.**

Healthcare professional survey results showed that ***'increased access to multidisciplinary, coordinated and holistic care'* was the highest prioritised opportunity to improve the childhood dementia care and support landscape** and *'**development of a standardised model of care for children with childhood dementia'*** **was the second highest prioritised opportunity (Figure 1).**

Challenges noted for provision of medical services also include:

- **The lack of specialist availability and capacity to attend MDTs in the private setting and an absence of an MBS item number** for attendance (that is not specific to cancer treatment[43]), was noted as a limitation by multiple privately practicing specialists that were consulted.

> *"Coordinating five experts in a room can be incredibly difficult. We're doing that without any funding for some of our [children with childhood dementia disorders]. It's just me turning up to someone else's clinic and then whether or not I bill, I don't know."*
>
> Metabolic geneticist

- The need for **greater integration and enhanced communication between community services and primary, secondary, and tertiary services** (including public and private) to support ongoing medical management of affected children.
- **Patient data that is fragmented and often lost between primary, secondary, tertiary and community care systems** thereby increasing the burden on families to convey complex medical history and the child's needs.
- **The need for some families to travel interstate to find expertise in childhood dementia and specialist care that their child requires** has been reported to CDI by families.
- **Paediatric services in regional and remote areas are less specialised** and so may have limited knowledge or expertise in complex and rare diseases such as childhood dementia, impacting the quality of care received.
- **Medication management can be fragmented,** often with multiple health professionals prescribing different medications in the absence of an identified lead clinician.

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[40] https://www.sanfilippo.org.au/about-sanfilippo/sanfilippo-clinical-guidelines

[41] https://www.rettsyndrome.org/wp-content/uploads/IRSF_PrimaryCareGdlns_REV2021.pdf

[42] https://rarevoices.org.au/national-recommendations/?gad_source=1&gclid=CjwKCAjwyfe4BhAWEiwAkIL8sAZszHX0a3IF-LEojFRnbLFhaIZXBJfJ_C2cpsnaYhFWxSPxW2bkYRoC1q0QAvD_BwE

[43] MBS item 872, information available online at https://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=872&qt=item

- Families often find **services inadequate immediately after diagnosis**, a period that clinicians identify as families needing intense support.

> *"After diagnosis, we don't support them very well because we are busy with a lot of patients – but they need to be seen frequently after [diagnosis] because they go through the phases of grief and shock."*
>
> Paediatric neurologist

### 6.1.2. What medical services exist currently?

While some high-quality medical services were reported by healthcare professionals, **none are tailored specifically for children with childhood dementia and their families**. Care pathways typically involve referrals to specialists (such as paediatric neurologists, metabolic physicians, clinical geneticists, and paediatricians) **rather than a dedicated clinical team. Care is provided across settings including inpatient, outpatient, primary care clinics, and at home**. Some health professionals reported offering telehealth services and others reported visiting families in regional and remote areas, but the availability of these services is highly variable.

The **Rare Care Centre**[44] (RCC) based at the **Perth Children's Hospital in WA** was provided as an example by multiple stakeholders of how a model of care for childhood dementia could operate. The current service **connects health and medical, education, and disability sectors through an 'interdisciplinary' team that supports NDIS funding, specialist care, healthcare navigation, and education support** for rare diseases.

It was reported to be an effective, but expensive service and a key limitation is its limited time, drop-in, drop-out model, meaning no ongoing consistency of care across the child's disease trajectory. The RCC services are also not specific to childhood dementia, but rather generalised to all rare diseases.

Some children may access **disease specific clinics offering specialist diagnostic and care services through an MDT clinic or service,** such as the Rett Syndrome clinic at the Children's Hospital at Westmead in NSW[45], and the Leukodystrophy clinic at the Royal Children's Hospital in Melbourne.[46] However, geographic fragmentation and low clinician awareness of these clinics and services outside their residing jurisdiction limits access to these services. Additionally, these clinics generally have eligibility criteria that must be met for referrals to be approved.

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[44] Information available online at; https://pch.health.wa.gov.au/Our-services/Rare-Care-Centre

[45] Information available online at; https://www.schn.health.nsw.gov.au/metabolic-genetics-childrens-hospital-westmead and https://kr.schn.health.nsw.gov.au/articles/2023/09/australian-leading-clinic-helping-children-rett-syndrome and https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10454341/

[46] Information available online at; https://www.rch.org.au/neurology/clinical_services/

A developmental regression clinic at Monash Children's Hospital in Victoria[47] is being piloted with funding from the Medical Research Future Fund (MRFF) in partnership with CDI. This research integrated clinical service, incorporating an MDT including developmental paediatricians, a clinical geneticist, a paediatric neurologist, psychologists, occupational therapists, and speech pathologists, aims to fast-track diagnosis, care and support for children experiencing global developmental delay and developmental regression. Although a large proportion of the children referred to the clinic will have developmental conditions such as autism, it also offers an avenue for diagnosis and care for the minority with childhood dementia.

### 6.1.3. What is needed?

**There is a stark absence of medical services specifically tailored to children with childhood dementia and their families in Australia**. The fragmentation and absence of tailored care exacerbates the difficulties in accessing treatments and continuity of care for these children.[48]

**The integration of specialist care including metabolic medicine, genetics, neurology, paediatrics and GPs into a standardised MDT, interdisciplinary model or a centre of expertise (a network of experts)**, was highly supported by healthcare professionals.

> *"I think the [centre of expertise] hub becomes a holistic hub…where you have medical clinical professionals…allied health…community development workers. So it's not separate; all those people work together and respect the roles each of them plays."*
>
> Bereavement care worker

Multiple healthcare professionals consulted noted that an integrated MDT needs a lead clinician or care coordinator to coordinate medical care for the child and their family (as discussed in Chapter 5).

The gaps and needs for childhood dementia medical services identified throughout consultations with healthcare professionals include:

- **A dedicated MBS item number for MDTs (outside of cancer care) would help alleviate administrative and capacity constraints** for clinician attendance and involvement in the private healthcare system.
- Bringing clinical and diagnostic experts together into a formal network of experts would promote training and **accelerate the diagnosis of individuals and provide direction as to the medical specialty that is best placed to manage the patient** on an ongoing basis.

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[47] Information available online at; https://www.monash.edu/medicine/scs/research/paediatrics-autism

[48] Childhood Dementia Initiative. Childhood Dementia: Family experiences of health systems in New South Wales report, March 2024. Available online at; https://www.childhooddementia.org/news/nswhealth

- **Greater access to specialist telehealth** especially for those located in regional and remote areas.
- There is **lack of real world data on the incidence and prevalence of childhood dementia to aid with medical service planning.**

**Potential areas for action:**

- Telehealth services for children with childhood dementia, especially in regional and remote areas, are limited and inconsistent, creating disparities in access to care.
- There is a lack of a standardised model of care for childhood dementia across Australia, leading to inconsistent quality of care and unequal outcomes for affected families.
- An integrated multidisciplinary team (MDT) model for childhood dementia is absent, resulting in fragmented care and a lack of coordination among healthcare providers.
- No national or state-based centres of expertise in childhood dementia exist, depriving families of comprehensive care, expert guidance, and support for navigating clinical trials and care pathways.

**Implementation considerations:**

- Standardising a model of care will require agreement across all Australian states and territories and various players across health and social support services. There are existing models (Appendix A) that could be leveraged and set precedence that it can be done in the Australian context.
- A national centre of expertise (or formal teams of experts), or several state/territory-based centres of expertise, in childhood dementia would require significant commitment to funding by the relevant state/territory and/or Australian Government.
- There may be opportunities to engage with federal and state health authorities to create supportive policies or potentially link childhood dementia to broader dementia strategies.
- New MBS items or changes to existing MBS items require applications through the Medical Services Advisory Committee (MSAC). MSAC reviews the application to assess the safety, clinical effectiveness, and cost-effectiveness of the proposed services before recommending whether they should be funded under Medicare. MSAC applications can be submitted by any stakeholder group including healthcare professionals, professional bodies, patient advocacy groups and individuals. There are costs related to preparing the necessary evidence and documentation to support an application, but only negligible costs to apply.

## 6.2. Allied health services

Allied health services including physiotherapy, speech therapy, occupational therapy, behavioural therapy and others are **crucial for maintaining the quality of life for affected children and their families**. These services play a key role in **providing holistic care, helping with daily functioning, mobility and communication**, and should coordinate with medical and community services to ensure comprehensive support is provided.

### 6.2.1. Current challenges

**A well-integrated, multidisciplinary approach to care is essential for families impacted by childhood dementia and should include specialised allied health services.** Healthcare professionals indicated that these services need to be accessible and seamlessly integrated with the medical services for childhood dementia patients.

Challenges for allied health care in the management of childhood dementia include:

- **Insufficient training for allied health professionals on childhood dementia, limiting their ability** to meet the complex and evolving needs of impacted children and their families.
- **Delayed and inflexible NDIS funding hinders access to appropriate allied health services** for those who are eligible.
- **Lack of clarity about responsibility of service between health and disability.**
- **Limited access to publicly funded allied health services due to eligibility criteria.**

> *"I know that local services for many allied health departments, like speech pathology, have very strict criteria; they've got an upper age limit and after that you're going into the private sector. The private sector is not regulated, so it's very difficult for these children with a rare disease, and for the parents, to be able to access the right services."*
>
> *Allied Health practitioner*

### 6.2.2. What allied health services exist currently?

Public and private allied health services, particularly occupational therapy, physiotherapy, behavioural therapy and speech therapy, are available across the country, predominantly in the community and large children's hospitals. However, **consultations with stakeholders did not identify any of these services collaborating with clinicians who were caring for children with childhood dementia.**

An allied health worker stated that **few of her colleagues in the allied health sector are aware of childhood dementia and the unique needs of these children.** Some care models, such as the one used by Rare Care Centre in Perth[49], have demonstrated effective coordination between allied health and medical care services. This provides an example of best practice in coordinating multi- or interdisciplinary care streams, including bringing allied health supports and services together with medical services.

Some allied health services such as physiotherapy and occupational therapy are available through **NDIS funding, however this is highly variable and depends on the plan and eligibility of every child,** with a member of a patient organisation noting that **parents and carers sometimes have to pay for private allied health to fill the gaps.** One education stakeholder noted that some special schools offer integrated allied health services to their students, however this requires the child to be well enough to be able to attend school.

### 6.2.3. What is needed?

Significant gaps exist in the delivery of allied health services for children living with childhood dementia. Health professionals consulted noted that a**ccess to allied health professionals is often fragmented**, **especially for those living outside of major cities**, with long wait times and limited availability of specialised care.

Additional needs for allied health care of childhood dementia include:

- **Training allied health professionals in childhood dementia** to provide specialised and patient appropriate services.
- **Enhanced and consistent communication and coordination between allied health services and medical, community and disability services.**
- **Access to telehealth services for allied health care** where possible to enable more equitable access for regional and remotely located patients.
- **Improved access to publicly funded allied health services for children with childhood dementia,** and/or a relaxation of eligibility criteria for this cohort.

> *"…it also becomes an issue in terms of accessing allied health services because they're a little bit few and far between outside of metropolitan areas, and may be much less specialised as well."*
>
> Paediatric neurologist

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[49] Information available online at; https://pch.health.wa.gov.au/Our-services/Rare-Care-Centre

**Potential areas for action:**

- Allied health services are not integrated into a standardised, multidisciplinary framework, leading to fragmented and uncoordinated care for children with childhood dementia.
- There is a lack of specialized training for allied health professionals in childhood dementia, limiting their ability to provide appropriate care.
- Inequitable access to allied health services in regional and remote areas persists due to insufficient availability of telehealth services.

**Implementation considerations:**

- Any future work to standardise a model of care for children with childhood dementia should consider incorporating allied health, palliative care, psychosocial support and hospice and respite care, and should identify whether provision /funding should be through disability or health.
- The implementation considerations outlined in healthcare professional awareness and training (Chapter 3) NDIS and disability services (Chapter 7) will also promote improvements to publicly funded allied health services.

# 7. NDIS and disability services

**The NDIS is Australia's primary system for providing support to individuals with disabilities**. It aims to **offer comprehensive services** and **assistance to those with various disabling conditions**, including **rare, progressive and mobility-affecting diseases** such as childhood dementia.

Families dealing with childhood dementia face **significant challenges navigating and accessing NDIS support**. These include insufficient funding, lengthy delays in obtaining necessary equipment and services, limited awareness of childhood dementia within the NDIS, and a lack of appropriate and accessible providers, particularly in rural and remote areas.

## 7.1. Current challenges

While there are universal challenges acknowledged with navigation of and access to NDIS support, the childhood dementia cohort faces additional unique challenges based on the nature of their conditions:

The NDIS system is **challenging to navigate** and **requires a high level of health literacy**. While the administrative burden of navigating the NDIS is well documented,[50] this is particularly pertinent for families experiencing childhood dementia, who are needing to act as 'project managers' across many aspects of their child's care.[51]

Families report that **funding can be insufficient** and does not cover all care needs. Healthcare professionals cited examples of families having to escalate their situation to their local politician, or to the media to secure support.

> *"Currently my kids need support 24/7…the expense of providing that service is about $4,000 a child per week. We have $0 in our budget for the NDIS, so I have no idea how I'm going to pay my support staff next week."*
>
> Lived experience stakeholder

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[50] Dickinson & Yates 2023, A decade on: The achievements and challenges of the National Disability Insurance Scheme's implementation, Available online at: https://doi.org/10.1002/ajs4.277

[51] Nous Group 2023. 'We don't fit': The lived experience of families affected by childhood dementia and their interactions with care and support services report

- The progressive nature of the disease means that support needs evolve rapidly, and the NDIS system is not responsive to this:

*"At the moment, if you have a change of circumstance then you apply to the NDIS. If your child needs an extra piece of equipment…the time for processing is averaging about six months."*

Lived experience stakeholder

- There is a **perception that the NDIS is geared towards capacity building** and is **not appropriate for life-limiting conditions such as childhood dementia**:

*"The NDIS doesn't really cater for chronic life-limiting and progressive conditions."*

Professional advisory group member

- With a scarcity of effective and available treatments, **children living with dementia spend the vast majority of their time in the community** rather than in hospitals, therefore they have **significant community support needs**
- There are a **limited number of NDIS providers available that have appropriate and accessible services for the childhood dementia cohort**, even less so in regional and remote areas
- **Awareness of childhood dementia is low amongst NDIS staff**, limiting their ability to design appropriate and comprehensive support plans:

*"There have been many children with childhood dementias, and indeed other related neurological conditions, that are given a diagnosis of cerebral palsy because that serves very much a purpose for that child in accessing funding through the NDIS."*

Clinician researcher

## 7.2. What NDIS and disability services currently exist?

The NDIS aims to offer **funding for services and resources tailored** to the **specific needs of each participant**. NDIS funding is used by families to **access a range of services and support**, including mobility aids, care support, and other equipment.

To access NDIS funding, families must complete **extensive application processes** to **prove eligibility**, requiring **significant time investment** from members of the child's care team, with most of the **burden falling on parents or carers**.

NDIS staff members can support the **development of a personalised support plan** via a planning meeting. However, **staff members often lack an understanding of childhood dementia, and the evolving care needs of families**. Some MDT services, such as **palliative care providers or care navigation services**, can provide families with **limited support with**

**NDIS applications**. Support plans also need to be **renewed periodically,**[52] requiring **additional administrative work**.

Programs like Queensland's Medical Aids Subsidy Scheme (MASS) or the Victorian Aids and Equipment Program (VA&EP) **may offer more responsive models** for providing medical aids and equipment, including end-of-life care, but **these are not integrated into the broader NDIS framework** and are specific to each jurisdiction.

## 7.3. What is needed?

With a scarcity of effective and available treatments, children living with dementia spend the vast majority of their time in the community rather than in hospitals. **Therefore, children with childhood dementia and their families need access to adequate and timely funding that can support the daily management of their child's life-limiting condition and allow access to support and services that contribute to quality of life.**

As reported by clinicians, lived experience stakeholders, and education stakeholders, this includes:

- **Adequate and flexible funding for life-limiting conditions**: Families need access to sufficient funding to support the daily management of childhood dementia and improve the quality of life for the child and the family. This requires flexible, responsive support plans that account for the progressive nature of the condition.
- **Simple and timely application process with compassionate support**: Families require a straightforward and timely application process, staffed by well-informed and compassionate individuals who can provide navigation support. A red flag system associated with a patient record to indicate a severe, degenerative, life-limiting condition could support this. The current system often creates additional challenges for families, especially when timely access to necessary resources and services is not available.

> *"Although there may not be a medical treatment or a curative treatment available, there are lots of supports and services that contribute to a better quality of life for the family and for family functioning, but also for the child at the centre of things."*
>
> Researcher and lived experience stakeholder

- **Challenges with the NDIS:** Families face significant difficulties in obtaining adequate support from the NDIS. The system's lack of understanding of childhood dementia leads

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[52] Plan reassessment dates vary significantly on a case-by-case basis and can be built around specific dates or milestones. Support plans can be as long as 3-5 years for those with stable support needs, but will typically be shorter for those who are younger or with progressive conditions: https://ourguidelines.ndis.gov.au/your-plan-menu/creating-your-plan/how-long-will-your-plan-go

to inadequate funding, which significantly impacts the quality of life for the child and the families.

> *"We had a patient recently and her living at home [arrangement] was really unacceptable. She didn't have enough NDIS... she didn't have the right equipment. She was laying on a mat on the floor. Her parents were carrying her, and she didn't even have the right toileting chair. She's waiting for NDIS to do her bathroom...that's really sad that they can't actually enjoy their time with their child because it's so burdensome, and they're getting injuries themselves because they don't have access to the right equipment."*
>
> Clinical stakeholder

> *"I only have one little fella that's on my books with childhood dementia. He's been really let down by NDIS. He had an NDIS package that was renewed in November of last year and the money was already gone by January. So it has been totally mismanaged by his support coordinator, and in the meantime he's been given this new diagnosis of dementia, so his needs have increased significantly and there's just no money - nothing at all, absolutely nothing at all."*
>
> Paediatric care coordinator

- **Lack of awareness and understanding of childhood dementia within the NDIS**: Survey respondents highlighted the lack of rare disease recognition in the NDIS, which results in delayed or inadequate support. *"Difficulties accessing care and support services due to lack of rare disease recognition"* was ranked as the greatest challenge in the care and support landscape (Figure 6).
- **Mismatch between funding and actual needs**: The system often fails to address the rapidly evolving and complex needs of children with childhood dementia. Equipment or services may arrive too late, sometimes even after the child has passed away.

> *"It's not fit for purpose... families with complex needs just aren't getting the rapid and timely service that they're needing."*
>
> Clinician researcher

> *"We do have the participants who pass and that's a really difficult thing when you're supporting a parent...if we know we didn't get their child everything their child deserved during that time frame, that healing process is so much more significant."*
>
> Support Coordination stakeholder

- **Inconsistent support plans:** Support plans vary significantly based on the case manager or specific diagnosis. This inconsistency often leads to inequities in care.
- **Limited access in regional, rural, and remote areas:** Families living in regional or remote areas have limited access to experienced NDIS-funded services, exacerbating inequities compared to those in metropolitan areas.

- **Siloing of health and NDIS services:** The separation between health services and the NDIS creates significant barriers to accessing comprehensive care and inhibits communication and coordination within the patient's care team.
- **High health and system literacy requirements:** Families need a high level of health and system literacy to advocate for the support they need, which disproportionately disadvantages CALD families.
- **Trauma caused by NDIS rejections:** Families report the emotional toll of repeatedly proving their child's deteriorating condition to receive NDIS support. Rejections from NDIS are often traumatic and leave families feeling unsupported.
- **Difficulty accessing essential services:** Some essential services, such as respite care, are hard to access under the current NDIS funding model. Additionally, NDIS funding cannot be used for psychological or wellbeing support for parents and carers, despite their need for such services.
- **Delays leading to private costs or prolonged hospital stays:** While waiting for NDIS applications to be processed, or when faced with rejection, families may need to cover the costs of private support[53]. Children may also spend more time in hospital than necessary, further exacerbating inequalities in access to care.

**Potential areas for action:**

- **Lack of awareness and understanding** of childhood dementia and other rare, progressive and degenerative conditions within the NDIS leads to **inconsistent support** for families with similar care needs.
- Cumbersome application and approval processes place unnecessary burdens on families and clinicians, **diverting focus from care** and limiting the flexibility needed to address the rapidly evolving needs of children with childhood dementia.
- **Geographic disparities in service availability and quality** create inequities in access to necessary support for families affected by childhood dementia.
- **Poor coordination and ineffective communication** between health and NDIS services hinder comprehensive care, leaving families without the cohesive support they need.
- **The creation of service-oriented guidelines for childhood dementia** could help support NDIS staff to better meet the needs of this cohort.

**Implementation considerations:**

- The NDIS eligibility criteria currently focus on capacity building and often do not cater to the life-limiting, progressive nature of conditions like childhood dementia. Investment needed to develop a deeper understanding of the issues in partnership with the NDIA and relevant advocacy organisations, to drive systemic changes to improve the process for families impacted by childhood dementia.

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[53] Nevin, SM. An In-Depth, Mixed Methods Study Investigating Quality of Life, Psychological and Healthcare Needs of Children with Dementia and Their Families: Interim Findings.; (personal communication, 2024).

# 8. Psychosocial support

Psychosocial support[54] needs of children with dementia and their families are explored in two sub-sections: **1)** Grief and loss, bereavement and counselling support, and **2)** Community support and networks.

## 8.1. Grief and loss, bereavement and counselling support

**Specialist grief and loss, bereavement and counselling support is essential for families impacted by childhood dementia, who reported experiencing chronic sorrow at watching their child regress sometimes over many, many years in the 'We don't fit' report[55].** This support **aims to address the significant emotional and psychological needs associated with caring for a child with a rare, progressive, and terminal condition.** It includes ongoing grief and loss counselling, programs to re-establish community connections, and opportunities for peer support. It often involves regular check-ins, newsletters, events, or tailored programs for different family members, aiming to form connections, provide therapeutic activities, and address isolation and/or loss of identity.

While some general supports exist, **families need tailored, ongoing psychosocial services during diagnosis through to bereavement and beyond, including support for siblings, regardless of where they live.**

### 8.1.1. Current challenges

Childhood dementia is a terminal diagnosis, and the **challenges around grief, loss and bereavement for families are significant**.

> *"When we're dealing with a significant clinical issue, which all of these conditions are, the huge burden of disease and the anxiety and the psychosocial issues just dwarf everything else. Because going into the community with a child with severe regression or with palliative needs is heartbreaking and it can destroy families."*
>
> Genetic metabolic specialist

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[54] Psychosocial support refers to support given to help meet the mental, emotional, social, and spiritual needs of patients and their families

[55] Nous Group, March 2023, 'We don't fit' The lived experience of families affected by childhood dementia and their interactions with care and support services report, accessible at: https://d1iap1m2kaw9nt.cloudfront.net/4296899de7646ce5d193bc96d8a49a31.pdf

Challenges noted by health professionals include:

- Although **childhood dementia is a terminal diagnosis,** it is generally **not possible to anticipate how long a child will live**, or **at what rate their disease will progress**. This leads to a **constant state of uncertainty and vigilance** for families.
- The **grief and loss** experienced by families is **complex and multifaceted**. Parents do not just grieve the **death of their child**, but they also **grieve the loss of the dreams they have** for their child, and **anticipatory grief begins well before the death** of their child:

> *"The grief starts the minute they recognise that something's not quite right."*
>
> Bereavement care and support stakeholder

- The underlying genetic causes of childhood dementia mean that sometimes multiple children within a family are affected, further compounding the psychosocial toll on families. These families will experience multiple bereavements and need to support their other affected children through this grief and loss.
- Clinical stakeholders reported that the child's **medical team often becomes a source of support and comfort for the families impacted by childhood dementia**. However, **this support network is typically lost after the death of the child**:

> *"What happens for families who have a child with a terminal condition is that their lives become smaller and more disconnected, because the focus becomes more on the care around the child who will eventually die… When that child dies, that family has lost all of their community connections [as] their connections have become the healthcare system."*
>
> Bereavement care and support stakeholder

- Families who do **seek psychological support** may find it **challenging to find specialist grief, loss and bereavement support**. They may have **more options in the private sector**, which **may be financially inaccessible for many families**:

> *"There are lots of wonderful psychologists out there, but….[some families] go to a psychologist, and are told, 'Oh, I don't do grief!'."*
>
> Advocacy group stakeholder

- There are **unique psychosocial impacts on siblings** of children with terminal conditions. They are often neglected or isolated as parents need to focus on managing the needs of the child with dementia. Siblings were also reported to grieve without formal support. Stakeholders indicated that while this is well known, **there is a lack of consistent support mechanisms**, and families are already overburdened in caring for a sick child:

> *"We know that siblings have much higher instances of mental health presentations into adulthood, and it's a developing field of research, but it shows issues stemming back to this de-prioritisation of their needs and their issues. If we're just talking about disability…something like 66% of adult siblings say they had depression in childhood if*

> *they had a brother or a sister with a disability; I can't imagine what level we're talking about if their brother or sister is getting a terminal diagnosis in childhood."*
>
> Psychosocial support stakeholder

- Psychosocial supports are **difficult to access in regional and remote areas.** Clinicians are often unaware of appropriate referral options for these families. Furthermore, parents and family members are often incredibly busy during their child's illness and are often unable to take time out for their own care and support needs:

> *"Families cope for as long as they can and then, suddenly, they stop coping."*
>
> CNC

### 8.1.2. What grief, loss, bereavement and counselling services currently exist?

While **no grief and loss services specific to childhood dementia were identified**, notable non-specialised examples raised by stakeholders include Very Special Kids,[56] Bear Cottage,[57] Ladybird Care Foundation,[58] and Feel the Magic.[59] Rare Voices Australia offer resources on mental health for rare diseases for people living with a rare disease and their carers and families,[60] but these are not specific to childhood dementia and they are not necessarily available on a whole of journey, national basis..

Some psychological services are provided through GPs via a mental health plan that will offer a Medicare rebate. There is also government-funded counselling offered through Carer Gateway. Both of these options are limited through a quota of sessions and do not provide any specialist service provision. It was also reported that some palliative care services employ grief counsellors.

There are various support models for siblings, parents, and extended family that aim to address the sense of isolation or loss of identity that family members may experience after the death of the child. However, their **capacity is often limited, and availability for those outside catchment areas is severely restricted or non-existent.**

Furthermore**, availability and awareness of these services are highly variable. Social workers, crucial for accessing support, are often not involved at diagnosis.**

High turnover within this workforce disrupts continuity of care and social workers may provide inconsistent support referrals or options. Clinicians also indicated they do not routinely suggest psychological support to families at the time of diagnosis.

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[56] Information available online: https://vsk.org.au/

[57] Information available online: https://bearcottage.schn.health.nsw.gov.au/home.php#/life-is-for-living

[58] Information available online: https://www.ladybirdcare.org.au/

[59] Information available online: https://feelthemagic.org.au/

[60] Information available online: https://rarevoices.org.au/wp-content/uploads/2024/02/DigitalMentalHealthFactsheet.pdf

### 8.1.3. What is needed?

There is a need for **specialised grief, loss and bereavement support services tailored to families that are impacted by childhood dementia**. These services should be **accessible during the diagnosis process, at diagnosis,** and **available throughout the disease trajectory** on an **ongoing basis**:

> *"The very best bereavement care begins well before the death of a child."*
>
> Bereavement care and support stakeholder

Cohesive support by therapists, counsellors, and/or psychologists with **consideration of cultural, spiritual and other support needs of the entire family unit** (inclusive of siblings, parents, guardians and the wider family network) is crucial. The psychosocial support **must extend after the death of the child or children.**

**Expanding the reach of existing services and developing new ones specifically for childhood dementia families** could significantly improve quality of life for affected children and their families. Additional provision of appropriate supports and services must also be given for the **compounded grief of families with multiple affected children. Comprehensive psychosocial support programs that include tailored counselling services are required.**

Stakeholders suggested modelling these programs on those used in paediatric cancer and other chronic illnesses:

> *"You've got cancer, you go to Redkite or they offer you all these other little services, but there's nothing really for childhood dementia or some of these rare conditions. So, having any sort of model that could help facilitate that and help families feel that they're not alone, I think is powerful."*
>
> Clinician researcher

Some families may need specialised psychosocial services while others may benefit from ongoing counselling support or support from within their social communities. **Early intervention and ongoing support during the diagnosis process is essential.**

> *"[The] whole family needs to be linked with emotional support immediately – it needs to be part of the process even if families don't need it immediately so that families can access this before it gets to a crisis point – we need to establish that relationship early."*
>
> Researcher

**Potential areas for action:**

- Families face anticipatory grief from the time of diagnosis of childhood dementia, yet there is insufficient recognition or structured support for their ongoing psychosocial needs throughout the disease journey.

- Children with childhood dementia, their siblings, and the extended family network have unique psychosocial and counselling needs that are not adequately addressed by current services.

**Implementation considerations:**

- Investment in workforce training to provide trauma-informed care, including upskilling healthcare professionals in grief management and psychosocial care, can help ensure that grief and loss support is embedded across the existing healthcare settings.
- A system-wide expansion of psychosocial support services will require collaboration between healthcare providers, schools, and community organisations to address the unique needs of the entire family, including siblings and extended family members.
- To ensure equitable access to psychosocial support, particularly for families in regional, rural or remote areas, it may be pertinent to explore telehealth service models and community-based programs.

## 8.2. Community support and networks

Community support and networks encompass both **formal and informal peer support models** providing **psychosocial and practical assistance for families** impacted by childhood dementia. These include structured **support groups, online forums, social media communities, and mentorship programs.** Peer support also **extends to healthcare professionals, to promote greater psychological health and safety among staff.** Tailored support services for both families and healthcare professionals are needed to improve outcomes and support families in coping with the burden of care.

### 8.2.1. Current challenges

**Experienced by children and families:** As described in section 8.1 , stakeholders emphasised the challenges that families face in caring for a child with a childhood dementia condition, and **the social isolation and loneliness that families experience:**

> *"Most of the families are nuclear families: families are either not available locally or they are spread out across the country or internationally, because there are a lot of immigrant populations. So, they don't have the support group that they need. I find it is a big challenge."*
>
> Paediatric neurologist

Additional challenges relating to community support and networks for families include:

- Some families can find **connecting with a peer family at a more advanced disease stage** a **daunting look into the future** that takes a significant toll. Furthermore, families can find **the experience of sharing or recounting information** to be **re-traumatising**.
- Families supporting a child with childhood dementia are very **time poor**, and were reported to **de-prioritise their own wellbeing over the needs of their sick child**, meaning they may report **not having time to engage with support opportunities.**
- **Uptake of opportunities for peer and community support can be variable.**
- Only five of 43 health professionals surveyed (11.7%) rated 'links with community groups that include members with lived experience' in their top 3 priority opportunities for improving the care and support landscape, with only one respondent rating it as a top priority (Figure 1). However, this would need to be reviewed with the lived experience cohort to determine how important it would be for them.
- It was noted that **some families want to avoid the perceived 'pressure' of participating in formalised peer support programs**, and that these families **might opt for more informal options** such as Facebook groups or other online chat-based opportunities.

**Experienced by healthcare professionals:** Healthcare professionals are often challenged as there may not be treatment options available for the affected children. A child's rapid decline can also be traumatic for the healthcare professionals involved in the care delivery. It is also **well understood that staff are time poor, and they may not prioritise their own health and wellbeing to cope with potential trauma at work.** The SickKids' Peer Support & Trauma Response Program in Canada is an example of a service that aims to promote greater psychological health and safety among healthcare professionals who are caring for sick children.[61]

### 8.2.2. What community support and networks exist currently?

**For children and families: There are no formal support opportunities available to all affected children and families in Australia.** While some rare diseases have established support groups, none are tailored to childhood dementia.

**Some examples were provided by stakeholders** of formal and informal peer support programs with a broader remit. For example, Bear Cottage[62] and Kiind[63] offer spaces for families to connect. The Carer Gateway[64] provides online and phone-based generalised supports for primary carers and young carers. These services are also tendered to different

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[61] https://www.sickkids.ca/en/learning/peer-support-trauma-response-program/

[62] Information available online: https://bearcottage.schn.health.nsw.gov.au/home.php#/life-is-for-living

[63] Information available online: https://www.kiind.com.au/

[64] Information available online: https://www.carergateway.gov.au/

providers in different locations across Australia. Siblings Australia[65] and Little Dreamers[66] offer programs for siblings, although awareness is limited, and stakeholders indicated that these are not sustainably funded. **Informal support avenues** include social media pages and online forums often established by parents looking to fill the gaps in knowledge and supports, whilst caring for their children and families. The common features of models considered best practice by stakeholders were **safe, welcoming, flexible environments that allowed families to have their need for support met at any stage of their journey**.

One stakeholder discussed emerging work in **compassionate communities**,[67] which are defined as *"naturally occurring networks of support in neighbourhoods and communities, surrounding those experiencing death, dying, caregiving, loss and bereavement."*[68] However, it was noted that implementation of this in Australia is still in the early stages, and most notably in the paediatric palliative care sector.

> *"When a child has a complex medical condition, they spend 5% of their life connected to the health system. 95% [of their time] is or should be within their homes and communities. The very best outcome for child in paediatric palliative care is keeping them connected to their natural social [world]. Whether that's school, friends, families, neighbourhoods, extracurricular activities… One of the opportunities is to start from the point of where do children and families live, and what can we do to enable their best lives where they live?"*
>
> Grief and bereavement stakeholder

**For healthcare professionals: There is no formal clinical peer support group specifically for childhood dementia healthcare professionals.**

Clinicians involved in MDTs or clinical networks such as the Undiagnosed Diseases Network of Australia[69], may share their feelings and seek support to reduce stress and find resilience.

> *"Sometimes, debriefing after challenging situations does help… We are always caring for patients and families, but sometimes we neglect our own mental wellbeing as well."*
>
> Metabolic geneticist

### 8.2.3. What is needed?

**For children and families: There is a need for tailored support groups specific to childhood dementia for families.** Sensitivity to families' **grief processes and mental wellbeing** must be considered when developing support programs and when they are recommended.

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[65] Information available online: https://siblingsaustralia.org.au/

[66] Information available online: https://www.littledreamers.org.au/

[67] Information available online: https://compassionatecommunities.au/

[68] Abel, J, Kellehear, A and Karapliagou, A, 'Palliative care – the new essentials', Annals of Palliative Medicine 7(Suppl 2) (2018), available online at: https://doi.org/10.21037/apm.2018.03.04

[69] Information available online: https://www.udnaus.org/

Bereavement care stakeholders **emphasised the value that peer support services have** for grieving family members, and the **importance of connection with peers who have lived experience**:

> *"…our founder spoke to a bereaved father whose adult son had died very suddenly about five months ago. This father said that without his peer—another bereaved father—he doesn't think he'd be in the world anymore; the only thing that kept him connected was the solidarity of someone who truly understands the pain and is able to witness it, and you can't do that if you haven't lived the experience."*
>
> Bereavement care stakeholder

A balance between **formal and informal support avenues** is needed to **cater to diverse individual preferences**. While not tailored to childhood dementia, **improved awareness of existing support services could help to provide families with more support options than they currently have**, notably in areas such as sibling support. **A central repository of information and resources on childhood dementia** could also provide practical guidance for families.

**For healthcare professionals:** There is a **need to provide avenues for clinicians to connect, share information, and seek support from one another**. This would also have flow-on effects including more opportunities for healthcare professional awareness and training (see Chapter 3) and could also lead to better outcomes for affected children.

**Potential areas for action:**

- Families of children with childhood dementia typically experience social isolation during the child's illness and after the child's death.
- There is a lack of tailored support programs that address the unique emotional and psychological needs of siblings of children with childhood dementia.
- Barriers to participation in formal peer support groups (not specific to childhood dementia) such as stigma, accessibility, and personal preferences should be addressed.
- Clinicians may lack the necessary structures to act as champions for childhood dementia care amongst their peers, limiting the peer-to-peer sharing of information and best practices within the medical community.

**Implementation considerations:**

- Understanding factors such as accessibility, cultural differences, and resource availability could help improve the uptake of peer support groups by families across diverse communities. The Department publishes funded mental health programs and initiatives.[70]

- Collaboration between people with lived experience, healthcare providers, educational institutions, and community organisations may be required to design and implement sibling support programs that address the unique needs of siblings of children with childhood dementia.
- Collaboration and co-design with clinicians are advisable to create peer-to-peer trauma support and information sharing mechanisms that will be most accessible and useful for healthcare professionals.

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[70] https://www.health.gov.au/topics/mental-health-and-suicide-prevention/what-were-doing-about-mental-health

# 9. Education support for children

**Education support** for children with childhood dementia **involves ensuring continued access to appropriate schooling and educational resources**. This support may be provided in various settings, including **mainstream government or independent schools with tailored support arrangements, dedicated special education schools with expertise in complex needs, home or distance schooling, and hospital schools**. Each setting should aim to accommodate the unique educational requirements of these children.

Many children with childhood dementia **face inadequate access to specialised, inclusive education support** due to resource shortages, lack of training, and poor coordination between schools, healthcare providers, and families, leaving parents to act as intermediaries in the management of their child's education, often without support.

## 9.1. Current challenges

Children with childhood dementia **face distinct challenges in educational settings**, even compared to other students who require modified schooling arrangements. Given the **progressive nature of the condition** and **the associated behavioural symptoms** that can occur, these children **need highly specialised, tailored, and adaptable educational approaches** to effectively support their participation and learning. **Schools generally lack the resources and specialist training necessary** to effectively support children and their families. Additionally, the **engagement between schools and other members of a child's care and support team is often inconsistent**, relying heavily on **parents to bridge the communication gap** and advocate for their child's needs.

Other areas of concern identified by health professionals were:

- Despite a mandate to support students regardless of disability or illness, it was noted that there is a **reluctance from mainstream schools to accept this cohort** due to the **stigma of paediatric death**.
- Stakeholders highlighted that **standard behaviour modification strategies in schools are often not appropriate for children with childhood dementia**, leading to frustration for both staff and students, and, in some cases, the exclusion of these children from social environments with their peers.

## 9.2. What education support exists currently?

Families can choose for their child with childhood dementia to attend a mainstream school or a special education school. Some stakeholders with lived experience also reported homeschooling their children. **Public schools are required to provide support to all students, regardless of disability or illness**:

> *"The most disabled child is able to go to a mainstream setting, and we're required to support them in that setting if that's the parent's choice…equally, a parent could choose that they want their child in a more specialised setting."*
>
> Education stakeholder

During consultations, it was noted that some schools, particularly **special education schools, offer inclusive environments that cater to the evolving needs of children with childhood dementia by adjusting educational strategies as the disease progresses.** These schools were regarded as having more expertise in providing necessary support, especially as children's needs become more complex. **However, the level of support varies, and not all schools are fully equipped to manage the changing requirements of children with childhood dementia.**

> *"The public mainstream system was good up to a point. I had an accommodating large school who were able to throw in additional funding to allow my daughter to get the support that she needed. It became untenable for her to be integrated because her disease progressed…so, we made the decision to move her because she was socially isolated, but the school had been very good at accommodating up until that point. We're at a severe to moderate intellectual disability school now and they're incredible and incredibly accommodating."*
>
> Lived experience stakeholder

There is some, inconsistent, engagement **between schools and healthcare services**, such as **palliative care teams**. The engagement was noted to be ad-hoc and reactive, often **driven by specific incidents or needs**. Consistent with other findings about parents as project managers of their child's condition[71], this support was noted to **heavily rely on parental coordination**.

> *"We have heard some very contrasting stories of different levels of support in school communities and how much that's impacted psychological wellbeing in a really ongoing way. There are the really good stories that we hear where the hospital team got in touch*

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[71] Nous Group 2023. 'We don't fit': The lived experience of families affected by childhood dementia and their interactions with care and support services report

*with the school and talked them through what to expect and some of the needs that the families might have, and it was a collaborative effort in supporting that family really holistically."*

Researcher

*"It's not only about the partnership between the school and the family, but also those other stakeholders that are wrapping around that family to support them in that other 80% of the week."*

Education stakeholder

## 9.3. What is needed?

**Children with childhood dementia require inclusive and appropriate educational opportunities to facilitate essential learning and social experiences.**

Stakeholders noted that these opportunities also offer **crucial respite for parents** and families. Schools must create **inclusive learning environments** staffed by **professionals trained in understanding and managing the specific challenges** associated with childhood dementia. As reported by clinicians, lived experience stakeholders, and education stakeholders, this includes:

- **Comprehensive awareness of childhood dementia conditions and the unique challenges of children with childhood dementia and their families:** Many schools and educators, especially in mainstream settings, lack the specialist training needed to effectively support children with progressive conditions like childhood dementia. Stakeholders identified a clear need for additional resources and specialised training for educators.
- **Provision of appropriate education for all children based on their disease progression and capabilities:** As the condition progresses, children require more nuanced support to ensure their continued participation in education. There is a notable lack of support for adjusted schooling arrangements, and a small number of stakeholders have prioritised this as an opportunity for improvement.
- **Specialised management of behavioural symptoms:** School staff require better understanding and management of behavioural symptoms associated with childhood dementia. This includes training to ensure appropriate responses in an educational setting, which is crucial to the child's overall wellbeing.
- **Effective coordination and two-way communication between education staff, healthcare providers, and parents:** A lack of coordinated engagement between schools and a child's healthcare team remains a significant gap. Communication often relies on

parents as intermediaries, placing undue burden on families to manage interactions between healthcare and education systems.

> *"It's really around what do we need to equip our schools and support our teaching staff to be able to support the kids, because they spend roughly—if they are in school full time—about 18 to 20% of their week at school."*
>
> Education stakeholder

- **Need for more special education places:** Stakeholders highlighted the need for more available places in special education schools, allowing families to choose the most appropriate learning environment for their child. Small community schools may lack the resources or budget to provide the necessary support, particularly in regional and remote areas, exacerbating inequities.
- **Variation in school support:** There is reported variation in how different schools provide support. While some schools are more equipped and proactive in managing the educational and health needs of these children, others fall short due to limited resources or knowledge, particularly in small or rural schools.

Further consultation is required to fully understand the gaps that exist across services providing education for children with childhood dementia.

**Potential areas for action:**

- Schools, particularly mainstream settings, often lack the specialised training and understanding needed to support children with childhood dementia, leading to inadequate educational experiences.
- Access to specialised education support varies across schools, with some, particularly in regional and rural areas, unable to provide the necessary resources or tailored learning environments for these children.
- For those families who choose to homeschool children with childhood dementia, they have inadequate resources, guidance, and support.
- Coordination between schools and healthcare providers is inconsistent, with parents often having to manage communication and advocate for their child's needs, adding to their burden. Integrating care coordinators to work closely with educators and school principals could improve communication and reduce this burden.
- There is a shortage of places in special education schools, which limits families' options for appropriate educational settings, particularly in rural and remote areas.
- Standard behaviour modification strategies in schools are often not suitable for children with childhood dementia, leading to frustration, exclusion, and additional challenges in managing the condition.

- Families in rural and remote areas face even greater challenges due to the lack of local resources, specialised training, and support services, resulting in inequities in educational access and quality.

**Implementation considerations:**

- Schools, especially in rural and remote areas, may face budget limitations and staffing shortages that hinder the adoption of new programs or specialised support. These constraints can affect both mainstream and special education schools, limiting access to tailored learning environments for children with childhood dementia.
- Mainstream schools may resist implementing changes due to a lack of understanding or stigma associated with childhood dementia, particularly related to paediatric death. Overcoming these cultural barriers and shifting attitudes will be essential to create more inclusive environments.
- Effective collaboration between schools, healthcare providers, and families will require clear communication channels and protocols. Without structured coordination, the burden may continue to fall on parents to manage these interactions, weakening the efficacy of solutions. Integration between education and health sectors will be critical but may face bureaucratic hurdles.
- Delays in diagnosis due to long turnaround times for genetic and medical testing could impact timely access to appropriate educational support.
- Educational and healthcare policies vary between states or regions, complicating a unified approach.

# 10. Palliative care

**Paediatric palliative care** is a specialised approach focused on supporting children with life-limiting conditions and their families. It aims to **improve quality of life through early intervention, comprehensive care coordination, and effective symptom management**. Delivered by MDTs, these services provide holistic support addressing the needs of both the child and their family. It differs from hospice and respite care, though closely related (discussed further in Chapter 11).

Children with childhood dementia face **inconsistent access to paediatric palliative care**, often delayed due to misconceptions that it only provides end-of-life care. **Capacity issues** in palliative care services **exacerbate delays, limiting support for families**.

## 10.1. Current challenges

A key challenge in paediatric palliative care is **inconsistent access to specialised services from diagnosis through to bereavement.** Palliative care workers stress that **timely referrals** from primary care providers and specialists**,** ideally soon after diagnosis, **greatly improve quality of life** for both child and family, but delays are common.

Families reported varying access to palliative care services,[72] misunderstandings and **negative perceptions about palliative care** are often seen as only for end-of-life that contribute **to delayed referrals**. Stakeholders frequently highlighted that early access to palliative care, even immediately after diagnosis, has a significantly positive impact on the children with childhood dementia and their families.

Another challenge is the **lack of coordination between palliative care and other support services** (e.g. medical, community, and psychosocial services). Stakeholders stressed the need for **seamless integration into a child's broader care plan**, but families often **experience fragmented services**, especially during their transition to adult palliative care. Differences between paediatric and adult palliative care systems exacerbate this issue. Growing capacity concerns within paediatric palliative care services, coupled with family worries that palliative care may negatively impact their NDIS funding, further complicates access and care decisions.

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[72] Childhood Dementia Initiative. Childhood Dementia: Family experiences of health systems in New South Wales report, March 2024. Available online at; https://www.childhooddementia.org/news/nswhealth

Survey respondents ranked **"Early access to palliative care and respite services" was the sixth biggest challenge** reported in the current care and support landscape for childhood dementia (Figure 6).

*"Paediatric palliative care is really about supporting a family as they live, and then some of our services are to do with death and after death support."*

Palliative care stakeholder

*"I think some families think that once you're referring them to palliative care that you're kind of giving up on them."*

Paediatric neurologist

## 10.2. What palliative care services exist currently?

Palliative care services in Australia vary significantly by location, with hospital-based and statewide programs offering different levels of support.[73] Some services, like **the Paediatric Palliative Care Service at Queensland Children's Hospital,**[74] provide comprehensive care, including telehealth for regional/rural areas, but these are not tailored for childhood dementia and are unevenly available across the country.

In many **rural areas**, adult services often **fill the gap** due to a lack of specialised paediatric care. Though some **paediatric services** offer training to **adult palliative care providers** to help bridge this gap, continuity of care is still disrupted for children during stable periods, leaving families without consistent support. Despite these efforts, the overall palliative care landscape for children with childhood dementia remains fragmented, with limited access and inconsistent service provision.

*"When we're looking at children it's about that quality of life care, and it can go over many, many years into young adults. It's that multidisciplinary support that can be provided with symptom management, social activities, grief and bereavement support and things like that."*

Palliative Care Australia

## 10.3. What is needed?

The current paediatric palliative care landscape has several significant gaps as identified by healthcare professional stakeholders consulted for this project:

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[73] Some include in-home care, inpatient beds, medication management, child therapies, and sibling support.

[74] Information available online at; https://www.childrens.health.qld.gov.au/services/palliative-care/palliative-care-queensland-childrens-hospital#:~:text=The%20Paediatric%20Palliative%20Care%20Service,support%20to%20families%2C%20including%20siblings.

- **Late referrals often stem from stigma, fear, and misconceptions about palliative care among both families and healthcare professionals.** There is a pressing need for widespread education and awareness initiatives to combat this.
- **Access is fragmented across Australia**, with some states lacking dedicated paediatric palliative care services, for example Tasmania.
- There is a **lack of specialised paediatric palliative care services in regional areas,** further exacerbating inequities for families outside of major cities.
- **Inconsistent transition processes from paediatric to adult palliative care services**, where required, create additional challenges and may negatively impact access to much needed services.
- **Capacity issues** in paediatric palliative care services are a growing concern among workers consulted.
- There is **ongoing concern among families around the impact of palliative care treatment on access to NDIS support and funding.**

> *"It's a bit of a double-edged sword…we could continue to advocate for referrals as early as possible and then worsen [our capacity issues]."*
>
> Palliative care paediatrician

**Potential areas for action:**

- Referrals to paediatric palliative care services are often delayed, and the impact of awareness raising campaigns among primary care providers and specialists on improving referral timing and access needs further exploration.
- Stigma and misconceptions persist around palliative care, particularly the belief that it is solely for end-of-life care. Education initiatives to address this issue and highlight the broader benefits of palliative care are needed.
- Integration between paediatric palliative care, community services, and adult palliative care is weak, requiring stronger collaborations to improve accessibility and the effectiveness of care.

**Implementation considerations:**

- Palliative care in Australia is jointly funded by state/territory and Commonwealth governments. States and territories primarily fund services in hospitals, hospices, and community settings, including in-home care. The Commonwealth supports national consistency, policy development, education, research, and subsidises some services, consultations, and medications through the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS).

- There is a shortage of healthcare professionals, particularly in regional and rural areas. This shortage could limit the effectiveness of awareness campaigns, early referrals, and the capacity of paediatric palliative care services to meet increased demand.
- The persistent stigma surrounding palliative care, including misconceptions about it being solely for end-of-life care, is deeply ingrained. Changing attitudes among healthcare professionals and the public may require long-term, systemic efforts that need to go beyond education initiatives.
- Implementing changes in referral timing or service integration may face regulatory hurdles. Policies governing palliative care and healthcare in general are complex, and aligning these with the necessary changes may be challenging.

# 11. Hospice and respite care

**Respite and hospice care are mostly state-based services** accessed through medical referrals and **focused on patient wellbeing** rather than imposing a clinical environment. These services often prioritise imminent end-of-life patients.

- **Respite care** offers short-term relief to primary caregivers, allowing them to rest while ensuring the patient continues to receive care, either in the patient's home or in a specialised facility.
- **Hospice care** focuses on providing comfort and support to those nearing end-of-life, prioritising quality of life and pain management over curative treatments.

While distinct from palliative care, as outlined in Chapter 8, there is significant overlap between all three services in the context of childhood dementia.

Children with childhood dementia face significant challenges **in accessing equitable and appropriate hospice and respite services**, with limited capacity, prioritisation for end-of-life care, and difficulties accommodating behavioural needs, leaving families without the consistent support they need throughout the disease trajectory.

## 11.1. Current challenges

**Access to appropriate hospice and respite services that meet the specific needs of children with childhood dementia is inequitable, posing significant challenges for families.** Children with childhood dementia can remain **stable for extended periods** or experience slow, prolonged deterioration over many years. As a result, respite care is needed throughout the disease trajectory, not just at the end-of-life, to give parents and families the opportunity to focus on their own health and **wellbeing.**[75]

Hospice and respite care must be tailored to **the unique needs of children with childhood dementia, particularly in managing behavioural symptoms common to some conditions, such as Sanfillipo syndrome.**[76] Many respite facilities report difficulties in accommodating these behavioural needs, often due to limitations in capacity and capability. These challenges highlight the need for services that can provide comprehensive care and adapt to the specific demands of these children and their families.

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[75] Nevin, S, McGill, BC, Kelada, L, Hilton, G, Maack, M, Elvidge, KL, Farrar, MA, Gareth Baynam, Katz, NT, Donovan, L, Grattan, S, Signorelli, C, Bhattacharya, K, Nunn, K & Wakefield, CE 2023, 'The psychosocial impact of childhood dementia on children and their parents: a systematic review', Orphanet Journal of Rare Diseases, vol. 18, BioMed Central, no. 1.

[76] Childhood Dementia Initiative. Childhood Dementia: The case for urgent action, November 2020. Available online at; *https://d1iap1m2kaw9nt.cloudfront.net/8c8d53b3f3f629c530cad2df51ef1f74.pdf*

## 11.2. What hospice and respite care services exist currently?

Across NSW, Victoria and Queensland, health professionals that were consulted noted **five well-regarded services that offer end-of-life and/or respite care as part of a holistic paediatric palliative care service**. These include Bear Cottage[77], the Adolescent and Young Adult Hospice (AYAH)[78], Allowah[79], Summer Hill House[80], Very Special Kids (VSK)[81] and Hummingbird House[82]. In addition, the Western Australian Government has announced plans to build the state's first children's hospice.[83]

Some services, such as Bear Cottage, involve parents with lived experience in decision-making processes to enhance their offerings. **Many also provide structured peer support and grief and bereavement programs.** However, despite the existence of these services, hospice and respite care providers reported that their capacity is often under strain, leaving families unable to access respite care when needed. This is particularly true on weekends, when demand for respite care is high, and services may lack the necessary resources to accommodate children with behavioural symptoms.

*"We say to the family at that time that they're part of [our] family forever, or for as long as they want to be."*

Bereavement care and support stakeholder

*"It's just not in [our] DNA to ever say no to anybody. [We] do everything we can for everyone, but… the facilities that we have just are not safe [enough for a child with behavioural symptoms]."*

Palliative care provider

## 11.3. What is needed?

Despite the presence of high-quality services, significant gaps in hospice and respite care for childhood dementia remain. Healthcare professionals noted several areas where improvements are needed:

- **Limited capacity**: The number of available beds at each facility is often restricted, which limits access for patients with childhood dementia, particularly on weekends.

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[77] Information available online at; https://bearcottage.schn.health.nsw.gov.au/home.php#/life-is-for-living

[78] Information available online at; https://www.hinfra.health.nsw.gov.au/projects/project-search/adolescent-and-young-adult-hospice-(ayah)

[79] Information available online at; https://www.allowah.org.au/

[80] Information available online at; https://gonest.com.au/property/21062019-summer-hill-house-short-term-accommodation-and-respite-services-summer-hill-2130

[81] Information available online at; https://vsk.org.au/?gad_source=1&gclid=Cj0KCQjw9Km3BhDjARIsAGUb4nw42VDL6CsaNSZr4qu8Ydc7i31M2hT07bdJY8sUTlcHlyI5rWCS-fwaArJ1EALw_wcB

[82] Information available online at; https://hummingbirdhouse.org.au/

[83] Information available online at; https://www.cahs.health.wa.gov.au/Our-services/Childrens-Hospice-Project

- **Prioritisation based on end-of-life**: Due to capacity constraints, services often prioritise patients who are nearing the end-of-life, which excludes many patients with childhood dementia who may be in a stable phase but still require care.
- **Behavioural challenges**: Many facilities struggle to accommodate children with behavioural symptoms related to childhood dementia, who require intensive one-to-one support and constant supervision.
- **Geographic gaps**: There is a lack of hospice and respite care services outside of Victoria, New South Wales and Queensland, which particularly affects families living outside these states and in regional, rural, or remote areas.

> *"There are three [dedicated] children's hospices in Australia and not 13… by population equivalency with the UK, there should be about 12 or 13 in Australia instead of three."*
>
> Grief and bereavement stakeholder

**Potential areas for action:**

- The current number of hospice and respite beds and facilities in Australia is insufficient to meet the needs of children with childhood dementia, particularly those not in an end-of-life phase, and access on weekends is especially limited.
- Facilities struggle to accommodate children with challenging behavioural symptoms, lacking the resources, specialised staff training, and adaptations necessary to ensure safe and suitable care.
- Families outside Victoria, NSW and Queensland as well as those living in regional/rural and remote areas face significant accessibility gaps due to the limited availability of hospice and respite care services.

**Implementation considerations:**

- Hospice and respite care are state-based services, meaning funding and resource allocation differ between states and territories. Any solution will need to navigate the variability in funding models and ensure sufficient financial support for expanding capacity and services.
- Some State governments are looking at investing in facilities to support caring for children that have behaviours of concern which could be leveraged to support families with children that have childhood dementia.

# 12. Research

Children with dementia **face significant challenges in accessing clinical trials**, which often provide the **only opportunity to receive potential treatments that could slow disease progression or improve quality of life.** Without sufficient access to these trials, **children are left without options for disease-modifying therapies, and research advancements in childhood dementia remain limited.** Clinical trials are also critical for future treatment development, benefiting the wider patient community.

Beyond clinical trials, **research gaps exist in psychosocial studies**, which address the emotional and social impacts on families, **and in pre-clinical research** focused on the underlying biology of childhood dementia and the identification and development of new innovative treatments. Greater support and coordination, such as through the Childhood Dementia Research Alliance,[84] is needed to accelerate research across all areas of the disease.

> *"We don't know how to do anything to prevent the progression of these diseases once they start. We don't really understand why they start and particularly for these childhood dementia diseases where they are monogenic and fully penetrant, we need therapies that are going to do something. We need to have increased research going on, trying to find ways that we can actually do something to lessen the burden of these conditions."*
>
> *Clinician researcher*

## 12.1. Current challenges

Stakeholders identified seven key challenges for childhood dementia clinical trials and research. These are presented in Figure 7.

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[84] Information available online at; https://www.childhooddementia.org/join-us/for-researchers

## Figure 7: Challenges for childhood dementia research

### Limited access to clinical trials

**Static number of trials:** Since the first clinical trials for childhood dementia were initiated in 2008, there has been minimal growth, with only 1 to 2 trials initiated annually on average[85]. Historic underfunding of childhood dementia research has significantly hindered progress[86].

**Inequality in access:** Fewer than 2% of children with dementia have the opportunity to join a clinical trial, in contrast to 100% of children with cancer in Australia, who have access to clinical trials or experimental treatments[87]. By comparison, as of December 2023, 100% of children with cancer in Australia have an opportunity to participate in a clinical trial or experimental treatment via a precision medicine platform[88].

**Strict eligibility criteria:** Clinical trials often have narrow recruitment criteria, including age cutoffs, and many children with childhood dementia miss these windows. Diagnostic delays, often exceeding two years (as discussed in chapter 5), further reduce the chances of participation.

**Perception of palliative care exclusion:** There is a perception among healthcare professionals that children in palliative care may not qualify for clinical trials. While there was no evidence found that this is the case, clinical trials do have strict exclusion criteria that varying by trial.

**Trial halts and failures:** In addition to fewer clinical trials being initiated, evidence was found of multiple trials halting or failing to initiate at a late stage due to regulatory and/or commercial barriers[89].

### Psychosocial research gaps

**Limited psychosocial research:** There is a significant gap in research on the psychosocial impact of childhood dementia on families and carers. This gap has delayed the development of multidisciplinary healthcare approaches and evidence-based psychosocial support systems.

### Insufficient infrastructure and resources

**Funding gaps:** Healthcare professionals outlined insufficient funding for infrastructure and specialist workforce to attract and conduct trials.

**Limited trial infrastructure:** Stakeholders report a shortage of dedicated infrastructure for trials in children's hospitals and a need to consolidate expertise across paediatric trial centres.

**Unattractive to overseas pharmaceutical companies** due to lack of clinical trial readiness/ infrastructure / expertise / data.

### Geographic and financial barriers

**Travel and logistical challenges:** Families, especially from regional or remote areas, face significant logistical and financial challenges in accessing trial sites, which are often based in capital cities. Large geographic distances between capital city based clinical trial facilities and clinical expertise means travel for the patient and families may be prohibitive due to the time commitment involved and the care needs of the wider family.

**Inconsistent travel support:** While some health departments provide travel assistance, support is inconsistent across jurisdictions. For example, the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) in NSW will cover the cost of travel for non-commercial clinical trials only[90], while the Victorian Patient Transport Assistance Scheme (VPTAS) will not cover transport costs for clinical trials at all[91].

### Awareness and engagement among healthcare professionals

**Low awareness:** Healthcare professionals have reported low awareness of ongoing trials for childhood dementia. Often, they learn about available trials from parents, who find them through online or social media platforms.

**Limited involvement:** Very few healthcare professionals are actively engaged in or facilitating research on childhood dementia within their organisations. The survey results also highlight that very few health professionals are engaging with or facilitating childhood dementia research in their own organisations (Figure 5).

### Lack of a comprehensive patient registry

**Scarce and fragmented registries:** Only a few childhood dementia conditions have dedicated patient registries, which are often underfunded.

**Absence of comprehensive data:** The lack of a well-maintained, comprehensive registry for childhood dementia in Australia limits understanding of the conditions and hampers research efforts by failing to capture crucial data on treatment outcomes, patient demographics, and the number of children affected.

### Disparate and siloed research

**Fragmented research focus:** Research into childhood dementia is often siloed, with individual disorders studied in isolation. This limits the potential for identifying common treatment pathways and developing platforms for targeted precision medicine approaches[92].

Source: Developed by HealthConsult based on stakeholder consultations, survey responses and literature review. The following articles are cited under relevant key challenges: Static number of trials[85], trial funding[86], inequality in access,[87] precision medicine platform[88], trial halts and failures[89], inconsistent travel support[90,91] and fragmented research focus[92].

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[85] Childhood Dementia Initiative. Childhood Dementia Global Clinical Trial Landscape Analysis.; March 2024. Available online at; www.childhooddementia.org/getasset/LZPRVX

[86] Childhood Dementia Initiative. Australian Childhood Dementia Research Funding Report, March 2024. Available online at; http://www.childhooddementia.org/getasset/2WX39O

[87] Childhood Dementia Initiative. State of Childhood Dementia in Australia Report; 2024. Available online at; https://d1iap1m2kaw9nt.cloudfront.net/2f9e6e3e0c96123950b620303dd1a6c6.pdf

[88] Precision medicine is now available to all children with cancer in Australia. Zero Childhood Cancer. 20 Dec 2023. https://www.zerochildhoodcancer..org.au/blog/precision-medicine-now-available-to-all-children-with-cancer-in-australia

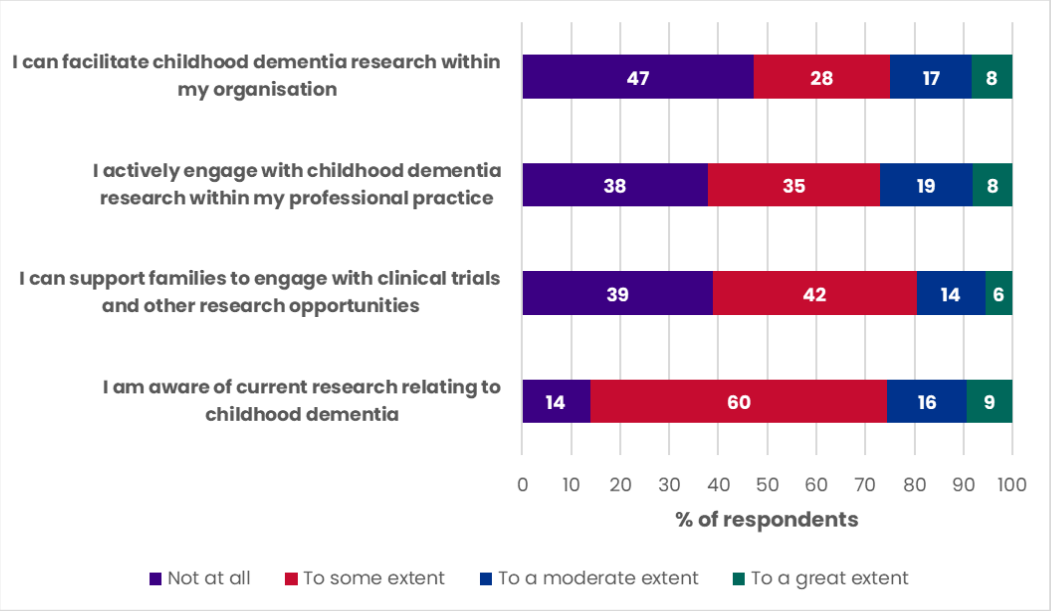
[89] Childhood Dementia Initiative. Childhood Dementia Global Clinical Trial Landscape Analysis.; March 2024. Available online at; www.childhooddementia.org/getasset/LZPRVX

[90] Information available online at; https://www.iptaas.health.nsw.gov.au/__data/assets/pdf_file/0006/920499/IPTAAS_Non-commercial-Clinical-Trial-Fact-Sheet.pdf

[91] Information available online at; https://www.health.vic.gov.au/rural-health/victorian-patient-transport-assistance-scheme-vptas

[92] Childhood Dementia Initiative. Australian Childhood Dementia Research Funding Report, March 2024. Available online at; http://www.childhooddementia.org/getasset/2WX39O

Figure 8: Awareness and involvement of healthcare professionals in childhood dementia research



Source: HealthConsult (2024) Healthcare professionals survey developed for CDI (n=43 answers)

> *"We believe that by maximising the number of clinical trials, Australians will have way more access to improve their [clinician] education, awareness and their ability to make a difference than anything else we could possibly do"*
>
> *Peak body representative*

## 12.2. What clinical trials research exists currently?

**The Childhood Dementia Global Clinical Trial Landscape Analysis** report[93] revealed that between 2000 and 2023, **only 29 of 386 global interventional clinical trials**[94] **for childhood dementia included Australian sites.**[95] As of December 2023, **only two trials were actively recruiting Australia for childhood dementia,** compared to 54 worldwide.[21]

With a lack of nationally available trials, some families have resorted to travelling internationally at great expense and personal social cost, with no guarantee of continued access to the treatment once the trial has ended. This is an unsustainable and inaccessible option for many. Additionally, as noted by a stakeholder, this diverts expertise and knowledge outside of Australia, weakening local capabilities.

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[93] Childhood Dementia Initiative, Childhood Dementia Global Clinical Trial Landscape Analysis, published March 2024. Available online at www.childhooddementia.org/getasset/LZPRVX

[94] listed on clinicaltrials.gov

[95] Childhood Dementia Initiative, Childhood Dementia Global Clinical Trial Landscape Analysis, published March 2024. Available online at www.childhooddementia.org/getasset/LZPRVX

In addition to the very limited clinical trials available for the childhood dementia cohort, **there are no centralised childhood dementia specific research or clinical trial networks that were identified by stakeholders**.

While global resources like clinicaltrials.gov exist, health professionals find them difficult to navigate and include inconsistent trial information (e.g. about inclusion/exclusion criteria, trial contact details etc). Similarly, the Australia New Zealand Clinical Trials Registry (ANZCTR),[96] despite being designed to provide localised clinical trial information and resources to patients, families and clinicians, it was not acknowledged or utilised by stakeholders that were consulted.

## 12.3. What psychosocial and laboratory-based research exists currently?

Currently, psychosocial and laboratory-based research in childhood dementia is limited but ongoing. **In collaboration with CDI, the University of New South Wales (UNSW) is leading a large-scale mixed-methods study focused on understanding quality of life, psychological, and healthcare needs of children with dementia, caregivers and bereaved caregivers.** This study explores the multifaceted psychosocial challenges families face, including physical, economic, social, emotional, and psychological impacts.[97] This research will aid the development of a multidisciplinary approach and evidence-based psychosocial support systems for affected families.[98,99]

**On the laboratory side, pre-clinical and laboratory research** is underway in various centres to investigate the **biological mechanism underlying childhood dementia conditions and identify and develop new treatments**. Despite the importance of both **the preclinical and psychosocial research streams, they remain constrained by funding limitations that are common across the** Australian research environment.

## 12.4. What is needed?

*"[We require] qualified nursing staff to help contribute to running the clinical trials… genetic counsellors for the counselling and recruiting patients into the trials… if you're talking about brain-based therapies where the delivery is going to be by intrathecal injection, you need operating theatre times, you need access to MRI scans…."*

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[96] Information available online at; https://www.anzctr.org.au/

[97] Nevin SM, McGill BC, Kelada L, et al. The psychosocial impact of childhood dementia on children and their parents: a systematic review. Orphanet J Rare Dis. 2023;18(1):277.doi:10.1186/s13023-023-02859-3

[98] Wiegand-Grefe S, Liedtke A, Morgenstern L, Hoff A, Csengoe-Norris A, Johannsen J, et al. Health-Related Quality of Life and mental health of families with children and adolescents affected by rare diseases and high disease burden: the perspective of affected children and their siblings. BMC Pediatr. 2022;22(1):1–9.

[99] Boettcher J, Boettcher M, Wiegand-Grefe S, Zapf H. Being the pillar for children with rare diseases-a systematic review on parental quality of life. Int J Environ Res Public Health. 2021;18(9):4993.

Paediatrician, geneticist and researcher

Healthcare professionals agreed that a clinical trial network with the following features could promote childhood dementia research and trials:

- Streamlined **trial start-up processes** to encourage pharmaceutical companies to bring novel and emerging therapies to Australia.
- Dedicated **infrastructure and consolidated expertise with sufficient capacity** located at children's hospitals to attract and retain clinical trial involvement.
- **Stronger connections between researchers and care providers** to accelerate research translation for therapeutic and non-therapeutic research.
- A **centralised resource** to provide fast, up to date, tailored information. For example, a clinical trial coordinator to perform horizon scans and with availability to answer questions from healthcare providers.
- **Equitable access to clinical trials across Australia,** irrespective of a patient's geographic location or financial status.
- In additional, healthcare professionals identified the need for **ongoing, large scale funding for laboratory-based and psychosocial research specific to childhood dementia** are needed, to improve knowledge of the molecular pathogenesis of childhood dementia conditions to develop treatments and evidence-based psychosocial resources for children and their families.

*"The only way children are going to access treatment is through clinical trials. The only way for them to access a clinical trial is if there is an Australian site. Particularly with childhood dementia they're going to have really tight windows and eligibility criteria, so making sure that data is readily available either through the clinical experts or through registries or through the patient groups."*

Patient advocacy group member

**Potential areas for action:**

- Investigate the possibility of a creating a centralised repository to capture childhood dementia data, including natural history and service utilisation. For example, a patient registry, linked to an outcomes registry, would enhance our understanding of the childhood dementia conditions and support the development of potential treatments.
- Public awareness and understanding of childhood dementia, including among healthcare professionals, is low.

- Regulatory frameworks often fail to account for the unique needs of children with dementia, resulting in inflexible clinical trial designs and underutilisation of surrogate endpoints.
- Research funding is insufficient across the pipeline, from basic to translational research, particularly for neglected subtypes of childhood dementia, with limited focus on leveraging economies of scale across related conditions.
- Childhood dementia clinical trials face inequity and commercial unviability, hindered by a lack of incentives, alternative funding models, and inefficiencies in trial processes.
- Australia's clinical trial infrastructure and capacity are inadequate to support clinical trials in childhood dementia, preventing locally initiated trials and deterring international trials, despite advances in genomics and drug development that have put effective treatments for childhood dementia within reach.
- Children and families should have equal access to clinical trials regardless of where they live. Australia currently has no completely decentralised trials,[100] but some elements like point-of-care blood testing allow participants to access services closer to home.
- Integrated research and care networks tailored for childhood dementia are lacking, unlike the established networks for childhood cancer trials.

**Implementation considerations:**

- The clinical trials 'One-stop-shop' is under development and aims to transform the ability of patients to access clinical trials and interventions.
- The rarity of these diseases mean that inter-jurisdictional travel and healthcare agreements and ethics approvals can make access to trials difficult.
- A patient registry could facilitate clinical trial recruitment by providing fast access to information about patients who may be eligible for a clinical trial. It would also facilitate clinical trial planning and could make Australia more attractive to overseas pharmaceutical companies looking for clinical trial sites.

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[100] Decentralised clinical trials are defined as where there are no physical trial sites and instead the clinical trials are brought closer to the participants

# 13. Conclusions and next steps

## 13.1. Conclusions

This report highlights systemic, deeply **interconnected challenges** faced by children with childhood dementia and their families, including **limited healthcare professional awareness** (Chapter 3), **complex diagnostic pathways** (Chapter 4) and **ineffective care coordination** (Chapter 5). The issues detailed in this report mirror broader **system-level problems** outlined in Australia's health reports from the Australian Institute of Health and Welfare (AIHW) in 2018[101], 2020[102] and 2024[103]. Fragmented systems and inconsistent and/or lack of data (at a patient and cohort level) exacerbate these challenges, impeding a comprehensive understanding of care needs and pathways.

The gaps in primary, secondary, and community health services (Chapter 6) and NDIS-supported disability services (Chapter 7) force families to navigate a complex, siloed support system that is not responsive to the rapidly changing needs of children with progressive conditions, like childhood dementia. Geographic disparities in service access, particularly for rural and remote families, further compound these challenges, as highlighted in AIHW's 2020[104] and 2024[105] reports.

**Access to genetic tests, critical for early diagnosis of rare and complex conditions like childhood dementia,** remains limited, especially in regional and remote areas. While advances in genetic testing promise earlier detection, significant barriers—including cost, access, and ethical considerations—remain, as noted in the 2018 AIHW report. [106]

The emotional burden on families is immense, exacerbated by a **lack of mental health and emotional support services** (Chapter 8). **Misalignment between existing services and the needs of children with rapidly deteriorating physical and cognitive capabilities is evident** in education (Chapter 9), palliative care (Chapter 10), and hospice and respite care (Chapter 11). **The underfunding of childhood dementia research (Chapter 12) significantly hinders progress in developing treatments and advancing therapeutics. Sufficient funding allocation is critical for exploring potential therapies, considering treatment development is a long-term process.**

The AIHW 2020 report[107] also highlighted critical **gaps in dementia-related data**, which is particularly concerning for childhood dementia. Consistent data on disease progression

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[101] 2.1 How does Australia's health system work?, Chapter 2 Australia's health system (Australia's health 2018) (aihw.gov.au)
[102] Australia's health 2020: in brief, Summary - Australian Institute of Health and Welfare (aihw.gov.au)
[103] https://www.aihw.gov.au/reports/australias-health/health-system-overview
[104] Australia's health 2020: in brief, Summary - Australian Institute of Health and Welfare (aihw.gov.au)
[105] https://www.aihw.gov.au/reports/australias-health/health-system-overview
[106] 2.1 How does Australia's health system work?, Chapter 2 Australia's health system (Australia's health 2018) (aihw.gov.au)
[107] Australia's health 2020: in brief, Summary - Australian Institute of Health and Welfare (aihw.gov.au)

and care pathways is essential for effective planning, and addressing this gap is crucial for improving outcomes and informing policy development.

In 2024, the Rare Voices Australia developed the National Recommendations for Rare Disease Health Care[108] which included eight recommendations. All of these are applicable to childhood dementia. Notably, this report, which focused on the perceptions of healthcare professionals, emphasised the need to foster collaboration between clinicians and researchers to promote the development of expertise in childhood dementia.

Overall, this report illustrates a **fragmented healthcare and social support system that is ill-equipped to meet the needs of children with childhood dementia**. This report calls for an **urgent, cohesive national model of care** that integrates health, disability, psychosocial services and access to clinical trials, providing seamless and equitable support throughout the disease trajectory and giving children with dementia the opportunity to access potential treatments that could slow disease progression or improve quality of life. Appendix A outlines models of care from other diseases that may serve as frameworks for childhood dementia.

Childhood dementia, like other rare diseases, **requires interdisciplinary and cross-border expertise**. While MDT meetings are crucial for coordinating care, their effectiveness is hampered by time and resource constraints, and **families often feel excluded** from the process. Suggestions for improvement could include **greater use of telehealth** and enhanced **cross-discipline collaboration**.

A broad consensus exists between the challenges raised by families and those identified by healthcare professionals, as shown in Table 2. The next steps could involve leveraging these insights to develop a coordinated framework that addresses systemic gaps, aligning with the national approach outlined in the AIHW 2020 report[109]. This includes improving dementia-related data, coordinating genetic testing, and developing adaptable, scalable, person-centred care models for all regions across Australia.

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[108] Rare Disease Awareness, Education, Support and Training (RArEST)Project. National Recommendations for Rare Disease HealthCare - Summary (2024). Available at: https://www.rarevoices.org.au/national-recommendations.

[109] Australia's health 2020: in brief, Summary - Australian Institute of Health and Welfare (aihw.gov.au)

Table 2: Families' and healthcare professionals' perspectives on key challenges faced in childhood dementia

| Challenge | Families' perspective | Healthcare professionals' perspective | Impact areas |
|---|---|---|---|
| Fragmented care and support services | Families report that the care and support system is disjointed and inconsistent, requiring them to manage their child's care across multiple services and sectors. This fragmentation increases stress and results in delayed access to care. | Healthcare professionals acknowledge that services are fragmented, and that there is a lack of coordination between health, disability, education, and community care services, which exacerbates difficulties for families. | All ten themes |
| Lack of care coordination | Families often describe the overwhelming burden of having to coordinate their child's care themselves. They face a fragmented system with limited support, which increases their stress and makes accessing services more difficult. | Healthcare professionals recognise that families are forced to navigate a complex and disjointed system, leading to significant strain. Both families and professionals point to the absence of an organised care coordination framework as a major issue. | All ten themes |
| Limited awareness and recognition | Families feel that childhood dementia is not well understood by healthcare professionals, educators, or the public. This lack of awareness results in delayed diagnoses, insufficient support, and unmet needs. | Healthcare professionals agree that childhood dementia is under-recognised, both within healthcare systems and broader policy frameworks, which contributes to delays in diagnosis and a lack of adequate resources for families. | All ten themes |
| Emotional and psychological strain | Families express ongoing emotional distress as they watch their child lose skills and cognitive abilities. The lack of sufficient emotional and psychosocial support throughout the disease trajectory leaves families feeling isolated and overwhelmed. | Professionals agree that the emotional toll on families is immense. They observe that families often lack access to adequate psychological and emotional support, leading to further emotional exhaustion and stress. | Care Coordination, Healthcare Professional Awareness and Training, Psychosocial Support, Education Support for Children, NDIS and Disability Support |
| Delays in diagnosis | Families frequently report long delays in receiving a diagnosis, which prolongs uncertainty and frustration. This delay often prevents families from accessing appropriate care and clinical trials in a timely manner. | Professionals acknowledge that diagnostic delays are common, largely due to a lack of awareness about childhood dementia among clinicians. Both families and professionals recognise the slow diagnostic process as a significant barrier to care. | Diagnostics Pathways, Health Services |
| Limited access to clinical trials and research | Families express concern about the limited availability of clinical trials in Australia, feeling that they are often left without options or must seek treatment abroad, which adds financial and emotional strain. | Healthcare professionals highlight that there are very few clinical trials for childhood dementia in Australia and agree that this limits treatment opportunities for affected children. Both groups see the lack of trials as a significant issue hindering progress. | Research, Health Services |
| Inadequate training for healthcare providers | Families frequently encounter healthcare providers who lack the necessary knowledge of childhood dementia, requiring parents to educate professionals about their child's condition. This creates additional burdens for families who are already navigating a complex care system. | Professionals acknowledge that healthcare providers often lack the training and awareness to diagnose and manage childhood dementia effectively. They recognise that this knowledge gap contributes to delays in diagnosis and insufficient care. | Healthcare Professional Awareness and Training, Health Services, Research, NDIS and Disability Support |
| Challenges with NDIS and disability services | Families consistently report difficulties navigating the NDIS system, finding it unresponsive to the rapidly changing needs of children with progressive conditions like childhood dementia. They often struggle to secure the funding and services their child requires. | Healthcare professionals agree that the NDIS is not well-equipped to handle the complexities of life-limiting, progressive diseases. Both families and professionals see the NDIS as a major challenge in securing timely and appropriate support. | Care Coordination, Psychosocial Support, Education Support for Children, NDIS and Disability Support |
| Geographic inequities in access to services | Families living in rural or regional areas describe significant difficulties in accessing specialised services, particularly for paediatric palliative care, allied health, and psychosocial support. This creates further hardship for those already managing a complex condition. | Healthcare professionals confirm that access to services is uneven across geographic locations, with families in non-metropolitan areas facing significant barriers. Both groups identify the geographic inequity in service availability as a critical issue. | Care Coordination, Healthcare Professional Awareness and Training, Psychosocial Support |

Source: HealthConsult based on stakeholder consultations and literature review

## 13.2. Next steps

Building upon the insights detailed in this report, the next phase suggested for CDI would be to focus on leveraging stakeholder feedback to enhance and tailor care and support strategies for childhood dementia. This should involve creating adaptable, scalable solutions that can be integrated across rural, remote and regional care settings in all states and territories. Next suggested steps for CDI are:

**Develop an impact analysis map:**

- Validate and consolidate lived experience with healthcare professionals' feedback on the ten care and support themes detailed in this report. The map should integrate all perspectives, highlight current gaps and suggest areas for immediate attention.

**Facilitate five co-design workshops with people with lived experience and healthcare professionals:**

- **Workshop 1: Synthesis and integration**

  **Objective:** Discuss common and unique challenges across regions and assess the scalability and adaptability of best practices from other care models to childhood dementia.
  **Outputs:** A prioritised and validated list of challenges and potential suitability of other disease care models for childhood dementia.

- **Workshop 2: Bridging gaps**

  **Objective:** Develop actionable solutions to the prioritised challenges identified in Workshop 1.
  **Outputs:** Action plans for the top 3 prioritised challenges detailing pilot projects, policy updates, and enhancements in care coordination and service delivery.

- **Workshop 3: Implementation strategy (one workshop per priority area)**

  **Objective:** From the action plans developed, select a priority area to devise a comprehensive business plan, outlining detailed steps, necessary resources, timelines, and assigned responsibilities.
  **Outputs:** A robust implementation roadmap complete with key performance indicators (KPIs) to track progress and evaluate impact.

This structured approach aligns with CDI's strategic goals and ensures that the priority projects are grounded in the lived experiences of those directly affected by childhood dementia, thereby enhancing the efficacy and appropriateness of care solutions developed.

# Appendix A A childhood dementia Model of Care

This Chapter outlines appropriate comparator models of care and support that may be relevant for childhood dementia, and were identified through consultation discussions, situational analysis and survey findings.

Table 3 broadly summarises the models of care that may be further explored to meet the care and support needs of children with childhood dementia and their families. Some of the models of care presented are specific to a certain disease, some models of care are more general in nature and describe the systems and coordinated care components that are utilised in well-functioning or "gold standard" clinical services such as the Paediatric Palliative Care Service at Queensland Children's Hospital or the Rare Care Centre in Western Australia. Given there is no established model of care for childhood dementia in Australia, or indeed internationally, all models described in Table 3 exhibit varying levels of applicability to the care of children with childhood dementia and have varying limitations on the ability to do so. The final model noted, highlighted in **dark green**, details **components of a hypothetical childhood dementia specific model of care that could be developed in Australia**, the components of which are defined based on feedback received throughout stakeholder engagement activities and discussions during interviews and focus groups. While not included in the list of most applicable models of care detailed in Table 3 several other models were mentioned throughout consultations or in response to the survey, such as:

- Redkite
- Care navigator models used in adolescent and young adult (AYA) cancer
- Dementia Support Australia Support Coaches
- Angleman's syndrome Centres of Excellence (CoEs) and The National Organization for Rare Disorders (NORD) criteria for CoE designation
- The Queensland Lifespan Metabolic Medicine Service.

## Table 3: Models of care and support that may be further explored to meet the care and support needs in childhood dementia

| Model name and location | Description | Target population | Applicability to CD | Care components | Limitations |
|---|---|---|---|---|---|
| **Cystic fibrosis (NSW Agency for Clinical Innovation)**[110] | MDT and coordinated care for cystic fibrosis (CF) patients in NSW. | CF patients across the lifespan with particular attention to young people aged 15-24 years old. Specifically for those in NSW. | Can be a 'terminal' diagnosis with significant incidence of premature death. CF is caused by multiple genetic variants therefore requires confirmatory screening. | • Multidisciplinary care<br>• Referral to specialties<br>• Respiratory scientist involvement<br>• Clinical services within tertiary healthcare<br>• Life-long coordinated care<br>• Genetics and genetic testing for definitive diagnosis<br>• Palliative care<br>• Transplant medicine<br>• Research and care audit<br>• Social work including grief and loss counselling<br>• Shared care with GPs<br>• Dietetics | Treatment and therapies have significantly improved over the last decades, meaning survival age is now well into adulthood. Treatment for CD is not as established. Symptomology does not include neurodevelopmental regression. |
| **Duchenne muscular dystrophy (general)**[111] | Treatments of patients with Duchenne muscular dystrophy (DMD), not specific to a centre or jurisdiction. | DMD patients across the lifespan with particular attention to childhood. | Caused by genetic variants, leads to rapidly progressing neuromuscular degeneration of previously achieved mobility skills and mobility challenges. Patients often experience disrupted sleep. There is no cure for DMD | • Disability and mobility support requirements<br>• Genetic testing for definitive diagnosis<br>• Respiratory and cardiac care<br>• Genetic counselling<br>• Behavioural difficulties<br>• Paediatric neurology<br>• Physiotherapy<br>• Exercise therapy<br>• Dietetics<br>• Palliative care | Some treatment options allow affected patients (mostly males) to live into their 30s. The majority of patients do not show signs of learning difficulties. |
| **Paediatric cancer care (general)**[112] | Treatment of paediatric cancer patients (of varying types), not specific to a centre or jurisdiction. | Paediatric cancer patients. | Can be terminal depending on the cancer subtype. Similar conceptual grouping of many cancer subtypes | • Multidisciplinary care<br>• Referral to specialties<br>• Statewide service<br>• Grief and loss counselling<br>• Palliative care<br>• Clinical services within tertiary healthcare | Depending on the cancer subtype there are generally well-defined treatment pathways and therapeutics. Paediatric cancer services are incredibly well-funded in |

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[110] For more information visit https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf, NOTE: due for review in 2024

[111] For more information visit https://www.mda.org.au/duchenne

[112] For more information visit https://www.cancer.nsw.gov.au/getattachment/a828caa6-e6fa-4cc3-a4e7-630facb5be3c/adolescents-and-young-adults-with-cancer-model-of-.pdf and https://www.canceraustralia.gov.au/sites/default/files/publications/pdf/2023_ACP%20Summary%20Report%20DIGITAL_V9.pdf

| Model name and location | Description | Target population | Applicability to CD | Care components | Limitations |
|---|---|---|---|---|---|
| | | | under a collective banner. | • Research, registries and clinical trials<br>• Radiotherapy<br>• Chemotherapy<br>• Surgery | comparison to CD, as is research and the availability of clinical trials. |
| **Paediatric palliative care model of care (QLD Children's Hospital, WA Cancer and Palliative Care Network)**[113] | MDT care for paediatric palliative care patients with a variety of conditions (specific to QLD and WA centres). | Children that meet clinic criteria with a life-limiting disease who are in need of palliative care services. | Palliative care will be used by all patients with CD. | • Multidisciplinary care<br>• Referral to specialties<br>• Grief and loss counselling<br>• Palliative care<br>• Pain and symptom management<br>• Medication management<br>• Community care<br>• Care coordination<br>• Disability care (including NDIS)<br>• Referral to respite care<br>• Clinical services within tertiary healthcare<br>• Social work | Uptake of palliative care services are viewed with hesitation by some members of the public – partially due to misunderstanding of the care. Must be referred to by a physician and often criteria must be met. May create difficulties with access to NDIS supports. May require transition to adult services. |
| **Rare Care Centre (WA)**[114] | The Clinical Centre of Expertise for Rare and Undiagnosed Diseases (RCC) at Perth Children's Hospital. A state-wide, state-funded service. | Children with rare and undiagnosed diseases. The patient has to have an 'unmet' need and be diagnosed with a rare disease. | Sees a number of patients with a CD condition in WA currently. CD is a rare genetic condition requiring multidisciplinary/cross-sector care and services. | • Cross-sector care and support<br>• Care coordination<br>• Multidisciplinary team<br>• Education<br>• Social work<br>• Counselling<br>• NDIS case work<br>• Digital care and solutions<br>• Advocacy<br>• Mental health<br>• Genetics and genetic testing | A time limited service where patients are discharged from care after being referred to appropriate services. A new referral has to be made to re-join the service. Patients can only be referred from within the Perth Children's Hospital. |
| **Regression clinic – pilot project (Monash Children's Hospital, VIC)**[115] | Aims to understand complex autism and neurodevelopmental conditions; housed within the Department of Paediatrics at Monash | Children exhibiting developmental regression, intellectual disability and skill loss in Victoria. | See and treat children who experience skill loss and motor regression. CD conditions come under the target population. | • Education - clinical<br>• Genetics<br>• Genetic counselling<br>• Neurology<br>• Paediatrics<br>• End-of-life care | Still in the establishment phase. Overlap with wider intellectual disability cohorts including autism; CD cohort likely to be fewer. No social worker support available. |

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[113] For more information visit https://www.childrens.health.qld.gov.au/services/palliative-care/palliative-care-queensland-childrens-hospital and https://www.health.wa.gov.au/~/media/Files/Corporate/general-documents/Health-Networks/WA-Cancer-and-Palliative-Care/Palliative-care/Paediatric-Adolescent-Palliative-Care-Model-of-Care.pdf

[114] For more information visit https://pch.health.wa.gov.au/Our-services/Rare-Care-Centre and https://pch.health.wa.gov.au/Our-services/Rare-Care-Centre/Clinical-Service

[115] For more information visit https://www.monash.edu/medicine/scs/research/paediatrics-autism

| Model name and location | Description | Target population | Applicability to CD | Care components | Limitations |
|---|---|---|---|---|---|
| | University and Monash Children's Hospital. Created in partnership with CDI, with MRFF funding. | | | - Palliative care<br>- Grief and bereavement support<br>- NDIS support<br>- Research<br>- Diagnostic assessment | |
| **Rehabilitation clinic 'Kids Rehab' (The Children's hospital at Westmead, NSW)**[116] | A specialist multidisciplinary clinic for rehabilitation of young people aiming to improve a child's function and participation in the home, school and community. Provide rehabilitation goals as part of care. | Children or young people who as a result of injury, health condition, or intervention would benefit from a multidisciplinary program of care. The child must reside in NSW or ACT or require a specialised rehabilitation program. | While not specific to children from the CD cohort, those with a CD condition often require a degree of mobility and physical care that is equitable with those using the rehabilitation clinic. The multidisciplinary approach was highlighted as being gold standard. | - Multidisciplinary team<br>- Rehabilitation<br>- Occupational therapy<br>- Allied health<br>- Case coordination<br>- Art therapy<br>- Clinical psychology<br>- Dietetics<br>- Education support<br>- Music therapy<br>- Neuropsychology<br>- Physiotherapy<br>- Social work<br>- Speech pathology | CD cohort isn't eligible for this service |
| **Rett Syndrome Multidisciplinary Management Clinic (The Children's hospital at Westmead, NSW)**[117] | Children are treated within the multidisciplinary metabolic genetics department at Westmead Hospital, led by Dr Carolyn Ellaway. The Rett clinic was mentioned by multiple stakeholders. | Children with suspected and diagnosed Rett Syndrome in New South Wales. | Rett Syndrome is a constituent condition under the childhood dementia umbrella. Successful practices could be expanded to the larger CD cohort. | - Multidisciplinary team<br>- Dental<br>- Genetics<br>- Metabolic medicine<br>- Genetic counselling<br>- Music therapy<br>- Occupational therapy<br>- Paediatrics<br>- Speech pathology<br>- Physiotherapy | Scope is limited to only children with Rett Syndrome. |
| **Neurodevelopment and Disability clinic (RCH VIC)**[118] | Children access every 6-12 months until discharged. Run by metabolic team at the | Children with developmental disabilities and their families. | Children with any of the CD conditions are appropriate to receive care in this clinic. | - Multidisciplinary team<br>- Genetics<br>- Genetic counselling<br>- Physiotherapy<br>- Paediatrics | Patients reviewed once per year. Needs active partnership with community care providers and greater |

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[116] For more information visit https://www.schn.health.nsw.gov.au/rehabilitation-kids-rehab-childrens-hospital-westmead

[117] For more information visit https://www.schn.health.nsw.gov.au/metabolic-genetics-childrens-hospital-westmead and https://kr.schn.health.nsw.gov.au/articles/2023/09/australian-leading-clinic-helping-children-rett-syndrome and https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10454341/

[118] For more information visit https://www.rch.org.au/neurodevelopment-and-disability/

| Model name and location | Description | Target population | Applicability to CD | Care components | Limitations |
|---|---|---|---|---|---|
| | Royal Children's Hospital, VIC. | | | - Speech pathology<br>- Dietetics<br>- Music therapy<br>- Dental | engagement from tertiary centre workforce. |
| **Kids Guided Personalised Service (Kids GPS) at Sydney Children's Hospital Network**[119] | Uses a modified integrated care model to establish a circle of care coordination around children with medical complexity. | Eligibility is defined by medical complexity, frequency of hospital utilisation and the family's psychosocial complexity. Rural arm services regional and rural patients. | The use of integrated and interdisciplinary care pathways that are tailored to the needs of individual patients. | - Care coordination<br>- Care navigation<br>- Rural, remote and regional care pathways<br>- Interdisciplinary care<br>- Primary, secondary tertiary and community care<br>- Chronic disease management<br>- Personalised care<br>- Medical complexity<br>- Dedicated paediatric care coordination staff<br>- Virtual care and telehealth<br>- Allied health<br>- ATSI care liaison<br>- Equitable service delivery | Only available within NSW. Patients are discharged after a period of care rather than ongoing. Limited known uptake by childhood dementia patients. |
| **McGrath breast cancer nurses**[120] | Registered nurses that are trained to manage care and coordination of care for patients with breast cancer and to provide support to their families. | Patients diagnosed with breast cancer and their families across Australia. | The need for integrated care coordination and navigation pathways that are tailored to each patient. Nurses provide a centralised support person for patients and families to liaise with. | - Care coordination across the disease continuum<br>- Care navigation<br>- Multidisciplinary teams<br>- Personalised care<br>- Private and public health<br>- Referral at time of diagnosis<br>- Psychosocial support<br>- Clinical trials<br>- Genetic testing<br>- Surgery<br>- Chemotherapy, immunotherapy, and/or radiotherapy<br>- Symptom management<br>- Primary care<br>- Employment and financial assistance | Specific and available only to breast cancer patients. Capacity is not at the level needed to provide a breast cancer nurse to every patient and family in Australia. |

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[119] Information available online at https://resources.schn.health.nsw.gov.au/policies/policies/pdf/2017-175.pdf

[120] Information available online at https://www.mcgrathfoundation.com.au/about/what-we-do/nurses/

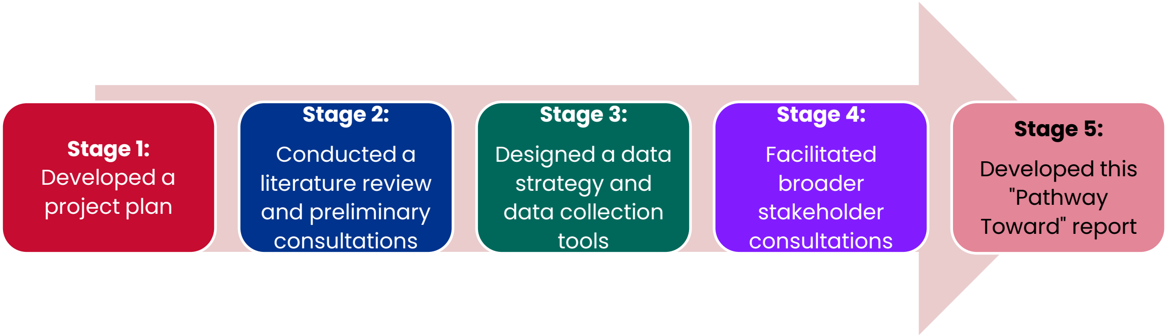
| Model name and location | Description | Target population | Applicability to CD | Care components | Limitations |
|---|---|---|---|---|---|
| **Childhood dementia (stakeholder feedback for future state)** | To provide a world-class MDT and cross-sector childhood dementia care and support model of care across Australia. | Children and families with any of the childhood dementia conditions, across all jurisdictions in Australia. | This model would be specific to childhood dementia in Australia. | - Cross-sector MDT<br>- NDIS support<br>- Social work<br>- Early diagnosis<br>- Allied Health<br>- Palliative Care<br>- Genetics and genetic counselling<br>- Early diagnosis<br>- Clinical trials, registry and research<br>- Metabolic medicine<br>- Neurology<br>- Acute care<br>- Infection control<br>- Psychiatry<br>- Respite care<br>- Community care<br>- Psychosocial support and counselling<br>- Care coordination<br>- Education – clinician and family<br>- Digital care solutions | Challenges with cross-jurisdictional integration and support. Ongoing funding and political support. Benefits of a centralised model at the jurisdictional level compared to the national level are unclear. |

Source: HealthConsult based on stakeholder consultations, survey findings and situational analysis

# Appendix B Project methodology

This Chapter describes the project methodology used to gather insights on the current care and support landscape for childhood dementia (Figure 9).

**Figure 9: Childhood dementia care and support landscape project overview**



Source: HealthConsult (2024)

## B.1. Source documentation

Childhood dementia prevalence was published in 2021.[121] The Childhood Dementia Global Clinical Trial Landscape Analysis report was published in March 2024.[122] This report identified that a total of 386 interventional clinical trials have been listed on clinicaltrials.gov for childhood dementia conditions globally from 2000 to 2023. As of December 2023, 54 clinical trials were listed as recruiting patients for various childhood dementia conditions globally but only two of those were actively recruiting in Australia[21].

Reports, documents and roundtable discussions on relevant policy areas, lived experience feedback, and previous findings published by CDI were included in the landscape analysis. A rapid review of the published literature was also conducted, whereby a total of 58 publications utilising the term "childhood dementia" were identified via PubMed search, the first having been published in 1984.[123] Notably published literature on the childhood dementia specific care and support landscape was limited, partly due to the relatively recent wider spread adoption of the terminology. The majority of published literature focuses on determining the medical and pathological determinants of disease and the clinical groupings and classifications of childhood dementia conditions.

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[121] Elvidge et al Brain, The collective burden of childhood dementia: a scoping review.

[122] Childhood Dementia Initiative, Childhood Dementia Global Clinical Trial Landscape Analysis, published March 2024. Available online at www.childhooddementia.org/getasset/LZPRVX

[123] Swift AV, Dyken PR, DuRant RH. Psychological follow-up in childhood dementia: a longitudinal study of subacute sclerosing panencephalitis. J Pediatr Psychol. 1984;9(4):469-483. doi:10.1093/jpepsy/9.4.469

## B.2. Engagement approach

Stakeholder input was sought in three parts:

1. **Virtual interviews:** 19 stakeholders holding a range of healthcare and support positions specialising in paediatric care, bereavement support, and clinical research participated in 1-hour interviews held via videoconference. The stakeholders represented various organisations focused on children's health and palliative care.
2. **Virtual focus groups:** 46 stakeholders holding a diverse range of positions in paediatric healthcare, support coordination, policy, advocacy, research, and care navigation participated in focus groups that were 60-90 minutes in duration. Eleven focus groups were held:
    - 2 multidisciplinary groups with healthcare professionals (specialist physicians, allied health professionals, psychologists, etc.)
    - 2 groups for social workers, case managers, and community support staff
    - 2 groups focused on community and support networks
    - 2 groups of clinician researchers
    - 1 group on information and training
    - 1 policy-focused group
    - 1 palliative care group.

The stakeholders engaged through interviews and focus groups are outlined in Table 4.

3. **Online healthcare professionals survey on childhood dementia:** 50 stakeholders primarily representing nurses, specialists and allied health workers based in hospitals and wider palliative care services provided feedback via an online survey.

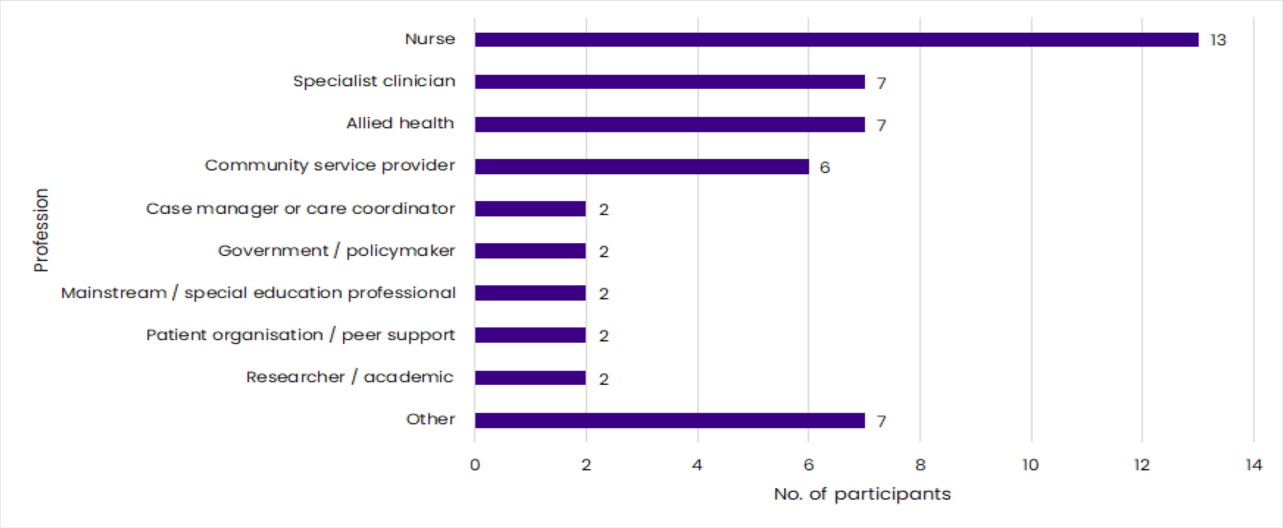
**Table 4: Stakeholder types engaged through interviews and focus groups**

| Stakeholder Group | Subgroup | Stakeholders consulted |
|---|---|---|
| **Clinical** | Specialist | 13 |
| | Nurse | 7 |
| | Allied Health Professional | 3 |
| | Palliative care | 1 |
| **Research and policy** | Clinician Researcher | 6 |
| | Policy | 7 |
| **Support** | Care coordinator | 5 |
| | Dementia support | 3 |
| | Psychosocial support | 3 |
| | Social worker | 6 |
| | Peak body representatives | 8 |
| | Patient organisation / peer support groups | 8 |

| Stakeholder Group | Subgroup | Stakeholders consulted |
|---|---|---|
| **Education** | School educator | 1 |
| | Healthcare professionals' educator | 2 |

Figure 10 describes the roles of the healthcare professionals that responded to the survey.

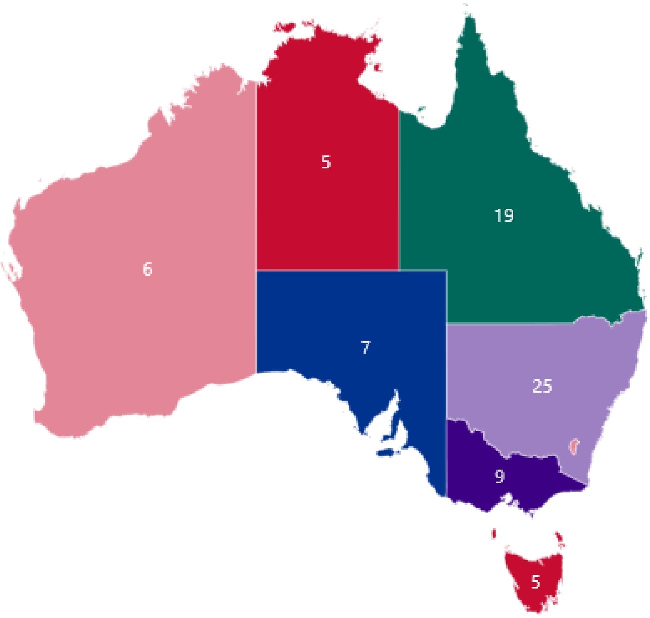
### Figure 10: Survey participants' profession



Source: HealthConsult (2024) Healthcare professionals survey developed for CDI (n=50)

Figure 11 presents the location of services provided by healthcare professionals that responded to the survey.

### Figure 11: Survey participants' provision of service by jurisdiction



Source: HealthConsult (2024) Healthcare professionals survey developed for CDI (n=50)

## B.3. Qualitative and quantitative analysis

Information gathered through the interviews and focus groups were thematically analysed to identify current services available and needed, the challenges faced by families, and potential improvements to the care and support landscape. Qualitative and quantitative analysis was then triangulated to provide a comprehensive summary of current resources and gaps in childhood dementia care and support landscape.

Identified grey-literature and CDI reports were comprehensively reviewed and analysed to provide supporting information and context to the quantitative and qualitative analysis conducted for this project. These documents, reports and their findings have been referenced throughout the body of this report and informed discussion points in Chapters 4 through 13. Additionally, rapid reviews were conducted for examples of models of care that were discussed in stakeholder engagements; these form the basis of information presented in Table 3.

## B.4. Data limitations

Two limitations of the engagement approach for this project are acknowledged:

- Stakeholders were primarily from the **existing pool of engaged stakeholders held by CDI.** As a result, the majority of those engaged had at least some familiarity with childhood dementia.
- Consultations did not include representation from primary care physicians, NDIS staff, teachers/other school staff, or those engaged in laboratory-based research. Consequently, the perspectives gathered primarily reflect the views of clinicians, including nurses, specialists (such as paediatricians, neurologists, metabolic physicians, and palliative care experts), and allied health professionals.