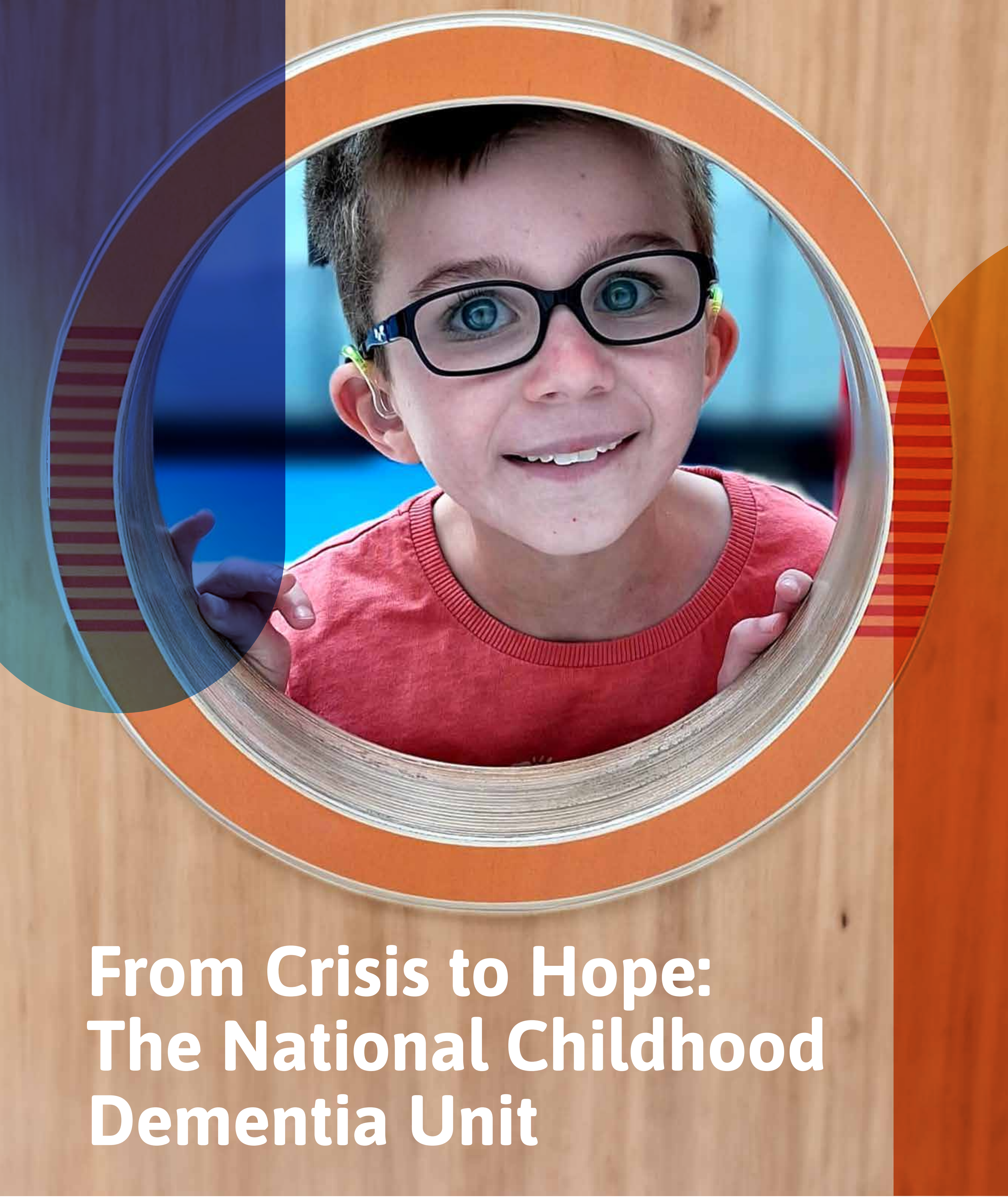

From Crisis to Hope: The National Childhood Dementia Unit

Leading the world in childhood dementia care with exceptional economic returns for Australia

childhood
dementia
INITIATIVE

Acknowledgement of country

In the spirit of reconciliation, Childhood Dementia Initiative acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their elders past and present, and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

Aboriginal and Torres Strait Islander readers are warned that this report may contain images and words of deceased persons.

Acknowledgements

Childhood Dementia Initiative would like to thank the Australian Federal Government for its continued support. We would also like to thank Nous Group and the many individuals and organisations who contributed to the development of solutions outlined in this report.

We would particularly like to extend our heartfelt gratitude to the families of children with childhood dementia who have so generously shared their insights and experiences.

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September 2025. Sydney, Australia.

www.childhooddementia.org
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Cover image: Toby, from Western Australia who lives with childhood dementia

Contents

> **“As a lawyer, I advocate for a living, but I feel I have never had to advocate as much as I’ve had to in order to get Charlotte diagnosed and to get her the support she needs.”**
>
> **Sarah, mum to Charlotte who lives with childhood dementia**

Executive summary

A child in Australia dies from dementia every 4 days. Yet there's no nationally coordinated approach to care for them.

The current system fails children with dementia and their families catastrophically. Care is fragmented, reactive, and inequitable, forcing families to battle disconnected systems without specialist expertise.

Right now, the standard of care a child receives relies too much on luck: where they are, the doctors and specialists they're connected to, and how well their family can fight and navigate complex care systems.

This creates inequities and risks the safety of these children. Families become their child's case manager, researcher, and advocate, spending over 10 hours weekly coordinating care–precious time that should be spent with their children. The system forces health professionals to spend countless hours researching unfamiliar conditions, creating massive inefficiencies and leading to frequent unplanned hospitalisations and emergency department visits.

> **"Addressing the challenges in childhood dementia research and treatment is not just a medical imperative, but a moral one. It offers the potential to alleviate immense suffering and provide hope to families facing one of the most devastating diagnoses a parent could imagine."**
> Health Executive

The National Childhood Dementia Unit (NCDU) offers a transformative solution. Childhood Dementia Initiative, working with the Federal Department of Health, Disability and Ageing, has consulted extensively with families and stakeholders across the healthcare sector to develop this comprehensive response.

The NCDU will be a virtual centre of expertise comprising 4 integrated components:

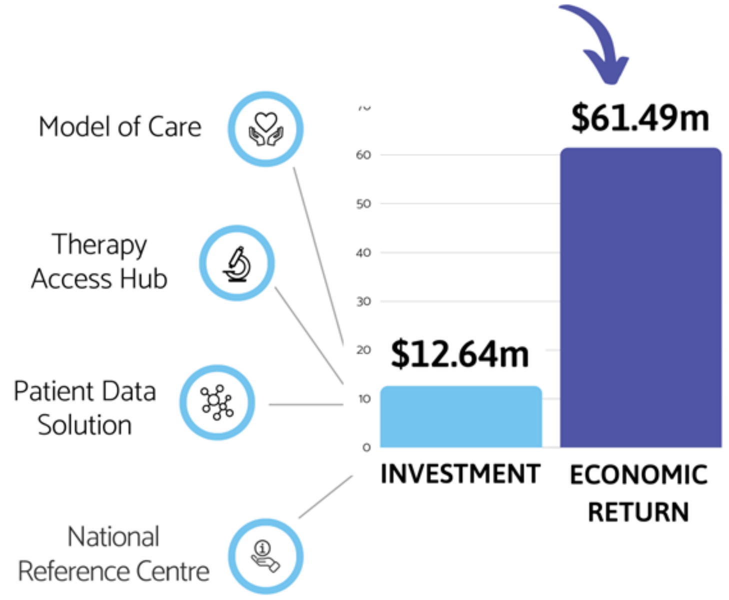
- Model of Care
- National Reference Centre
- Therapy Access Hub
- Patient Data Solution.

Childhood dementia costs families and the health system millions in reactive care. The NCDU will flip the model, delivering proactive, expert-led care that reduces health system strain while allowing children with dementia and their families access to the care and support they need.

The economic case is compelling. **Investing $12.64 million over 5 years will deliver $61.49 million in quantified benefits – a return of $4.86 for every $1 spent.**

The true value extends far beyond these figures with unquantified benefits, including time savings for health professionals, system efficiency gains, pharmaceutical investment attraction, research acceleration, and quality of life improvements, representing millions more in returns that current data limitations do not enable us to measure. Given these constraints, the economic case presented should be viewed as a conservative estimation for expected returns on investment.

Quantifiable return on investment 4.9 : 1



Broad benefits*

*True value includes significant unquantified benefits

Improve care and quality of life for children and young people with dementia

Improve support for carers

Improve equity of service access

Improve understanding of childhood dementia

Improve health system efficiency

Improve health professionals' capacity

The NCDU will:

- Set nationally consistent standards of care for children with dementia
- Give health professionals access to expertise and resources that will enable them to deliver high quality, evidence-based care for children with dementia
- Make children with dementia visible in our health system through the comprehensive national collection, analysis, and sharing of childhood dementia data
- Improve access to potentially life-saving emerging treatments and clinical trials.

This isn't a funding plea – it's an investment opportunity. The NCDU would position Australia as a global leader in childhood dementia innovation while ensuring every child receives equitable, expert care no matter where they live.

The time has come to recognise childhood dementia as a systemic healthcare crisis demanding coordinated national action. The NCDU is an opportunity to change the trajectory of these children's lives – from crisis to hope.

Childhood Dementia Initiative is calling on the Australian Federal Government to fund the establishment of the National Childhood Dementia Unit (NCDU) — a $12.64 million investment over five years that will transform care for Australia's most vulnerable children and deliver $61.49 million in quantified economic returns, together with significant unquantifiable benefits.

Childhood dementia overview

Critical care crisis for children with dementia

Due to the historically fragmented approach to childhood dementia, the needs of this cohort have not only been ignored, they have been largely invisible. As a result, childhood dementia has seen no notable improvement in survivorship[1]. Every single child diagnosed faces premature death–half before their 10th birthday[2]–making this Australia's most devastating paediatric health crisis.

Childhood cancer once faced mortality rates similar to childhood dementia, yet coordinated care and clinical trials have achieved 84%[3] survival rates–demonstrating the transformative power of systematic action across disease groups. Not only is the lack of survivorship for children with dementia devastatingly unacceptable, the care that is available is grossly inadequate. It's fragmented, reactive, and inequitable. Families have no other option than to battle through disconnected systems without guidance and expertise, while health professionals exhaust valuable time researching conditions beyond their knowledge and expertise. This results in profound inefficiencies that cost the system millions annually in crisis-driven healthcare. It also leaves families traumatised by prolonged diagnostic odysseys, and forced to become reluctant experts on their children's conditions while watching them deteriorate without adequate care.[5]

The key problems faced are:

- Diagnostic delays and lack of expertise
- Fragmented, reactive care without standardised pathways
- Limited access to emerging therapies and clinical trials
- Children unidentifiable in health system data
- Families bearing an impossible burden

These children require complex, non-linear care across health, disability, psychosocial and palliative services. These unique, extensive needs and the lack of a coordinated national approach mean that children with dementia currently carry the highest level of unmet need in the Australian paediatric health system.

One in every 2,900 babies

is born with a condition that causes childhood dementia

Parents of children with dementia **experienced moderate to severe anxiety at rates 2 to 3 times greater** than the general population experienced during COVID-19 lockdowns.

Children with dementia experience chronic, increasingly severe symptoms. They:

- Lose their speech and ability to move
- Suffer increasing levels of confusion, distress, pain, sleeplessness and personality changes
- Often develop seizures, vision & hearing loss, and multi-system failure including skeletal, cardiovascular, respiratory, and digestive

On average, **diagnosis is delayed by**

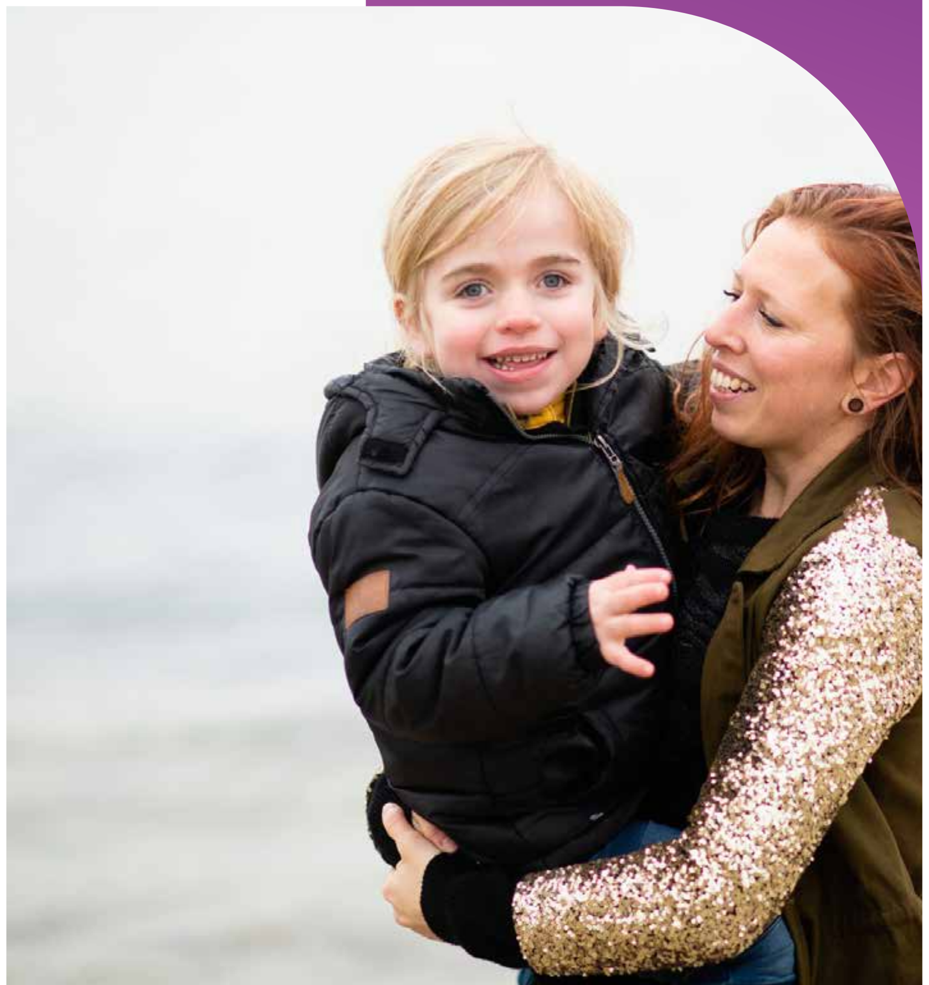
2 years or more
after symptom onset

1 in 5

affected families have multiple children with dementia

1 in 3
parents
gave up their careers to care full-time for their children.

> **"For the average person, it would be "look how far this child has come", but for myself and probably other parents in this position, it's "look at how much they've lost". At 2 or 3 years old, my child had the peak of their mobility, language, and comprehension. Every year you look back, they've progressed further in the disease and lost more."**
>
> Sarah, mum to Callum who lives with childhood dementia.



Pathway to solutions

Childhood Dementia Initiative, founded in 2020, has led international efforts to raise awareness and improve care for children with dementia, advocating for system-wide reform and policy change. Childhood Dementia Initiative takes a world-first approach by considering all conditions that cause childhood dementia collectively.

Central to this approach is collaboration with stakeholders from healthcare, research, education, and social services, alongside policymakers and families with lived experience. This cross-sector collaboration enables world-class solutions to be developed and implemented.

Australia is leading a global transformation in childhood dementia care. It is uniquely positioned to lead the world in this critical health innovation with its universal healthcare, world-class research infrastructure, and manageable population size that enables us to solve this crisis faster than anywhere else and to export the solution globally.

Australia is the first country in the world to consider the collective group of childhood dementia disorders in a system-wide approach. The National Dementia Action Plan, released in 2024, recognised children as a priority population and acknowledged that children living with dementia face significant challenges accessing dementia care and support services.[4] To address this, the Australian Federal Government partnered with Childhood Dementia Initiative to undertake a groundbreaking 2-year project to identify gaps in care and support services, and co-design much-needed solutions for children with dementia.

As part of this project, Childhood Dementia Initiative engaged international management consultancy, Nous Group, to help develop a national solution. A broad and diverse group of stakeholders contributed their insights, including organisations outside the childhood dementia field such as the McGrath Foundation, Canteen, the Australian Rare Cancer Portal, and the National Eating Disorders Collaboration. Over 60 participants, including families and health professionals, were engaged, with more than 40 focus groups and interviews conducted.

The outcome of this project includes the scoping and business case for the National Childhood Dementia Unit as outlined in this report.[5]

Australia is the first country in the world to consider the collective group of childhood dementia disorders in a system-wide approach.

National Childhood Dementia Unit

The National Childhood Dementia Unit (NCDU) will establish Australia's first virtual centre of expertise for childhood dementia capability, knowledge and data. This initiative will embed expertise nationwide and ensure a unified approach to care and support for children with dementia and their families–regardless of where they live or their family's capacity to navigate complex systems.

The NCDU aligns with the priorities defined in the 2024 National Dementia Action Plan[4] by addressing the complex needs of this priority population, as well as aligning with the pillars identified in the Department of Health and Aged Care's National Strategic Action Plan for Rare Diseases[6] and the top 10 rare disease research priorities defined by The Kids Research Institute Australia and Rare Voices Australia.[7]

A national and collaborative approach

A virtual centre of expertise will enable health professionals across Australia–from rural GPs to metropolitan specialists–to access expert guidance and support when they need it, ultimately ensuring all children with dementia receive quality care regardless of where they live.

The NCDU will work in close collaboration with health professionals, state and territory health departments, patient organisations, service providers, researchers and industry to create the coordinated system that childhood dementia has never had. This partnership approach leverages existing infrastructure while addressing the unique needs that have made these children invisible in traditional health systems.

The NCDU is a financially sustainable model that will embed consistent, evidence-based practices across the health system, addressing geographic disparities and enabling earlier diagnosis and intervention, better symptom management, more proactive care planning and improved access to innovative therapies.

Healthcare professionals within each state will be supported by the NCDU through national expert guidance and knowledge sharing, improving confidence and the capacity to deliver compassionate care. This will improve job satisfaction, reduce burnout, and foster a more capable and resilient workforce.

> **"I don't have time on my side, so I can't just sit back and hope that something's going to change."**
>
> Renee, mum to Hudson (left), Holly (centre), and Austin (right) who all live with dementia, on why she advocates for change. Renee participated in consultations to map out challenges and solutions for families like hers.

Four integrated components

The NCDU transforms care through 4 core components that work together to address the childhood dementia care crisis. These 4 components are:

MODEL OF CARE	A nationally standardised, evidence-based framework encompassing diagnosis, care, post-diagnostic support and timely connection to community and psychosocial services. It will cover the entire care pathway, including genetic counselling, clinical trials, end-of-life planning and bereavement and beyond.
NATIONAL REFERENCE CENTRE	A virtual hub of expertise, guidance and support to build capacity among health professionals treating children with dementia. The centre will be comprised of multidisciplinary experts and host regular forums to discuss complex cases and share best practices.
THERAPY ACCESS HUB	A centralised service to identify and facilitate access to emerging therapies and clinical trials. It will proactively connect clinicians, researchers, pharmaceutical companies and government (including regulators) to support planning and recruitment and drive innovation in the sector. Activities include horizon scanning, personalised scoping reports for clinicians and stakeholder outreach.
PATIENT DATA SOLUTION	A secure, user-friendly platform for self-nominating carers and/or their chosen delegates to input and share data on their child or children with dementia. With consent, this data will support clinical trial recruitment, care planning and policy development.

The NCDU will deliver wide-reaching benefits by improving the quality and accessibility of care for children with dementia and their carers. It will enhance patient care, reduce carer burden and promote equitable access to services across Australia. It will also strengthen the health system by reducing the burden on primary health care, deepening understanding of childhood dementia, and building health professional capacity by providing them with the tools and knowledge they need to deliver compassionate, effective and efficient care.

The NCDU's 4 components are designed to work together, with each element reinforcing the others to comprehensively address the current issues in the delivery of care for children with dementia. This integrated approach creates a system-wide solution rather than isolated fixes. Together, these components will enable families to focus on their child and make precious time count, rather than fighting systems that were never designed for their needs.

Problem: Diagnostic delays and lack of expertise

Families often wait years for a diagnosis, attending dozens of appointments with different specialists, resulting in wasted time and healthcare resources and avoidable trauma for families. The average age of symptom onset is 2.5 years, but diagnosis typically occurs around age 4[2]. In a New South Wales study, 30% of families surveyed reported waiting over 5 years for a diagnosis, and half attended over 15 appointments with different health professionals during the diagnostic process.[8]

This diagnostic odyssey results in children missing critical windows for early intervention and exposure to inappropriate, expensive tests, unnecessary procedures and potentially harmful medications due to misdiagnosis.[9]

Post diagnosis, health professionals frequently encounter clinical situations that extend beyond their expertise and experience. As a result, they invest substantial time conducting extensive literature reviews and investigating unfamiliar medications, interventions, and treatment protocols. Many health professionals cite the limited and variable understanding of childhood dementia as the “primary challenge” in the care landscape for this cohort.

> **“Sometimes you do feel apprehensive about taking medical advice from whoever it is, whatever department you’re seeing…I think they know very little about it – probably looked at journal articles, and have actually indicated that they know nothing…They’re caring for my child. But I don’t know if I can trust what they’re saying is actually best practice.”**
>
> Parent of a child with a dementia condition

Economic Impact:
Resources wasted on inappropriate testing, repeated specialist appointments, and health professionals’ valuable clinical time being diverted from direct patient care.

System Impact:
Inefficient use of specialist services, bottlenecks in referral pathways, delayed access to appropriate care, and overburdened specialists.

Family Impact:
Prolonged uncertainty and anxiety for families, children suffering through unnecessary procedures and potentially harmful treatments, families losing faith in the health system, and missed therapeutic windows that could have improved their child’s quality of life and developmental outcomes.

Solution: National Reference Centre

The **National Reference Centre** will provide Australian clinicians with direct access to multidisciplinary childhood dementia expertise. The expert panel will offer clinical guidance on diagnosis, care planning, medication management, and care transitions. Monthly virtual forums will discuss complex cases, while a 24/7 digital platform will provide evidence-based resources and consultation pathways. This transforms isolated clinical decision-making into supported, expert-informed care and builds the capability of clinicians regardless of geographic location.

Other NCDU elements that will support the solution:

The **Model of Care** will establish clear diagnostic pathways and referral protocols, ensuring children reach appropriate specialists efficiently. The **Patient Data Solution** will increase understanding of childhood dementia, support clinical decision making and improve quality of care. The **Therapy Access Hub** will enable identification and connection with suitable therapeutic opportunities.

Problem: Fragmented, reactive care without standardised pathways

There is currently no national consistency for the care of children with dementia, creating significant challenges for families and inefficiencies within the healthcare system. The lack of consistent referral pathways can result in patients being sent to specialists who may not be best suited to address their needs, creating bottlenecks in the system and delaying access to optimal care.

Without coordinated care planning and consistent clinical oversight, families frequently find themselves unprepared for predictable disease progression milestones, leading to reactive care management and crisis-driven healthcare utilisation. Emergency visits and unplanned hospitalisations cost the Australian health system millions each year. This reactive model drives families to seek urgent care for conditions and complications that could have been managed through planned interventions.[5]

The absence of a unified approach leaves families to navigate disconnected services independently, and results in substantial inequities in care. The complexity of navigating this fragmented system disproportionately impacts families with lower health literacy or limited English proficiency.

With multiple specialists prescribing medications independently, families become responsible for managing complex drug regimens despite lacking the clinical expertise–a burden that puts children’s safety at risk.

> **“You kind of work out from other parents what you need to offer your child. I don’t know what we should be accessing in terms of allied health, in terms of other specialists, and what we need to be monitoring.”**
>
> Parent of a child with a dementia condition

Economic Impact:
Preventable hospital and emergency department costs, duplicated services, inefficient resource allocation, and lost productivity from families managing constant crises rather than focusing on their child’s wellbeing.

System Impact:
Increased pressure on emergency services and hospitals, suboptimal care delivery, missed opportunities for proactive symptom management, and strained healthcare resources being used reactively.

Family Impact:
Amplified inequities based on geography and socioeconomic status, families living in constant crisis mode, children experiencing preventable complications and hospitalisations, and profound disparities in care quality depending on a family’s ability to advocate.

Solution: Model of Care

The **Model of Care** will establish evidence-based care pathways that guide families and professionals through every stage of childhood dementia, with standardised protocols enabling consistent care nationwide. The model will be embedded into services nationally, transforming reactive crisis management into proactive, planned care.

Other NCDU elements that will support the solution:

The **National Reference Centre** will continuously refine and update the **Model of Care** based on real-world experience and emerging evidence so that care standards evolve with the latest insights from clinical practice. The **Patient Data Solution** will enable information sharing across providers, improving continuity of care. The **Therapy Access Hub** will integrate treatment and clinical trial opportunities into care pathways at optimal stages, ensuring therapeutic decisions are coordinated with overall care planning.

Problem: Limited access to emerging therapies and clinical trials

Due to the lack of treatments for childhood dementia disorders, clinical trials offer the only opportunity to access potentially life-saving treatments. However, currently fewer than 2% of Australian children with dementia have access to a clinical trial.[1] The fragmented approach to childhood dementia creates significant barriers to participation and clinical research, and undermines the country's attractiveness as a clinical trial site for pharmaceutical companies. The lack of patient data and a central point of contact and coordination leads pharmaceutical companies to bypass Australia for other countries.

The current system fails to support health professionals in connecting patients with relevant clinical trial opportunities.

Families shoulder most of the work of researching and pursuing emerging therapies and clinical trials because clinicians do not have the time or specialised knowledge to stay abreast of the latest progress in clinical research for the breadth of conditions. This places an immense administrative and emotional burden on families who often describe a fear of "missing something" that could help their child.

> **"We usually hear about trials from the parents. They're often the first to tell us about some new treatment that they've heard about either through a support group, or through a Facebook group, or through the media."**
>
> Paediatric Neurologist

Economic Impact:

Missed opportunities for pharmaceutical industry investment, lost research sector partnerships, reduced clinical trial revenue, continued high care costs without treatment advances, and families spending substantial out-of-pocket expenses pursuing treatments overseas.

System Impact:

Australia loses international standing in rare disease research, reduced clinical trial expertise and infrastructure development, missed opportunities to attract global research investment, and inability to build specialised research capabilities that would benefit the broader health system.

Family Impact:

Families denied hope and treatment options, children dying without access to potentially life-saving treatments, families forced to relocate overseas, and profound inequity compared to childhood cancer which has universal access to clinical trials.

Solution: Therapy Access Hub

The **Therapy Access Hub** will position Australia as a leader in childhood dementia clinical trials through horizon scanning, efficient patient identification, and direct research and industry partnerships. Clinicians will have access to expert guidance about relevant therapies and trials for specific patients, reducing the family research burden.

Other NCDU elements that will support the solution:

The **Patient Data Solution** will enable systematic patient identification for trial recruitment, replacing accidental discovery with strategic matching of eligible children to relevant studies. Comprehensive patient data will enable proactive engagement with pharmaceutical companies to attract trials to Australia. The **National Reference Centre** will provide expert evaluation of emerging treatments and guidance on trial suitability for individual patients. The **Model of Care** will integrate therapy access into standardised care pathways, ensuring no child misses the opportunity to access potentially life-saving treatment.

Problem: Children unidentifiable in health system data

There is a chronic absence of data, which means that children with dementia are not identifiable within our current health systems.

Accessing data about these children and their use of health, disability, and support systems is nearly impossible, severely hampering service development and efficiencies.

Data captured in medical health records is not standardised or accessible, and no patient registry exists that captures childhood dementia as a collective group of conditions. This invisibility also impacts research coordination. Without systematic data collection, researchers cannot identify suitable participants for clinical trials, health services cannot plan appropriate resources, and families cannot access information about what to expect from their child's condition or treatment options.

> **"If we have one central place to put all this information in... health professionals can go back to that place, find similar conditions or similar kids with the similar symptoms."**
>
> Parent of a child with a dementia condition

Economic Impact:

Value or cost-effectiveness of interventions cannot be demonstrated, inability to plan resource allocation efficiently based on evidence, missed opportunities for systematic service improvements, and wasted research investment due to disparate data systems that prevent learning from collective experiences.

System Impact:

Evidence-based care improvements are impossible without baseline data, service planning occurs in a vacuum without understanding of actual needs, research efforts are fragmented and duplicated, and quality improvement initiatives cannot be measured or sustained across the system.

Family Impact:

Children's experiences and outcomes remain invisible to policymakers, families cannot access information about disease progression or treatment outcomes, missed opportunities for clinical trial participation, no systematic learning from collective family experiences, and the perpetuation of isolation and uncertainty.

Solution: Patient Data Solution

The **Patient Data Solution** will enable family-controlled data collection that makes these children visible across the healthcare system while enabling evidence-based improvements. A secure platform will enable families to input information once with dynamic consent for sharing. This will support clinical trial planning and recruitment, care planning, policy development, and systematic learning from collective experiences. Evidence-based improvements will replace guesswork and enable the healthcare system to see and respond to these children's needs.

Other NCDU elements that will support the solution:

The **National Reference Centre** will use patient data to share and publish insights broadly that will improve knowledge about childhood dementia. The **Model of Care** will incorporate data collection points at key milestones, creating systematic understanding of care effectiveness. The **Therapy Access Hub** will use comprehensive data to identify research opportunities, notify families of potential clinical trial opportunities and inform pharmaceutical companies about Australian patient populations, attracting investment and trials to Australia.

Problem: Families bearing an impossible burden

The burden of unsupported care management significantly impacts the mental health of carers, driving heightened levels of anxiety, grief and financial stress for families. Parents and carers are often left to research treatments, coordinate care and educate providers independently.[5]

Parents have to regularly repeat their child's story across settings. The lack of communication pathways between healthcare providers results in service duplication and critical gaps in care delivery, wasting valuable time and resources while placing unnecessary burden on already stressed families.

Many parents leave the workforce entirely, with a recent study revealing that 94% of caregivers had to modify their work status due to their child's condition, and 1 in 3 gave up their careers entirely to care full-time. Caregiving duties are disproportionately taken on by mothers.[10]

A 2025 study found that 100% of caregivers surveyed reported grief symptoms prior to the loss of their child that significantly impaired their lives and wellbeing. 70% scored in the moderate to severe range for generalised anxiety, and 60% needed to access mental health resources.[10]

> **"Parents have to spend so much time and energy navigating and fighting systems, and advocating for their child's needs and to find a cure, when the focus should be on making the most of what time you have left with them."**
>
> Bereaved parent of a child with a dementia condition

Economic Impact:

$12.1M annually in quantified family costs, significant workforce participation losses with 29% of carers unable to work, reduced household incomes, and gendered economic disparities affecting long-term financial security.[5]

System Impact:

Health professionals inappropriately relying on parents for medical information, inefficient communication pathways, service duplication, wasted clinical time from repeated storytelling, and safety risks from siloed medication management.

Family Impact:

Chronic anxiety and anticipatory grief, isolation and burnout, families missing precious time together due to system navigation burden, siblings' childhoods consumed by overwhelming care needs, and mental health deterioration across the entire family unit.

Solution: Families supported through an unimaginable journey

The NCDU fundamentally shifts responsibility from families to coordinated professionals across all components. The **Model of Care** will clearly define professional responsibilities and provide structured pathways, removing the burden from families to source and coordinate their child's care across disconnected services. The **National Reference Centre** will provide expert guidance directly to clinicians, alleviating families' role as educators. The **Therapy Access Hub** will deliver personalised treatment information through professional channels, replacing exhausting family research responsibilities. The **Patient Data Solution** will eliminate repetitive storytelling through shared information systems, allowing families to input their story once while maintaining control over sharing.

Cost-benefit analysis

Investment overview

Investment required:
$12.64 Million over 5 years

Economic return:
$61.49 Million over 4 years (quantified benefits)

Return on investment:
4.9:1

This isn't a funding plea – it's an investment opportunity. For every dollar spent on the NCDU, Australia will see nearly 5 dollars in economic return.[5]

The numbers tell a compelling story. With total funding required to establish and operate the NCDU over 5 years estimated at $12.64 million, and quantified benefits of $61.49 million over 4 years, the NCDU represents a strong return-on-investment opportunity in Australian healthcare.

But this conservative economic analysis captures only a fraction of the true value. The $61.49 million represents just 2 of 6 major benefit categories, with the remaining 4 unable to be quantified due to data limitations.[5] The real transformation extends far beyond what can be measured today – from the health professional who no longer spends hours researching unfamiliar conditions and whose time is freed up to spend with other patients, to the family who can focus on making precious time count.

The diagnostic odyssey and constant battle for healthcare isn't just a family trauma that puts children's lives at risk – it's also a fiscal inefficiency. The NCDU tackles the fragmentation, inequity, and neglect that have plagued childhood dementia care, delivering system-wide efficiencies that benefit families, providers, and taxpayers alike.

Costs

Investment breakdown

The $12.64 million investment covers a comprehensive, 5-year program to establish and operate the NCDU.[5] This includes an initial implementation year (Year 0) followed by 4 years of full operation, with costs informed by rigorous desktop research into similar initiatives, extensive expert consultation, and analysis of comparable healthcare programs. Investment will be in expert staff, proven technology platforms, and evidence-based interventions.

Investment by component:

Component	Primary Purpose	Cost ($m)					
		Year 0	Year 1	Year 2	Year 3	Year 4	Total
Model of Care	Standardised care pathways	1.16	0.47	0.77	0.50	0.81	3.70
National Reference Centre	Expert consultation network and information	0.45	0.62	0.71	0.62	0.75	3.16
Therapy Access Hub	Emerging treatment access	0.45	0.57	0.69	0.60	0.73	3.04
Patient Data Solution	National registry and data infrastructure	0.65	0.46	0.56	0.48	0.59	2.74
Total NCDU	**Integrated national system**	**2.71**	**2.12**	**2.73**	**2.20**	**2.87**	**12.64**

Year 0 includes $1.63 million investment for implementation – establishing governance structures, building digital platforms, recruiting specialist staff, and co-designing care pathways with families and clinicians. The remaining $11.02 million supports 4 years of operations, with costs escalated for inflation and wage growth based on Australian Bureau of Statistics data.[5]

This financial model reflects lessons learned from successful healthcare initiatives,[5] with built-in evaluation frameworks to measure outcomes and ensure continuous improvement. The cost structure is designed for sustainability, with ongoing operations representing the true investment in transforming care delivery across Australia.

Quantified economic benefit

Economic return: $61.49 Million Over 4 Years

Economic modelling reveals substantial measurable returns from the NCDU's coordinated approach. Using established health economic methodologies and data from over 40 stakeholder consultations, researchers were able to quantify benefits in 2 critical areas where sufficient baseline data exists. These quantified benefits – representing just 2 of 6 major benefit categories identified – demonstrate immediate, measurable value while establishing a conservative foundation for the true economic impact of transforming Australia's approach to childhood dementia.[5]

Health system savings: $10.87 Million

The NCDU delivers immediate relief to Australia's overstretched health system by preventing the crisis-driven care that currently characterises childhood dementia management. This includes:

- **$7.13M** from reduced unplanned hospitalisations (258 fewer annually)
- **$3.3M** from reduced emergency department visits (761 fewer annually)
- **$0.44M** from time savings to health professionals from streamlining diagnostic pathways

Improved support for families: $50.62 Million

The economic burden on families caring for children with dementia extends far beyond direct medical costs, encompassing profound mental health impacts and the exhausting unpaid labour of care coordination. Benefits delivered by the NCDU include:

- **$35.35M** from reduced anxiety through structured care pathways
- **$14.90M** in time savings through standardised care pathways
- **$0.36M** in time savings from streamlined diagnoses

Critical unquantified benefits: why the true value is much higher

The quantified benefits represent a significant underestimation of the true economic value of the NCDU. Of the 6 benefit areas identified, only 2 could be quantified and then only partially. The unquantified benefits — excluded not because they're insignificant, but because system fragmentation lacks the data to measure them — represent the most transformative aspects of the NCDU.

Professional time savings

Individual doctors currently spend countless hours researching unfamiliar conditions, investigating appropriate medications, and exploring clinical trial opportunities for their patients. Due to the lack of expertise and standards, each clinician must essentially become a childhood dementia researcher for every case they encounter. This incredibly inefficient and inequitable practice means specialist time is diverted from patient care to tasks that could be centralised and systematised.

Time savings from standardised care protocols, expert consultation networks, and up-to-date treatment databases represent millions in productivity gains across Australia's health workforce.

System efficiency gains

The NCDU will eliminate inappropriate referrals, reduce test duplication, and ensure efficient use of specialist services through coordinated pathways. Primary and tertiary care providers will gain confidence and competence, reducing inappropriate referrals to emergency departments and specialists. Rural families will access the same expertise as metropolitan families, addressing geographic inequities that currently waste resources and perpetuate poor outcomes.

Research acceleration

The NCDU will systematically collect data that currently doesn't exist, enabling evidence-based improvements to care protocols and treatment approaches. This research infrastructure will accelerate treatment development, leading to breakthrough therapies that could transform survival rates for childhood dementia globally, positioning Australia as a global leader in rare disease innovation.

Quality of life and survivorship improvements

Earlier intervention through expert-led diagnosis, consistent evidence-based care regardless of location, and improved access to experimental therapies all contribute to better quality of life for children and longer survival. These children currently face a 70% mortality rate before adulthood – improved survivorship represents immeasurable value to families and society.

By connecting Australian children with cutting-edge research, emerging therapies, and coordinated expert care, we're not just improving current quality of life – we're creating the infrastructure that could extend and save lives.

Pharmaceutical investment attraction

Australia currently struggles to attract clinical trials for childhood dementia from pharmaceutical companies due to a lack of systematic patient identification and coordinated research infrastructure. The NCDU's Patient Data Solution and Therapy Access Hub will transform Australia into an attractive destination for international clinical trials, attracting substantial industry investment through research partnerships, clinical infrastructure development, and high-skilled employment.

The imperative for action

The time has come to recognise childhood dementia as a systemic healthcare crisis demanding coordinated national action. The NCDU is a once-in-a-generation opportunity to change the trajectory of the lives of Australia's most vulnerable children — from crisis to hope.

This initiative will position Australia as a global leader in childhood dementia innovation, while ensuring every child can receive equitable, expert care regardless of their postcode. The strong economic case, combined with the profound human benefits, makes the NCDU not just a moral imperative but a sound investment in Australia's healthcare future.

The numbers demand action. Childhood dementia receives 4.6 times less Government research funding per patient than childhood cancer, despite causing a similar number of deaths.[11] While every child with cancer has access to clinical trials, fewer than 2% of children with dementia have the same opportunities.[1] This disparity is not just tragic – it's fiscally inefficient.

Australia is uniquely positioned to lead this transformation. We have universal healthcare, world-class research, and a manageable population size – we can solve this faster than anywhere else and export the solution globally. Australia was the first country to recognise children in dementia policy[4] and the first to provide targeted research funding for childhood dementia.[12] This is our opportunity to lead a transformation that will define Australia's role in global health innovation.

With a $12.6 million investment, Australia can unlock $61.49 million in quantified benefits – but more importantly, give children with dementia a fighting chance.[5]

The choice is clear: continue with expensive, reactive crisis management, or invest in proactive, expert-led care that saves money, improves outcomes, and ultimately saves lives.

> **"He just deserved to have had everything. He deserved to be here for a good time and a long time."**
>
> Jane, mum to Noah, who died with childhood dementia when he was 8.

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Back cover image: Niki (left), mum to Angelina (right), who died in 2025 aged 21 with childhood dementia.

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