The New Frontier: Transforming Childhood Dementia

Childhood Dementia Initiative
Strategy 2026-2031

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 families and stakeholders who contributed their insights to this report.

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Cover image: Louis, who died with dementia in 2024 in Sydney, Australia, when he was 2 years and 5 months old.

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> **"It really hurts me to think about the families who aren't in it yet. Who are going to find out their child has a condition under the childhood dementia umbrella. I struggle to think about these families, knowing what we went through - the stress and worry and the worst hurt of my life. This can't keep happening to children. It's unacceptable. Something has to happen."**
>
> **James, dad to Louis featured on the cover, who died with dementia in 2024 aged 2 years and 5 months of age**

Message from our CEO

Five years ago, we embarked on an unprecedented journey. Childhood Dementia Initiative was founded with a bold vision: to drive a world-first collective approach that considers all conditions causing childhood dementia together, revolutionising how all children with dementia are seen, treated and cared for.

Today, we stand at a pivotal moment. Together with a network of stakeholders, we've transformed childhood dementia from an invisible crisis into a recognised health priority. And Childhood Dementia Initiative has emerged as the trusted leader driving behavioural and systemic change for children with dementia across Australia and beyond.

As we look ahead to the next 5 years, we're not just continuing our work, we will deliver transformative solutions that will change the trajectory for every child with dementia in Australia and set the standard globally.

We have built the trust of families, of government, and of the healthcare sector. We have built the evidence base, mobilised critical stakeholders, and created infrastructure. All of this is a foundation for lasting impact. Our next horizon is where research becomes reality, where every child with dementia has access to world-class care, and where Australian innovation transforms global health.

Join us at this new frontier. Together, we will transform childhood dementia from crisis to the world's most inspiring healthcare revolution. A revolution that means life, hope, and countless futures restored.

With hope and gratitude,
Megan Maack, CEO and Founder

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Why this moment matters

Three converging factors make this the defining moment for childhood dementia:

1. **Australia-led global leadership opportunity: the collective approach to childhood dementia is an Australian-led model.** Childhood Dementia Initiative was founded in Australia and secured bi-partisan state and federal government support, action and policy inclusion. With universal healthcare, world-class research, and a manageable population size, Australia can solve this faster than anywhere else and export solutions globally.

2. **Rare disease: the next frontier for healthcare innovation.** Advances in genetic testing, precision medicine and data capabilities are converging with growing investment in gene therapies, evolving regulatory frameworks, and rising advocacy efforts. The childhood dementia model offers a transformative approach – a blueprint that could alleviate fragmentation and duplication across the 7000+ rare conditions, drive economic efficiency and policy inclusion, and accelerate outcomes for millions worldwide.

3. **Childhood dementia is a greenfield: Everything we develop now will define international best practice.** Every breakthrough is a first. Our starting point is zero – every child currently faces 100% mortality – which means every initiative creates exponential impact. We have the ability to build optimal solutions from the outset, learning from other sectors to get it right the first time.

Childhood dementia: a hidden health crisis

Over 140 genetic disorders cause dementia,[1] but until the establishment of Childhood Dementia Initiative, they were treated as separate, individually rare diseases. There was no recognition that across all of these conditions, children's young brains were being progressively damaged and they were all experiencing dementia. As a result, no specialised support ever developed.

Research was, and is, fragmented and grossly underfunded[2,3] and focused on individual conditions in pockets around the world. As a result, there's been no improvement in survivorship. Ever. All children with dementia will die prematurely, with half dying before age 10.[1]

"I was told to go home, to love her and not waste my time trying to find a cure." – Meg, mum to Isla and Jude

Childhood dementia doesn't just take young lives. It takes everything. Children lose their speech, their ability to move. They suffer increasing confusion, distress, pain, sleeplessness, and personality changes. Seizures, vision and hearing loss, and multi-system failure can follow.

"You watch your child disappear over the years. Jessie could say a phrase, and then she could only say a word, and then she couldn't say anything. Not even a noise came out of her." – Cindy, mum to Jessie Mei Mei

Symptoms like hallucinations, severe behavioural changes, and aggression - the very signs of their deteriorating condition - paradoxically can lead to their exclusion from the education, health services, and even palliative care[4] that they need, leaving families to manage increasingly complex needs alone.

"Her anxiety is huge at the moment. Sometimes she bites and she has this almost primal scream, which is just awful." – Felicity, mum to Orla

Families were utterly isolated, many believing they were alone as they watched their children endure this suffering and slowly die. They were sent home with no care guidance or pathways to draw on, left to figure out health care and support for their children, and to then find and coordinate a complex web of specialists and support services.[5,6,7]

"No one has suggested to us we should see a neurologist. I'm trying to find answers about who else I need to talk to." – Teresa, mum to Ethan and Ronin

There was no hope of a cure, no unified voice, no potential for better healthcare or support. Just scattered families, invisible in health systems data, facing unimaginable loss; and health and care professionals not equipped or supported to alleviate their devastating reality.[8]

"It just feels like you're just living a nightmare that you can't wake up from. In fact, it's probably worse than any nightmare that I've ever been able to conjure up." – Renee, mum to Austin, Holly and Hudson

- **One in every 2,900 babies** is born with a condition that causes childhood dementia.[1]
- On average, **diagnosis is delayed by 2 years** or more after symptom onset.[1]
- **1 in 5 affected families** have multiple children with dementia.[19]
- 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.[13]
- **Globally, there are 24 times more clinical trials** for every child with cancer, than for every child with dementia.[2]
- **Every 11 minutes**, childhood dementia takes another life.[23]
- **50% of children with dementia die by the age of 10**. Approximately 70% will die before adulthood.[1]
- **Each year in Australia, childhood dementia causes 91 deaths.** In comparison, childhood cancer causes 92 deaths in children aged 0-14.[1]

Jobe

Twins Jobe and Tate have been inseparable since birth. In their early years, they grew and learned side by side – crawling, walking and discovering the world together. But at around 18 months, their parents, Tenille and Tim, noticed that Jobe's development began to slow.

Just after the twins' second birthday, doctors delivered devastating news. Jobe was diagnosed with Sanfilippo syndrome, a condition that causes childhood dementia. Tenille and Tim learned that it would steal his abilities, independence, health – and, in time, his life.

Since then, life has been a mix of love, loss and constant adaptation. Now 10, Jobe cannot count to 5, write his name or draw a circle. He struggles to remember family members' names. Tate continues learning to read, spell and ride bikes, while Jobe's world becomes increasingly confusing. Tenille describes watching Jobe's childhood dementia progress as, "grieving for your child's life in front of your eyes, before they've even started it".

"There is not a day that goes by that you do not wake up and think about this terrible disease and wish that there was a cure, not just for Jobe but also for the kids yet to be born."

Tenille wants progress in research, access to clinical trials, and a future where no family must face this again.

"I am angry at the moment that there is not more available."

"One of the things that broke our hearts the most is that it is not only us grieving for Jobe. How is Tate, his twin and best friend, also going to cope?"

Tate (back), Tim (left), Tenille (middle), Jobe (right)

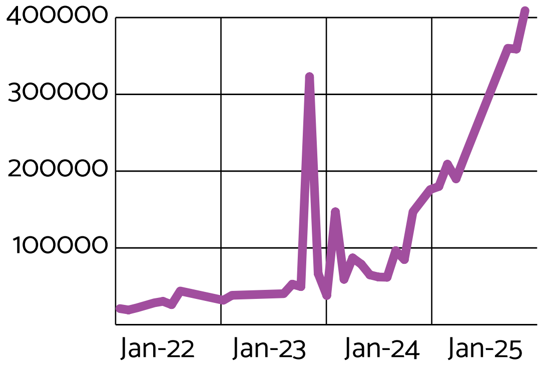
Five years of impact: 2020 to 2025

In its first 5 years, Childhood Dementia Initiative exposed a hidden crisis affecting children globally, amplified the voices of families navigating unimaginable challenges, brought together a powerful movement, and catalysed unprecedented policy reform. We:

Revealed and evidenced the extent and impact of childhood dementia

We built a comprehensive evidence base and generated awareness, shifting childhood dementia from hidden and unrecognised, to a documented health priority through:

- Academic research on the collective impact and extent of childhood dementia in peer-reviewed, globally renowned journals.[1 9 10 11 12]
- Landmark 'State of Childhood Dementia' reports documenting the reality of childhood dementia.[13 14]
- Comprehensive analysis of clinical trials, research investment, and healthcare and disability system opportunities and gaps.[2 3 15 16 17]
- Deep-dive state-based consultations and family experience studies (NSW, WA) on the barriers to care.[6 7]
- Reports commissioned by the Federal Department of Health, Disability and Ageing on care coordination, early diagnosis, healthcare data gaps, and the business case for a National Childhood Dementia Unit.[8 18 19 20 21 22]
- Strategic media engagement, online campaigns, and over 100 conference presentations, reaching millions worldwide, generating global awareness, and catalysing new collaborations with some of the world's brightest minds.



Graph: Google's estimated results for "childhood dementia"

> **"Amazing methodology, one of the most powerful and profound events I have attended in my 40-year career in children's health care services."**
>
> – Health professional on Childhood Dementia Initiative's 2024 Long Table Consultation in Perth, Western Australia

Put family voices and lived experience at the centre of change

Families' lived experience informs everything we do. We:

> **"First and foremost, there is hope. Not false hope that dismisses reality, but the genuine kind that helps us face each day with purpose."**
>
> – From 'Finding Hope: a letter from one parent to another', a support resource created with parents

- Established a world-first Family Advocates Program, providing direct input into policy, service development, research and awareness activities.
- Facilitated meetings between families and the Prime Minister, the Minister for Health and Aged Care, and other policymakers across the country.
- Co-designed with families a suite of trusted information and support resources and an online peer-support community, reaching families across Australia.

Drove policy breakthroughs and meaningful system change

Working with policymakers and engaging stakeholders across sectors, we drove policy and systems improvements for families, including:

- Recognition of children with dementia as a priority population in Australia's National Dementia Action Plan, the first meaningful policy inclusion in the world.
- Peak-body recognition and the extension of adult dementia services to include children.
- The inclusion of children in the WHO-endorsed National Dementia Education and Training Standards Framework.
- Bi-partisan political support for action across federal and state governments.
- The world's first government funding call for childhood dementia research.

Built stakeholder networks, capacity and collaborations

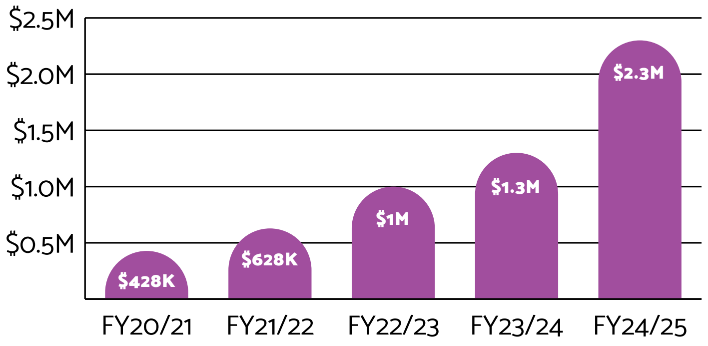
Engaged and connected stakeholders across fields and spanning policy, health, education, disability, palliative care, rare disease, and research. We:

- Established the Childhood Dementia Community of Practice, a free education platform connecting health professionals, and deployed healthcare professional education materials and information sessions nationally.
- Launched the Childhood Dementia Knowledgebase as a central resource hub.
- Fostered research collaborations and inspired new researchers to enter the field.
- Built collaborative global networks, including a partnership with Alzheimer Scotland, sharing our approach in Australia to accelerate global progress.
- Built a sustainable organisation capable of delivering our ambitious vision

Attracted a highly experienced, mission-driven team

- Secured revenue growth of 446% from 2021 to $2.335 million in 2025
- Achieved an average return of $5 for every $1 invested in fundraising, with multi-year funding commitments from across philanthropy, and a diversified fundraising portfolio.
- Launched a Childhood Dementia Legacy Fund for long-term financial security.
- Established strong governance across our Board, Scientific Medical Advisory Committee, and Strategic Advisory networks.

Revenue



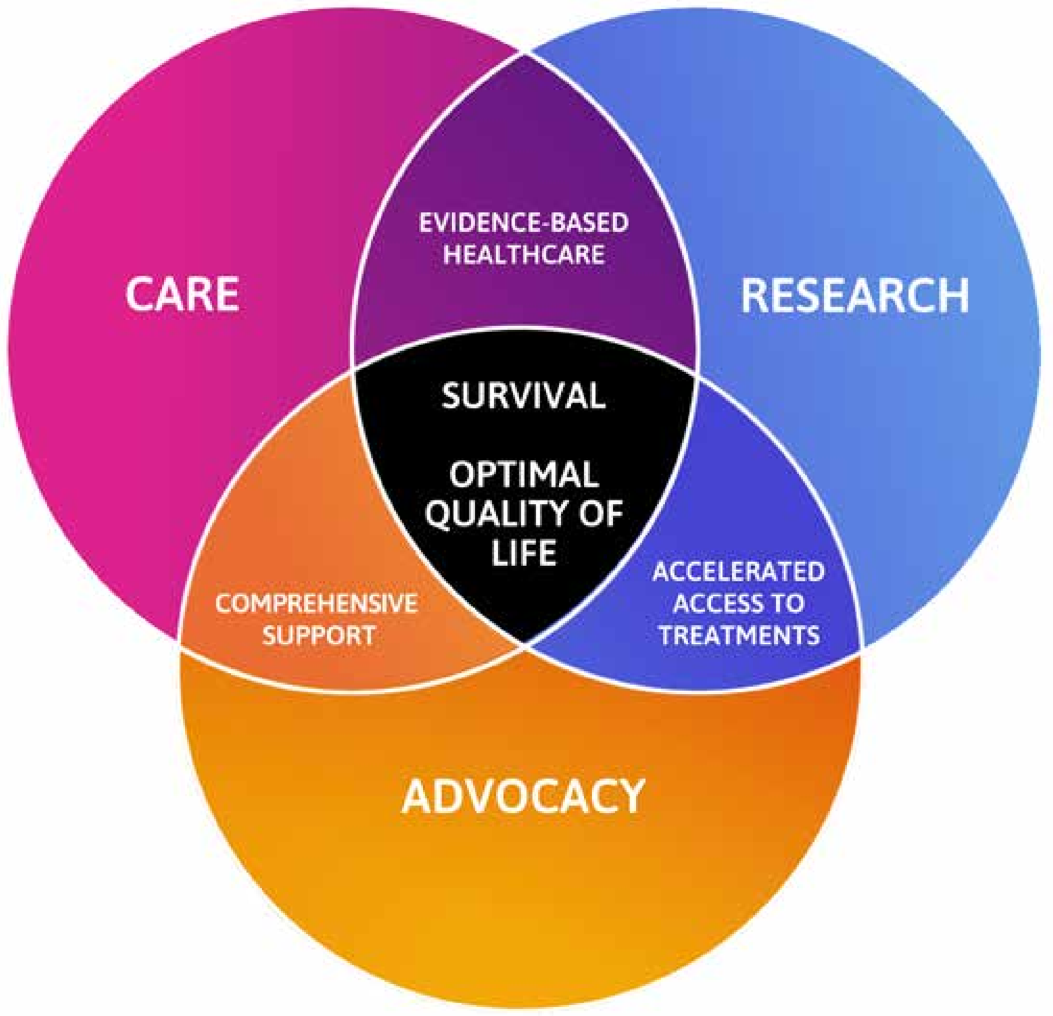
> **"I don't feel as isolated or alone. I have other parents, and I have Childhood Dementia Initiative, who are constantly advocating for us. Literally they are saving lives, saving families. I'm so incredibly thankful."**
>
> - Nicole, mum to Toby (below)

Childhood Dementia Initiative: a bold vision and expert approach

Our approach

An integrated approach is essential to creating lasting systems change and scalable solutions. This approach has identified 3 key goals for the 2026 - 2031 Horizon:

- Evidence-based healthcare
- Comprehensive support
- Accelerated access to treatments.



Underpinning all we do

Principles that guide all of Childhood Dementia Initiative's work

Sustainable solutions: We create lasting solutions that can be sustained into the future.

Systemic change: We don't duplicate services and supports, we drive the adaptation of existing systems to ensure embedded, lasting, and equitable inclusion and support.

Scalable impact: We create change that is replicable and scalable to amplify impact.

Childhood Dementia Initiative's values

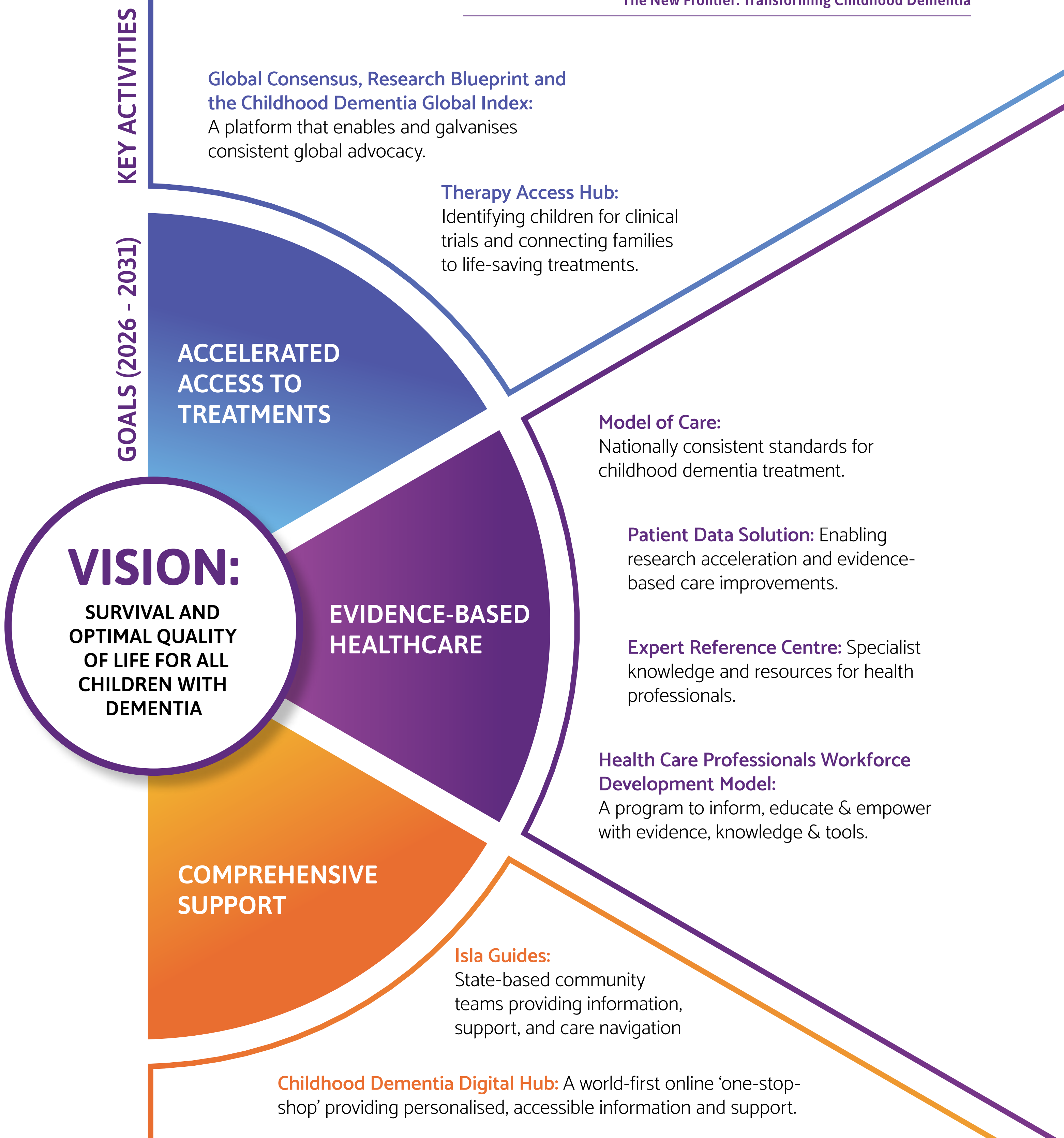
We are **BOLD** in all we do and seek to achieve.

We **AMPLIFY** the voices of our families and the case for change.

We are **TRANSPARENT** in all aspects of our work.

We **UNITE**, bringing together those who can make the changes needed.

We remain **FLEXIBLE** and responsive in our approach, adapting to emerging challenges and opportunities.



KEY ACTIVITIES

GOALS (2026 - 2031)

VISION:
SURVIVAL AND OPTIMAL QUALITY OF LIFE FOR ALL CHILDREN WITH DEMENTIA

ACCELERATED ACCESS TO TREATMENTS

Global Consensus, Research Blueprint and the Childhood Dementia Global Index: A platform that enables and galvanises consistent global advocacy.

Therapy Access Hub: Identifying children for clinical trials and connecting families to life-saving treatments.

EVIDENCE-BASED HEALTHCARE

Model of Care: Nationally consistent standards for childhood dementia treatment.

Patient Data Solution: Enabling research acceleration and evidence-based care improvements.

Expert Reference Centre: Specialist knowledge and resources for health professionals.

Health Care Professionals Workforce Development Model: A program to inform, educate & empower with evidence, knowledge & tools.

COMPREHENSIVE SUPPORT

Isla Guides: State-based community teams providing information, support, and care navigation

Childhood Dementia Digital Hub: A world-first online 'one-stop-shop' providing personalised, accessible information and support.

Powering change

The **$25 million 5x5 Campaign** will fund 5 years of transformation. It will enable Childhood Dementia Initiative to scale proven programs, launch critical solutions, and ensure every Australian family affected by childhood dementia has comprehensive support, setting a new global standard.

The next 5 years: transforming childhood dementia

This strategy represents a fundamental shift from crisis-driven, fragmented care to proactive, coordinated, family-centred support. It transforms childhood dementia from isolation and hopelessness into a condition **where every family has access to the right information and support, every child has a fighting chance, and every professional is empowered to deliver expert care that helps children thrive**. Childhood Dementia Initiative is positioned to deliver transformative solutions across Australia, while leading a consistent global response.

ON THE GROUND:

Isla Guides: Personalised Family Support

State-based community teams who walk alongside families, providing the information, support and guidance they need:

- Meeting families where they are, whether that's at home, in hospital, or in their local community.
- Delivering ongoing support that adapts to each family's changing needs.
- Helping families to navigate the maze of health and disability services.
- Giving compassionate, trauma-informed support for families dealing with devastating diagnoses.

Health Care Professionals Workforce Development Model

A program informing, educating and empowering those responsible for the care and treatment of children with evidence, knowledge and tools. This will include:

- Identifying and engaging the critical talent and key influencers to the care community for children with dementia.
- Equipping them with information and knowledge of childhood dementia, including emerging evidence and the lived experience of families.
- Supporting them with the tools, infrastructure and peer collaboration to drive change within their immediate field.
- controlled data collection that makes these children visible across the healthcare system and drives evidence-based improvements.

ACCESS AT ALL TIMES:

Childhood Dementia Digital Hub

A world-first online 'one-stop-shop' providing personalised, accessible information and support to families and those who treat and care for children with dementia:

- Empowering families and health professionals with evidence-based resources tailored to individual needs.
- Reducing burden on families through streamlined access to services and support.
- Building workforce capacity through professional development and education resources.
- Connecting families to specialist services across disability, dementia, allied health and more.

AT A NATIONAL LEVEL:

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 while delivering significant social and economic returns.[22] The NCDU will:

- **Establish a Model of Care** setting nationally consistent standards for childhood dementia treatment enabling consistent and equitable care.
- **Create an Expert Reference Centre** providing health professionals access to world-first multidisciplinary childhood dementia expertise.
- **Build a Therapy Access Hub** accelerating treatment access by connecting children to clinical trials, addressing barriers to emerging therapies, and positioning Australia as a research leader.
- **Implement a Patient Data Solution** enabling family-controlled data collection that makes these children visible across the healthcare system and drives evidence-based improvements.

Australia-Led Global Leadership

Childhood Dementia is a global problem that demands a global response

In just 5 years of operation, Childhood Dementia Initiative set the foundations to accelerate progress on a global scale. This included:

- **Pioneering International Partnerships**: Our partnership with Alzheimer Scotland has created a blueprint for cross-border collaboration, demonstrating how shared expertise accelerates progress.
- **Uniting Global Voices**: We initiated the Global Consensus Project to unite international expertise and create coordinated, strategic change.
- **Knowledge Exchange**: Through stakeholder engagement, global collaborations, conference presentations, and a prestigious Churchill Fellowship awarded to our pioneering Director of Programs, we built bridges across continents, sharing learning and fostering global engagement.

> **"Recognising dementia as a condition that can affect people at any age is transformative for research and care. This integrated approach will accelerate the development of treatments and improve outcomes for patients of all ages."**
>
> - Professor Sameer Zuberi, paediatric neurologist, University of Glasgow and Royal Hospital for Children, Glasgow, and Global Childhood Dementia Steering Group member.

LEADING GLOBAL CHANGE (2025-2030)

Childhood Dementia Initiative is leading the global response to childhood dementia, building an international advocacy platform for coordinated action and lasting change. We are:

- **Establishing international consensus on childhood dementia** through standardised global definitions and inclusion criteria. This consensus creates the shared language and frameworks necessary for coordinated action and positioning childhood dementia within global health policy.
- **Building a Global Research Blueprint** that prioritises research needs and opportunities, and establishes standardised protocols to enable more efficient and effective trials.
- **Creating a Childhood Dementia Global Index** a unified platform that reveals the scope of childhood dementia across geographies and empowers effective, consistent advocacy worldwide.

Through this platform, Childhood Dementia Initiative is engaging critical stakeholders internationally, sharing our world-first evidence-based models, and driving coordinated action that will deliver sustainable impact for all children with dementia.

Professor Zuberi in New York where he presented at the UNGA Brain Health Summit in September 2025, raising global awareness of childhood dementia and the need to make it a health policy priority.

What this really means. By 2031:

FOR CHILDREN WITH DEMENTIA

Tailored support	Personalised care plans tailored to their specific condition, circumstances, and family context.
Equity	From Sydney to regional Western Australia, children will receive consistent, evidence-based care, ending the geographic health inequity that currently exists.
Proactive healthcare and reduced emergencies	Proactive and coordinated care, reducing preventable hospital admissions and emergency presentations, and providing families with clarity about what to expect rather than managing constant crises.
A chance at survival and optimal quality of life	Access to cutting-edge treatments and clinical trials integrated into standard care pathways and more global clinical trials attracted to Australia. Faster and more accurate diagnoses, ending years of uncertainty, and enabling earlier interventions when they are most able to have an impact on the quality of life and survivability for a child.

FOR HEALTH PROFESSIONALS

Connection to experts and resources	Health professionals who care for children with dementia will have access to expert knowledge and resources, ending the current reality of researching unfamiliar conditions in isolation.
A model of care to guide them	A clear, evidence-based model of care will guide professionals through the right steps to take. No matter where a professional is, or what system they are working within, they will have the information and confidence to provide quality care.
Capacity and knowledge to give quality care	Through a community of practice, information resources, and webinars, professionals will learn from and collaborate with peers across disciplines. Professional development and education will build workforce capacity and expertise in childhood dementia nationally, ensuring professionals have the foundations to provide appropriate care.

FOR PARENTS AND FAMILIES

An end to isolation	Peer support programs and online communities will connect parents and families with other families who truly understand.
Quality healthcare and support without having to fight	Isla Guides will give support and care navigation while also building capacity across a family's team. As a result, across disability, education and health, a family will be guided by an informed and supported team of professionals.
Reduced anxiety and more time	Structured, clear pathways will reduce anxiety by helping families know what to expect and where to turn. Streamlined diagnosis and care coordination will give families back precious time.
Information	The Digital Hub will provide reliable, evidence-based information at their fingertips, delivering answers to urgent questions when and how the families most need it.
Knowledgeable health professionals	Families will have access to specialist services delivered by professionals who understand childhood dementia.

We will address the entire ecosystem of treatment and care, and create sustainable, systemic change that will benefit every child with dementia now and for generations to come.

> **"An end to childhood dementia would mean that my children wouldn't have to suffer. It would mean that they wouldn't lose all of their abilities. It would mean they wouldn't lose each other and I wouldn't lose them."**
>
> **Renee, mum to Holly (left), Austin (middle) and Hudson (right)**

Why Childhood Dementia Initiative

We're the only organisation doing this globally

Childhood Dementia Initiative is the only organisation globally taking a collective approach to childhood dementia, uniting 140+ individual rare diseases under one coordinated strategy.

We deliver systemic change

Childhood Dementia Initiative operates at a systems level. Rather than simply helping families navigate fragmented systems, we work to transform those systems. Our track record demonstrates this impact and we are trusted partners in building national healthcare infrastructure and building critical policy.

We operate our work with measurable ROI

The proposed National Childhood Dementia Unit delivers $61.49 million in quantified benefits for a $12.64 million investment, returning $4.90 for every $1 invested. Beyond these measurable outcomes, the initiative will accelerate research, attract pharmaceutical investment, and improve survival rates. This represents philanthropic capital deployed with significant, measurable impact.

Impact building from the ground up

We are building from the ground up. Every initiative sets new standards, evolving and creating systems that have never existed before, establishing international benchmarks from the outset.

We have proven execution capability

Our growth trajectory speaks to our organisational capability: from 1.1 FTE to 9.4 FTE in 5 years, 446% growth in income, and evolution from zero recognition to bi-partisan political support and inclusion in national policy. We have commissioned research that informs government strategy and have demonstrated the ability to translate vision into measurable outcomes.

We're positioning Australia to lead a global healthcare transformation

Australia has unique conditions to lead in childhood dementia solutions: universal healthcare, concentrated population centres, world-class research infrastructure, and a culture of healthcare innovation. The solutions we develop here will establish international standards, positioning Australia as a leader in rare disease innovation.

Your timing matters: we're at the tipping point

Over 5 years, we have built essential foundations: evidence, relationships, credibility, and infrastructure. We are now ready to implement solutions that will fundamentally change outcomes for children. The National Childhood Dementia Unit, Digital Hub, Isla Guides, Healthcare Professional Workforce Development, and Global Research Blueprint are not aspirational. They are ready for launch. Philanthropic investment now will accelerate implementation and turn foundational work into transformation.

Investment in Childhood Dementia Initiative means supporting the only organisation with the vision, capability, and strategic positioning to transform childhood dementia from a life-limiting condition to a treatable one - in a way that has implications for rare disease healthcare globally. This represents strategic philanthropy at scale.

Outstanding leaders and a bold, visionary team

Our team brings decades of experience in healthcare innovation, policy development, fundraising and organisational leadership, as well as the representation of the lived experience of childhood dementia. The team built Childhood Dementia Initiative from a concept into a trusted leader in childhood dementia, demonstrating the strategic acumen and execution capability required to deliver on our ambitious vision.

Board of Directors

Childhood Dementia Initiative's Board provides strategic oversight and governance, bringing expertise across healthcare policy, medical research, business strategy, philanthropy, and lived experience. The Board ensures organisational sustainability, financial accountability, and alignment with our mission to transform outcomes for every child with dementia.

Scientific and Medical Advisory Committee

Our Scientific & Medical Advisory Committee comprises leading clinicians, researchers, and academics with expertise in paediatric neurology, genetics, rare diseases, clinical trials, and health services research. This committee ensures our work is grounded in the latest scientific evidence and clinical best practice.

Strategic Advisory Network & Ambassadors

Childhood Dementia Initiative's Strategic Advisory network and Ambassadors connect us with expertise across government, healthcare systems, research institutions, and international organisations. These relationships enable us to navigate complex systems, anticipate policy changes, and position Childhood Dementia Initiative at the forefront of rare disease innovation globally.

Join us at this new frontier. Together, we will transform childhood dementia from crisis to the world's most inspiring healthcare revolution. A revolution that means life, hope, and countless futures restored.

> **"Childhood Dementia Initiative is absolutely critical to creating the change we need for children with dementia and for the wellbeing of families. You can't ignore thousands of families in this country going through what we're going through."**
>
> Sarah (back right), mum to Callum (front right)

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I’m proud to work alongside Childhood Dementia Initiative to create meaningful change for children with dementia. Their work is changing the entire conversation on an international basis and opening up new avenues for understanding, support and research that were previously unavailable. The family-centred approach means that patients and families affected are always at the table and given a voice in the discussions. **For me, this has been one of the most meaningful initiatives for decades.**”

- Professor Simon A. Jones, consultant in paediatric inherited metabolic diseases (Manchester, UK)

“The impact of caring for a child or children with dementia is immense. We know from families that children with dementia don’t fit within the established systems of health, disability and social care, and this means it’s difficult for them to access the support their children so desperately need. **The Albanese government congratulates Childhood Dementia Initiative for their work in this area**.”

Mark Butler MP, Australia’s Minister for Health and Ageing, Minister for Disability and the National Disability Insurance Scheme

“Congratulations to everyone involved with the Childhood Dementia Initiative. It is such an important endeavour. **Already you have provided real progress and given so many families realistic hope. I thank you and wish you all the best for the next 5 years and beyond**.

- Greg Hunt, former Health Minister of Australia (2017 - 2022)

“Childhood Dementia Initiative is leading meaningful change for children and families affected by childhood dementia. **At Dementia Training Australia, we are proud to work in collaboration with Childhood Dementia Initiative and ensure that children living with the disease are not forgotten or left behind in Government reforms**. Embedded throughout our newly released National Dementia Education and Training Standards Framework are the needs and experiences of children living with dementia, which is a world first. The Framework will improve the consistency and quality of dementia education and training across Australia.”

- Isabelle Meyer, Executive Director, Dementia Training Australia

“**I was privileged to be part of the Childhood Dementia Initiative Board from its inception in 2020, and am amazed by the significant impact of Childhood Dementia Initiative since that time**. The team, guided by Meg’s visionary leadership, has catalysed national and international awareness of the plight of children living with – and dying from – childhood dementia. They have galvanised the medical and research community to the potential of collectively considering conditions that cause childhood dementia. They are striving for system-wide change to provide family-centred support, coordinated care, and access to life-changing advanced therapeutics.

I am confident that Childhood Dementia Initiative will shape a future strategy that brings hope to children with childhood dementia, and their families.”

- Tiffany Boughtwood, Australian Health Genomics Commissioner and Founding Board member, Childhood Dementia Initiative

> **“Before we found Childhood Dementia Initiative, it was like being out in the wilderness. But now we’re connected, and I know that the changes we’ve helped create are directly helping other families. I can’t tell you what that feels like. We’re speaking up to make change for families now and also for future generations.”**
>
> - Rachel and Eli, parents to Benjamin (left) and Hannah (right) who lives with childhood dementia.

childhood dementia INITIATIVE

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