State of Childhood Dementia In Australia 2024

childhood dementia INITIATIVE

> **“They said: ‘Look, this is what your son has’. And I said, ‘Okay, so what does that mean for the future?’ And they said, ‘Oh, well, it’s a progressive, fatal disease and he will likely only survive until his teenage years’. There was no real delivery about what symptoms to expect or anything like that. The crux of it was just take him home and enjoy him and see you later.**
> **It was quite challenging.”**

Pip (left) who is mum to Thomas (centre front) who has childhood dementia, Annabelle (left front) and Jessica (right front), and wife to Paul (back right).

Acknowledgements

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.

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And 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.

Cover: Mia, who died with childhood dementia

> “When we were given Louis’s diagnosis, we were devastated and heartbroken. We focused on giving him the best life possible, living by the motto it’s no longer about what he can’t do but what he can do, which ended up being a lot. We could not stop caring for him, fighting for him, giving him every life experience possible, and, of course, loving him. He deserved this and so much more.”

Amy and James, mum and dad to Louis.

We are very sad to share that Louis died while this report was being written.

Contents

Foreword

Families are the experts in their children. Parents of children with dementia not only know their children best, they must become disease experts, and through their lived experience, they truly understand the inequity, burden and need for change. All of Childhood Dementia Initiative's work is led by the experience of children with dementia and their families. This foreword is co-authored by parents of children with dementia.

Every day with childhood dementia is a rollercoaster of emotions, challenges, and uncertainties. As parents of children with these rare, life-limiting conditions, we live in a world that most people — even many health professionals — struggle to comprehend.

Our daily lives are consumed by the relentless demands of caring for our children. **We juggle countless medical appointments, navigate complex health systems, and fight tirelessly for the support and understanding our children desperately need.** The unpredictability of our children's conditions adds another layer of stress to an already overwhelming situation. Some of us have other children in our family and we watch their childhoods also get consumed by the overwhelming needs of their siblings. It deeply affects everyone who loves our families.

The profound grief and anticipatory loss we experience is ever-present. We watch helplessly as our children slowly lose abilities they've worked so hard to gain. Each regression is a painful reminder of the cruel nature of these conditions. **The joy we get from seeing our kids smile, or turn their heads to our voices is tinged with the grief of wondering whether that will be the last time they are able to do that.** The emotional toll is immense, compounded by the fact that we often can't fully understand what our children are experiencing.

The isolation we feel is suffocating. We yearn for connection with others who understand our reality, but the rarity of these conditions often leaves us feeling alone. 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.** Even with all our knowledge, we're frequently in the dark about what the future holds.

Despite the challenges, we persevere. We fundraise, travel great distances for clinical trials, and turn our pain into purpose by supporting other families. We do this because our children deserve a chance at life, like every other child. Their resilience and joy in the face of such adversity are both heartwarming and heartbreaking. **Our kids are like all your kids, except our kids are dying.**

Our greatest hope lies in advancing understanding and research into these conditions. With more knowledge comes power – the power to change lives and offer hope where once there was none. **We dream of a world where no parent has to watch their child slowly fade away, where effective treatments and even cures are a reality.**

Knowing that our children's diagnoses, symptoms and stories can help understand these diseases and one day cure them helps give us purpose, even on the worst days. But that can only happen if we make it happen, and if people pay attention.

As you read this report, please remember that behind every statistic are real families like ours, fighting each day to give our children the best possible life in the time we have. We need your help to drive change.

Childhood dementia causes a similar number of deaths as childhood cancer, yet receives a fraction of the attention and funding. This disparity is not just unfair – it's devastating for our children and families. **We're not just fighting against time; we're fighting against a lack of awareness, understanding, and resources.**

Our children are running out of time. Their lives are difficult and always too short, but they are filled with love, moments of laughter, and glimmers of pure joy. They deserve better than what current systems and society offer them. They deserve a chance at a future.

Will you join us in the fight against childhood dementia? Your understanding, your voice, and your support can make a real difference. Together, we can change the narrative for children with dementia and their families. Our children's lives depend on it.

– Cindy, Felicity, Nicole, Peta, Renee and Sam on behalf our children

Cindy's child,
Jessie Mei Mei

Felicity's child, Orla

Nicole's child, Toby

Peta's child, Mia

Renee's children,
Hudson, Holly & Austin

Sam's child, Caleb

> “I think the heartbreaking part of childhood dementia is the regressive nature of it. Having a child, watching them grow, watching them achieve and then watching that slowly be unpicked until there’s nothing left. To me, that is what makes it different, watching someone stage by stage die, parts of them dying. It’s a very slow and very cruel disease.”

Nicole, mum to Toby

Executive Summary

About Childhood Dementia

A baby is born every 3 days in Australia with a childhood dementia disorder from which they will die. Half of all children with dementia die before the age of 10, and 70% of them will die before they reach adulthood. Throughout their short lives, these Australian children suffer and die slowly, without access to therapies or adequate care.

There has been no notable improvement in survival rates for children with dementia. By comparison, death rates from childhood cancer in Australia almost halved in the 20 years between 1997 and 2017, and more than 84% of children with cancer now survive.

Historically, the 100+ conditions that cause dementia in childhood were considered in isolation, despite the commonality of disease mechanisms, symptoms and needs. This resulted in widespread fragmentation and exclusion across care, policy and research on a global scale.

The state of childhood dementia in Australia

Australia is the first country in the world to begin considering the collective group of childhood dementia disorders in a system-wide approach, including research funding and policy. Childhood Dementia Initiative, founded in 2020, is spearheading this work. This approach involves focusing on the presentation of childhood dementia – the symptoms and how children are impacted – rather than the biological basis of each of the underlying diseases. Viewing childhood dementia as a collective enables the delivery of solutions with economies of scope and scale. It also generates broader community understanding.

Evidence is now emerging that paints a devastating picture of the state of childhood dementia in Australia in 2024.

The unique attributes of childhood dementia and the lack of a coordinated national approach means that **children with dementia carry arguably the highest level of unmet need in the Australian paediatric health system.** Childhood dementia is complex and crosses many areas of health and social care. It does not fit neatly into any one established area, and as such, the needs of this cohort have continued to be unmet.

- There are no cures for childhood dementia and it is life-limiting for all affected children.
- Children experience chronic, increasingly severe symptoms and their intellectual and physical disabilities progress until they die prematurely. Children suffer from confusion, distress, unhappiness, and pain. The complex childhood dementia disorders can also cause seizures, loss of vision and hearing, and problems with bones, joints and cardiovascular, respiratory, or digestive systems.
- There is, and has always been, gross inequity and underinvestment in research.
- The challenges facing children with dementia are not currently addressed by any national dementia policies globally.

- In the absence of national guidelines and expertise across health and care systems, the level of care children receive depends on their families' advocacy capacity and health literacy, creating inequity at best and, more concerningly, risk to children's safety.
- Childhood dementia disorders are individually rare. Families report struggling to get diagnoses, and can subsequently go on to have more than one child without knowing about their genetic risk.
- There is a significant burden on families to take responsibility and manage all aspects of their child's care.
- The psychological toll on families is severe and enduring. Family dynamics are profoundly affected and financial burdens add another layer of stress. Mental health of the entire family unit is impacted.

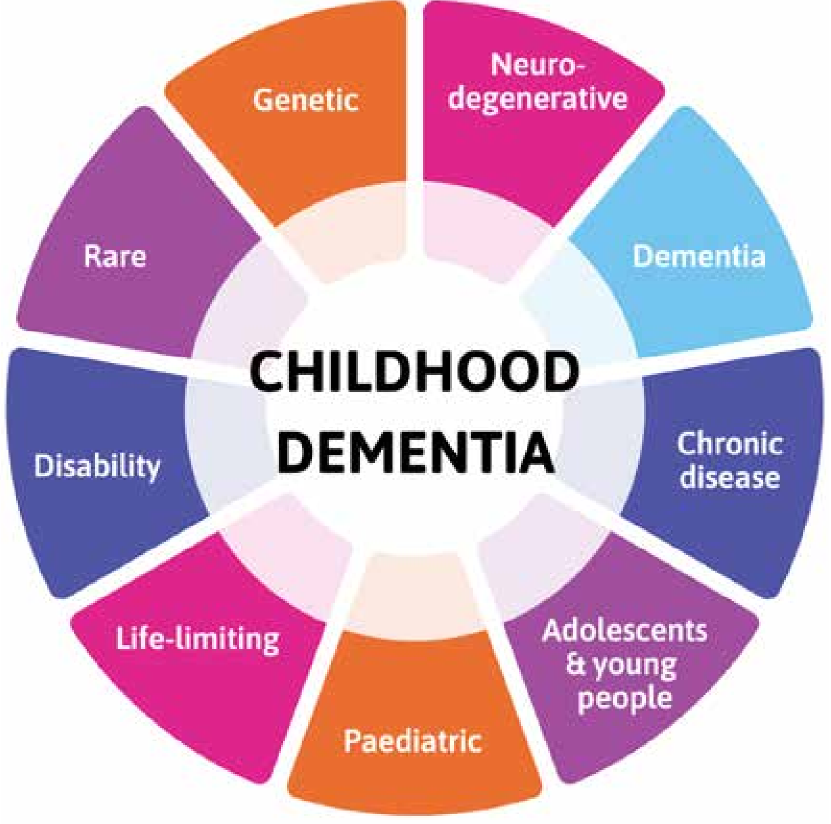
A coordinated national approach is needed

Despite the dire state of childhood dementia in Australia, new and emerging evidence is revealing clear pathways to solutions.

Focussed investment into a coordinated national approach to childhood dementia has the potential to deliver:

1. Improved survivorship and symptom management through accelerated access to therapy and therapeutic development.
2. Equitable access to consistent and quality care and support for children with dementia and their families.

Figure 1: Unique attributes of childhood dementia



Current state	Opportunity for change
There are no treatments and cures for the vast majority of childhood dementia disorders and there has been no notable improvement in survivorship over the last decades.	Reduce the 100% mortality rate of childhood dementia through: • Increased and targeted research funding across the entire therapeutic pipeline. • A more cohesive and collaborative research approach, including research-enabling infrastructure and platforms for therapeutic development across multiple subtypes of childhood dementia. • Increased clinical trial capacity and readiness in Australia, including data registries and clinical trial networks, both to enable locally initiated trials and attract more international trials. • Early diagnosis through expanded newborn screening and rapid diagnosis pathways to enable access to clinical trials and emerging treatments. • Government-funded access arrangements for new medicines approved overseas until they are available in Australia.
Expertise and knowledge are limited among professionals within Australia's health system. There is no centralised source of information or resources to inform the care they deliver.	Address workforce capacity and capability constraints currently hampering care provision by: • Delivering a quality education and training program to enable service providers to meet the needs of children with dementia and their families. • Providing access to dedicated resources, information and expertise relating to childhood dementia.
Healthcare is inadequate and inequitable. There are no national standards, no specialist models of care, and no standard pathways.	A coordinated national approach to childhood dementia leveraging established processes and functions would vastly improve outcomes for families and deliver efficiencies across the spectrum of care and support for children with dementia. This can be enabled by: • Developing and implementing a National Framework for Care for Childhood Dementia. • Enabling effective care coordination to reduce the burden on families and improve care for children. • Improving psychological support for families impacted by childhood dementia. • Improving NDIS processes to recognise and support the progressive nature of childhood dementia conditions and the unique needs of affected children.

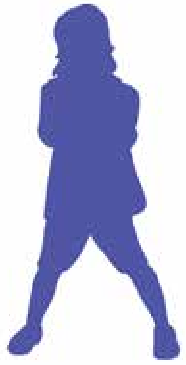
Childhood dementia overview

One in every 2,900 babies

is born with a condition that causes childhood dementia

50%

of children with dementia die by the age of 10



Approx.

70%

of children die before their 18th birthdays

Children with dementia experience:

- Memory loss
- Confusion
- Trouble concentrating, understanding, learning and communicating
- Personality changes
- Severely disturbed sleep
- Behaviour changes such as hyperactivity
- Emotional issues like anxiety and fear

CHILDHOOD DEMENTIA RESULTS FROM PROGRESSIVE BRAIN DAMAGE CAUSED BY 100+ GENETIC CONDITIONS

Estimated in Australia every year:

91 deaths in people with childhood dementia

92 deaths from childhood cancer (0-14 yrs)

Delayed diagnoses

On average, **diagnosis is delayed by 2 years or more** after symptom onset

1 in 5

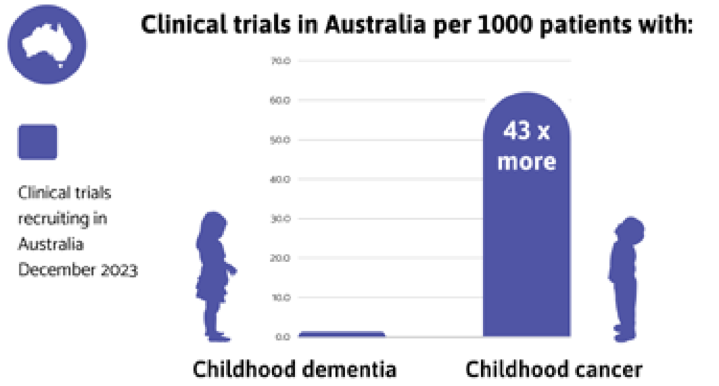
affected families have multiple children with dementia

92%

of families reported **their work status changed** due to their child's condition

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

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.



Clinical trials in Australia per 1000 patients with:

FEWER THAN 2%:

children with dementia in Australia who can join a clinical trial

INVISIBLE IN THE HEALTH SYSTEM:

Over 80% of the childhood dementia disorders

have no specific International Classification of Diseases (ICD-10) code

100% of researchers

surveyed need more funding to progress research

Childhood Dementia Initiative

Childhood Dementia Initiative is leading world-first action for every child with dementia.

The organisation drives solutions for the conditions that cause childhood dementia as a collective. This approach compels awareness and greater efficiencies, scale and impact.

Childhood Dementia Initiative employs a systems change approach to transform how children with dementia are viewed, treated, and cared for. 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 will enable world-class solutions to be developed and implemented in Australia.

To drive system change, Childhood Dementia Initiative supports the development of a body of comprehensive evidence that is validated by:

- Data
- Lived experience
- Expert insight

Childhood Dementia Initiative's approach aligns with the UN Sustainable Development Goals, particularly 'Ensuring Healthy Lives and Promoting Wellbeing for All at All Ages' and 'Reducing Inequality' and adheres to the National Strategic Action Plan for Rare Diseases, recognising the need for collaborative, person-centred research that systematically addresses gaps in rare disease management. The organisation's work is also guided by broader relevant strategic frameworks in Australia, including but not limited to, the National Strategic Framework for Chronic Conditions, the National Dementia Action Plan (when published) and the Paediatric Palliative Care National Action Plan.

Progress for children with dementia

2020

Childhood Dementia Initiative launches.

Burden of disease study identifies the significant impacts of childhood dementia on children, carers, the healthcare system and economy in Australia[1].

2021

First Childhood Dementia Day

2022

Childhood Dementia Knowledgebase released giving a central source of data on the conditions that cause childhood dementia.[2]

Inaugural Childhood Dementia Research Symposium held.

The Australian Government commits $3M for research on multiple childhood dementia conditions.[3]

World's first childhood dementia information resources for health professionals developed.

2023

Research report, 'We don't fit', details the lived experiences of families in Australia affected by childhood dementia with care and support services.[4]

UNSW publishes a review of the psychosocial impacts of childhood dementia on families globally.[21]

Children with dementia included in Australia's Draft National Dementia Action Plan.[6]

Research identifying 145 individual childhood dementia disorders gives global clarity on the scale of childhood dementia.[7]

2024

The Australian Government commits to comprehensive analysis of gaps in care and support for affected children and families and to develop solutions.[11]

State-based consultations give new insights into the lived experience of families in NSW and WA.[5,8]

Analyses of global clinical trial activity[9] and childhood dementia research funding in Australia[10] reveal concerning trends and inequity.

No treatments. No cure.

Childhood dementia represents a devastating and inequitable reality in paediatric health. Every child diagnosed with a childhood dementia disorder faces premature death. There has been no notable improvement in survivorship over recent decades. This stark situation contrasts sharply with other paediatric conditions that have seen remarkable advancements in treatment and survival rates.

In Australia, childhood dementia claims approximately 91 lives annually, a number comparable to childhood cancer deaths for patients aged 0-14 years (92).[7] However, while over 84% of children with cancer now survive, every child living with a childhood dementia disorder is expected to die prematurely – half before their 10th birthdays.[7,12] During the same period that childhood dementia has seen no progress, death rates from childhood cancer have halved, and life expectancy for cystic fibrosis has doubled.[12,13]

> **“It is heartbreaking watching her fade away.”**
>
> **Cindy, mum to Jessie Mei Mei**

Figure 2: Survivorship among children aged 0-14 years in Australia living with dementia and cancer

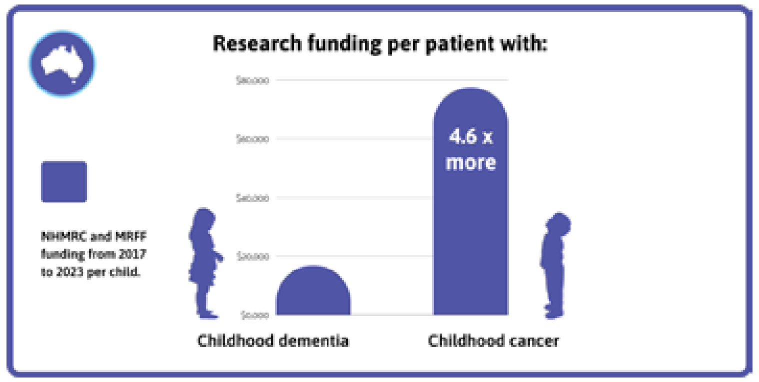


Figure 3: Australian Government research funding per patient

The vast majority of childhood dementia disorders lack treatments or cures,[7] and opportunities to access emerging therapies are severely limited.

Inadequate funding

Historic underfunding of childhood dementia research has significantly hindered progress. Despite Australia's Government being the first in the world to commit targeted funding for childhood dementia research, investment into this group of conditions has been limited compared to other conditions. Just over $23 million was directed to childhood dementia in the period 2017 - 2023. Childhood cancer research, in comparison, received $154 million in funding during that same period.[10] This underinvestment spans the therapeutic pipeline, from basic research to clinical trial infrastructure and translation. On a per-patient basis, this equates to 4.6 times more research funding being directed to childhood cancer than to childhood dementia.

> **“Research funding and its continuity is the biggest challenge for these less well-known conditions and is a major barrier to producing high-quality research and outcomes for patients.”**
>
> Senior Principal Research Fellow.

Fragmented approach to research

Research into childhood dementia disorders is disparate and siloed, with single disorders typically researched in isolation. This limits the potential for identifying common pathways and developing broadly applicable treatments.[14] A survey revealed that 77% of researchers believe a lack of fundamental research to understand the commonalities between childhood dementia conditions significantly hampers their ability to develop treatments. There is also a lack of research infrastructure, with 70% of researchers needing improved access to biosamples linked to patient clinical data to progress their research.[15]

Delayed diagnosis

Early diagnosis can accelerate the development of treatments and cures. However, diagnosis is typically delayed, often by 2 years or more after the onset of symptoms[7].

Halting neurodegeneration once it has started is extremely difficult. As such, early diagnosis is crucial for children with childhood dementia disorders to ensure they can access potential treatments and clinical trials. The limited treatment options that are available for a minority of children are often not effective because children are diagnosed and treated too late. Additionally, clinical trials for potential new treatments often have narrow recruitment criteria, with age cutoffs that many children miss due to delayed diagnosis.

Due to the genetic nature of childhood dementia, many families (15-20%) are at risk of having more than one child with the condition. The proportion of families caring for 2 or more terminally ill children with dementia could be reduced by earlier diagnosis. This is because it allows families to understand their risk for future pregnancies and plan accordingly, including the possible use of IVF techniques to reduce the risk.

The reasons for delayed diagnosis are multifaceted, including:

- Delays in referral due to health professionals' lack of awareness of childhood dementia and understanding of the importance of early diagnosis for these conditions
- Non-specific early symptoms that often lead to misdiagnosis of more common conditions such as autism
- Long waiting times to see specialists
- Limited access to genomic testing

> **"I think as a parent, sometimes you kind of get dismissed and treated like you're silly. But we know our kids best, and if you know your child's going backwards, something is wrong."**
>
> Parent of a child with dementia

Newborn screening could play a crucial role in early detection, but current tests are too limited. While Australia has a well-subscribed newborn screening process, several childhood dementia conditions widely screened in other countries are not yet included in Australia's program (Biotinidase deficiency, Hunter syndrome, Hurler syndrome, X-linked adrenoleukodystrophy and Krabbe disease).[16]

Expanding newborn screening and the implementation of rapid diagnostic pathways could potentially enable access to approved and emerging treatments and clinical trials, which have the potential to significantly improve and lengthen the lives of children with dementia.[17]

> **"We need to get these children seen earlier and by the right specialists because that's the only way that we're going to be able to access a potentially disease-modifying treatment for them."**
>
> Paediatrician.

Lack of clinical trials and enabling infrastructure

There is a notable absence of critical infrastructure to support emerging therapies, including comprehensive data registries, clinical trial networks, and resources for horizon scanning.

The disparity in clinical trial activity for childhood dementia compared to other conditions,such as childhood cancer, is particularly concerning.[9] In Australia in December 2023, there were 43 times more clinical trials recruiting children with cancer than children with dementia per patient. Alarmingly, no new clinical trials for childhood dementia were initiated in Australia that year. **This means that fewer than 2% of children with dementia currently have any prospect of joining a clinical trial in Australia, despite clinical trials providing the only opportunity to access potentially life-saving therapy for the vast majority.** 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.[18]

The comparable lack of clinical trial activity for childhood dementia extends much further. Globally, clinical trial activity for childhood dementia slowed in the 5 years from 2018 to 2023.[9] This is despite continued growth in overall clinical trial activity and scientific advances that should be enabling rapid therapy development.

> **"We are often contacted by industry regarding clinical trials but often do not have the staff (especially clinical trial coordinators) or infrastructure within the hospital to take on extra trials."**
>
> Clinical research coordinator

Access to emerging therapies

There are treatments for some types of childhood dementia approved overseas. However, historically, Australians have waited on average 5 years to receive reimbursed access to new medicines after they have registered internationally.[19,20] In the period 2017 to 2024, at least 5 drugs were approved in the USA and/or Europe and more continue to move through the approval pipeline.[17] These therapies are not available in Australia, and children don't have 5 years to wait. Access arrangements need to be put in place until they are approved by the Therapeutic Goods Administration and funded by the Government.

> **"We moved our life over there [to the USA] for 10 months. And now we go back every 6 months."**
>
> Parent of a child with dementia

> **"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

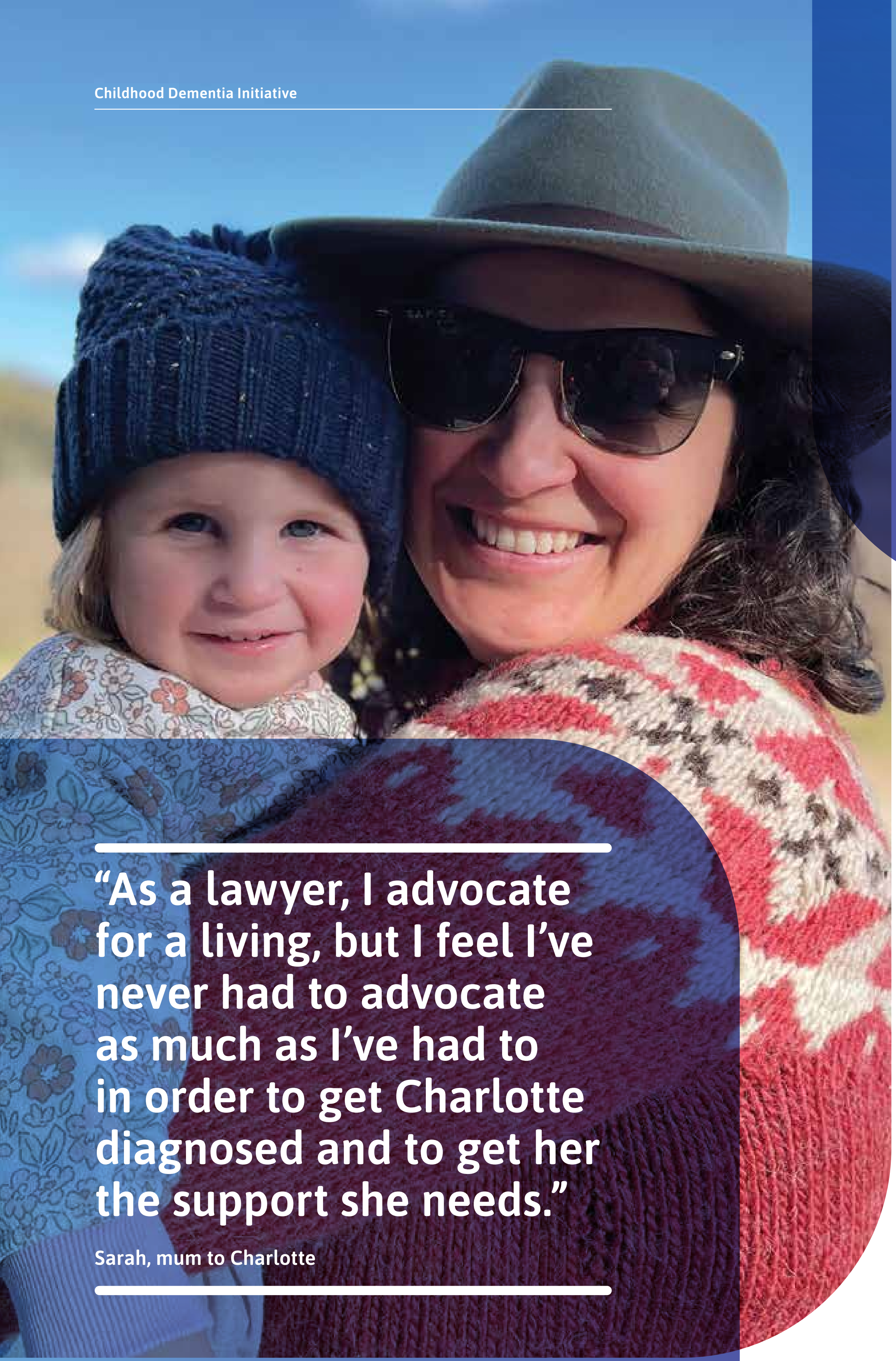
Without urgent action...

The lack of progress in childhood dementia research and treatments has a profound effect on affected families. Parents face the heartbreaking reality that their child's condition is fatal, with no effective treatments available. The limited clinical trial options, especially in Australia, mean that families often have no access to potentially life-changing or life-saving therapies. Those who are able to access international trials need to travel large distances, further disrupting family life and precious time with children while driving up expenses.

This situation places an enormous emotional, physical, and financial burden on families. Moreover, the lack of research progress means that families have little hope for improvement in their children's conditions. This stark reality contrasts sharply with the hope offered to families facing other paediatric conditions, where ongoing research and clinical trials provide a sense of possibility for the future.

What needs to change?

1. Increased and targeted research funding across the entire therapeutic pipeline.
2. A more cohesive and collaborative research approach, including research-enabling infrastructure and platforms for therapeutic development across multiple subtypes of childhood dementia.
3. Increased clinical trial capacity and readiness in Australia, including data registries and clinical trial networks, both to enable locally initiated trials and attract more international trials.
4 Early diagnosis through expanded newborn screening and rapid diagnosis pathways to enable access to clinical trials and emerging treatments.
5 Government-funded access arrangements for new medicines approved overseas until they are available in Australia.



> **“As a lawyer, I advocate for a living, but I feel I’ve 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**

Healthcare needs not met

Families affected by childhood dementia face a range of challenges as they seek and engage with healthcare and support services, causing tremendous psychosocial distress.[4,21] Severe systemic lack of knowledge and understanding, coupled with a chronic absence of expert care and associated standards, is resulting in poor quality healthcare. This issue extends from pre-diagnosis through to end of life, and beyond.

Limited expertise and information

Research paints a grim picture: families are desperately seeking the appropriate care for their children, and health professionals are struggling to provide appropriate support. Families frequently encounter medical professionals unfamiliar with their children’s conditions.[4,21] Following usually protracted delays[7], diagnoses are often delivered without the required information and support.[4,5,8,14,21]

Parents report becoming ‘experts’ on their children’s conditions and searching for answers with multiple health professionals in different healthcare settings over prolonged periods.

Many health professionals cite limited and variable understanding of childhood dementia as the primary challenge in the current care landscape.[14] This lack of expertise can lead to inappropriate care, missed opportunities for early intervention, and inadequate psychosocial support for already struggling families.

Families and health professionals identify a need for more comprehensive information about childhood dementia.[14] This includes the associated behavioural and psychological symptoms and appropriate responses, as well as clinical guidelines to support health professionals in caring, prescribing, and referring based on identified clinical needs. Furthermore, local care teams require a source of expertise to consult on clinical care. Health professionals operate in isolation with little or no peer support to enable their practice. In addition to inconsistent outcomes for families, this also results in negative experiences for the clinical workforce.

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

Data gaps

Underpinning the lack of expertise among health professionals is a chronic absence of data. Children with dementia are not identifiable within our current health systems, hampering service development.

Australian health systems currently use the World Health Organisation’s International Classification of Diseases ICD-10 classification. Fewer than 20% of childhood dementia disorders have a specific ICD-10 code, accounting for only a third of childhood dementia births.[22] This means accessing data about these children and their use of health, disability, and support systems is nearly impossible. For example, the Australian Institute of Health and Welfare is not able to accurately include data about childhood dementia in their ‘Dementia in Australia’ reporting.

> **"When palliative care was suggested, first we were horrified; we couldn't believe they were already trying to plan for our child's death. But once we started meeting with them, we understood that it wasn't just that. There were so many ways they could support us."**
>
> Parent of a child with dementia

Childhood dementia patient registries are scarce and fragmented. Only a few specific types of childhood dementia have dedicated registries, and these are often underfunded, leading to poor data quality and sustainability issues.[23] This lack of comprehensive, well-maintained registries hinders research efforts and limits our understanding of these conditions.

Without investment in data collection, evidence-based improvements in care and outcomes will not take place or keep pace with rapid advances in medical technologies, particularly in genomics and precision medicine.

Lack of national consistency

There are no national standards or models of care. This is despite the fact children with dementia require high levels of support from a vast range of specialists for their complex, progressive conditions.

Within this setting, a family's' ability to advocate can determine the quality of care and support received, resulting in inequity within this already underserved cohort. Families without high levels of health literacy are clearly at risk. This is likely to include culturally and linguistically diverse families and those facing socioeconomic challenges.

Systemic inconsistencies extend to palliative and hospice care, to which families are not routinely referred.[4] Almost universally, parents expressed that an earlier referral to palliative care would have been beneficial.

Children with dementia can face many years of increasing care needs, making respite care essential, yet it is largely unavailable within current systems.[14] Children's hospices provide some opportunity for respite. However, both parents and hospice staff report challenges with access. Eligible families are often deprioritised due to capacity issues, and hospices are often not resourced to manage the psychological and behavioural symptoms of dementia.

> **"We never want to say no to anybody, and we kind of bend over backwards to do everything we can for everyone, but … there is a window in time when the facilities that we have are not safe."**
>
> Clinical Nurse Specialist,
> Paediatric Hospice.

Lack of care coordination

Due to a lack of effective care coordination across the complex set of health systems,[4,14] families are left to coordinate healthcare at all stages. This is despite the genetic, progressive and life-limiting nature of their children's conditions, and the high level of currently unmet need.

Care coordination includes sourcing clinicians, managing communication between different specialties, and managing medication. Across years of disease progression, and in the absence of centralised information, families must repeat their stories over and over again. Often one parent holds all medical history and current care details, including complex drug regimes often prescribed by multiple health professionals. Families regularly express concerns about the absence of medication management, with some reporting significant concerns for their child's safety in relation to drug interactions that medical professionals were not considering.[5]

> **"It feels like Tasmania is even more of a wilderness for families with even less of a skeleton of support and services."**
>
> **Katrina (right), mum to Lauren (second from right), who has childhood dementia.**

> **"It forces the parent, no matter their health literacy, their other family pressures, whatever their background is, it makes them the case manager."**
>
> Speech pathologist

Inadequate psychological support

Childhood dementia places an extraordinary burden on families, impacting every aspect of their lives. The progressive nature of childhood dementia, coupled with its lack of effective treatments, creates unique and overwhelming challenges for parents, siblings, and extended family members.

From diagnosis and across a child's remaining life, a family faces severe and ongoing grief, loss and chronic sorrow. This continues beyond the death of a child when families face a lifetime of grief. Grief is compounded by a parent's regret that their attention was diverted away from their child's limited life, with time spent 'fighting' systems in which they report they 'don't fit'.[4] Tragically, most families report that they were not connected with psychological support,[5] a failing that further compounds the catastrophic impacts of childhood dementia on the whole family.

> **"[The] whole family system 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."**
>
> Psychosocial researcher, palliative care

NDIS is essential but challenging

The National Disability Insurance Scheme (NDIS) provides essential support but is universally challenging to access and manage[4]. Lack of knowledge and understanding of National Disability Insurance Agency (NDIA) staff, particularly in relation to the regressive nature of childhood dementia, often results in longer and more complex assessments, the need for greater justification for necessary supports, and inconsistent funding decisions. Each review requires families to retell their story, to educate the allocated case worker on their child's

> **“The NDIS is brilliant, and when you get the funding you need, it can transform your ability to care for your child. But in order to get to that point, there is so much you need to do to educate and advocate. And this is not just once; this happens every review, sometimes more than once a year.”**
>
> Parent of a child with dementia

condition, prognosis and increasing needs. Some families report insensitive and unsympathetic approaches from NDIA staff who lack understanding.

In addition, the onerous and inflexible NDIS assessment processes make it difficult to plan ahead. Wait times and review processes can result in a child being left without essential supports for extended periods, severely impacting their quality of life.

These challenges are exacerbated in families who have more than one child affected and those already overburdened by their child’s extreme and time-intensive care needs.[24]

> **“Nothing’s easy, nothing comes without having to fight … Like we’ve been down this pathway for so many years, still fighting for the same things.”**
>
> Parent of a child with dementia

Without urgent action…

Childhood dementia disorders are genetic, progressive and life-limiting, leaving affected children with arguably the highest level of unmet need in paediatric health. Without urgent action, they will continue to miss out on essential health care and support. In the absence of national standards and coordination, children whose families are less able to advocate will be more severely impacted.

Of particular concern is the ongoing risk to children’s safety. Health professionals cannot give optimal care without access to adequate knowledge and expertise; families will continue being reluctant experts on their children’s care and conditions.

The emotional and financial strain is crushing, and parents must fight at every turn for their children’s needs. This constant battle leads to isolation, burnout, and despair, with inadequate access to psychological support.

The implication of this situation is that, without urgent action, both health professionals and families will continue being burdened by inefficiencies.

What needs to change?

1. Develop and implement a National Framework for Care for Childhood Dementia.
2. Deliver a quality education and training program to enable service providers to meet the needs of children with dementia and their families.
3. Provide access to dedicated resources, information and expertise relating to childhood dementia.
4. Enable effective care coordination to reduce the burden on families and improve care for children.
5. Improve psychological support for families impacted by childhood dementia.
6. Improve NDIS processes to recognise and support the progressive nature of childhood dementia conditions and the unique needs of affected children.

The impact of childhood dementia on Australian families

In the absence of effective, available treatments and cures for children with dementia, families will know from the point of diagnosis that their child will die.

The psychological toll on families is severe and enduring. Parents experience chronic sorrow, anticipatory grief, and prolonged traumatic stress as they witness their child’s relentless cognitive and physical decline.[21] One parent described this experience as “a slow car crash that never ends and you never recover from”.[5] The unpredictability of disease progression and the constant threat of loss creates a pervasive sense of anxiety and helplessness. Parents of children with dementia report higher levels of stress, anxiety, and depression compared to parents of children with other chronic conditions.[21]

> **“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.**

Family dynamics are profoundly affected. Siblings often feel neglected or overshadowed by the intense care needs of the affected child. They may experience their own grief and anxiety, as well as take on caregiving responsibilities beyond their years.[5] Relationships between parents are frequently strained, with some stakeholders noting high rates of separation and divorce.[24] Social isolation is common, as families struggle to maintain connections with friends and community.

Financial burdens add another layer of stress. Families face significant out-of-pocket expenses for medical care, equipment, and home modifications. The need for parents to reduce or leave employment entirely to provide care creates long-term financial insecurity. One in 3 parents give up their careers and almost all families reported their work status changed due to their child's condition.[24]

Accessing appropriate support through systems like the National Disability Insurance Scheme (NDIS) can be a constant battle, with one parent sharing: "Nothing's easy, nothing comes without having to fight. Like we've been down this pathway for so many years, and we're still fighting for the same things."[8]

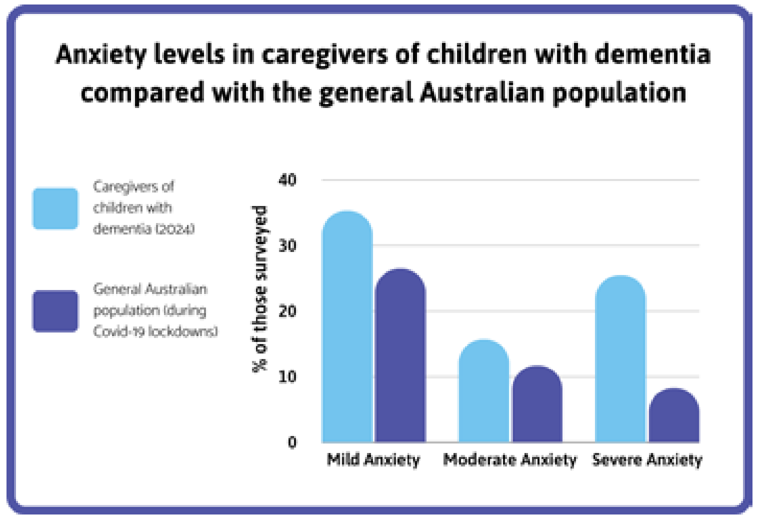


Figure 4: Anxiety scores for caregivers of children with dementia compared to the general Australian population during COVID-19 lockdowns.

Anxiety was measured using the Generalised Anxiety Disorder 7-item (GAD-7) screening tool. General population data was gathered during COVID-19 lockdowns, 25 caregivers were surveyed in 2024[24]. This is preliminary data and likely to change.

> **"If I could change one thing it would be that they wouldn't suffer. I think that's the most frightening part of it all. And I'd do anything to take it away from them."**
>
> **Renee, mother to Hudson (right), Holly (centre) and Austin (left)**

Preliminary data[24]* indicates that:

Around 3 out of 4 parents of children with dementia experience a notable level of anxiety.

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

Emerging research points to a high incidence of prolonged grief disorder among bereaved parents and high levels of pre-loss grief among non-bereaved families.

92% of families reported that their work status changed due to their child's condition.

One in 3 (34%) of parents gave up their careers to care full-time for their children.

Marital breakdowns were frequently reported due to the strains of their child's condition.

*This preliminary data is likely to change with ongoing analysis.

Health professionals consistently emphasise the **all-encompassing nature of caring for a child with dementia** and the undue burden placed on families to 'project manage' their child's care.[14] This burden is exacerbated by the lack of coordinated care pathways and limited understanding of childhood dementia among many healthcare providers.

Families need significant mental health support. However, there are critical gaps in specialist services for families affected by childhood dementia. Research is revealing significant levels of anxiety, prolonged grief disorder, high levels of pre-loss grief, and marital breakdowns, with 60% of caregivers reporting they needed to access additional mental health resources to support them through their child's diagnosis and care.[24]

Families are facing these mental health challenges without specialist grief, loss, and bereavement support, support for siblings, or formal peer support that can give essential psychosocial and practical assistance. This leaves them to cobble together support in systems that don't recognise or cater to their unique needs.

A baby is born every 3 days in Australia with a childhood dementia condition. These challenges will extend into the future and reach thousands more families without action.

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

Pathway to solutions: a coordinated national approach

While the current state of childhood dementia in Australia as outlined in this report is alarming and, for children and families, grossly inadequate and inequitable, it is not without hope or opportunity. New and emerging evidence is revealing a clear pathway to solutions.

Focussed investment in a coordinated national approach for childhood dementia has the potential to efficiently deliver:

1. **Improved survivorship and symptom management through accelerated access to therapy and therapeutic development.**
2. **Consistent, quality and equitable access to care and support for children with dementia and their families.**

Building on the comprehensive evidence developed on the gaps in established care, in 2025 Childhood Dementia Initiative, in partnership with the Federal Department of Health and Aged Care, will co-design much-needed solutions to support children with dementia and their families. This is an important first step toward addressing the historic inequity in both access to appropriate healthcare and improving survivorship for children with dementia.

A coordinated national approach to childhood dementia will be critical to ensure the solutions defined through this project are implemented and should:

- Incorporate co-design principles and be validated by data, lived experience and expert insights
- Deliver the recommendations outlined in this report
- Leverage established processes and functions, investigating their scalability and adaptability to address the unique needs of children with dementia and their families
- Improve the integration of existing services and address capacity and capability constraints in the workforce
- Introduce standards and national consistency that will:
  - improve diagnosis
  - enable early intervention and access to services
  - create opportunities to access emerging therapies and clinical trials
- Deliver improvements and efficiencies across all stakeholder groups impacted by childhood dementia, but most importantly, children with dementia.

> **“Families with kids with childhood dementia are facing a lot of similar challenges. I think the key thing for everybody is to realise these kids by themselves are almost forgotten. More awareness can make some really massive differences to the kids’ lives and the consistency of support that they receive, and help them live their best lives.”**
>
> **John, dad to Eleanor and Joshua who both live with childhood dementia**

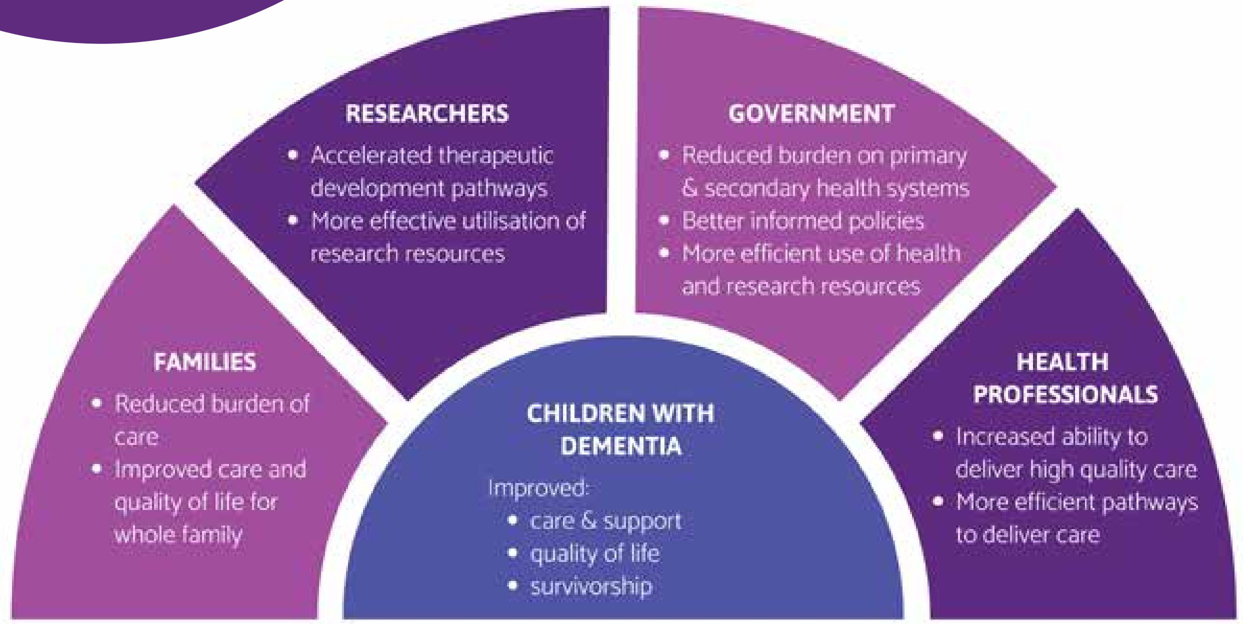


Figure 5: Benefits of a coordinated national approach to childhood dementia.

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> **"What would Mia's life have looked like if she was born in 15 years time from now? Will it be a different story for the next generation of children yet to be diagnosed or will things be at a standstill?"**
>
> **Peta, mum to Mia, who died with childhood dementia**

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