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Brick wall after brick wall

The NDIS Experience for Childhood Dementia Families

This research and report was commissioned by the Childhood Dementia Initiative.

We acknowledge the Aboriginal and Torres Strait Islander peoples as the First Australians and the Traditional Custodians of the lands on which this report was prepared.

We thank all the families and individuals who provided their time and valuable insights for the preparation of this report. Their generosity, openness and determination to assist others by their involvement, despite the personal emotional toll, is greatly appreciated.

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Executive Summary

In Australia, a child is born every three days with a childhood dementia condition. Half of these children will not reach their tenth birthday, and 70% will not survive to adulthood. These short lives are characterised by relentless progression of disability, with children experiencing profound physical and cognitive decline that necessitates increasingly complex disability support. As their needs escalate and change rapidly, these families are among the most intensive users of the National Disability Insurance Scheme (NDIS). This report examines how these families navigate the NDIS, revealing systemic challenges that compound their already devastating circumstances.

This study identified six critical themes:

1. Fundamental Systemic Barriers for Degenerative Conditions: The NDIS framework, designed for stable or improving conditions, fundamentally fails to accommodate the rapid, often unpredictable decline characteristic of childhood dementia. The system's rigid planning cycles, fixed review timeframes, and focus on building capabilities cannot adapt to conditions where abilities are being relentlessly lost, often at an accelerated pace. With no mechanism for anticipating and planning for inevitable decline, families must repeatedly wait for deterioration before accessing essential support. This structural misalignment forces families to operate within an impossible model that neither recognises nor responds to their reality of constant, often rapid deterioration.

2. Lack of Workforce Understanding Significantly Impacts Families: NDIA staff demonstrate minimal comprehension of childhood dementia, with 90% of families reporting fundamental misunderstandings of progressive conditions. This lack of understanding leads to inadequate support plans, delayed approvals, and forces families to repeatedly relive their child's decline through constant explanation and justification.

3. The Overwhelming Administrative Burden: Weekly, families spend hours upon hours on NDIS paperwork and coordination, reducing precious time they could spend with their children. The process requires constant documentation of decline, creating significant psychological strain.

4. The Lottery of Care - Inconsistent Support: Access to appropriate care varies dramatically based on individual planners. Additionally, geography can add an extra layer of variability, with rural and regional families facing particular challenges in accessing services and finding qualified support workers.

5. Equipment and Modification Challenges – The Battle for Essential Support: Families face extensive delays in accessing essential equipment, often waiting months or years for basic necessities. These delays create serious safety risks for both children and their carers, while equipment, when finally approved, may no longer meet the child's changed needs.

6. Fighting on All Fronts - The Failure to Align Support Systems: Critical gaps exist between the NDIS and other support systems, particularly in managing hospitalisations and palliative care. Families often avoid mentioning palliative care needs for fear of losing NDIS support.

These findings underscore the urgent need for systemic reform to better serve families facing childhood dementia, ensuring their limited time together is spent on being a family rather than bureaucratic battles. Taking into consideration the findings of this report; the following recommendations are made :

1. **Creating a specialised pathway for childhood dementia that includes:**
    a. Mechanisms for proactive planning based on predicted disease progression.
    b. Rapid response processes for urgent equipment and support needs, with streamlined approval pathways that recognise the predictable nature of decline.
    c. Reduction of administrative burden through simplified processes that don't require repeated justification of degenerative conditions.
    d. Improved coordination between health, disability and palliative care services.
    e. Flexible funding models that can adapt to rapidly changing needs.

2. **Establishing and enabling a specialised workforce for childhood dementia that includes:**
    a. A dedicated team within NDIS with expertise in degenerative conditions to ensure consistent, informed decision-making.
    b. Comprehensive childhood dementia training programs for NDIS staff and disability support workers to enable best practice care and support.
    c. Specialised support coordinators trained in managing complex, progressive conditions.

90% of families reported NDIS planners fundamentally misunderstood progressive conditions.

"If you are outside the tick box, you are in the too hard basket." (Parent of child with dementia)

80% of families reported insufficient therapy funding.

70% of families had to appeal plan decisions.

Less than 15% of families felt consistently understood by their support team.

Fewer than 10% of planners demonstrated comprehensive understanding of childhood dementia.

“We only have a short time with our kids. They have high needs and the system won’t have to support them for very many years. As families, we need to be spending quality time with our families, not spending it creating evidence and fighting ridiculous decisions because the planners and systems don’t have the right training and understanding and because the system isn’t set up to meet the needs of degenerative conditions.

“What is particularly frustrating is that we provide evidence and they just ignore it or misinterpret it. Our doctor feels there is no point in her writing letters and reports because they do not listen to her. This is the worst point that we are beating our head against the wall, and it is going to deaf ears because they don’t understand”

Mother of a child with dementia

Introduction: The Urgent Context of Childhood Dementia

In Australia, a baby is born every three days with a childhood dementia condition—a devastating reality where half of these children will die before reaching their 10th birthday, and 70% will not survive to adulthood. These short lives are characterised by relentless progression of disability, with children experiencing profound physical and cognitive decline that necessitates increasingly complex disability support. As their needs escalate and change rapidly, these families are among the most intensive users of the National Disability Insurance Scheme (NDIS).

Childhood dementia represents one of the most challenging and overlooked healthcare challenges in Australia. These genetic, progressive, and life-limiting conditions create a unique and heart-wrenching journey for families, who find themselves navigating a health and social care system fundamentally unprepared to support their children's complex and constantly changing needs. For some families, the genetic nature of these conditions means they are supporting multiple children with childhood dementia, each with their own trajectory of decline, creating exponentially more complex care requirements. With time against them, families need rapid, responsive support that anticipates and plans for inevitable decline.

As one parent poignantly described, childhood dementia is "a slow car crash that never ends and you never recover from." The experience is characterised by watching a child "slowly be unpicked until there's nothing left"—a cruel progression that strips away developmental milestones, abilities, and ultimately, life itself. For these families, every day of delay or administrative burden represents precious time lost.

In this already devastating landscape, families face an additional challenge: a disability support system that fails to understand, recognise, and adequately support children with rare, progressive conditions. Every family interviewed for this report expressed gratitude for the NDIS, acknowledging it as a world-leading disability support scheme that provides access to vital equipment and services they could never otherwise afford. However, in practice, accessing this support has become yet another battleground for families already fighting an overwhelming battle. The scheme often falls short of delivering the critical support needed, with processes and systems that can actively work against the urgent, changing needs of children with degenerative conditions. These challenges are particularly acute for families supporting multiple children with childhood dementia, where the complexities of navigating the system are exponentially increased.

Research Methodology

This research employed a comprehensive, co-design methodology that placed families with lived experience of childhood dementia at the heart of the investigative process. Recognising that families are the true experts in their children's experiences, the research design was collaboratively developed to ensure authentic and meaningful insights.

It incorporated multiple data collection methods:

1. In-Depth Interviews

- 20 individuals, from 15 families participated in detailed interviews.
- Participants included:
    - Parents with multiple children with childhood dementia
    - Siblings
    - Bereaved parents
    - Families who, in addition to their child/ren with dementia, had other children on the scheme for different conditions.
- Interviews allowed for rich, narrative exploration of families' experiences.

2. Online Survey

- 14 additional families provided insights through a comprehensive survey.
- Some of the participants had multiple children with childhood dementia on the NDIS

3. Professional Focus Group

- Conducted with professionals from key support and advocacy organisations.
- Included representatives from the National Disability Insurance Agency (NDIA)
- Provided systemic and professional perspectives on NDIS interactions.

Participant Diversity

The research deliberately sought a wide-ranging participant group to capture diverse experiences:

- Geographic representation *(*metropolitan, regional, and rural areas across multiple Australian states)
- Socioeconomic backgrounds (diverse economic circumstances, varied educational backgrounds and a range of family structures)
- Diagnostic diversity (families with different childhood dementia conditions, varying stages of condition progression, different ages of children)

It also incorporated insights and data from previous studies conducted into childhood dementia, focusing on understanding the impact on families and highlighting lived experience.

Data from interviews and surveys were analysed using:

- Thematic analysis
- Comparative methodology
- Lived experience validation
- Professional expert review

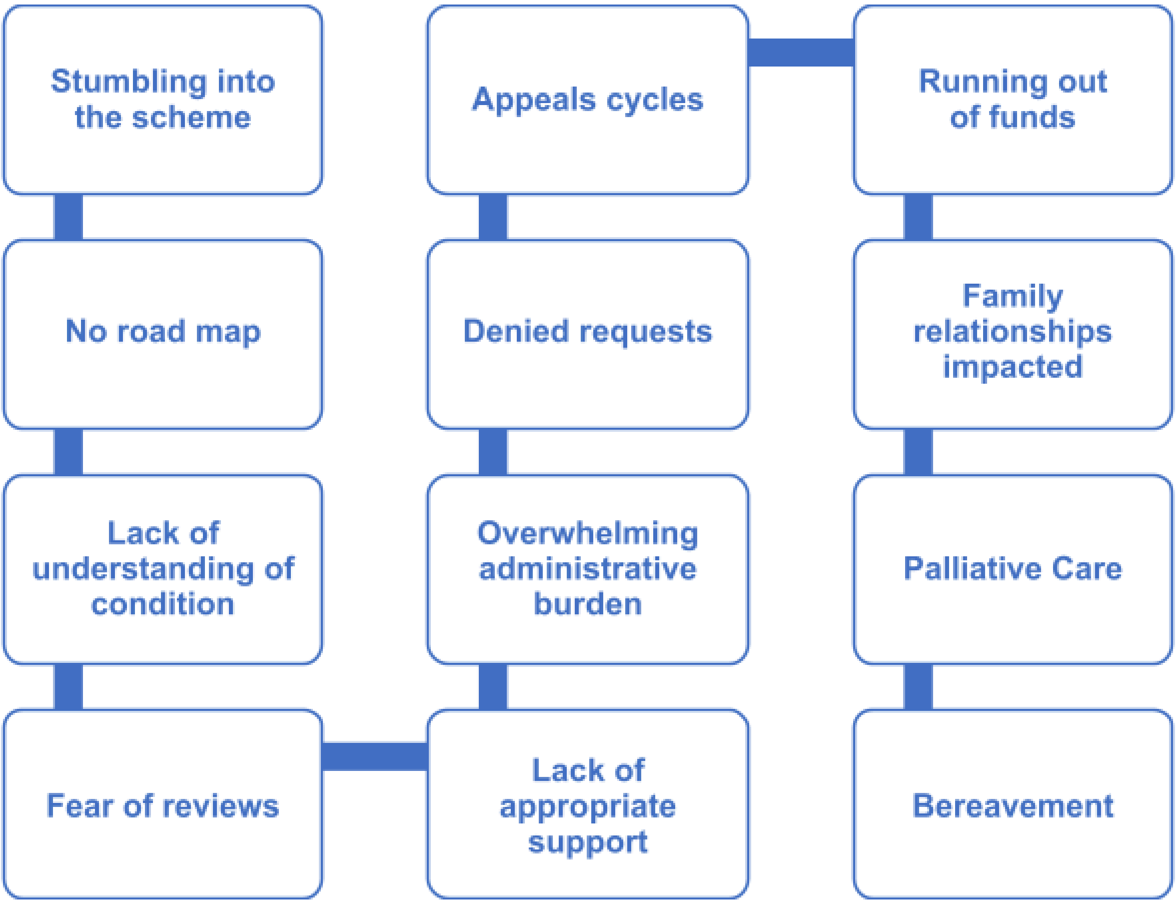
Journey Map: A Family's Experience

In keeping with previous research into childhood dementia and family experience, a Human Centred Design (HCD) methodology utilised the interview content and detailed analysis to create a “Journey Map”. This Journey Map provides a portrayal of 'typical' family interactions with the NDIS, through the narrative of a fictional family with a childhood dementia diagnosis. By following one family's journey, we can clearly demonstrate the interconnected nature of the challenges identified in our research and their cumulative impact on families already facing devastating circumstances. While the experiences reflect the commonalities from the 15 families' interviews rather than one specific family, the quotations are taken verbatim from the interviews.

It is worth noting that every family interviewed expressed at some level their appreciation for the scheme. There was recognition that it was a world-leading initiative and that the NDIS had provided access to support and equipment that they would have been unable to fund themselves. There was genuine gratitude. However, every individual, every family, had significant challenges and issues, and all called for change.

Indi’s Family Journey with the NDIS

After some early concerns by her parents Nadia and Will, Indi initially received a vague diagnosis of ‘global developmental delay’ by medical professionals. Subsequently, Indi tested positive, aged four, for a condition that causes childhood dementia. She has an older sister, Amber who does not have the same condition.



STUMBLING INTO THE SCHEME

Following months of testing and uncertainty, now with Indi's formal diagnosis, Will and Nadia are overwhelmed with paperwork and medical appointments. While grappling with their child's increasing support needs as her developmental delays become more pronounced, a doctor casually mentions the NDIS. With no clear guidance about how to navigate the scheme for a degenerative condition, they begin a complex application process, unsure if they're even eligible or how to effectively communicate their child's changing needs.

"If you are outside the tick box, you are in the too hard basket".

NO ROAD MAP

Will and Nadia feel lost in a maze of NDIS terminology and processes, discovering their child's degenerative condition doesn't fit into any of the system's standard categories. Through trial and error, they learn that using specific language is crucial for applications, but this knowledge comes at a cost - both in time spent researching online and connecting with other parents through Facebook groups, and in money spent on repeated assessments. While they struggle to understand the system, precious time passes where Indi misses out on potentially beneficial therapies.

"By the time they look at that and knock you back for that, then you got to redo it all again… And by then, we've already deteriorated even more".

LACK OF UNDERSTANDING OF CHILDHOOD DEMENTIA

During their first planning meeting, Will and Nadia find the planner has no knowledge of childhood dementia. Instead of discussing Indi's urgent support needs, they spend most of the meeting explaining the basic nature of the condition. Despite providing comprehensive medical reports, the planner appears not to have read them and seems skeptical about the progressive nature of Indi's condition. Most concerning, they keep pushing for improvement goals and developmental milestones - fundamentally misunderstanding that their child will lose, not gain, abilities over time. This lack of understanding means crucial early support opportunities are missed while they repeatedly explain and justify their child's condition. The constant need to detail and discuss their child's deterioration takes an emotional toll, yet seems unavoidable as they try to secure essential support.

"The planner kept asking about her goals and how she would improve. We tried to explain that she wouldn't improve - that's the nature of childhood dementia. But they didn't seem to understand or believe us. It felt like we were speaking different languages."

FEAR OF REVIEWS

Each plan review brings overwhelming anxiety. Nadia dreads answering unknown numbers, fearing an unexpected NDIS call she won't be prepared for. Living in a regional area, they struggle to find appropriate services that understand degenerative conditions, creating a cruel paradox - they worry about losing funding if they don't use all their allocated supports, yet can't find qualified providers to deliver them. They try their best to fill care gaps themselves, adding to their exhaustion. The review process forces them to repeatedly detail Indi's deterioration, leaving them feeling disloyal to their child and traumatised by continually discussing their "worst days". Each review requires them to prove again that their child's condition is still degenerative, still incurable.

"I have to dwell on the terrible, awful, heartbreaking parts of my child… I really have to paint a picture of how truly dreadful everything is, and none of it's a lie, but when you're completely focused on those awful, awful parts of your life, the psychological impact that has on you as a parent is quite profound".

APPEALS CYCLE

Will and Nadia reluctantly learn to navigate the appeals process, adding another layer of expertise they must develop while managing their child's declining condition. They feel like they're constantly fighting to prove Indi's obvious needs, even though her condition is documented and progressive. Each appeal demands more paperwork, more evidence, more time spent describing deterioration - precious hours taken away from being with their children and spending time as a family. Sometimes they calculate it might be quicker to wait for the next review than to pursue an appeal, forcing impossible choices between urgent needs and system processes. The constant cycle of rejection, appeal, and waiting wears them down, yet they have no choice but to continue advocating for essential support.

"The NDIS is so slow at getting the reviews in and getting the plans in and getting a new plan. By the time they get the plan, then those needs have changed again".

DENIED REQUESTS

Essential equipment and basic home modification requests are repeatedly denied or delayed through multiple rounds of paperwork. A wheelchair takes multiple applications over eight months to approve - precious time during which Indi's mobility significantly declines, making the eventual approved model potentially unsuitable for her deteriorated condition. The delays create real safety risks: Nadia hurts her shoulder when Indi grabs her trying to get stable. Their application for basic safety equipment like grab bars stalls because, being in a regional area, they can't find NDIS-approved tradespeople to install them. Caught between their child's urgent needs and the slow approval process, the family spends their own money purchasing necessary equipment - creating financial strain while still fighting for NDIS funding.

"By the time they approve a wheelchair, my child might have lost the ability to even be positioned in it. Each month of delay is a month of my child's limited life that we can never recover. The NDIS treats these delays as administrative procedures, but for us, they are stolen moments of potential connection, of potential joy."

OVERWHELMING ADMINISTRATIVE BURDEN

Nadia takes on the role of coordinating all NDIS care and administration. She is spending up to 20 hours per week managing paperwork, arranging assessments, and chasing responses, while simultaneously trying to find qualified support providers who understand degenerative conditions. The complexity and volume of this administrative work forces her to give up her part-time job, adding financial stress to their situation. Will works extra hours to compensate for the lost income, reducing the time he can spend with Indi during her limited life. What should be precious family time is instead consumed by constant paperwork and coordination, with each form requiring them to document their child's decline in detail.

"The administrative workload leaves no time for me to be a parent. I'm just managing paperwork".

LACK OF APPROPRIATE SUPPORT

Their first plan is inadequate for Indi's needs and fails to account for the progressive nature of her condition. They receive minimal support hours, with the planner dismissing her inability to sleep (a known symptom of childhood dementia) as their 'parental responsibility' to manage, despite the serious impact on their health and Will's ability to work safely. Without understanding of degenerative conditions, basic support needs are misclassified as behavioral issues. They realise they desperately need a support coordinator to help navigate the complex system, but aren't funded for one. Meanwhile, Amber begins showing signs of stress and acts out, feeling forgotten in the constant focus on her sister's urgent needs, adding another layer of family strain.

"It's like they pushed back so she would die before they had to do anything".

"Trying to find a high intensity support worker is like finding a needle in a haystack".

RUNNING OUT OF FUNDS

Nine months into their current plan, critical support hours are depleted due to Indi's escalating needs - a predictable outcome of her degenerative condition that expert reports detailed, but the system failed to accommodate. They face impossible choices about which essential supports to maintain: the parents have to decide which therapies to focus on, or to resource support hours knowing each is crucial for Indi's quality of life. The strain of these decisions begins showing in their marriage as they argue about priorities and funding allocation. The fear of running out of support is profound - they hear of another parent considering moving to a hospice with her child when support hours run out, a desperate solution to a preventable problem. While they could request a plan review for additional funding, the process is so lengthy that their needs will likely have increased again before it's approved.

"They keep telling us, you're using too much money per week. You can run out of funds. But we've had to pay for support hours to keep our child safe".

FAMILY RELATIONSHIPS IMPACTED

The cumulative impact on family relationships becomes increasingly evident. Amber withdraws, feeling neglected in the constant focus on NDIS battles and Indi's care needs. Will and Nadia barely spend time together, their relationship strained by constant stress and the endless administrative burden. Family outings become rare as any spare time is consumed by paperwork, care coordination, or fighting for support. Finding qualified carers who understand both the behavioral aspects of childhood dementia and the physical care needs proves increasingly difficult, limiting opportunities for respite. What should be precious family time during Indi's limited life is instead dominated by system demands and care coordination, creating grief and guilt for all family members.

"The constant stress has left me burnt out. I feel like I am failing my family".

"The impact is on the entire family and not just one person. It's an entire family impacted 24/7".

PALLIATIVE CARE

When palliative care is suggested for symptom management and quality of life support, Will and Nadia initially resist, having heard repeatedly that mentioning palliative care can lead to losing NDIS support. The system's inability to distinguish between palliative care and end-of-life care creates another barrier to appropriate support. They eventually accept palliative care services but deliberately avoid mentioning this to their planner, living in constant fear of losing their NDIS package. This forced silence prevents proper coordination between services and creates additional stress at an already overwhelming time. They find themselves managing yet another fragmented piece of the healthcare system while trying to focus on making the most of their time with Indi. They eventually accept palliative care support but don't discuss it with their planner, living in constant fear of losing their NDIS package.

"The minute you say your child is palliative, they wipe their hands of you…They don't get what 'palliative' means".

BEREAVEMENT

After Indi dies, Will and Nadia discover their journey with the NDIS isn't over. Outstanding equipment bills remain unpaid, and they struggle to get clear answers about final plan reconciliation while processing their profound grief. The sudden and complete cessation of all support services - from equipment collection to cancellation of therapy appointments - feels brutally abrupt. The system that required such intense engagement during Indi's life now seems to have no process for supporting families through the transition of bereavement. They feel abandoned at their most vulnerable time, left to navigate administrative loose ends while mourning their child.*"…because there were issues post death, which is a whole other level of billing and NDIS and nightmare".*

THEMES

Six common themes emerged from the interviews, supported by findings in the survey, the focus group and previous research. These speak to some of the greatest challenges and opportunities for the system in recognising and responding to the needs of childhood dementia families.

THEME 1: FUNDAMENTAL SYSTEMIC BARRIERS FOR DEGENERATIVE CONDITIONS

The NDIS framework is fundamentally misaligned with childhood dementia as it is designed for static or improving conditions rather than progressive decline, forcing families to operate within an impossible model of goal setting and improvement.

THEME 2: LACK OF WORKFORCE UNDERSTANDING SIGNIFICANTLY IMPACTS FAMILIES

There is a profound lack of understanding and empathy among NDIA staff about childhood dementia, forcing families to repeatedly explain and justify their children's needs while dealing with the emotional toll of constantly focusing on their child's deterioration.

THEME 3: THE OVERWHELMING ADMINISTRATIVE BURDEN

NDIS paperwork and coordination creates an exhausting administrative workload for families that takes precious time away from caring for their children and forces them to continuously document their child's decline.

THEME 4: THE LOTTERY OF CARE: INCONSISTENT SUPPORT

Access to appropriate care varies dramatically based on individual planners and geographical location, with families facing particular challenges in finding qualified support workers and accessing services, especially in rural and regional areas.

THEME 5: EQUIPMENT AND MODIFICATION CHALLENGES - THE BATTLE FOR ESSENTIAL SUPPORT

Families face extensive delays in accessing essential equipment and home modifications, often waiting months or years for basic necessities, which can render the equipment obsolete as children's conditions deteriorate.

THEME 6: FIGHTING ON ALL FRONTS: THE FAILURE TO ALIGN SUPPORT SYSTEMS

Critical gaps exist between the NDIS and other support systems, particularly in managing hospitalisations and palliative care.

THEME 1: FUNDAMENTAL SYSTEMIC BARRIERS FOR DEGENERATIVE CONDITIONS

The Fundamental Disconnect: A System Not Built for Rapidly Progressing Conditions

Childhood dementia represents a cruel paradox that the NDIS framework is fundamentally unprepared to address. Where most disability support systems are designed around improvement, stabilisation, or long-term management, childhood dementia follows a relentless path of decline that defies traditional support models.

> *“The NDIS is suited to kids who are more stable, who are possibly going to improve. It’s not designed to help kids going the other way” (Mother of child with dementia)*
>
> *“The system doesn’t understand it [childhood dementia]” (Mother of child with dementia)*
>
> *“The unpredictability and rapid progress on the disease cannot fit within the current framework” (Bereaved parents)*

When Progress Isn’t a Possibility

The NDIS’s focus on improvement and goal setting directly conflicts with degenerative conditions. This creates significant stress for families who must frame their needs within an unachievable model. Each NDIS planning meeting becomes a surreal performance of pretence, where families are expected to construct goals that everyone knows (or should understand) are often impossible. One parent described this experience with heartbreaking clarity:

> *"In every meeting, I'm forced to sit and discuss potential skill development for a child who is literally losing abilities every single month. We've gone from discussing communication strategies to fighting just to get equipment that might provide a moment of comfort." (Mother of child with dementia)*
>
> *“Getting that message across to the NDIA that you know, the reports that I am going to give you are not going to show success... We are not going to be that. We’re on another path, which is the regression” (Mother of child with dementia)*
>
> *“Our child will lose everything. Those preventative measures seem to be missing” (Mother of child with dementia).*

Early Intervention and Capacity Building: Critical for Maintaining Skills Longer

Families consistently emphasised that despite the degenerative nature of childhood dementia, early intervention and capacity building are crucial for all children with these conditions. Parents highlighted how intensive early support can help maintain skills for longer periods and significantly improve quality of life throughout the child's journey.

> *"Early intervention and capacity building are vitally important and can improve quality of life. Intensive early capacity building (including skills that are not needed now but will be needed in the future) can make a tremendous difference in how long abilities are retained."* (Mother of child with dementia)

A significant concern raised was that NDIS approaches allocating funding according to current functional impairments rather than diagnosis create a critical systemic barrier—children with childhood dementia may not receive crucial early intervention because they don't yet display severe functional impairment, despite the medical certainty of future decline.

> *"Young people may not receive the early intervention they need at the time and in the intensity they need because they do not yet have the functional impairment. Important skills can be learned early on which cannot be learned later, and with proper support, these skills can be maintained longer."* (Mother of child with dementia)

For all childhood dementia conditions, including those where progression may be slower (where individuals may live into their 20s or 30s), parents stressed the value of continued skill development and appropriate therapeutic interventions that can slow functional decline.

> *"I felt as if my child had been 'written off' at age 7 when she was diagnosed. But we have goals. Over the past year, we have been able to reduce her Parkinson's shuffle. This has been due to extensive therapy and exercise. So the right support makes real differences in what's possible."* (Mother of child with dementia)

This highlights another dimension of the system's misalignment—the inability to understand that early and intensive intervention can significantly impact how long skills are maintained, even as the condition progresses. Parents emphasised that maintaining abilities for even a few additional months or years represents precious time and quality of life improvements that the current system fails to value appropriately.

The High Cost of Waiting

The urgent and unpredictable nature of the needs of children with degenerative conditions conflicts with the NDIS's lengthy approval processes. The administrative approach creates life-altering consequences:

- Funding reviews that fail to recognise deterioration - particularly rapid changes
- Equipment approvals often taking months, sometimes years.
- A system designed for static conditions, in a context of constant, accelerating change.

> *"By the time that they look at that and knock you back for that, then you got to redo it all again…And by then, we've already deteriorated even more" (Mother of child with dementia)*
>
> *"I don't know what he will need next year, I don't have a crystal ball. He is neurodegenerative" (Mother of child with dementia).*

"By the time they approve a wheelchair, my child might have lost the ability to even be positioned in it. Each month of delay is a month of my child's limited life that we can never recover. The NDIS treats these delays as administrative procedures, but for us, they are stolen moments of potential connection, of potential joy." (Mother of child with dementia)

“Dementia is time. Every day we are losing neurons, and we can’t wait…I don’t think the NDIS understands” (Father of child with dementia).

THEME 2: LACK OF WORKFORCE UNDERSTANDING SIGNIFICANTLY IMPACTS FAMILIES

The reported lack of understanding and empathy about childhood dementia among NDIA staff creates significant barriers for families. Families are forced to constantly explain and educate about their child's condition. They are overwhelmed with frustration at reports that at best are not understood, and at worse, perceived to not even be opened.

> *"They have taken no notice of reports…I don't think they even read the paperwork" (Mother of child with dementia)*
>
> *"They hadn't even read it…he could be dead before he was on the NDIS" (Bereaved parents)*
>
> *"I think I spent that plan review…I spent the first hour or 45 minutes talking about the condition…I just feel like you should know this" (Mother of child with dementia)*
>
> *"I have never, ever, in all of the meetings I've had with the NDIS, had someone who was familiar with not only Sanfilippo, but with childhood dementia, never, ever" (Parent of two children with dementia)*
>
> *"The NDIS doesn't understand diagnosis versus functional needs" (Mother of two children with dementia)*
>
> *"It was just brick wall after brick wall after brick wall, having to explain everything and educate them" (Mother of child with dementia)*

The Complexity of Multiple Children with Dementia in the NDIS

An additional issue is the failure or inability of the system to recognise the exponential loading of families who have more than one child with dementia. Not only does having multiple children create additional support needs, the potentially different progressive nature of the disease and associated challenges of managing multiple needs, seems to be unrecognised. A parent who is coping with two, or in some cases more, children with dementia is faced with sometimes very different individual experiences of decline that have to be concurrently managed.

> *"The NDIS doesn't cope when you have two kids in the family" (Mother of two children with dementia).*

The Emotional Toll of Repeated Justification

Families become unwilling performers in a system that demands they continuously prove their child's deterioration. Each meeting becomes an emotional minefield where parents must:

- Quantify their child's losses
- Provide extensive medical documentation
- Justify increasingly complex support needs

- Fight against a system that seems designed to minimise support. One parent was told *“there was no point in her child even doing therapy”.*

Another captured the emotional exhaustion of this repetitive process:

> *"I'm constantly forced to explain that my child will not improve. He will not reach milestones. He will die. But the NDIS wants reports, goals, potential. How do you create a goal for a child whose only trajectory is decline?"*
>
> *“It’s beyond my levels of comprehension and sanity dealing with the NDIS. I have to laugh, or I would be an absolute wreck” (Mother of child with dementia)*

Psychological Impact of Repeated Storytelling

The administrative process becomes a persistent source of psychological distress, contributing to emotional exhaustion and potentially leading to secondary trauma as families are repeatedly forced to focus on their child's deterioration. Families must:

- Repeatedly tell their most painful story
- Relive their child's declining condition
- Justify their child’s need for support
- Prove their credibility as caregivers
- Live in fear of their funding being removed
- Be constantly available and ready to answer calls from NDIA team members without warning or time for preparation, leading to a perpetual state of anxiety.

> *“I have to constantly dwell on the horrible, heartbreaking part of my child…it’s inhumane” (Mother of child with dementia)*
>
> *“I don’t think there is any humanity in the system” (Mother of child with dementia)*
>
> *“It doesn’t have to be this hard. It makes it worse” (Mother of child with dementia)*
>
> *“Fight. All you do is fight, fight, fight” (Mother of child with dementia)*

Cumulative Trauma

Ultimately, the result of this barrage is that families lose faith in the system and the professional relationships become adversarial. The support networks for children, their parents and families, fragment under pressure and isolation intensifies as advocacy consumes resources.

> *“My kids are just budget items” (Mother of two children with dementia)*
>
> *“I haven’t had a moment to myself in years. The system doesn’t see the toll it takes on parents” (Mother of young person with childhood dementia)*

The result is an accumulation of trauma.

- Each rejection compounds existing emotional burden
- Families internalise systemic failures as personal ones
- Children sense parents' distress and anxiety
- Long-term impact on family mental health

> *“The constant stress has left me burnt out. I feel like I am failing my family” (Mother of child with dementia)*
>
> *“This paperwork and fighting for this…made it more distressing. And I'm like, my daughter's dying. Do you not understand? And you want to grill me…. just come here and see like it's just exhausting to have to be fighting. You know, it's like you're begging for help, and you shouldn't have to beg.” (Mother of child with dementia)*

Compounding Family Stress

It was also felt that the NDIS fails to look at the family as a whole; that it focuses on the child, without context. As one parent argues, the NDIS “does not recognise family is an eco-system and we need to prevent burnout” (*Mother of a child with childhood dementia*).

The inconsistent support created ripple effects:

- Siblings felt increasingly neglected
- Parental relationships became strained
- Social isolation intensified
- Mental health of entire family units deteriorated

> *“The impact is on the entire family and not just one person. It’s an entire family impacted 24/7” (Mother of a child with childhood dementia condition)*

Some parents even spoke about feeling pushed to *“the point of relinquishment”* of their child due to the battle with the system. The guilt about not being able to support their child was overwhelming.

THEME 3: THE OVERWHELMING ADMINISTRATIVE BURDEN

The administrative burden imposed by the NDIS transcends mere paperwork—it becomes an all-consuming occupation of emotional and psychological warfare, further burdening families already stretched to their absolute limits by caring for children with progressive, life-limiting conditions.

> *“It works out to about eight to ten hours a week on average. Just that’s not caring, that’s just admin NDIS and medical…I feel like I am running two businesses” (Parent of two children with dementia)*
>
> *“It’s a full-time job – paperwork, appeals, meetings. I’m always exhausted” (Mother of a child with dementia)*
>
> *“The administrative workload leaves no time for me to be a parent. I’m just managing paperwork” (Mother of two children with dementia)*

The Additional Trauma of Constant Documentation

As well as the administrative load, each document becomes a painful dissection of a child's declining capabilities. Families are forced to transform their most intimate, heart-wrenching experiences into clinical language, reducing their children to lists of deficits and challenges.

> *"To access support, I have to create a 'Day in the Life' document that reads like a timeline of our most devastating moments. I feel terrible that my son, whom I love deeply, is having all of his flaws and shortcomings exposed and focused on. It leaves me feeling guilty and ashamed, an emotionally exhausted shell of myself." (Mother of a child with dementia)*
>
> *“My child is not paperwork” (Mother of a child with dementia)*

The documentation process demands:

- Extensive reports from multiple specialists, often just repeating or reiterating previous information. Families consistently reported that it was apparent that these reports were not even read by the relevant NDIA team member prior to reviews.

  “It’s the mental load of prepping for a review. I just don’t want to do it anymore… I roll over the plan because it’s easier… I have to ask, “have you read the papers?” (Mother of two children with dementia)

- Detailed impact statements, which were constant re-articulations of every painful aspect of their child's condition. They felt trapped between having to continually produce these in order to access funding at the required level and the re-traumatisation that occurred each time.

  "I have to dwell on the terrible, awful, heartbreaking parts about my child... I have to dwell on his disability. I have to dwell on his behaviour challenges, and I really have to paint the picture of how shit everything is, and none of it's a lie, but when

> *you're completely focused on those awful, awful parts of your life, the psychological impact that has on you as a parent is quite profound" (Mother of a child with dementia)*

Disappointingly, this effect has already been acknowledged, in a 2023 report by the Australian Parliament's Joint Standing Committee on the NDIA, which noted that the scheme's assessment and planning approaches reinforce a deficit model of disability. Yet, it is still a daily occurrence for families impacted by childhood dementia.

The Financial Burden of Proving Changing Needs

The financial cost of documentation adds another layer of difficulty and creates additional barriers.

Families must:

- Pay for extensive reports using their child's limited NDIS funding to prove their need for NDIS funding when the burden had already been established. They felt this diverted funds from actual support (or savings to the system itself).

  “The reports, it costs a lot of money in terms of your therapy money, they will charge you for every hour that they do administrative work…I mean they are hugely, huge, long reports” (Mother of a child with dementia)

  “It’s like thousands of dollars to look at these reports. They come and see me for, you know, an hour, and then they charge $500 for that service, and then they go and write this report, and it's so many hours and it’s $2000” (Mother of child with dementia)
- Navigate complex billing systems. Many families paid for support coordination purely out of fear of accidentally making an error and being penalised.
- Absorb costs themselves that should be covered by the NDIS.
- Constantly battling to prove need. For example, multiple parents spoke about being denied funding for nappies as they were told their children were too old to need them - disregarding the reality of incontinence and lack of control as a result of dementia.

Fear of “Getting it Wrong”

Parents consistently spoke of living in a “constant state of fear” when dealing with the NDIS. For many, it was based on concern about making a mistake and losing vital funding. This led a number of families to choose not to self-manage their packages as they felt this left them too open to claims of misuse.

The constant threat of losing funding impacts all areas. One parent spoke of how they were fearful of plan reviews or seeking assessments for additional funding as it *“feels like I am gambling”*. In more than one case, parents had opted to roll over plans, not because they didn’t need the additional support, but because they thought the risk of losing funding was too great.

Parents repeatedly spoke of feeling like they were cast as trying to ‘rort’ the system and always viewed with suspicion.

> *“We are treated like we are the criminals’ (Mother of child with dementia)*
>
> *“It’s like nobody believes you. I am not asking for ridiculous things” (Mother of child with dementia)*
>
> *“You get put through the ringer” (Mother of two children with dementia)*
>
> *“It made me feel like I trying to rort the system” (Mother of child with dementia)*

Yet, ironically, in accessing services parents see the ‘rorting’ and are deeply concerned about the wastage, with numerous examples of providers putting a “disability tax” on basics like nappies or on home modifications.

> *“Families get questions, dollars taken away, but waste is on the providers side” (Mother of child with dementia)*

Lack of Consistent Contact

Parents also struggled with the lack of relationship with the NDIA. Having no key contact and staff consistently turning over, meant there was no on-going understanding or consistency.

One parent, a mother of two children with dementia, shared her frustration: *“I’ve called so many times, left countless messages for our planner to call me back, and I’ve never heard from her. It’s exhausting.”*

The high turnover exacerbates these issues, as families often have to start from scratch, re-explaining their circumstances and needs. This inconsistency erodes families’ trust in the system. Parents describe feeling as though they are in a constant state of limbo, unable to plan effectively for their child’s care. The system hinders both the ability to manage the care now and has no capacity to plan for care in the future – two things that are absolutely key for families dealing with a constantly changing scenario.

And while they were unable to contact the NDIA staff, families particularly felt the burden of having to always be ‘available’ to answer any questions from the NDIA. Many spoke of how calls came without warning, leaving them feeling unprepared to represent their child to their best capacity, but unable to refuse to participate for fear of losing funding.

> *“They call you and you're not prepared. They don't schedule calls. They just call you.” (Mother of child with dementia)*

Greater Inequity Amongst an Already Problematic System

While all families reported challenges interacting with the NDIS, many also acknowledged that they thought this burden was heavier for some. They were concerned that those who face exponentially more challenging navigation of the system include those with lower health literacy, limited financial resources, linguistic or cultural barriers, single-parent structures, and multiple children on the scheme. Parents struggling themselves, questioned how others coped and feared that they may be even more disadvantaged.

> *"For less literate people or less articulate people, I don't know how they do it. I really, really don't. You know, English as a second language, different cultures, all the rest of it, I don't know how they manage, unless they've got somebody really, really good in their corner guiding them through. That will determine how much funding they get for their child." (Mother of child with dementia)*
>
> *"I have the ability to do those things [write reports], but not everyone does" (Mother of child with dementia)*

THEME 4: THE LOTTERY OF CARE: INCONSISTENT SUPPORT

Navigating an Unpredictable Landscape

Support for childhood dementia families resembles a high-stakes game of chance, where the quality of support depends on an individual coordinator’s understanding, empathy, and expertise.

> *“It comes down to the NDIS person you get… it’s the roll of the dice” (Mother of child with dementia)*
>
> *“I can have all the evidence in the world, but it comes down to the person I get on the day…it doesn’t recognise how many medical professionals are involved in her care” (Mother of child with dementia)*
>
> *“The assessments take ages, they cost everyone a lot of money. Then they want more evidence and more evidence and more evidence. It’s costing four or five thousand dollars for these therapists to create these assessments based on what they see in front of them, their client. Yet the NDIS will go “well, no, not really. Maybe not. I don’t really think he needs that” (Mother of child with dementia).*

The complexity of managing NDIS plans creates significant challenges and all families reported a lack of guidance or assistance.

> *"I was just told, Oh, they just pay the bills. So, I thought, why wouldn't anyone want that?... I had no idea what a support coordinator was. Nobody has told me you could get one." (Mother of child with dementia)*
>
> *"We had a Support Coordinator. She's like, “You should be getting a lot more than what you are”. And I'm like, should I? I don't know." (Bereaved mother)*

The Expertise Vacuum Lottery

Families encountered a stark reality: it is not only NDIA team members, but most support coordinators also had minimal understanding of childhood dementia and how to navigate the system. While some families spoke of how finding someone knowledgeable about their child’s needs was an incredible asset, for many this was not the experience. It was “hit and miss” who they got, and therefore what the outcomes were for their child was unpredictable. This knowledge gap created multiple layers of systemic failure:

- Coordinators lacking specialised training
- Inconsistent interpretation of support needs
- Minimal understanding of childhood dementia's complexity

> *“The LAC changes every six months… We did ask at one of his plan reviews about moving up into the NDIA proper complex care team or something like that. And she said, no. No, there be no need for that” (Mother of two children with dementia)*

Complex Care: Beyond Standard Support Models

One of the great challenges once funding is granted is finding appropriate support workers. Supporting children with childhood dementia demands extraordinary skills that far exceed traditional support worker training. The care requirements can include specialised medical training, understanding of complex behavioural changes, ability to adapt and manage rapid physical and cognitive decline, and emotional resilience.

One parent whose son with dementia had complex medical needs, described the challenge:

> *"I've had to get a lot of support workers trained in intravenous injections. I've got them to be trained for all different types of seizures and how to administer medication... These support workers are supposed to be trained like nurses. But then they go, "What?! This isn't what I signed up for."*

Due to the nature of childhood dementia, a team of professionals are necessary to support the health and care needs of the child. This means parents are also managing and training multiple care providers.

> *"We do therapy integration, so speech therapy, occupational therapy, physiotherapy... there's always something new to be training them on and bringing them up to speed." (Parent of two children with childhood dementia)*

Additional Challenge for Regional and Rural Families

Families in regional areas face additional barriers, particularly limited options for appropriate local providers.

> *"Being in regional Victoria, there is no one, there's no companies at all who will help. My daughter's case is too challenging. There were about 20 companies called here to see if they could help, you know, care for her, and none of them could." (Mother of a child with childhood dementia condition)*

For some the lack of carers has been *"too challenging... it's a whirlwind of frustration and pain. It doesn't make sense. It is emotionally draining*" (*Mother of a child with childhood dementia condition*). Similar problems were frequently reported with accessing providers for home modifications, with some waiting months, even years to find a local option.

The need to travel long distances to appointments and for assessments for reports creates additional strain, including financial stress.

> *"Every time we go to Wagga, which is done at the moment fortnightly... it's three hours, three hours' drive, 150 kms to Wagga and back... plus the petrol." (Mother of a child with dementia)*

THEME 5: EQUIPMENT AND MODIFICATION CHALLENGES - THE BATTLE FOR ESSENTIAL SUPPORT

The Critical Nature of Equipment Access

Every family interviewed had struggled to access appropriate equipment in a timely manner for their child, some fighting for basics and waiting months or years. The struggle for essential equipment represents more than a bureaucratic challenge—it embodies the systematic barriers families face in maintaining their children's quality of life. Each piece of equipment denied or delayed represents lost opportunities for comfort, safety, dignity, and development. And the time lag can be devastating.

> *“You can’t wait six to twelve months without a wheelchair when you’ve got a child that can’t walk” (Mother of a child with dementia)*
>
> *“We are asking because we need it, and we need it now” (Mother of a child with dementia)*
>
> *“By the time you get it, it could no longer be useful” (Bereaved mother)*
>
> *“The delays are endless. We’ve been waiting for basic equipment approval for over a year” (Mother of a child with dementia)*
>
> *“It feels like they pushed back so she would die before they had to do anything” (Mother of a child with dementia)*

The Dehumanising Battle for Basic Necessities

Families reported feeling like they were undertaking a constant battle, asking for equipment or home modifications. Essential equipment often requires multiple applications and appeals before approval. And families recognise that time spent fighting for equipment is time lost with their children. Examples included two years spent fighting for a shower chair and another family who had to take their child to the local pool for months to shower her while waiting for approval for home modification.

> *“We want to make the most of our children and their lives” (Mother of a child with a dementia condition)*

There is also fear for the physical safety of their child and themselves without access to the right equipment. Families gave example after example of how injuries had occurred either to their child or themselves due to not being provided with appropriate or sufficient support, equipment and home modifications such as safety rails or bathroom facilities. Families also reported being limited as a result of being denied access to vital equipment, unable to leave the house due to not having the appropriate car seats, disability strollers or wheelchairs to keep their child safe in the community.

> "*Do you want me to show you the bruises? Do you want me to show you the holes in the walls where she literally grabbed at the towel rail in the bathroom as a grab rail and pulled it off the wall?" (Mother of a child with a dementia)*

Additionally, there is the lack of understanding about childhood dementia conditions and the associated behaviours and psychological symptoms of dementia such as agitation, aggression, anxiety, disinhibition, psychosis and sleep/wake disruption. These symptoms have created situations where NDIA team members misunderstand the use and safety implication of certain equipment such as seatbelts or pool fencing. Parents have faced intrusive and accusatory questions about restrictive practices, rather than sense being applied in respect to understanding about keeping children with dementia safe.

> *"When I'm asking for a seat belt on a disability dedicated stroller, they're questioning whether that's a restrictive practice... If my child's going to run in front of traffic, then I will restrain him. I call that parenting safety, not a restrictive practice." (Mother of child with dementia)*

The Hidden Costs

Beyond the visible challenges of equipment delays, families bear numerous unseen burdens that compound their already overwhelming situation:

- Financial burden of temporary solutions while waiting for approval (rental costs severely depleting packages)
- Psychological toll of constant advocacy and rejection
- Physical strain of managing without proper equipment
- Impact on siblings and family dynamics

> *“I am just trying to keep my family together” (Parent of two children with dementia)*
>
> *"We've been fighting this now for three to four years, having to resubmit, resubmit, and we've just resubmitted again, just to try and get the bathroom modified, but they just keep knocking you back, knocking you back. Do we have to wait for it to be too late before they’re going to do something?" (Mother of young person with childhood dementia)*
>
> *“It’s not to make my house fancy, it’s to make my life possible” (Mother of child with dementia)*

THEME 6: FIGHTING ON ALL FRONTS: THE FAILURE TO ALIGN SUPPORT SYSTEMS

The intersection between the NDIS and other systems, such as health, is a minefield of overlapping needs and gaping holes. The challenges of knowing how to work within and across them, creates significant complications and stress for families. Rather than offering additional and seamless support, the NDIS interface with these systems creates more confusion, administration and fear.

Some examples of these challenges are listed below.

Hospitalisation

Families face particular challenges during what can be frequent hospitalisations, particularly the impact it has on support hours. Parents spoke of not being allowed to "intertwine" services. They were not able to use their support teams to provide support if a child was in hospital, even though it often meant they are forced to provide 24-hour care (as hospitals will not assign extra care to meet the needs). This is the case regardless of whether the illness is related to their condition or not.

> *"If you have a carer, and essentially you can't take a carer into a hospital, because it was considered that you double up and doubling up on the government assistance…But if they are going in there for the flu - why can't the carers be in there?" (Bereaved parent)*

As well as the impact of the additional care needs on parents (and in turn, any siblings who bear the brunt of less family connection), the formal support team themselves also face challenges of inconsistent work and insecure income. This can lead to seeking other work arrangements, leaving families again scrambling for care.

Transition

Transitions between different stages of care, such as from paediatric to adult services, are fraught with challenges. Families describe a lack of continuity, with established networks and supports disappearing almost overnight. This can leave families scrambling to rebuild a care plan while managing their child's evolving needs.

One parent whose son transitioned to adult services, explained: *"When my son turned 18, everything we'd built vanished. We had to start all over."* Another parent highlighted the broader issue: *"The gap between paediatric and adult services is massive. It feels like falling through the cracks."*

Transition into Supported Independent Living arrangements was also noted as particularly challenging, with some complex issues arising for the child or young person and their families.

Palliative Care

Due to the lack of curative treatments for childhood dementia, all care from the point of diagnosis is palliative in nature. The topic of palliative care was particularly fraught for families. The commonly held understanding by parents is that if you inform the NDIA your child is accessing specialist state-delivered palliative care services, you are deemed ineligible to use the scheme, or it will be limited. This understanding has come from statements made by NDIS staff who could not distinguish between palliative care and end of life care, meaning that their children were unable to access invaluable support (such as pain management) for fear of losing NDIS funding, even though they may yet live for years.

> *“NDIS doesn’t seem to understand the difference between palliative care and end of life” (Mother of a child with dementia)*
>
> *"I've never used the language [palliative] because I've heard that... I've always avoided it. I mean, I'm quite upfront that they will die... but very cautious about using the language of palliative"(Parent of two children with dementia)*
>
> *“It’s common knowledge, don’t say palliative. If you say they are dying, they won’t fund you” (Mother of a child with dementia)*

Conclusion

The experiences of families affected by childhood dementia reveal significant gaps in the current NDIS model. While the scheme provides essential support for which families are grateful, substantial system changes are needed to better serve this vulnerable population. The progressive nature of these conditions requires a fundamentally different approach to disability support.

The findings of this research show that the current NDIS framework fails to meet the needs of children with progressive conditions like childhood dementia, creating systemic barriers that place an immense burden on families. A lack of workforce understanding, excessive administrative demands, and inconsistent support force families into a constant battle for essential care, often at the cost of precious time with their children. Consideration of this unique cohort is urgently needed to ensure timely access to support, reduce bureaucratic obstacles, and create a system that truly understands and responds to the realities of childhood dementia conditions.

On the basis of what was heard through this research; key recommendations to address these issues include:

- Creating a specialised pathway for childhood dementia conditions, recognising the complex and constantly changing needs of these families
- Using the principle of predictability, streamlining equipment and home modification approval processes to reduce the administrative burden
- Improving coordination between health, palliative and disability services
- Developing specialised training and professional development for NDIS staff and disability support workers

Implementation of these recommendations would significantly improve the NDIS's ability to support families affected by childhood dementia, lessening the trauma and administrative burden, while ensuring more timely and appropriate support delivery.

“We are all human too… We never asked for it… We just want something simple and easy for her as long as possible. Just nothing, nothing too dramatic, just to make life a little more simpler”. (Mother of two children with dementia)