



'We don't fit'

The lived experience of families affected by childhood dementia
and their interactions with care and support services

Nous Group | March 2023

nous

Nous Group acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians and the Traditional Custodians of country throughout Australia. We pay our respect to Elders past, present and emerging, who maintain their culture, country and spiritual connection to the land, sea and community.

This artwork was developed by Marcus Lee Design to reflect Nous Group's Reconciliation Action Plan and our aspirations for respectful and productive engagement with Aboriginal and Torres Strait Islander peoples and communities.

Disclaimer:

*Nous Group (**Nous**) has prepared this report for the benefit of Childhood Dementia Initiative*

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Background to this report

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CHILDHOOD DEMENTIA

Childhood dementia results from progressive brain damage caused by more than 70 rare, genetic, progressive neurodegenerative conditions. These conditions lead to impaired mental and physical function that become progressively worse over time. Most children and young people affected by childhood dementia die before turning 18. The use of 'childhood dementia' as an umbrella term is relatively recent and provides a vital platform for action.

CONTEXT FOR THIS RESEARCH

Previous research established that families experiencing childhood dementia had challenging journeys interacting with health and social care ('care and support') services, commonly expressing that they 'do not fit'¹. Childhood Dementia Initiative (CDI) identified the opportunity to conduct targeted research in order to articulate and represent the current 'lived experience' of families in their interactions with care and support services and identify the key challenges and opportunities for change. Nous Group (Nous) supported CDI in conducting this research and developing this resulting report, with the ultimate aim of enabling advocacy and systemic change – namely, to ensure appropriate, equitable and high-quality care for families affected by childhood dementia.

It should be noted that this research focuses on the family experience accessing services and does not specifically address the lack of treatments, therapies, and cures for childhood dementia, which of course must continue to be a focus.

A NOTE OF THANKS

Nous and CDI would like to thank the families who generously participated in this research. We are grateful and honoured for you to have shared your lived experience with us for the purposes of this project.

OUR APPROACH

Nous facilitated, in partnership with CDI, eight in-depth interviews with parents of children affected by childhood dementia and focused on understanding interactions with care and support services throughout their journey. Families that took part in the research represented a breadth of different backgrounds and experiences including:

- A range of different childhood dementia conditions
- Experiences with many care and support services
- Families from different parts of Australia
- Families at different stages of their journey, including bereaved parents.

THIS REPORT IS IN TWO PARTS:

1. A journey map which articulates a 'typical' experience of a family navigating care and support services.
2. A set of themes that speak to common family experiences, including key pain points and opportunities for change.

¹ Nevin, S. M., McGill, B. C., Kelada, L., Hilton, G., Maack, M., Elvidge, K. L., Farrar, M., Baynam, G., Katz, N. T., Donovan, L., Grattan, S., Signorelli, C., Bhattacharya, K., Nunn, K., & Wakefield, C. E. (2022).⁴ The psychosocial impact of childhood dementia on children and their parents: A systematic review [Under Review]

Journey Map:

A typical family's experience
navigating care and support services

Journey Map – A typical family's experience navigating the care and support services

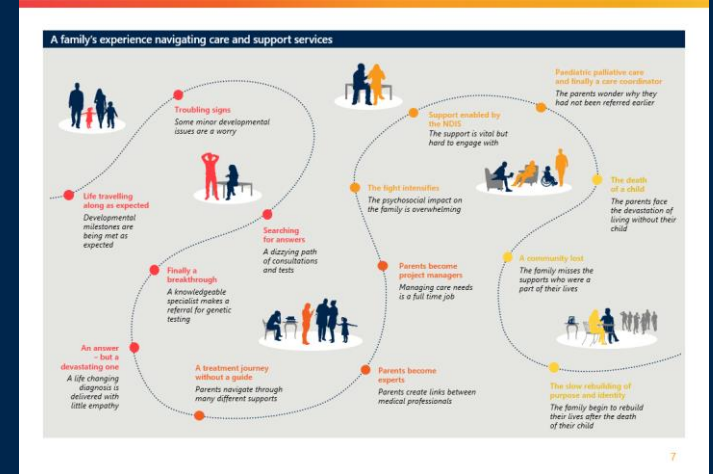
Following the interviews, and a thorough analysis of the different experiences across the eight families, Nous employed Human Centred Design (HCD) methodology to articulate the lived experience through a Journey Map.

The Journey Map that follows, graphically portrays a fictional family Deb, Mark and their child Tali in their interactions with care and support services through Tali's life.

The Journey Map and the supporting narrative and quotations under 'Tali's story', do not reflect any single family that took part in this research. Rather the Journey Map is representative of the collective families interviewed and tells a story which combines common experiences and challenges into a single example.

The Journey Map is divided into four chapters with the first page acting as a dual high level overview of the journey and a contents page. The four chapters that follow are divided into separate sections, one chapter per page.

A high level overview of the journey is on page 7



Chapters for each part of the journey are on pages 8-11

DIAGNOSTIC ODYSSEY | Length of time: 5 years.

Family Journey

Life travelling along as expected
Dad and Mark love their child Tali and it appears she is meeting her milestones. They have no idea that there is anything to worry about.

Troubling signs
Over time Deb and Mark start to notice some minor developmental issues that worry them. Teachers at Tali's school also have some concerns about Tali's development which triggers more questions. Deb and Mark connect with a range of health professionals and have regular sessions with different therapists, who address some specific concerns but do not identify any deeper issues.

Searching for answers
Tali develops additional concerning symptoms which seem to be getting worse and Deb and Mark have a strong feeling that there's something more serious going on. They search for answers, following a dizzying path of consultations and tests with a range of different health professionals. None of them find anything specific, and most of them dismiss Deb and Mark's concerns.

Finally a breakthrough
Deb and Mark's own research led them to a new paediatrician, who took a particular interest in Tali's global symptoms. This paediatrician refers Tali to a specialist who has knowledge of conditions that cause childhood dementia. This specialist finally refers Tali for genetic testing. It took a long time but Deb and Mark were relieved to get closer to some answers.

An answer - but a devastating one
Following the tests, and another long wait for the results, Deb and Mark are asked to come into the hospital. After an agonising couple of days waiting for this appointment, they are delivered a devastating diagnosis with little empathy or explanation about what lies ahead and no coordinated support or follow-up.

Tali's story

"We were delighted by our new baby Tali - she brought so much love into our lives and gave our big Alex a cousin to grow-up with."

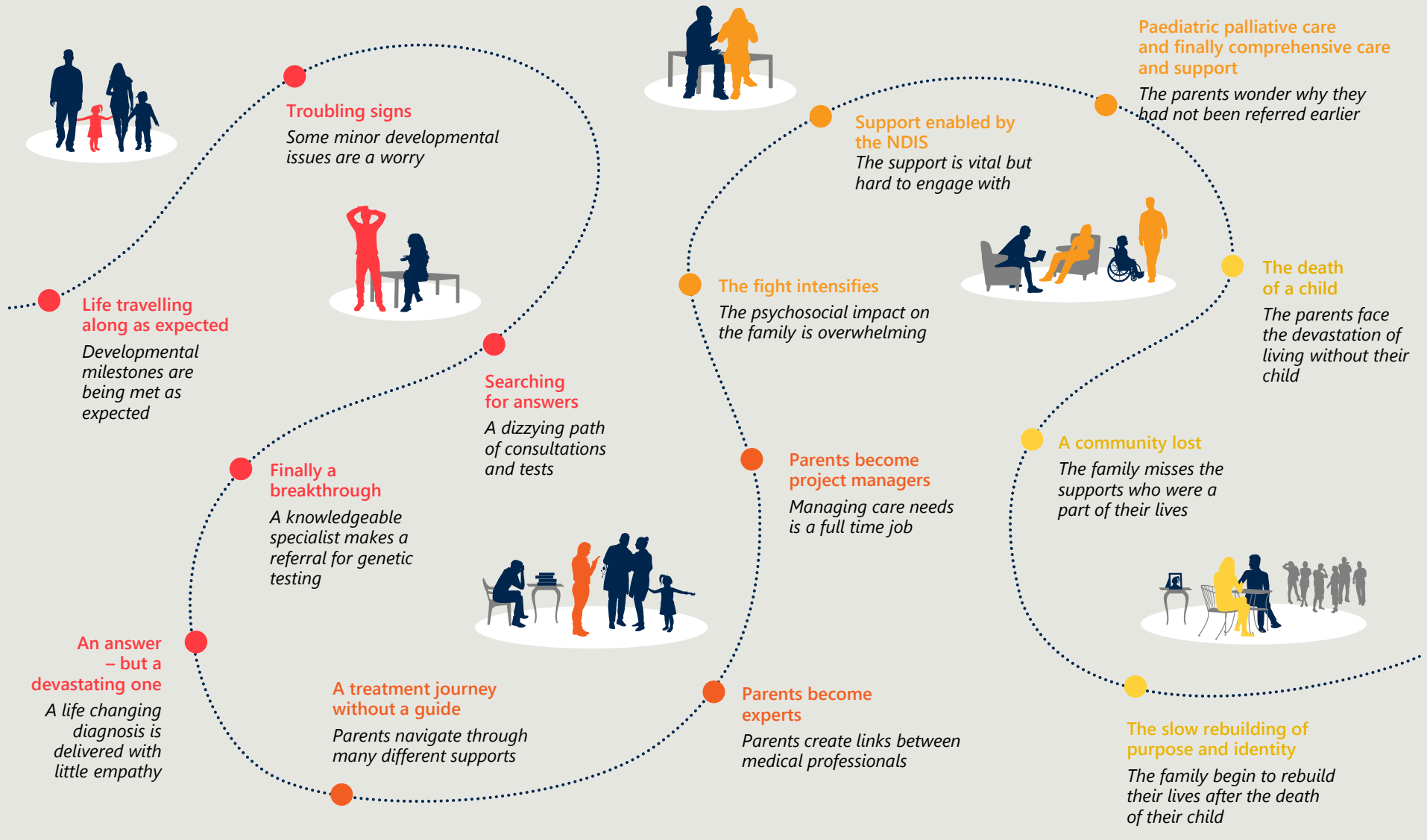
"We noticed a few minor issues. Our paediatrician, who we'd seen a few times for regular checks since Tali was born, didn't think there was much to worry about, but did refer us to a speech pathologist who we worked with for a year. At this stage we just had our best to put it all on our worries and accept that Tali just had some 'normal kiddo issues'."

"She had some developmental issues, but it wasn't just that. I knew there was something more. Her classroom wasn't normal, and her behaviour was awful - and getting worse. I stopped a couple with our Paediatrician, and the OT both dismissed me. They thought we just a neurotic mother. Not so talented. And started blaming myself for her naughtiness, maybe I was just a bad parent."

"Eventually after connecting with some parents through a local Facebook group, we were recommended a new paediatrician. When we finally met her it was as if something clicked, she asked so many questions about Tali, she was really interested in everything about her, and us. She suggested we go for some tests."

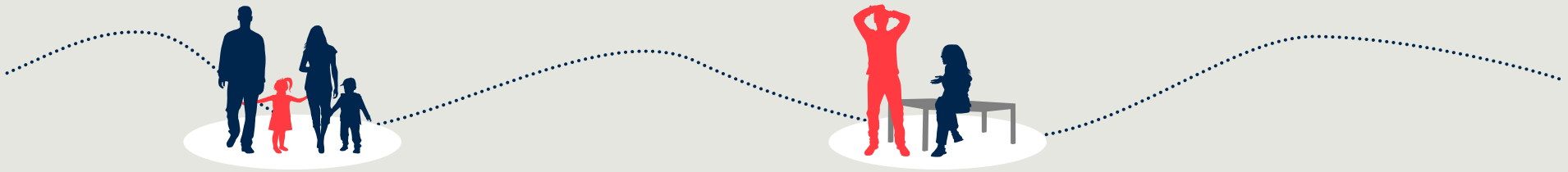
"The room was full of doctors, looking nervous. One of them eventually said to Deb that a new genetic condition, but didn't give any more detail. It was obvious it was bad, but we had no idea how bad. They told us that we would be connected to some specialists at the children's hospital, but then sent us home. It was basically 'Thank you and goodbye'."

A family's experience navigating care and support services



DIAGNOSTIC ODYSSEY | Length of time: 5 years

Family journey



Life travelling along as expected

Deb and Mark love their child Tali and it appears she is meeting her milestones. They have no idea that there is anything to worry about.

Troubling signs

Over time Deb and Mark start to notice some minor developmental issues that worry them. Teachers at Tali's pre-school also have some concerns about Tali's development which triggers more questions. Deb and Mark connect with a range of health professionals and Tali has regular sessions with different therapists, who address some specific concerns but do not identify any deeper issues.

Searching for answers

Tali develops additional concerning symptoms which seem to be getting worse and Deb and Mark have a strong feeling that there's something more serious going on. They search for answers, following a dizzying path of consultations and tests with a range of different health professionals. None of them find anything specific, and most of them dismiss Deb and Mark's concerns.

Finally a breakthrough

Deb and Mark's own research leads them to a new paediatrician, who takes a particular interest in Tali's global symptoms. This paediatrician refers Tali to a specialist who has knowledge of conditions that cause childhood dementia. This specialist finally refers Tali for genetic testing. It took a long time but Deb and Mark are relieved to get closer to some answers.

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Following the tests, and another long wait for the results, Deb and Mark are asked to come into the hospital. After an agonising couple of days waiting for this appointment, they are delivered a devastating diagnosis with little empathy or explanation about what lies ahead and no coordinated support or follow up.

Tali's story

"We were delighted by our new baby Tali – she brought so much love into our lives and gave our boy Kevin a sister to grow up with."

"We noticed a few minor issues. Our paediatrician, who we'd seen a few times for regular checks since Tali was born, didn't think there was much to worry about, but did refer us to a speech pathologist who we worked with for a year. At this stage we just tried our best to put a lid on our worries and accept that Tali just had some 'normal kid issues'."

"Yes she had some developmental issues, but it wasn't just that, I knew there was something more. Her clumsiness wasn't normal, and her behaviour was awful – and getting worse. I flagged it again with our paediatrician, and the OT, both dismissed me. They thought I was just a neurotic mother. I felt so alienated. And started blaming myself for her naughtiness, maybe I was just a bad parent."

"Eventually after connecting with some parents through a local Facebook group, we were recommended a new paediatrician. When we finally met her it was as if something clicked, she asked so many questions about Tali, she was really interested in everything about her, and us. She suggested we go for genetic tests."

"The room was full of doctors, looking nervous. One of them awkwardly told us Tali had a rare genetic condition, but didn't give any more detail. It was obvious it was bad, but we had no idea how bad. They told us that we would be connected to some specialists at the children's hospital, but then sent us home, it was basically 'thank you and goodbye.'"

TRANSFORMATION OF PARENTING ROLE | Length of time: 7 years

Family journey



Now that they have a diagnosis, Deb and Mark expect to be told what care and support Tali needs, and how they should go about accessing those services.

But there doesn't seem to be anyone to support them in finding this information. They have to navigate their own way through care and support services, and Deb and Mark end up once again, zig zagging between different professionals often receiving contradicting advice.

Without a set pathway, or a clinician coordinating their case, Deb and Mark must find and make links between medical professionals and other care and support services to manage Tali's care.

They shoulder the burden of becoming the expert in this complex condition, even though they often don't feel heard or respected by professionals that they encounter.

As Tali's condition progresses and her needs intensify, Deb and Mark become reliant on care and support from a range of care and support services.

Managing these services and the administration involved is nearly a full time job. This lands on Tali's mother Deb on top of already being a full time carer for Tali. Deb is forced to give up her job, causing more financial strain and a loss of identity. The relationship between Deb and Mark becomes strained with the pressure of the full time care needs of their daughter while also trying to find time to care for their son Kevin.

Tali's story

"We found out by Googling, that Tali's condition was terminal, They hadn't even told us that. Even then, every doctor seemed to have different views, one doctor gave her a year to live, another said she will be here longer, one wanted to put her on one drug to manage her symptoms, another said it wouldn't work and suggested something different. It was like jumping stepping stones, trial and error - I just wanted one care path that I could trust."

"The specialist team at the children's hospital kept track of us and saw us once or twice a year. But they didn't help us to co-ordinate anything else, provide psychological support or address any of Tali's other health needs. In fact they seemed annoyed when I would reach out to share research or ideas, that came from international experts or to suggest that we see other specialists as well."

"Tali's condition affected her in many different ways, so we ended up going to specialists for each issue, we had metabolics, orthopaedics, ENT, the GP, the paediatrician...so many appointments. You can imagine how exhausting it was driving, meeting, coordinating, processing the information... and each time I had to tell the same story and fill in similar forms. The stress and exhaustion was immense. I had to give up work to fit it all in. I was angry and frustrated. I needed support and there was none!"

FIGHTING AN ENDLESS BATTLE | Length of time: 2 years

Family journey



As Tali's health worsens and her care and support needs continue to intensify, additional pressure is put onto Deb and Mark – as the expert in Tali's needs as well as the project managers and carers.

The journey seems to be relentless, with new issues and challenges every day. The knock on impact on the family is huge, financially, emotionally and has significant impacts on Deb and Mark's physical and mental health.

As Tali's condition continues to decline, NDIS support is vital but Deb and Mark find the scheme challenging to engage with.

Tali's regressive condition is rare and her needs are not well understood. Deb and Mark feel that they are constantly having to build and defend their case for support. However, the funding that they do receive through the NDIS, is hugely valuable to enable them to access necessary care and supports.

**Note: experiences accessing NDIS varied widely (see Theme 5, page 18)*

The family are referred to the paediatric palliative care service and Deb and Mark wonder why they had not been connected earlier.

The palliative care team help coordinate Tali and her family's care and support needs holistically, communicate with various specialists, refer them to supports, help deal with the NDIS, gently introduce conversations about advance care planning and end of life, and overall, provide a compassionate ear that has been missing.

**Note: experiences of palliative care services varied widely (see Theme 4, page 17)*

Tali's story

"Tali was in a wheelchair and could not feed herself. She had to have two people to care for her at all times and her behaviour was really erratic. This meant I couldn't work anymore, so our finances took a hit. Our marriage and family life was also at breaking point. I was so busy caring for Tali that Mark and I never had time together. But most of all it was the sorrow of witnessing Tali deteriorate that really wore us down."

"The NDIS were constantly pushing back and would say: 'is this really needed? They did not seem to understand that Tali was regressing – how in a few months, she would need new equipment, like when she lost mobility in her arms. We knew it would happen, and it would happen soon, but until it happened it was not seen as reasonable and necessary. Dealing with them was emotionally draining and a constant struggle. It was around this time my husband and I separated. The stress of caring for Tali and not having any time for our relationship was too much."

"Once we came to terms with Palliative Care not being just about the end of life and we met with them, it was an absolute game changer. The paediatric palliative care team knew what we needed before we knew what we needed. They helped us navigate the NDIS and get the supports we needed as Tali declined, they came to meetings with me, they connected up our various doctors. They stepped into the clinical care and coordination role that I was struggling with. But I think the thing I remember most is the compassion and empathy they showed us after being so misunderstood for so long. I wish we'd had them sooner."

A LIFETIME OF ADJUSTMENT | Length of time: 1+ years

Family journey



The death of a child

Eventually the brain can no longer keep Tali's body functioning and the family prepare themselves for her inevitable death.

The palliative care team help Deb and Mark plan for the dying process and funeral for Tali. Tali dies at home. Friends, family, and community gather for the funeral, and surround Deb, Mark and Kevin with love and support, but the pain of losing Tali is overwhelming.

A community lost

The family's community of social and health supports quickly fades away with little in the way of coordinated bereavement care, leaving them to cope with grieving alone.

The family misses all the care and support professionals who had become part of their daily lives. Many family and friends have disconnected throughout Tali's long illness, causing more isolation for the family in bereavement.

The slow rebuilding of purpose and identity

With the death of Tali, Deb and Mark relinquish their roles as carer, expert and project managers in Tali's life.

Coupled with grief, Deb and Mark explore ways to reclaim their purpose and identity and ways to support Tali's brother Kevin to navigate his grief.

Tali's story

"These were the hardest days of our lives and nothing could take away our grief. Tali died at home, peacefully in her own bed and I was grateful to the palliative care team for supporting us to achieve this. Over the weeks and months that followed, in one way we had our lives back but it was just a constant struggle to know what that life actually was about now that our dear Tali was gone."

"We had this team around us when Tali was alive. Support workers would be sitting at the dinner table with us, reading Tali and Kevin a story. Our doctors, therapists and support workers were all so involved too. And then she's dead and this whole community that knew our daughter and our family is taken away."

"Each day was a challenge to function, for example just going out to a supermarket which I had visited with Tali. I would end up weeping in the shop thinking of her. I think it must have been after a year or two that I felt ready to start working again. I am now working in an advocacy role supporting other parents dealing with childhood dementia. It feels good to be making a difference!"

Emerging themes and opportunities for change

Emerging themes and opportunities for change

The interview analysis identified six themes that speak to common family experiences when interacting with care and support services, and where there might be opportunities for change. In this section you will find six themes:

THEME 1

Conditions that cause childhood dementia are rare, difficult to diagnose and diverse, which combined with low awareness results in delayed diagnosis.

THEME 2

Following diagnosis, there is no defined care pathway and parents find it difficult to access and navigate the various health services and supports that their child needs.

THEME 3

Parents inevitably become the project managers for their child's care, an all-encompassing role with a high administrative burden.

THEME 4

Paediatric palliative care can provide comprehensive care and support but is not consistently accessed.

THEME 5

NDIS packages are an essential support for families, but are universally challenging to access and manage.

THEME 6

Following the death of their child, families find comfort in informal and formal supports, yet these can be difficult to access and sustain.

THEME 1

Conditions that cause childhood dementia are rare, difficult to diagnose and diverse, which combined with low awareness results in delayed diagnosis

FAMILY EXPERIENCE



- Early symptoms of childhood dementia tended to be subtle and when flagged by parents were dismissed or downplayed by health professionals, often explained as 'developmental delay' or early signs of conditions such as autism or ADHD. Even when symptoms became more severe, they were misdiagnosed, for example seizures led to an epilepsy diagnosis, or vision issues to a diagnosis of vision impairment.
- Parents continued to search for answers, often undertaking significant research to identify that their child's symptoms might point to an underlying genetic disorder; and/or by seeking input from different GPs, paediatricians, and other health providers. In some cases, a chance conversation with a knowledgeable expert, friend or health professional prompted the family to further explore disorders that cause childhood dementia. For most families the journey to specific testing and genetic screening, leading to diagnosis, was lengthy and extremely challenging (and has come to be termed a "Diagnostic Odyssey").



"My mothers intuition told me that there was something wrong, but I was dismissed multiple times as a neurotic mother including by my GP and the paediatrician."

"It was a massive relief when the ophthalmologist (who had knowledge about their child's rare condition) started asking the right questions – it finally felt like someone was listening, taking it seriously, after so many years."

"Unfortunately he (the neurologist) misdiagnosed my child with a form of epilepsy. The medication provided for epilepsy actually progressed her condition."



Opportunities for change



Map routine health and social system touchpoints where childhood dementia symptoms may first be recognised.

Build health professionals awareness and knowledge of childhood dementia, especially those involved in routine childhood touchpoints such as GP's and paediatricians.

Build general public awareness and knowledge of childhood dementia.

Identify and promote options for earlier intervention through more streamlined and timely genetic screening, including consideration of equity of access.

THEME 2

Following diagnosis parents find it difficult to access and navigate the various health services that their child needs

FAMILY EXPERIENCE



- Children were usually assigned to a medical specialist, who became their key point of contact and primary clinician. Parents were often dissatisfied with this relationship, noting that they were seen periodically through generic clinics, with limited proactive, individualised care or support, and little acknowledgement of their child's complex, holistic and rapidly changing needs.
- In the absence of proactive personalised support from the primary clinician, parents tended to seek additional input and expertise by finding and engaging other specialists. This resulted in parents investing significant time seeking and interpreting multiple viewpoints to identify and decide on what care pathway they should take. Then as they engaged, they needed to tell their story each time, relaying details on diagnosis, care, medication and so on. Parents described this as a stressful and overwhelming experience.
- Parents reported that behavioural and psychological symptoms, including aggressive behaviours, hyperactivity, agitation, inability to communicate and toileting challenges were particularly draining and distressing. At times parents found the challenging behaviours led to exclusion from some supports, such as respite services. Managing these issues on top of all of their child's other supports was particularly hard and had a significant impact on parents' and other family members' mental and physical wellbeing.
- Parents who were connected with paediatric palliative care services reported the challenge of navigation and coordination was much reduced, however referral and access was inconsistent across families (see Theme 4).
- For those who reached eighteen years, their care was transferred from paediatric to adult services. This transition was often a challenging one, with a lack of continuity, resulting in parents once again taking a lead in seeking the required supports and relaying information to various different care and support care service providers.



"Treatment options and information provided is very confusing and we are given multiple viewpoints from different people. In our case the haematologist said have a bone marrow transplant, and paediatrician said 'you don't need to do this' which meant we ended up having to do a lot of our own research."

"Repeating the same story every time to new doctors is really hard, especially when the disease is so complicated and rare, and it's even worse when they don't even listen, or respect the knowledge that you've gained."

"It really needs to be a collaborative 'holistic view'. We can't have these siloes."

"Paediatric palliative care in the children's hospital are amazing at connecting up all the supports including the specialist team, the nurse coordinator, physio, OT, music therapist, and more."



Opportunities for change



Develop a 'standard model of care' to ensure a consistent and coordinated approach to referrals and support.

Draw on existing care coordination models to inform development of a centralised care coordinator role for the main childhood dementia conditions.

Develop a transitional model of care to guide young people and their families movement between child and adult health services.

Activate peer support relationships for parents and carers through a formal peer mentoring program.

THEME 3

Parents inevitably become the project managers for their child's care, an all-encompassing role with a high administrative burden

FAMILY EXPERIENCE



- Parents rely on a complex web of care and support services to support the needs of their children. These include medical specialists, allied health therapies, in-home carers, special education schools, respite services, NDIS and more. With multiple care and support services to navigate, the parents, (or typically one parent, usually the mother), take on the 'project management' role, coordinating between services, managing referrals and appointments, briefing and/or overseeing various carers, managing complex medication regimes, and more. Parents also noted the stress of the significant amount of administration required, including repetitive, complex forms requiring them to detail their child's information, history and needs, over and over again.
- Parents struggled with the demands of being a full-time project manager, on-top of their existing career, family and household duties. Usually at least one parent has also given up their paid jobs, and describe the loss of identity that this brought, in addition to feeling resentment at the project management duties taking over their primary role as a parent. As a parent of a child with a life-limiting condition, parents wanted to spend their time enjoying the life of their child and making memories.
- Overall, the pressure of managing their child's care had devastating impacts on many families including significant financial stress, diminished time with well siblings, relationship stress between parents, marriage breakdown, and mental health issues like anxiety, depression and trauma.



"There is no real distinction between being mum, carer, project manager and you are on call 24/7. No time to be a partner anymore... that is why many couples do not make it through their time with Childhood Dementia."

"It is frustrating and exhausting being a project manager as there are so many unnecessary steps. Like even though we have a specialty Neurology care team, you have to go through Emergency Department to get into hospital and they don't seem to have access to our file and our history - I'm losing my mind telling the Emergency Department team the same information each time I go in."

"There were so many forms all the time, especially dealing with the NDIS and Centrelink. I would rely on my husband to step in. I can see why other parents without supportive partners, might end up mortgaging their houses to support their child rather than keep fighting with the system for funding – it just becomes so emotionally draining."



Opportunities for change



In the development of a 'standard model of care' (as in Theme 2), ensure a consistent and coordinated approach to referrals and support to relieve the administrative burden from parents.

Explore opportunities for access to in home and out of home respite care for children with dementia.

Develop a system for family engagement with informal networks to assist with daily household activities.

Identify appropriate carer support organisations and networks and develop appropriate supports for carers of children with childhood dementia.

THEME 4

Paediatric palliative care can provide comprehensive care and support but is not consistently accessed

FAMILY EXPERIENCE



- Parents were not routinely referred to a paediatric palliative care service, but when they were, in most instances they highly valued the service's support. The timing of the referral and the extent of support that families received from paediatric palliative care also varied. In some instances the team became the single point of contact, playing a vital navigation and care coordination role, taking a huge burden off the parents. Their support included connecting with the right care and support services, conveying information between services, helping the parents to interpret clinical advice and make informed decisions around their child's care and decision making around their child's end of life and place of death.
- If a child reaches eighteen years, they are transferred from paediatric to adult palliative care teams. Adult palliative care approaches were less likely to embrace the longer term palliative care trajectory as experienced in paediatric palliative care, with some adult palliative care teams expressing confusion as to why families would be seeking a referral at their child's stage of illness. Where families had experienced this transition, parents noted the difference in the two systems. They found the adult system focused on caring for a single patient in one care setting as they near death, in contrast to paediatric palliative care who provided more holistic, comprehensive support, over a longer period across multiple settings, supporting the needs of the whole family.



"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."

"The paediatric palliative care team knew what we needed before we knew what we needed. They'd been through it before. For example they knew she would need support with her mobility in the future so they helped us with the process of negotiating with the NDIS to modify my bathroom and get a lift."

"The adult palliative care team seem stretched. They certainly could not offer the same type of support as we had before. The paediatric palliative care team used to reach out once a month to check on us. In the adult system we heard from a Social Worker when our child was first admitted but we then lost contact."



Opportunities for change



Ensure transitions to paediatric palliative care, and between paediatric and adult palliative care are incorporated into the 'standard model of care' to ensure a consistent and coordinated approach to referrals and support. (As per Theme 2)

Enhance opportunities for education of health professionals on the role of paediatric palliative care in the lives of children with dementia and their families.

Identify and enable access to resources for families on the role of paediatric palliative care for children with dementia and their families.

NDIS packages are an essential support for families, but are universally challenging to access and manage

FAMILY EXPERIENCE



- While the NDIS does provide for people with support needs resulting from a degenerative condition, families found that NDIS staff were often not familiar with these types of conditions, and how to apply the NDIS structures and criteria. This meant that parents often had to go through longer, more complex negotiations to gain access to the required supports, and often experience inconsistent assessment and funding decisions. In addition, the onerous NDIS process made it difficult to plan ahead; parents knew that further supports would be required as the child's condition deteriorated but were not able to seek or secure these supports until the regression had occurred.
- Parents found the capability and knowledge of support co-ordinators, engaged under their NDIS packages, to be highly varied. In the case where some families connected with support coordinators with a strong understanding of childhood dementia and the underlying conditions, they had a more positive, and less stressful experience than other families.
- Parents highlighted the importance of continuity of carers, which was often a challenge to achieve. As children's conditions deteriorated and their support needs intensified, they needed a regular team of carers who understood the complexities and had a close working relationship with the child, parents and other carers. This prompted several families to self-manage their NDIS plan, and in some cases to set up their own company through which to employ carers. Although this added a significant administrative burden, it provided families the opportunity to build and maintain a fit-for-purpose care team for their child.



"The dementia symptoms were causing severe behavioural and psychological issues. We needed a wheelchair just to get out the house and keep everyone safe. But we were told that was just challenging behaviour, and our 'parental responsibility'. They couldn't see that it was as a result of the dementia. And it meant we couldn't even get out to the shops or to bring the kids to the playground."

"The NDIS is brilliant and when you get 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 not just once...this will happen every review...and often more than once a year."

"We have never been able to prove that our child is as disabled as other children who need care but once we were connected to specialist complex care coordinators it's been totally different. They've been total life savers."



Opportunities for change



Introduce specialist childhood dementia NDIS teams, resources and/or processes, to enable consistent, appropriate application of NDIS structures for this cohort.

Provide practical resources to support families seeking NDIS support for children with childhood dementia conditions (e.g. step-by-step processes, case studies, communities of practice).

Ensure families are connected with appropriate NDIS support co-ordinators and service providers that are experienced at supporting children with childhood dementia.

THEME 6

Following the death of their child families find comfort in informal and formal supports, yet these can be difficult to access and sustain

FAMILY EXPERIENCE



- While family's experience grief throughout their child's life, the experience of becoming a bereaved parent is devastating and life changing. Parents struggled to find hope and joy in the face of immense grief.
- Childhood dementia, and caring for a child with very complex needs, becomes a core part of the parents identities, and one which they are connected with 24-7. Parents whose children died experienced a sudden and extreme loss of identity as carer and experienced a loss of meaning and purpose in their lives.
- The informal and formal community of care and support which had been their everyday life for months and years suddenly disappears, leaving behind a void and a sense of lost community. Meeting new bereavement care professionals who did not know the family's child or story is difficult and less meaningful.
- Some parents described the challenge of re-entering the workforce due to their long term carer role.



"You've had such a big team around you, these support workers would be sitting at the dinner table with us reading a story and suddenly all these people are gone, paediatrician, schools...it's a really bizarre absence...this was the community that knew your son and suddenly it's all gone."

"I now work in support coordination... I wanted to help other families who weren't as fortunate as me in knowing how the healthcare system worked. It feels good to be making a difference and to have my identity back."

"It was so important to know my friends were there. A friend planted a lemon tree and had their own little ceremony and said 'we can't be with you, we can't fathom how it is for you at the moment, but we're always going to remember your child and your family through our lemon tree and the fruit she is going to bear for us'. They sent me a photo of the lemons. People did amazing things."



Opportunities for change



Develop a transitional model of bereavement care to support families movement between pre-bereavement and post-death support, and to identify and respond to psychosocial concerns.

Where new models and roles are developed (e.g. 'standard model of care' and 'care coordination approach' Theme 2), ensure supports extend beyond the death of the child.

Develop peer support approaches where parents can meet prior to the death of a child and this trusted relationship transitions into bereavement.

There is an urgent need for systemic change to improve the experience of families affected by childhood dementia as they access care and support

IN CONCLUSION

This report highlights a range of challenges faced by families living with childhood dementia as they engage with care and support services, causing significant psychosocial distress. Families are forced to navigate a complex and often fragmented system, where most services have very limited awareness of the existence or experience of childhood dementia and are not adequately equipped to meet their unique and complex needs.

The journey map and the six themes identified in this report illustrate and expand on the challenges that families affected by childhood dementia are facing. They also identify opportunities for change, with the aim of improving the quality of life for children and families and ensuring appropriate, equitable, and high-quality care.

To activate systemic change, a collaborative response is needed at multiple levels across the health and social services sectors. Childhood Dementia Initiative will draw on this report to drive advocacy and systemic change to ensure that families affected by childhood dementia are heard and receive appropriate care and support, including through raising awareness, improving access to services, and promoting research and clinical trials to find treatments for childhood dementia. Childhood Dementia Initiative seeks support and engagement from other organisations to play a key role in partnering for change.

FURTHER RESEARCH IS NEEDED

It should be noted that whilst a conscious effort was made to engage with a range of different families in different situations, families who responded to our expression of interest to be interviewed were primarily mothers from white, middle-class backgrounds and living in metropolitan areas with only one child affected by childhood dementia. Further research with a larger and more diverse population would be valuable, to test and refine the challenges and opportunities identified through this work.



"I can't leave to do anything, I'm stuck at home. We just need more nurse care. It's getting harder and harder to fight. And I don't think I should have to fight so hard, especially when they get my child is progressing."



Families like this one, affected by childhood dementia, are desperate 'to fit' within care and support services. There is urgency to their mission.



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