Childhood Dementia Initiative

Submission to Inquiry into the recognition of unpaid carers

Childhood Dementia Initiative welcomes the opportunity to make a submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry on the provisions and operation of the *Carer Recognition Act* (2010).

Childhood Dementia Initiative is the peak organisation advocating for children and young people and their families impacted by childhood dementia, including bereaved families. Our purpose is to transform research, care and quality of life for children with dementia so they may live long fulfilling lives. No family should be left to watch their child suffer and die from dementia.

Key points:

- Unpaid carers for children and young adults with dementia are a distinct cohort that need to be recognised within the provisions and operation of any reforms to legislation in relation to unpaid carers.

- Evidence points to excessive support being borne by family carers with children due to the assumption of 'parental responsibility' and the 'natural parenting role' (Nous Group, 2023).

- All parents and families caring for a child or children with dementia will experience bereavement, complex grief and the end of their caring role.

- In the absence of appropriate and responsive care pathways and support services, parents and families impacted by childhood dementia are left to fill the gaps. This leads to manifold psychosocial challenges which encompass economic, social and psychological implications for parent carers (Nevin et al., 2022).

- Unaffected siblings need to be recognised as young carers as they can be adversely impacted as parents spend increased time and energy on the child with dementia (Needham et al., 2014) (Grant et al., 2012) (Dermer et al., 2020) (Hoffmann et al., 2020).

> ***"Childhood dementia is a common and understood terminology that gives people a connection to understand the severity of this group of diseases. These children are not in the playground, mainstream school or supermarket. They are at home with their parents who are trying to help them die comfortably."***
>
> ***Bereaved parent of child who died from childhood dementia***

Background

At present, an estimated 2,300 children in Australia are suffering and slowly dying from dementia. These children do not have access to appropriate care or therapies that might help them. It is not a large population, but it is underserved, largely unrecognised and almost entirely ignored, not just in Australia but globally. It is not only these children who are impacted by their dementia. Parents, siblings, extended families, and friends are all affected by the experience of a child living with dementia and given the genetic nature of childhood dementia, many families have more than one child living with the condition. Nearly 9,000 Australians are estimated to share a household with a child living with dementia. This impacts their capacity to work, socialise and many other elements of their lives.

These disorders lead to severe symptoms, high care needs, extended chronic grief, and poor quality of life for children and their families. Less than 5% of the disorders that cause childhood dementia have effective treatments, and 75% of affected children will die before they turn 18 (Tilden et al., 2020).

Issues

Diagnosis

Parents report a diagnostic odyssey that can extend for years (Nous Group, 2023). As parents express concern around a growing range of symptoms with health professionals, they are often dismissed as 'neurotic' (Nous Group, 2023; Childhood Dementia Initiative, 2022). Parents regularly report a lack of awareness of childhood dementia by GPs and, given that this group is the first point of contact for many primary care issues, dementia education of GPs should be prioritised. This is particularly important given that many parents report that they are often not listened to when they initially raise concerns about their children's progress or lack thereof or other symptoms (Nous Group, 2023). Mothers, in particular, report that their concerns are downplayed or ignored and that they face 'medical misogyny' when dealing with GPs and other healthcare professionals on behalf of their children (Nous Group, 2023). Broad awareness of childhood dementia is required across health, disability and education settings to support early diagnosis and ongoing responsive care for children with dementia.

Following diagnosis of childhood dementia, parents report feeling adrift without clear post-diagnostic information or prognosis for their child. Some parents report that it was not made clear their child's diagnosis was terminal until they 'Googled it' (Nous Group, 2023). Adjustment to the diagnosis of a child's terminal condition is fraught for parents (Brouwer et al., 2021) (Nous Group, 2023). Immediate, effective post-diagnostic support should include not simply clinical and allied health support but also specialist psychosocial support given the significant psychosocial challenges experienced by children with dementia and their families.

"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"

Parent of child with dementia

National Disability Insurance Scheme (NDIS)

Regression is simply not understood within the NDIS. According to Bruce Bonyhady, founding Chair of the National Disability Insurance Agency (NDIA), the NDIS has built into it 'an incentive to make short-term investment in participants aimed at increasing their independence and participation in the community and the workforce in the hope of reducing long-term costs' (Buckmaster, 2016). This mindset governs much of its decision-making. As a result, the NDIS is not well-positioned to address the needs of children who are progressively losing skills and abilities rather than building and improving them. Yet maintaining skills, and support to do so, is critical for this cohort.

The timeliness of NDIS service has also proven to be an issue. Several families have reported that equipment deemed as necessary has arrived after their child died, causing additional and unnecessary distress and frustration (Nous Group, 2023). Lack of NDIA staff knowledge and understanding of dementia significantly affects the quality of assessment and care received by children with dementia and their families. Families must repeatedly explain their child's condition, are refused reasonable requests, experience inconsistent decision making and psychological impacts due to the constant 'battle' they face to access necessary support (Childhood Dementia Initiative, 2021). These challenges are exacerbated for families with more than one child living with dementia. NDIS planning is often not designed to accommodate multiple family members with similar needs.

"The NDIS ..... 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"

Parent of child with dementia

Lack of accessible and appropriate respite services for children, young people with dementia and their carers

The burden of caring for a child with dementia is immense, with one study indicating that mothers spent, on average, 88 hours per week caring for their child (Ammann-Schnell et al., 2021). Despite considerable need, there are very limited respite services available for children with dementia and their families. This results in significant psychosocial impacts, which are further compounded when a family has more than one child with dementia. Families report (Nous Group, 2023) that established paediatric respite services do not understand the needs of children with dementia, particularly behavioural and psychological symptoms of dementia (BPSD), and are unable to manage the complex and high level of care and support required.

Additional respite services for children delivered in an appropriate setting are critically needed to support their parents and families. Routines for children with dementia, as with many adults with dementia, can be vitally important to their wellbeing and, as a result, respite services delivered in out-of-home settings may not be appropriate for all children, with significant impacts on their parents and families. Removing children from their family setting with parents and/or siblings may also prove distressing and disruptive, and services provided in the home more effective in some instances. Respite services should be provided, whether in or out-of-home, in hospice or other settings, in a place appropriate to the child receiving care, as well as respite services specific for their carers and families. This flexibility is essential to providing effective and targeted care and reducing carer burnout.

Lack of awareness and understanding between parental responsibility and caring role

Many parents of children with dementia are told that there is a ‘natural parenting role’ that they should perform before seeking to access services to support their children. This is simply not an experience reported by other groups of carers within the dementia community. Parents struggle 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.

Parents and family members are less likely to identify or be recognised as unpaid carers. to their child or children with dementia. This can limit parents and families’ access to services and supports but also this cohort is consequently omitted from evidence collected about the caring role and unpaid carers in Australia.

> ***“The dementia symptoms were causing severe behavioural and psychological issues. We needed a wheelchair just to get out of 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 dementia. And it meant we couldn’t even get out to the shops or to bring the kids to the playground”***
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> ***Parent of children with dementia***

Psychosocial impacts on unpaid carers for children with dementia, including parents, siblings and grandparents, and broader family network.

Psychosocial impacts of childhood dementia affect the entire family unit – the child/ren experiencing dementia, their parents, siblings, and the broader family network. Children with dementia suffer from severe sleep disturbance, deterioration of communication skills, loss of hearing and vision, movement disorders, mood disorders, incontinence and psychosis. The conditions they have are severely life-limiting and life-threatening with their cause of death including respiratory complications such as pneumonia, neurological complications and cardiac events (Nevin et al., 2022). Behavioural challenges associated with dementia, including aggressive behaviours, hyperactivity, agitation, inability to communicate and toileting challenges are particularly draining and distressing.

Parents frequently report a lack of available information and support to assist with management and coping (Hoffmann et al., 2020). Watching a child experience these challenges while having to manage them has a significant impact on parents’ and other family members’ mental, physical and financial wellbeing (Nous Group, 2023). Parents with children who have dementia usually spend an extended amount of time and energy visiting clinicians to obtain a diagnosis and report heightened chronic stress during this period. This is regularly followed with decisional uncertainty after a diagnosis due to limited access to information about how to manage their child, facing obstacles to managing the daily care required and a lack of help and advice on how best to support their child. In addition, over time, children become reliant on full-time supportive care, with the impact on family members significantly exacerbated where there is more than one child with dementia.

Given the age of children with dementia, much of the impact of caring for them falls on working-age parents (primarily mothers) who find their careers interrupted, often leading to long-term effects on their career progression with flow-on consequences on superannuation and financial security. A recent report found that, with current subsidy settings, Australian carers lose an average of $392,500 in lifetime earnings to age 67 and $175,000 in superannuation at age 67. Some people who are carers for extended periods lose substantially more, with the most affected 10% losing at least $940,000 in lifetime income and $444,500 in retirement savings (Furnival & Cullen, 2022). This is a substantial personal loss with significant societal and economic implications in terms of lost productivity and workforce participation.

> ***"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".***
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> ***Parent of a child with dementia***

Disparate access to paediatric palliative care

A critical element of child-specific pathways to post-diagnostic support is timely and immediate referral to paediatric palliative care, a different approach to adult palliative care. Referral to specialised paediatric palliative care is associated with improved quality of life for children and better caregiver outcomes (Marcus et al., 2020). As such, it should be uniformly provided to all families whose child is diagnosed with a disorder that will lead to dementia in childhood.

Parents generally report positive experiences once connected with palliative care, but timeliness of referral is vastly inconsistent. Health professional communication about what palliative care is and what it can offer is varied. This inconsistency in knowledge and understanding about what support is available means, in the absence of an appropriate care pathway, that parents cannot effectively advocate for a connection to the palliative care team. In addition, parents report that there is no coordination between palliative care and NDIS services and, in fact,they can work against each other. If palliative care is mentioned in an NDIS assessment this can result in the reduction of the NDIS support provided.

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

Parent of child with dementia

Increased burden during transitions across care and service systems for carers and families impacted childhood dementia.

To address these challenges, health and care systems must be better designed to meet families' needs and provide appropriate support. This is even more essential at times when children transition between life stages and/or between key systems with parents identifying these moments as major pain points (Childhood Dementia Initiative, 2021) (Nous Group, 2023). The transition from children to adult health and disability systems results in a multitude of issues, often leaving families with reduced support at a time when care needs increase (Nous Group, 2023). Frameworks for care that address these matters are essential to guide improvements in systems and services to better meet needs and minimise the impacts on parents and families who once again take a lead in seeking the required support and relaying information to various different care and support care service providers.

"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"

Parent of young adult with dementia

Recommendations for increased recognition carers of children and young people with dementia

Recommendation 1: Expanding the description of carers within the Act to capture the unique experiences and diversity of unpaid caring roles in Australia.

Description of carers needs to be expanded to include complex conditions that include more than one category within the current meaning of a carer as listed in the *Carer Recognition Act* (2010). Unpaid carers of children with dementia care for complex conditions that are categorised as disability, life-limiting, have mental health conditions and frailty. Reform to this description should include unpaid carers who provide complex care.

The current description does not include recognition for the dynamic nature of caring for children and young people with dementia. The family unit caring for children with dementia needs to be recognised; this requires inclusion of family units within the description of a carer within the Act, including siblings.

Recommendation 2: Public inquiry with carers, including community forums.

A public inquiry needs to be held, to consult further with the community, including with carers, families and people receiving care to provide further scrutiny and suggested reform for the *Carer Recognition Act* (2010) . This public inquiry needs to provide community forums and other diverse means for consultations, and with specific cohorts of carers including parents and families of children with dementia to better understand the diverse and unique experiences and needs of these groups.

Recommendation 3: Increased financial support for unpaid carers including Carer Payment, Carer Allowance and provision of superannuation.

Unpaid carers for children and young people with dementia need additional financial support as they are largely unable to find the services and support to meet their child or children's increasing care needs, and consequently they fulfill numerous roles, including project manager for their child's complex care. In addition, increased financial support needs to be provided for parents and families caring for multiple children with dementia. as the complexity of their caring role is dramatically increased, including experiencing multiple bereavements within their caring role. Increased financial support for parents and families of children with dementia needs to include provision of superannuation to enable long-term financial stability, as the duration of their caring role falls on working-age parents who are no longer able to work or progress their careers.

Recommendation 4: Development of National Policy Framework, Strategy and Standards for complex care including health and education for consistent referral, access, provision and pathways to care services and supports provided by States and Territories.

National policy frameworks, strategy and standards need to be developed for diagnosis, treatment, care and support for rare genetic conditions that cause childhood dementia to reduce the inequity experienced by those families that are impacted. Families need to receive equitable and consistent access to diagnosis, post-diagnostic care and support including respite, and paediatric palliative care across all States and Territories in Australia to reduce the stress and burden of unpaid caring for children with dementia. Consistent national policy frameworks, strategy and standards will reduce the burden and stress placed on parents and families impacted by childhood dementia to access and navigate support and services, including health, and education.

Recommendation 5: Increased recognition and support for young carers of children and young people with dementia.

Greater recognition of young carers impacted by childhood dementia needs to be recognised in policy and programs for young carers, including access to appropriate respite and bereavement support and services, Young carers of children with dementia, including siblings who provide unpaid care, are overlooked current in young carer policies and programs that concentrate on cohorts within secondary and tertiary education. Increased recognition of young carers for children with dementia need to to be provided with appropriate and timely access to grief and bereavement support.

Recommendation 6: Better provision of timely and appropriate respite services, including investment in services to support the behavioural and psychological symptoms of dementia (BPSD) in children and young people.

There is a significant need to develop and provide respite services to support the behavioural and psychological symptoms in children and young people, to reduce the burden and stress on parents and families of children with dementia. Flexible, timely and appropriate respite care for children and young people with dementia would include in-home options, in hospice options and other settings, to reduce carer burnout. Investment should include greater collaboration and consultation with parents and families of children with dementia to develop appropriate respite services and support, as children with dementia are currently ineligible for many existing services due to BPSD, resulting in no respite options for families.

Recommendation 7: Increased access and availability of grief and bereavement support and services for carers of children and young people with dementia, including recognition of families with multiple children with dementia.

All parents and families caring for a child or children with dementia will experience bereavement and complex grief associated with progressive life-limiting conditions and they require specialised grief and bereavement support and services. In addition, families caring for multiple children with dementia will experience palliative care and end-of-life care, while still providing for their other children.

There is significant need for greater investment and access to grief and bereavement services for parents and families caring for a child or children with dementia.

Recommendation 8: Increased funding for further research into the psychosocial impacts on carers and families impacted by childhood dementia.

Greater funding needs to be provided for further research into the psychosocial impacts on carers and families impacted by childhood dementia, including culturally and linguistically diverse communities, First Nations communities and other minority populations to evidence their experiences and improve carer outcomes, including young carers.

Conclusion

·To conclude, the unpaid carers for children and young adults with dementia are a distinct cohort that need to be recognised within the provisions and operation of any reforms to legislation in relation to unpaid carers. Recommended reforms include expanding the descriptions of carers with the Act to include parents and families and the complex care they provide to children and young people with dementia. In addition, reform needs to include better access and provision of respite, grief and bereavement services and support to parents and families caring for children and young people with dementia. Young carers impacted by childhood dementia are a specific cohort that need acknowledgement and inclusion in reform of the Carer Recognition Act (2010). Reform to the Act must include the development of national frameworks, strategy and standards for care support and services delivered by States and Territories in Australia to reduce the exhaustive burden placed upon parents and families as they seek and navigate across systems in order to care for their children impacted by dementia. Increased financial support of carers including provision of superannuation must be considered in future reforms for unpaid carers in Australia, including additional provisions for those caring for children with dementia.

Within the significant population of unpaid carers in Australia, parents and families caring for a child or children with dementia will experience bereavement, complex grief and the end of their caring role and they require specific recognition and provision of services and support to address and reduce carer stress, burden and burnout. Childhood Dementia Initiative welcomes further opportunities to build greater awareness and understanding of childhood dementia and the unpaid caring role to improve the outcomes for families through the development of a public inquiry into unpaid carers and further research into the psychosocial impacts of caring.

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