House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry into the recognition of unpaid carers

A Dementia Australia Submission

02 August 2023

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Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. Our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the living experience of dementia across Australia. Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields. The Dementia Australia Policy team can be contacted on **policyteam@dementia.org.au**

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person's functioning. Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia is one of the largest health and social challenges facing Australia and the world. In 2023, it is estimated there are more than 400,000 people living with all forms of dementia in Australia. This number will continue to grow to more than 800,000 by 2058.[1] In February, the Australian Institute of Health and Welfare released data showing dementia is now the leading cause of disease burden among Australians aged 65 and over. Dementia is the second leading cause of death for Australians and the leading cause of death of women.[2]

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry into the recognition of unpaid carers. In preparing this submission, we have consulted with our national network of Dementia Advocates, which includes former and current informal carers of people living with dementia. The consultation involved surveying carers on the effectiveness of the Carer Recognition Act 2010, the needs of carers of people living with dementia, and general feedback on what recognition means to them. We have outlined their perspectives, priorities and recommendations for recognising and acknowledging unpaid carers. Additionally, we have previously made submissions to **the Draft National Strategy for the Care and Support Economy**, **the Senate Select Committee on Work and Care**

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[1] AIHW (2023) Dementia in Australia. https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary

[2] AIHW (2023) Dementia in Australia, Summary, Impact https://www.aihw.gov.au/reports/dementia/dementia-inaus/contents/summary

Inquiry and the **Productivity Commission Carer Leave inquiry** which reiterates the key issues carers face and can serve as a guide for enhancing the act to ensure it is relevant to carers of people living with dementia.

Recognition involves acknowledging and valuing the significant contribution of carers, respecting their work, understanding their challenges, and providing them with practical, financial, and emotional support. It means being seen, heard, and supported in their caregiving role, and having their experiences and knowledge respected. Recognition also includes raising awareness in the community about the essential role carers play and creating a supportive environment for them to thrive while caring for their loved ones. Understanding what recognition means to carers is key to enhancing the effectiveness of the act.

“If the role and challenges of a person caring for someone with dementia are understood and therefore appropriate support and services are designed, and if services / policies / requirements etc that make the caring role more difficult and complex are removed, that would be the foundation of recognition.” Former carer

Summary of recommendations

1. That the Department of Social Services evaluate the impact of the Carer Recognition Act 2010, the associated Guidelines and the Statement for Australia’s Carers.
2. Consider a communications strategy for generating greater awareness of the Act, including how the principles will be put into practice.
3. Consider expanding the scope of the Act to organisations outside of the Australian Public Service
4. Consider monitoring carer wellbeing as a part of the responsibilities and obligations of public service agencies, public service care agencies and associated providers.
5. That a future inquiry examines the adequacy of financial support for carers including Carer Allowance, Carer Payment and the long-term financial security of carers such as improved superannuation arrangements.
6. Consider amending the statement for carers to include rights to range of measures to support carers including appropriate income support, employment flexibility, access to respite and easier navigation of services.

The effectiveness of the Act and the associated Statement of Australia’s Carers in raising recognition and awareness of the unpaid caring role, including its obligations on public service agencies

Lack of recognition and support for carers

Overall, the feedback received from our survey indicates that while the Carer Recognition Act aims to provide recognition and support to carers, there are several gaps and challenges in its implementation, scope and evaluation, leaving many carers feeling unsupported and undervalued in their role.

“Unpaid carers, are predominately not recognised and very undervalued within their community despite the economic savings they make to different governments.” Current carer

The Carer Recognition Act 2010 states that it is “intended to increase recognition and consideration of carers and drive much-needed cultural and attitudinal change throughout [Australian Public Service] APS agencies and associated providers, and as a result, the community as a whole.”

Many carers expressed that this Act has not achieved what it intended. Carers still feel undervalued by the government, community and employers. This is likely due to the lack of awareness among employers of the needs of carers of people living with dementia as well as the lack of awareness of the Act in general. Improving community messaging and dementia education can help organisations, employers, and community members have a better understanding of dementia to better support carers.

Additionally, the Act states that “Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers”. However, the reality is that as they are often not considered as partners with other care providers, leading to exclusion from important decisions and struggles to be heard about the person they are caring for.

> “Carers are not considered partners with other care providers, such as medical staff. Many times, I was left out of important decisions and at other times struggled to be heard about what my husband was suffering.” Former carer
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> “Not enough is done to support carers when decisions are made about the person they are caring for. Very little consultation is made with the carer, to ensure that a decision is in the best interests of the person they are supporting.” Former carer
>
> “Provisions should be made for providers to consult with carers when making decisions about the person they are providing services to.” Former carer

Inadequate implementation and awareness of the Act

Most carers indicated in our survey that they were not aware of the Carer Recognition Act 2010 and its provisions, suggesting a need for better awareness and communication about the existence and purpose of the Act.

““Increase awareness of what the Carer Recognition Act is. What is its purpose? How can it support and protect the rights of caters?” Former care

Only three per cent of carers that responded to our survey indicated that the Act has been effective at increasing recognition and consideration of carers by public service agencies. The remaining 97 per cent either selected no or unsure while indicating that they were not aware of the Act at all.

> “I have not heard about this Act and am unaware of what it is meant to achieve and after reading the Act am not surprised as it is just nice words with little action.” Current carer

Awareness and understanding of the Carers Recognition Act 2010 among carers, service providers, and the broader community is insufficient, and the Act is not effectively integrated into the support systems, such as Centrelink. Carers that responded to our survey expressed disappointment in the lack of effective implementation of the Act. It is also unclear on how the effectiveness of the Act is being monitored and whether it is evidence-based.

Further, the Act is only applicable to the Australian Public Service and associated providers which limits the scope of the Act and its ability to effect real change. The Act is currently not legally enforceable, and most carers believe the Act should have legally enforceable rights and operational requirements, especially regarding the implementation and enforcement of its obligations.

> “The legislation has no teeth, it does not create any legally enforceable rights. There need to be operationalised requirements for the implementation and enforcement in particular of s 7 of the Act.” Current carer

> “True recognition would be to have understanding and support rather than suspicion when speaking to government bodies like Centrelink, Services NSW etc. Not having to repeat details of why help is required over and over again due to nothing being recorded/filed the first time.” Current carer

Effective implementation of the Act's provisions and its associated Guidelines, including the dissemination of information and accessibility of support services, is crucial to ensure its intended benefits reach carers effectively. There needs to be more clarity on how these principles will be put into practice and examples of how they will be implemented in real-life caregiving situations. Additionally, consideration to expanding the scope of the Act to organisations outside of APS could garner more change.

Well-being for carers and care recipients

The Act emphasises supporting carers’ well-being and social participation, but most carers find this difficult to achieve due to the demanding nature of caregiving, limited respite options, difficulties in accessing support services and lack of understanding of the carers’ needs among employers, services and wider community.

Carers often experience social isolation, depression, and a loss of identity as they prioritise their caregiving role over personal needs and express the need for more practical support, monitoring of their well-being, and assistance in reducing carer stress, such as increased availability of respite, to avoid burnout and health risks.

> “Recognising that carers deserve opportunities for their wellbeing to be monitored - so they can continue to provide a lot of unpaid support to people who need it.” Current care

Financial security

Long term financial security is essential to achieving the economic well-being and sustainability set out in the Statement for Australia's Carers and fundamental to adequately acknowledging carers for their contribution to society. Many carers feel that the current state of financial assistance is inadequate, especially considering the significant savings they contribute to the government at a sacrifice to their own personal wellbeing and income.

Better financial support for carers to alleviate the financial burden associated with caregiving is crucial. Carers have suggested numerous was to improve financial security including, increasing the Carer Allowance, superannuation arrangements, and tax deductions for care expenses.

> "More support and opportunities to participate in employment and education. Financial assistance more accessible and most carers have to give up their jobs to be full-time carers. Their superannuation will be affected due to early retirement. Many carers have to struggle without any financial assistance." Former carer

Statement for Carers

The Statement for Carers along with its ten key principles are too vague in their intent. Feedback from carers of people living with dementia indicated overall agreement with the key principles for carers, recognising the importance of their rights, support, and wellbeing. However, there were calls for more specificity in implementation, greater support for carers' physical and emotional needs, recognition of cultural diversity, and increased access to financial and practical support. The responses highlight the need for practical actions to translate the principles into meaningful support for carers in Australia.

Some respondents suggest that the key principles should be more specific and provide detailed expectations for achieving them, such as including the right to access suitable respite. They believe that without specific guidelines, accountability may be lacking, and the principles might remain as mere rhetoric.

> "The key principles should be more specific and provide detailed expectations of how those principles can be achieved. Without this, the government and other accountable agencies can all too quickly ignore. They would also be more meaningful and memorable if more specific." Former carer
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> "Maybe a little less "should" in the wording and more will. It is just a collection of motherhood statements and really in that form does very little as it has no force behind it to make things happen. Typical "polly-waffle" Current carer
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> "I agree with the principles but feel that there should be a mention that respite should be provided when wanted and be easy to get" Current carer

There is a need for more clarity on how these principles will be put into practice and examples of how they will be implemented in real-life caregiving situations.

Obligations on public service agencies

Dementia Australia supports Obligation 2.2.2 which states that "each public service care agency is to consult carers, or bodies that represent carers when developing or evaluating care supports Carer Recognition Act 2010 Part 3 s8(2)".

The aim of this obligation is for public service care agencies to include carers, or peak representative bodies, at relevant stages of government work directly affecting carers and the people they care for. To meet this obligation public service care agencies will need to demonstrate how they have included carers, for example through formal consultations, meetings, or submissions, in the policy development and evaluation process.

Involving people with lived experience in developing or evaluating care supports can be achieved through a variety of methods, including focus groups, surveys, and one-on-one consultations. Half the story is a guide to meaningful consultation with people living with dementia, families, and carers and can provide a useful tool when consulting carers. Half the story can be found here: **www.dementiafriendly.org.au/find-resources/half-story-meaningful-consultation**.

Developments in the policy landscape at a Commonwealth level since the Act's passage in 2010

The feedback indicates that while there have been some policy developments to support carers, there is a need for greater awareness and communication about these initiatives. Many carers call for improved access to respite services, training, and support for their wellbeing. The bureaucratic complexity in accessing services is also a major concern, and there is a call for more streamlined and accessible support systems.

> "Marketing is needed so that Carers like me are advised of what is available to them to assist them. It is all very well putting these policies in place but how do the agencies inform the Carers???" Former carer
>
> "Provide a guide for carers about those support measures and resources and how to access them." Current carer
>
> "Carers need to see the policies actively enacted in a practical form" Former carer

How to better identify the role of unpaid carers in Australian society and the role of a reformed Act, with regard to:

Understanding the value of unpaid care

The value of unpaid care needs to be publicly recognised and measured; the sustainability of the care sector depends in large part on the enormous contribution of informal family carers to the economy. It has been estimated that there around 2.8 million Australians providing nearly 2.2 billion hours of care per year, including 906,000 primary carers. The financial value of this care was estimated to be $77.9 billion in 2020,[3] representing a substantial saving to government and the community. The care provided by informal carers reduces the demand for publicly funded services across the ageing, disability and veteran's care sectors, including for acute and residential care. Informal carers also understand their loved one's needs well. They advocate for and assist their loved ones to get the best outcomes from care and support services, improving the quality of care. It is imperative to the sustainability of the future care economy that informal carers are recognised and well supported in their caring role.

> "Recognition in the workplace and community in general that carers are essential to a civilized community. Any financial assistance offered to carers is not a cost to the budget it is an investment in our community just like building roads is. Carers to be seen as community providers of care and support" Former carer

The needs of specific cohorts such as young carers, First Nations carers, LGBTIQA+ carers, or culturally and linguistically diverse carers,

The findings from our carers survey emphasise the importance of acknowledging the diverse backgrounds and circumstances of carers and implementing targeted initiatives to address their specific needs. Ensuring that support services are culturally sensitive, linguistically accessible, and inclusive will help provide equitable care and support for all carers, regardless of their background.

> "Improvement in culture-appropriate respite, so the family carer is not the only person who can help the person with dementia who has reverted to mother tongue." Current carer
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> "For carers from culturally diverse backgrounds, the availability of culturally sensitive navigation support can help them access appropriate services and resources more effectively." Current carer

The Government's broad agenda in relation to the care and support economy, the importance of employment participation, and a strong focus on gender equity, and

As outline in our submission to the Draft National Strategy for the Care and Support Economy, Australia needs a sustainable care sector that delivers high quality care with a trained and supported workforce. The priority for reforms to the care sector should be on enabling high quality, person-centred care to be delivered across different service

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[3] Deloitte Access Economics (2020) The value of informal care in 2020.

environments, with investment in workforce development and education backed by strong regulatory and compliance frameworks.

To obtain high quality care, we need an educated workforce with clear career pathways. Pathways for rewarding long-term careers in the care sector can attract and retain qualified, experienced and satisfied staff. In the aged care sector, a care workforce with the capability to provide quality dementia care is a necessary and core element of quality care. Dementia is one of the largest challenges for the aged care sector. Dementia Australia's position is that:

- All care workers in the aged care sector should be required to undertake compulsory dementia education, tailored to their role.
- All care workers in the veteran's, disability and early childhood care sectors should have access to information and training about dementia, its impact, and the delivery of person-centred supports.

The care provided by informal carers reduces the demand for publicly funded services across the ageing, disability and veteran's care sectors, including for acute and residential care. Informal carers also understand their loved one's needs well. They advocate for and assist their loved ones to get the best outcomes from care and support services, improving the quality of care. It is imperative to the sustainability of the future care economy that informal carers are recognised and well supported in their caring role.

Conclusion

We thank the House of Representatives Standing Committee on Social Policy and Legal Affairs for considering this submission and would welcome any further opportunities for consultation. The feedback received from carers reflects recommendations for the Act to specify the rights of carers to have better access to support services, enhanced financial assistance, respite and greater recognition of their role as a carer. The feedback highlights the vital role of carers in society and calls for practical measures to address the challenges they face in their caregiving role. Meaningful implementation of the Act, it's principles and obligations will ensure that carers receive the recognition, respect, and support they truly deserve.