Dementia Australia®

Review of the South Australia Carers Recognition Act 2005

Dementia Australia Submission

December 2023

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].

There are few families that are untouched by dementia.

There are estimated to be more than 33,300 people living with all forms of dementia in South Australia and this is expected to increase to more than 55,000 by 2058.

Dementia does not just affect older people. There are thought to be around 2,000 people living with younger onset dementia in South Australia, which is dementia diagnosed under the age of 65. There are also children living with dementia, arising from a broad range of genetic disorders. In fact, childhood dementia is more common than well-known disorders like cystic fibrosis and causes a similar number of deaths each year as childhood cancer.

[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-in-aus/contents/summary**

“Unsung Heroes”

Testimony by Vern Marshall to the Federal Senate Inquiry into Recognition of Unpaid Carers, 2023. Vern is a South Australian carer and volunteer Dementia Advocate with Dementia Australia. Dementia Australia is including this statement in our submission to the Review of the South Australian Carer Recognition Act 2005 because it powerfully expresses a carer’s experience in their own voice.

> I cared for my late wife, Rosemary, who had Lewy Body Dementia, for 10 years, and I also convene a robust and popular social support group for dementia carers here in the Adelaide Hills where I live. I can draw on my own lived experience, and the anecdotal experience of others I know well, to support Dementia Australia’s submission to the Inquiry.
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> In doing so, I would like to bring two things to the Committee’s attention in relation to dementia caring.
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> The first is that caring for someone with dementia, spouse, partner, parent or whomever, is indubitably one of the most difficult and stressful civilian activities one can find themselves in. Psychologists, who measure such things, rate it only a few notches down from being on the front line in a war zone.
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> The reason for this, just to select two from a list of many, is that, unique to dementia caring, the carer at some point, and increasingly, ends up caring for someone whom, in terms of behaviours and responses, they no longer recognise as the loved one they have known for ages and sometimes a lifetime.
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> The other overwhelming reason is that it is usually an incredibly isolating, lonely experience. Friends, and often even other family members, find the condition awkward to deal with, even confronting in many cases, and begin, maybe in subtle ways at first, a continuing process of tactical withdraw from the situation.
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> So, to be a dementia carer is hugely stressful, emotionally draining, and is destructive of the very practical and emotional support and connectedness that carers need as they face what is invariably the greatest challenge of their life.
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> Add to that a dementia caring world which is notoriously difficult to negotiate, with a plethora of hard to distinguish clinical, therapeutic, and support organisations that often overlap and have their own agendas and funding orientated parameters and objectives, along with an unforgiving and relentless condition that only becomes demonstrably worse over time – and you have some picture of the appalling world into which dementia carers find themselves thrust.
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> A world that is overwhelmingly tiring, excruciatingly demanding, and invariably a

> lonely and for many depressing, journey!
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> Having said all that, the second matter I would draw to the Committee's notice, is that despite all that I have said, in the vast majority of cases, carers 'soldier on' bravely, determined to give their loved one the very best quality of life that is achievable for as long as possible.
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> They are without doubt the unsung heroes of the dementia world.
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> In doing so, their impact on the care economy is immeasurable. They keep patients out of expensive full-time care for as long as they possibly can. They significantly reduce the demands on short term respite care and home-care provision until matters have moved beyond the ability of anyone to care singlehandedly anymore and still retain some semblance of their own health and wellbeing.
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> They do this often because, whatever the cost, they have an intuitive appreciation that, whatever the good intentions of others, they are the ones who know and understand best what is in the interests of those for whom they care, often long after the patients have lost the ability to articulate this reliably for themselves.
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> Most of all, they do it, despite great cost to themselves, because of love. Dementia caring, and this I'm sure it shares with the other forms of caring, is an enormous action of selfless love. It's the kind of action that this world is crying out for, and it's happening right here, all around us, under our noses, every day.
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> I think it's time we found ways of recognising more formally, this action. Consequently, I highly recommend to the Committee's attention the **Dementia Australia's submission** and thank the committee for giving me some time today.

Carer Recognition in South Australia

Dementia Australia is grateful for the opportunity to have input into the Review of the South Australian Carers Recognition Act 2005. We have dedicated policy, consumer engagement, community development and client services staff in South Australia supporting people living with dementia and their carers across the state.

We work closely with a network of Dementia Advocates, who are people living with dementia, carers and former carers to inform our advocacy. In this submission, we highlight key themes from our ongoing engagement with carers which are relevant to South Australia.

Carers have told us that:

- There needs to be more respite available for carers and families, and this needs to be accessible and regularly available. Caring can be exhausting, and carers need time out.
- Services need to be easier to access and navigate, with significantly reduced administrative complexity. A central access point for carers would be beneficial.
- Carers need access to training or education and support groups are also helpful.
- Carers need better financial and income support.
- A system which supports carers well helps to enable people with dementia to remain living at home when they choose to.
- Carers need access to flexible working arrangements including extra leave.

Dementia Australia understands that many issues related to carer recognition and support, including those listed above, are framed by Commonwealth legislation and services.

However, there is much that can be done at a state level to improve carer recognition and experience in South Australia and improve the interface between Commonwealth and state systems. In this submission, we outline a range of relevant issues and make recommendations for actions to improve carer recognition and support for South Australians.

Dementia carers

Many people living with dementia are supported by family carers, with up to 337,000 informal primary carers for people living with dementia in Australia in 2021.

Informal carers of people living with dementia are typically a spouse or child. They provide a wide range of supports including emotional support, personal care and activities of daily living to the care recipient, as well as responding to changed behaviours.

Carers are involved in making decisions about treatment and care, services and finances. They must navigate complex administrative and bureaucratic systems which are not user friendly.

Carers understand the care recipient's needs well. They advocate for and assist the care recipient to get the best outcomes from care and support services, improving the quality of care.

Dementia Australia has previously surveyed carers of people living with dementia and found that 78 per cent are women. Ninety-eight per cent of carers are family members with the majority of those identifying as a partner or spouse (64 per cent). Forty-six per cent are under the age of 65 and defined as of working age. Ninety per cent of those under 65 are women, reinforcing that women are more likely to take on caring responsibilities and to experience impacts on their workforce participation.

A national study by Carers NSW has further shown that carers of people living with dementia are likely to be older than other carers, and the vast majority are caring for someone aged 65 or above. Twenty per cent of carers of people with dementia identify as Culturally and Linguistically Diverse and 1.5 per cent identity as Aboriginal or Torres Strait Islander.

Ongoing impact of caring

There are different demands on carers depending on their age, and the age of the person that they are caring for.

Carers supporting someone with younger onset dementia are in a different stage of life, still in the workforce with financial obligations and other active care commitments such as children or elderly parents.

The care recipient may have been the primary source of income, causing financial difficulties. The experience of dementia is also likely to be different, with the person living with younger onset dementia more likely to be active and experience greater frustration with loneliness, boredom and loss of income, independence, and self-esteem. There are likely to be less respite options available to families.

On the other hand, carers for older people with dementia are more likely to have their own health issues, and their loved one is more likely to be frail or have comorbid health issues.

Across the board, carers are likely to experience a financial impact from their caring role. Caring is a full-time role, and paid employment is often significantly affected to the point that many carers must withdraw from paid employment entirely. Their own physical and mental health is often affected as carers strive to meet the needs of the person they care for.

Dementia is a progressive, terminal condition. Carers continue to provide support when the person they care for transitions to residential, specialist or palliative care settings. Carers advocate and coordinate services to meet the person with dementia’s needs, as well as providing other support like managing finances, legal matters and providing practical and emotional care.

Because the financial, psychological, health and social impacts of caring for someone with dementia continue regardless of the care setting, and even after the person living with dementia has passed away, carers continue to need recognition and support in their caring role.

Recognition

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.
>
> ~ Carer of a person living with dementia

Recommendations

Dementia Australia recommends a range of strategies for your consideration, that could lead to improved outcomes for South Australian carers:

1. That the Act redefine recognition to strongly acknowledge the vital role and contribution of carers in the community and their right to support.
2. That the Act recognise carers regardless of whether the care recipient has transitioned to residential care, and that it recognise formers carers.
3. That the Act expand the range of public services agencies considered as applicable organisations to include all state government funded agencies, any devolved agencies and any contracted agencies.
4. That accountability requirements for reporting agencies be strengthened under the Act. That agencies be required to report on both actions and outcomes for carer support including:
    a. Implementation of flexibility in employment contracts and conditions.

   b. Actions which support wellbeing of employees who are carers.

   c. How the agency workforce is trained and educated to provide better service responses for carers.

   d. How the agency is raising awareness of carer rights and reducing stigma.

5. That reporting agencies are not limited to those which provide services to carers, in recognition that carers interact with a wide range of agencies or are employed in a range of agencies.

6. That the Act redefine the requirement for consultation of carers in planning and programs, to a requirement for meaningful engagement of carers and genuine co-production of agency initiatives and approaches.

7. That the Department of Human Services consider developing a communications strategy to generate greater awareness of the Act and Charter across the community.

8. That the Department of Human Services consider developing a statewide Action Plan for Carer Recognition, in partnership with state government agencies, carers, peak and consumer groups, health and aged care providers, Primary Health Networks and local government, to:

   - engage a broader cross section of the South Australian community in carer recognition and support actions
   - develop interagency solutions to improve service navigation for carer supports
   - raise awareness and respect for carers in the community
   - advance carer rights and raise awareness of support available
   - promote carer support strategies such as flexible employment conditions
   - develop interagency responses to specific challenges for certain communities including First Nations carers, young carers and carers in regional and remote communities.

9. That the South Australian government continue to provide funding for advocacy and support services for carers across the state.

Lastly, we note that there has recently been a significant inquiry at a Commonwealth level into carer recognition and support – the **Senate Inquiry into Recognition of Unpaid Carers**. We suggest that South Australia review the findings of this Inquiry once released and seek to align initiatives with the Government response, to ensure as much consistency as possible for carers.