Review of Queensland's Carers (Recognition) Act 2008

June 2026

Introduction

Dementia Australia welcomes the opportunity to provide input into the Review of the Carers (Recognition) Act 2008 (Qld). Our submission draws on feedback from current and former carers in Queensland engaged through our **Dementia Advocates Program** and reflects lived experience of caring within the context of dementia.

This submission focuses on whether the Act is achieving its intended purpose of recognising carers and identifies opportunities to strengthen the Act as well as its practical application.

The Queensland Carers (Recognition) Act 2008 sits alongside the Commonwealth Carer Recognition Act 2010, which applies to Commonwealth agencies and associated providers. The Queensland Act is particularly relevant to carers of people living with dementia due to their interactions with Queensland Government departments, Hospital and Health Services, and Queensland-funded disability and community services. Given many carers navigate services across both Commonwealth and Queensland systems, it is important that the Queensland Act remains aligned with broader national approaches to recognising and engaging carers.

Background

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, capturing the diversity of the living experience of dementia across Australia. We advocate for positive change for people living with dementia, their families and carers.

Dementia is the leading cause of death in Australia.[1] In Queensland in 2026, there are an estimated 88,200 people living with all forms of dementia. This is projected to increase to an estimated 168,300 by 2054.[2] An estimated 5,900 Queenslanders under the age of 65 are living with young onset dementia.[2]

Dementia often requires significant ongoing support and care from family members and friends over many years. As dementia progresses, informal carers commonly provide assistance with daily living activities, decision-making, service navigation, advocacy, financial management and emotional support, often while balancing employment, family responsibilities and their own health and wellbeing. People living with dementia and their carers commonly interact with

multiple systems including primary care, hospitals, specialist services, aged care, disability and community supports.

The number of carers supporting people living with dementia is difficult to quantify. The Australian Institute of Health and Welfare estimates there were at least 101,900 informal carers of people with dementia living in the community in 2024.[3] However, this likely understates the true number of carers due to limitations in available data, including that the estimate is based on self-reported caring relationships, excludes many caring relationships that continue after entry into residential aged care, and may not capture people who provide substantial unpaid support but do not identify as carers.

Despite the scale and value of this contribution, carers of people living with dementia often report feeling excluded from decision-making, insufficiently recognised by services and systems, and unsupported in their caring role. These experiences are particularly pronounced for carers of people living with young onset dementia, who often face additional employment, financial and family pressures.

Summary of recommendations

- Improve awareness of the Act, Charter and Queensland Carers Advisory Council (QCAC) among carers, public authorities and service providers by developing a coordinated approach to communication, education and promotion.
- Update the Carers Charter to better reflect contemporary caring experiences, including dementia, young onset dementia, carers as partners in care, carers' own wellbeing, and caring relationships that continue across care settings.
- Strengthen consultation requirements for public authorities to ensure carers and representative organisations are meaningfully engaged in the development of policies, programs and services that affect carers.
- Introduce reporting requirements for relevant public authorities on implementation of the Charter.
- Improve the visibility and accessibility of QCAC through greater engagement, communication and public reporting.

Effectiveness of the Act and Carers Charter

Awareness and understanding of the Act and Carers Charter

Dementia Australia supports the intent of the Carers (Recognition) Act 2008 (Qld) in formally recognising the significant contribution carers make to the people they support and to the wider Queensland community.

Most carers were unaware of the Act, Charter or Carer Advisory Council prior to our consultation. While carers generally supported the principles underpinning the Act and Carers

Charter, many were unsure whether the Act had improved recognition of carers or influenced how services and organisations engage with them.

> *“there is NO awareness of it especially among CALD communities”*
>
> *“I am not specifically aware of how the Act has definitely helped carers.”*
>
> *“what I’ve personally experienced is there is extremely limited respect or recognition for the hardship our family is experiencing due to the need to support and care for our loved one”*

Recommendation 1: Improve awareness of the Act, Charter and Queensland Carers Advisory Council (QCAC) among carers, public authorities and service providers by developing a coordinated approach to communication, education and promotion.

Recognition in practice

A consistent theme throughout our consultation was that carers want recognition to extend beyond acknowledgement of their role. Carers highlighted the importance of being included in decisions affecting the person they care for, having their perspectives and expertise considered by services and organisations, and having their own health, wellbeing and support needs recognised. Most carers identified involvement in decisions about the person they care for as an important aspect of recognition and supported stronger requirements for services to involve carers in decisions.

Feedback suggests that while carers support the intent of the Act and Carers Charter, many do not feel recognition consistently translates into practice.

> *"The Act is a good start but needs more teeth and an avenue to redress people/organisations for not following the Act."*
>
> *“There is always room and need for more recognition and support.”*

Carers also highlighted the importance of recognition of their own health, wellbeing and support needs:

> *“Carers of people living with dementia need robust physical, emotional, and practical support to avoid burnout.”*
>
> *“Recognise burnout faster.”*

Carers further described the significant burden associated with navigating fragmented health, aged care, disability and government systems. Repeated interactions with multiple agencies, duplicated processes and a lack of clear information were identified as adding to the stress and complexity of the caring role.

> *"The time and complexity of managing for your loved one with little guidance. Unless you know what to ask, what services are available, families and carers are at a huge disadvantage."*

> *"The time and stress dealing with a 'red tape world' to get services etc stops carers from being able to care for the person and the illness in a timely manner."*

These experiences highlight that recognising carers requires acknowledging the practical demands of caring and ensuring systems and services are designed to consider carers' needs, reduce unnecessary administrative burden and provide accessible information and support.

Reflecting diverse caring experiences

Carers raised concerns that the Carers Charter does not fully reflect the diversity and complexity of contemporary caring experiences. Feedback identified the experiences of carers of people living with dementia, carers of people living with young onset dementia, carers from culturally and linguistically diverse backgrounds, male carers and carers in complex family situations as requiring stronger recognition.

Some carers highlighted the importance of recognising the differing experiences and needs of carers from diverse backgrounds:

> *"We are not all the same; young carers need different support than old carers. Carers of people from CALD backgrounds especially those whose loved ones revert to their mother tongue need different support."*

Dementia Australia also notes the importance of ensuring the Charter reflects the breadth of caring experiences across Queensland, including Aboriginal and Torres Strait Islander carers, carers from LGBTQIA+ communities, and carers in rural and remote communities who may experience additional cultural, social or geographic barriers to accessing appropriate and inclusive supports.

For some carers, particularly those supporting people living with young onset dementia, caring responsibilities can have significant impacts on employment, financial security and family circumstances.

> *"Carers who need to work to support a spouse are a special case. Our needs are particularly challenging, requiring a transition from being one of two earners to being the sole earner and a carer."*

Carers also highlighted that caring relationships may continue after a person enters residential aged care, with carers continuing to provide emotional support, advocacy, decision-making support and care coordination.

> *"The carer role does not end when the person enters residential care, especially if the person cannot eat Australian meals and does not speak English."*

These findings demonstrate the need for the Carers Charter to reflect the diversity of caring experiences, recognise the different circumstances in which caring occurs, and acknowledge that caring relationships may continue across different care settings.

Other jurisdictions have recognised the need to modernise carers legislation to better reflect contemporary caring experiences. For example, recent reforms in South Australia strengthened recognition of diverse caring experiences, while legislation in Victoria and the Australian Capital Territory adopts a broader care relationship approach that recognises both carers and the person they support as individuals within an ongoing caring relationship.

Recommendation 2: Update the Queensland Carers Charter to better reflect contemporary caring experiences, including dementia and young onset dementia, carers as partners in care and decision-making, carers' own health and wellbeing needs, the diversity of caring experiences, and caring relationships that continue across different care settings.

Obligations on public authorities, consultation and accountability

The Act places obligations on public authorities to reflect the principles of the Carers Charter, consider carers in relevant workforce policies and engage with organisations representing carers when developing strategic policies and plans that affect carers. However, these obligations are not enforceable, and Queensland is currently the only Australian jurisdiction without reporting requirements under carers recognition legislation.

Although carers generally support the principles underpinning the Act, many feel there is limited accountability for how organisations recognise and involve carers and that the Act does not translate into meaningful change in practice.

> *"The Act probably needs more teeth and an avenue to address people/organisations for not following the Act. Some way carers can appeal decisions."*

> *"It looks fine as far as it goes. The issue is that as a Charter it is really just high-level guiding statements. The challenge is in its interpretation and application."*

Carers want greater involvement in decisions affecting both themselves and the people they support. Most carers supported stronger requirements for services to involve carers in decisions and supported greater accountability for organisations to follow the Carers Charter.

Dementia Australia supports the principle that public authorities should actively consider the perspectives of carers and their representative organisations when developing policies, programs and services that affect them. Yet feedback suggests carers do not consistently experience this in practice.

Feedback indicates that Queensland government agencies and services do not consistently consult with carers or follow the principles of the Carers Charter.

"Some are aware and act accordingly, while others appear not to have a clue."

Awareness and application of the Charter may vary considerably between organisations and sectors, contributing to inconsistent experiences for carers.

Carers described feeling excluded from decisions, wanting stronger involvement in care planning and service design, and seeking greater accountability from organisations to demonstrate how carers' views have been considered.

> *"Increase consultation and understanding of the demanding roles carers often find themselves in."*

Dementia Australia's **Half the Story** emphasises that meaningful consultation involves more than seeking feedback. It requires organisations to actively involve people with lived experience of dementia in decisions that affect them and to demonstrate how their views have influenced outcomes. This resource emphasises the importance of engaging people with lived experience in decisions that affect them.

Dementia Australia considers there is an opportunity to strengthen implementation of the Act through clearer consultation expectations and greater transparency regarding how public authorities apply the Charter in practice. Providing guidance and examples of best practice inclusion and recognition of carers is also recommended. Consistent with approaches adopted in other jurisdictions, reporting requirements for agencies whose policies, programs and services directly affect carers and the people they support should be established.

Recommendation 3: Strengthen consultation requirements and guidance for public authorities to ensure carers and representative organisations are meaningfully engaged in the development of policies, programs and services that affect them.

Recommendation 4: Introduce reporting requirements for relevant public authorities on implementation of the Carers Charter, consistent with approaches adopted in other Australian jurisdictions.

Queensland Carers Advisory Council

The Queensland Carers Advisory Council (QCAC) plays an important role in advancing the interests of carers, promoting the principles of the Carers Charter and advising government on matters affecting carers. However, awareness of QCAC among carers of people living with dementia was limited, with most feedback indicating low awareness of the Council prior to this consultation.

Carers also expressed uncertainty about how QCAC engages with carers and how its advice informs government decision-making.

> “I don't really know who is represented or how they provide guidance in reality.”

Feedback suggests there is an opportunity to improve awareness of QCAC’s role, increase transparency regarding its activities and advice, and strengthen mechanisms for ongoing engagement with carers and representative organisations.

Recommendation 5: Strengthen the visibility, accessibility and transparency of QCAC, including through improved communication about its role, activities and advice to government, and clearer opportunities for carers and representative organisations to engage with the Council.

Conclusion

Dementia Australia welcomes the Review of the Carers (Recognition) Act 2008 (Qld) and the opportunity to consider whether it remains fit for purpose.

Feedback from carers of people living with dementia suggests there is strong support for the intent of the Act and the principles of the Carers Charter yet recognition does not consistently translate into practice, and carers are not always meaningfully involved in decisions that affect them.

This Review presents an opportunity to strengthen the Act through a modernised Carers Charter that better reflects contemporary caring experiences, improved awareness of the Act and QCAC and stronger consultation and accountability mechanisms.

This would help ensure the recognition of carers extends beyond legislative principles and is consistently reflected in the policies, services and systems that affect carers.

Dementia Australia welcomes the opportunity for further consultation as the Review progresses.

References

1. Australian Bureau of Statistics, *Causes of Death Australia, 2024*. 2025, Australian Bureau of Statistics.
2. Dementia Australia, *Commissioned AIHW Dementia Prevalence Data 2024-2054*. 2023, Dementia Australia.
3. Australian Institute of Health and Welfare. *Dementia in Australia: Carers of people with dementia*. 2025 2025-12-05; Available from: **https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/carers-findings-survey-of-disability-ageing-carers/carers-of-people-with-dementia**.