

Carers of people living with dementia and discrimination



October 2020

Joint position statement
between Dementia Australia
and Carers Australia

About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care. We advocate for positive change and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible. No matter how you are impacted by dementia or who you are, we are here for you.

Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

About Carers Australia

Carers Australia is the national peak body representing Australia's unpaid carers, advocating on their behalf to influence policies and services at a national level. Our vision is

Issue

People living with dementia experience discrimination. Their experiences suggest that they can face discrimination as they lose cognitive ability or as their ability to navigate their environments and communities changes. A change in mood, behaviour or response, for example, may make other people uncomfortable or confronted, or they may not know what to say or do. This, in turn, may result in members of the public, and even health and service providers, to avoid people living with dementia and, in some cases, disrespect the person.

What is even less well recognised, however, is that family members and care partners who care for a person living with dementia are also likely to experience discrimination.

This can lead to carers feeling isolated from the support of their friends, family and community to such a point that they avoid social interactions and activities. This can have detrimental impacts to carers' mental health and their likelihood of seeking support.

"People become very clever at being able to avoid you. It becomes a very lonely experience for many years" (carer)

Carers report that even family and friends of a person with dementia may feel awkward in their presence and seek to avoid them, which can cause the carer to feel embarrassed, outcast and very lonely.

"Old friends [of the person with dementia] stopped calling and visiting" (carer)

"They have trouble coping with the loss of the person they used to know. Our son often doesn't want to speak to his father because he claims 'it's pointless...he forgets anyway!'" (carer)

Fear of discrimination can exacerbate the social isolation already experienced by carers of people with dementia, as they dedicate many hours of their lives to their caring role. They also report experiencing increased anxiety, isolation and fatigue, which can lead to burn out and poorer mental wellbeing than those not in a caring role. It is important for the mental health and wellbeing of carers that they receive a break from their caring role to maintain their own independence and participate in social activities.

The impact of COVID-19 has made these experiences even more acute, with people living with dementia, families and carers sharing stories with Dementia Australia and Carers Australia of loneliness, frustration, stress and fatigue. They have also highlighted their concerns about the quality of care of their loved one, the pressures they are experiencing and the lack of support services available to them.

In 2019, more than 5,000 people from across Australia completed a survey to help Dementia Australia better understand how discrimination for people living with dementia and their carers occurs and what it would take to end discrimination. Alarminglly:

- 71% of family, friends and carers who responded to the survey say they haven't been included in family activities
- 80% of family, friends and carers who responded to the survey say they haven't been invited to social functions
- 86% of family members, friends and carers who responded to the survey felt the discrimination came from friends or other people they know socially

an Australia that values and supports the contribution that carers make both to the people they care for and to the community as a whole.

Carers Australia advocates and lobbies on a wide range of issues that affect carers, and manage the delivery of national programs, support and services for carers across Australia. We work in collaboration with carers, Carers Associations, government and peak bodies to develop policy, advocacy, programs and events to improve the lives of Australia's 2.65 million carers. During our lifetime many of us will provide care to a family member or friend, or will need care ourselves. Carers are people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- That are no longer in a caring role (former carers).

The discrimination faced by carers is largely inseparable from the discrimination associated with those they care for, despite the World Health Organisation stating that people living with dementia, their families and carers have the right to be free from discrimination, including intended or unintended discrimination on the grounds of a diagnosis of dementia.

Carers Australia and Dementia Australia recommend and advocate for improved awareness and understanding of the discrimination faced by people caring for someone living with dementia through increasing community conversation and developing a robust body of data. Through ongoing communications, education and information with consistent messaging, levels of awareness can improve, having a positive impact on peoples' attitude to, and discrimination towards carers of people living with dementia and people living with dementia themselves.

Our position

Carers Australia and Dementia Australia share the position that it is critical for carers of people living with dementia to be supported in their caring role and able to live lives free from stigma and discrimination. They need to be able to access high-quality respite care that is responsive, respectful and culturally appropriate, and which addresses the needs of the person they care for as well as respecting the person's individuality and promoting a good quality of life.

While there are some communication techniques that can help carers to avoid negative responses from others and some mental health techniques that can help them avoid internalising stigmatisation, the key to systemic change is better educated communities and better educated families. Small acts of support and understanding can make a big difference in the lives of people living with dementia, their families and carers. When communities work together to become more inclusive and support people living with dementia and their carers, they can continue to engage in activities that are important to them. A concerted effort to improve community awareness to alleviate the discrimination faced by carers of people living with dementia is key.

Specifically, we recommend:

- The development of an awareness campaign - raising awareness by sharing stories of discrimination with the media as well as social posts around types of discrimination that carers of people living with dementia might experience.
- Creating additional carer support services such as respite services, community support groups, and counselling to better meet the needs of carers caring for a person living with dementia. This is particularly important for the mental health and wellbeing of carers.
- Providing a multi-component early intervention support program for carers of people living with dementia that combines education and training opportunities to equip carers to fulfil caring duties - with access to psychosocial interventions and supports that help to maintain the carer's mental health and wellbeing.
- Designing a service access gateway and a holistic assessment process that recognises the importance of carer supports alongside services for people with dementia.
- Ensuring aged care support packages place equal importance on the needs of carers and people living with dementia.
- Making mental health support services more broadly publicised, available and accessible for people who are specifically impacted by dementia.
- Information and education about people living with dementia and the caring role people undertake be widely available on government and relevant service provider websites.

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