

Discrimination and dementia – **enough is enough**

Dementia Action
Week Report 2021

20 September 2021



In 2021, the estimated number of Australians living with **dementia** is

472,000



1.6million

people are involved
in their care

Introduction

A key strategic focus for Dementia Australia over the past three years has been tackling the discrimination that people living with dementia, their families and carers experience at all levels of society. The social research we have conducted has identified and reinforced that discrimination against people living with dementia is real and even those at risk expect to experience some form of discrimination.

There are an estimated 472,000 Australians living with dementia and 1.6 million people involved in their care.¹ Dementia is the second leading cause of death of Australians and the leading cause of death of women.²

For all the increased recognition of human rights over the past decades and the United Nations Convention on the Rights of Persons with Disabilities coming into force, people living with dementia still report experiencing discrimination and not feeling fully included within society.

The Convention on the Rights of Persons with Disabilities affirms that all persons with all types of disabilities (including people living with dementia) must enjoy the same rights as everyone else, including rights to autonomy in decision-making, independent living, community inclusion, and liberty. The challenge, however, is to shift attitudes, and design and deliver services, businesses and infrastructure that are flexible, innovative, accessible, appropriate and culturally safe to ensure people with dementia, their families and carers are well supported and included within the Australian community.³

It's up to **everyone** to bring about this change.

There has been recognition of the impact discrimination has on people living with dementia by governments at all levels, and there has been a shift in a number of government policies to acknowledge this. However, a whole of community commitment is needed to truly have an impact in this space. Data from a 2020 survey showed that 63 per cent of people living with dementia and 73 per cent of family, friends or carers of people living with dementia believe discrimination against people living with dementia is common or very common. Recent figures suggest that the discrimination towards people with dementia has changed very little over the last few years.

A 2021 survey shows **65%** of people surveyed who live with dementia and **58%** of those who feel at risk of dementia believe



**discrimination
towards people
living with dementia
is common or
very common⁴.**

In fact, systemic and societal discrimination against people living with dementia, their families and carers is still so strong that many individuals report anticipatory discrimination – that is, they expect to be discriminated against because they have dementia or care for someone living with dementia.⁵

This expectation makes individuals less likely to identify or fight for their fundamental human rights and sadly, it demonstrates that we have a long way to go to truly tackle discrimination against people impacted by dementia.

“

I think most discrimination is unintentional, people just do not know how to deal with it. ”

- Carer



Research demonstrates that the impact of discriminatory behaviour is profound. It impacts all aspects of a person's life; from the way they engage socially to the types of services they access and receive and the way their human rights are interpreted.⁶ And COVID-19 has intensified these experiences. Examples of the discrimination experienced by people living with dementia and carers continue to include:

- Families and friends dropping off and people with dementia reporting they are less likely to be included in social occasions and engagement.
- Doctors and other health professionals communicating only with the person's carer, making an assumption that the person with the diagnosis no longer has the capacity to contribute to a conversation and/or make decisions for themselves.
- A widespread assumption that, because people living with dementia are experiencing a progressive decline, they are not offered the same access as everyone else to wellness, enablement and reablement services.⁷
- People who share their diagnosis with their employers being less likely to receive the same level of support to continue to work or transition out of work as do people who are diagnosed with other chronic diseases.
- Carers of people living with dementia being less likely to receive support from employers and potentially experiencing heightened financial and mental health impacts.^{8,9}

“ They say I am stupid or faking it ”

- Person living with dementia

75
per cent

of respondents who identified themselves as at risk of dementia indicated that they expect they will be treated differently if they are diagnosed.¹⁰

**more than
90
per cent**

of professionals, volunteers and people not impacted by dementia agree that people living with dementia are likely to be treated differently once they are diagnosed.¹¹

In fact, this discriminatory behaviour and thinking is still so powerful that even those who see themselves as being at risk of developing dementia expect to experience discrimination.

The impact of anticipated discrimination can lead to:

- People living with dementia and carers not disclosing their fears of dementia or a diagnosis, or being reluctant to present for diagnosis when symptoms appear, which results in self-isolation and poor mental health outcomes as well as hindering their access to services and supports.
- People living with dementia, families and carers accepting discriminatory behaviour because they do not feel empowered to speak up when their rights are compromised.
- People with dementia, families and carers experiencing poorer care and fewer treatment options than those with other chronic diseases and not feeling able to challenge the system.¹²

COVID-19 has had a pervasive impact on all of us. As a society we have experienced first-hand the impact of social isolation and loneliness on our lives. This sense of dislocation reflects to some degree what people with dementia experience every day.^{13,14}

And for those impacted by dementia, the COVID-19 pandemic has also exacerbated the impact of this discrimination.

32%

of family carers indicated they had experienced poorer mental health or loneliness due to COVID-19 restrictions.

37%

also noticed these impacts on the person they care for with dementia



Enough is enough.

Now more than ever we need to shift our thinking around dementia and stop adding discrimination to the symptoms that people with dementia experience.

The good news is, despite the challenges of the ongoing pandemic, a lot can be done to improve the dementia experience for people living with dementia and carers.

“

**I want to be seen for what I
can do rather than for what
I am not able to do!** ”

- Person living with dementia

A little
support
makes a big
difference

“

It is always a worry that people may take advantage of people with dementia when it comes to cash so it is really nice to know there are businesses out there doing the right thing and supporting people with dementia in our community to enjoy everyday activities that we may take for granted. ”

- Carer

We know systemic change takes time and with the theme for Dementia Action Week 2021, **A Little Support Makes a Big Difference** we aim to show there are many ways that everyone and anyone can help to eliminate discrimination against people living with dementia, their families and carers:

The community can visit the **Dementia Action Week hub** or **dementiafriendly.org.au** to explore ways of increasing understanding about dementia and how – as a family member, friend, neighbour or a local organisation – anyone can learn to better support people living with dementia and carers to remain engaged and active in their community.

“

Discrimination can be not speaking to them because of their diagnosis—instead talking to the family or carer. ”

- Health professional

Health and allied health professionals can receive dementia-specific education to increase their understanding about how to be more inclusive and empower their patients impacted by dementia to access appropriate services, information and supports that can enable them to maintain their independence and functional capacity for as long as is possible.

Employers can increase their knowledge and understanding of their obligations and the human rights of their employees diagnosed with dementia. To consider and acknowledge the right to request workplace modifications, flexibility and adaptations to support them to continue to work, and sensitively and respectfully transition out of employment as symptoms progress.

Employers of carers of people living with dementia can increase their knowledge and understanding of their obligations and respect the entitlement to carers leave and the right to request flexible work to enable them to balance their caring and work responsibilities.



Dementia Australia is calling on **local communities, health professionals and employers** to consider the **small changes** they can make that will make a **big difference** to people living with dementia and carers.

For more information and examples on how **A little support makes a big difference** visit dementia.org.au.

While this paper invokes the power of the combined forces of the community, health professionals and employers to show that **A little support makes a big difference**, to truly eliminate discrimination there is an obligation for all levels of government, the health, disability and aged care sectors to lead from the top, to take action and to develop policies to more formally recognise and articulate dementia in relation to the Australian and internationally accepted anti-discrimination and human rights conventions.

Everyone has a responsibility to learn about dementia and change behaviour – it could be you the reader, a family member or a close friend who will be diagnosed next or is already fearful – that they may be dealing with a diagnosis along with multiple forms of discrimination.

Dementia Australia intends to continue with this research focus on dementia and tackling discrimination, beyond the pandemic, to ensure all people living with dementia are treated with the same dignity, respect and rights as everyone else.

“

**Treat me with dignity
and respect. I once was
just like you. ”**

- Person living with dementia

Dementia Australia research

November 2020 - One Day the Support was Gone...The mental health impact of COVID-19 on people living with dementia, their families and carers.

October 2020 - Joint position paper with Carers Australia - Carers of people living with dementia and discrimination.

September 2020 - Dementia and discrimination survey.

July 2020 - Dementia Australia submission to the Royal Commission into Aged Care Quality and Safety - The impact of COVID-19 on people living with dementia, families and carers.

September 2017 - Dementia and the Impact of Stigma.

September 2016 - Dementia and Loneliness.

1. Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra
2. Australian Bureau of Statistics (2018) Causes of Death, Australia, 2017 (cat. no. 3303.0)
3. Dementia Australia (2021) Promoting Inclusion - A submission to the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability
4. Dementia Australia Dementia and Discrimination Survey September 2020
5. Dementia Australia (2021) Dementia and Discrimination Survey, 2021 Unpublished data
6. Mental Health Foundation (2015) Dementia, rights, and the social model of disability - A new direction for policy and practice?
7. Dementia Australia (2020) A Wellness and Enablement Approach for People Living with Dementia, A submission to the Royal Commission into Aged Care Quality and Safety
8. Dementia Australia Dementia and Discrimination Survey 2021 Unpublished data
9. Dementia Australia and Carers Australia (2020) Joint Position Statement: Carers of people living with dementia and discrimination
10. Dementia Australia Dementia and Discrimination Survey 2021 Unpublished data
11. Dementia Australia Dementia and Discrimination Survey September 2020
12. Dementia Australia Dementia and Discrimination Survey 2021 Unpublished data
13. Dementia Australia (2020) One Day the Support was Gone...The mental health impact of COVID-19 on people living with dementia, their families and carers
14. Dementia Australia (2020) The impact of COVID-19 on people living with dementia, families and carers - Submission to the Royal Commission into Aged Care Quality and Safety

“

**Ask me questions,
give me choices. ”**

- Person living with dementia





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. 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.

No matter how you are impacted by dementia or who you are, we are here for you.



The impact of discrimination and COVID-19 on people living with dementia, their families and carers*

In the lead up to Dementia Action Week 2021 Dementia Australia surveyed 900 people about dementia, discrimination, and the impacts of COVID-19. The respondents identified as people living with dementia, family carers, family/friends of a person with dementia, healthcare professionals, or not impacted by dementia.

65% of people surveyed who live with dementia and **58%** of those who feel at risk of dementia **believe discrimination towards people with dementia is common or very common.**

“ **Learn to understand me, not blame me.** ”

- Person living with dementia

More than 90% of professionals, volunteers and people not impacted by dementia agree that **people living with dementia are likely to be treated differently** once they are diagnosed.[^]



91%

of people who have a loved one with dementia indicated people don't keep in touch with the person living with dementia as they used to.

43% of people living with dementia

38% of family carers

had postponed health or medical visits due to COVID-19 restrictions.

55% of professionals surveyed believe that often or always a doctor will speak to the carer/support person rather than the person living dementia.



“ Please don’t label me, I’m not a product. ”

- Person living with dementia

More than two-thirds

of people living with dementia anticipated they might experience discrimination.

32
per cent

of family carers indicated they had experienced **poorer mental health or loneliness** due to COVID-19 restrictions

37
per cent

also noticed these **impacts on the person they care for** with dementia

87%

of people living with dementia surveyed felt people **patronise them and treat them as if they are not smart.**

75%

of respondents who identified themselves as at risk of dementia indicated that they **expect they will be treated differently** if they are diagnosed.

34% of family carers

30% of people living with dementia

indicated their **physical wellbeing had declined** due to COVID-19 restrictions.

*Dementia Action Week Report September 2021, Discrimination and dementia – enough is enough

^ Dementia and Discrimination Survey 2020

National Dementia Helpline

1800 100 500



For language assistance
call **131 450**

Find us online
dementia.org.au

