

## People living with dementia continue to struggle under a non-responsive aged care system

### Alzheimer's WA's response to the Royal Commission into Aged Care Quality and Safety Interim Report – *Aged Care in Australia: A Shocking Tale of Neglect*

Alzheimer's WA welcomes the hard hitting interim report of the Royal Commission into Aged Care Quality and Safety and in particular the spotlight it puts on a failing aged care system that is putting Australia's most vulnerable citizens at risk. The report highlights a number of systemic and service failures that have made Australian aged care a lottery in both accessibility and quality for older members of the Australian community.

Commissioners Richard Tracey AM, RFD, QC and Lynelle Briggs's AO description of the aged care system as "a shocking tale of neglect" and that it is "a sad and shocking system that diminishes Australia as a nation" requires urgent Government response and deserves a community demand for immediate solutions.

People living with dementia make up a large percentage of people requiring aged care support and the Commission has paid particular attention to the way the aged care sector responds to the often complex health and social needs of this group. Sadly many of the case studies of neglect and abuse heard so far have involved a person living with dementia. Alzheimer's WA believes this is a reflection of a lack of skills, knowledge and empathy of an under pressure aged care workforce; and a pervasive culture of misunderstanding the lived experience of dementia that pathologises the condition and sees the person as a shadow of their former self, of being of unequal human value and of being objectified. In his testimony to the Royal Commission, Alzheimer's WA's Head of Dementia Practice and Innovation, Jason Burton, describes "an urgent need for organisations and aged care leaders to shift to a truly person-centred care philosophy if we are to fundamentally change the medicalised institutional culture of care in our aged care environments."

The Commission's focus on restrictive practices has shown a breach of fundamental human rights and Alzheimer's WA calls for immediate action to stop the chemical and physical restraint of people living with dementia. Drugs used to sedate a person in distress have been shown to be largely ineffective at treating the cause of the person's distress and have been proven to be dangerous, and in many cases fatal. The inappropriate use of medication to sedate vulnerable older Australians and to ineffectively treat a person living with dementia who is in distress must be stopped.

Alzheimer's WA commends the Commission for setting the reduction of the waitlist for community care services as a Government priority. Supporting a person living with dementia at home is a tiring and stressful situation, with many carers being elderly themselves. Alzheimer's WA has heard from many families who are waiting

18 months or longer to access a care package suitable for their loved ones needs. This is putting enormous stress and strain on families and leading to a decline in health of carers and the person living with dementia being admitted to residential care sooner than is necessary. Increased home care packages and increased access to community respite is critical and must be responded to immediately.

Alzheimer's WA Acting CEO, Danielle Wrench said "Too many people are struggling at home with no support, or fill in services less than they need. It is critical we address this issue immediately or people's health, quality of life and safety will be at risk".

Alzheimer's WA has submitted to the Royal Commission and provided testimony on what good dementia care looks like. This statement can be found at:

<https://www.alzheimerswa.org.au/about/information-media-professionals/royal-commission-into-aged-care-quality-and-safety/>

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#### **Notes to media:**

Stories in the media about dementia may prompt concerns or cause distress for audiences and readers. When writing or talking about dementia, please encourage your audience/readers with the number for our Customer Support line on 1300 66 77 88, a free call, telephone information and support service.

#### **What is appropriate language for talking about dementia and why we need it?**

The words used to talk about dementia can have a significant impact on how people with dementia are viewed and treated in our community. In particular please avoid the use of the word sufferer or suffering – the preferred language is a person/people living with dementia. Please read the [Dementia Language Guidelines](#) that have been developed by people living with dementia and carers.

#### **About Alzheimer's WA**

As the dementia experts Alzheimer's WA works with those living with dementia and the organisations that care and support them, to have the greatest beneficial impact on their dementia journey.

Our client services, advocacy work, training and consultancy programs are based on a philosophy of understanding the lived experience of dementia. We are guided by people living with dementia and our approach views dementia as a holistic experience for the person rather than just a biological illness. Call our Customer Support line on 1300 66 77 88 or visit [www.alzheimerswa.org.au](http://www.alzheimerswa.org.au)