

**ALZHEIMER'S AND DEMENTIA
AUSTRALIA AND HOPE**

**PEOPLE WITH DEMENTIA DESERVE TO
LIVE WELL**



**ALZHEIMER'S AUSTRALIA
2016 FEDERAL ELECTION CAMPAIGN**

A MESSAGE TO AUSTRALIA'S POLITICAL LEADERS FROM ALZHEIMER'S AUSTRALIA.



Dementia is the second leading cause of death in Australia. It is a National Health Priority, and there is no cure.

Dementia is the largest health and social challenge facing Australia today. It is estimated that there are now more than 353,800 Australians living with dementia and approximately 1.2 million people involved in their care. By 2050 there will be almost one million people living with dementia.

The estimated cost of dementia to the health and aged care system is at least \$4.9 billion per annum. Dementia will become the third greatest source of health and residential aged care spending within two decades, with the costs to these sectors alone reaching 1% of GDP.

People living with dementia continue to struggle to get access to the services and supports they require to achieve a high quality of life. People with dementia experience delays in diagnosis, stigma and social isolation, unpredictable quality of care within residential care and difficulty accessing services and supports to stay connected with their communities.

Family carers find it difficult to balance work, life and caring responsibilities, often resulting in reduced workforce participation and adverse physical and mental health outcomes. For people from diverse backgrounds (Culturally and Linguistically Diverse (CALD), people from Aboriginal and Torres Strait Islander backgrounds, Lesbian, Gay, Bisexual, Transexual and Intersex (LGBTI), Homeless, and those living alone) access to quality care and appropriate services can be even more difficult.

There is both an economic and social imperative to ensure that the significant investment in dementia care and support leads to better outcomes for people with dementia and their families.

Alzheimer's Australia welcomed the Government's \$200 million commitment to boost dementia research in Australia but we not only have to beat this disease tomorrow but also provide better dementia care today. Alzheimer's Australia believes people with dementia deserve to live well.

Alzheimer's Australia is calling for all political parties to support the implementation of a comprehensive, funded National Dementia Strategy with measurable outcomes based on the *National Framework for Action on Dementia 2015-2019*. The Framework identifies key areas for action but without leadership from our political representatives to implement a targeted, outcome focused, funded strategy, little progress will be made in developing better supports for people with dementia.

The implementation of a National Dementia Strategy would build on existing areas of success and develop a strategic, collaborative and cost effective response to dementia across Australia.

As a first step Alzheimer's Australia is asking all political parties to commit to:

- **\$1.3 million** to make Australia a more dementia-friendly place for people with dementia
- **\$15 million** per annum for dementia-specific respite services
- **\$1 million** per annum to improve quality of care in aged care - led by consumers

Attached is Alzheimer's Australia's election campaign that outlines the action necessary to ensure that people living with dementia are supported to live a high quality of life with meaning, purpose and value.

On behalf of people with dementia and their families, I am asking for your support to achieve the changes in our health and social systems that will improve the quality of life for people with dementia.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Graeme Samuel'.

Professor Graeme Samuel AC
National President
Alzheimer's Australia

PEOPLE WITH DEMENTIA DESERVE TO LIVE WELL

There are 353,800 Australians living with dementia and more than a million involved in their care. **68%** of Australians have been affected by dementia in some way¹. Dementia is the second leading cause of death in Australia² and is a National Health Priority. Without a medical breakthrough dementia is set to become the most significant health, social and economic challenge of the 21st century.

Yet people with dementia still struggle to get access to the care and support they need. They face discrimination and misunderstanding in the community and services which are not equipped to support people with a cognitive impairment. In a recent survey **60%** of Australians felt not enough was being done in the area of care and support for people with dementia and their carers³. **76%** of Australians believe with the right care and support, people with dementia can continue to live a meaningful life⁴.

Alzheimer's Australia is calling for all political parties to implement a comprehensive, funded national approach to supporting people with dementia based on the *National Framework for Action on Dementia 2015-2019*. The Framework identifies key areas for action but does not enjoy the leadership from Government as has been shown in other chronic diseases such as cancer or diabetes. The National Dementia Strategy must have a focus on supporting people with dementia to live well with a high quality of life. **89%** of Australians agreed or strongly agreed that dementia needs a funded, comprehensive national approach from government⁵.

As a first step in the Strategy, Alzheimer's Australia is calling for action on three key priorities: tackling stigma and discrimination, developing respite services to better support people with dementia in the community and committing to ensuring high quality care in residential care.



¹ Research conducted by Roy Morgan Research for Alzheimer's Australia (May 2016)

² Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013*: Cat no. 3303.0

³ Ipsos (2015) *Perceptions and Understanding of Dementia: Report for Alzheimer's Australia*

⁴ Research conducted by Roy Morgan Research for Alzheimer's Australia (May 2016)

⁵ Research conducted by Roy Morgan Research for Alzheimer's Australia (May 2016)

ALZHEIMER'S AUSTRALIA IS ASKING GOVERNMENT AS PART OF A NATIONAL DEMENTIA STRATEGY TO:

1. COMMIT TO ENDING DEMENTIA DISCRIMINATION SO PEOPLE WITH DEMENTIA CAN LIVE WELL

Imagine knowing that **25%** of people find you frightening⁶? Or that one in ten people try to avoid spending time with you because of your diagnosis? This is the reality people with dementia are faced with every day in Australia. People are often afraid of what they don't understand. We need to help Australians understand dementia, to break down the stigma and misconceptions that go with a dementia diagnosis so people living with it are not discriminated against.

PEOPLE WITH DEMENTIA DESERVE TO LIVE WELL

They deserve a life of meaning and purpose. You can help to enable this and end discrimination by investing in a dementia friends campaign, modelled on the success of other countries such as the UK and Japan.

Alzheimer's Australia is asking government to commit to **\$1.3 MILLION to create a large scale, national dementia friends program, which will educate the public, businesses and organisations about how to better support and care for the 353,800 Australians currently living with dementia.**

2. COMMIT TO RESPITE SO PEOPLE WITH DEMENTIA CAN LIVE WELL

70% of people living with dementia are still living in the community.⁷ Respite is essential to ensuring carers and family members can continue to care for the person with dementia at home and that people with dementia have access to opportunities for social engagement. A failure in respite support and community care will put more pressure on already stretched aged care services.

Unfortunately few respite services offer dementia-specific programs and often respite providers turn away people with dementia. One recent survey found that nearly 1 in 5 carers had been refused access to respite for the person with dementia on at least one occasion.

PEOPLE WITH DEMENTIA DESERVE TO LIVE WELL

By offering meaningful, dementia appropriate respite which provides *real* social engagement and value for the person living with dementia, their quality of life can be improved. This will also increase the likelihood of a carer being able to continue to care for their loved one at home in their community where most people would prefer to be.

Alzheimer's Australia is calling on government to commit **\$15 MILLION to improve respite care for people living with dementia.**

⁶ Ipsos (2015) Perceptions and Understanding of Dementia: Report for Alzheimer's Australia

⁷ Australian Institute of Health and Welfare (2012) Dementia in Australia

3. COMMIT TO QUALITY

SO PEOPLE WITH DEMENTIA CAN LIVE WELL

In a recent survey 3 in 4 Australians were not confident that high quality aged care would be available to them or a family member if they needed it⁸. **82%** of Australians feel that Government should be providing more information (such as ratings) about the quality of life of residents in aged care facilities⁹. **63%** would be willing to pay more in taxes if it meant better quality aged care¹⁰.

Currently there is not a single publically reported quality measure in aged care. Despite some positive accounts, many people with dementia and their families have raised concerns regarding physical, psychological and sexual abuse, inappropriate use of restraints, unreported assaults, and people in extreme pain at end-of-life not having access to palliative care.¹¹

Significant investment has already been made by Government to work with consumers and providers to develop quality indicators within aged care. But more work is needed to ensure that measures of quality that are meaningful to consumers are implemented and reported.

Transparent measurement and reporting of quality and consumer-experience in aged care are the cornerstone of changing the culture and increasing leadership in aged care. This has successfully been achieved in the health system through the Australian Commission on Safety and Quality in Health Care and needs to also happen in aged care.

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Access to quality care should be a basic human right. The key to improving consumer-experience of care is the shift from minimum standards through the accreditation process to establishing quality measures that empowers consumer choice through better information.

Alzheimer's Australia is calling on government to commit to implementing and reporting mandatory measures of quality of life within residential aged care, and investing **\$1 MILLION to improve quality of care which will lead to better quality of life for people with dementia.**

⁸ Research conducted by Roy Morgan Research on behalf of Alzheimer's Australia (May 2016)

⁹ Research conducted by Roy Morgan Research on behalf of Alzheimer's Australia (May 2016)

¹⁰ Research conducted by Roy Morgan Research on behalf of Alzheimer's Australia (May 2016)

¹¹ Alzheimer's Australia (Nov 2013), Paper 38: Quality of residential aged care: The consumer perspective p4.

<https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-37.pdf>

FIGHTDEMENTIA.ORG.AU

Alzheimer's Australia is the peak body representing people with dementia, their families and carers. It provides advocacy, support services, education and information. More than 353,800 people have dementia in Australia. This number is projected to reach more than half a million by 2030.

For information and advice contact the
National Dementia Helpline on:

1800 100 500

The National Dementia Helpline is an Australian Government funded initiative

