



**WHERE DO
AUSTRALIANS
STAND ON
DEMENTIA?**

**UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

CONSULTATION FINDINGS

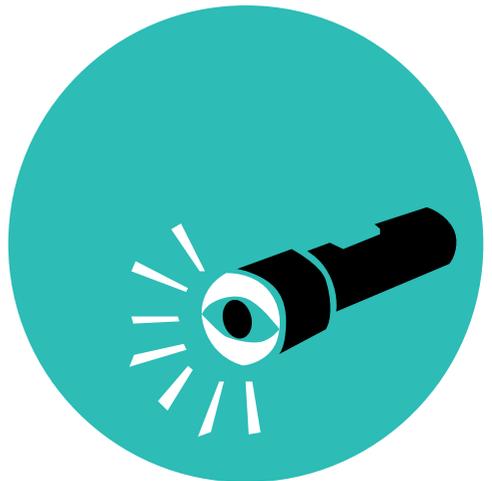
This booklet summarises the latest survey information telling us what Australians understand and think about dementia, supplemented with the latest facts and statistics.

The survey information comes from two surveys commissioned by Alzheimer's Australia:

- A 2015 survey of 1,046 Australians, undertaken by Ipsos
- A 2016 survey of 1,007 Australians, undertaken by Roy Morgan Research.

The information from these surveys tells us quite a bit about where Australians stand on dementia, and there might be a few surprises!

BUT FIRST...



HOW MUCH DO YOU THINK YOU KNOW ABOUT DEMENTIA?

TEST YOUR KNOWLEDGE!

In our 2015 survey of more than 1,000 Australians, we asked people whether they agreed with a number of statements about dementia. Take our quiz and see how you compare with our survey participants.

TRUE OR FALSE?

Dementia is a normal part of ageing

TRUE FALSE

With the right treatment, dementia can be cured

TRUE FALSE

People in their 30s and 40s can develop dementia

TRUE FALSE

Dementia is fatal

TRUE FALSE

There is nothing anyone can do to reduce the risk of dementia

TRUE FALSE

A healthy diet plays a part in reducing the risk of dementia

TRUE FALSE

TURN OVER FOR THE ANSWERS...

“DEMENTIA IS A NORMAL PART OF AGEING” TRUE OR FALSE?

THE CORRECT ANSWER IS: FALSE. DEMENTIA IS A SET OF DISEASES, NOT A NATURAL PART OF AGEING.

When we asked Australians this question in 2015, 3 in ten people thought this statement was true, 6 in ten people thought it was false, and 1 in ten said they didn't know. We need more Australians to understand that dementia is a disease process, not a natural part of ageing.

FACT: Dementia is the term used to describe the symptoms of a large group of illnesses which cause progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy Bodies.

“WITH THE RIGHT TREATMENT DEMENTIA CAN BE CURED” TRUE OR FALSE?

THE CORRECT ANSWER IS: FALSE. RESEARCH IS HELPING US TO UNDERSTAND MORE ABOUT THE DISEASE PROCESS AND RISK FACTORS, BUT AT THIS POINT UNFORTUNATELY WE HAVE NO CURE.

Our 2015 survey found that about 2 in ten people thought this statement was true, about 6 in ten thought it was false, and 2 in ten said they didn't know. Younger people were more likely to think the statement was true.

We also asked people whether they believe there is enough research being done to find a cure for dementia. Only 1 in five people surveyed agreed there is enough research being done to find a cure.



“PEOPLE IN THEIR 30s AND 40s CAN DEVELOP DEMENTIA” TRUE OR FALSE?

THE CORRECT ANSWER IS: TRUE. DEMENTIA DOESN'T ONLY AFFECT ELDERLY PEOPLE. WHILE RATES OF ONSET OF DEMENTIA DO INCREASE WITH ADVANCING AGE, THE CONDITION ALSO AFFECTS SOME YOUNGER PEOPLE.

25,100

THE ESTIMATED NUMBER OF AUSTRALIANS AGED UNDER 65 WHO HAVE DEMENTIA TODAY - INCLUDING PEOPLE AS YOUNG AS 30.

38,600

THE EXPECTED NUMBER OF AUSTRALIANS UNDER 65 WITH DEMENTIA BY 2050.

Source: Australian Institute of Health and Welfare (2012) Dementia in Australia.

In our 2015 survey, 8 in ten people correctly identified that younger people can also develop dementia. It's really encouraging that people are beginning to understand the issue of younger onset dementia.

“DEMENTIA IS FATAL” TRUE OR FALSE?

**THE CORRECT
ANSWER,
UNFORTUNATELY,
IS TRUE. DEMENTIA
IS A TERMINAL
CONDITION.**

In our 2015 survey, almost half of the survey participants thought the statement was true, but more than half either thought it was false or said they didn't know.



“THERE IS NOTHING ANYONE CAN DO TO REDUCE THE RISK OF DEMENTIA” TRUE OR FALSE?

THE CORRECT ANSWER, AND THIS IS GOOD NEWS, IS: FALSE. THERE IS MOUNTING EVIDENCE ABOUT THE VALUE OF HEALTHY LIVING IN REDUCING THE RISK OF DEMENTIA.

In our 2015 survey, 6 in ten people correctly identified this statement as false, while about 2 in ten thought it was true, and about another 2 in ten said they didn't know. It's worrying that 4 in ten Australians still don't understand that there are actions they can take to reduce their risk of dementia.



Source: Barnes DE, Yaffe K (2011) The projected effect of risk factor reduction on Alzheimer's disease prevalence.

FACT: Research over the last decade has shown that up to a third of cases of Alzheimer's disease are potentially attributable to preventable risk factors. Addressing issues such as type 2 diabetes, hypertension, obesity, depression, physical inactivity, smoking and cognitive inactivity could prevent up to 3 million cases of Alzheimer's disease worldwide.

**“A HEALTHY DIET PLAYS
A PART IN REDUCING
THE RISK OF DEMENTIA”
TRUE OR FALSE?**

**THE CORRECT ANSWER IS: TRUE.
A HEALTHY DIET CAN ASSIST IN
MAINTAINING A HEALTHY WEIGHT, AND
AVOIDING OR MANAGING CONDITIONS
SUCH AS HYPERTENSION AND TYPE 2
DIABETES. THIS CAN REDUCE A PERSON’S
RISK OF DEVELOPING DEMENTIA.**

Nearly 7 in ten of our survey participants correctly identified this as being true, with more than 3 in ten either thinking the statement was false, or saying that they didn't know.

It's encouraging that nearly 7 in ten people realise that a healthy diet can reduce the risk of dementia, but with 3 in ten still not understanding this, there is more work to be done.

Our 2015 survey also asked people whether they would like to know more about how to reduce their risk of dementia. The response to this question shows that there's a real interest in the community to know more, with over 8 in ten people surveyed keen to have more information about how to reduce their risk. The figure is even higher for women and for people aged over 50.

83% The proportion of people who say they would like to know more about how to reduce their risk of dementia.

Source: Ipsos research for Alzheimer's Australia on Perceptions and Understandings of Dementia, 2015



HOW DID YOU DO IN OUR QUIZ?

If you didn't get a perfect score, you're certainly not alone, as you can see from the results of our survey. There's definitely more work to be done to ensure Australians gain a better understanding of dementia. In fact, our 2015 survey asked people about their knowledge of dementia, and more than 6 in ten respondents admitted that they knew very little – this was particularly so for men, and for people aged under 50.

63%

**THE PROPORTION OF PEOPLE
WHO SAY THEY KNOW VERY
LITTLE ABOUT DEMENTIA**



Source: Ipsos research for Alzheimer's Australia on Perceptions and Understandings of Dementia, 2015

HOW BIG AN ISSUE IS DEMENTIA?

The care and support of people with dementia is one of the largest healthcare challenges facing Australia, and this challenge is set to increase sharply over the coming years.

353,800

THE NUMBER OF PEOPLE ESTIMATED TO BE LIVING WITH DEMENTIA IN AUSTRALIA TODAY.

900,000

THE NUMBER OF PEOPLE EXPECTED TO BE LIVING WITH DEMENTIA IN AUSTRALIA BY 2050, IF THERE IS NO MEDICAL BREAKTHROUGH.

Source: Australian Institute of Health and Welfare (2012) Dementia in Australia.



**\$4.9
BILLION**

**THE ESTIMATED COST
OF DEMENTIA TO THE
HEALTH AND AGED
CARE SYSTEM TODAY.**

Source: Australian Institute of Health and Welfare (2012) Dementia in Australia.

AS WELL AS PRESENTING MAJOR CHALLENGES FOR OUR HEALTH AND AGED CARE SYSTEMS, DEMENTIA ALSO HAS A PROFOUND SOCIAL IMPACT. PEOPLE WITH DEMENTIA STILL, UNFORTUNATELY, EXPERIENCE STIGMA AND SOCIAL ISOLATION, AND FAMILY CARERS OFTEN FIND IT DIFFICULT TO BALANCE WORK, LIFE AND CARING RESPONSIBILITIES.

Reflecting the huge impact of dementia in the community, the majority of respondents to our surveys report that they have been impacted in some way by dementia. Nearly 7 in ten of those surveyed in 2016 have been personally impacted by dementia, with many (more than one third) having had a close family member diagnosed with the disease. More than 1 in ten of those surveyed have helped to care for or support a person with dementia.

68% **35%** **12%**

The proportion of people who say they have been impacted in some way by dementia.

The proportion of people who have had a close family member with dementia.

The proportion of people who have helped care for or support a family member or friend with dementia.

ARE WE IN DENIAL ABOUT DEMENTIA?

57%

THE PROPORTION OF PEOPLE WHO SAY THEY WOULD RATHER NOT THINK ABOUT DEMENTIA

Source: Ipsos research for Alzheimer's Australia on Perceptions and Understandings of Dementia, 2015

It would seem that we are in denial! More than half of the people we surveyed in 2015 said they would rather not think about dementia, and this proportion seems to be actually increasing over time (compared with a previous survey undertaken in 2012). This level of denial indicates that the fear and stigma surrounding dementia remain very strong in our community.

In fact, 25% of the people in our 2015 survey said that they find people with dementia frightening, and men and people aged under 50 were more likely to feel this way. We have a long way to go in breaking down this fear and stigma, and building dementia friendly communities in Australia.

SHOULD WE BE DOING MORE TO SUPPORT PEOPLE WITH DEMENTIA?

17%

**THE PROPORTION OF PEOPLE
WHO BELIEVE THAT THERE IS
ENOUGH BEING DONE IN THE
AREA OF CARE AND SUPPORT
FOR PEOPLE WITH DEMENTIA**

Fewer than 1 in five people surveyed in 2015 believe there is enough being done in the area of care and support for people with dementia, and only around 1 in ten people over 50, who are likely to have more experience and insight, agreed that enough is being done.

Source: Ipsos research for Alzheimer's Australia on Perceptions and Understandings of Dementia, 2015

76%

THE PROPORTION OF PEOPLE WHO BELIEVE THAT THE RIGHT CARE AND SUPPORT CAN MAKE A REAL DIFFERENCE FOR PEOPLE WITH DEMENTIA

Three quarters of people surveyed in 2016 believe that with the right care and support, people with dementia can continue to live a meaningful life.

At Alzheimer's Australia, we are privileged to meet people with dementia every day, whose lives remain meaningful and whose experiences have been immeasurably improved by having access to good care and support.

Source: Roy Morgan research for Alzheimer's Australia, 2016

88%

THE PROPORTION OF PEOPLE WHO WANT TO SEE A FUNDED NATIONAL APPROACH TO DEMENTIA

The vast majority of Australians, almost 9 in 10 participating in our 2016 survey, support a funded comprehensive national approach to tackling dementia. Fewer than 2% of people disagreed with this. This lends weight to Alzheimer's Australia's calls for a funded national dementia strategy.

Source: Roy Morgan research for Alzheimer's Australia, 2016

MORE THAN 50%

**THE PROPORTION
OF RESIDENTS
IN AUSTRALIAN
GOVERNMENT-
SUBSIDISED AGED
CARE FACILITIES
WHO HAVE
DEMENTIA**

While 70% of people with dementia live in the community, and only 30% live in residential aged care homes, **people with dementia make up more than half of residential aged care places.** Family members have long voiced concerns to Alzheimer's Australia about the quality of care their loved ones are receiving in some of these facilities. There are also broader concerns about the care provided to people with dementia who are living in the community.

Our survey shows that most Australians share these concerns.

Source: Australian Institute of Health and Welfare (2012) Residential aged care in Australia 2010-11: A statistical overview

26%

**THE PROPORTION
OF PEOPLE WHO
ARE CONFIDENT
THEY COULD FIND
GOOD CARE FOR
THEMSELVES
OR A FAMILY
MEMBER WITH
DEMENTIA.**

Source: Roy Morgan research for Alzheimer's Australia, 2016



It is very concerning that only 1 in four people surveyed in 2016 were confident that if they had to find an aged care facility for themselves or a family member with dementia, high quality services would be available where they were needed. Unfortunately however, it reflects only too well the reality that Alzheimer's Australia hears from consumers.

A major concern for people with dementia and their carers is the difficulty that consumers experience in judging the quality

of an aged care service. The vast majority of Australians in our 2016 survey – more than 4 in five people – want to see better information provided by Governments about the quality of life of residents in aged care facilities – information such as ratings.

The majority of Australians, more than 6 in ten of those surveyed, say they would be prepared to pay more in taxes if it meant better quality aged care.

63%

**THE PROPORTION
OF PEOPLE WHO
SAY THEY WOULD
BE PREPARED TO
PAY MORE TAXES
IF IT MEANT
BETTER QUALITY
AGED CARE.**

WHAT NEEDS TO BE DONE?

ALZHEIMER'S AUSTRALIA IS CALLING FOR THE GOVERNMENT TO IMPLEMENT A COMPREHENSIVE, FUNDED NATIONAL DEMENTIA STRATEGY WITH MEASURABLE OUTCOMES.

It's clear from our surveys that many Australians know little about dementia, but want and need to know more so that they can take action to reduce their risk. There are high levels of fear and stigma surrounding the disease. Yet dementia has touched the majority of people in some way. Many have had a family member or close friend diagnosed with the disease, and a considerable number have been involved in the care and support of a person with dementia. Most Australians are concerned about the quality of care and support offered to people with dementia, and want to see a comprehensive national approach to tackling the disease.

Investment in this integrated approach to dementia can help rein in the costs of dementia to the health and aged care system by helping people with dementia to live safely and well in the community for longer. Most importantly, this investment will improve the wellbeing of the increasing number of people with dementia and their families in Australia.



THE STRATEGY NEEDS TO INCLUDE:

- A community driven, collaborative approach to reducing the stigma and social isolation associated with dementia, through support for dementia-friendly communities.
- A national campaign to promote awareness about dementia risk-reduction strategies and to create partnerships with other health promotion campaigns.
- A timely diagnosis initiative, to promote timely and accurate diagnosis for all Australians with dementia.
- A coordinated approach to improving post diagnosis care and support.
- Initiatives to improve the quality of care provided to people with dementia through dementia-specific respite, consumer driven quality programs for home and residential aged care services, workforce education and training, and continued investment in support for people who experience distressing behavioural and psychological symptoms.
- An end-of-life care program, to support the choices of people with end-stage dementia, including having access to appropriate palliative care, and bereavement support for carers.
- Investment in dementia research, and support for consumer involvement in dementia research.

FIGHTDEMENTIA.ORG.AU

Visit the Alzheimer's Australia website
for comprehensive information about
dementia, care information, education, training
and other services offered by member organisations.

Or for information and advice contact the
National Dementia Helpline on

1800 100 500

The National Dementia Helpline is an Australian Government funded initiative