Dementia is everybody’s business

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The Pfizer Health Report “Dementia is everybody’s business”, was developed by Alzheimer’s Australia and supported by Pfizer Australia to highlight the need for more awareness about the impact of dementia in the community.

About the research

The research was carried out by StollzNow Research using a quantitative permission-based online panel of 2,500 Australian adults aged 18 years and over. To ensure that the survey is representative of the Australian adult population quotas were set for gender, age, state and region (metro / rural and regional areas).

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Dementia is one of the most disabling of all chronic diseases. This is because it progressively destroys brain cells and their connections and as a consequence reduces the capacity of the individual to function normally without support from family and friends.

The impact of dementia cannot be underestimated. Each week, there are 1,500 new cases of dementia in Australia. That is expected to grow to 7,400 new cases each week by 2050. The number of people with dementia is projected to increase to almost 1 million by 2050 and this will have a huge impact on the number of Australians caring for someone with dementia.

Most Australians associate dementia with memory loss. But many are still unclear about how common dementia is or what other symptoms are associated with dementia. For example, 44% of Australians underestimate or do not know the prevalence of dementia. Only 1 in 5 is aware that dementia is a terminal illness even though dementia is the third leading cause of death in Australia, after heart disease and stroke. Most people are also unaware of the behavioural symptoms and language difficulties that can be associated with dementia.

Ita Buttrose, President of Alzheimer’s Australia says, “People once thought of dementia as something only older people had to worry about. It’s now apparent that people of all ages need to be concerned because so many people have the condition or are family carers, and because the disease is so disabling.”

What is Dementia?

Alzheimer’s disease and other causes of dementia result in physical changes in the brain that cause impaired memory, thinking and behaviour. Alzheimer’s disease accounts for approximately 70% of all dementias.

As brain cells die, the substance of the brain shrinks. Abnormal material builds up as “tangles” in the centre of the brain cells and “plaques” outside the brain cells. This disrupts messages within the brain, damaging connections between brain cells, leading to the eventual death of brain cells and preventing recall of information as well as other cognitive and functional impairment.

The disease is named for the German physician Alois Alzheimer, who first described it in 1907. Glenn Rees, CEO of Alzheimer’s Australia says, “Alois Alzheimer was the first person to put the condition into medical terminology, but references to age-related cognitive impairment are found as far back as Greek literature and even in Shakespeare’s writing. And it has been wrongly regarded for centuries as a natural part of ageing.”

He adds, “Dementia research is really only 25 years old, and we still don’t know the cause. But there are exciting developments in terms of delaying the onset and identifying those at risk.”
Older Australians are significantly more afraid of getting Alzheimer’s disease or another form of dementia than any other health condition. Among 50 to 59 year olds, 71% worry about contracting Alzheimer’s – a figure that rises to 75% among those aged 60 and over.\(^{15}\)

It may be feared, but 83% of Australians believe people with dementia can still enjoy everyday activities.\(^{16}\)

Glenn Rees, CEO of Alzheimer’s Australia says, “People develop dementia at different speeds - if they’re young they tend to decline more rapidly, so the experience varies. A person can live for eight to 20 years with dementia.”

The potential for discrimination

Across all Australians, 44% believe people with Alzheimer’s disease or other forms of dementia are discriminated against or unfairly treated.\(^{17}\)

Carers are more likely to believe there is discrimination, with 56% saying a person with dementia may be unfairly treated or discriminated against.\(^{18}\)

Stigma associated with dementia can take many forms. Many individuals with dementia and their families report that they experience social isolation as their friends and family stop visiting or spending time with them. This is supported by the finding that 22% of Australians would feel uncomfortable spending time with someone who had dementia.\(^{19}\)

President of Alzheimer’s Australia, Ita Buttrose, says, “People may experience discrimination when accessing health services. Some people feel there is an attitude among service providers of ‘why bother’ if somebody has a terminal condition such as dementia.”

22% of Australians would feel uncomfortable spending time with someone who had dementia.
Perhaps reflecting the social stigma attached to dementia, 16% of Australians say they know someone who might have dementia who has not sought diagnosis or treatment. Among carers this figure rises to 41%.21

Glenn Rees says, “There are a number of strategies people can use to encourage family members and friends to seek treatment. A good starting point is attendance at an information talk about memory. When Alzheimer’s Australia delivers these talks we don’t discuss dementia or Alzheimer’s, we simply try to help people understand the difference between everyday memory failures, which we all have, and concerns that go deeper.

“A second strategy is to see your doctor. Alternately, people can ring the National Dementia Helpline. About 15% of the calls to our Helpline are from people who have concerns about their memory or who already have a diagnosis of dementia, and we provide an opportunity to talk through the issues with somebody who’s familiar with the situation.”

Avoiding diagnosis

National Dementia Helpline:

1800 100 500
Alzheimer’s Australia has developed *Mind your Mind*, a public education program designed to promote awareness of the lifestyle changes that may reduce the risk of dementia. This program includes seven ‘mind your mind’ signposts that point to a healthy brain and can also lead to other health benefits such as lowering your risk for heart disease, stroke or diabetes. The evidence shows that people who stay active and look after their vascular health in particular are less likely on average to develop dementia. And if they do get dementia, the onset may be delayed so they have more years of healthy life. There are no guarantees but it can do no harm.

Professor Henry Brodaty, Director of the Primary Dementia Collaborative Research Centre says, “We should be as concerned at all ages about the health of our brains as we are about our bodies. Research has shown that dementia starts to develop perhaps 20 or more years before diagnosis.”

To learn more about reducing your risk for dementia visit the *Mind your Mind* website [www.mindyourmind.org.au](http://www.mindyourmind.org.au)

Seven ‘*Mind your Mind*’ signposts point the way to a healthy brain and reduced risk of dementia.

**1. Mind your Brain**

keep your brain active through learning, working and mentally stimulating leisure activities.

**2. Mind your Diet**

a healthy, low fat, high fruit and vegetable diet is good for cardiovascular health, so there’s every reason to expect it can benefit brain health as well.

**3. Mind your Body**

studies have shown an association between lower dementia risk and higher levels of regular physical activity undertaken at different stages of life.
Risk Reduction

It may be possible to reduce the risk of dementia with a ‘brain healthy’ lifestyle.

Although there is no cure for dementia there is increasing evidence that there is a link between healthy lifestyles and brain health. There are a number of ways in which people can reduce their risk of developing dementia, such as keeping mentally and physically active, having a healthy diet, and avoiding activities that increase the risk of head injuries.

Only half of Australians believe that it is possible to reduce the risk of developing Alzheimer’s disease and other forms of dementia. Although there is no cure for dementia there is increasing evidence that there is a link between healthy lifestyles and brain health. There are a number of ways in which people can reduce their risk of developing dementia, such as keeping mentally and physically active, having a healthy diet, and avoiding activities that increase the risk of head injuries.

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Mind your Social Life

studies have shown an association between lower dementia risk and higher levels of social interaction, mostly at late life.29

Mind your Health Checks

High blood pressure, cholesterol and diabetes each increase dementia risk.30

Mind your Habits

excess alcohol consumption, smoking and obesity are associated with increased incidence of dementia.31

Mind your Head

serious head injury increases dementia risk, so avoiding head injury can help avoid an increased risk of developing dementia.32
Early detection

Market research shows that Australians associate Alzheimer’s disease and other forms of dementia with loss of memory (90% of respondents), inability to undertake functions of daily life (68%) and an inability to organise life (65%).

Early symptoms of dementia can include memory problems, difficulties in finding words, changes in personality or behaviour, or changes in day-to-day function at home or work. Depression and anger can also be exhibited as a symptom or in response to the diagnosis. Sometimes early symptoms may be missed as they are attributed to normal ageing or because symptoms develop slowly over time.

Would we share the diagnosis?

People who believe they were in the early stages of Alzheimer’s disease or dementia would feel most comfortable sharing this information with their family (76%) and close friends (63%). Only 4% would prefer to say nothing at all.

When it comes to people who think someone close to them might have Alzheimer’s disease or dementia, Glenn Rees says, “The question of whether to say anything to the person involved comes down to individual choice. Alzheimer’s Australia would encourage somebody who has concerns, either their own concerns or concerns for somebody else, to seek advice. If it’s really the case that the person might be better off not knowing, then that’s something we’d respect. But the argument for knowing is very strong in terms of planning your finances and planning your future care.”

Is early detection beneficial?

Although there is no cure for dementia there are multiple reasons why early diagnosis can be beneficial.

A number of other conditions can produce dementia-like symptoms, including vitamin deficiencies, undiagnosed thyroid problems, depression, and side effects of medicines. Seeking advice from a doctor soon after experiencing symptoms is important so that potentially reversible causes of cognitive change can be ruled out or treated.

An early diagnosis of dementia also gives individuals and their families time to adjust to the diagnosis and start making legal and financial decisions while the individual with dementia can still have an active role in decision making.

A diagnosis can also help in the management of symptoms which may accompany dementia, such as depression or irritability. Medicines may also be used to help maintain function and quality of life in some people.

Younger Onset Dementia

There are also 16,000 Australians with Younger Onset Dementia - that is people under the age of 65 years. Dementia is much less common in younger people but it is often misdiagnosed and can go untreated for a longer period than an older person experiencing dementia symptoms.

Leo, who was diagnosed with Younger Onset Dementia, describes his experience with getting an early diagnosis: “My experience was unlike many others. My diagnosis of dementia was relatively quick. From the time I went to see the doctor the first time to preliminary diagnosis was three or four months. The diagnosis was a relief. I knew something was seriously wrong with me and my biggest fear was that they were going to tell me that nothing was wrong. I would have thought I was going crazy. Once I got the diagnosis I thought ‘now I know what I am dealing with’.”
Seven per cent (7%) of Australians currently care for a person with dementia\textsuperscript{37} and 64\% believe it is likely they may have to care for a person with dementia in the future.\textsuperscript{38}

Approximately 60\% of people with dementia are living in the community, and the majority have a family member or friend who cares for them. This care can range from occasional help with shopping or driving to more intensive assistance with bathing and other daily care activities. The average hours of care provided by a primary carer of a person with dementia is estimated to be around 40 hours per week.\textsuperscript{39}

Australians who are not carers vary in how much time they would be prepared to give to caring for someone with dementia. Seventeen percent (17\%) have no time at all and 41\% would be prepared to give under 10 hours per week. The types of support Australians are most comfortable providing are the practical ones such as shopping, domestic assistance, transport and assisting in social activities. They are less likely to be willing to provide personal care such as showering and toileting.\textsuperscript{40}

**Support for carers**

The physical and emotional demands of caring for someone with dementia can be high. There are a number of different types of support available through government programs and organisations like Alzheimer’s Australia. Carers can access financial support provided by the carer pension and carer allowance available through Centrelink. Organisations like Alzheimer’s Australia can offer carers access to support groups, educational materials and information about services. The National Dementia Helpline (1800 100 500) and the Alzheimer’s Australia website www.alzheimers.org.au are valuable sources of information and support.

Respite care can be an important part of supporting individuals who care for a person with dementia. Unfortunately respite care is often underutilised. Carers give a number of reasons for not using respite care, including concern about quality and flexibility. Another concern is about whether the respite service provides appropriate activities for the person with dementia.

Danijela cares for her mum who has dementia. She describes her experience with respite care: “The best thing the service providers did for me was to arrange 48 hour respite care once a month. The carer spoke my parents’ language and looked after mum and dad, so I was able to concentrate on my business. After moving to a new location, the service providers changed and I was offered only a couple of hours of care per week and there were no bilingual respite carers available. I suppose I felt that it was my responsibility anyhow so if there weren’t other people - bad luck for me. If I had better respite care mum would have stayed at home with me for at least another year or two, which we both wanted.”

**Communicating with people who have Alzheimer’s**

- Introduce yourself
- Maintain eye contact all the time
- Remain calm and speak in a matter of fact way
- Involve carers
- Keep sentences short and simple
- Focus on one instruction at a time
- Give time for responses
- Repeat yourself – don’t assume you have been understood
- Do not give too many choices

Planning for the future

Dementia is a progressive disease for which there is presently no cure, and it will, eventually, lead to death. As the disease progresses, there will be a time when a person with dementia loses the capacity to make decisions for themselves.

Forty-nine per cent (49%) of Australians have not taken any actions in case they lose the ability to make decisions at some point in the future due to an illness like dementia. The most common action is to have made a will (42%). Fewer people have made plans for their health care (10%) or have appointed someone to look after their finances (19%).

Glenn Rees, CEO of Alzheimer’s Australia says, “In the context of dementia there are three key decisions to make early on - who you trust with your finances; who you trust to make decisions about your future care, and the care you want at the end of your life.”

Despite not having documented their wishes, many Australians have clear ideas about what they would like to happen if they were terminally ill with only a few weeks left to live:

- 54% want to determine the care options through advance care directives
- 53% want to be given the option to refuse all treatment even if this meant dying sooner
- 42% would take the option of euthanasia if available
- 9% wish to be kept alive as long as possible through medical intervention such as artificial feeding or hydration

Professor Colleen Cartwright, an expert on end of life issues says, “Individuals with dementia have a right to the best quality of life possible, to have their wishes respected within the limits of the law and at the end of life they need – and have a right to – exemplary care, especially in relation to pain and symptom management.”
Fifty six per cent (56%) of Australians do not know if there are any medicines which can help people with Alzheimer’s disease or other forms of dementia.\(^{46}\)

Only thirty per cent (30%) of people believe there are treatments available for dementia,\(^{47}\) and among these people 61% believe the treatments are effective.\(^{48}\)

There are, in fact, several medicines approved for use by people with dementia in Australia. While every person’s journey with dementia will be unique, there is some evidence that the earlier a person begins using medicines, the more effective they will be.

According to Professor Henry Brodaty, an expert on dementia, “The current medications can be effective for a time for some people in treating the symptoms of dementia and make a difference to the lives of people with dementia and their families. However they are not a cure; there are no drugs yet that can halt or reverse the underlying pathological process. There is a need for more investment in dementia research to develop new medicines, and ways to reduce the risk of developing Alzheimer’s disease. Australia spends considerably less on dementia research than any of the other major chronic illnesses, despite the increasing number of people affected by dementia.”

As with any chronic disease, an important strategy in the treatment of dementia is identifying those most at risk in order to delay onset of the disease. New medications are in trial that hold out the possibility of delaying or modifying the progression of dementia but they have yet to be proven effective.

Ita Buttrose, President of Alzheimer’s Australia notes, “Dementia is the poor cousin to other chronic diseases in regards to research funding. More research into the cause, prevention and treatment of dementia is needed to reduce the prevalence of dementia in the future.”\(^{49}\)