Media Release

Dementia second most feared disease: new survey

Dementia is the second most feared disease amongst seniors, recent research by Alzheimer’s Australia NSW has revealed.

The research also showed that most seniors believed that the general public had a very poor understanding of dementia.

These findings are contained in a discussion paper, Addressing the Stigma associated with Dementia, released today by Alzheimer’s Australia NSW, which has found that stigma can have a profound effect on people with dementia and their loved ones.

To combat this, Alzheimer’s Australia NSW is calling for a national campaign to increase the understanding of dementia and to ensure the retained abilities of people with dementia are recognised so they can participate in mainstream community life.

The CEO of Alzheimer’s Australia NSW, The Hon. John Watkins, said the stigma associated with dementia can often lead to exclusion, discrimination and disempowerment for both the person with dementia and their family members or carers.

“It can also affect whether people with genuine worries about their memory seek medical help early, which is a big concern,” Mr Watkins said.

“If the symptoms are caused by dementia, getting a diagnosis as early as possible is important in helping to get the right information, treatment and support.

“What we have found is that a lack of understanding of dementia and fear of dementia are the major cause of stigma.

“The fear ranges from ignorance and fear of the illness itself, to fear of how to communicate and interact with a person with dementia.”

In surveys conducted for the discussion paper, carers of people with dementia talked about the negative community attitudes towards the person with dementia. One said: “I explained my husband’s problem; the answer was ‘If you are going to have an idiot on the street put a muzzle on him’”.

Carers also talked about the isolation and loneliness that can be associated with dementia. One carer said: “People become very clever at being able to avoid you. It becomes a very lonely experience for many years”.

Another said: “Friends stayed away and treated the person as ‘contagious”’. 
The surveys also found that 61% of people did not believe the general public had an understanding of dementia and that dementia is the second most feared disease after cancer.

As well, 76% of carers surveyed stated they had, at some time, felt embarrassment or shame for the person they care for because of inappropriate social behaviour caused by the dementia – an aspect of the illness which is not well understood by the general public.

Many carers reported ignorance of dementia as a major reason for people’s negative attitudes.

People with dementia interviewed as part of the survey said the community needs to recognise that a person in the early stages of dementia still retains many of the abilities that allow them to participate meaningfully in every day life.

An estimated 257,000 Australians currently live with dementia, which, without a significant medical breakthrough, is expected to soar to almost 1 million people by 2050.

“There is an urgent need for a national dementia awareness campaign to increase understanding of dementia and to decrease stigma,” Mr Watkins said.

“As well, the community needs to realise that life does not stop with a diagnosis of dementia. People can continue to lead a fulfilling and rewarding life and should be encouraged and supported to continue to participate in mainstream community life.

“The number of people with dementia is only going to increase and, as physical disability has been increasingly integrated into mainstream society, so too should dementia.”

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person’s cognitive ability. Alzheimer’s disease is the most common type of dementia. Dementia is not a normal part of ageing.

The release of the discussion paper, Addressing the Stigma associated with Dementia, coincides with the start of Dementia Awareness Week 2010, which runs from September 16 - 26. For more information, visit www.alzheimers.org.au > NSW.

Dementia Awareness Week is supported by Ageing, Disability and Home Care, Department of Human Services NSW, and Home and Community Care (HACC).

Alzheimer’s Australia NSW is the peak body for people with dementia and their families and carers. It provides advocacy, support services, education and information.

National Dementia Helpline: 1800 100 500
(The National Dementia Helpline is an Australian Government Initiative)
Dementia is a National Health Priority www.alzheimers.org.au

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Addressing the Stigma associated with Dementia Discussion Paper

Key Recommendations

- Australian Government develop and fund National Dementia Awareness Campaign to increase understanding of dementia to decrease stigma
- Australian and NSW Governments fund social inclusion initiatives such as leisure and access programs that recognise the retained abilities of people with dementia and enable them and their carers to participate in mainstream community life
- The Australian Government amends aged care legislation to include enforceable quality dementia care standards, such as those developed by Alzheimer’s Australia, which can be applied across aged care services
- The Australian and NSW Governments fund programs for early diagnosis and timely referral to dementia support services to avoid the impact stigma has in delaying access to diagnosis and medical support
- The Australian and NSW Governments fund and support dementia-specific education and training for all personnel working in dementia care services to reduce prejudice and stereotyping amongst dementia care workers
- The Australian Government invest in further social research into the effect of stigma on the lives of people living with dementia, their carers and families

What is dementia?
Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person’s cognitive ability. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and physical functioning. Alzheimer’s disease is the most common type of dementia, accounting for between 50 – 70% of all dementia cases.

Dementia can happen to anybody, but it is more common after the age of 65. However, people in their 40s and 50s can also have dementia.

Dementia is fatal and, as yet, there is no cure. It is not a normal part of ageing.

Dementia is the third¹ leading cause of death in Australia, after heart disease and stroke.

An estimated 257,000² Australians currently live with dementia. Without a significant medical breakthrough, that is expected to soar to almost 1 million by 2050.

¹ Causes of Death, Australia 2008 – Australian Bureau of Statistics, March 2010
² Caring Places: Planning for Aged Care and Dementia 2010 – 2050, Access Economics, July 2010