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Committee Secretary
House of Representatives Standing Committee on Health & Ageing
PO Box 6100
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Dear Committee Secretary

Inquiry into Dementia: Early diagnosis and Intervention

Thank you for providing Pfizer Australia with the opportunity to contribute to the House of Representatives Standing Committee on Health and Ageing inquiry into *Dementia: Early diagnosis and Intervention*.

Pfizer Australia¹ is the nation's leading pharmaceutical company, employing approximately 1,600 colleagues. Since 1849, Pfizer has been dedicated to discovering and developing new, and better, ways to prevent and treat disease and improve the health and quality of life for people around the world. Pfizer manufactures innovative and generic medicines in Australia and overseas. Pfizer Australia is the sponsor of the anti-dementia medicine² donepezil (Aricept[®]), which has been listed on the Pharmaceutical Benefits Schedule for the treatment of mild to moderately severe Alzheimer's disease since 2002.³ Pfizer remains committed to the development of novel and innovative medicines and vaccines for Alzheimer's disease.⁴

The government has recently released their comprehensive report, *Living Longer. Living Better.*, which recognises one of the challenges facing the aged care system and the ageing population, is the complex management arrangements for dementia and the increasing prevalence of the disease. A number of key initiatives to improve the lives not only of those individuals with dementia, but also their carers, are included in the report. We commend the Government for their report and the recognition that dementia should be considered as a National Health Priority⁵.

Dementia is a progressive condition with multiple causes, for which there is presently no cure. Alzheimer's disease and other causes of dementia result in impaired memory, thinking and behaviour. Alzheimer's disease accounts for the majority of dementia cases, approximately 70%. Dementia, and therefore Alzheimer's disease, is recognised as a national epidemic⁶.

¹ This submission has been prepared by Pfizer Australia – a wholly owned subsidiary of Pfizer Inc., based in New York. Pfizer Australia is a member of Medicines Australia – the peak industry body for the innovative medicines industry in Australia.

² Defined by WHO Body System Classification, NO6D www.pbs.gov.au

³ Other medicines PBS listed for the treatment of mild to moderately severe Alzheimer's disease are galantamine and rivastigmine.

⁴ Pfizer's pipeline includes several molecules in Phase 1, a vaccine in Phase 2 and a beta amyloid inhibitor in Phase 3 testing, representing the range of research into a complex and complicated disease area. For more information see www.pfizer.com/research/product_pipeline/product_pipeline.jsp

⁵ Standing Council on Health. (2012). *Communique 27th April 2012*. Retrieved from [http://www.health.gov.au/internet/main/publishing.nsf/Content/26D7A8371CE29ED4CA2579ED002047B9/\\$File/120427.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/26D7A8371CE29ED4CA2579ED002047B9/$File/120427.pdf)

⁶ Commonwealth of Australia. (2012). *Living Longer. Living Better*. Retrieved from [http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA2578620005D57ACA2579E2007B9DFC/\\$File/D0769-Living-Longer-Living-Better-200412.pdf](http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA2578620005D57ACA2579E2007B9DFC/$File/D0769-Living-Longer-Living-Better-200412.pdf)

In 2011 it was estimated that 266,574 Australians had dementia, with this figure expected to double by 2030 (553,285), increasing to 942,624 affected individuals by 2050⁷. This is consistent with international estimates, with dementia recognised as a global public health challenge as populations' age⁸.

Dementia is often overwhelming not just for individuals but for their families and caregivers; it is estimated that while there are 260,000 Australians with dementia there are over 1.2 million caregivers. This represents not only a significant health and medical challenge but also an increasing social and economic challenge for communities and governments. The current cost of dementia care in Australia is \$6 billion per annum and as more people develop dementia, the cost to Australia is estimated to grow to \$83 billion by the 2060s⁹.

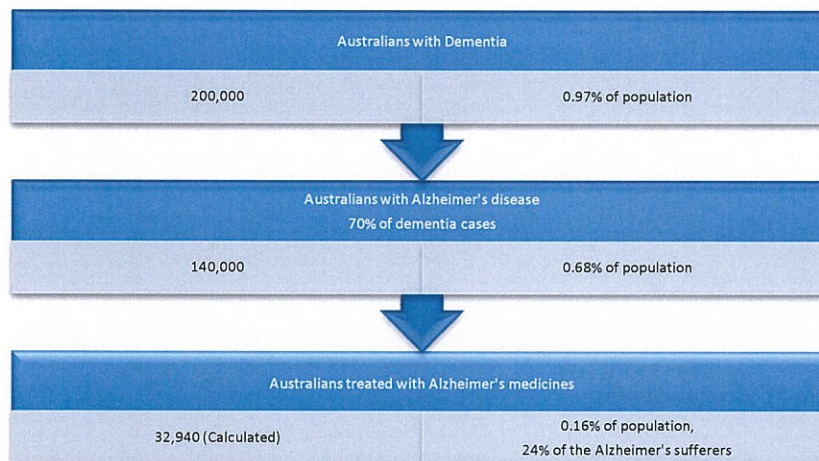
Our submission focuses on the issue of *support for more timely diagnosis*, with the flow-on benefits to sufferers and their families and carers.

There is a need for greater community awareness

Dementia has been incorrectly regarded as a natural part of ageing. The level of understanding and awareness of the disease amongst the general community is very low. The *Dementia is Everybody's Business* Health Report¹⁰, published in 2011, highlighted the need for more awareness about the impact of dementia in the community. While most Australians associate dementia with memory loss, they are still unclear about how common dementia is or what other symptoms are associated with dementia. While dementia is the third leading cause of death in Australia, only 1 in 5 Australians is aware that dementia is a progressive illness and sufferers experience a reduced life expectancy. Approximately 63% of Australians fear getting Alzheimer's disease or another form of dementia, this is second only to the fear of having cancer (reported by 66% of respondents)¹¹.

A study¹² of the utilisation of medicines to treat Alzheimer's disease in Australia highlighted the low diagnosis rates, as illustrated by Figure 1 below.

Figure 1 Estimated number of Australians receiving pharmacotherapy for Alzheimer's



⁷ Deloitte Access Economics. (2011). *Dementia Across Australia 2011-2050*. Retrieved from

http://www.fightdementia.org.au/common/files/NAT/20111014_Nat_Access_DemAcrossAust.pdf

⁸ World Health Organisation and Alzheimer's Disease International. (2012). *Dementia: A Public Health Priority*. Retrieved from www.who.int/publications/2012/9789241564458_eng.pdf

⁹ Fight Alzheimer's Save Australia. (2012). *Media Release: Australia dementia research is falling behind*, 4 April 2012. Retrieved from www.fightdementia.org.au/common/files/NAT/20120403_Nat_MR_DemResearchFallingBehind.pdf

¹⁰ 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.

¹¹ Pfizer Health Report. (2011). *Issue 45: Dementia is Everybody's Business*. Retrieved from

http://www.fightdementia.org.au/common/files/NAT/20110314_Nat_report_Pfizer-Health-Report-2011.pdf

¹² Hollingworth S, Byrne G. (2011). *Prescribing trends in cognition enhancing drugs in Australia*. *International Psychogeriatric*, 23:2, 238-45.

The rate of treatment for Alzheimer's is probably lower than 24%, reported in Figure 1, with some estimates indicating the rate of treatment could be as low as 16.5%. The hypothesis behind the low treatment rate is that insufficient access to diagnostic and treatment services, complex prescribing rules for anti-dementia medications and negative perceptions about the efficacy of these medicines contribute to a low treatment rate in this population¹³.

Greater access to information and a better understanding of dementia should increase help-seeking and help-giving and promote awareness of the lifestyle changes that may reduce the risk of dementia. This would encourage diagnosis and intervention as early as possible for individuals who are suspected to be suffering from dementia. It is essential in any health related condition that a diagnosis is followed by the appropriate support for the individual and their family/carer not only from healthcare professionals but also any social, housing and medico-legal issues which may arise. It is important to ensure that awareness-raising and support is not limited to the pre-diagnosis and diagnosis stage.

The Alzheimer's Society UK ran a successful *Worried about your memory?* awareness campaign spanning public, GP clinics and pharmacy environments in 2008 which increased patient referral to GPs.¹⁴ The Department of Health in the United Kingdom supported the campaign as part of their commitment to a National Dementia Strategy, where raising public awareness and increasing rates of diagnosis were big recommendations. In relation to the committee's terms of reference on raising community awareness of dementia and dementia-related services, we would like to draw the Committee's attention to the 2012 WHO and ADI *Dementia: A Public Health Priority* report which provides case studies of awareness campaigns across the world including Japan, UK and Brazil.¹⁵ The WHO review identified these key tenets for dementia awareness-raising campaigns:

- raising public awareness and understanding of dementia;
- reducing the stigma of dementia and challenging discriminatory behaviour;
- recognising the early signs of dementia to aid early diagnosis;
- living well with dementia;
- the importance of a healthy lifestyle and reducing risk.

In Australia Pfizer has supported the dementia awareness activities of Alzheimer's Australia over the last 12 years. These activities have generated significant information sharing and awareness-raising across a broad cross-section of the population. We believe there needs to be a national communication strategy in Australia which addresses the objectives put forward above, and involves a broad range of stakeholders including Alzheimer's Australia.

Raising community awareness will open avenues for disease support and management for patients and break down the stigma sometimes associated with the disease. It will provide caregivers and families helpful information and opportunities to seek assistance.

Access to early diagnosis, intervention and treatment

There is presently no cure for dementia, however early diagnosis and intervention have the capacity to provide benefits for patients, carers and the community.

An early diagnosis of dementia gives the individual and their family 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. An early diagnosis can also help in providing much needed access to services and medicines to help maintain function and quality of life in some people. When dementia services are accessed early, they can potentially avoid "emergency" admissions to nursing homes by providing caregivers with the necessary information and support to facilitate care in the community.

In 2004 the Australian Institute of Health and Welfare reported that in nursing homes almost 96% of residents requiring the two highest levels of care were those individuals with probable or possible dementia.

¹³ Hollingworth SA, Byrne GJ. (2011). *Prescribing trends in cognition enhancing drugs in Australia*. International Psychogeriatric, 23:2, 238-245.

¹⁴ Alzheimer's Society Memory campaign boosts dementia diagnosis, April 2009. www.alzheimers.org.uk/site/scripts/news_article.php?newsID=446

¹⁵ World Health Organisation and Alzheimer's Disease International. (2012). *Dementia: A Public Health Priority*. Retrieved from www.who.int/publications/2012/9789241564458_eng.pdf

Of all the residents in nursing home care approximately 80% were classified as having dementia.¹⁶ If the average onset of Alzheimer's disease could be delayed by even 5 months, starting

In response to a review by the Productivity Commission review in 2005 it was reported that if the average onset of Alzheimer's disease could be delayed by even 5 months, starting, in 2005, then by 2020 \$1.3 billion dollars would be saved.¹⁷ Clearly, reducing the prevalence or delaying the onset of Alzheimer's disease would be very important in reducing the impact of the disease, both financially and on individuals.

Since the introduction of the first cholinesterase inhibitor in 1997, most clinicians and probably most patients would consider the cholinergic drugs, donepezil, galantamine and rivastigmine, to be the first line pharmacotherapy for mild to moderate Alzheimer's disease.¹⁸ This supports the recommendations by the Pharmaceutical Benefits Advisory Committee to list donepezil, galantamine and rivastigmine on the PBS for the treatment of Alzheimer's disease diagnosed as mild to moderately severe.

To quantify the benefits to individuals and their caregivers a 2004 study¹⁹ demonstrated that those individuals receiving no active treatment required almost 2 hours more care per day after one year of follow-up, whereas those individuals receiving donepezil required almost 45 minutes of extra care per day. This highlights not only the benefits to the sufferer of active treatment but also the benefits to caregiver. Although the patients receiving treatment did not show an improvement in care required, there is clearly a case for a delay or slowing in the inevitable burden of disease with a progressive illness such as dementia and more specifically Alzheimer's disease.

An Australian study²⁰ has shown the persistence and adherence to the anti-Alzheimer's medicines are reasonable (57.3% and 79.4%) once treatment was established; prompting the authors to conclude there was an unexpectedly high continuation rate beyond the initial six months of treatment.

The physical and emotional demands of caring for someone with dementia can be high. As the disease progresses, and the patient remains in the community, an increasing amount of time is spent by the caregiver²¹, often at the expense of their own health²², well-being and finances²³. A general study in 1999²⁴ concluded that elderly caregivers who reported strain in caring for their disabled partner experienced a significantly higher risk of mortality than elderly participants whose spouses were not disabled, effectively *caregivers who report strain associated with caregiving are more likely to die than noncaregiving controls*.

A timely diagnosis helps facilitate access for caregivers to different types of support programs, respite care and access to financial support. It is essential to ensure there is reasonable and equitable access to diagnostic services, the best treatment management options, the appropriate healthcare professionals, respite care, home assistance and nursing homes, for example. The ability to provide an early diagnosis and appropriate disease management is clearly changing with the advances in care, the recognition of the value of a multi-disciplinary team approach and this will need to be balanced in view of the increasing prevalence of dementia in Australia. Any roadmap for the management of aged care and more specifically dementia must include recognition of the need for the appropriate infrastructure to support delivery of existing and innovative management options.

¹⁶ Australian Institute of Health and Welfare 2004. The impact of dementia on the health and aged care systems. AIHW Cat. No. AGE 37. Canberra: AIHW. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442454088>

¹⁷ *Delaying the Onset of Alzheimer's Disease: Projections and Issues*, Access Economics, August 2004.

¹⁸ Birks J. (2006). *Cholinesterase inhibitors for Alzheimer's disease*. Cochrane Database of Systematic Reviews 2006, 1: CD005593. Retrieved from: <http://summaries.cochrane.org/CD005593/cholinesterase-inhibitors-cheis-donepezil-galantamine-and-rivastigmine-are-efficacious-for-mild-to-moderate-alzheimers-disease>

¹⁹ Wimo A, Winblad B, Shah SN, Chin W, et al. (2004). *Impact of donepezil treatment for Alzheimer's disease on caregiver time*. Current Medical Research and Opinions, 20, 8:1221-1225.

²⁰ Le Couteur DG, Robinson M, Leverton A, et al. (2011). *Adherence, persistence and continuation with cholinesterase inhibitors in Alzheimer's disease*. Australasian Journal of Ageing, published online 4 Sep 2011.

²¹ Wimo A, von Strauss E, Nordberg G, et al. (1994). *Time spent on informal and formal caregiving for persons with dementia*. Gerontologist, 34:199-205.

²² Schulz R, O'Brien AT, Boolwala J, et al. (1995). *Psychiatric and physical morbidity effect of dementia on caregiving: prevalence, correlates, and causes*. Gerontologist, 35:771-91.

²³ Stommel M, Collins CE, Given BA. (1994). *The costs of family contributions to the care of persons with dementia*. Gerontologist, 34:199-205.

²⁴ Schulz RS, Beach SR. (1999). *Caregiving as a Risk Factor for Mortality: The Caregiver Health Effect Study*. Journal American Medical Association, 282:2215-2219.

However access to a diagnosis isn't always easy. Often this is the first step in a potentially long and complicated journey for individuals to access post-diagnosis services, services which ensure the benefits of early diagnosis are realised. In Australia, symptoms of dementia were noticed by families on average of 1.9 years prior to the first health professional consultation and there was an average of 3.1 years before a firm diagnosis was made.²⁵

The 2011 *Dementia is Everybody's Business* Health Report reported that 16% of Australians know someone who might have dementia who has not sought diagnosis or treatment.²⁶ Amongst carers this figure rises to 41%. There is a stigma and fear associated with dementia, leading to an aversion by some in the community to actively seek a diagnosis.²⁷

Further, in the absence of a treatment that can reverse the underlying pathological process some doctors remain reluctant to offer a diagnosis to patients.²⁸ This further limits access to services and medication that can be used to help treat the symptoms and make a difference to the lives of people with dementia and their families.

Access to early diagnosis and treatment is crucial to helping patients maintain their ability to perform activities of daily living for longer. This also has very important implications for families who devote time and resources to caring for a loved one.

The community, through its governments and health systems, should work to reduce barriers to diagnosis and treatment.

Treatment advances are needed

Currently around 260,000 Australians are estimated to have dementia and unless an effective prevention or cure is discovered, that number will grow to almost one million by 2050²⁹. Current medicines treat symptoms rather than the disease. More needs to be done.

Pfizer continues to invest in the research and development necessary to advance the treatment and/or prevention of Alzheimer's disease and neurological and neurodegenerative disorders.

Discovery, innovation and the development of medicines is high risk and resource intensive with thousands of promising compounds investigated to bring only one or two innovative treatments to patients who need them. It routinely requires a decade to get a new medicine to patients.

The Government has committed to the significant investments in the health and aged care sector in response to the growing prevalence of dementia within the setting of an ageing population. As part of this system reform we urge government to be mindful of medical advances and the role they play in the public health, social and fiscal challenges that dementia presents. Ensuring access to treatment is timely and equitable is compassionate, efficient and effective. Early diagnosis and intervention as central tenets to ensuring long-term quality of life of dementia sufferers, their families and carers and to the broader community is clear from the terms of reference the committee is considering.

Pfizer Australia thanks the Committee for the opportunity to contribute to this inquiry. Pfizer is available at any time to provide further information if it would assist the Committee.

Yours faithfully

John Latham

²⁵ Timely Diagnosis of Dementia: Can we do better? A report for Alzheimer's Australia, Paper 24, Philipps J, Pond D, Goode S, 2011

²⁶ Pfizer Health Report. (2011). *Issue 45: Dementia is Everybody's Business*.

²⁷ Pfizer Health Report 2011 found that 44% of people interviewed believe people with Alzheimer's disease or other forms of dementia are discriminated against or unfairly treated, whereas 56% of carers believe there is discrimination.

²⁸ Hansen EC, Hughes C, Routley G, Robinson AL. (2008). *General practitioners' experiences and understandings of diagnosing dementia: factors impacting on early diagnosis*. *Social Science and Medicine*, 67:11, 1776-1783.

²⁹ Deloitte Access Economics. (2011). *Dementia Across Australia 2011-2050*.

www.fightdementia.org.au/common/files/NAT/20111014_Nat_Access_DemAcrossAust.pdf