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**SUBMISSION TO THE PRIMARY HEALTH
CARE ADVISORY GROUP**

**Discussion paper: Better outcomes for
people with chronic and complex health
conditions through primary health care**

SEPTEMBER 2015

EXECUTIVE SUMMARY

This submission from Alzheimer's Australia is made in response to the Primary Health Care Advisory Group (PHCAG) August 2015 discussion paper, *Better outcomes for people with chronic and complex health conditions through primary health care*.

Alzheimer's Australia is strongly supportive of an enhanced role for primary health care in chronic disease, and urges the PHCAG to include consideration of dementia in any strategies that are developed to better manage chronic conditions in the primary health care setting.

The care and support of people with dementia is one of the largest health care challenges facing Australia. It is estimated that there are now more than 340,000 Australians living with dementia¹ and over a million people involved in their care². By 2050 there will be nearly 900,000 people with dementia³. Each week there are 1,800 new cases of dementia in Australia, and this is expected to increase to 7,400 new cases each week by 2050⁴.

Dementia has an enormous impact on the health and aged care system, with the cost of dementia to these sectors calculated to be at least \$4.9 billion per annum⁵. Dementia also has a profound social impact. People with dementia experience stigma and social isolation⁶, and family carers often find it difficult to balance work, life and caring responsibilities⁷.

Many of us will be diagnosed with dementia over the years ahead, or will have loved ones faced with the diagnosis. As our population ages, and as more of us survive the diseases of mid-life, more of us – both in terms of raw numbers, and as a proportion of the population – will experience dementia. The Framingham Study has found that for those of us who reach the age of 65 without having developed dementia, the risk we have of developing dementia in our remaining lifespan is 20% for women and 17% for men⁸. The higher lifetime risk for women is mainly due to women's longer life expectancy.

So in broad terms, one out of every five of us who survive to late middle age can expect to develop dementia, and even more of us will be involved in the care of family members or other loved ones with dementia.

We all need to know that our social, health, and aged care systems will be ready and able to respond, and that we as a society can achieve the best possible quality of life for people with dementia and their carers, at a cost that is affordable to us as a country.

¹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

² Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

³ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁴ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁶ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

⁷ Brodaty & Green (2002) *Who cares for the carer? The forgotten patient*

⁸ Sehadi S, Belser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB et al, The lifetime risk of stroke: Estimates from the Framingham Study. *Stroke*, 2006; 37 (2):345-50; cited in Alzheimer's Association (USA) 2013 *Alzheimer's Disease Facts and Figures* p 19. www.alz.org/downloads/facts_figures_2013.pdf

To achieve this we urgently need a national strategy for dementia that will prepare us for the challenges of the coming decades. This strategy needs to encompass:

- Greater effort to promote awareness of the risk factors for dementia and risk reduction, so that fewer people develop dementia.
- Timely diagnosis and post-diagnostic support, including early intervention, so that people can live successfully in the community for longer, and admissions to aged and acute care facilities are delayed or avoided.
- Effective education and training for health professionals and others working in the field.
- Improved carer support and respite, so that the experience of carers is improved, and carers can continue to participate socially and economically.
- Better access to ongoing support and treatment services, so that the journey for people with dementia, and their carers, is improved.
- Better access to end of life palliative care.
- Increased investment in dementia research, with emphasis on translational research and consumer involvement in all aspects of dementia research in Australia.

Primary health care professionals have a critical role to play in timely diagnosis and treatment of dementia, and primary health care must be a key part of the national strategy for dementia. Supporting primary health care professionals, particularly GPs and primary health care nurses, to deliver timely diagnosis, and effective referral and ongoing care, is a sustainable and cost-effective means of improving the journey for people with dementia and their carers.

Alzheimer's Australia recommends that the PHCAG include consideration of dementia as a core element of approaches to improve outcomes for people with chronic and complex conditions through primary health care; and that the PHCAG consider strategies to achieve better management of dementia in primary health care, as outlined in this submission. These strategies encompass:

- Improved payment mechanisms to support diagnosis and management of dementia in primary health care.
- Improved education and training on dementia for primary health care professionals.
- Greater utilisation of primary health care nurses and specialist nurses for dementia management, in the multidisciplinary primary health care team context.
- Better access to specialist dementia services.
- Development and promotion of contextualised primary health care referral pathways.
- Improved care co-ordination.

Alzheimer's Australia also recommends that the PHCAG consider two issues which are not covered in detail in the discussion paper:

- The role of primary health care in prevention and risk factor reduction in relation to chronic disease. This is an important issue for dementia and for other chronic diseases, and the primary health care system potentially has an important role in prevention, which is not currently being optimised.
- The role of consumers in guiding health reform and service delivery (consumer-directed care), and the importance of measuring and responding to the patient experience in addition to measuring and responding to clinical outcomes.

CONTEXT: ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the national peak body representing people with dementia and their families and carers. Our vision is for a society committed to the prevention of dementia, while valuing and supporting people living with dementia.

Alzheimer's Australia represents and supports the more than 340,000 Australians living with dementia, and the more than one million family members and others involved in their care⁹. Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information.

Alzheimer's Australia is a member of Alzheimer's Disease International, the umbrella organisation of Alzheimer's associations across the world. Alzheimer's Australia also represents, at national level, the interests of its federation of state and territory members, on all matters relating to people with dementia and their carers.

Our organisation advocates on the basis of evidence-based policy, promotes awareness of dementia, delivers national projects and programs under contract from the Commonwealth, and provides research grants to emerging researchers. We are committed to a strong consumer focus and have a number of consumer advisory mechanisms, which actively seek and represent the voice of people with dementia themselves, as well as carers. We participate on many Ministerial and Departmental Committees, and contribute to consultation forums and advisory groups. We are also a sponsoring member of the National Aged Care Alliance and are involved in other key groups progressing aged care reforms including the Aged Care Sector Committee and the Aged Care Quality Advisory Council.

We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

KEY ISSUES: THE ROLE OF PRIMARY HEALTH CARE IN DEMENTIA

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. It is a terminal and devastating condition that robs people of their abilities and memories.¹⁰ It is cloaked in stigma and misunderstanding,¹¹ isolates people with dementia and their carers from social networks,¹² and carries significant social and economic consequences.¹³

Traditional responses to dementia based on residential care are becoming unsustainable due to high and steadily growing service demands. In addition, changes in community expectations are

⁹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

¹⁰ Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.

¹¹ George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-7

¹² Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

¹³ Access Economics (2003). *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia. Available: www.fightdementia.org.au/research-publications/access-economics-reports.aspx

creating greater demand for community based, consumer-driven models of support and a broader range of specialist services, with 70% of people with dementia choosing to remain living at home¹⁴.

General practice is the first point of contact for people with dementia, and the primary health care system is responsible for the bulk of their ongoing medical management and care throughout the 5-15 years of the dementia journey. 94% of Australians indicate that they would see their General Practitioner (GP) if they were worried about their memory¹⁵, and appropriate assessment, referral and management of these individuals from the first point of contact is essential to achieve optimal health outcomes. Health economics analyses also suggest savings to health and aged care budgets from early diagnosis and quality medical care¹⁶.

Issues relating to assessment and diagnosis of dementia in primary health care

There are clear benefits to early diagnosis¹⁷ and management of dementia, yet as many as two thirds of people with dementia live and die with the condition without ever being diagnosed.¹⁸ Amongst the minority who do receive a diagnosis, the average time between first symptoms and diagnosis is 3.1 years¹⁹. As a consequence of non- and late-diagnosis, the majority of people with dementia and their families in Australia slip through the gaps and miss out on crucial opportunities for early intervention in the form of treatment, support, advance planning and understanding of their condition²⁰.

Thorough assessment and accurate diagnosis of dementia requires the attention and time of experienced and trained healthcare professionals. GPs are the first point of contact for people concerned about their memory as well as people with unrecognised signs who present for other health reasons. Consequently, they should ideally offer interventions including: identification of dementia symptoms; undertaking appropriate assessment; making provisional diagnosis where possible; referring to specialist services if uncertain about symptoms and to confirm provisional diagnoses; providing ongoing medical management of the condition; and referring to community services.²¹

Some of the major reasons behind non- and late-diagnosis of dementia in primary health care are:

- Many GPs (as well as nurses and allied health professionals) have difficulty differentiating normal ageing from early stages of dementia,²² and lack specific knowledge about

¹⁴ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

¹⁵ Market research conducted for Alzheimer's Australia by Newspoll. September, 2004.

¹⁶ World Alzheimer's Report. *The Benefits of Early Diagnosis and Intervention*. Alzheimer's Disease International, September, 2011.

¹⁷ Alzheimer's Australia uses the term early diagnosis in this submission to refer to a diagnosis as soon as possible after symptoms are brought to the attention of the health care system. Defined in this way, early diagnosis is similar to timely diagnosis, and Alzheimer's Australia supports the use of either term. It should be noted that the use of early diagnosis in this submission excludes diagnosis of pre-symptomatic Alzheimer's disease or other causes of dementia using biomarkers, as these are presently limited to the research domain.

¹⁸ Brodaty, H. (2005). *Six reasons why diagnosis of dementia does not occur, and 10 reasons why it is important*. Dementia Collaborative Research Centres. Available: www.dementia.unsw.edu.au

¹⁹ Speechly, C. (2008). The pathway to dementia diagnosis. *Medical Journal of Australia*, 189, 487-9

²⁰ Phillips, J., Pond, D., & Goode, S., (2011). *Early Diagnosis of Dementia: Can we do Better?* Alzheimer's Australia Paper No 24. Available: www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx

²¹ Phillips, J., Pond, D., & Shell, A. (2010). *No time like the present: The importance of a early diagnosis of dementia*. Alzheimer's Australia Quality Dementia Care Standards Series, Number 7. Available: www.fightdementia.org.au/research-publications/quality-dementia-care-papers.aspx

²² Brodaty, H., Howarth, G., Mant, A. & Kurrle, S. (2004). General practice and dementia: A national survey of Australian GPs. *Medical Journal of Australia*, 160(1), 10-14.

dementia assessment, management or appropriate referral pathways.²³ A significant percentage of GPs also consider assessment of cognitive symptoms to be the domain of specialists, or report reluctance to assess for dementia because of concerns about damaging the doctor-patient relationship, or because of incorrect perceptions that there is nothing that can be done and therefore no benefit of a diagnosis to the patient.²⁴

- Rigorous cognitive screening measures and assessment tools, as specified in clinical guidelines²⁵, are not routinely used by GPs²⁶, and as many as 90% of cases of early dementia are not detected on first contact with the primary care system²⁷.
- GPs may not be satisfied with existing screening measures. 93% of surveyed GPs are not satisfied with the Mini Mental Status Examination (MMSE; a widely used cognitive screening test that does not perform well in people with high or low education levels or from non-English speaking backgrounds²⁸), and indicated that they'd use brief screening tools – shorter than MMSE – if available.²⁹
- Many people in the community lack knowledge and understanding of dementia. When combined with the stigma surrounding dementia and a general belief that memory loss is a normal part of ageing³⁰, along with fear and denial, some people with early signs of memory loss or behavioural concerns delay seeking medical assessment until symptoms become serious, or until triggered by a crisis.

Obtaining a timely diagnosis of dementia can be even more difficult for people with younger onset dementia;³¹ those from culturally and linguistically diverse backgrounds and from Aboriginal and Torres Strait Islander communities;³² people with less common forms of dementia; and for those living alone or in regional or remote areas.³³

Issues relating to ongoing management of people with dementia in primary health care

Poor ongoing management of people with dementia in primary health care also occurs. Many GPs feel under-equipped to deal with post-diagnosis management of issues such as palliative care, behavioural and psychological symptoms of dementia, referral to services, and carer health and well-being³⁴.

²³ Turner, S., Iliffe, S., Downs, M., Wilcock, J., Bryan, M., Levin, E., Keady, J., & O'Carroll, R. (2004). General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age and Ageing*, 33(5), 461-67.

²⁴ Hansen, E., C., Hughes, C., Routley, G., & Robinson, A. (2008). General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis. *Social Science & Medicine*, 67(11), 1776-83

²⁵ Bridges-Webb, C. (2003). Care of patients with dementia in general practice Guidelines. RACGP.

²⁶ Milnea, A., Culverwella, A., Gussa, R., Tuppena, J., & Wheltona, R. (2008). Screening for dementia in primary care: A review of the use, efficacy and quality of measures. *International Psychogeriatrics*, 20(5), 911-26.

²⁷ Bond et al. (2005). Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey, *International Journal of Clinical Practice*; 59:s146

²⁸ Wind, A., Schellevis, F.G., Staveren, G., Van Scholten, R., Jonker, C. & Eijk, J. (1997). Limitations of the Mini-Mental State Examination in diagnosing dementia in general practice. *International Journal of Geriatric Psychiatry*, 12, 101-108.

²⁹ Bush, C., Kozak, J., & Elmslie, T. (1997). Screening for cognitive impairment in the elderly. *Canadian Family Physician*, 43, 1763-8.

³⁰ For example, a recent community survey found that 60% of respondents would feel ashamed if they or someone close to them was diagnosed with dementia. (Publication in preparation, University of Wollongong.)

³¹ Luscombe, G., Brodaty, H., & Freeth, S. (1998). Younger people with dementia: Diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry*, 13, 323-30.

³² Storey, J., Rudas, J., Conforti, D., & Dickson, H. (2004). The Rowland Universal Dementia Assessment Scale (RUDAS): a multicultural cognitive assessment scale. *International Psychogeriatrics*, 16(1), 13-31.

³³ Teel, C. S. (2004). Rural practitioners' experience in dementia diagnosis and treatment. *Ageing and Mental Health*, 8(5), 422-9.

³⁴ Bush, C., Kozak, J., & Elmslie, T. (1997). Screening for cognitive impairment in the elderly. *Canadian Family Physician*, 43, 1763-8.

Evidence shows that large numbers of people with dementia are missing out on potentially beneficial symptomatic medications,³⁵ are being over-prescribed potentially dangerous psychotropic medications (often as a blunt means of suppressing behavioural and psychological symptoms of dementia³⁶) and are at risk of unnecessary hospitalisations where they may receive invasive surgical or medical interventions that do little to improve quality of life or wellbeing.³⁷

There are many systemic barriers to best practice management of dementia in primary health care, including: insufficient training in dementia identification, assessment and management for primary care providers; a lack of guidelines and referral pathways to specialists for further assessment and diagnosis; inconsistent availability of and long waiting times for publicly funded specialist services such as memory clinics; a lack of funding for greater utilisation of primary health care nurses and specialist nurses in identification, assessment and post-diagnosis management of dementia; and a lack of clarity around appropriate Medicare items for different aspects of dementia assessment and management³⁸.

Potential benefits of improving dementia diagnosis and management in primary health care

Early diagnosis and intervention has the potential to improve the quality of life and assist people with dementia to remain independent as long as possible. Understanding the cause of the symptoms brings relief for many people in having an explanation. Assessment and treatment of reversible causes occurs in some cases, and although uncommon, is a first step that should be routine for all people with symptoms of cognitive impairment. More commonly, timely diagnosis allows access to community services and support networks, including through Alzheimer's Australia, when these can be most beneficial; as well as early access to potentially beneficial symptomatic Alzheimer's medications (cholinesterase inhibitors and memantine) that can assist some people to maintain their cognitive function for a period of time³⁹. There is also potential to reduce the risk of medication complications that may be exacerbated by undiagnosed early dementia (including the risks of exacerbated cognitive impairment from benzodiazepines and drugs with an anticholinergic load, and increased risk of delirium following anaesthesia.⁴⁰)

Timely diagnosis allows the opportunity to engage in a variety of lifestyle changes, including healthy diet and exercise, smoking cessation, and socially and mentally stimulating activities that may help to slow the progression of the disease, or to minimise the impact of cognitive, behavioural and psychological symptoms of dementia. It allows for opportunities to exercise choice by planning ahead for legal and financial matters, and for future medical care. It also allows the opportunity to implement important choices and life changes relating to family, employment, accommodation and social relationships before the dementia progresses; the opportunity, if desired, to take part in clinical trials of new dementia treatments or interventions, and the

³⁵ Bradford, A., Kunik, M., Schulz, P., Williams, S., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer's Disease and Associated Disorders*, 23(4), 306-14.

³⁶ Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: Time for action*. A report for the Minister of State for Care Services, UK Department of Health.

³⁷ Finucane, T. Et al (1999). Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA*, 282, 1365-70

³⁸ Department of Health and Ageing (2007). Draft Report on *Dementia in Primary Care*.

³⁹ Gautier, S., Cummings, J., Ballard, C., Brodaty, H., Grossberg, G., Robert, P., & Lyketsos, C. (2010). Management of behavioural problems in Alzheimer's disease. *International Psychogeriatrics*, 22(3), 346-72.

⁴⁰ Pratico, C., et al. (2005). Drugs of anesthesia acting on central cholinergic system may cause post-operative cognitive dysfunction and delirium. *Medical Hypotheses*, 65(5), 972-982.

opportunity to establish new social networks (through dementia support groups, for example) in order to minimise the stigma and social isolation that generally accompany a diagnosis of dementia.

Timely diagnosis may also reduce stress for the family carer through awareness and education of techniques to respond to behavioural and psychological symptoms of dementia that cause most difficulty to carers⁴¹, and which are experienced by over 90% of people with dementia at some stage during the course of their illness.⁴² Timely diagnosis allows the person with dementia and their carer the opportunity to work with healthcare providers, community organisations and family members to plan for changes in mobility, including the need to change driving habits, and eventually to cease driving⁴³, opportunities to plan for and establish processes to cater for changes in care needs over the course of dementia, including making a range of enabling alterations and modifications to home and environment, and preparing for a change in accommodation; the opportunity to establish a routine of planned respite to assist family carers to better manage the caring role, and consequently to help the person with dementia to remain living in the community for as long as possible; and the opportunity to ensure a better death for the person with dementia, and to ameliorate the associated grief for carers and family members through advance care planning and quality palliative care, starting with palliative care services and consultation shortly after the dementia diagnosis⁴⁴.

As well as improving the quality of life for people with dementia and their carers, better diagnosis and management of dementia in primary health care also has the potential to save costs to the health and aged care systems. Timely diagnosis, effective early intervention, and good care in the community including psychosocial support for people with dementia and their carers, can delay admissions to residential aged care facilities and enable people diagnosed with dementia to live in the community for longer, with better quality of life. Each year that a person can live in the community before being admitted to residential care offers significant savings to the health and aged care system, as well as benefits for the individual's quality of life.

Better management by primary health care professionals both for people with dementia living in the community, and for those in residential aged care, also has the potential to reduce avoidable hospital admissions. People with dementia are major users of hospital services, largely due to the fact that dementia is a chronic health condition, which most commonly affects older people who are more likely to have other chronic conditions. People with dementia generally have a longer length of stay within a hospital than other patients, leading to greater costs to the health system.⁴⁵ There are several reasons that people with dementia may end up in hospital unnecessarily, including limited availability of appropriate care in an alternative setting (particularly respite care), no or limited family support, lack of availability of medical services in the home, or a need for care whilst

⁴¹ Black, W. & Almeida, O. (2004). A systematic review of the association between the BPSD and burden of care. *International Psychogeriatrics*, 16(3), 295-315.

⁴² Brodaty, H., Draper, B. & Low, L-F. (2003). Behavioural and psychological symptoms of dementia: A seven-tiered model of service delivery. *Medical Journal of Australia*, 178(5), 231-4

⁴³ Gilley, D. W. et al. (1991). Cessation of driving and unsafe motor vehicle operation by dementia patients. *Archives of Internal Medicine*, 151(5), 941-6.

⁴⁴ Abbey, J. (2006). *Palliative care and dementia*. Alzheimer's Australia discussion paper 7. Available: www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx

⁴⁵ Australian Institute of Health and Welfare (2013) Dementia care in hospitals: costs and strategies.

awaiting admission to another care facility.⁴⁶ Effective programmes in the community and residential care can reduce unnecessary admissions to hospital; and dementia-focused programs in acute care can reduce length of hospital stay and associated expenditure.

Strategies to improve dementia diagnosis and management in primary health care

Strategies that should be considered to improve diagnosis and management of dementia in primary care include:

- **Appropriate payment mechanisms:** It is well recognised that the MBS fee-for-service payment system is not ideal for supporting management of chronic conditions in primary health care, and dementia is no exception. There are ways in which GPs can obtain appropriate remuneration for the time required to provide proper dementia assessment and ongoing management through the MBS⁴⁷, and some GPs do an excellent job of identifying symptoms, undertaking thorough physical and cognitive assessments, making provisional diagnoses, and referring to specialist services. Unfortunately however, many general practices do not perceive a sustainable business case to focus on this work. Incentives are needed for primary care providers to incorporate detailed assessment and management of cognitive impairment into sustainable business models.
- **Additional education and training for GPs and other primary health care professionals** is clearly required to improve identification and assessment of dementia symptoms in primary care, and management of dementia. Programs are currently under development aiming to increase confidence and capacity of general practitioners and primary health care teams to diagnose dementia, to facilitate greater linkages and integration between local primary care and specialist services, and to enhance networking between local health services and local social care services to assist people with dementia, their families and carers. Improved clinical guidelines and improved uptake of guidelines are also needed.
- **Greater involvement of General Practice Nurses, Aged Care Nurse Practitioners and other specialist nurses, including dementia CNCs,** should be encouraged. GPs work under time and financial constraints, and are in short supply in many parts of the country, particularly in rural and regional areas. As such, there is both a need and an opportunity to do more to improve identification, assessment and management of dementia by facilitating the involvement of appropriately trained and experienced nurses and other allied health professionals. This is also important because nurses and allied health professionals are often amongst the first to encounter people with early signs of dementia⁴⁸. To support the increased role of nurses it is necessary to develop and provide accredited training in these functions, and to ensure that appropriate specialist support is available.

⁴⁶ Australian Institute of Health and Welfare (2013) Dementia care in hospitals: costs and strategies.

⁴⁷ Abbey, J. (2006). *Palliative care and dementia*. Alzheimer's Australia discussion paper 7. Available: www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx

⁴⁸ Manthorpe, J., Iliffe, S., & Eden, A. (2003). Early recognition of dementia by nurses. *Journal of Advanced Nursing*, 44(2), 183-91.

- **Improved access to specialist dementia services** is needed, to support the ability of primary health care providers to diagnose and manage dementia in the community. Geriatricians, psychogeriatricians, neurologists, psychiatrists and clinical neuropsychologists all play an important role in assessing and diagnosing dementia. Moreover, access to symptomatic Alzheimer's medications in Australia is conditional upon confirmation of a diagnosis by a medical specialist. Specialist assessment and diagnosis of dementia is often provided by specialist memory clinics such as the Cognitive, Dementia and Memory Service (CDAMS) in Victoria. These multidisciplinary services bring together medical specialists with allied health professionals and play an essential role in diagnosis of cognitive symptoms, and referral to appropriate services, and have the skills and expertise to assess, diagnose and manage less common forms of dementia, including Younger Onset Dementia.
- **The development and promotion of contextualised primary care referral pathways** is also an important element. One of the major barriers to better assessment and management of dementia in primary care is the lack of referral from GPs to specialists to assist with the assessment of complex cases or confirm diagnosis, and health and community services to provide necessary support and management to people once diagnosed⁴⁹. Many of the benefits of early diagnosis will only flow if prompt referrals are made to care and support services to assist the person and with dementia and their family carer. Overcoming this barrier and assisting all GPs to appropriately refer patients with memory concerns will require the range of incentive and training strategies outlined previously, as well as the development and promotion of clear protocols for the assessment and referral of patients with dementia or suspected dementia.
- **Each person with a chronic and complex condition such as dementia should have an identified care co-ordinator** with expertise in their issues, available over time and across settings to assist the person and their carers to navigate the system (health care, community care, acute care, aged care, disability services, etc), and to make informed decisions in relation to their care.

What should we be working towards?

We should aim to improve assessment, diagnosis and management of dementia, and in so doing, to improve the quality of life and social, medical and care outcomes of people living with dementia and their families. Suggested outcome measures that may be considered include:

- A reduction in the average treatment gap from first symptoms to diagnosis from the current 3.1 years to 12 months over the next 5-10 years;
- Increased rates of dementia assessment and diagnosis in primary care (measurable, for example, through analysis of MBS data, or through increases in symptomatic Alzheimer's medication prescriptions);
- Increased community understanding and awareness of dementia to increase help-seeking and reduce stigma and discrimination (measurable through ongoing population surveys);

⁴⁹ *Ibid*, 11.

- Increased rates of referral (above the rate of dementia prevalence growth) of people with memory and related concerns to specialist medical, nursing and allied health services;
- Increased utilisation of dementia-specific community services, including services provided under the National Dementia Support Program;
- A reduction in the rate of prescription of antipsychotic medications to people with dementia (as endorsed, for example, by the National Health Service in the UK);
- An increase in the number of people with dementia who have in place formal advance health directives and related substitute decision making arrangements;
- A reduction in the rate of hospitalisations and inappropriate or 'heroic' interventions for people with dementia who have stipulated in advance that they do not want this to occur.

RESPONSES TO QUESTIONS IN THE PHCAG DISCUSSION PAPER

Note that the responses below specifically relate to the role of primary health care in diagnosis and management of dementia.

Question 1: What aspects of the primary health system work well for people with chronic and complex health conditions?

For people with dementia, access to general practice services funded through the MBS, and preferably in a bulk billing model, is important. Access to general practice services is currently believed to be good for most people, but exceptions include people living in areas of workforce shortage (particularly many rural, regional, and remote areas), and people living in residential aged care facilities.

A multidisciplinary approach to care, and particularly the involvement of nurses as well as GPs, has significant benefits as outlined earlier. Nurses can play an important role, for example in assessment of the person in their home context and in co-ordination of the person's care, including linking the person with a disability and the carer with community services. Primary health care nurses have frequent contact with older people in general practice and other health care and community settings; however, their role in relation to the assessment, diagnosis and management of dementia is not well defined and could potentially be expanded. Community health nurses/district nurses often play an important role in assessment and referral, in helping people with dementia to manage their condition and live safely in their own homes for longer, and in assisting with issues such as medication management. There is potential for this role to be broadened and better supported across the primary health care nursing profession (including general practice nurses), within the context of the primary health care team.

We are aware of models that have been developed locally, for example to improve engagement of general practice with residents of aged care facilities. One model utilises the general practice nurse to undertake initial assessment of residents following which the GP visits to work with the practice nurse and the staff of the aged care facility, to finalise and implement care plans. Given that the GP's time is a scarce and relatively expensive resource, any model which increases the involvement of nurses in a way which ensures safety and quality, is worthy of consideration.

Evidence-based care, promoted through guidelines, is also important. Work has been done to develop guidelines and approaches to promote best practice in dementia management in general practice. For example, the Royal Australian College of General Practitioners (RACGP) has developed a number of guidelines and clinical updates on dementia diagnosis and management⁵⁰, but as noted earlier it would appear that the uptake and implementation of these approaches is not optimal.

Question 2: What is the most serious gap in the primary health care system currently provided to people with chronic and complex conditions?

Some key problems are:

- MBS fee-for-service funding is geared to episodic care rather than long-term care, and long consultations for people with chronic conditions are not adequately incentivised given the high acuity level and complexity of treatment.
- There is fragmentation and poor communication between providers; and a lack of identified care co-ordinators and lack of funding for this role.
- There is inadequate engagement of general practice with residents in aged care facilities – better incentives are needed to increase participation by GPs and primary health care nurses in care provision in this setting. Better engagement would assist in reducing avoidable hospital admissions.

For people with dementia, as noted earlier there is a high level of non- and late-diagnosis which may be due partly to a lack of adequate and specific education and training on dementia for GPs and other primary health care professionals. There may also be a resistance by some GPs to providing a diagnosis of dementia due to the stigma attached to the disease, and the terminal nature of this disease to which there is no known cure. In addition, a comprehensive cognitive assessment is time consuming, and GPs may consider that they are not adequately remunerated for this time. Delays may also, of course, be due to the individual's reluctance to present for diagnosis. As a consequence of non- and late-diagnosis, many Australians with dementia and their families slip through the gaps and miss out on crucial opportunities for early intervention in the form of treatment, support, advance care planning and understanding of their condition. There are also, as noted earlier, gaps in the provision of ongoing management of people with dementia in primary health care.

Some potential strategies for addressing these issues might include:

- Embedding a systematic, competency-based approach to cognitive assessment in general practice. This should include the input of family members and carers to play a more prominent role in the assessment, diagnosis and management of dementia.
- Including cognitive assessment in the 75+ health assessment.
- Promoting home medicine reviews to check for medications that may cause or exacerbate cognitive impairment, and to ensure adequate management of current medication.

⁵⁰ For example: RACGP, *Guidelines for preventive activities in general practice*, 8th ed, Section 5.4, Dementia <http://www.racgp.org.au/your-practice/guidelines/redbook/preventive-activities-in-older-age/dementia/>; Pond D (2012) Dementia: An update on management. *Australian Family Physician*, 41(12), pp 936-939; Carmody D, Traynor V, Steele A (2015), Dementia, decision aids, and general practice *Australian Family Physician*, 54(5), pp 307-10.

- Developing clear referral pathways to specialist dementia services, that are accessible to all individuals regardless of financial situation or geographical location, once a concern about memory or cognition is identified by a GP or other primary health care professional.
- Providing education and support to enable primary health care nurses to play a greater role in assessing, diagnosing and managing dementia, as part of the primary health care team.

Question 3: Do you support patient enrolment with a health care home for people with chronic and complex health conditions?

It is vital to improve care co-ordination and continuity of care for people with dementia. Any health care home model needs to be developed in such a way that providers are not in any way incentivised to exclude the most complex patients with the highest needs, including many people with dementia and potential co-morbidities (ie no cherry picking). In fact there should be incentives for providers to enrol and provide appropriate services to these complex patients.

Question 4: What are the key aspects of effective co-ordinated patient care?

Each person with a chronic and complex condition such as dementia should have an identified care co-ordinator with expertise in their issues, available over time and across settings to assist the person and their carers to navigate the system (health care, community care, acute care, aged care, disability services, etc), and to make informed decisions to manage their care.

The Alzheimer’s Australia Younger Onset Dementia Key Worker Program is an excellent example of the difference such care co-ordination can make. The Key Worker provides person-centred care through a single-point, long term contact that can adapt to changing needs over time, and help the person and their carers navigate the system; and ensures the person with younger onset dementia and their family has a long term relationship of trust with a “real person”.

For consumers, the dementia journey begins with the first symptoms and should ideally proceed within 12 months to an early diagnosis and referral to services and support. However, early diagnosis and referral to services in and of themselves are not sufficient to ensure good outcomes for consumers. The dementia journey can cause massive upheaval and significant changes for the person with the condition and their families, and as well as a diagnosis and appropriate medical care, there is a need for consistent and ongoing information, support and advice, from the point of diagnosis until death, and including post-bereavement care.

Consumers indicate a strong preference for information from a real person rather than from extensive documentation. Furthermore, there is a very strong preference for this personal contact to be face-to-face where that is possible, rather than from a call centre.

The care co-ordinator for a person with dementia should provide support, advice and advocacy for the person with dementia and their family. The goal should be to link people to support and services early in diagnosis before they may actively seek out formal supports and to provide a continuity of support throughout the dementia journey. Individuals with dementia and their families should be referred to the care co-ordinator after diagnosis. The care co-ordinator would then assist in linking the person with dementia and their families to support groups, education and

information. The care co-ordinator may also provide information and support about advanced care planning, carer stress, and access to services such as respite

Such care co-ordinators could be nurses or allied health professionals (usually with a background in social work, psychology or occupational therapy) who have extensive knowledge of local services, and higher level training and experience in dementia care (for example, Masters level qualifications as offered in Australia by the University of Wollongong.⁵¹)

Alzheimer's Australia recommends a program be established to build up a critical mass of care co-ordinators for people with dementia, including through the development and endorsement of an accreditation program with appropriate competencies and professional development requirements.

In considering care co-ordination at a systems level, the new Primary Health Networks potentially have a critical role to play in areas such as:

- Ensuring co-ordination and collaboration between Commonwealth-funded and State/Territory funded services, across the health, aged care, and disability sectors in particular, to ensure that people with dementia and their carers have access to seamless, person-centred care and support services.
- Developing and promoting locally contextualised referral pathways for people with dementia or memory concerns, from front-line primary care to appropriate specialist and community services. The need for such pathways has been identified in consultation with consumers, service providers, clinicians, and experts, and has been recommended by at least two Australian reports in recent years⁵².

Question 5: How might the technology described in Theme 2 improve the way patients engage in and manage their own health care?

A comprehensive and reliable electronic health record which includes Advance Care Planning would help ensure decisions made by a person with dementia in the period following diagnosis can be acted upon, as their condition progresses and they may be unable to express their wishes.

There is also specific equipment and technology that is helpful for people with dementia. Examples include: electronic gadgets to help people find lost items such as keys or wallets; automatic pill dispensers that make a sound or a flash when it's time to take a medication; night lights and automatic lights; sensors that detect smoke, carbon monoxide, high or low temperatures, or gas; gadgets that indicate when someone might have fallen; sensors that detect if the front door has been left open; sensors that detect if someone has got out of bed at night and hasn't returned, or hasn't moved from their chair; alarm systems/call buttons when the person needs help; tracking devices to enable a lost person to be located. These sensors and alarms may alert an outside organisation through telecare arrangements. Such equipment can help people live more independently and remain living in their own home for longer, reduce risk of accidents, help improve confidence and quality of life, and reassure families and carers.

[http://www.innovationsindementia.org.uk/Getting%20equipped%20to%20tackle%20forgetfulness.](http://www.innovationsindementia.org.uk/Getting%20equipped%20to%20tackle%20forgetfulness)

⁵¹ See www.uow.edu.au/handbook/yr2012/pg/hbs/H12000014.html

⁵² KPMG (2011) *Dementia services pathways – an essential guide to effective service planning*. This report also refers to a NSW Health project making similar recommendations.

[pdf](#)). The key enablers would include the availability of funding for such equipment, and affordable access to external support arrangements through telecare.

Question 6: What enablers are needed to support an increased use of the technology described in Theme 2 of the Discussion Paper to improve team based care for people with chronic and complex health conditions?

A good eHealth record accessible by all providers would help ensure continuity of care for people with dementia – a key enabler is to require or incentivise uptake and participation in an integrated system by all providers, irrespective of setting (general practice, community health, pharmacy, acute care, residential aged care, etc).

Question 7: Reflecting on Theme 3, is it important to measure and report patient health outcomes?

Yes, but it is also important to measure and report on the patient health experience. Patients may receive good clinical care but may be unhappy with their care if it is not person-centred. Patients, including people with dementia, need to be consulted and their input and feedback should guide service provision models.

Question 8: To what extent should patients be responsible for their own health outcomes?

It is well demonstrated that poor health status is strongly correlated with socio-economic disadvantage and poor health literacy. Patients with the greatest health need, including but not limited to those with dementia, should be supported to participate in their own health care but should not be held accountable for their health outcomes in a punitive way.

Question 9: How should primary health care payment models support a connected care system?

MBS fee-for-service funding is geared to episodic care rather than long-term care, and long consultations for people with chronic conditions are not adequately incentivised given the high acuity level and complexity of treatment.

There is often fragmentation and poor communication between health care providers. The identification of care co-ordinators and funding through the MBS for this role would be of great assistance to people with dementia and their carers.

General practice providers should be incentivised to provide comprehensive and continuing care to people with dementia, and should have a role in care co-ordination with the rest of the health and aged care systems and with other services, such as disability services. This is likely to require a move from pure fee-for-service funding to at least a blended payments model, probably with elements of capitated funding and outcomes-based funding.

It is well recognised that engagement of general practice with residents in aged care facilities is often inadequate, and this contributes to costly hospitalisations. Better incentives are needed to

increase participation by GPs and primary health care nurses in care provision in this setting. Better engagement would assist in reducing avoidable hospital admissions.

General practice providers could be incentivised to keep people with dementia living successfully in the community for longer and to reduce avoidable admissions to hospital and residential aged care, through the provision of high quality, safe care and support in the community setting for the person with dementia and the carer.

Alzheimer's Australia supports the recommendations made by the Ministerial Dementia Advisory Group in 2012, proposing changes to the MBS to better support people with dementia to have access to timely diagnosis and effective management of dementia in primary care. These recommendations call on the Government to:

- Allow reimbursement through the MBS for time spent by health professionals assessing, diagnosing and managing dementia and consulting with carers.
- Add MBS item numbers for cognitive function assessment, using validated tools, to allow GPs and credentialed health professionals to conduct an assessment if they have concerns; and for general practice nurses to do in-home cognitive function assessment.
- Expand existing psychology MBS item numbers for neuropsychological testing of people who may have dementia.
- Modify MBS item numbers 348 and 350 to make them available to GPs for discussions with informants, both before and after diagnosis, including family members and carers.
- Modify MBS item number 707 to allow targeted examination and assessment of symptomatic changes in memory and thinking.
- Modify MBS item numbers 734–799 to recognise a carer as an important person who qualifies as a 'service provider' for case conferences, and allow the inclusion of someone (eg practice nurses, dementia link nurse from Medicare Local) in the role of case coordinator.

Other strategies that could be considered might include:

- Developing and implementing an accreditation program to allow specially trained GPs to confirm dementia diagnoses and prescribe symptomatic Alzheimer's medications (cholinesterase inhibitors and memantine), with provision of supplementary payments for a range of dementia services;
- Actively promoting wider and more effective use of existing MBS items such as health assessments, management plans and team care arrangements;
- Reviewing and where necessary revising MBS items to ensure that they can effectively support identification, assessment and management of dementia;
- Introducing additional MBS items where necessary; for example, to allow independent consultation with carers as part of a comprehensive assessment and management process;
- Increasing MBS incentives or rebates for the provision of primary care services in residential aged care facilities;
- Creating incentives for cognitive screening and assessment as part of the 75+ health assessment.

Question 10: What role could private health insurance have in managing people with chronic and complex health conditions, in primary care?

Private health insurers have a strong interest in programs that reduce preventable hospital admissions, and are increasingly investing in new models for management of chronic conditions.

As private health insurers have financial incentives to keep members out of hospital, they are well positioned to develop innovative programs to support their members with chronic and complex conditions in the community, including dementia. Several health insurers have well developed approaches and models for addressing the needs of their insured members with dementia⁵³.

It will be important however to ensure that we do not develop a two-tiered system, where people without private health insurance lack access to best practice models of dementia care.

Government could potentially partner with private health insurers in the development of innovative models, or purchase such programs for non-insured populations, with appropriate quality and safety assurance in place.

Other points:

- The PHCAG discussion paper does not deal with the role of primary health care in prevention and risk factor reduction in relation to chronic disease. These are important issues for dementia and for other chronic diseases, and the primary health care system potentially has an important role in prevention, which is not currently being optimised.
- The discussion paper does not fully address the role of consumers in guiding health reform and service delivery (consumer-directed care), or the importance of measuring and responding to the patient experience in addition to measuring and responding to clinical outcomes.

CONCLUSION

Dementia is one of the major chronic diseases of this century. The Government needs to implement a holistic plan to tackle dementia over the next decade and more, with a focus on providing appropriate services and supports and tackling the social isolation and stigma associated with dementia. This plan must include a comprehensive approach to improving quality of care and supporting people in the community, including through primary health care.

Building our capacity to address dementia now will save billions in lost productivity for years to come, as well as improving the quality of life of the millions of Australians who are in some way impacted by dementia.

This submission focuses on the role of primary health care in addressing dementia, in the context of a much-needed national dementia strategy. As outlined in the submission, there are currently

⁵³ For example, Bupa's approach is outlined at: <http://bupaagedcare.com.au/our-approach/Dementia-Hub/Dementia-Best-Practice>

significant barriers to timely diagnosis and optimal management of dementia in primary health care in Australia, and the submission recommends several strategies to address these barriers:

- Improved payment mechanisms to support diagnosis and management of dementia in primary care.
- Improved education and training on dementia for primary health care professionals.
- Greater utilisation of primary health care nurses and specialist nurses for dementia management, in the multidisciplinary primary health care team context.
- Better access to specialist dementia services.
- Development and promotion of contextualised primary health care referral pathways.
- Improved care co-ordination.

Alzheimer's Australia is hopeful that the work of the Primary Health Care Advisory Group will contribute to the development of a holistic and comprehensive response to dementia through a National Dementia Strategy that includes the role of primary health care, and is integrated into the national approach for addressing all chronic conditions.