

Mal

Submission No. 044

(Dementia)

Date: 02/05/2012



**House of Representatives Standing
Committee on Health and Ageing**

**Inquiry into Dementia: Early Diagnosis and
Intervention**

**Submission from Alzheimer's Australia
National Office**

2 May, 2012

Contents

1. Summary and Recommendations	3
1.1 Introduction	3
1.2 Overview.....	4
1.3 Recommendations	5
1.4 Objectives and outcomes	6
1.5 The consumer experience.....	7
2. Benefits of Early Dementia Diagnosis and Intervention.....	8
3. Barriers to Early Dementia Diagnosis and Intervention	10
3.1 Consumer level barriers	10
3.2 Primary care provider level barriers.....	11
3.3 Health system barriers	12
3.4 Service context barriers	12
4. Strategies to Achieve Early Diagnosis	14
4.1 Creating business incentives to encourage appropriate assessment and management of dementia in primary care.....	14
4.2 Involving practice nurses, nurse practitioners and specialist nurses in the assessment and management of dementia symptoms.....	15
4.3 Training and education for GPs and nurses	16
4.4 Improving access to specialists	17
4.5 Developing and promoting contextualised primary care referral pathways	18
5. Strategies to Improve Post-Diagnosis Intervention and Management	20
5.1 National awareness campaign	20
5.2 Community programs and information for consumers through the National Dementia Support Program.....	21
5.3 Dementia Link Worker program	22
5.4 Increase access to early diagnosis and intervention to diverse groups	23
5.5 Expansion of community and respite care and improved co-ordination between primary and community care.....	24
6. Preparing for the Future: Likely Developments in Early Diagnosis and Intervention.....	26
6.1 New diagnostic criteria and assessment technologies for Alzheimer's disease.	26
6.2 Dementia research funding	27
7. Conclusions	29
8. References	30

1. Summary and Recommendations

"I had trouble getting a diagnosis for my husband Brian. He has younger onset dementia. I was referred to a psychiatrist who said Brian could have Alzheimer's. But that they didn't want to diagnose young people with it, so they told him he had depression. My husband said 'I am not depressed' but they took no notice. Brian was given the wrong medication and denied access to services. If we want to keep people out of aged care and help them to stay at home longer we need the right diagnosis."

1.1 Introduction

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. There are 280,000 people living with dementia in Australia now, and there will be almost 1 million by mid-century.¹ It is a terminal and devastating condition that robs people of their abilities and memories.² It is cloaked in stigma and misunderstanding,³ isolates people with dementia and their carers from social networks,⁴ and carries significant societal and economic consequences.⁵ Almost 1.2 million people care for or provide support to people with dementia⁶ (165,000 of these as full-time primary carers⁷) and the total direct cost of dementia to the health and aged care systems exceeds \$6 billion per annum.⁸

General Practice is the first point of contact for people with dementia, and the primary 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 memory,⁹ 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 care.¹⁰

There are clear benefits of early diagnosis^a and management of dementia,¹¹ yet as many as two thirds of people with dementia live and die with the condition without ever being diagnosed.¹² Amongst the minority who do receive a diagnosis, the average time between first symptoms and diagnosis is 3.1 years.¹³ 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 condition.¹⁴

Poor assessment and diagnosis also leads to poor medical management.¹⁵ Evidence shows that large numbers of people with dementia are missing out on potentially beneficial symptomatic medications,¹⁶ are being over-prescribed potentially dangerous psychotropic medications (often as a blunt means of suppressing behavioural and psychological symptoms of dementia¹⁷) 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.¹⁸

^a 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.

Obtaining a early diagnosis of dementia is even more fraught for people with younger onset dementia;¹⁹ those from different cultural backgrounds and from Aboriginal and Torres Strait Islander communities;²⁰ people with less common forms of dementia; and for those living alone or in regional or remote areas.²¹

Clearly we need to do better. The Australian Government has recognised this fact by allocating additional funding to support early diagnosis and a number of dementia services as part of the ***Living Longer, Living Better*** aged care reform package. This Inquiry into Dementia: Early Diagnosis and Intervention by the House of Representatives Standing Committee on Health and Ageing now provides an important and well-timed opportunity to refine strategies and develop programs that will make best use of this new funding within the context of the health and aged care reform process.

The Inquiry also provides a vital opportunity to explore additional strategies to optimise the assessment, diagnosis and ongoing management of the 280,000 people with dementia in Australia now, and the many hundreds of thousands who will follow over the coming decades.

1.2 Overview

The terms of reference (TOR) for this Inquiry focus on how early diagnosis and intervention can improve social, medical and care outcomes for people living with dementia (TOR 1-3), and how best to improve community understanding of dementia and dementia-related services (TOR 4).

While early diagnosis and intervention can undoubtedly improve outcomes for people with dementia and their families, these improvements depend on overcoming significant structural and systemic barriers that prevent most people with dementia from receiving a diagnosis or intervention in the first place. These barriers exist at the levels of the consumer, the healthcare professional, health system, and service context, and range from general lack of awareness and understanding of dementia – a barrier recognised under TOR 4 – to lack of training and education, inadequate Medicare incentives, inconsistent access to specialist services, and many other barriers that aren't directly addressed by the TOR.

To assist the Committee to consider the full range of issues relevant to the identification, assessment, diagnosis and ongoing management of dementia, this submission will go beyond the stated terms of reference and discuss a range of issues and strategies for improving early diagnosis and ongoing management of dementia.

The submission is structured in five parts.

1. The benefits of early dementia diagnosis and intervention to the consumer, and the broader social and economic benefits to the health and aged care systems. (Section 2)
2. Barriers to better diagnosis and management at the levels of the consumer, the primary care provider, the health system and the service delivery context. (Section 3)
3. Strategies to achieve early diagnosis of dementia. (Section 4)
4. Strategies to improve post-diagnosis intervention and management. (Section 5)
5. Factors that will need to be considered in preparing for likely developments in the assessment and treatment of dementia in the future. (Section 6)

1.3 Recommendations

If early diagnosis and intervention is to become a reality, multiple strategies will be needed at local and national levels to address significant barriers across the primary health care system. The success of these strategies will depend on the implementation of healthcare and aged care reforms; in particular, access to specialist diagnostic services, the expansion of community and respite care services which will give people with dementia and their carers the support they need.

The submission concludes that:

- The current primary and health care system is failing in the early diagnosis of dementia and intervention.
- The barriers to early diagnosis are significant and complex.
- The potential benefits of early diagnosis are significant.
- There are multiple strategies to achieve early diagnosis.
- Critical to the realising the potential of early diagnosis are strategies to improve part diagnosis intervention and management.

Alzheimer's Australia recommends that the Australian Government:

- | | |
|--|------------------------|
| 1. Work with stakeholders to develop, trial and implement an accreditation program to allow specially trained GPs to confirm dementia diagnoses, prescribe symptomatic Alzheimer's medications, and receive supplementary payment for these and other services. | Section 4.1
Page 15 |
| 2. Promote wider use of existing MBS items for the assessment and management of dementia symptoms by GPs and Aged Care Nurse Practitioners. | Section 4.1
Page 15 |
| 3. Review existing MBS items and where necessary revise or create new items to ensure effective remuneration to support identification, assessment and management of dementia in primary care. | Section 4.1
Page 15 |
| 4. Create financial incentives to support cognitive screening as part of the 75+ health assessment, and to encourage dementia-related GP consultation in residential aged care. | Section 4.1
Page 15 |
| 5. Develop and implement an accredited training program and incentives to promote greater involvement of Practice Nurses, Aged Care Nurse Practitioners and other specialist nurses in dementia identification, assessment and management in primary care settings. | Section 4.2
Page 16 |
| 6. Commit to the development of dementia education and professional development programs for GPs and Specialist and Practice Nurses to improve rates of assessment and diagnosis of dementia in primary care and considers linking training for GPs to supplementary benefits. | Section 4.3
Page 17 |

7. Review with the states the costs and benefits different models of service delivery with the objective of improving access to publicly funded specialists and specialist memory clinics.	Section 4.4 Page 18
8. Work with key stakeholders to promote contextualised dementia primary care service pathways through the developing Medicare locals network and through existing specialist networks.	Section 4.5 Page 19
9. Funds Alzheimer's Australia to undertake a comprehensive dementia awareness campaign to increase community and professional understanding of dementia, and to reduce high levels of stigma and social isolation experienced by people with dementia and their carers	Section 5.1 Page 21
10. Increase funding in line with the increasing prevalence of dementia for services for people with dementia and their carers through the National Dementia Support Program administered by Alzheimer's Australia.	Section 5.2 Page 22
11. Implement a national key dementia worker program in the context of the health and aged care reforms.	Section 5.3 Page 23
12. Ensures that measures to achieve early dementia diagnosis and intervention are sensitive to the needs of diverse groups.	Section 5.4 Page 24
13. Give urgency to implementing respite care reforms including social engagement and activities for the person with dementia.	Section 5.5 Page 25
14. Prioritise funding for research into dementia in primary care in order to allow better assessment, and evidence-based interventions to support people with dementia and their carers living in the community.	Section 6.2 Page 28

1.4 Objectives and outcomes

The objective of these strategies and recommendations is 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 Medicare Benefits Scheme (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);
- 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.

1.5 The consumer experience

It is the people with dementia and their carers living with the condition today, and those who will be living with dementia in the future who stand to gain the most from early diagnosis and management of this devastating condition. To illustrate the human side of the many difficult issues covered in this submission, quotes from consumers are included throughout. These quotes have been expressed and recorded over the past decade during consultations and support activities conducted by Alzheimer’s Australia member organisations in their daily activities as consumer support and advocacy organisations. Some of these quotes appear in other publications; others do not. Where relevant, names have been changed to protect the identity of consumers.

“Part of the answer is early diagnosis. When the person has capacity to make directives for the family, they can make decisions for their own life.”

2. Benefits of Early Dementia Diagnosis and Intervention

“We went to the GP, then went straight to the geriatrician, then to Alzheimer’s Australia, and never looked back. AA said come along to the ‘living with memory loss’ course, and it started us on our journey.”

Early diagnosis and intervention has the potential to improve the quality of life and assist people with dementia remain independent as long as possible because:

- understanding the cause of the symptoms, and the relief for many people in having an explanation;
- assessment and possible treatment of reversible causes (uncommon, but a first step that should be routine for all people with symptoms of cognitive impairment);
- access to community services and support networks, including Alzheimer’s Australia when these can be most beneficial;
- 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 time;²²
- reducing 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.²³)
- the opportunity to engage in a variety of lifestyle changes, including healthy diet and exercise, smoking cessation, and engaging in 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;²⁴
- opportunities to exercise choice by planning ahead for legal and financial matters, and for future medical care;
- the opportunity to implement important choices and life changes relating to family, employment, accommodation and social relationships before the dementia progresses to advanced stages, or before a crisis point is reached that forces suboptimal decisions;
- the opportunity, if desired, to take part in clinical trials of new dementia treatments or interventions;
- the 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;
- reduced 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 carers,²⁵ and which are experienced by over 90% of people with dementia at some stage during the course of their illness;²⁶
- 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 driving;²⁷
- 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 the quality palliative care, starting with palliative care services and consultation shortly after the dementia diagnosis.²⁸

These potential benefits will only be realised if significant barriers are addressed across the health and care systems and in the wider community understanding of dementia.

3. Barriers to Early Dementia Diagnosis and Intervention

“My three main concerns are diagnosis, diagnosis, diagnosis...convincing GPs to diagnose and families to get it.”

Rigorous cognitive screening measures and assessment tools, as specified in clinical guidelines,²⁹ are not routinely used by GPs,³⁰ and as many as 90% of cases of early dementia are not detected on first contact with the primary care system.³¹ Australian research indicates that consumers first notice symptoms an average of 1.9 years before seeking medical assistance, and that on average a further 1.2 years go by before a diagnosis is made (an average of 3.1 years from first symptoms to diagnosis).³² This delay or ‘treatment gap’³³ is much longer than that of Europe, where the average time to diagnosis after symptoms are first noticed is 20 months.³⁴

Recent empirical studies and reviews of the literature on barriers to early diagnosis and management of dementia in primary care indicate that the key barriers to better practice can be grouped into four broad levels:^{35, 36}

1. Consumer level barriers;
2. Primary care provider level barriers;
3. Health system level barriers; and
4. Service context barriers.

3.1 Consumer level barriers

“We went to six doctors in 20 years. George died two years after he was finally diagnosed. People with dementia think there’s nothing wrong with them. They think ‘Its you!’”

Many people 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 ageing, some people with early signs of memory or behavioural concerns delay seeking medical assessment until symptoms become serious, or until triggered by a crisis (a serious fall, a car accident,³⁷ onset of severe BPSD,³⁸ or illness or injury to the primary carer for example.) Specific factors include:

- denial of or lack of awareness of problems on the part of the person with dementia or their carers;
- uncertainty about the symptoms, or about where to seek help;³⁹
- concerns about stigma, and not wanting to be labelled;^b
- a fear of detrimental consequences (losing a driver’s licence for example); and
- lack of confidence in GPs to appropriately diagnose the symptoms.⁴⁰

^b 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.)

3.2 Primary care provider level barriers

“Going for the initial appointment and tests, there is such a lack of understanding of the disease by GPs.”

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 perform functions 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.⁴¹

However, many GPs (as well as nurses and allied health professionals) have difficulty differentiating normal ageing from early stages of dementia,⁴² and lack specific knowledge about dementia assessment, management or appropriate referral pathways.⁴³ 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 nihilistic perceptions that there is nothing that can be done and therefore no benefit of a diagnosis to the patient.⁴⁴

There are also issues 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 backgrounds⁴⁵), and indicated that they'd use brief screening tools – shorter than MMSE – if available.⁴⁶ Many GPs also 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-being.⁴⁷

Specific barriers that stand in the way of better identification, assessment and management of patients with dementia by GPs and other primary healthcare workers include:

- lack of knowledge about dementia and lack of skills or confidence in assessing and diagnosing the condition at early stages (many GPs consider assessment of early symptoms to be a matter for specialists);⁴⁸
- a lack of time to undertake assessment;
- the incorrect belief that dementia is a natural part of ageing, or that there is no point diagnosing or disclosing a diagnosis because nothing can be done; and
- lack of knowledge and/or availability of appropriate referral and support pathways.⁴⁹

3.3 Health system barriers

“There is a lot of talk about hospitals, but the hospital is too late. We need a good [primary] health care system.”

Australia's primary care system is not currently structured in a way that is conducive to high quality assessment, diagnosis and management of dementia. Issues include a lack of processes to identify people with cognitive impairment in acute care (a first point of contact for many people with early signs and symptoms⁵⁰); a lack of business incentives for primary care providers to assess and appropriately manage patients with dementia (including issues around appropriateness of MBS items and remuneration levels); a lack of dementia specific training; a lack of promotion and support for appropriate screening and assessment measures; a lack of access to or utilisation of skilled practice nurses, nurse practitioners and clinical nurse consultants; and lack of established referral pathways to specialists who can make or confirm a diagnosis; and a lack of standard models of interdisciplinary care.⁵¹

Specifically, there is:

- Inadequate processes for identification or assessment of cognitive impairment in acute care in primary care;
- Insufficient training in dementia identification, assessment and management for primary care providers (including GPs and nurses and allied health professionals);
- 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 practice nurses and specialist nurses in identification, assessment and post-diagnosis management of dementia;
- A lack of clarity around appropriate Medicare items for different aspects of dementia assessment and management.⁵²

3.4 Service context barriers

“We found it a struggle just to get my mother diagnosed. Then she was put on a wait list. I did not know how neglected or isolated the Turkish community was until I experienced it. We need trained staff that can diagnose people from all backgrounds. I had to get the diagnosis done privately because I was confronted with a dead end wall.”

Australia's primary health care system encompasses over 25,000 practicing GPs, more than 10,000 practice nurses, and a patient-base of 23 million consumers from an enormous diversity of settings, geographies, cultures and backgrounds. The context in which primary care is delivered is consequently a significant determinant in the type and quality of care experienced by consumers.

The range of contextual factors that have a significant influence on early diagnosis and intervention include:

- **Geography** – there are very different challenges and opportunities regarding dementia assessment, diagnosis and management in urban, regional and remote areas, and in areas that are well serviced as opposed to poorly-serviced by specialist and community services;
- **Age of onset** – people with Younger Onset Dementia (YOD; onset of symptoms before the age of 65) report very significant challenges in having their symptoms appropriately assessed and diagnosed. In part, this is because YOD is rare (dementia prevalence amongst people 65 and under is 0.05%), and because symptoms are more likely to be atypical, meaning that people with YOD are often misdiagnosed. On the other hand, individuals with YOD are less likely to be told that problems are simply part of getting old, and given the different nature of the impact of dementia on younger people and their families, the individuals and those around them may be more persistent in seeking an explanation for the symptoms;
- **People from different Cultural and Linguistic Backgrounds** – different cultures have different approaches and attitudes to dementia and to help seeking. Behaviours that might be considered unusual and a possible indication of cognitive impairment in mainstream Australian culture can be normal amongst individuals from other cultural backgrounds. Furthermore, the majority of information and services in Australia are English-language only, posing particular challenges for many individuals from non-English speaking backgrounds;
- **People from Aboriginal and Torres Strait Islander communities** – Aboriginal and Torres Strait Islander communities have different risk factors and patterns of dementia incidence and prevalence than other parts of the Australian community.⁵³ Preliminary data indicate that there is a relatively high prevalence rate of dementia amongst younger Aboriginal people.⁵⁴ This creates particular issues for diagnosis and management of dementia in primary care settings in Aboriginal and Torres Strait Islander communities.
- **Access to services and support** – the effectiveness of early intervention is dependent on prompt referral of people with dementia and their family carers to information and support including legal and financial advice. Even where services and support may exist it is often the case that referrals are not made. There has been little emphasis in service design (for example in respite services) of the need not just to give the carer a break but also to ensure that the person with dementia benefits from social engagement and activities.

4. Strategies to Achieve Early Diagnosis

4.1 Creating business incentives to encourage appropriate assessment and management of dementia in primary care.

"I made an appointment with the GP and listed out all the signs I had noticed. I asked that she do an assessment of him. But when it came to his mental assessment, she said his cognitive skills were good. She said he had slightly impaired social skills. This is not at all what my husband is like. The longer it goes without diagnosis the worse it gets."

Neither thorough assessment nor ongoing management of dementia are tasks that can easily fit into a 20 minute consultation, yet an extended consultation with the person and their carer (although not the carer alone) is all that is easily available to GPs when confronted by an individual with memory concerns.

There are certain ways in which GPs can obtain appropriate remuneration for the time required to provide proper dementia assessment and ongoing management through the MBS,⁵⁵ 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, due to the range of factors outlined in sections 3.2 and 3.3, and as evidenced by feedback provided by consumers on numerous occasions,⁵⁶ such GPs are the exception in Australia rather than the norm.

Additional training for GPs is clearly required to improve identification and assessment of dementia symptoms in primary care, as is the greater involvement of Practice Nurses, Aged Care Nurse Practitioners and other specialist nurses, including dementia CNCs. However, a fundamental barrier to better assessment and management of dementia in primary care is the fact that for many GPs, it is not attractive to provide these services under current administrative and funding arrangements.

To address this critical issue, there needs to be a review of the financial incentives available through the MBS or through other avenues, with a view to creating incentives for primary care providers to incorporate detailed assessment and management of cognitive impairment into sustainable business models. An incentive model for complex medical care exists in the form of the *Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS* program (including learnings from its implementation and administration), and a number of proposals for incentive systems have been put to the Government through the Minister's Dementia Advisory Group.^c

These strategies include:

1. Developing and implementing an accreditation program to allow specially trained GPs to confirm dementia diagnoses and prescribe symptomatic Alzheimer's medications

^c See Professor Henry Brodaty's paper for the Ministerial Dementia Advisory Group. *Dementia in Primary Care*. 26.04.2011

(cholinesterase inhibitors and memantine), with provision of supplementary payments for a range of dementia services;

2. Actively promoting wider and more effective use of existing MBS items such as health assessments, management plans and team care arrangements;
3. Reviewing and where necessary revising MBS items to ensure that they can effectively support identification, assessment and management of dementia;
4. Introducing additional MBS items where necessary; for example, to allow independent consultation with carers as part of a comprehensive assessment and management process;
5. Increasing MBS incentives or rebates for the provision of primary care services in residential aged care facilities;
6. Creating incentives for cognitive screening and assessment as part of the 75+ health assessment.

Recommendation One. That the Australian Government work with stakeholders to develop, trial and implement an accreditation program to allow specially trained GPs to confirm dementia diagnoses, prescribe symptomatic Alzheimer's medications, and receive supplementary payment for these and other services.

Recommendation Two. That the Australian Government promote wider use of existing MBS items for the assessment and management of dementia symptoms by GPs and Aged Care Nurse Practitioners.

Recommendation Three. That the Australian Government review existing MBS items and where necessary revise or create new items to ensure effective remuneration to support identification, assessment and management of dementia in primary care.

Recommendation Four. That the Australian Government create financial incentives to support cognitive screening as part of the 75+ health assessment, and to encourage dementia-related GP consultation in residential aged care.

4.2 Involving practice nurses, nurse practitioners and specialist nurses in the assessment and management of dementia symptoms

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 dementia.⁵⁷

The Practice Nurse Incentive Program, introduced on 1 January, 2012,^d provides funding to accredited practices to support Practice Nurses' involvement in a broad range of activities. This new program should allow Practice Nurses to undertake cognitive assessment of patients with memory concerns (as stand-alone assessments or as part of 75+ health assessments), and to assist GPs in making provisional diagnoses of dementia.

To support the increased role of Practice Nurses in the identification, assessment, and ongoing management of people with dementia, it is necessary to develop and provide accredited training in these functions, and to ensure that appropriate specialist support is available to assist Practice Nurses to undertake these roles.

In most cases, the first line of support for Practice Nurses is the practice GP. However, there are also opportunities to provide support through specialist nurses (including Aged Care Nurse Practitioners, Community Mental Health Nurses and dementia Clinical Nurse Consultants). These specialties already exist, and are integrated into support and practice networks in some areas of Australia.⁵⁸ An effective model of specialist nurse support for Practice Nurses (using hub-and-spoke arrangements and clinical networks) has also been developed and demonstrated in the cancer area. The Australian National Cancer Nursing Education Project provides education services, benchmarking and competencies for general and specialist cancer nurses, many of whom are situated in positions where they support a number of allied health and community-based primary health care providers.

As well as providing support, Aged Care Nurse Practitioners and other specialist nurses are also able to provide a high-level of independent assessment and to diagnose people with dementia.⁵⁹ A recent pilot study in the UK showed that home-based assessment by specialist nurses of people with clear symptoms identified dementia with 94% accuracy and sub-diagnosed dementia with 84% accuracy when compared to subsequent diagnosis by a full multi-disciplinary team.⁶⁰

Recommendation Five. That the Australian Government develop and implement an accredited training program and incentives to promote greater involvement of Practice Nurses, Aged Care Nurse Practitioners and other specialist nurses in dementia identification, assessment and management in primary care settings.

4.3 Training and education for GPs and nurses

"It took the doctor so long to give us a diagnosis. I had to explain everything to the doctor in front of my husband, which was so hard, before he finally agreed to send us to the geriatrician. When we finally did see the geriatrician, she was wonderful. GPs need better education and to just refer you to specialists who can help."

Comprehensive action is required to increase the level of dementia literacy and assessment and management skills amongst Australia's 25,000 GPs and 10,000 practice nurses. Education is needed not only to achieve best-practice assessment, diagnosis and management of dementia

^d www.medicareaustralia.gov.au/provider/incentives/pnip.jsp

now, but also to prepare the primary care sector for the significant developments in assessment and diagnosis that will become clinically available within the next decade (see Section 6). There are good opportunities to implement such a strategy through the current COAG health reforms and through the new Medicare locals.

A detailed proposal for a targeted \$3 million program was developed by the Australian General Practice Network (AGPN) in partnership with Alzheimer's Australia and submitted to the Department of Health and Ageing's Aged Care Service Improvement Flexible Fund in December, 2011. This proposed program aims 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.

Recommendation Six: that the Australian Government commit to the development of dementia education and professional development programs for GPs and Specialist and Practice Nurses to improve rates of assessment and diagnosis of dementia in primary care and considers linking training for GPs to supplementary benefits.

4.4 Improving access to specialists

"The neuropsychological testing was very extensive and detailed; it gave me lots of information about how my dementia was affecting my memory. Anything the Committee can do to get this testing covered by Medicare would go a long way toward improving the time of diagnosing dementia."

Mr. Leo White, member of the Alzheimer's Australia Consumer Dementia Research Network. Excerpt from a separate submission to this Inquiry

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 Victorian CDAMS model in particular is unique in Australia in providing a state wide service for people with memory concerns that that enables people to walk off the street and have an assessment that is fully covered by Medicare. A review of the CDAMS model in Victoria in 2003 concluded that the services were effective in providing assessment, diagnosis and education to people from a range of backgrounds at a relatively low cost the Victorian State Government,⁶¹ Consideration should be given to

assessing the costs and benefits of different models of care including the CADMs to get a more systematic approach across Australia.

Public access to specialists outside of the memory clinic setting is also problematic, particularly in regional and rural areas, and for those from non-English speaking backgrounds. A range of strategies will be needed to increase access to specialists in the assessment and management of dementia. One strategy put forward by the Australian Psychological Society in their 2012-13 pre-budget submission⁶² outlines a plan to provide neuropsychological services to nearly 20,000 additional people with dementia each year.

Recommendation Seven. That the Australian Government review with the states the costs and benefits different models of service delivery with the objective of improving access to publicly funded specialists and specialist memory clinics.

4.5 Developing and promoting contextualised primary care referral pathways

“Three years with annual visits to a neurologist with a final report saying, “There is something wrong but I don’t know what” without thought of referral to other help was very disappointing.”

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 diagnosed.⁶³

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.

Clinical practice guidelines are one element of the approach, and the single Australian guideline relating to the management of dementia in General Practice (developed by the late Professor Charles Bridges-Webb for NSW Health in the early 2000s), is now somewhat dated and is not widely used. As such, there is a need for the development and wide promotion of new and updated guidelines to assist primary care providers in their role.

However, clinical guidelines, and more concise practice guides (including online information, or information built into clinical decision tools such as *Medical Director* or *Better Practice*) need to be contextualised to the local area, and include information on the available specialist, allied health and community services that are available for referral of people with dementia or memory concerns from front-line primary care.

The need for such contextualised referral pathways has been identified by two recent dementia service pathway projects in Australia: the first developed by KPMG for the Department of Health and Ageing to present a high-level guide to assist jurisdictions in dementia service planning;⁶⁴ and the second by NSW Health, mapping out a 5-year plan for dementia services in NSW on the basis of extensive consultations with consumers, service providers, clinicians and experts.⁶⁵

Both of these reports identified new and existing primary health care organisations and networks, including Medicare Locals and the AGPN as appropriate agencies to undertake the work of developing and promoting such pathways. There are also opportunities to draw upon existing state-based clinical dementia networks (in Qld and Tasmania for example), and specialist memory services such as the Victorian Cognitive, Dementia and Memory Service to increase referral of people with dementia or with memory concerns from primary care to appropriate specialist and community services. There will also be important opportunities develop new referral processes through the National Broadband Network and developments in e-Health technologies.

Recommendation Eight. That the Australian Government work with key stakeholders to promote contextualised dementia primary care service pathways through the developing Medicare locals network and through existing specialist networks.

5. Strategies to Improve Post-Diagnosis Intervention and Management

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. The Inquiry's terms of reference identify some of the key areas where strategies are needed to achieve social engagement and community participation for people with dementia, assistance with planning, and awareness. Specific strategies and recommendations in response to the Committee's terms of reference are set out below.

5.1 National awareness campaign

“Good awareness will reduce stigma, and make early diagnosis easier. This will result in less denial and more discussion about end of life. We won't get it unless we get a good overall community awareness program going.”

With limited funding Alzheimer's Australia has been able to promote a wider understanding of dementia in the last decade and has reached large audiences with advertising equivalent value a multiple up to 15 times the cost of the activities undertaken. But market research in Australia and elsewhere suggests there remains limited understanding of the symptoms of dementia beyond memory loss. This includes poor understanding of the fact that dementia can affect younger people, that it is a terminal disease, that the symptoms develop decades before diagnosis, or that lifestyle changes may offer some the possibility of risk reduction.

A national dementia awareness campaign is required to de-stigmatise dementia, and to raise understanding and awareness of the condition amongst the general community and within the primary care sector. Such a campaign would have the objective of making all Australians aware of the symptoms of dementia, and the importance of seeking medical help.

Alzheimer's Australia has prioritised awareness as a key issue to be addressed and submitted a detailed proposal for a targeted \$6.5 million national dementia awareness campaign to the Department of Health and Ageing's Aged Care Service Improvement Flexible Fund in December, 2011. Through a strategic communication plan, we aim to change behaviour and attitude in three focus areas:

1. **Stigma** – raising the public awareness and understanding of dementia. Most Australians have a relatively poor understanding of dementia. Many are aware that dementia is associated with memory loss but are unaware of the changes that can occur in behaviours, mood and language. 56% of carers report that people with dementia are discriminated against, and almost a third of Australians say that they would feel uncomfortable spending time with someone with dementia.⁶⁶
2. **Risk reduction** – prompting those at risk of dementia to *identify and respond* by communicating symptoms and precursors to dementia; prompting help seeking and / or change of lifestyle and environmental factors. 50% of Australians are unaware that they may be able to reduce their risk of dementia.⁶⁷ For example, even after prompting,

around 40 percent did not agree that reducing blood pressure or high cholesterol would help.

3. **Recognising the early signs of dementia** – increasing awareness and understanding of dementia amongst those concerned about their memories, health and aged care professionals generally, including the importance of early diagnosis and intervention.

In developing this proposal Alzheimer's Australia had the assistance of Porter Novelli, a national Public Relations firm that has worked pro bono with Alzheimer's Australia on the Fight Dementia Campaign.

Recommendation Nine: that the Australian Government funds Alzheimer's Australia to undertake a comprehensive dementia awareness campaign to increase community and professional understanding of dementia, and to reduce high levels of stigma and social isolation experienced by people with dementia and their carers.

This recommendation directly addresses the fourth dot point of the Inquiry's terms of reference.

5.2 Community programs and information for consumers through the National Dementia Support Program

"I have found Alzheimer's Australia an incredibly helpful source of help by way of information, support group, library, counselling and more."

Strategies to improve the assessment, diagnosis and management of dementia will only lead to better outcomes for consumers if they are accompanied by strategies to increase the availability of and access to community-based support and information services for consumers once diagnosed. The importance of information for older people has been recognised in ***Living Longer, Living Better***.

There are a range of organisations that act as points of referral from primary care, and which provide advice, information and support to people with dementia and their families. These organisations include aged care providers, local health services, pharmacies, government agencies, and community organisations such as Alzheimer's Australia and Carers Australia. It is important to build on these networks.

Alzheimer's Australia delivers an integrated suite of services including the National Dementia Helpline, help sheets, a richly resourced website, counselling services, support groups, education and training for informal and formal carers, and Living with Memory Loss Programs to tens of thousands of individuals each year^e through the Commonwealth funded National Dementia Support Program (NDSP). The NDSP has been funded by the Department of Health and Ageing since 2005 when it was announced as part of the *Dementia Initiative; Making Dementia a National Health Priority*. NDSP services can be a helpful point of referral for patients diagnosed with dementia however, funding for the NDSP has not kept pace with the increasing numbers of people with dementia, limiting access and availability of this important program.

^e Almost 120,000 NDSP client contacts were recorded in 2010-11

Recommendation Ten: that the Australian Government increase funding in line with the increasing prevalence of dementia for services for people with dementia and their carers through the National Dementia Support Program administered by Alzheimer's Australia.

5.3 Dementia Link Worker program

“When mum was diagnosed I got a pile of advice in papers, but I will never read all that. What I actually wanted was someone to talk to me and explain the options and tell me what we need to do.”

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.

Alzheimer's Australia has done some initial work on the issues to be addressed in setting up dementia link workers.^f The term Dementia Link Worker is adopted here to indicate that:

- The role covers a broad range of dementia support across all levels of the dementia triangle: consumers; family carers; and health care provider.
- The Dementia Link Worker is based in practice settings across a wide range of health and aged care services; and
- The focus of the role is to link individuals with dementia and their families to services and support.

The primary role of a Dementia Link Worker would be to provide support, advice and advocacy for the person with dementia and their family. The goal is 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 would be referred to a Dementia Link Worker soon after diagnosis. The Dementia Link Worker would then assist in linking the person with dementia and their families to support groups, education and information. The Dementia Link Workers may also provide information and support about advanced care planning, carer stress, and access to services such as respite

Dementia Link Workers could be nurses or allied health professionals (usually with a background in social work, psychology or occupational therapy) who have extensive knowledge

^f Dementia Link Workers are also variously referred to as a 'key dementia workers', 'dementia key workers', 'community dementia nurses', 'system navigators', 'admiral nurses', or 'practice consultants'.

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.⁹)

Implementation of a national Dementia Link Worker program will require the development and endorsement of an accreditation program with appropriate competencies and professional development requirements.

The program could be delivered by a range of existing community aged care providers, health provider organisations or community organisations such as Alzheimer's Australia or Medicare Locals, and should build on existing networks.

Alzheimer's Australia recommends that this program should be implemented progressively as part of the aged care reforms.

Recommendation Eleven: That the Australian Government implement a national Dementia Link Worker program in the context of the health and aged care reforms.

5.4 Increase access to early diagnosis and intervention to diverse groups

“For indigenous people in remote communities, if they need particular levels of care, they have to come to Alice Springs. I wonder about their issues, and how it fits with wanting to be with families.”

Individuals from regional and remote areas, from Culturally and Linguistically Diverse backgrounds, Indigenous people, individuals who are gay and lesbian and people with Younger Onset Dementia all face particular challenges when confronting dementia. These groups also make up a significant number of individuals who are facing dementia in Australia. In 2009, some 97,000 (39%) of people with dementia lived outside capital cities, and approximately 35,000 (14%) of people with dementia did not speak English at home.⁶⁸ In 2011, it was estimated that approximately 16,000 people (6% of total dementia numbers) are living with younger onset dementia.⁶⁹

Many of these groups have difficulty accessing services for a variety of reasons. For example, CALD and Indigenous population groups often have lower levels of awareness of dementia which results in later presentation to health services, later diagnosis and less access to support services. In part this lack of awareness is a result of differing health beliefs and perceptions about dementia, but it may also be attributable to the inequitable distribution of existing funding for dementia services. It is important to consider how to increase service delivery to these groups in a culturally sensitive and linguistically appropriate way. Individuals from rural and remote communities also have difficulty accessing services, and often pay high fees for community care workers to travel to their home. Many also find it difficult to access convenient respite care.

⁹ See www.uow.edu.au/handbook/yr2012/pg/hbs/H12000014.html

Individuals with Younger Onset Dementia face a separate set of issues. In 2008, COAG agreed that responsibility for this group should be included under the new National Disability Agreement. As such, issues around providing care for Younger Onset Dementia have been addressed by both the Productivity Commission Inquiry into Caring for Older Australians and their Inquiry into Disability Care and Support.

Alzheimer's Australia has raised concerns about:⁷⁰

- How the disability sector is going to gain an understanding of the care and support needs of people living with dementia?
- What resources are available to develop services appropriate for people with younger onset dementia?
- What requirement there is on jurisdictions to include younger people with dementia within the current initiatives?

There is a significant risk of younger people with dementia being shifted between disability and aged care services and losing continuity of support and care. When disability services are no longer able to meet a younger person's needs due to the progression of dementia, for example, the person and their family carers are required to navigate a second unfamiliar system. The progression of dementia in younger people can be quite rapid. The challenge is to develop a smooth and seamless service. One option might be to remove age limits for access to aged care services for those with dementia, and to ensure the services received are appropriate. For those with a disability, ongoing support from their existing service to avoid disruption might be the preferable course with those services drawing on the dementia expertise of the aged care service providers as appropriate.

The provision in ***Living Longer, Living Better*** for improved support for people with younger onset dementia through Dementia Link Workers (see section 5.3) is an important step forward in recognising the special needs of this group.

Recommendation Twelve. That the Australian Government ensures that measures to achieve early dementia diagnosis and intervention are sensitive to the needs of diverse groups.

5.5 Expansion of community and respite care and improved co-ordination between primary and community care

"I put my husband in [respite] care and had to pick him up again because they couldn't handle him."

Respite care is a crucial component of support for carers and can enable individuals with dementia to continue to live at home for as long as possible. Unfortunately, many family carers of individuals with dementia have difficulty accessing respite services that meet their needs. According to the ABS Survey of Disability, Ageing and Carers in 2003, there were 10,000 individuals caring for someone with dementia who had an unmet need for respite care, compared to just 15,000 who had accessed respite.⁷¹ This means that for every three carers who have used respite, there are two dementia carers who need respite but have not used it.

The differences between need for and use of respite on the part of dementia carers and all carers are striking. Dementia carers are:

- About half as likely to say that they had no need and had not used respite;
- 50% more likely than other carers to need and have used respite; and
- More than 10 times more likely than other carers to say they need respite but had not used it.⁷²

In 2009 Alzheimer's Australia released a publication, *Dementia and Respite Care: "More than just a short break"* which identifies a number of barriers to accessing respite and recommends major changes in the provision of respite care.⁷³

One of the main barriers to accessing respite services is a lack of flexibility and choice. This includes flexibility in when the respite is available, where the respite is provided, and what types of activities are included in the respite care. One means of promoting flexibility is by providing consumer directed care. Carers could be provided with a respite budget which they could use to purchase respite services that met their needs. The recent announcement of 200 consumer directed respite care packages as part of the **Living Longer, Living Better** package is a first step towards providing consumers with greater flexibility and choice. This program needs to be expanded to allow for wider access to consumer directed respite care.

A reason advanced by carers for not utilising respite is a concern about the quality of care that will be provided to the person with dementia. Carers not only want a break from providing care but also want services that meet the needs of the person with dementia, including age and culturally appropriate social and community engagement. Activities provided in respite need to be appropriate for the varying needs of individuals with dementia. This requires staff who have been provided with dementia specific training, mentoring, and monitoring of care practices.

There is also a need for specialised dementia respite care. Family carers often report to Alzheimer's Australia that once the person with dementia develops any behavioural symptoms of dementia or becomes incontinent, they are no longer able to access much needed respite services. Service providers argue that there are not enough staff to adequately respond to the specialised needs of individuals with dementia. It is clear, therefore, that there is a need for specialist dementia respite care services that respond flexibly to the needs of both people with dementia and their family carers at any stage of the dementia journey.

For all these reasons Alzheimer's Australia strongly supports the improvements in respite care services in **Living Longer, Living Better** and especially the intention to streamline respite arrangements and explore new models for carers to have greater choice in how they use their respite entitlements.

Recommendation Thirteen. That the Australian Government give urgency to implementing respite care reforms including social engagement and activities for the person with dementia.

6. Preparing for the Future: Likely Developments in Early Diagnosis and Intervention

“We have come so far with breast cancer research because of all the funding. We all know the stats of dementia and there is no cure. We need more money for research.”

Assessment, diagnosis and early intervention for people with dementia will look very different in 10 years time. This is primarily because:

1. it is now understood that the pathology of Alzheimer’s disease and other dementias develops decades before symptoms become evident; and
2. new techniques are being developed that will soon make it possible to identify those with pre-symptomatic pathology who are at greatest risk of developing dementia in the future.

Reflecting these new understandings and advances, new classifications are also under consideration that will render the term dementia obsolete. Specifically, the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) being prepared for release in 2013 by the American Psychiatric Association (APA) proposes to introduce the new classifications of *Major Neurocognitive Disorder*, and *Minor Neurocognitive Disorder* to replace the clinical syndromes *dementia* and *mild cognitive impairment*.^h The impact of this change in classification and terminology cannot be underestimated, particularly when considering the already poor awareness and understanding of dementia (few people, for example, can explain the difference between dementia and Alzheimer’s disease).

Within the next 5-10 years, it is also likely that there will be:

- additional symptomatic medications approved for use in people diagnosed with dementia;
- a remoter possibility of medical interventions to delay the progression of Alzheimer’s disease and other forms of dementia
- stronger evidence around risk and protective factors for dementia and the linkages between these risk factors and those of other chronic diseases such as vascular disease, diabetes and obesity. This evidence will require new thinking in preventive health programs;

6.1 New diagnostic criteria and assessment technologies for Alzheimer’s disease.

Alzheimer’s disease is the most common cause of dementia, and has been the main focus of most of the dementia-related research into its nature and causes, early detection, and therapeutic interventions to slow, arrest or reverse the disease process.

^h See www.dsm5.org/proposedrevision/pages/neurocognitive disorders.aspx for the full clinical and scientific rationale and for neurocognitive disorder subtypes: for example, *Major Neurocognitive Disorder Associated with Alzheimer’s Disease*. These new classifications have not yet been confirmed for the DSM-V

This global research effort has led to two important and related developments that will affect the assessment and management of Alzheimer's disease within the next 5-10 years.

The first of these is a revision to the diagnostic criteria and guidelines for Alzheimer's disease developed by the US Alzheimer's Association in association with the National Institutes on Ageing, released in 2011.⁷⁴ These criteria and guidelines have added a new diagnostic classification of 'preclinical Alzheimer's disease' to the existing classifications of 'dementia due to Alzheimer's disease' and 'mild cognitive impairment due to Alzheimer's disease'.

Diagnosis of preclinical Alzheimer's disease is made by means of biomarkers (biological rather than symptomatic indications of disease presence) that can be detected by analysing cerebrospinal fluid (CSF), brain scans and blood samples. Development and validation of Alzheimer's disease-specific biomarker tests is still underway, and as such, diagnosis of preclinical Alzheimer's disease using biomarker technologies is confined to research settings.

However, these technologies will become available in clinical settings within the next five years,ⁱ and will enable clinicians both to screen at-risk populations for Alzheimer's disease, and to assess those with early symptoms using new biomarker tests that will provide much more certainty for diagnosis.

This development will revolutionise the assessment and diagnosis of Alzheimer's disease (and, eventually, other forms of dementia) in primary care, and they must therefore be taken into account in the design of any new programs or policies designed to improve assessment and diagnosis of dementia over the next decade.

There will be funding implications of these new tests, as well as ethical considerations around the possibility of screening for a condition for which there is not yet a cure. It is important that planning start now, and that it involve all of the stakeholders who will be impacted: clinicians, health service providers, community organisations and consumers.

6.2 Dementia research funding

Dementia research is underfunded in Australia in comparison to other chronic disease research areas, and in comparison to dementia research funding levels internationally.^j This applies across all areas of dementia research, and is an issue on which Alzheimer's Australia has campaigned for change over a number of years, including through a recent submission to the McKeon Review of Health and Medical Research in Australia.⁷⁵

In relation to research into dementia in primary care there are significant gaps and questions that remain to be answered. These were highlighted in a recent review of the dementia research literature undertaken for the Department of Health and Ageing by the Dementia Collaborative Research Centres.⁷⁶

ⁱ One of the outcome measures for the Commonwealth Government funded Mental Health CRC, for example, is the development of clinic-ready biomarker tests for Alzheimer's disease by the end of its current 5-year funding period.

^j France, the USA and the UK have all recently announced substantial increases in dementia research funding. See: www.hhs.gov/news/press/2012pres/02/20120207a.html; <http://alzheimersweekly.com/content/french-president-takes-global-dementia-challenge>; www.guardian.co.uk/society/2012/mar/26/dementia-research-funding-to-double

This report identified the following key research questions and priorities relating to dementia in primary care:

- The development and validation of rigorous diagnostic tests for Alzheimer's disease and other forms of dementia;
- The development of standardised diagnostic criteria for causes of dementia other than Alzheimer's disease;
- Further work to establish rates of and times to diagnosis of dementia in Australia;
- Development of new pharmacological treatments for dementia symptoms;
- Development and validation of new and existing non-pharmacological approaches to managing behavioural and psychological symptoms of dementia;
- Identification and treatment of risk factors for dementia in primary care;
- The relationship between dementia and other chronic diseases, and implications for treatment and management in primary care;
- The development and validation of psychosocial interventions that can be delivered by primary care providers to improve the cognitive functioning, health and wellbeing of people with dementia and their carers;
- Development and validation of cost-effective models of care for people with dementia and their carers in the primary healthcare system.

Research is essential to answer these questions, and to develop evidence-based programs and strategies that can be implemented by service providers, policy makers and community organisations across the public health system.

Recommendation Fourteen: That the Australian Government prioritise funding for research into dementia in primary care in order to allow better assessment, and evidence-based interventions to support people with dementia and their carers living in the community.

7. Conclusions

This submission has shown that the current primary care system is failing to deliver early diagnoses of dementia or effective ongoing treatment and support to people with dementia and their carers. The reasons for these failings are complex. However, they can and must be redressed using multiple and complimentary strategies.

It is clear that while dementia changes lives, when an individual receives a early diagnosis and referral to services, the trauma of the diagnosis and dementia journey can be lessened and the quality of life of the person and their carers can be person improved. Early diagnosis of dementia and appropriate management and intervention does happen – David's example below shows how it can. However, the system as a whole is not up to delivering this level of care to everyone, and for this reason, significant government action is needed.

"In January, 2007 (two months after I turned 52), a psychological assessment suggested an Adjustment Disorder with depressed mood (I had just been through a very stressful work year). Throughout 2007 I had frequent migraines, headaches and depressive feelings, often daily. In late 2007 I was sent to James Cook University for a neuropsychological assessment. The NUCOG test [Neuropsychiatry Unit Cognitive Assessment Tool] resulted in 19 or 20/20 for four of the five components but only 10/20 for short term memory. These psychology students identified that I may have had early-onset Alzheimer's before my doctors did (this is not a complaint of the latter). I was referred to an excellent psychiatrist at the Royal Melbourne and diagnosed with highly probable Alzheimer's, following intensive psych tests and fMRI and PET scans of my brain in mid 2008 at the Epworth Hospital in Melbourne.

I have been very fortunate compared to most with Alzheimer's. I was diagnosed relatively early. My wife has a PhD in nursing, is an exceptional carer, works very effectively with medical doctors and we had full health coverage. Our family also had excellent connections with the medical profession. Most people with Alzheimer's are not so fortunate. The early diagnosis and subsequent prescription of Alzheimer's -specific drugs (Aricept and Memantine) and the effectiveness of these drugs for me made a huge difference to both me and my family. Stress and relationship problems have decreased greatly and more than four years later I live a relatively normal, independent life - as long as I remember to take my drugs."

*David Williams
April, 2012*

8. References

-
- ¹ Deloitte Access Economics (2011). *Dementia Across Australia, 2011-2050*. Report for Alzheimer's Australia. Available: www.fightdementia.org.au/research-publications/access-economics-reports.aspx
 - ² Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.
 - ³ George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-7
 - ⁴ Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.
 - ⁵ 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
 - ⁶ Pfizer Health Report (2011). *Dementia is Everybody's Business*. Report #45. Available: www.fightdementia.org.au/research-publications/pfizer-health-reports.aspx
 - ⁷ Access Economics (2010). *Caring Places: Planning for Aged Care and Dementia: 2010-2050* (Volume 1). Report for Alzheimer's Australia. Available: www.fightdementia.org.au/research-publications/access-economics-reports.aspx
 - ⁸ *Ibid* 5.
 - ⁹ Market research conducted for Alzheimer's Australia by Newspoll. September, 2004.
 - ¹⁰ World Alzheimer's Report. *The Benefits of Early Diagnosis and Intervention*. Alzheimer's Disease International, September, 2011.
 - ¹¹ 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
 - ¹² *Ibid*, 10.
 - ¹³ Speechly, C. (2008). The pathway to dementia diagnosis. *Medical Journal of Australia*, 189, 487-9.
 - ¹⁴ 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
 - ¹⁵ 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.
 - ¹⁶ *Ibid*, 10
 - ¹⁷ 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.
 - ¹⁸ Finucane, T. Et al (1999). Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA*, 282, 1365-70
 - ¹⁹ 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.

-
- ²⁰ 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.
- ²¹ Teel, C. S. (2004). Rural practitioners' experience in dementia diagnosis and treatment. *Ageing and Mental Health*, 8(5), 422-9.
- ²² 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.
- ²³ 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.
- ²⁴ *Ibid*, 23.
- ²⁵ Black, W. & Almeida, O. (2004). A systematic review of the association between the BPSD and burden of care. *International Psychogeriatrics*, 16(3), 295-315.
- ²⁶ 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
- ²⁷ 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.
- ²⁸ 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
- ²⁹ Bridges-Webb, C. (2003). Care of patients with dementia in general practice Guidelines. RACGP.
- ³⁰ 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.
- ³¹ Bond et al. (2005). Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey, *International Journal of Clinical Practice*; 59:s146
- ³² *Ibid*, 13.
- ³³ *Ibid*, 10.
- ³⁴ Wilkinson, D. et al. (2005). Implications of the facing dementia survey for health care professionals across Europe. *International Journal of Clinical Practice*, 59, 27-31.
- ³⁵ Pond, D., Paterson, N., Swain, J., Stewart-Williams, J., & Bryne, J. (2008). Dementia identification, assessment and management in community-based primary health care: A review of the international literature 1995-2008: University of Newcastle.
- ³⁶ Koch, T., & Iliffe, S. (2010). Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: A systematic review. *BMC Family Practice*, 11(52).
- ³⁷ Robinson, L. et al. (2011). The transition to dementia – individual and family experiences of receiving a diagnosis. A review. *International Psychogeriatrics*, 23(7), 026-43.
- ³⁸ *Ibid*, 26.
- ³⁹ Werner, P. (2003). Knowledge about symptoms of Alzheimer's disease: Correlates and relationship to help-seeking behaviour. *International Journal of Geriatric Psychiatry*, 18, 1029-36.
- ⁴⁰ Downs, M. et al. (2006). Family carers' accounts of general practice contact for their relatives with early signs of dementia. *Dementia*, 5(3), 353-73.
-

-
- ⁴¹ 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
- ⁴² 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.
- ⁴³ 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.
- ⁴⁴ 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
- ⁴⁵ Wind, A., Schellevis, F.G., Stavereen, 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.
- ⁴⁶ Bush, C., Kozak, J., & Elmslie, T. (1997). Screening for cognitive impairment in the elderly. *Canadian Family Physician*, 43, 1763-8.
- ⁴⁷ *Ibid*, 36.
- ⁴⁸ *Ibid*, 43.
- ⁴⁹ *Ibid*, 44.
- ⁵⁰ Yates, M., Theobald, M. & McIntyre, I. (2011). An all of hospital education program to improve the awareness of and communication with people with dementia linked to a visual cognitive impairment identifier. See www.health.vic.gov.au/archive/archive2011/improvingcareforums/1104/yates.pdf
- ⁵¹ *Ibid*, 10.
- ⁵² Department of Health and Ageing (2007). Draft Report on *Dementia in Primary Care*.
- ⁵³ Smith, K. et al. (2008). High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology*, 71(19), 1471-3.
- ⁵⁴ *Ibid*, 53.
- ⁵⁵ Dementia Collaborative Research Centre (DCRC; 2010). *Medicare Benefits Schedule (MBS) Fees. DEMENTIA Related GP Management Plan (GP Mx Plan)*. Available: www.nsgpn.org.au/dcrc%20flow%20chart%20a4%20landscape.pdf
- ⁵⁶ Alzheimer's Australia (2012). Report for the Department of Health and Ageing in relation to services for consumer engagement in the aged care reform process. Available: www.fightdementia.org.au/too-many-failures-in-dementia-care-1.aspx
- ⁵⁷ Manthorpe, J., Iliffe, S., & Eden, A. (2003). Early recognition of dementia by nurses. *Journal of Advanced Nursing*, 44(2), 183-91.
- ⁵⁸ *The NSW Dementia Services Framework, 2010-2015*. NSW Department of Health, September 2010. Available: www.health.nsw.gov.au
- ⁵⁹ Trapp-Moen, B., Tyrey, M., Cook, G., Heyman, A., Fillenbaum, G. (2001). In-home assessment of dementia by nurses. Experience using the CERAD evaluations. *The Gerontologist*, 41(3), 406-09.
- ⁶⁰ Page S, Hope K, Bee P, Burns A. Nurses making a diagnosis of dementia - A potential change in practice? *International Journal of Geriatric Psychiatry* 2008;23(1):27-33.
-

-
- ⁶¹ *Review of the Cognitive, Dementia and Memory Clinics*. A Report Prepared For The Department of Human Services. Final Report. Australian Institute for Primary care. Lincoln Gerontology Centre. January 2003
- ⁶² See www.psychology.org.au/Assets/Files/APS-Pre-Budget-Submission-2012-2013.pdf
- ⁶³ *Ibid*, 11.
- ⁶⁴ KPMG (2011). *Dementia services pathways – an essential guide to effective service planning*. Available: [www.health.gov.au/internet/main/publishing.nsf/Content/48EFBFA3F0CE468DCA25790B000B6FDA/\\$File/Dementia-services-pathways\(ext2\).pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/48EFBFA3F0CE468DCA25790B000B6FDA/$File/Dementia-services-pathways(ext2).pdf)
- ⁶⁵ *Ibid*, 58.
- ⁶⁶ *Ibid*, 6.
- ⁶⁷ *Ibid*, 6.
- ⁶⁸ Access Economics (2006). *Dementia prevalence and incidence amongst Australians who do not speak English at home*. Report for Alzheimer's Australia. Available: www.fightdementia.org.au/research-publications/access-economics-reports.aspx
- ⁶⁹ *Ibid*, 1
- ⁷⁰ Alzheimer's Australia (2011). *Response to the Productivity Commission Draft Report: Caring for Older Australians*. Available: www.fightdementia.org.au/common/files/NAT/20110321_Nat_Sub_PCResponse.pdf
- ⁷¹ Australian Bureau of Statistics (2004). *Disability, Ageing and Carers, Australia: Summary of Findings, 2003*. Cat No: 4430.0
- ⁷² Bruen, W. & Howe, A. (2009). *Respite Care for People Living with Dementia*. "It's more than just a short break." Alzheimer's Australia Discussion Paper 17. Available: www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx
- ⁷³ *Ibid*, 73.
- ⁷⁴ Jack, C. et. al. (2011). Introduction to the recommendations from the National Institute on Ageing – Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, 7(3), 257-62.
- ⁷⁵ Anstey, K., & Kiely, K. (2012). *Evaluation of NHMRC Data on the Funding of Dementia Research in Australia*. A report for Alzheimer's Australia. Alzheimer's Australia Paper Number 26. Available: www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx
- ⁷⁶ Brodaty, H., Seeher, K., & Withall, A. (2011). *The Dementia Research Mapping Project – 2010 Update*. Available: www.dementia.unsw.edu.au/search-results.html?view=dcrc&layout=project&pid=50