SUBMISSION TO THE HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH

Inquiry into best practice in chronic disease prevention and management in primary health

JULY 2015
EXECUTIVE SUMMARY

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 dementia\(^1\) and over a million people involved in their care\(^2\). By 2050 there will be nearly 900,000 people with dementia\(^3\). 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 2050\(^4\).

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 annum\(^5\). Dementia also has a profound social impact. People with dementia experience stigma and social isolation\(^6\), and family carers often find it difficult to balance work, life and caring responsibilities\(^7\).

Many of us will be diagnosed with dementia over the years ahead, or will have loved ones faced with the diagnosis. 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.

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 key role to play in timely diagnosis and treatment of 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.

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\(^1\) Australian Institute of Health and Welfare (2012) *Dementia in Australia.*
\(^3\) 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*
RECOMMENDATIONS

Alzheimer’s Australia recommends that the Government:

1. Develop a National Dementia Strategy to enable a comprehensive and coordinated approach to addressing dementia.
2. Include dementia as a core component of the National Strategic Framework for Chronic Conditions, recognising it represents a significant burden of disease and is closely linked with other chronic disease, including through common risk factors.
3. Embed 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.
4. Include cognitive assessment in the 75+ health assessment.
5. Promote home medicine reviews to check for medications that may cause or exacerbate cognitive impairment, and to ensure adequate management of current medication.
6. Develop 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.
7. Provide 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.
8. Allow reimbursement through the Medicare Benefits Schedule (MBS) for time spent by health professionals assessing, diagnosing and managing dementia and consulting with carers.
9. Add MBS item numbers for:
   a) Cognitive function assessment, using validated tools, to allow GPs and credentialed health professionals to conduct an assessment if they have concerns.
   b) Practice nurses to do in-home cognitive function assessment.
10. Expand existing psychology MBS item numbers for neuropsychological testing of people who may have dementia.
11. Modify MBS item numbers:
    a) 348 and 350 to make them available to GPs for discussions with informants, both before and after diagnosis, including family members and carers.
    b) 707 to allow targeted examination and assessment of symptomatic changes in memory and thinking.
    c) 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 (e.g. practice nurses, dementia link nurse from Medicare Local) in the role of case coordinator.
12. Implement a comprehensive ongoing social marketing campaign to create awareness among Australians about brain health, and alert people to the links between their health behaviours, their risk of cognitive impairment and dementia, and their risk of developing other chronic conditions.
13. Implement a multi-pronged, multi-sectoral approach to facilitate the integration of dementia risk reduction with risk reduction for other chronic diseases, including through partnerships and local education initiatives.
INTRODUCTION

Alzheimer’s Australia welcomes the opportunity to provide a submission to the House of Representatives Standing Committee on Health Inquiry into Best Practice in Chronic Disease Prevention and Management in Primary Health.

Dementia poses a unique challenge for Australia due to increasing rates of prevalence, increasing economic costs and social implications. A health and social issue of this dimension is unprecedented in this country and has arisen due to successes in the treatment of chronic diseases, an ageing population, and increased longevity.

The increasing prevalence of dementia means that there is both an economic and social imperative for governments to develop initiatives to address dementia and ensure that people with dementia have access to appropriate care and support from the moment of diagnosis. Initiatives that focus on prevention and early intervention and timely diagnosis, and on supporting people with dementia to live in the community, are particularly important given the long term benefits they deliver.

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 care. 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.

8 Australian Government 2015 Intergenerational Report
RATIONALE: ISSUES AND RECOMMENDATIONS

Dementia has an enormous and growing impact on the health and aged care system. The cost to the system is estimated to be at least $4.9 billion per annum, and dementia will become the third greatest source of health and aged care spending within two decades\textsuperscript{10}. Dementia also has a profound social impact, with people with dementia experiencing stigma and social isolation\textsuperscript{11}; and family carers often finding it difficult to balance work, life and caring responsibilities.

The significant economic and social impact of dementia has been recognised by the Australian Government with the 2012 decision to make dementia a National Health Priority Area. Unfortunately, many people with dementia and their families are still struggling to get access to the care and support they require.

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 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 home\textsuperscript{12}.

It is imperative to build the capacity of the primary care system to better meet the needs of people with dementia. Building our capacity to address dementia in primary care will save billions now and into the future, as well as improving the welfare of the millions of Australians who are in some way impacted by dementia.

For example, better access to primary care and community-based services has potential to reduce avoidable hospital admissions for people with dementia. 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\textsuperscript{13}. 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 awaiting admission to another care facility. The cost of preventing hospital admissions is estimated to be $888 per day in savings\textsuperscript{14}.

To give another example, a greater focus at primary care level on risk reduction and timely diagnosis of dementia could reduce the number of people developing dementia, providing early intervention to enable people diagnosed with dementia to live in the community for longer. 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.

Any strategy to improve the engagement of the primary health care system with people with dementia and their carers, needs to be developed in the context of a broader strategy on dementia. In a period of increasing fiscal demand on national economies and growing health needs, it is

\textsuperscript{12} Australian Institute of Health and Welfare (2012) Dementia in Australia.
\textsuperscript{13} Australian Institute of Health and Welfare (2013) Dementia care in hospitals: costs and strategies.
\textsuperscript{14} Australian Institute of Health and Welfare (2013) Dementia care in hospitals: costs and strategies.
imperative that Governments direct resources to those parts of the system that will most effectively deliver the optimal health and social support services to people with dementia and their carers and families. It is also clear that these services are most effective when they span the continuum of care and support, from prevention and early intervention, to timely diagnosis, carer and client support in the community, to high level end of life support. A national strategy is needed which addresses all of these areas.

**A National Dementia Strategy**

Alzheimer’s Australia strongly urges the Government to develop and implement a National Dementia Strategy, to ensure a comprehensive and co-ordinated approach to addressing dementia in Australia. Alzheimer’s Australia understands the Dementia Working Group, a joint jurisdictional group under the Australian Health Ministers’ Advisory Council, has finalised the draft National Framework for Action on Dementia. While we continue to support this Framework, we are cognisant that the public and sector consultations on this strategy took place in 2013. We recommend that the work done towards the Framework be taken further to develop a full National Dementia Strategy taking into account the issues and priorities raised below.

A holistic approach to dementia care begins with raising awareness amongst the general population, and spans the provision of services to people with dementia and their families from point of diagnosis, through to appropriate end of life care. An individualised approach to care involves understanding not only the unique characteristics of the disease but also what it means for that person to live well with dementia and how they can be supported to do so. This involves focusing on the social, emotional, physical, and health needs of the person with dementia as well as their carers and family members.

A comprehensive approach has the potential to produce significant social and economic benefits. While dementia is not curable, effective risk reduction and preventative health measures can delay the onset of dementia for up to five years. Effective early intervention and psychosocial support for people with dementia and their carers can increase quality of life, reduce stress and sometimes delay admission to residential care. 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 hospitals stay and associated expenditure.

Evidence suggests that the complex needs of people with dementia cannot be supported through mainstream health and aged care services alone\(^\text{15}\). There is a need to also fund dementia-specific specialist services which can provide the care, support and social engagement that people with dementia and their families need. Targeted programs and services can lessen the burden and reduce dementia-related costs across the broader health and aged care sector.

Alzheimer’s Australia has identified **seven priority areas** that need to be addressed in a National Dementia Strategy\(^\text{16}\):

1. Awareness and risk reduction;
2. Timely diagnosis and post diagnostic support (including early intervention);
3. Sector education and training;
4. Carer support and respite;
5. Access to ongoing care and support;

\(^{15}\) Report for the Department of Health and Ageing commissioned from Alzheimer’s Australia, December 2011

\(^{16}\) As prioritised by people living with dementia and their carers and families.
6. Access to end of life and palliative care; and
7. Increased investment in dementia research, with an emphasis on translational research and consumer involvement in all aspects.

A coordinated National Dementia Strategy should include:
- Awareness raising of dementia within the general community;
- A national awareness campaign to reduce the stigma and social isolation associated with the disease;
- Promotion of risk reduction and preventive health measures, which are critical in the absence of a cure for dementia;
- Facilitation of easy access to comprehensive information about dementia for the general public as well as people with dementia, their families and carers;
- Awareness raising and training for GPs and relevant health professionals to improve diagnosis and reduce the average length of diagnosis (which currently takes on average three years);
- Opportunities for people with dementia to continue to be active participants in their community or workplace after diagnosis (including volunteer opportunities);
- Support for carers and family members who care for or support a person with dementia through services that include information provision, social support, respite, and counselling;
- A commitment to working with people with dementia to better understand what person-centred care means for them, and in turn educate service providers on service delivery co-design;
- Facilitating the use of dementia-friendly environmental design in hospitals and residential care homes;
- Ongoing development of assistive technologies that improve communication, sensory and therapeutic interventions and safety;
- Increased use of technology to ensure a better service reach to rural and remote areas.
- Sustained investment in training and support for a qualified workforce;
- Development of an evidence based strategy to reduce the use of chemical and physical restraint on people with dementia, particularly in residential care;
- Better recognition that dementia is a terminal illness and that people with dementia have the right to access end of life care that respects their wishes and dignity;
- Involvement of people with dementia in all levels of service and research design to ensure that best practice care is meeting the needs of those most affected;
- Increased investment in dementia research, with consumer involvement in all aspects of dementia research in Australia.

Alzheimer’s Australia has also been involved in the initial stages of the development of the National Strategic Framework for Chronic Conditions. Through the initial stages of this process and in ongoing consultation for this, Alzheimer’s Australia will be reinforcing the importance of dementia being recognised as a core focus area, given the current associated burden of disease and dementia’s links to other chronic conditions.
Recommendations

That the Government:

1. Develop a National Dementia Strategy to enable a comprehensive and coordinated approach to addressing dementia.

2. Include dementia as a core component of the National Strategic Framework for Chronic Conditions, recognising it represents a significant burden of disease and is closely linked with other chronic disease, including through common risk factors.

The role of primary care in the diagnosis and treatment of dementia

General practice is often the first point of contact for people with dementia, and the primary care system is responsible for much of the ongoing medical management and care throughout the 5-15 years of the dementia journey. It is critical that general practice and other primary health care providers can effectively deliver timely diagnosis of dementia, accurate assessment, and access to appropriate information, interventions, care and support.

Given the significant burden of dementia in our community, the involvement of primary health care professionals in the diagnosis and treatment of dementia is not yet optimal. Each year, 0.5% of all GP visits (approximately 500,000) involve dementia, with 0.02% of government-subsidised prescriptions being dementia-specific. It would appear that there is potential for greater engagement of primary health care professionals, particularly general practitioners and primary health care nurses, in the diagnosis and treatment of dementia.

Timely detection and better diagnosis can facilitate appropriate interventions to enable dementia to be better managed; can reduce the requirement for repeated GP visits and tests; and can enable the individual to consider forward planning issues such as advance care directives, guardianship, and power of attorney. The vast majority (94%) of Australians indicate that they would see their GP if they were worried about their memory. Yet as many as two thirds of people with dementia live and die with the condition, without ever being diagnosed. Amongst the minority who do receive a diagnosis, the average time between first symptoms and diagnosis is 3.1 years.

The diagnosis of dementia is different from that of many other diseases as there is no simple test that provides a definitive diagnosis. Instead, cognitive assessment must be combined with information from family members, medical tests and self-reporting in order to determine a diagnosis. As a result, many GPs find it difficult to differentiate dementia from the normal changes in memory and thinking associated with ageing.

This high level of non- and late-diagnosis 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.

17 Australian Institute of Health and Welfare (2012) Dementia in Australia
18 Australian Institute of Health and Welfare (2012) Dementia in Australia

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Delays may also be due to the individual’s reluctance to present for diagnosis. In a recent Australian survey, 60% of respondents indicated that they would feel a sense of shame or humiliation should they be diagnosed with dementia, and would fear that their diagnosis would mean they would be discriminated against both in the community and the health sector. As a result, nearly a quarter of people indicated that they would delay seeing a health practitioner for as long as possible. In addition, family members may have noticed signs of change in the cognitive function and capacity of a loved one, but may not be able to discuss their concerns with the loved one’s GP, because of confidentiality issues or because the GP is not reimbursed to spend time consulting with carers.

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. Obtaining a timely diagnosis of dementia can be even more problematic for people with younger onset dementia, those from diverse cultural backgrounds, and those from Aboriginal and Torres Strait Islander communities.

Primary health care professionals, including GPs, may also lack information and confidence with regard to treatment and referral pathways for people with dementia. The development of clear referral pathways to specialist dementia services would assist in this area.

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.

Alzheimer’s Australia supports the introduction of system wide changes to the diagnosis of dementia in primary care to better support GPs and primary health care nurses, and provide improved outcomes for people with dementia.

**Recommendations**

That the Government:

3. Embed 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.

4. Include cognitive assessment in the 75+ health assessment.

5. Promote home medicine reviews to check for medications that may cause or exacerbate cognitive impairment, and to ensure adequate management of current medication.

6. Develop 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.

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7. Provide 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.

Enhancements to the Medicare Benefits Schedule (MBS)
In 2012, the Ministerial Dementia Advisory Group made the following recommendations on changes to primary care to better support people with dementia to have access to timely diagnosis and effective management of dementia in primary care. Alzheimer's Australia continues to support these recommendations, and would encourage the Committee to consider the recommendations in relation to the MBS Review Taskforce announced in the 2015-16 Federal Budget, which will consider how services can be aligned with contemporary clinical evidence and improved health outcomes. As noted above, these recommendations were made with a view to improving timely diagnosis and disease management at the primary care level, which reflects clinical best practice and aims to improve patient outcomes.

Recommendations
That the Government:
8. Allow reimbursement through the Medicare Benefits Schedule (MBS) for time spent by health professionals assessing, diagnosing and managing dementia and consulting with carers.
9. Add MBS item numbers for:
   a) Cognitive function assessment, using validated tools, to allow GPs and credentialed health professionals to conduct an assessment if they have concerns.
   b) Practice nurses to do in-home cognitive function assessment.
10. Expand existing psychology MBS item numbers for neuropsychological testing of people who may have dementia.
11. Modify MBS item numbers:
   a) 348 and 350 to make them available to GPs for discussions with informants, both before and after diagnosis, including family members and carers.
   b) 707 to allow targeted examination and assessment of symptomatic changes in memory and thinking.
   c) 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.

Prevention and risk reduction
Research over the last decade has shown that addressing behavioural and related clinical risk factors can help to reduce a person’s risk of dementia. Research indicates that up to a third of cases of Alzheimer’s disease are potentially attributable to preventable risk factors. It is estimated that a 10-25% reduction in type 2 diabetes, hypertension, obesity, depression, physical inactivity, smoking and cognitive inactivity could prevent as many as 1.1-3.0 million cases of Alzheimer’s disease worldwide.

Most of these behavioural and related clinical risk factors are common risk factors for other chronic conditions. While there is increasing community awareness of the link between behavioural risk factors and physical health status, there is little awareness of the links between these behaviours and the risk of dementia.

Two out of three Australians are afraid of developing dementia – a fear second only to the fear of developing cancer\(^{26}\). There is a real opportunity to translate this fear into a motivation to make behavioural changes in an effort to avoid dementia. Behavioural changes which reduce risk for dementia will of course have the added benefit of reducing people’s risk of developing other chronic conditions.

A comprehensive social marketing campaign is needed to create awareness amongst Australians about brain health, and alert people to the links between their health behaviours, their risk of cognitive impairment and dementia, and their risk of developing other chronic conditions.

A multi-pronged, multi-sectoral approach across services and settings is needed to facilitate the integration of dementia risk reduction with risk reduction for other chronic diseases. The sharing of resources across these settings will ensure a cost-effective national preventive health strategy. It may also provide increased incentive for individuals to not only look after their physical health but their brain health as well. Further resources are needed to support these partnerships as well as local education initiatives.

**Recommendations**

That the Government:

12. Implement a comprehensive ongoing social marketing campaign to create awareness among Australians about brain health, and alert people to the links between their health behaviours, their risk of cognitive impairment and dementia, and their risk of developing other chronic conditions.

13. Implement a multi-pronged, multi-sectoral approach to facilitate the integration of dementia risk reduction with risk reduction for other chronic diseases, including through partnerships and local education initiatives.

**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 vital need for a national dementia strategy; the role of primary health in addressing dementia; the ways in which the Medicare Benefits Schedule can support this role; and the importance of risk reduction and prevention programs in dementia, in particular as they relate to lifestyle factors and other chronic disease.

The recommendations outlined in this document focus on the importance a comprehensive and strategic approach to dementia, including the role of the primary health care sector. Alzheimer’s

\(^{26}\) Pfizer Health Report (2011) *Dementia’s Everybody’s Business*
Australia is hopeful this Inquiry leads 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.