



HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH

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

SPEAKING NOTES FOR AANO REPRESENTATIVES

21 AUGUST 2015

OPENING ADDRESS

Graeme Samuel, National Chairperson

Thank you for the opportunity to address the Committee. As you know, Alzheimer's Australia is the peak national body supporting and advocating for people with all forms of dementia, and their carers.

It won't surprise you to hear that we strongly believe that dementia is the most significant of the chronic disease that will face our nation in the decades ahead, and also the least recognised and least well understood.

Dementia is a terminal and devastating condition that robs people of their abilities and memories. It is cloaked in stigma and misunderstanding, it isolates people from their social networks, and it carries enormous social and economic consequences.

As our population ages, and as more of us survive the diseases of mid-life, more of us – both in terms of raw numbers, and as a proportion of the population – will experience dementia. The Framingham Study has found that for those of us who reach the age of 65 without having developed dementia, the risk we have of developing dementia in our remaining lifespan is 20% for women and 17% for men¹. The higher lifetime risk for women is mainly due to women's longer life expectancy.

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

Yet dementia is one of the most under-diagnosed of chronic diseases. I've said that one fifth of us in this room can expect to develop dementia, but if nothing changes, only one in three of those of us who get dementia can expect to be correctly diagnosed. Without timely diagnosis, what chance do we have to receive the appropriate interventions and treatment?

I know that if I'm in that one in five of us who develops dementia, I'd want to be diagnosed as early as possible. I would want to have the opportunity to put an advance care plan in place for my future medical treatment, and to put other measures such as power of attorney in place to be well prepared for the future point where I may no longer be able to make clear, informed decisions.

I'd want to have access to the latest, evidence-based interventions and treatments, because I know that although there is currently no cure for dementia, there are interventions such as targeted medications that can help some people to maintain their cognitive function for longer. I'd also want to have good care and support in the community, so that I could keep living in my own home for as long as possible; and I'd want my carers to also have education, support, and access to respite care to help them in their journey.

¹ Sehadri S, Belser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB et al, The lifetime risk of stroke: Estimates from the Framingham Study. *Stroke*, 2006; 37 (2):345-50; cited in Alzheimer's Association (USA) *2013 Alzheimer's Disease Facts and Figures* p 19. www.alz.org/downloads/facts_figures_2013.pdf

If the point comes where I need to be admitted to residential care, I want to know that I'll receive high quality, personalised and compassionate care, and that I won't be repeatedly hospitalised simply because there is inadequate medical care available at the facility where I live. And as my journey draws towards its end, I would want to be provided with high quality palliative care so that I can have a good death, and so that the stress and grief for my family members can be ameliorated.

But just to be clear, my preference would be to not develop dementia in the first place. I'm keen to know now what the evidence says I can do to reduce my risk of dementia, and to put this into action. I'm also keen to see more research on what can be done to prevent dementia, to slow down its progress, and perhaps even in the future to reverse its effects.

What I want for myself is of course also what I'd want for my loved ones, and I believe it's what each of you, likewise, would want for yourselves and your loved ones. And it's what we should all be trying to achieve for the people of Australia. We are, unfortunately, very far from that vision at the moment.

As leaders and policy makers, we urgently need to take action to better equip Australia to respond to the challenge of dementia. We need to act both in the interests of improving the lives of people with dementia and their carers, and also in the interests of ensuring the sustainability of our health and aged care systems. Our nation needs a serious plan to achieve this, a plan which includes, and goes beyond, the role of primary health care in dementia.

I'll hand over now to our National CEO, Carol Bennett.

Carol Bennett, National CEO

Thank you. Continuing on from what our Chair has said, at a systems level, the care and support of people with dementia is one of the largest health care challenges facing Australia.

- It's estimated that there are now more than 340,000 Australians living with dementia² and over a million people involved in their care³.
- By 2050 there will be nearly 900,000 people with dementia⁴ - much more than double the number we have now.
- 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 2050⁵.
- Dementia already 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 annum⁶. This can only be expected to grow exponentially.

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

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

⁴ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁵ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

⁶ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

To answer the enormous challenge that dementia presents, at both a human level and a systems level, we urgently need a **national dementia strategy**, and this is the first and over-arching recommendation Alzheimer's Australia makes to this Inquiry. Any initiatives to enhance the role of primary care in dementia should be considered in the context of a comprehensive national strategy. 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.
- And increased investment in dementia research, with an emphasis on translational research and consumer involvement in all aspects of dementia research in Australia.

We also recommend that dementia be included as a **core component of the National Strategic Framework for Chronic Conditions**, as it represents a significant burden of disease and is closely linked with other chronic diseases, including through common risk factors.

This brings us to the **role of primary health care in dementia**. Primary health care professionals have a key role to play in timely diagnosis and treatment of dementia, and appropriate referral to other services. Supporting and educating primary health care professionals, particularly GPs and primary health care nurses, to work more effectively in dementia, is a sustainable and cost-effective way of improving the journey for people with dementia and their carers.

To better utilise the role of **primary health care professionals**, Alzheimer's Australia recommends that the Government:

- Embed a systematic, competency-based approach to cognitive assessment in general practice, including the input of family members and carers.
- Include cognitive assessment in the 75+ health assessment.
- Promote home medicine reviews to check for medications that may cause or exacerbate cognitive impairment, and to ensure adequate management of current medication.
- Develop clear referral pathways to specialist dementia services, that are accessible to all individuals regardless of financial situation or geographical location.
- 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.

Our **financing system** for primary health care, particularly general practice, needs to support the role of primary health care in the diagnosis and management of dementia, and this is why Alzheimer's Australia recommends that the Government:

- Allow reimbursement through the MBS for time spent by health professionals assessing, diagnosing and managing dementia and consulting with carers.
- Add MBS item numbers for cognitive function assessment, using validated tools, to allow GPs and credentialed health professionals to conduct an assessment if they have concerns; and for practice nurses to do in-home cognitive function assessment.
- Expand existing psychology MBS item numbers for neuropsychological testing of people who may have dementia.
- Modify several other MBS item numbers as specified in our written submission, to facilitate GP discussions with informants such as family members and carers, both before and after diagnosis; to allow targeted examination and assessment of symptomatic changes in memory and thinking; and to recognise a carer as an important person who qualifies as a 'service provider' for case conferences, and allow the inclusion of an appropriate professional such as a general practice nurse in the role of case coordinator.

Finally, Alzheimer's Australia strongly argues for a greater focus on prevention of dementia, through greater awareness of and reduction in risk factors. Surveys show that Australians are afraid of developing dementia, in a way that we're not particularly afraid of developing diabetes or heart disease. We can harness this fear in a positive way, by letting people know that there are things they can do to reduce their risk of dementia. And if people take action to reduce their risk of dementia, for example by exercising more, eating better, and staying socially engaged as they get older, the spin off will be that they'll also be reducing their risk for other chronic conditions like diabetes and heart disease. We recommend that the Government:

- 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.
- Implement a multi-pronged, multi-sectoral approach to facilitate the integration of dementia risk reduction with risk reduction for other chronic diseases.

Dementia is one of the major chronic diseases of this century. Our nation needs 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.

Thank you, we would be happy to take any questions or expand on anything we've said.

QUESTIONS AND ANSWERS ADDRESSING THE TERMS OF REFERENCE

Term of reference 1: Examples of best practice in chronic disease prevention and management, both in Australia and internationally.

Can you give us any examples of best practice in the prevention and management of dementia?

One example is the specialist assessment and diagnosis of dementia 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 the diagnosis of cognitive symptoms, and referral to appropriate services. The services also 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 enables people to walk off the street and have an assessment that is fully covered by Medicare. A review of the CADMS model in Victoria found that the services were effective in providing assessment, diagnosis and education to people from a range of backgrounds at a relatively low cost. Consideration should be given to assessing the costs and benefits of models such as this to get a more systematic approach across Australia.⁷

Term of reference 2: Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management.

How could the MBS system support better care for people with dementia?

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

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

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

It is well recognised that engagement of general practice with residents in aged care facilities is often inadequate, and this contributes to costly hospitalisations. Better incentives are needed to increase participation by GPs and primary health care nurses in care provision in this setting. Better engagement would assist in reducing avoidable hospital admissions.

⁷ Alzheimer's Australia National Office (2012) Submission to the House of Representatives Standing Committee on Health and Ageing Inquiry into Dementia: Early Diagnosis and Intervention, pp 17-18.

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

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

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

Term of Reference 3: Opportunities for the Primary Health Networks to co-ordinate and support chronic disease prevention and management in primary health care.

Do you have any ideas regarding how the Primary Health Networks could co-ordinate and support prevention and management of dementia in primary care?

The new Primary Health Networks potentially have a critical role to play in areas such as:

- Ensuring co-ordination and collaboration between Commonwealth-funded and State/Territory funded services, across the health, aged care, and disability sectors in particular, to ensure that people with dementia and their carers have access to seamless, person-centred care and support services.
- Developing and promoting locally contextualised referral pathways for people with dementia or memory concerns, from front-line primary care to appropriate specialist and community services. The need for such pathways has been identified in consultation with consumers, service providers, clinicians, and experts, and has been recommended by at least two Australian reports in recent years⁸.

⁸ KPMG (2011) *Dementia services pathways – an essential guide to effective service planning*. This report also refers to a NSW Health project making similar recommendations.

Term of Reference 4: The role of private health insurers in chronic disease prevention and management.

Do you see a role for private health insurers in improving care for people with dementia?

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

As private health insurers have financial incentives to keep members out of hospital, they are well positioned to develop innovative programs to support their members with chronic and complex conditions in the community, including dementia. Several health insurers have well developed approaches and models for addressing the needs of their insured members with dementia⁹.

It will be important however to ensure that we do not develop a two-tiered system, where people without private health insurance lack access to best practice models of dementia care. Government could potentially partner with private health insurers in the development of innovative models, or purchase such programs for non-insured populations, with appropriate quality and safety assurance in place.

Term of Reference 5: The role of state and territory governments in chronic disease prevention and management.

Do you have any comments on the role of state and territory governments in the prevention and management of dementia?

State and Territory governments have an important role in areas such as:

- Providing appropriate community-based and specialist services which support people with dementia to live at home and reduce potentially avoidable hospitalisations.
- Ensuring that people with dementia who are admitted to hospital are provided with care that aligns with their advance care plans, where these exist, and are not provided with “heroic” interventions which do not comply with their expressed choices.

Co-ordination with Commonwealth-funded services is vital, and the Primary Health Networks should have a key role in facilitating this co-ordination.

Term of Reference 6: Innovative models which incentivise access, quality, and efficiency in chronic disease prevention and management.

Are there innovative models in dementia prevention and management that could be considered for broader adoption?

Care co-ordination is an area ripe for innovation. Each person with chronic and complex conditions, particularly dementia, should have an identified care co-ordinator with expertise in their issues, available over time and across settings to assist the person and their carers to navigate the system (health care, community care, acute care, aged care, disability services, etc), and to make informed decisions to manage their care.

⁹ For example, Bupa's approach is outlined at: <http://bupaagedcare.com.au/our-approach/Dementia-Hub/Dementia-Best-Practice>

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

Alzheimer's Australia supports the broader development of a Dementia Link Worker model, with the role of the worker being to provide support, advice, and advocacy for the person with dementia and their family/carers. Such workers would be based in a wide range of settings across health and aged care services, and would link people with support groups, education and information, and services¹⁰.

Term of reference 7: Best practice of multidisciplinary teams chronic disease management in primary health care and hospitals.

How can primary health care be improved for people with dementia?

General practice is often the first point of contact for people with dementia¹¹, 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.

Are there best practice models in place in Australia?

Work has been done to develop guidelines and approaches to promote best practice in dementia management in general practice. For example, the Royal Australian College of General Practitioners (RACGP) has developed a number of guidelines and clinical updates on dementia diagnosis and management¹², but we do not have information on the level of uptake and implementation of these approaches.

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

¹⁰ Alzheimer's Australia National Office (2012) Submission to the House of Representatives Standing Committee on Health and Ageing Inquiry into Dementia: Early Diagnosis and Intervention, pp 22-23.

¹¹ Australian Institute of Health and Welfare (2012) Dementia in Australia

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

Are there issues around timely diagnosis of dementia by GPs?

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 memory¹³. Yet as many as two thirds of people with dementia live and die with the condition, without ever being diagnosed¹⁴. Amongst the minority who do receive a diagnosis, the average time between first symptoms and diagnosis is 3.1 years¹⁵.

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.

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.¹⁶ 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 communities¹⁷.

¹³ Market research conducted for Alzheimer's Australia by Newspoll. September, 2004.

¹⁴ 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

¹⁵ Speechly, C. (2008). The pathway to dementia diagnosis. Medical Journal of Australia, 189, 487-9

¹⁶ Phillipson, L., Magee, C., Jones, S., & Skladzien, E. (2012). Exploring Dementia and Stigma Beliefs. Alzheimer's Australia.

¹⁷ 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.

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.

Alzheimer's Australia recommends a systematic, competency-based approach to cognitive assessment be embedded 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. Cognitive assessment should also be included in the 75+ health assessment; and home medicine reviews should be promoted, to check for medications that may cause or exacerbate cognitive impairment, and to ensure adequate management of current medication. There is also a need to 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.

Could nurses potentially play a bigger role in the assessment and management of dementia in primary care?

Yes. 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. This includes the provision of 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. An accredited training program and incentives to promote greater involvement by nurses should be considered.

Can better primary care for people with dementia save costs to the system?

Yes, undoubtedly. To give just a few examples of areas where major cost savings are possible:

- **Greater focus on risk reduction at primary care level could reduce the number of people developing dementia or delay its onset in many people.** While dementia is not curable, effective risk reduction and preventative health measures can delay the onset of dementia for up to five years.
- **Timely diagnosis, effective early intervention, and good care in the community including psychosocial support for people with dementia and their carers, can delay admissions to residential aged care facilities** and enable people diagnosed with dementia to live in the community for longer, with better quality of life. Each year that a person can live in the community before being admitted to residential care offers significant savings to the health and aged care system, as well as benefits for the individual's quality of life.

- **Better access to primary health care both for people with dementia living in the community, and for those in residential aged care, has the potential to reduce avoidable hospital admissions.** People with dementia are major users of hospital services, largely due to the fact that dementia is a chronic health condition, which most commonly affects older people who are more likely to have other chronic conditions. People with dementia generally have a longer length of stay within a hospital than other patients, leading to greater costs to the health system.¹⁸ 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.¹⁹ Effective programmes in the community and residential care can reduce unnecessary admissions to hospital; and dementia-focused programs in acute care can reduce length of hospital stay and associated expenditure.

Term of reference 8: Models of chronic disease prevention and management in primary health care which improve outcomes for high end frequent users of medical and health services.

Do you know of any models for primary care for people with dementia which improve outcomes for high end users?

Key approaches to improve outcomes for high end users [as outlined above] include:

- Uptake of best practice guidelines in general practice.
- Implementation of care co-ordination through models such as the Key Worker program/Dementia Link Workers.
- Referral to specialist services such as the Cognitive, Memory and Dementia Service (CDAMS) in Victoria.

OTHER QUESTIONS AND ANSWERS

How would we measure the success of any new strategies to improve the role of primary care in diagnosis and management of dementia?

Suggested outcomes measures that could be considered include:

- A reduction in the average treatment gap from first symptoms to diagnosis from the current 3.1 years, down to 12 months, over the next 5 to 10 years;
- Increased rates of dementia assessment and diagnosis in primary care (measurable through analysis of MBS and PBS data);
- Increased community understanding of dementia, to increase help-seeking and reduce stigma and discrimination (measurable through ongoing population surveys);
- Increased rates of referral (above the rate of the growth in dementia prevalence) of people with memory and related concerns to specialist medical, nursing, and allied health services;

¹⁸ Australian Institute of Health and Welfare (2013) Dementia care in hospitals: costs and strategies.

¹⁹ Australian Institute of Health and Welfare (2013) Dementia care in hospitals: costs and strategies.

- 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;
- An increase in the number of people with dementia who have in place formal advance health directives and other 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.²⁰

Are there particular issues for Aboriginal and Torres Strait Islander people with dementia?

Yes. Aboriginal and Torres Strait Islander people have different risk factors and patterns of dementia incidence and prevalence than other parts of the Australian community. Preliminary data indicate that there is a relatively high prevalence of younger onset dementia amongst Aboriginal people²¹. Aboriginal and Torres Strait Islander people may also face barriers in implementing the mainstream primary health care system and require culturally appropriate care. This creates particular issues for diagnosis and management of dementia in primary care settings in Aboriginal and Torres Strait Islander communities.

Alzheimer’s Australia is committed to ensuring that the needs of Aboriginal and Torres Strait Islander people are met in all aspects of service provision, information, support and education. We have established a National Aboriginal and Torres Strait Islander Dementia Advisory Group to provide consultation and advice on these issues. We released a report last October reviewing all the research relevant to Aboriginal and Torres Strait Islander people with dementia²², which put forward several recommendations as follows [these are paraphrased]:

- Dementia should be incorporated into pre-existing preventive health strategies and programs aimed at lowering the risks associated with diabetes and cardiovascular disease.
- The *Your Story Matters* resources (which promote brain and body health for Indigenous Australians) should be disseminated widely to target modifiable risk factors associated with dementia.
- Access to support services for Aboriginal and Torres Strait Islander people with dementia and their carers needs to be improved, particularly in remote areas.
- Awareness and education programs should be delivered to Aboriginal and Torres Strait Islander communities to raise the profile of dementia.
- Training packages including culturally appropriate assessment tools are needed for primary health care professionals, to improve timely diagnosis.
- Alzheimer’s Australia key works should be funded to work alongside Aboriginal Health Workers, to support better access to services.
- Mainstream aged and community care services need to work closely with Aboriginal community controlled health organisations.
- Education and awareness of palliative care is needed, for Aboriginal and Torres Strait Islander communities and health works.

²⁰ Alzheimer’s Australia National Office (2012) Submission to the House of Representatives Standing Committee on Health and Ageing Inquiry into Dementia: Early Diagnosis and Intervention, pp 6-7.

²¹ Smith, K et al (2008) High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology*, 71(19), 1471-3.

²² Flicker L, Holdsworth K (2014), *Aboriginal and Torres Strait Islander people and dementia: A review of the research*. A report for Alzheimer’s Australia, Paper 41. https://fightdementia.org.au/sites/default/files/Alzheimers_Australia_Numbered_Publication_41.pdf

- Further research is needed on appropriate palliative care for these communities.

Can you tell us more about what you think needs to be in a National Dementia Strategy?

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. We need to make it possible for people with dementia, and their carers, to be supported to live well with dementia.

A comprehensive approach has the potential to produce significant social and economic benefits. Alzheimer's Australia, after consulting with people with dementia and their families, has identified **seven priority areas** that need to be addressed in a National Dementia Strategy:

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;
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.

Why the strong interest in 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 factors²³. 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 worldwide²⁴.

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 cancer²⁵. 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.

50% of Australians are unaware that they may be able to reduce their risk of dementia²⁶. 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.

Alzheimer's Australia recommends the development and implementation of a comprehensive ongoing social marketing campaign to create awareness among Australians about brain health,

²³ Barnes DE, Yaffe K. (2011) *The projected effect of risk factor reduction on Alzheimer's disease prevalence*.

²⁴ Barnes DE Yaffe K (2011). *The projected effect of risk factor reduction on Alzheimer's disease prevalence*

²⁵ Pfizer Health Report (2011) *Dementia's Everybody's Business*

²⁶ KPMG (2011) *Dementia services pathways – an essential guide to effective service planning*, p.6.

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. We are also keen to see 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.

What is the role of 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 care²⁷. 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.

Is there anything you'd like to say in conclusion?

Just to reiterate, 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.

²⁷ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

We need a comprehensive and strategic approach to dementia, encompassing and going beyond the role of the primary health care sector. Alzheimer's 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.