The Parliament of the Commonwealth of Australia

Thinking Ahead

Report on the inquiry into dementia: early diagnosis and intervention

House of Representatives
Standing Committee on Health and Ageing

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Canberra

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Foreword

In less than 40 years the number of people living with dementia in Australia is projected to triple. This equates to around 900,000 people with dementia by 2050. It is clear that Australia must plan now to develop a strong system of services and supports to meet the ongoing needs of people living with dementia, and their families and carers.

The potential benefits of early diagnosis and early intervention are far-reaching. An early diagnosis of dementia allows those who receive it to access appropriate treatments at the earliest opportunity, and to make informed choices about their current and future care needs. They can also make important decisions about their legal and financial affairs, while they have capacity to do so. Early diagnosis has the potential to improve quality of life for a person with dementia, and for their family and carers.

The basis of the Committee's report is the diverse and wide-ranging evidence acquired during the 17 public hearings held across Australia, and featured in the 112 written submissions. Evidence was received from professionals working within the health, aged, disability and dementia care sectors, including medical researchers, medical practitioners, community workers and advocates from a range of consumer groups. Importantly, the Committee also heard directly from people affected by dementia – that is from people living with a diagnosis of dementia, their family members and their carers. This latter group a real insight into the challenges they experience and priorities for the future.

Unfortunately, evidence indicates that there is a lack of dementia awareness within the wider community. Misinformation about dementia has contributed to a widespread belief that dementia is an inevitable consequence of ageing, and that nothing can be done to delay onset or slow progression. Furthermore, stigma remains a significant barrier. It seems that many people are reluctant to seek an assessment when they notice signs of cognitive decline, and that doctors can be reluctant to give a diagnosis of dementia. The need for greater dementia awareness and for destigmatisation to increase opportunities for early diagnosis and intervention was a consistent message.

Aside from the need for greater awareness, several other key themes emerged. Within the health system, the Committee heard there was a lack of linkages and clear pathways of services and supports from diagnosis, to ongoing treatment and management. People felt they needed a 'real person', a case manager, to help connect them and their families and carers to appropriate services and supports.

The Committee heard that GPs, often the first point of contact for a person concerned about signs of cognitive decline, sometimes have difficulty in making a diagnosis of dementia and do not always sufficiently understand the referral pathway to ongoing treatment and support.

The Committee was impressed by the world class and innovative dementia research being conducted in Australia. The Committee believes that further development in research on early diagnosis and intervention is needed. The Committee encourages ongoing government and non-government support for the many facets of dementia research, and has called for an increased effort to determine the influence of psychosocial interventions on brain health.

One of the most important messages which came from the dementia experts in this inquiry was simple: there are choices that people can make right now to improve brain health, and possibly delay the onset of dementia. A healthy lifestyle and continued social engagement appear to be crucial. The Committee has recommended that national awareness campaigns promoting healthy lifestyle choices should feature prominently messages about brain health.

Finally, the Committee heard there is a call to create dementia friendly communities in Australia. These communities engage not only our health sector, but also our banks, transport services, public spaces and all other facets of society, to ensure that people with dementia and their families are valued and able to continue to contribute to society.

In concluding, I offer my thanks to those individuals and organisations that have contributed to the inquiry through submission or by attending one of the public hearings. In particular, I acknowledge the people with dementia and their carers who openly and generously shared their stories with us. I would also like to thank my Committee colleagues for their participation and commitment.

Ms Jill Hall MP
Chair

Membership of the Committee

Chair	Ms Jill Hall MP *(from 27/11/12)*
Deputy Chair	Mr Steve Irons MP
Members	Mr Mark Coulton MP
	Mr Steve Georganas MP *(Chair to 27/11/12)*
	Mr Geoff Lyons MP
	Ms Deborah O'Neill MP
	Mr Ken Wyatt MP

Committee Secretariat

Secretary	Dr Alison Clegg
Inquiry Secretary	Mr Muzammil Ali *(to 11/11/12)*
	Mrs Renee Toy *(from 12/11/12)*
Research Officers	Dr Phillip Hilton *(from 19/11/12)*
	Mr Sean Kelly *(to 11/05/12)*
	Ms Belynda Zolotto
Administrative Officers	Ms Fiona McCann
	Ms Kathy Blunden

Terms of reference

Australia's population is ageing and over the next 20 years the number of people with dementia is predicted to more than double. Early diagnosis and intervention has been shown to improve the quality of life for people with dementia, as well as for family members and carers.

The Committee will inquire into and report on the dementia early diagnosis and intervention practices in Australia, with a particular focus on how early diagnosis and intervention can:

- improve quality of life and assist people with dementia to remain independent for as long as possible;
- increase opportunities for continued social engagement and community participation for people with dementia;
- help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements; and
- how best to deliver awareness and communication on dementia and dementia-related services into the community.

List of recommendations

Recommendation 1

The Australian Government, in collaboration with Alzheimer's Australia and relevant consumer groups, develop and implement a national communication strategy and public awareness campaign to promote greater awareness of dementia, using (but not limited to) the following themes:

- Better public awareness and understanding of dementia;
- Reducing the stigma of dementia and challenging discriminatory behaviour;
- Recognising the early signs of dementia to aid early diagnosis;
- Living well with dementia; and
- The importance of a healthy lifestyle and reducing risk. *(para 3.60)*

Recommendation 2

The Australian Government Department of Health and Ageing, in collaboration with the Minister's Dementia Advisory Group and the Royal Australian College of General Practitioners, develop a national evidence-based dementia training program for General Practitioners, with an emphasis on diagnosis.

Elements of the training program should include:

- Challenging stigma and misconceptions;
- Managing sensitive and difficult conversations in the context of the doctor-patient/carer relationships;
- Current best-practice and implications of latest research; and
- Diagnosis, care and support pathways for people with dementia, their families and/carers. *(para 3.82)*

Recommendation 3

The Australian Government, through the Dementia Outcomes Measurement Suite, develop best practice guidelines for diagnosis of people with intellectual disability. *(para 4.66)*

Recommendation 4

The Australian Government collaborate with the state and territory governments, through the Standing Council on Law and Justice, to develop uniform definitions and guidelines relating to capacity. *(para 4.115)*

Recommendation 5

The Australian Government collaborate with the state and territory governments, through the Standing Council on Law and Justice, to develop uniform definitions and guidelines relating to powers of attorney. *(para 4.136)*

Recommendation 6

The Australian Government collaborate with the state and territory governments to develop a toolkit or guidelines to assist medical/legal professionals, or a person diagnosed with dementia and their carer understand future planning options. *(para 4.154)*

Recommendation 7

The Australian Government Department of Health and Ageing undertake a comprehensive review of the use of existing MBS items to determine whether it is necessary to expand existing items or create new items to support identification, assessment and management of dementia in primary care. *(para 5.38)*

Recommendation 8

The Australian Government Department of Health and Ageing implement early and timely diagnosis in regional, rural and remote communities where access to specialist diagnosis is limited by coordinating multi-disciplinary teams comprising primary health care practitioners and visiting medical specialists, supplemented by primary or specialist assessment provided via telehealth facilities.

The need for multi-disciplinary teams should be assessed at a local level, via Medicare Locals, or other such local health networks. *(para 5.64)*

Recommendation 9

The Australian Government, in consultation with Health Workforce Australia, develop an accredited training and support program to increase capacity for specialist nurses to provide dementia assessment and diagnosis in primary care settings, as part of multi-disciplinary teams. *(para 5.91)*

Recommendation 10

The Australian Government Department of Health and Ageing complete and promote practice guidelines for the care of dementia in general practice (or primary care). In consultation with Medicare Locals or other such local health networks, these guidelines should be contextualised and provide information on local dementia care pathways, including information on future planning services, such as legal services. *(para 6.38)*

Recommendation 11

The Australian Government establish clear and streamlined local referral pathways for dementia diagnosis, treatment and support, through Medicare Locals, localised primary health care networks, or other specialist dementia networks such as Memory Clinics. *(para 6.60)*

Recommendation 12

The Australian Government Department of Health and Ageing, in collaboration with the Minister's Dementia Advisory Group, Alzheimer's Australia and Health Workforce Australia, evaluate the creation of a nation-wide multi-disciplinary approach to dementia diagnosis, treatment and support.

Such an approach should build upon the existing workforce and localised infrastructure, such as Medicare Locals and/or Memory Clinics. *(para 6.61)*

Recommendation 13

The Australian Government Department of Health and Ageing examine the case for establishing a Dementia Link Worker program to assist in the ongoing case management of people with dementia and their carers.

A proactive case management approach, utilising a Dementia Link Worker, should include regular scheduled follow up from the time of diagnosis through the progression of the condition. *(para 6.76)*

Recommendation 14

The Australian Government Department of Health and Ageing, as part of the *Living Longer. Living Better.* reforms and through the Council of Australian Governments, trial the following initiatives to investigate their capacity to assist in improving dementia care in acute hospital settings, with a view to these initiatives being implemented nationally:

- The introduction of Clinical Nurse Specialists in dementia in hospitals;
- The introduction of a Cognitive Impairment Identifier in hospitals; and
- The introduction of a protocol for the identification of cognitive issues at the point of triage. *(para 6.95)*

Recommendation 15

The Australian Government should ensure that messages on brain health and dementia prevention are included in all relevant national initiatives and public health awareness campaigns which promote healthy lifestyle choices through diet, exercise, smoking cessation and responsible consumption of alcohol.

Key messages to be included in any future campaigns with relevance to brain health should also promote the importance of mental activity and social engagement. *(para 7.36)*

Recommendation 16

The Australian Government Department of Health and Ageing and/or the National Health and Medical Research Council initiate targeted research into the influence of psychosocial interventions on brain health and the implications for the risk of developing dementia. *(para 7.62)*

Recommendation 17

The Australian Government collaborate with Alzheimer's Australia to develop a set of flexible values and standards which would inform the creation of dementia friendly communities around Australia. *(para 7.86)*

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Conduct and context of the inquiry

1.1 Australia has an ageing population. Between 2010 and 2050 the number of older people (65 to 84 years) in Australia is expected to more than double, whilst the number of very old people (85 and over) is expected to more than quadruple.[1]

1.2 As Australia's aged population increases, so too will the number of individuals suffering from dementia. It is estimated there were 266,574 people with dementia in Australia in 2011.[2] Without new medications to treat dementia, this number is projected to increase to 553,285 people by 2030, and 942,624 people by 2050.[3]

1.3 Internationally, the number of people with dementia is also projected to increase at a similar rate to that of Australia. These projections have resulted in dementia now being recognised as a global public health priority. Concern over the impending escalation of numbers of people with the condition prompted the World Health Organization (WHO) to release a report in April 2012 urging nations to prepare for the increasing burden and cost of dementia. The report notes that:

> There is little doubt that dementia poses one of the greatest societal challenges for the 21st century that must be addressed internationally, nationally and locally, as well as at family and personal levels. Dementia is exceptional in terms of size, cost and impact...worldwide, the large majority of people with dementia and their family caregivers do not benefit from the positive

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[1] Australian Government, *Australia to 2050: future challenges, the 2010 intergenerational report overview*, 2010, p.4.

[2] Deloitte Access Economics Pty Ltd, *Dementia across Australia: 2011-2050*, 9 September 2011, p.15.

[3] Deloitte Access Economics Pty Ltd, *Dementia across Australia: 2011-2050*, 9 September 2011, p.15.

> intervention and support that can promote independence and maintain quality of life.[4]

1.4 Despite this, dementia is underdiagnosed in most if not all health systems in the world, and when diagnosis does occur it is typically at a relatively late stage of the disease process.[5] In releasing the latest aged care reform package, the Commonwealth Government noted that:

> Between 50 to 80 per cent of people with early stages of dementia are not being diagnosed in primary care. For those who are diagnosed, many do not receive a diagnosis until three years after they first notice symptoms.[6]

1.5 Although there is currently a lack of quantitative data, expert opinion is generally of the view that early diagnosis of dementia can be beneficial to patients, carers and society, and should therefore be promoted.[7] The most evident of these benefits is that early diagnosis provides people with the condition the opportunity to plan ahead while they still have the capacity to make important decisions about their future care. This can have important ramifications for continuing quality of life for not only the person with dementia, but also their carers and family.

Referral and conduct of the inquiry

1.6 The inquiry into Dementia: early diagnosis and intervention (the inquiry) was referred to the House of Representatives Standing Committee on Health and Ageing (the Committee) on 20 March 2012. The inquiry was referred to the Committee by the Minister for Mental Health and Ageing, the Hon Mark Butler MP.

1.7 Immediately after referral, details of the inquiry were made available on the Parliament of Australia website and an advertisement was placed in *The Australian* calling for written submissions. The inquiry was also promoted through an extensive mail out to interested parties, including peak bodies and organisations, research institutions and the relevant government departments inviting submissions.

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[4] World Health Organisation (WHO) and Alzheimer's Disease International (ADI), *Dementia: A Public Health Priority*, 2012, p.90.

[5] Alzheimer's Disease International (ADI) 2011, *World Alzheimer's Report 2011: the benefits of early diagnosis and intervention*, September 2011, p.10.

[6] Commonwealth of Australia, *Living Longer. Living Better.*, April 2012, p.22.

[7] ADI 2011, *World Alzheimer's Report 2011: the benefits of early diagnosis and intervention*, September 2011, p. 30.

1.8 Over the course of the inquiry the Committee received 112 submissions from organisations, government authorities and individuals. A list of submissions is at Appendix A. A range of publications, documents and supplementary material tendered during the inquiry was received as exhibits. A list of exhibits is at Appendix B.

1.9 In addition, the Committee undertook an extensive program of public hearings. Between June 2012 and March 2013 the inquiry held 17 public hearings, including 12 interstate public hearings. Details of the public hearings, including a list of witnesses, are at Appendix C.

Context of the inquiry

1.10 The implications for policy and services of Australia's ageing population are increasingly being recognised by all governments at all levels. This is evidenced by the highly dynamic policy environment which seeks to identify, quantify and address the needs of older Australians.

1.11 In this developing and changing policy environment, it is important to consider evidence submitted to the current inquiry in the context of other relevant but parallel processes.

Relevant policy inquiries and reports

1.12 In 2005, the House of Representatives Standing Committee on Health and Ageing tabled a draft report developed by the previous 40th Parliament titled *Future Ageing*.[8] The inquiry focused on the long-term strategies to address the ageing of the Australian population over the next 40 years. The draft report noted the increasing prevalence of dementia and discussed the availability and quality of care for people with dementia. This inquiry did not consider early diagnosis and intervention into dementia, however members of that committee did note that:

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[8] Parliament of Australia, House of Representatives Standing Committee on Health and Ageing, *Report on a draft report of the 40th Parliament: Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years*, March 2005.

> The diagnosis of dementia is not straightforward and the Committee heard that many GPs are not well informed about its diagnosis and treatment.[9]

1.13 The Senate Community Affairs References Committee also released a report in 2005, titled *Quality and equity in aged care*.[10] The terms of reference for the inquiry directed the Committee to investigate the adequacy of aged care arrangements in Australia. This Senate Committee's final report contained extensive discussion regarding the provision of aged care to people with dementia, though did not delve into any matters relating to early diagnosis of the condition.

1.14 In July 2011 the Senate Community Affairs References Committee tabled a report titled *Disability and Ageing: lifelong planning for a better future.*[11] This inquiry examined the planning options and services available to assist people with a disability, and their carers, to plan for the future. Throughout the inquiry, Senate Committee members received evidence detailing the difficulties individuals and carers face in advance planning. Building on some of the evidence received by this Senate inquiry, the current inquiry examines the relationship between early diagnosis of dementia and improved planning for the future.

1.15 Within the 2011 Senate inquiry the Committee also considered the situation of the small minority of people who experience disability coupled with younger-onset dementia. Evidence received raised scenarios in which individuals with early-onset dementia were turned away from aged care services because they were too young. Processes to effectively diagnose, and intervene into, the condition of early-onset dementia is considered further within the current report.

1.16 The Productivity Commission has also published reports relating to aged care. In September 2008 it released *Trends in Aged Care Services: some implications*[12] which examined a range of issues including:

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[9] Parliament of Australia, House of Representatives Standing Committee on Health and Ageing, *Report on a draft report of the 40th Parliament: Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years*, March 2005, p.136.

[10] Parliament of Australia, Senate Community Affairs References Committee, *Quality and equity in aged care*, June 2005.

[11] Parliament of Australia, Senate Community Affairs References Committee, *Disability and Ageing: lifelong planning for a better future*, July 2011.

[12] Australian Government Productivity Commission, *Trends in Aged Care Services: some implications*, Research Paper, 25 September 2008.

- Trends in the demand for, and supply of, aged care services and implications in terms of emerging challenges for services to become more flexible, responsive and efficient;
- Capacity of the aged care workforce to accommodate demands for services in the long term; and
- The scope for productivity improvements in the aged care sector to contain future costs while improving service quality.[13]

1.17 In June 2011 the Productivity Commission released a further report titled *Caring for older Australians*.[14] The report arose from a broad ranging inquiry in which the Productivity Commission was asked to 'develop detailed options to redesign and reform Australia's aged care system and to recommend a transition path to a new system.'[15]

1.18 The report identified several key weaknesses with the current system of aged care noting:

> It is difficult to navigate. Services are limited, as is consumer choice. Quality is variable. Coverage of needs, pricing, subsidies and user co-contributions are inconsistent or inequitable. Workforce shortages are exacerbated by low wages and some workers have insufficient skills.[16]

1.19 The Commission made a number of proposals to address these weaknesses including:

- simplified 'gateway' for consumers to be assessed for services and to access services;
- consumer directed care with more consumer choice and greater flexibility for service delivery;
- simplify and regulate funding options; and
- more support for informal (family) carers and improved career paths and more opportunities for formal carers to make the paid workforce more attractive.[17]

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[13] Australian Government Productivity Commission (Productivity Commission), *Trends in Aged Care Services: some implications*, Research Paper, 25 September 2008, pp. xv.

[14] Productivity Commission, *Caring for older Australians*, Inquiry Report no. 53, 2011.

[15] Productivity Commission, *Caring for older Australians*, Inquiry Report no. 53, 2011, p. xxiii.

[16] Productivity Commission, *Caring for older Australians*, Inquiry Report no. 53, 2011, p. xxii.

[17] Productivity Commission, *Caring for older Australians*, Inquiry Report no. 53, 2011, p. lxxix.

1.20 The Australian Government's May 2012 response to the Productivity Commission report states:

> The Productivity Commission found that Australia's aged care system has many weaknesses and is not well placed to meet the future challenges associated with an ageing population. In particular, the Commission argued the aged care system is difficult to navigate; provides limited services and consumer choice; supplies services of variable quality; suffers from workforce shortages that are exacerbated by low wages and some workers having insufficient skills; and is characterised by marked inequities and inconsistencies in the availability of services, pricing arrangements and user co-contributions.[18]

1.21 The Government response notes that the outcomes of the Productivity Commission's report have 'substantially informed development of the Government's *Living Longer, Living Better* aged care reform package.'[19] The Government response advises however:

> The Department of Health and Ageing estimates that fully implementing the Commission's proposals would involve a significant cost to the Budget. In the current fiscal environment, these costs could not be absorbed in the Budget without significant reductions in other government policy areas and programs.
>
> The Government's aged care reform package, *Living Longer Living Better*, seeks to address the problems identified by the Commission but gives greater weight to the potential difficulties the sector would face in absorbing and responding to significant structural change in the short to medium term.[20]

1.22 The *Living Longer. Living Better.* - aged care reform package is discussed in more detail later in this chapter.

1.23 In February 2013 the Senate Community Affairs References Committee initiated an inquiry into *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD).* The inquiry is examining the scope, adequacy and

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[18] Australian Government, , *Australian Government's Response to the Productivity Commission's Caring for older Australians Report*, May 2012, p. 1.

[19] Australian Government, *Living Longer. Living Better.* April 2012.

[20] Australian Government, *Australian Government's Response Productivity Commission's Caring for older Australians Report*, May 2012, p. 1.

resourcing of various models of care for people living with dementia and BPSD. The Senate Committee is due to report on 26 June 2013.[21]

Australian Government policy frameworks

1.24 Over the years successive governments have implemented a range of policy initiatives to tackle dementia and meet increasing and changing demands for dementia support and services. The following section reviews significant policy initiatives introduced during the last decade.

Dementia as a health priority

1.25 In the 2005-2006 Budget, the then Government acknowledged the significance of dementia by announcing $320.6 million would be provided over five years to support people with dementia and their carers through the *Helping Australians with Dementia and their Carers – Making Dementia a National Health Priority* initiative (the Dementia Initiative).[22] According to a DoHA Budget 2005-2006 Factsheet:

> Identifying dementia as an Australian Government National Health Priority provides focus for collaboration between the Australian Government, State and Territory Governments and other organisations to improve the quality of life and care for people living with dementia.[23]

1.26 The package provided funding for the following measures:

- Dementia – a national health priority supporting:
  - ⇒ additional research;
  - ⇒ improved care initiatives;
  - ⇒ early intervention programs to care for people with dementia;

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[21] Parliament of Australia, *Senate Committees*: *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/dementia/info.htm> viewed 14 March 2013.

[22] Australian Government Department of Health and Ageing (DoHA), *Ageing Budget*, <http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-abudget-afact1.htm> viewed 3 June 2013.

[23] DoHA, *Ageing Budget*, <http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-abudget-afact1.htm> viewed 3 June 2013.

- Extended Aged Care at Home Dementia (EACHD) packages designed to assist people with dementia to remain at home and in their community; and
- Training to Care for People with Dementia initiative to provide dementia training for residential aged care workers and people in the community who come into contact with people with dementia, such as police, emergency services and transport staff.[24]

1.27 In 2009 DoHA commissioned an independent evaluation of the Dementia Initiative. The evaluation found that the Dementia Initiative had made 'a substantial contribution to supporting people living with dementia and their carers', but that 'the lack of integration across Projects and Measures remained the most significant outstanding issue for the Initiative limiting the realisation of its full potential'.[25] The evaluation recommended continuation of the Dementia Initiative albeit with some restructuring to better align with the *National Framework for Action on Dementia 2006-2010* and to address concerns about coordination of projects.[26]

1.28 Another significant milestone was reached in April 2012 when the Standing Council on Health (which brings health ministers across all Australian jurisdictions and New Zealand together) received notice that the Commonwealth Government intended to propose dementia as a National Health Priority Area (NHPA) on the grounds that this would help focus attention and drive collaborative efforts aimed at tackling dementia at national, local and state and territory levels.[27]

1.29 On 10 August 2012 Health Ministers agreed to designate dementia as the ninth NHPA on the basis that this was warranted due to the increased burden of disease and opportunities to make significant gains in the health and well-being of people with dementia, their carers and families.[28] Health Ministers noted:

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[24] DoHA, *Helping Australians with Dementia, and their Carers – Making Dementia a National Health Priority*, Budget 2005-2006, Ageing Factsheet 1, <http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-abudget-afact1.htm> viewed 20 April 2012.

[25] LAMA Consortium, *Dementia Initiative National Evaluation Overview and Summary of Main Findings Final Report*, October 2009, p. 13 & p. 11.

[26] LAMA Consortium, *Dementia Initiative National Evaluation Overview and Summary of Main Findings Final Report*, October 2009, p. 13.

[27] Australian Government, *Living longer. Living Better.* April 2012, p.21. See also, Standing Committee on Health, Communiqué, 27 April 2012, p.1.

[28] The other eight NHPA are: cancer control; cardiovascular health; injury prevention and control; mental health; diabetes mellitus; asthma; arthritis and musculoskeletal conditions; & obesity.

> Recognising dementia as a National Health Priority Area will enhance the development of a new National Framework for Action on Dementia [2013-2017] which will contribute to the current and future work undertaken in response to dementia across Australia.[29]

National Framework for Action on Dementia (NFAD)

1.30 In 2006, Australian health ministers agreed on an action plan to coordinate existing dementia care and support activities. The resulting N*ational Framework for Action on Dementia 2006-2010* (the framework) was developed following a nation-wide consultation that included the combined input of governments, service providers, peak bodies, and people with dementia, their families and carers.[30]

1.31 The five priority areas of the framework were:

- Care and Support services that are flexible and can respond to the changing needs of people with dementia, their carers and families.
- Access and Equity to dementia information, support and care for all people with dementia, their carers and families regardless of their location or cultural background.
- Information and Education that is evidence-based, accurate and provided in a timely and meaningful way.
- Research into prevention, risk reduction and delaying the onset of dementia as well as into the needs of people with dementia, their carers and families.
- Workforce and Training strategies that deliver skilled, high quality dementia care.[31]

1.32 In 2011 the framework was reviewed[32] and the following key findings summarised in the final report:

- The vision, objectives, principles and priorities for action identified within the NFAD were appropriately aligned to that of the various governments (where relevant).

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[29] Standing Committee on Health, Communiqué, 10 August 2012, p.1.

[30] NSW Department of Health on behalf of the Australian Health Ministers Conference, 2006, *National Framework for Action on Dementia 2006-2010*.

[31] NSW Department of Health on behalf of the Australian Health Ministers Conference, 2006, *National Framework for Action on Dementia 2006-2010*, p. 7.

[32] *The Review of the National Framework for Action on Dementia 2006 – 2010* was undertaken by Quantum Consulting Australia Pty Ltd in conjunction with Professor Barbara Horner (Curtin University) and Dr Colleen Doyle (National Ageing Research Institute).

- The NFAD assisted in prioritising the discussion of 'dementia' and formalised the priority for developing appropriate plans and strategies within their jurisdiction.
- There remains a need for a future NFAD, however there are divergent views as to how the NFAD should be designed in the future, for example:
  - ⇒ a series of principles to guide and support jurisdictions' action plans (including articulation with other dementia initiatives that have associated funding); or
  - ⇒ a series of principles and an implementation plan (which demonstrates the relationship of jurisdictional priorities and associated planning with the principles of the NFAD).[33]

1.33 Following the review, the Australian Health Ministers Advisory Council agreed on the need for a new and updated national dementia policy framework. Development of the *National Framework for Action on Dementia 2013-2017* is currently in progress. The NFAD 2013-2017 is being informed by a series of consultations held between April and May 2013 in various locations across Australia. The consultation process also allows for written feedback in response to a consultation paper. According to the consultation paper:

> The new Framework follows the stages of dementia care most people will experience in their journey of dementia as outlined in the Service Pathways Model. It is acknowledged that not all people living with dementia will experience each stage of care or will progress through the stages at the same pace. The new Framework is focused on the following stages of care:
>
> - Risk Reduction, Awareness and Recognition
> - Assessment, Diagnosis and Post Diagnostic support
> - Management, Care, Support and Review
> - End of Life[34]

1.34 Public consultations and submissions on the NFAD 2013-2017 were expected to be completed by 17 May 2013. At the time of writing, the

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[33] Quantum Consulting Australia 2011, *Review of the National Framework for Action on Dementia 2006 – 2010*, Summary of Final Report, pp. 7-8, <http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad-summary-2011> 14 May 2013.

[34] Australian Government, *Consultation Paper National Framework for Action on Dementia 2013-2017*, p. 2, <http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad2013-217> viewed 14 May 2013.

outcomes of the public consultation processes have not been published, though it is expected that these will be available in the near future.[35]

Living Longer. Living Better. – aged care reform package

1.35 The latest initiative of the Australian Government is the *Living Longer. Living Better.* package which came into effect in July 2012. Total funding of $3.7 billion for the package includes designated funding of $268.4 million over five years to tackle dementia.[36]

1.36 Noting that it can take over three years from noticing symptoms to receiving diagnosis, the package included a commitment to provide greater support for the timely diagnosis of dementia. Specifically the package has provision for:

> … primary health care providers to undertake more timely dementia diagnosis. GPs and practice nurses will receive much needed training and education programs and improved support to help them better diagnose dementia. This will reduce the period from symptom onset to diagnosis.[37]

1.37 Other aspects of the dementia package include:

- expansion of the Dementia Behaviour Management Advisory Services (DBMAS)[38] into acute and primary settings;
- a new Dementia Supplement to provide additional financial assistance to those receiving dementia care;
- increased annual funding for service providers to endow staff with training, guidelines and procedures to ensure best practice dementia care;
- additional assistance to people receiving home care packages;
- training for staff in hospitals to identify early signs of dementia particularly at the point of admission and be able to implement appropriate protocols; and

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[35] DoHA, *National Framework for Action on Dementia 2013-2017,* <http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad2013-2017> viewed 3 June 2013.

[36] Australian Government, *Living Longer. Living Better.* April 2012, <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-aged-care-review-measures-living.htm> viewed 20 April 2012.

[37] Australian Government, *Living Longer. Living Better.* April 2012, p. 22.

[38] The Dementia Behaviour Management Advisory Services (DBMAS). See Chapter 2 for more information on DBMAS.

- improved care and support for people with younger onset dementia, their families and carers.[39]

Scope of the inquiry

1.38 The scope of the inquiry is largely defined by the terms of reference which direct the Committee to consider how early diagnosis and intervention can assist people living with dementia and their families to maximise quality of life and plan for the future.

1.39 The timing of the inquiry coincides with a period of significant policy activity resulting in reforms to initiatives to tackle dementia. structural and funding reforms which have implications for access to and delivery of a range of health and aged care services.

1.40 While acknowledging the dynamic policy environment and the broad implications of reforms to the health and aged care sectors, in accordance with the inquiry's terms of reference consideration will be confined to the implications of these reforms in the context of dementia early diagnosis and intervention.

Structure of the report

1.41 Following the introductory material and context presented in Chapter 1, Chapter 2 presents an overview of the demographics of dementia in Australia and a brief outline of the main services available to people living with dementia, and their families and carers.

1.42 Chapter 3 examines the lack of awareness of dementia and stigmatisation of the condition. The chapter considers who needs to be better informed about dementia and their specific information needs.

1.43 Dementia diagnosis is considered in Chapter 4. The chapter outlines the benefits of a timely diagnosis, and examines processes for obtaining a diagnosis. Issues associated with future planning for people once they have received a dementia diagnosis are also considered.

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[39] Australian Government, *Living Longer, Living Better,* April 2012, pp. 22-24.

1.44 Chapter 5 examines barriers to obtaining a timely diagnosis of dementia in a range of medical settings, focusing on how to address barriers at the primary care provider level and at health system level more broadly.

1.45 The post-diagnosis pathway for people with dementia and their carers is discussed in Chapter 6. The focus of the chapter is on how early intervention of dementia may assist to improve quality of life, help individuals to remain independent for as long as possible, and increase opportunities for continued social engagement and community participation. It also examines the need for post-diagnostic services that are designed to meet the differing needs of people with dementia and their families.

1.46 The theme for Chapter 7 is a dementia friendly future. It examines current understanding of actions that can be taken by all Australians to reduce their risk of developing dementia or to slow progression of the condition. The chapter considers the dementia research in Australia, and concludes by investigating the concept of dementia friendly communities.

2

Dementia in Australia – demographics and services

2.1 This chapter offers key data on the prevalence of dementia in Australia. It is not a comprehensive account, but simply provides sufficient context to enable consideration of matters raised in later chapters.

2.2 The chapter also presents an overview of core government supports and services available to people living with dementia, their families and carers. The chapter concludes by acknowledging the contribution by the non-government sector.

2.3 The chapter draws on a range of the available literature, which is vast. Readers interested in a more thorough account should look to the Australian Institute Health Welfare's 2012 publication *Dementia in Australia* which provides a much more comprehensive review of dementia demographics and the delivery of dementia care services.[1]

Impact of dementia

2.4 Dementia is a leading cause of death in Australia. In 2010 (the most recent year for which the data is available) it was the third most common cause of death (after ischaemic heart disease and cerebrovascular disease), with an average of 25 people dying of it each day.[2] This accounts for 6 per cent of all deaths.[3]

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[1] Australian Government Australian Institute of Health and Welfare (AIHW) 2012, *Dementia in Australia*, catalogue no. 70.

[2] Australian Bureau of Statistics (ABS) 2012, *Causes of Death: 2010*, reference number 3303.0, Canberra, p.6.

[3] AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 9.

2.5 Noting the longer life expectancy of women compared to men, it not surprising that data for 2010 indicates that twice as many women died from dementia. The number of deaths directly due to dementia increased by an order of magnitude: 2.4 times between 2001 and 2010. This was due in part to the ageing of the population, but there were also changes in how dementia is recorded on death certificates which may have increased the figures.[4]

2.6 Furthermore, it should be understood that people with dementia also die of other illnesses. Dementia may compound any number of other conditions; thus dementia was recorded as the underlying or an additional cause of 14 per cent of deaths in 2010.[5]

2.7 Medical analysts also rely on a concept called 'burden of disease'. The Australian Institute of Health and Welfare (AIHW) states:

> Estimates of burden of disease quantify the amount of healthy life lost due to premature death and prolonged illness or disability. Estimates for 2011 suggest that dementia was the fourth leading cause of overall burden of disease, and the third leading cause of disability burden. For people aged 65 and over, dementia was the second leading cause of overall burden of disease and the leading cause of disability burden, accounting for a sixth of the total disability burden in older Australians.[6]

2.8 The severity of the condition varies. Dementia was classified as 'mild' in 163,900 people (55 per cent of people with dementia), 'moderate' in 89,400 people (30 per cent) and 'severe' in 44,700 (15 per cent).[7]

2.9 Dementia is also a leading cause of disability and dependency, particularly among older people.[8]

2.10 Dementia has wide ranging implications for carers, families and friends of people living with the condition. For these individuals dementia imposes all manner of stresses and costs, including the cost of opportunities foregone and careers, education or retirement neglected.

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[4] AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 9.

[5] AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 9.

[6] AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 10.

[7] AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 9.

[8] World Health Organisation (WHO) and Alzheimer's Disease International (ADI), *Dementia: A Public Health Priority*, 2012.

What is dementia?

2.11 Dementia is not a single condition. Rather it is an umbrella term that encompasses a range of conditions that affect memory, thinking, behaviour and ability to perform everyday activities.

2.12 Although dementia occurs more commonly in older people, contrary to popular belief it is not an inevitable or 'normal' part of the ageing process. Therefore it is often ignored, rather than viewed as a condition requiring active attention. Furthermore, dementia is not limited to older people. Dementia occurring in people under 65 years is referred to as Younger Onset Dementia (YOD). In 2011, there were an estimated 23,900 Australians under the age of 65 who had dementia, with men accounting for 53 per cent of those diagnosed. Those under 65 represented 8 per cent of all people with dementia in Australia.[9]

2.13 Dementia has been broadly described in the following testimony from Alzheimer's Australia (Victoria):

> Dementia describes a collection of symptoms that are caused by disorders affecting the brain. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life. Most people with dementia are older, but not all older people get dementia and it is not a normal part of ageing.[10]

2.14 Dr Fiona Bardenhagen defined dementia as:

> … a term used to refer to an acquired impairment in memory and cognition. Dementia can take many different forms, can arise from a number of conditions, and while memory impairment is the most common feature, some forms of dementia involve changes in behaviour and language rather than memory in the early stages. As a result, there are a number of different diagnostic criteria for dementia. Some are based on clinical features, and some are based on pathology.[11]

2.15 There are over 100 illnesses and conditions that can result in dementia.[12] The most common types of dementia in Australia are:

- dementia in Alzheimer's disease, estimated to be responsible for around 50–70% of dementia cases, involving abnormal plaques and tangles in the brain;

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[9] AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 15.

[10] Alzheimer's Australia (Victoria), *Submission 35*, p. 2

[11] Dr Fiona Bardenhagen, *Submission 46*, p. 1.

[12] AIHW 2007, *Dementia in Australia: National data analysis and development,* catalogue no. 53, p.5.

- vascular dementia (formerly known as arteriosclerotic or multi-infarct dementia), resulting from significant brain damage caused by cerebrovascular disease—onset may be sudden, following a stroke, or gradual, following a number of mini-strokes or because of small vessel disease;
- dementia with Lewy bodies, in which abnormal brain cells (Lewy bodies) form in all parts of the brain. Progress of the disease is more rapid than for dementia in Alzheimer's disease;
- frontotemporal dementia (e.g. Pick's disease), in which damage starts in the front part of the brain, with personality and behavioural symptoms commonly occurring in the early stages;
- mixed dementia, in which features of more than one type of dementia are present. For example, many people with dementia have features of both Alzheimer's disease and vascular dementia.[13]

2.16 There are also a number of less common types of dementia, including (but not limited to):

- dementia in Parkinson's disease, resulting from the loss of the neurotransmitter, dopamine, in the brain (dopamine is implicated in the control of voluntary movements)—dementia is common in people with Parkinson's but not everyone with Parkinson's develops dementia;
- alcohol-induced dementia (e.g. Wernicke/Korsakoff syndrome), in which brain function deterioration is associated with excess alcohol consumption, particularly in conjunction with a diet low in Vitamin B1 (thiamine);
- drug-related dementia, where neurological deficits result from substance abuse, such as petrol sniffing;
- head injury dementia, which involves brain damage resulting from head injuries;
- Huntington's disease, an inherited disorder of the central nervous system, which is characterised by jerking or twisting movements of the body and is usually eventually accompanied by dementia;
- other forms of dementia such as that developing in the course of human immunodeficiency virus (HIV), or Creutzfeldt-Jakob disease;
- reversible forms of dementia, such as dementia from B12 deficiency or hypothyroidism, which, although rare, are important to identify.[14]

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[13] AIHW 2007, *Dementia in Australia: National data analysis and development,* catalogue no. 53, pp. 5–6.

[14] AIHW 2007, *Dementia in Australia: National data analysis and development,* catalogue no. 53, p. 6.

2.17 Conditions causing dementia are typically progressive, degenerative and irreversible.[15]

Signs and symptoms of dementia

2.18 The common characteristics of dementia involve impairment of brain functions, including speech, memory, perception, personality and cognitive skills. Onset is typically gradual, progressive (in that as the condition develops, the patient deteriorates, and does not improve) and irreversible.[16]

2.19 In the early stages of dementia, individuals may experience difficulty with familiar tasks such as shopping, driving or handling money. As the disease progresses, more basic or core activities of daily living such as self-care (e.g. eating, bathing, dressing, reading, using numbers) may be affected. In some cases dementia results in the affected individual displaying uncharacteristic behaviours (e.g. agitation, apathy or aggression). [17]

2.20 The specific cognitive, psychiatric and behavioural manifestations of dementia may include:

- memory problems, especially for recent events (long-term memory usually remains in the early stages);
- communication difficulties through problems with speech and understanding language;
- confusion, wandering, getting lost;
- personality changes and behaviour changes such as agitation, repetition, following; and
- depression, delusions, apathy and withdrawal.[18]

2.21 For the majority of people with dementia, assistance will eventually be required for activities such as making decisions, managing relationships, coping with feelings or emotions, and undertaking cognitive or emotional tasks.[19] As the condition progresses, people with dementia become increasingly dependent on their care providers in most or all areas of daily living. The AIHW reports that:

> Among the older population, dementia is more likely than other health conditions to be associated with a severe or profound

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[15] Access Economics 2009, *Keeping dementia front of mind: incidence and prevalence 2009-2050*, p.2.

[16] AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 2.

[17] AIHW 2007, *Dementia in Australia: National data analysis and development,* catalogue no. 53, p. xiii–xiv.

[18] AIHW 2007, *Dementia in Australia: National data analysis and development,* catalogue no. 53, p. 5.

[19] AIHW 2007, *Dementia in Australia: National data analysis and development,* catalogue no. 53, p. xiii–xiv.

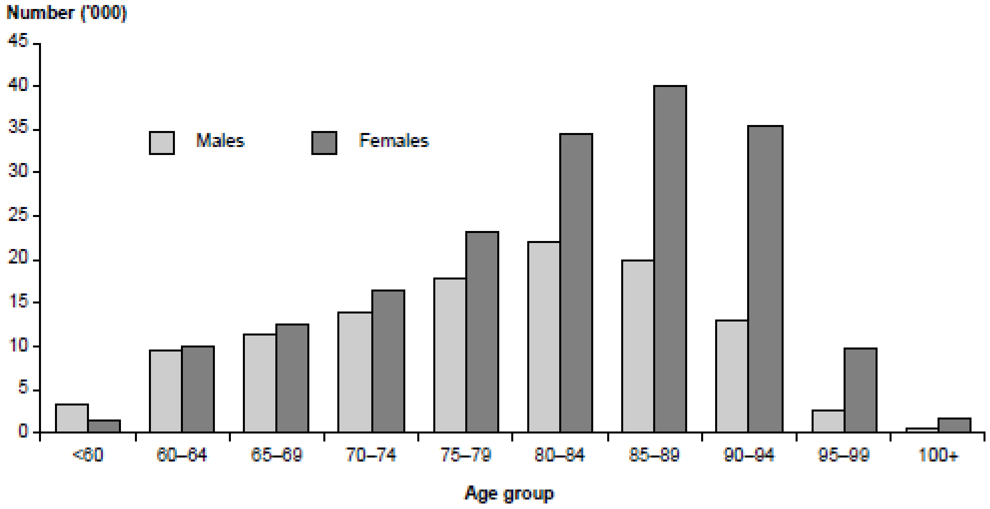
limitation in self-care, mobility or communication, to be a main disabling condition and to be associated with multiple health conditions.[20]

Prevalence of dementia

2.22 In 2011, there were an estimated 298,000 people with dementia, of whom 62 per cent were women and 70 per cent lived in the community. Among Australians aged 65 and over, almost 1 in 10 (9 per cent) had dementia, and among those aged 85 and over, 3 in 10 (30 per cent) had dementia. There were also an estimated 23,900 Australians under the age of 65 with dementia.[21]

2.23 Old age is the greatest risk factor for dementia. After the age of 65, the likelihood of being diagnosed with dementia doubles every five years.[22] This is indicated by dementia prevalence rates, in which dementia prevalence is relatively low until the age of 70 years, after which prevalence rates increase exponentially.[23] Besides age-related risk, dementia prevalence rates also suggest that females are at greater risk of developing dementia than males, particularly at older ages (Figure 2.1).[24]

Figure 2.1 Estimated number of people with dementia, by age and sex, 2011



Source Australian Institute of Health and Welfare (AIHW); Dementia in Australia, catalogue No. AGE 70, 2012, p. 15.

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[20] AIHW 2007, *Dementia in Australia: National data analysis and development,* catalogue no. 53, p. xiii–xiv.

[21] AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 11.

[22] Access Economics 2009, *Keeping dementia front of mind: incidence and prevalence 2009–2050*, p. 4.

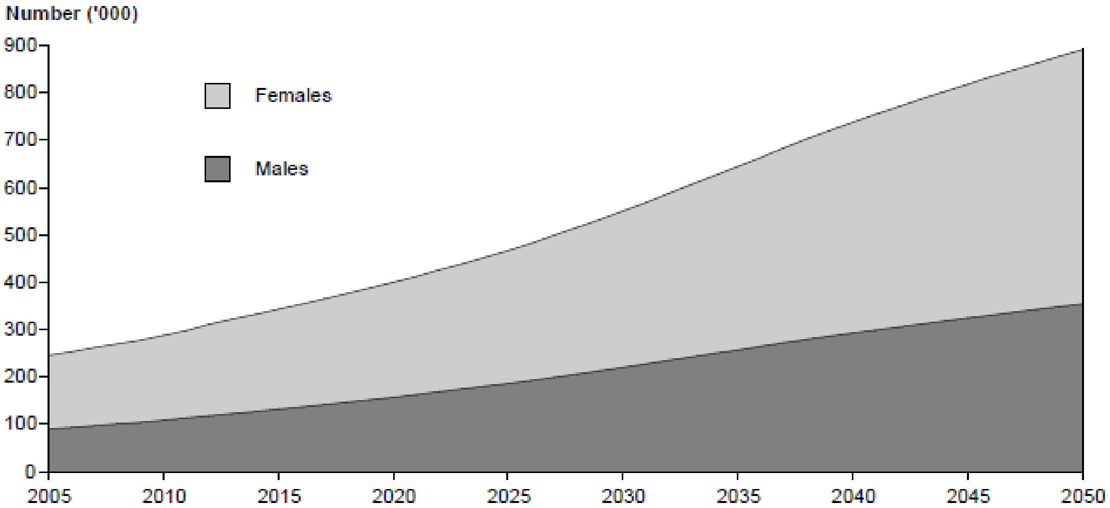
[23] Deloitte Access Economics 2011, *Dementia across Australia: 2011–2050*, p.14.

[24] Access Economics 2009, *Keeping dementia front of mind: incidence and prevalence 2009–2050*, p. iv.

2.24 The most recent figures from the Australian Bureau of Statistics (ABS) indicate that deaths due to dementia and Alzheimer's disease have more than doubled in the period 2001 to 2010, rising from 2.2 per cent to 6.3 per cent of all deaths.[25] Dementia and Alzheimer's disease are now the third leading cause of death overall. When assessed by gender, dementia and Alzheimer's disease are the third leading cause of death amongst females, compared to sixth for males.[26]

2.25 The prevalence of dementia in Australia is projected to triple to around 900,000 Australians by 2050 (Figure 2.2). The projected tripling will coincide with a doubling of the population aged over 65 years. The largest growth in prevalence is expected to occur in the decade leading up to 2020 which coincides with the 'baby boomer' generations moving into the older age groups, which have a higher risk of dementia. By 2050, it is expected that women will continue to account for around 60 per cent of people living with dementia.[27]

Figure 2.2 Estimated number of people with dementia, by sex, 2005-2050



Source *Australian Institute of Health and Welfare (AIHW); Dementia in Australia, catalogue No. AGE 70, 2012, p. 18.*

2.26 Rates of dementia are higher for Indigenous people than other Australians. In Indigenous communities of Australia, particularly in the Northern Territory and Western Australia, the prevalence of dementia is at least five times that of the general population. The rate of dementia is 26

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[25] ABS 2012, *Causes of death 2010*, catalogue no. 3303.0, Canberra, p.6.

[26] ABS 2012, *Causes of death 2010*, catalogue no. 3303.0, Canberra, pp. 7–8.

[27] AIHW 2012, *Dementia in Australia*. catalogue no. 70, p. 11.

times higher in the 45 to 69-year-old age group and about 20 times higher in the 60 to 69-year-old age group.[28]

Data limitations

2.27 Whilst estimates of dementia prevalence can provide some indication of the extent of the condition, there are limitations on how the data is interpreted. For example, as the World Health Organization (WHO) has observed:

> The way in which the diagnosis of dementia is defined and applied may be among the most important sources of variability [amongst data].[29]

2.28 In relation to projections for the prevalence of dementia in Australia, the AIHW cautions:

> Changes in risk factors and in the prevention, management and treatment of the condition may affect the accuracy of these estimates. For example, improved medical and social care might increase prevalence by allowing more people to survive longer with dementia …. The estimates are also sensitive to deviations from projected changes in the age-sex structure or total size of the projected populations. Therefore, these estimates (especially those further into the future) should be interpreted with caution.[30]

2.29 With regard specifically to estimates of prevalence in Indigenous communities, the AIHW states:

> Due to the lack of national data on the prevalence of dementia among Indigenous Australians, most information is drawn from a small number of localised, largely community-based studies.[31]

Ageing Australia and demand for services

2.30 In 2010 the Productivity Commission published its report on *Caring For Older Australians*. Key findings from the report relating to projected future demands for aged care services include the following:

- The number of people aged 85 and over is projected to more than quadruple (from 0.4 million to 1.8 million) between 2010 and 2050. This

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[28] Mr Brian Gleeson, Office of the Coordinator General for Remote Indigenous Services, *Official Committee Hansard*, 8 February 2013, p. 1.

[29] WHO 2012, *Dementia: A Public Health Priority*, p. 31.

[30] AIHW 2012, *Dementia in Australia,* catalogue no. 70, p. 19.

[31] AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 38.

is expected to drive a major increase in the demand for aged care services over the next 40 years.[32]

- The people demanding care services will be increasingly diverse, with a relative rise in proportion of older people who are culturally and linguistically diverse, Aboriginal and Torres Strait Islander people and living in regional and rural areas.[33]
- There is already a growing demand by consumers for higher quality services, as well as a growing demand for control and choice, since many older people want to age in their own home, while the relative availability of family and informal carers is expected to decline. This decline is expected to add to the demand for residential aged care.[34]
- Developments in information and assistive technology have the effect of enhancing the ability of people to meet their own needs for longer.
- Adjusting policy settings in areas such as the provision of alternatives to hospitalisation for frail older people who do not have acute care needs is important.[35]

Dementia services and supports

2.31 The Australian health system is complex. Dementia services are delivered within the well-established institutional and professional context of the health care system, and the closely related aged care system. While these systems are used by people with dementia, the systems deal with a diverse range of morbidities and ageing in general.

2.32 Responsibility for funding and provision of services is shared across all levels of government and the private sector. In broad terms, the Australian Government sets national policy and contributes to health funding, primarily through Medicare, the Pharmaceutical Benefits Scheme and Private Health Insurance rebates. The Australian Government also funds some services directly and provides payments to state and territory governments for the delivery of other services.

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[32] Productivity Commission Inquiry Report, *Caring For Older Australians*, No. 53 June 2010, 'Drivers for future demand', volume 1, p. 37.

[33] Productivity Commission Inquiry Report, *Caring For Older Australians*, No. 53 June 2010, 'Drivers for future demand', volume 1, p. 37.

[34] Productivity Commission Inquiry Report, *Caring For Older Australians*, No. 53 June 2010, 'Drivers for future demand', volume 1, p. 37.

[35] Productivity Commission Inquiry Report, *Caring For Older Australians*, No. 53 June 2010, 'Drivers for future demand', volume 1, p. 37.

2.33 State and territory governments are also responsible for the funding and delivery of public health services through hospitals and a range of community settings. Private sector involvement in primary care and the delivery of community services also adds to the complexity.

Medicare and the Pharmaceutical Benefits Scheme

2.34 As noted above the Australian Government is responsible for two significant national health subsidy schemes:

- Medicare; and
- the Pharmaceutical Benefits Scheme (PBS).

2.35 Dementia-focussed medical services increasingly concentrate on prevention. Medicare provides a new item for general practitioners, the 45–49 year old health check, which is available to all general practitioners whose patients are identified as at risk for a chronic disease. This complements Medicare items for comprehensive annual health assessments for those 75 years of age and over (and for Indigenous Australians 55 years of age and over).[36]

2.36 Some patients with mild to moderate Alzheimer's disease are eligible for a six month supply of subsidised cholinesterase inhibitors (i.e. donepezil hydrochloride, galantamine hydrobromide and rivastigmine hydrogentartrate) under the PBS.[37] For access beyond six months, there must be evidence of clinical improvement.[38] Memantine hydrochloride is another dementia specific drug available under the PBS for people with more severe Alzheimer's.[39]

2.37 The anti-psychotic medication risperidone is also available under the PBS for 'behavioural disturbances characterised by psychotic symptoms and aggression in patients with dementia where non-pharmacological methods have been unsuccessful'.[40]

Primary care and acute care services

2.38 Primary care providers, most notably general practitioners, play a key role in the initial identification and management of dementia. A survey of

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[36] Brodaty and Cummings, *Dementia Services in Australia*, International Journal of Geriatric Psychiatry, 2010, 25: 887-895, p. 889. See also: DoHA, *Submission 89*, pp. 7-8.

[37] Brodaty and Cummings, *Dementia Services in Australia*, International Journal of Geriatric Psychiatry, 2010; 25: 887–895, p. 889.

[38] Brodaty and Cummings, *Dementia Services in Australia*, International Journal of Geriatric Psychiatry, 2010; 25: 887–895, p. 889.

[39] AIHW 2012, *Dementia in Australia,* catalogue no. 70, p. 81.

[40] Brodaty and Cummings, *Dementia Services in Australia*, International Journal of Geriatric Psychiatry, 2010; 25: 887–895, p. 889.

carers for people with dementia suggests that over 80 per cent of GPs were the first health professionals approached when the symptoms of dementia emerged.[41] Recognising the vital role for primary care providers, the 2012 *Living Longer. Living Better.* package has provided additional support for educating and training primary health care providers to diagnose dementia in a more timely manner.[42]

2.39 People with dementia are also over represented in the acute care setting. Dementia was the principal diagnosis in 21 per cent of those aged over 75 years who were hospitalised. This figure increases to 36 per cent for people aged over 85 years.[43] The *Living Longer. Living Better.* package provides additional funding to improve hospital services for people with dementia. Funding will be used to help staff in the acute care setting to identify the signs of dementia and apply appropriate protocol.[44]

Community aged care services

2.40 There are a number of community care services available to help older people to manage daily activities and remain living in their own homes. Services provided may be general or dementia specific.[45]

2.41 The Aged Care Assessment Program (ACAP) provides assessments of older people to ensure that they access the most appropriate types of care to meet their specific needs. Assessment is conducted by Aged Care Assessment Teams (ACATs). As explained by the Australian Government Department of Health and Ageing (DoHA):

> The role of ACATs is to determine the overall care needs of frail older people and to assist them to gain access to the most appropriate types of care services. In doing this, ACATs comprehensively assess older people taking account of the restorative, physical, medical, psychological, cultural and social dimensions of their care needs.
>
> This includes determining whether a person has dementia or other cognitive conditions, or behavioural problems related to these or other conditions and/or the presence of depression or delirium.[46]

2.42 The outcome of the ACAT assessment determines eligibility for a range of government subsidised aged care services including:

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[41] AIHW 2012, *Dementia in Australia,* catalogue no. 70, p. 63.

[42] Australian Government, *Living Longer. Living Better.,* April 2012, p. 22.

[43] AIHW 2012, *Dementia in Australia,* catalogue no. 70, p. 70.

[44] Australian Government, *Living Longer. Living Better.,* April 2012, p. 24.

[45] For discussion regarding Community Care Packages, see Life Care, *Submission 29.*

[46] Department of Health and Ageing (DoHA), *Submission 89*, p. 9.

- Home and Community Care (HACC);
- Community Aged Care Packages (CACPs);
- Extended Aged Care in the Home packages (EACH);
- Extended Aged Care in the Home Dementia packages (EACHD); and
- Access to Residential Aged Care Facilities (RACF).

2.43 These services offer different levels of assistance ranging from low-level care provided to people in their own homes through HACC or the CACP program, to more intensive home-based care through the EACH and EACHD packages, through to residential care in aged care facilities.

2.44 From 1 July 2013, subject to legislative reform, there will be four levels of Home Care Packages, to allow a seamless continuum of care at home and catering to the full spectrum of care needs. These reforms were summarised by DoHA as follows:

> - Level 1 – a new package to support people with basic care needs;
> - Level 2 – a package to support people with low level care needs, similar to the existing CACP;
> - Level 3 – a new package to support people with intermediate care needs; and
> - Level 4 – a package to support people with high level care needs, similar to the existing EACH package.
>
> It will no longer be necessary to have a separate EACHD level, as a new Dementia Supplement will be available to all consumers who meet the eligibility criteria for the Dementia Supplement (across any of the four levels of Home Care Packages).[47]

2.45 From July 2015, the Australian Government will establish the national Commonwealth Home Support Program. The CHSP will combine under the one program all the services currently providing basic home support, including the HACC services for older people and services provided under the NRCP.[48]

2.46 Culturally appropriate aged care services are also available for Indigenous Australians under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program.

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[47] DoHA, *Living Longer. Living Better.*, 'Home Care Packages Program', <http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/Consumer-Directed-Care-Home-Care-Packages> viewed 12 June 2013.

[48] Australian Government, *Living Longer. Living Better.* April 2012, p. 3.

2.47 Veterans, war widows and widowers can also access home assistance through the Veterans' Home Care program provided through the Department of Veterans' Affairs.[49]

Home and Community Care

2.48 The HACC program is the largest national community care program providing support for frail older people in Australia. Since 2012 the Australian Government has taken full funding, policy and operational responsibility for HACC services for older people in all states and territories (except Victoria and Western Australia).[50]

2.49 Commonwealth HACC services are available to:

- People aged 65 years and over (or 50 and over for Aboriginal and Torres Strait Islander people) in all states and territories (except Victoria and Western Australia);
- People who are at risk of premature or inappropriate admission to long term residential care; and
- Carers of older Australians eligible for services under the Commonwealth HACC Program.[51]

2.50 The range of services available under HACC include:

- Clinical care (e.g. nursing care and allied health services);
- Domestic assistance (e.g. cleaning, washing, shopping, food preparation);
- Personal care (e.g. bathing, dressing, grooming and eating);
- Social support;
- Home maintenance and modifications;
- Transport;
- Assessment, client care coordination and case management;
- Counselling, information and advocacy services;
- Centre-based day care; and
- Support for carers including respite services.[52]

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[49] For further information on dementia-related programs for veterans, see Department of Veterans' Affairs, *Submission 90*.

[50] In Victoria and Western Australia the state governments continue to deliver services for older people under joint funding arrangements with the Australian Government. HACC services for younger people with disabilities continue to be the responsibility of state and territory governments.

[51] DoHA, *Living Longer. Living Better.*, 'Commonwealth HACC Program', <http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm> viewed 6 June 2013.

Community Aged Care Packages

2.51 Community aged care packages (CACP) are designed to provide flexible support which is tailored to individual needs. The CACPs target older people living in the community with care needs equivalent to at least low-level residential aged care. The types of services available through CACPs include:

- Help with personal care;
- Meals;
- Domestic assistance; and
- Transport.

2.52 Extended Aged Care at Home (EACH) packages target older people living at home with care needs equivalent to high-level residential aged care. EACH packages generally include qualified nursing input, particularly in the design and ongoing management of the package. Services available through EACH include:

- Clinical care;
- Help with personal care;
- Meals;
- Domestic assistance;
- Assistance to access leisure activities;
- Emotional support;
- Therapy services; and
- Home safety and modification.[53]

2.53 Similar to the EACH packages, Extended Aged Care at Home Dementia (EACHD) packages offer a range of services that are tailored specifically to meet the needs of older Australians with behavioural concerns or psychological symptoms associated with dementia. The criteria for obtaining a package are that the applicant:

- Is experiencing behaviours and psychological symptoms associated with dementia that is significantly impacting upon their ability to live independently in the community;
- Requires a high level of residential care;

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[52] DoHA, *Living Longer. Living Better.*, 'Commonwealth HACC Program',<http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm> viewed 6 June 2013.

[53] DoHA, *Living Longer. Living Better.*, 'Home-based care', <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-commcare-comcprov-eachdex.htm> viewed 6 June 2013.

- Prefers to receive an EACHD package; and
- Would be able to live at home with the support of an EACHD package.[54]

2.54 The packages provide a range of services including:

- Clinical care (e.g. nursing care and allied health services);
- Personal care;
- Transport to appointments;
- Social support;
- Home help; and
- Assistance with oxygen and/or enteral feeding.[55]

2.55 A new Dementia Supplement of 10 per cent on top of base level funding for home care packages is included under the *Living Longer. Living Better.* package.[56]

2.56 Indigenous Australians may be able to access a range of residential and community care services available through the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. The aim of the program is provide quality, flexible and culturally appropriate aged care for older Indigenous Australians. The *Living Longer. Living Better.* package provides additional funding to support more aged care places under this program.[57]

2.57 The Veterans' Home Care (VHC) program aims to assist veterans and war widows and widowers who wish to continue living independently in their own home and local community by providing low level home care services. The range of services include:

- Domestic assistance;
- Personal care;
- Safety-related home and garden maintenance; and
- Respite care for carers who have responsibility for a person who requires ongoing care, attention or support.[58]

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[54] DoHA, *Living Longer. Living Better.*, 'Home-based care',<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-commcare-eachd.htm> viewed 6 June 2013.

[55] DoHA, *Living Longer. Living Better.*, 'Home-based care',<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-commcare-eachd.htm-copy3> viewed 6 June 2013.

[56] Australian Government, *Living Longer. Living Better.*, April 2012, p. 23.

[57] Australian Government, *Living Longer. Living Better.*, April 2012, p. 26.

[58] Department of Veterans Affairs, Fact sheets, <http://factsheets.dva.gov.au/factsheets/> viewed 6 June 2013.

Respite services

2.58 Support for families and carers is essential if people with dementia are to be supported to live in their own homes for as long as possible.[59] As outlined by the AIHW in its *Dementia in Australia* report:

> Respite care offers support to older people and their carers who may need a break or who require some extra care for a short period (such as during, or while recovering from, illness). Care may be provided for a few hours on a one-off or regular basis, for a couple of days or for a few weeks. Respite can occur in a variety of settings, including homes, centres, residential aged care services and other locations, with care provided by volunteers and/or paid respite workers. Respite is especially important for people caring for someone with dementia … the demands of the caring role may involve the provision of substantial amounts of physical, psychological, cognitive and social support, while behaviour changes may add to the complexity of caring.[60]

2.59 The Australian Government funds the National Respite for Carers Program (NRCP) which targets carers of four groups: frail older people, younger people with disabilities, people with dementia, and people with dementia who have 'changed behaviours'.[61]

2.60 The program provides direct respite care in a number of settings, including day respite in community settings, in the home and in respite 'cottages' (but not in residential aged care facilities). Indirect respite care, such as domestic assistance, social support and personal care for the care recipient, is also provided by the NRCP. An ACAT assessment is not required to access the NRCP, but the program has assessment procedures focussing on the needs of the carers and the people for whom they care.[62]

Residential aged care services

2.61 The Australian Government provides funds to support aged care facilities for older Australians whose needs are such that they are no longer able to remain in their own homes. Eligibility for publicly funded residential care places is typically determined by an ACAT assessment.

2.62 Residential care varies in the type of accommodation and the level of support for residents. It may be available on a permanent basis or simply

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[59] See for example, Life Care, *Submission 29*; East Lake Macquarie Dementia Service Inc, *Submission 99*.

[60] AIHW 2012, *Dementia in Australia,* catalogue no. 70, p. 111.

[61] AIHW 2012, *Dementia in Australia,* catalogue no. 70, p. 112.

[62] AIHW 2012, *Dementia in Australia,* catalogue no. 70, p. 112.

used for respite care as required. Typically, residential care in Australia is described as either low level or high level care.

2.63 Low level care facilities may assist residents with the basic activities of daily living such as dressing, eating and bathing, as well as support services such as cleaning, laundry and meals. They may offer some allied health services, such as physiotherapy. Nursing care can be given when required.

2.64 High level care provides people who need almost complete assistance with most activities of daily living with 24 hour care, either by registered nurses, or under the supervision of registered nurses. Nursing care is combined with accommodation, support services, personal care services and allied health services.[63]

2.65 Significant reforms to residential aged care are proposed under the *Living Longer. Living Better.* package, including:

- More residential facilities being built,
- Supporting the viability of services in regional, rural and remote areas,
- Trialling Consumer Directed Care in residential aged care,
- Strengthening means testing for residential care by combining the current income and asset tests,
- Establishing a new Aged Care Financing Authority, and
- Improving the Aged Care Funding Instrument.[64]

Dementia Behaviour Management Advisory Services

2.66 The Dementia Behaviour Management Advisory Services (DBMAS) initiative commenced in 2007. Its main purpose is to provide support to those who provide care for people with dementia associated behavioural and psychological problems. This is achieved by improving the dementia care capacity of care workers, family carers and service providers. DBMAS services include:

- Assessment of the person with dementia;
- Provision of clinical support, information and advice;
- Care planning, case conferences and short term case management;
- Mentoring and clinical supervision; and

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[63] DoHA, *Aged Care Australia*, <http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/Types%20of%20care > viewed 7 June 2013.

[64] DoHA, *Living Longer. Living Better.*, 'Residential Care', <http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/Residential-care#5> viewed 12 June 2013.

- Education and training.[65]

2.67 Under the *Living Longer. Living Better.* package additional funding has been provided to extend DBMAS into acute and primary care settings.[66]

National Dementia Support Program

2.68 The National Dementia Support Program (NDSP) was established in 2005 under the Dementia Initiative (*Making Dementia a National Health Priority)* to provide and promote education programs, services and resources that:

- Improve awareness and understanding about dementia and the services available to people living with dementia, their carers, families, service providers and health professionals; and
- Increase the skills and confidence of people living with dementia, their carers, families, health professionals, volunteers and community contacts.[67]

State/territory governments and the non-government sector

2.69 As noted earlier in the chapter, funding and provision of services for people living with dementia and their families/carers is shared across all levels of government and the private sector.

2.70 While drawing on health and aged care funding from the Australian Government, state and territory governments manage services delivered through public hospitals and fund a range of community health services. In addition many localised and community based services for dementia patients are delivered directly by the state and territory governments, or by subcontracted non-government agencies.

2.71 The contribution of non-government agencies to the aged care sector, and to the provision of services for people with dementia and their families is diverse. While some are focused on representation, support and advocacy (e.g. Carers Australia and the Consumers Health Forum of Australia), others deliver services directly those living with dementia or those caring for them (e.g. Brotherhood of St Laurence and Baptcare), while yet others do both (Alzheimer's Australia).

2.72 For example, organisations typically provide supports and services for people with dementia and their families/carers, including:

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[65] Australian Government DBMAS, <http://dbmas.org.au/> viewed 6 June 2013.

[66] Australian Government, *Living Longer. Living Better.* April 2012, p. 23.

[67] DOHA, *Dementia*, <http://www.health.gov.au/internet/main/publishing.nsf/Content/dementia-support#National%20Dementia%20Support> viewed 6 June 2013.

- Advocacy;
- Information and referral services;
- Counselling;
- Support groups;
- Recreational and social activities;
- Education; and
- Care services, such as respite and residential care.

2.73 It is beyond the scope of the report to provide a comprehensive and detailed description of the full range of services and supports available. However, while many non-government organisations rely heavily on funding from public sources in order to provide these supports and services, it is equally the case that without the valuable contribution of the private sector governments would struggle to meet demand. The ensuing synthesis between the public and private sectors can be complex, but administrators in both sectors work to ensure that the system operates effectively.

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People are scared of going for diagnosis. A lot of doctors are not properly trained and do not diagnose or inform or support properly. People will not tell family to get support. There is an enormous amount of stigma.[1]

Awareness

3.1 A recurrent theme which emerged from the evidence to this inquiry was the pressing need for greater awareness about all aspects of dementia.

3.2 The Brotherhood of St Laurence, a not-for-profit organisation and service-provider, considered that greater awareness and understanding of dementia across all levels of society could improve the quality of life of people with dementia and their carers.[2]

3.3 The Committee was told that greater awareness would inevitably lead to higher rates of early diagnosis and intervention of dementia. As stated by Professor Henry Brodaty, of the Minister's Dementia Advisory Group (MDAG):

> Without awareness of people in the community, awareness of families, awareness of people with dementia themselves, awareness amongst health practitioners, then we will not get timely diagnosis, we will not get referral, we will not get good management, we will not get services that are required and we are not going to get people attending to…enduring power of attorney and enduring guardianship advanced care directives, speaking to palliative care. That is number one, awareness.[3]

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[1] Ms Sue Pieters-Hawke, Minister's Dementia Advisory Group (MDAG), *Official Committee Hansard*, Canberra, 8 February 2013, p. 16.

[2] Brotherhood of St Laurence, *Submission 53*, p. 3.

[3] Professor Henry Brodaty, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, p. 15.

3.4 Lack of awareness of dementia is said to have contributed to the stigmatisation of dementia, leading to people living with dementia experiencing social isolation, discrimination and disempowerment. [4]

3.5 To achieve greater rates of early diagnosis and intervention of dementia, awareness of dementia needs to be increased across the population. Specifically, the Committee heard that the following groups would benefit from greater awareness of dementia:

- People with dementia and their families and carers, who need information on:
    - ⇒ Preventive measures and lifestyle factors to maintain good brain health;
    - ⇒ Dementia symptoms and assessment options;
    - ⇒ The various pathways available for treatment and care of dementia, including options for respite care and care packages available; and
    - ⇒ The future planning options available to them, including advanced care directives, wills and estate planning and powers of attorney;
- The wider community, who need information on:
    - ⇒ How to maintain a brain-healthy lifestyle;
    - ⇒ Dementia as a condition, including the needs of those living with dementia;
    - ⇒ The need to support carers and people with dementia; and
    - ⇒ The symptoms, as well as diagnostic and treatment options for dementia; and
- Health professionals including allied health service providers, General Practitioners and Nurse Practitioners, who need education and training on:
    - ⇒ The symptoms to look out for;
    - ⇒ The assessments and interventions available; and
    - ⇒ The referral options for treatment and community support.

3.6 In this chapter, the Committee considers the lack of awareness and stigmatisation of dementia within the community; how greater awareness of dementia could be raised; and the need for more education and training within the medical community.

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[4] See for example: Alzheimer's Australia Victoria, *Submission 35*, p. 8.

Lack of community awareness

3.7 The Australian Institute of Health and Welfare (AIHW) reported that 41 per cent of Australians aged between 15 and 74 had a level of health literacy (that is, the ability to understand and use information relating to health issues) that was adequate or above. A less than adequate health literacy level is said to have a direct impact on a person's health and the costs to the broader community.[5]

3.8 Coupled with the low rates of health literacy is a lack of awareness and understanding about dementia within both the health sector and in the wider community.[6]

3.9 Pfizer Australia told the Committee:

> Dementia has been incorrectly regarded as a natural part of ageing. The level of understanding and awareness of the disease amongst the general community is very low. The 'Dementia is Everybody's Business' Health Report, published in 2011, highlighted the need for more awareness about the impact of dementia in the community. While most Australians associate dementia with memory loss, they are still unclear about how common dementia is or what other symptoms are associated with dementia. While dementia is the third leading cause of death in Australia, only 1 in 5 Australians is aware that dementia is a progressive illness and sufferers experience a reduced life expectancy.[7]

3.10 Mr Andrew Larpent, of Southern Cross Care (SA and NT), explained the impact of a lack of health literacy regarding dementia services and support:

> It should also be obvious that there is a need within the wider community for information on where to go for referral to specialists and service providers of all sorts. Probably because of the historic marginalisation of those with dementia and their carers, there is far too little overall 'healthy literacy' about what an

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[5] Australian Institute of Health and Welfare (AIHW), *Australia's Health 2012: The thirteenth biennial health report of the Australian Institute of Health and Welfare*, 2012, p. 182.

[6] See for example: Home Instead Senior Care, *Submission 9*, p. 2.

[7] Pfizer Australia, *Submission 49*, p. 2. See also: Alzheimer's Australia, Pfizer Health Report Issue 45, *Dementia is everybody's business*, <http://www.fightdementia.org.au/common/files/NAT/20110314_Nat_report_Pfizer-Health-Report-2011.pdf> viewed 4 June 2013.

> individual should do to seek help for themselves or one they are caring for.[8]

3.11 Jenny, a carer who called for a major public awareness campaign on dementia, observed that in the past there had been little in the media about dementia:

> In 10 years, you do not regularly hear any media advertisements re dementia. When we look back re cancer, prostate cancer, depression, suicide, addictions, heart disease, stroke, diabetes etc. they are so regularly advertised and discussed, but not dementia.[9]

3.12 Professor Barbara Horner, of Curtin University, explained there was still an enormous gap in education, awareness and understanding of dementia. Despite the fact there was an abundance of information available on dementia, people only paid attention to it when it was relevant to them:

> Education—like good health promotion programs, for example—is only picked up by people when they think that the condition has relevance for them. So, while we have a plethora of information out there, there are still an awful lot of people in the community who do not pick it up and do not pay attention to it. That is not an uncommon pattern in terms of health promotion and other conditions that we have had. We may have information out there, but there still is a big gap in terms of knowledge and understanding, or ignorance in terms of where it is in their life.[10]

3.13 Professor Horner noted there was a community attitude towards making light of memory loss:

> There is still, also, a community attitude towards making light of the fact that you have memory loss, and we all know lots of flippant comments and jokes that are passed around in terms of things that you have forgotten. I think that comes out of ignorance and lack of understanding.[11]

3.14 Carers Australia considered that carers and family members of a person with dementia needed greater awareness of the condition, as they had an important role to play in determining a person's care needs:

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[8] Mr Andrew Larpent, Southern Cross Care (SA & NT), *Official Committee Hansard*, Adelaide, 4 March 2013, p. 8.

[9] Jenny, *Submission 20*, pp.1-2.

[10] Professor Barbara Horner, Curtin University, *Official Committee Hansard*, Perth, 12 November 2012, p. 22.

[11] Professor Barbara Horner, Curtin University, *Official Committee Hansard*, Perth, 12 November 2012, p. 23.

> Family members and carers of a person with early stage dementia are often the first to notice cognitive decline, changes in mood and behaviour and changes in the person's care needs associated with the onset of the disease. They therefore have a critical role to play in early diagnosis. They can, however, only play this role if they are aware that the changes they notice are changes which are commonly experienced by people with dementia rather than, for example, being assumed to be a consequence of ageing. Unfortunately many people are not aware of the early symptoms of dementia.[12]

3.15 Baptcare, a service provider in Victoria, considered that people with Younger Onset Dementia, or people at the early stages of dementia, may be prevented from remaining active in the workplace, because of a general lack of understanding about dementia:

> Many younger people are still working at the time of diagnosis. Some find all of a sudden they 'can't cope' with certain aspects of their work. If changes are made in the workplace, many find they can't learn new things or adapt to new technology. Work colleagues start to notice changes. Some people leave work without realising what is happening to them and then find six or twelve months or more there is a diagnosis of dementia. Some leave work without realising they are entitled to superannuation or disability insurance.[13]

3.16 The Brotherhood of St Laurence explained how a lack of awareness within the workplace could impact on a person's quality of life:

> A consequence of lack of understanding in the workplace is stigmatisation and the inability for the person with early onset dementia or first stage dementia to maintain employment. This has an impact not only on the person's economic and social wellbeing but also on society which loses the wealth of human knowledge and resources which the person contributed.[14]

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[12] Carers Australia, *Submission 80*, p. 4. See also, Em (NSW), *Submission 2*, and Ms Dianne Stewart, *Submission 11*, p. 3.

[13] Baptcare, *Submission 58*, p. 8. See also: Professor Barbara Horner, Curtin University, Official *Committee Hansard*, Perth, 12 November 2012, p. 22.

[14] Brotherhood of St Laurence, *Submission 53*, p. 5. See also: MDAG, *Submission 48*, p. 7; Denise Chaston and Kylie Wood, *Submission 52*, pp. 2-3; Department of Health and Ageing (DoHA), *Submission 89*, p. 5; Professor Fiona Bardenhagen, *Official Committee Hansard*, Launceston, 27 July 2012, pp. 31-32.

Stigma

3.17 The lack of awareness regarding dementia has led to the stigmatisation of dementia within society. This stigma is said to prevent people from seeking an assessment of dementia, and diminish the quality of life and independence of people with dementia.

3.18 The Committee was told that approximately 63 per cent of Australians feared getting Alzheimer's disease or another form of dementia, second only to the fear of having cancer.[15] Further, 56 per cent of carers reported that people with dementia were discriminated against, and almost one third of Australians said that they would feel uncomfortable spending time with someone with dementia.[16]

3.19 Dr Roderick McKay, of the Royal Australian and New Zealand College of Psychiatrists (RANZCP), argued that the public perception of ageing in general formed part of the stigma attached to dementia:

> The stigma of dementia has two elements to it. There is the stigma of old age and there is the stigma of something going wrong with the mind, be it mental illness or not. The stigma is that something is going wrong with the mind.[17]

3.20 The National Ageing Research Institute (NARI) stated that the media was a powerful medium for translating knowledge about dementia for carers, people living with dementia and the general public, and yet many ageing-related stories in the media were negative. NARI submitted:

> The media is potentially a powerful tool to help spread health awareness and influence perceptions, beliefs and attitudes yet we have not fully developed the supports necessary for effective knowledge translation using the media. The media's role as disseminators of information on dementia is particularly important due to the potential to influence public perception of the risk reduction and early intervention.[18]

3.21 McAdam Aged Care Art Recreation Therapy believed that the media and individuals within the aged care sector itself perpetuated the myth that people with dementia were incapable of learning new things and incapable of showing anything but decline.[19]

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[15] Pfizer Australia, *Submission 49*, p. 2.

[16] Alzheimer's Australia (National Office), *Submission 44*, p. 20.

[17] Dr Roderick McKay, Royal Australian and New Zealand College of Psychiatrists (RANZCP), *Official Committee Hansard*, Newcastle, 8 November 2012, p. 15.

[18] National Ageing Research Institute (NARI), *Submission 59*, pp. 3-4.

[19] McAdam Aged Care Art Recreation Therapy, *Submission 21*, p. 16.

3.22 Dr McKay feared that the way dementia was publically promoted could inadvertently perpetuate the stigma surrounding the condition:

> As we grow older society should value the fact that most people grow older and grow wiser. It is not just a saying; it is actually true. But we have a society that expects that as we grow older we lose wisdom, and the promotion of dementia as a serious problem—which it is—raises the question from society and from people individually: why are we getting more and more people with dementia?[20]

3.23 Dr Carmel Lum, Senior Clinical Neuropsychologist and Clinical Psychologist, whose father had dementia, noted that fear was a common emotion experienced when a person received a diagnosis of dementia:

> As a clinician, I observe fear as a very common emotion in spouses and family members when first informed of a diagnosis of dementia. It is the 'new cancer' and initial reactions include 'all is lost' and feelings of helplessness. The public's knowledge of dementia is largely informed by the often over-dramatised negative manifestations of dementia in a TV soap drama, or a journalist's investigative account of a failed nursing home, complete with images of ailing elderly residents in the advance stages of dementia.[21]

3.24 HammondCare submitted that efforts to improve the quality of life of people living with dementia would continue to be hampered by the stigma associated with dementia, if it was not addressed.[22]

3.25 Dr McKay said changing the way society viewed dementia was important in ensuring that people sought access to assessment and treatment:

> Changing the frame of how we look at it is much more important. Eighty per cent of people at 80 will not have dementia. We can look at it the other way around: 20 per cent of people at 80 have dementia. One hundred per cent of people at 80 fear getting dementia. We have to turn that around because people are not going to seek help if they think that seeking help will mean they will be told what they fear most. We have to reframe that.[23]

3.26 Woy Woy Community Aged Care agreed that education about dementia was needed:

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[20] Dr Roderick McKay, RANZCP, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 15.

[21] Dr Carmel Lum, *Submission 93*, p. 8.

[22] HammondCare, *Submission 86*, pp. 4-5.

[23] Dr Roderick McKay, RANZCP, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 15.

> Education is a must and needs to be ongoing, widespread public education campaigns are required to help reduce the stigma associated with dementia. It needs to encourage people to seek diagnosis and support early, often the person themself is acutely aware of their declining cognitive ability but hides it as best they can, whereas with other diseases people are more willing to seek help earlier.[24]

Committee comment

3.27 The importance of health literacy (and brain health literacy in particular) cannot be underestimated. Boosting brain health literacy and awareness of dementia can assist in achieving earlier diagnosis and intervention in a number of ways.

3.28 Firstly, providing relevant information on brain health and the symptoms and risk factors of dementia enables people to take preventive steps to achieve better brain health, or potentially delay the onset of dementia.

3.29 Secondly, achieving greater awareness of dementia assists in helping people (or their families and carers) identify symptoms of potential concern and seek appropriate assessment, treatment and support at the earliest opportunity.

3.30 The lack of understanding about dementia within the community has resulted in the stigmatisation of dementia and the perpetuation of negative attitudes about dementia.

3.31 As the Committee heard, the stigmatisation of dementia poses a major barrier to people achieving a timely diagnosis and intervention. The stigma surrounding dementia has led to people with dementia being ostracised, feeling socially isolated or even being discriminated against.

3.32 Further, because of the stigma surrounding dementia, many people are left with the misconception that nothing can be done to delay the onset or assist with the symptoms of dementia. This prevents people from seeking diagnosis and assistance.

3.33 Worse still, this view is held by some medical practitioners, preventing them from making a diagnosis. The barriers for medical practitioners in making a diagnosis of dementia are discussed further in Chapter 5. The need for medical practitioners to have a greater understanding of dementia is discussed further below.

3.34 Demystifying and de-stigmatising dementia will help ensure that people seek assessment when they first experience symptoms of cognitive

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[24] Woy Woy Community Aged Care, *Submission 102*, p. 4.

decline. In turn, medical practitioners will be more likely to provide an accurate and timely diagnosis, and make appropriate referrals for treatment and support.

3.35 Raising awareness of dementia will also ensure that people who receive a diagnosis of dementia are not discriminated against, isolated or marginalised at the very time when they have most need of support. They will be more likely to remain social engaged and participate in the local community, whether it be by remaining in the workplace while they have capacity to do so, or involving themselves in the community in other ways.

3.36 How greater awareness of dementia might be raised is discussed further below.

Raising greater awareness of dementia

3.37 In considering how best to raise awareness and improve communication on dementia and dementia-related services in the community, numerous organisations and individuals called for the development of a comprehensive national awareness campaign on dementia.[25]

3.38 Ms Sue Pieters-Hawke considered that a national awareness campaign could address the range of misconceptions that underpin the many negative, prejudicial and stigmatic attitudes and ideas that existed about dementia. In this way she reasoned, raising awareness of dementia through a public awareness campaign could lead to a big change in a person's health outcomes:

> Really we are missing opportunities for very different life courses and life outcomes for want of really addressing fundamental attitudes and information and possibilities as well as the potential for risk reduction and reducing long term the numbers of people who have dementia. We really need an all-out campaign such as occurred around disability, around mental illness, around HIV. It can be done, but we have to recommend and fund that it be done.[26]

3.39 There were numerous submissions containing suggested ways to raise greater awareness of dementia. These include:

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[25] See for example: Greypath Pty Ltd, *Submission 1*, p. 2; Australian Women's Health Network and Community Vision, *Submission 38*, p. 4.

[26] Ms Sue Pieters-Hawke, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, p. 16.

- Mental health promotion activities that focus on the needs of older people and their carers;
- A national three-year anti-stigma campaign that incorporates lessons learned from the New Zealand campaign;
- A national mental health literacy campaign to promote recognition of early signs of illness, the need to seek help and the value of early action;
- Improved promotion and linkages to local and regional services from the national dementia helpline;
- Raising awareness using a multimedia approach, including:
  - ⇒ Use of television programmes, newspaper articles and other media promoting dementia stories;
  - ⇒ Use of the arts, for example creating children's books like Mem Fox's 'Wilfred Gordon Partridge';
  - ⇒ Use of social networking to create positive messages;
  - ⇒ Innovative media programmes such as the Israeli Alzheimer's awareness campaign;[27]
- Using community resources such as:
  - ⇒ presentations in local clubs;
  - ⇒ presentations in local shopping centres;
  - ⇒ presentations/promotions at local shows and other events;
- Plain language fact sheets;
- Providing opportunities for people with early stage dementia to express their views and influence government policy and government-funded services;
- Creating a supportive environment that provides opportunities for people with dementia and their families/carers to share their experiences; and
- A change of focus to early detection; preventative health and wellbeing; and the positive lives that could be led by people who have a diagnosis of dementia.[28]

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[27] As per Denise Chaston and Kylie Wood, *Submission 52*, pp. 5-6, <http://www.youtube.com/watch?feature=player_embedded&v=7kKAq6lHgeY#!> viewed 20 May 2013.

[28] See for example: RANZCP, *Submission 45*, p. 4; Denise Chaston and Kylie Wood, *Submission 52*, pp. 5-6; ECH, Resthaven, Eldercare, *Submission 55*, p. 5; KinCare, *Submission 63*, p. 9, Traynor, Devries, Fares and Pilkington, *Submission 70*, p. 5.

3.40 Carers Australia supported a broadly targeted dementia awareness campaign, however considered that such a campaign should recognise the role of carers:

> An initiative in awareness raising would need to be targeted broadly and address not just community ignorance but also prejudice and in some cases commercial practice. As a society we need to be less inhibited in talking about dementia…This idea of carers being considered as 'partners in care' could usefully be incorporated into a dementia awareness initiative. [29]

3.41 The Brotherhood of St Laurence submitted that awareness-raising needed to be relevant to the context and audience.[30] Accordingly, information for carers needed to aid their understanding of dementia and provide information on the skills they needed to assist in caring, as well as information on respite and financial support.[31]

3.42 Ms Kate Swaffer, who was diagnosed with Younger Onset Dementia, believed the best way of understanding the needs of someone with dementia was to ask them about their experiences and involve them in any public awareness campaign about living with dementia:

> It is people with their own stories who can have the biggest impact on change, and so people with dementia should be encouraged to become involved in education and awareness programs, run by Alzheimer's Australia, or other service providers to help bring about change. These people have the power to create change in attitudes, and public awareness.[32]

3.43 The Pharmacy Guild of Australia argued that community pharmacy could support early diagnosis and intervention through active participation in consumer awareness campaigns regarding the signs of dementia and raising awareness that dementia was not a natural part of ageing:

> This established network of highly qualified health professionals provides a nationally accessible platform to disseminate clear and consistent messages and support. Both well and unwell people visit their community pharmacy, providing an opportunity to

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[29] Carers Australia, *Submission 80*, p. 5. See also: Frontline Care Solutions, *Submission 7*, and Home Instead Senior Care, *Submission 9*, for further argument regarding the need to train carers to assist them support people with dementia.

[30] See also: Aged and Community Services Australia, *Submission 47*, p. 3; Ethnic Communities' Council of Victoria, *Submission 62*, p. 2.

[31] Brotherhood of St Laurence, *Submission 53*, p. 3.

[32] Ms Kate Swaffer, *Submission 77*, p. 18.

> engage people along the health spectrum and hard-to-reach populations who do not utilise other health services.[33]

3.44 Evidence to the Committee advocated for the need for positive language to be used around dementia, to reduce the stigma and fear around the condition.

3.45 Dr McKay explained that the fear and stigma attached to dementia was leading people with treatable conditions to avoid assessment:

> 'Ageing wisely' is the phrase that comes most to mind because it is promoting what goes right in old age rather than what goes wrong in old age. If you set the expectation that things should go right in old age then you should be worried in a constructive way if things are not going right, and you promote the things that you can effectively do—things that people can relate to that you can effectively do—if that is not happening. It could be as simple as a change in medication. It often is. It could be a very simple medical illness. It could be an infection in the urine, which keeps going because you fear that you have dementia instead. It can be something simple such as depression or anxiety that can be effectively treated and improved. Focus on the very positive things that can be done rather than focus on the fact that it might be dementia.[34]

3.46 Mr Larpent was of the view that the language around dementia needed to be recalibrated:

> What I hope to try and encourage is that parliament moves towards a national dementia strategy and a whole-system approach, one that focuses on people living well with their dementia and one that recalibrates the language. We should stop talking about suffering; we should stop talking about patients; we should talk about people living with their dementia and how we can help them to live well… We need to think about that in terms of the language we use. Dementia is a condition. People talk about it as a disease. You could categorise it as a disease but it is more helpful to categorise it as a condition which the whole of society needs to recognise and understand… We particularly need to recognise that people are people a lot longer than they are patients.[35]

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[33] The Pharmacy Guild of Australia, *Submission 57*, p. 9.

[34] Dr Roderick McKay, RANZCP, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 16.

[35] Mr Andrew Larpent, Southern Cross Care (SA & NT) Inc, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 8.

3.47 Royal District Nursing Services (RDNS) noted that the use of the term 'dementia' at times could be a barrier in itself:

> There are also instances where the use of the term 'dementia' can in fact be a barrier in itself due to the fear and stigma still attached to this term. In such cases it has can be beneficial to focus attention on understanding and treating the particular signs and symptoms, rather than emphasising the diagnosis of dementia.[36]

3.48 The National Ageing Research Institute (NARI) submitted that the media was a powerful tool for raising awareness of dementia, if harnessed appropriately:

> There is a substantial literature on quality of reporting health information in the media, especially with respect to stigma and mental illness but little attention has been paid to the reporting of dementia. The media is potentially a powerful tool to help spread health awareness and influence perceptions, beliefs and attitudes yet we have not fully developed the supports necessary for effective knowledge translation using the media. The media's role as disseminators of information on dementia is particularly important due to the potential to influence public perception of the risk reduction and early intervention. An independent body that monitors the quality of news stories about dementia and supports the translation of latest research findings from researchers to the general public would assist in raising awareness of the condition.[37]

3.49 The National Cross Cultural Dementia Network (NCCDN) advised that the Australian Multicultural Foundation had undertaken a community awareness campaign on dementia for a number of ethnic communities using ethnic radio and print media, which had proven successful. The NCCDN called for further resources to be placed into raising awareness of dementia among ethnic communities.[38]

3.50 Alzheimer's Australia prioritised awareness as a key issue to be addressed, advocating for a comprehensive national dementia awareness campaign to de-stigmatise dementia, and raise understanding and awareness in the general community and within the primary care sector.[39]

3.51 COTA Australia (COTA), the national policy arm of the eight State and Territory Councils on the Ageing, joined the call for a comprehensive national awareness campaign to increase community understanding of

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[36] Royal District Nursing Services, *Submission 78*, p. 5.

[37] National Ageing Research Institute (NARI), *Submission 59*, pp. 3-4.

[38] National Cross Cultural Dementia Network (NCCDN), *Submission 32,* p. 2.

[39] Alzheimer's Australia (National Office), *Submission 44*, p. 20.

dementia. COTA added that such a campaign should address the needs of specific community groups:

> Alzheimer's Australia is best placed to lead such a campaign but there would need to be provision for them to work with other groups to ensure it addresses the needs of specific groups including Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse backgrounds and the lesbian, gay, bisexual, transgender and intersex communities.[40]

3.52 COTA submitted that a national awareness campaign would have a number of benefits:

> Such a campaign would reduce the stigma of dementia and be better accepted in the community. This should reduce social isolation for people with dementia and their carers, and so would make a big difference to their quality of life. As one carer said "Norm was a keen bowler but after his diagnosis his bowling club friends were a bit scared of how he might behave. If they only understood his condition I feel sure they would be more supportive".[41]

3.53 Pfizer Australia outlined a successful national awareness campaign run in the UK:

> The Alzheimer's Society UK ran a successful *Worried about your memory?* awareness campaign spanning public, GP clinics and pharmacy environments in 2008 which increased patient referral to GPs. The Department of Health in the United Kingdom supported the campaign as part of their commitment to a National Dementia Strategy, where raising public awareness and increasing rates of diagnosis were big recommendations.[42]

3.54 Pfizer drew the Committee's attention to the 2012 World Health Organization (WHO) and Alzheimer's Disease International (ADI) report called *Dementia: A Public Health Priority*,[43] which considered the key tenets of dementia-raising campaigns that had been undertaken around the world. These were:

- Raising public awareness and understanding of dementia;

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[40] COTA Australia (COTA), *Submission 82*, p. 2.

[41] COTA, *Submission 82*, p. 2.

[42] Pfizer Australia, *Submission 49*, p. 3.

[43] World Health Organization (WHO) and Alzheimer's Disease International (ADI), *Dementia: A Public Health Priority*, 2012, <http://www.who.int/mental_health/publications/dementia_report_2012/en/> viewed 21 May 2013.

- Reducing the stigma of dementia and challenging discriminatory behaviour;
- Recognising the early signs of dementia to aid early diagnosis;
- Living well with dementia; and
- The importance of a healthy lifestyle and reducing risk.

3.55 Pfizer submitted that a national communication strategy should be developed in Australia which addressed the above objectives:

> In Australia Pfizer has supported the dementia awareness activities of Alzheimer's Australia over the last 12 years. These activities have generated significant information sharing and awareness-raising across a broad cross-section of the population. We believe there needs to be a national communication strategy in Australia which addresses the objectives put forward above, and involves a broad range of stakeholders including Alzheimer's Australia. Raising community awareness will open avenues for disease support and management for patients and break down the stigma sometimes associated with the disease. It will provide caregivers and families helpful information and opportunities to seek assistance.[44]

Committee comment

3.56 The Committee heard a number of suggestions about how greater awareness of dementia could be raised within the community. The main proposal to improve awareness was for a comprehensive national awareness campaign to educate people about dementia, reduce the stigma surrounding the condition, and promote early diagnosis and intervention.

3.57 The Committee notes there have already been a number of public awareness and education campaigns launched by the Australian Government and/or Alzheimer's Australia, including the *Mind Your Mind* campaign[45] and the more recent *Your Brain Matters* campaign[46]. Noting the focus of *Your Brain Matters* is on brain health and the prevention of dementia, this campaign and prevention more generally will be discussed in Chapter 7.

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[44] Pfizer Australia, *Submission 49*, p. 3.

[45] WHO and ADI, *Dementia: A Public Health Priority*, 2012, p. 86, <http://www.who.int/mental_health/publications/dementia_report_2012/en/> viewed 21 May 2013.

[46] Alzheimer's Australia, *Your Brain Matters*, <http://www.yourbrainmatters.org.au/> viewed 21 May 2013.

3.58 The Committee notes the suggested themes for a national awareness campaign, as outlined by the World Health Organisation (WHO) and Alzheimer's Disease International (ADI) in the report, *Dementia: A public health priority,* as had been adopted by the United Kingdom in its national awareness campaign. These themes are:

- Raising public awareness and understanding of dementia;
- Reducing the stigma of dementia and challenging discriminatory behaviour;
- Recognising the early signs of dementia to aid early diagnosis;
- Living well with dementia; and
- The importance of a healthy lifestyle and reducing risk.

3.59 The Committee supports the proposal for a comprehensive national public awareness campaign to create better awareness of dementia among the community, based on the themes identified above. The Committee encourages the Australian Government to work with Alzheimer's Australia and in consultation with consumers and other relevant community groups, to undertake a comprehensive national awareness campaign on dementia. Such a campaign should operate on a multimedia platform, and target specific population groups in need of greater awareness, such as carers and special needs groups at particular risk of dementia.

Recommendation 1

3.60 **The Australian Government, in collaboration with Alzheimer's Australia and relevant consumer groups, develop and implement a national communication strategy and public awareness campaign to promote greater awareness of dementia, using (but not limited to) the following themes:**

- **Better public awareness and understanding of dementia;**
- **Reducing the stigma of dementia and challenging discriminatory behaviour;**
- **Recognising the early signs of dementia to aid early diagnosis;**
- **Living well with dementia; and**
- **The importance of a healthy lifestyle and reducing risk.**

Awareness for General Practitioners (and other health professionals)

3.61 The Committee heard evidence from a range of consumers, medical practitioners and other stakeholders, that there was a need for a greater awareness of dementia within the medical profession itself, if there was to be early and timely diagnosis and intervention of dementia.

3.62 Mrs Fiona Young, a Clinical Nurse Consultant in Tasmania, said it should not be assumed that health professionals had a good understanding of dementia, as it was a specialised area:

> For health professionals there needs to be awareness too. We cannot assume that because people are health professionals they have a good understanding of dementia because it is a specialised area. Not all health professionals do, but a lot of them are in the ideal space to identify people and refer them on to enable them to be assessed appropriately and aid them in getting a diagnosis. The same applies to GPs too. We cannot assume that they understand what the signs and symptoms of dementia are and how that affects people's day-to-day lives.[47]

3.63 Specifically, there was concern regarding the level of awareness among General Practitioners (GPs), who were often the first point of call for a person seeking assistance for symptoms of memory loss or cognitive

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[47] Mrs Fiona Young, Community Dementia Service, Tasmanian Health Organisation North, *Official Committee Hansard*, Launceston, 27 July 2012, p. 20.

decline. As stated by the Royal Australian College of General Practitioners (RACGP):

> General practitioners (GPs) play an important role in recognising, assessing, diagnosing and managing dementia, and maintaining effective and ongoing communication and coordination between the patient, carer and family with primary and specialist providers.[48]

3.64 The Committee was told that GPs needed greater awareness and education of dementia to assist them to identify the symptoms of dementia, provide advice about the assessment and treatment process, and give appropriate referrals for further treatment and support.

3.65 Mr Jack Sach, of Alzheimer's Australia Victoria, told the Committee that dementia was often not well recognised by GPs, due to a lack of training:

> Many GPs are not well trained in the application of cognitive screens such as the mini-mental and so forth. Many GPs have difficulty just keeping pace with the latest science in this area, which is very, very rapid at the moment. Some GPs may be reluctant to refer to specialists, hence there is misdiagnosis occurring. Many GPs do not fully appreciate the services that are available and therefore do not refer on…
>
> … There is also a limited understanding of the evidence, which is now becoming quite well established, that you can actually reduce your risk of dementia through lifestyle factors, and many still believe that you cannot influence the progression of dementia.[49]

3.66 The Committee was given anecdotal evidence that some GPs were either fearful of providing their patient with a diagnosis, or falsely believed that providing a diagnosis was futile.[50]

3.67 Ms Helga Merl, a Nurse Practitioner from Hunter Medicare Local, said one of the barriers to GPs providing a diagnosis of dementia was that they did not understand what could be done once a diagnosis was made:

> What do they do after they have diagnosed someone with early dementia? A lot of people feel there is nothing much that can be done, but of course we can do so much. We can look at treating reversible causes and managing symptoms that are present. We

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[48] Royal Australian College of General Practitioners (RACGP), *Submission 83*, p. 4.

[49] Mr Jack Sach, Alzheimer's Australia Vic, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 23. See also: AGPN, *Submission 87*, pp. 9-12.

[50] See for example: Mr Mark Howland, Dementia (Community Health), Hunter New England Local Health District (Tablelands, Mehi and McIntyre Clusters), *Official Committee Hansard*, Moree, 27 August 2012, p. 20.

> have a big push now on health promotion, and that is also really valuable for people with early diagnosis or early symptoms. It is never too late to do something positive for your brain, the same as it is never too late to do something positive for your heart or your physical activity or your diet. All those things contribute to memory problems.[51]

3.68 Mr Mark Howland, a Clinical Nurse Consultant, said that the lack of understanding of dementia across the medical community caused cases of misdiagnosis:

> Certainly, when you are talking to people there are a whole range of differential diagnoses that you need to make before you come up with a diagnosis of dementia. Unfortunately, what people tend to do is see someone who is old, see that they are confused, add one and one together and get six. And they come up with a dementia diagnosis. If not a diagnosis that is certainly a belief that people then hold about a patient. The rest of the care for that patient is based on the idea that it is probably dementia.[52]

3.69 The RACGP recognised that people with early stages of dementia were not being diagnosed in primary care and advised that GPs needed ongoing training and awareness across a range of issues regarding dementia diagnosis and management:

> In addition to the challenges of diagnosis, GPs needs to keep abreast of the latest available services, networks, guidelines, therapies and legal aspects in addressing dementia treatment. The RACGP recognises the need for ongoing professional training for GPs to improve knowledge and confidence in early diagnosis and management as well as awareness of available support services.[53]

3.70 Speech Pathology Australia (SPA) detailed what it saw as a lack of awareness within the medical community about the communication difficulties a person with dementia could experience and how this impacted on the quality of care provided to them:

> SPA wishes to highlight the fact that there is a significant lack of awareness and understanding of the communication difficulties for some people who have a diagnosis of dementia. This exists at the community level within GP practices where the GP may fail to

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[51] Ms Helga Merl, Mobile Memory Clinic, Hunter Medicare Local, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 7.

[52] Mr Mark Howland, Hunter New England Local Health District (Tablelands, Mehi and McIntyre Clusters), *Official Committee Hansard*, Moree, 27 August 2012, p. 16.

[53] RACGP, *Submission 83*, p. 6, 9.

> pick up severe progressive aphasia as the first sign of dementia; at the acute level when people are hospitalised into dementia assessment and care beds; at the rehabilitation level where intervention can improve communication function and also delay deterioration; as well as at a residential care level for staff and carers and at a social level for family and friends. This lack of awareness and recognition of the severe communication impairment for some people with dementia causes unintended discrimination and inequity for this group.[54]

3.71 The Community Dementia Service from Tasmania proposed the establishment of a support service to assist GPs with diagnosis, treatment and ongoing management of people diagnosed with dementia, including assistance for their carers.[55]

3.72 Professor Dimity Pond, of MDAG, informed the Committee of a GP education trial that had been undertaken in specific regions around Australia. Professor Pond said of the trial:

> We did a GP education trial using evidence based education strategies. A lot of people complain about educating GPs—they don't listen, et cetera—but if you use evidence based strategies in doing it then it does work, and ours did work. We raised the identification rate for dementia from under 50 per cent to 65 per cent amongst the GPs who were in our intervention arm. It did not change at all in the control group. That was through two half-hour detailing visits when we asked GPs to audit their patients and give their view. We fed back to them after the second visit. It was not a difficult thing to do and it would not be hugely expensive, but that was the sort of thing that worked because the GPs could talk about it. We aimed at destigmatising dementia for the GPs.[56]

3.73 An article reporting on part of this study, which focussed on the difficulties GPs had in communicating a diagnosis to their patient, stated:

> Analysis revealed that diagnosis of dementia was inherently challenging in the context of GP consultation, although attaining a correct diagnosis was seen as imperative. Three main themes emerged that captured the diagnostic challenges and associated disclosure issues: the GPs' confidence in having a correct diagnosis of dementia to disclose; acting in patients' best interests in

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[54] Speech Pathology Australia, *Submission 74*, pp. 2-3.

[55] Community Dementia Service Primary Health North, *Submission 14*, p. 4.

[56] Professor Dimity Pond, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, p. 16. See also: Jill Phillips et al, 'Difficulties in disclosing a diagnosis of dementia: a qualitative study in general practice', *British Journal of General Practice*, August 2012, p. e.548.

> disclosure of the diagnosis; and dealing with the negative implications of the diagnosis.[57]

3.74 MDAG supported the call for an evidence-based training program for GPs, containing regular assessments, random monitoring and reviews on a number of dementia-related topics, including risk factors and prevention, diagnosis, specific population groups, assessment tools and treatment options.[58]

3.75 The Australian Government, through the Department of Health and Ageing (DoHA), has outlined a commitment of $27 million towards achieving timely diagnosis, as part of the *Living Longer. Living Better.* reforms. This includes a commitment to improve training and support for those who are at the frontline of the first presentation of someone with dementia (such as GPs).[59]

3.76 Ms Rosemary Huxtable, of DoHA, explained that as part of the *Living Longer. Living Better.* reforms, there was a focus on providing greater guidance to clinicians about how an early diagnosis was an essential step in enabling people to better understand the path they were on and access services and medication at an earlier stage.[60]

3.77 The program of reform aims to assist primary health care providers to undertake more timely diagnosis by providing GPs and Practice Nurses with training and education programs and by improving support to help them better diagnose dementia:

> Funding will be provided to support general practice staff, assist with take up of training, assist in developing appropriate referral pathways and support General Practitioners, practice nurses and all ancillary staff employed in the primary care setting. The program also aims to improve understanding of the medical and social support available to improve the lives of people with dementia and the importance of an accurate diagnosis.[61]

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[57] Jill Phillips et al, 'Difficulties in disclosing a diagnosis of dementia: a qualitative study in general practice', *British Journal of General Practice*, August 2012, p. e.548.

[58] MDAG, *Submission 48*, pp. 4-5. For an example of a dementia education campaign for GPs, see Australian Institute for Primary Care and Ageing, *Submission 60*.

[59] Ms Rosemary Huxtable, DoHA, *Official Committee Hansard*, Canberra, 8 February 2013, p. 13. See also: Australian Government, *Living Longer. Living Better.*, April 2012, p. 22.

[60] Ms Rosemary Huxtable, DoHA, *Official Committee Hansard*, Canberra, 8 February 2013, p. 13.

[61] DoHA, *Submission 89*, p. 15. See also: Australian Government, *Living Longer. Living Better.*, April 2012, p. 22.

Committee comment

3.78 A GP, or another practitioner in a primary care setting, such as a specialist nurse, is often the first port of call for a person who is experiencing memory loss or symptoms of cognitive decline. Accordingly, enhancing awareness and knowledge about dementia diagnosis, treatment and management options within the primary health care community will undoubtedly assist in increasing the number of people who receive a timely diagnosis of dementia. The benefits of a person receiving a timely or early diagnosis of dementia are detailed further in Chapter 4.

3.79 The Committee understands that the Australian Government, through the *Living Longer. Living Better.* reforms, aims to provide GPs and practice nurses with further training and education to assist them to provide a timely diagnosis of dementia.

3.80 The Committee supports the high priority placed on education and training for GPs regarding dementia diagnosis. In particular, the Committee supports the roll-out of evidence-based training for GPs, such as the model already trialled by Professor Pond and others.

3.81 The Committee will discuss training and workforce issues regarding specialist nurses in Chapter 5.

Recommendation 2

3.82 **The Australian Government Department of Health and Ageing, in collaboration with the Minister's Dementia Advisory Group and the Royal Australian College of General Practitioners, develop a national evidence-based dementia training program for General Practitioners, with an emphasis on diagnosis.**

Elements of the training program should include:

- **Challenging stigma and misconceptions;**
- **Managing sensitive and difficult conversations in the context of the doctor-patient/carer relationships;**
- **Current best-practice and implications of latest research; and**
- **Diagnosis, care and support pathways for people with dementia, their families and/carers.**

4

> *By continuing to insist that what was happening inside my brain was definitely not usual I was diagnosed while still at a relatively early stage and therefore I have been able to have my say about our lifestyle decisions. But had the diagnosis been in 2006 when I first became aware of changes I would have had much greater capacity to make decisions and therefore more choices from which to make them…*
>
> *… I would have retained my identity and continued to be financially independent.*[1]

Diagnosis

4.1 'Early' or 'timely' diagnosis of dementia can have significant benefits for a person with dementia, their families and carers.

4.2 These benefits are far-reaching and can include:

- The ability to plan early and prepare for the future; and
- The ability to obtain a diagnosis and appropriate treatment early.[2]

4.3 In addition, having timely access to appropriate medical treatment for dementia may improve cognitive function, prolong independent living, reduce carer burden and improve quality of life.[3]

4.4 Despite the obvious benefits to early or timely diagnosis, the Committee heard that as many as two-thirds of people with dementia live and die with the condition without ever being diagnosed. Those people who do receive a diagnosis wait an average of approximately three years from first symptoms to diagnosis.[4]

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[1] Robert, *Submission 19*, pp. 1-2.

[2] Alzheimer's Australia, *Early diagnosis of dementia*, paper 10, March 2007, p. 2.

[3] Australian Government Department of Health and Ageing (DoHA), *Submission 89*, p. 9.

[4] Alzheimer's Australia (National Office), *Submission 44*, p. 3. See also: Alzheimer's Australia (National Office), *Submission 44.1*, p. 1.

4.5 The Committee was told that primary care practitioners, such as General Practitioners, have a major role in improving early diagnosis. Consequently, there is a need to improve early or timely diagnosis by General Practitioners and other primary care practitioners.

4.6 Cognitive Dementia and Memory Services (CDAMS) told the Committee that ensuring timely diagnosis requires a multi-faceted approach:

> Ensuring availability of timely diagnosis and advice will require a multi-pronged approach including education and up-skilling of GP's, practice nurses, and service providers, provision of specialist services to provide assistance and advice particularly in more complex presentations, along with increased community awareness of dementia and the benefits of early diagnosis.[5]

4.7 The concepts of early and timely diagnosis, the benefits to achieving a timely diagnosis, and how a timely diagnosis might be obtained, are discussed below. The barriers to achieving early and timely diagnosis are discussed in Chapter 5.

4.8 The need to increase community awareness about the benefits of early diagnosis is discussed in detail in Chapter 3.

What is 'early' or 'timely' diagnosis?

4.9 The optimal time for a person to receive a diagnosis of dementia was the subject of some discussion during the inquiry. The Committee has considered the difference between the concepts of 'early' and 'timely' diagnosis in the context of this discussion.

4.10 Minister Butler's Dementia Advisory Group (MDAG) distinguished 'timely' diagnosis from 'early' diagnosis:

> For example a person with undiagnosed moderately advanced dementia first coming to medical attention on admission to hospital should receive a diagnosis; this would be timely though not early. Early diagnosis refers to reducing the gap from first symptoms to receiving a diagnosis.[6]

4.11 Alzheimer's Australia National Office defined 'early diagnosis' as 'a diagnosis as soon as possible after symptoms are brought to the attention

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[5] Cognitive Dementia and Memory Services (CDAMS), *Submission 39*, p. 5.

[6] Minister Butler's Dementia Advisory Group (MDAG), *Submission 48*, p. 1.

of the health care system.' Defined in this way, Alzheimer's Australia considered that 'early' diagnosis was in fact similar to 'timely' diagnosis.[7]

4.12 Alzheimer's Australia Victoria believed that a 'timely' diagnosis coincided with action being taken at the point that concern was expressed, and the timely provision of advice, treatment and support services.[8]

4.13 In this regard, it was submitted that a 'timely' diagnosis was preferable to an 'early' diagnosis:

> Health professionals involved in diagnosing dementia must be careful to balance, and be sensitive to, the perceived and potential positive and negative effects of a dementia diagnosis. The RACP (Royal Australasian College of Physicians) and the ANZSGM (Australian and New Zealand Society for Geriatric Medicine) support a person-centred approach to diagnosis that responds to the person with dementia and their carers' needs and preferences. Often timely diagnosis will be more appropriate than early diagnosis.[9]

4.14 While acknowledging the potential benefits of an 'early' diagnosis, the Royal District Nursing Services Ltd (RDNS) considered that for interventions to be successful, the person with dementia, along with their family and friends, had to be ready to seek information, diagnosis, and treatment. RDNS stated, 'This readiness will come at different times for different people but when it does expeditious and timely assessment is then critical.'[10]

4.15 MDAG explained the factors a practitioner was required to balance in making a diagnosis:

> The advantages of a diagnosis are that it can be a relief (paradoxically) and trigger support, medications and planning ahead. On the other hand it is important to respect peoples' preferences not to know and acknowledge possible distress. The clinician's skill is to navigate these issues sensitively.[11]

4.16 Dr Owen Davies, of the South Australia Division of the Australian and New Zealand Society for Geriatric Medicine (ANZSGM), considered the ideal point at which to make a diagnosis of dementia:

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[7] Alzheimer's Australia (National Office), *Submission 44*, p. 3.

[8] Alzheimer's Australia Vic, *Submission 35*, p. 2. See also, Tasmanian Government Department of Health and Human Services, *Submission 41*, p. 7.

[9] The Royal Australasian College of Physicians (RACP) and the Australian and New Zealand Society for Geriatric Medicine (ANZSGM), *Submission 22*, p. 8.

[10] Royal District Nursing Services Ltd, *Submission 78*, p. 2.

[11] MDAG, *Submission 48*, p. 2. See also: Dr Lyndon Bauer, Health Promotion Central Coast, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 30.

> My view is that we should be making a diagnosis at the point where someone is struggling to manage to live a day-to-day life at home or they are just beginning to develop those problems.[12]

Committee comment

4.17 This inquiry focusses on how an 'early' diagnosis of dementia might improve a person's quality of life, as well as the lives of their family and carers. In hearing evidence about the benefits of receiving a 'timely' diagnosis, the Committee considers that 'early' diagnosis in the context of this report has the same meaning as 'timely' diagnosis.

4.18 'Early diagnosis' sometimes includes reference to a diagnosis of pre-symptomatic Alzheimer's disease or other causes of dementia using biomarkers (biological rather than symptomatic indications of disease presence). The Committee was told that preclinical diagnosis is currently confined to research settings.[13]

4.19 The Committee heard that the time of readiness to receive a diagnosis varies from person to person. A General Practitioner or other medical professional must consider their patient's readiness with a number of other factors, such as the risk of damaging the patient-doctor relationship, and the need to commence beneficial treatment or interventions.

4.20 The Committee accepts that in the majority of cases, the appropriate and timely point for a person to receive a diagnosis of dementia is when they are experiencing symptoms which begin to impact upon their everyday lives.

4.21 It is clear that there is currently an unacceptable delay between when a person first displays symptoms of dementia, and when they receive a diagnosis (if they receive a diagnosis at all). These delays, along with the barriers which contribute to a delay or failure to receive a diagnosis, are discussed in Chapter 5.

4.22 How a diagnosis is obtained, as well as the benefits to achieving a 'timely' diagnosis, are discussed further below.

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[12] Dr Owen Davies, ANZSGM, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 14. See also: Dr Lyndon Bauer, Health Promotion Central Coast, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 33.

[13] Alzheimer's Australia National Office, *Submission 44*, pp. 3 and 27. See also: MDAG, *Submission 48*, p. 1; NSW Department of Health, *Submission 95*, p. 1.

Benefits of timely diagnosis

4.23 The Committee was told that the benefits to receiving an early diagnosis were three-fold:

- It gives a person the power to control their life and plan for their future, including organising enduring powers-of-attorney and discussing advance care directives;
- It empowers the person with dementia, their carer and their family to accept the diagnosis and reach a better understanding about the person's condition; and
- Treatment, services and support are usually built around a diagnosis, so achieving an early diagnosis provides a person with access to dementia care services.[14]

4.24 The Committee acknowledges the significant challenges faced by families of people who receive a diagnosis of dementia. It follows that the benefits of timely diagnosis will extend to families, so that they can also access the range of available support services for carers.

4.25 Mrs Judy Ratajec, of Uniting Church Frontier Services, told the Committee that appropriate and timely diagnosis should be promoted:

> The benefits of that timely and appropriate diagnosis would obviously be around being able to rule out any other cause for the symptoms that are presenting, to look at treating other risk factors, to look at linking the family and/or the carers into support systems so that they actually have that support system to go with them through the journey…
>
> … The earlier a person is diagnosed the more able they are to actually look at self-determining for the journey, so empowering them through the decision-making.[15]

4.26 The Australian General Practice Network (AGPN) submitted there were a number of potential clinical benefits associated with timely diagnosis of dementia, including the opportunity to:

- treat the reversible causes of dementia
- help slow the progression of dementia through pharmaceutical and lifestyle interventions

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[14] Associate Professor Mark Yates, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, p. 17. See also: Associate Professor Yates, MDAG, *Official Committee Hansard*, Canberra, 21 August 2012, p. 21.

[15] Mrs Judy Ratajec, Uniting Church Frontier Services, *Official Committee Hansard*, Broome, 13 November 2012, p. 25.

  - support symptom management through pharmaceutical and lifestyle interventions (many of which are likely to be more effective earlier in the course of disease progression) and minimise the impact of symptoms, for example through the establishment of routines that can help patients and families manage declining cognitive function.[16]

4.27 It was argued there was also a range of non-clinical benefits of timely diagnosis and management of dementia, for both a person with dementia and their family. These benefits included offering insight into the symptoms a person was experiencing and a greater understanding of disease progression and what the future may hold. The AGPN considered:

> In this sense, timely diagnosis can provide an important opportunity for the patient to experience a sense of self determination at a time when it can feel that their self-agency is being eroded. [17]

4.28 Jill, who appeared in a private capacity, believed that an earlier diagnosis for her husband may have assisted in easing his symptoms and allowing her to take control of business decisions sooner:

> There are medications that help slow it and the earlier they get on them the more effective they are. He could have perhaps been on medication. As I said in my opening speech, for a month or two he would not be able to do anything and then he seemed to come all right and I would let him take over again. Perhaps if I had realised that it was a real problem with his brain, I would not have been allowing him to step in and out of the business.[18]

4.29 The benefits of early diagnosis could also be seen in the health and aged care systems, as early diagnosis, effective treatment and support could lead to a reduction in unnecessary hospitalisations and crisis interventions, and delay a person’s entry into residential or hospital-based care. [19]

4.30 In addressing the inquiry’s terms of reference, MDAG noted the following benefits to achieving a timely diagnosis:

- In improving the quality of life and assisting people with dementia to remain independent for as long as possible:
  - ⇒ By reversing dementia if a reversible cause could be discovered;
  - ⇒ By enhancing safety in workplace for those still working;

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[16] Australian General Practice Network (AGPN), *Submission 87*, p. 7.

[17] AGPN, *Submission 87*, p. 8.

[18] Jill, private capacity, *Official Committee Hansard*, Moree, 27 August 2012, p. 9.

[19] AGPN, *Submission 87*, pp. 8-9.

  - ⇒ By monitoring and if necessary assessing driving so as to enhance safety with driving;
  - ⇒ By optimising management of other medical conditions;
  - ⇒ By alerting the person, and his or her family, friends and doctor to the need to assist the person psychologically;
  - ⇒ By helping families and friends to understand changes in people with dementia leading to better relationships and development of strategies to compensate for cognitive deficits;
  - ⇒ By receiving advice from health professionals such as occupational therapists and from Alzheimer's Australia (Living with Memory Loss course) on strategies to compensate for memory loss; and
  - ⇒ By enabling medications to be commenced earlier, which could help someone stay independent for longer. [20]
- ▪ In increasing opportunities for continued social engagement and community participation for people with dementia and their carers:
  - ⇒ By alerting others to make them more tolerant and supportive;
  - ⇒ By structuring social engagements so as not to be overwhelming;
  - ⇒ Through support groups for people with early dementia; and
  - ⇒ By building on retained strengths of person with early dementia.[21]
- ▪ In helping people with dementia and their carers plan for their futures:
  - ⇒ Enabling planning for future life decisions, living arrangements, proximity to services and family;
  - ⇒ Alerting the person and the family to the need for financial planning; and
  - ⇒ Enabling affairs to be arranged in timely manner while person with dementia still has legal mental capacity.[22]

How is a diagnosis of dementia obtained?

4.31 In considering what barriers exist in achieving a diagnosis of dementia, it is important to examine how a diagnosis of dementia is obtained in Australia.

4.32 International guidelines recommend that an initial assessment of a patient for dementia include obtaining a comprehensive medical history,

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[20] MDAG, *Submission 48*, p. 7.

[21] MDAG, *Submission 48*, p. 8.

[22] MDAG, *Submission 48*, p. 8.

undertaking a physical examination and conducting necessary laboratory and imaging tests.[23]

4.33 The Australian Institute of Health and Welfare (AIHW) stated in its report, *Dementia in Australia*, that there was no single definitive diagnostic test:

> There is no single or simple test that will definitively diagnose dementia. The assessment process may vary according to who is conducting it and the symptoms the person presents with. In general, the aim of the assessment is to gather sufficient information about changed behaviours, functional capacity, psychosocial issues and relevant medical conditions to allow for a diagnosis to be made. Often, the information gathering process includes input from third parties (for example, carers, family members and service providers) and the use of screening tools.[24]

4.34 If the results from a screening test suggest cognitive impairment, it is recommended that a person be referred to a medical specialist (such as a geriatrician, psychiatrist or neurologist) for further assessment. On the advice of the specialist, other tests, such as radiological and laboratory investigations, may be undertaken.[25]

4.35 The strengths and weaknesses of screening tests for dementia are outlined below.

Screening tests

4.36 There are a number of screening tools available to medical practitioners who are tasked with making a diagnosis of dementia. These tools include:

- The Mini-Mental State Examination (MMSE);
- Modified Mini Mental Exam (3MS);
- The General Practitioner assessment of Cognition (GPCOG);
- The 7-Minute Screen;
- The Addenbrooke's Cognitive Examination – Revised (ACE-R);
- The Rowland Universal Dementia Assessment Scale (RUDAS);
- The Montreal Cognitive Assessment (MoCA);
- The CogState; and

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[23] Royal Australian College of General Practitioners (RACGP), *Submission 83*, pp. 5-6.

[24] Australian Institute of Health and Welfare (AIHW) 2012, *Dementia in Australia*, catalogue no. 70, p. 4. See also: Alzheimer's Australia, *Timely diagnosis of dementia: can we do better*, paper 24, September 2011, p. 14; Mr Mark Howland, Hunter New England Local Health District (Tablelands, Mehi and McIntyre Clusters), *Official Committee Hansard*, Moree, 27 August 2012, p. 18.

[25] AIHW, *Dementia in Australia*, 2012, p. 4.

- The Kimberly Indigenous Cognitive Assessment Screen (KICA).[26]

4.37 A positive screen does not mean that a person has dementia. Rather, a score below a threshold on a cognitive test merely indicates poor performance, and a more detailed assessment is required before a diagnosis can be made.[27]

4.38 Professor Dimity Pond, a professor of General Practice, explained how conducting screening tests was not an exact science:

> Doing a mini mental state exam or even our GP cog exam on everyone does not work because it is not an exact science. Those screening tests can overdiagnose or underdiagnose people. You can do really well. I have had people score 30 out of 30 and they cannot find their way out of my surgery. They have dementia to the degree that they get lost every time they walk out of my door and yet they score perfect scores. Then other people might score a 22 or 23 but they have been like that all the[ir] lives. They did not have a good education. People in their 80s often did not get much beyond primary school. Their literacy might not be that good. They do not spend a lot of time listening to the news. They might be a bit stressed by the questions and they just do not score well. It does not mean they have dementia. There is not an easy way for GPs to make this diagnosis.[28]

4.39 The Australian Psychological Society (APS) submitted that competent use of diagnostic instruments and valid interpretations of the results was crucial in developing treatment plans that responded to a person's needs. For example:

> It is recognised that people not trained in the administration of the MMSE can inadvertently or unwittingly affect the results and scoring of the test; thus increasing the chance of under- or over-estimating the level of cognitive impairment, and in turn affecting treatment decisions…
>
> … The implications of inaccurate or possibly erroneous diagnosis of a person with dementia are vast and varied including

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[26] See: AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 4; RACP and ANZSGM, *Submission 22*, p. 8; Queensland Health, *Submission 23*, p. 4; and Dementia Collaborative Research Centres, *Cognitive Assessment Measures*, <http://www.dementia-assessment.com.au/cognitive/index.html>, viewed 7 June 2013. For further discussion on dementia assessment and screening, see Dr Ross Colquhoun, *Submission 66*.

[27] MDAG, *Submission 48*, p. 1.

[28] Professor Dimity Pond, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 39.

> prescription of the wrong medication or, put simplistically, failure to treat.[29]

Screening challenges

4.40 While the proportion of patients who are incorrectly diagnosed using the most common diagnostic instruments is low, the Committee was told that the risk is amplified for patients who are highly educated, speak English as a second language and/or have a sensory impairment.[30]

4.41 Associate Professor Mark Yates, of MDAG, explained that the gaps in some of the language-based screening tools were well recognised and therefore could be addressed:

> When you use these tools a lot, it is like anything else: if you know the holes or if you know when the tool is not going to work, it is often as useful as having a tool that works perfectly in every scenario because you can use its gaps and you know its blind spots. So that is quite useful. There are other tools we can use. There are validated equivalents to the Mini Mental State Examination, such as the RUDAS, which has been validated in Australia and has multiple language capability. That is what I would use in my clinic if I had someone who was of a non-English-speaking background.[31]

4.42 Queensland Health stated the importance of recognising a variety of validated tools such as the MMSE, the RUDAS and the KICA tool, to assist in the diagnosis of people from a range of backgrounds.[32]

4.43 The Committee was told that the KICA screening tool had been introduced in Alice Springs and surrounding desert communities, to assist in the diagnosis of dementia in Indigenous Australians. However, it was recognised that the application of KICA in Central Australia was in its preliminary stages and training was necessary to achieve the full benefit of the testing.[33]

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[29] Australian Psychological Society, *Submission 50*, p. 4.

[30] Queensland Health, *Submission 23*, pp. 3-4. See also Leo, *Official Committee Hansard*, Launceston, 27 July 2012, pp. 1-2; DutchCare Ltd, *Submission 17*, p. 2; and Multicultural Communities Council of SA, *Submission 24*, p. 2.

[31] Associate Professor Yates, *Official Committee Hansard*, Canberra, 21 August 2012, p. 21.

[32] Queensland Health, *Submission 23*, pp. 3-4. See also, Mr Mark Howland, Hunter New England Local Health District (Tablelands, Mehi and McIntyre Clusters), *Official Committee Hansard*, Moree, 27 August 2012, p. 18; Fronditha Care, *Submission 72*, p. 5; Doutta Galla Community Health, *Submission 75*, p. 4.

[33] Ms Wilma Gibson, Central Desert Shire Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 39.

4.44 Ms Nina Bullock, of MacDonnell Shire Council (servicing remote Indigenous communities outside of Alice Springs) told the Committee that the context of the tool needed to be taken into account:

> The KICA is a good example of an assessment tool that works in its context. Its context is tropical north territory. In many ways it is a good step forward but it is not the tool for us right now from the shire's perspective.[34]

4.45 Mr Graham Kraak, of Queensland Health, said KICA had been trialled for Indigenous communities in Queensland, but further evaluation of its effectiveness was required:

> Often the challenge with these is that it might work for one particular community but it is not necessarily generalisable to all Indigenous communities or to Torres Strait Islanders. Often they are grouped together, but the cultural needs and the cultural nuances are very, very different across the country—even within Queensland. [35]

4.46 Ms Cate Young, of Tangentyere Council, told the Committee that inaccurate assumptions were often made during the assessment process for Indigenous Australians, due to language barriers:

> I have seen a Ngaanyatjarra woman having a dementia assessment with the help of a Pitjantjatjara interpreter who thought she was a bit mixed up because the Pitjantjatjara interpreter did not understand Ngaanyatjarra. It was only because a Ngaanyatjarra person walked past and said, 'Oh, she is speaking Ngaanyatjarra,' that we actually realised that this lady was not mixed up at all and the interpreter was mixed up. It is not just those kinds of things but even some of the assessments. There are huge cultural divides and language divides that are not well addressed.[36]

4.47 Ms Young also illustrated the cultural issues associated with obtaining a diagnosis of dementia:

> I have assessed a lady who, when you asked her that question about how many animals can you name when going hunting, only named one. But then her family told me later that she only named one because she is only officially allowed to speak about one, not

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[34] Ms Nina Bullock, Macdonnell Shire Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 38.

[35] Mr Graham Kraak, Queensland Health, *Official Committee Hansard*, Brisbane, 1 August 2012, p. 31.

[36] Ms Cate Young, Tangentyere Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 25. See also: Mr Brian Gleeson, Office of the Coordinator General for Remote Indigenous Services, *Official Committee Hansard*, 8 February 2013, p. 4.

> but because she could not name them. There are lots of discrepancies and mixed up assessments that are being not done well and not followed up well because of quite big cultural and language divides. They leave hospital and then there is not that follow up. So there is an opportunity missed.[37]

4.48 Mrs Stephanie Waters, of Kimberley Aged and Community Services, told the Committee that language and distance barriers exacerbated difficulties in achieving an accurate diagnosis. Mrs Waters outlined the methods used to assist in diagnostic testing for dementia in Indigenous communities, such as the use of interpreters:

> Sometimes people will come in with a daughter or an escort, a family member, so sometimes that will be one of the strategies used. We try to use the Kimberley Interpreting Service. I guess getting awareness across all the hospitals that that even exists is difficult with the high turnover of doctor staff and nursing staff. A lot of them are not aware initially that that service exists. And then there is the timeliness of having someone able to come and interpret, especially in an acute setting, if someone is really unwell. But it is a common occurrence. With all the many languages—and do not ask me how many there are, but there are lots—an interpreter who can actually speak in that language is not always available.[38]

4.49 Due to the cultural bias embedded in some of the screening tools, CDAMS recommended that a best practice model for the assessment and diagnosis of dementia for people from culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander backgrounds be identified to assist in achieving a more timely diagnosis.[39]

4.50 Dr Jennifer Torr submitted that diagnosis of dementia in people with intellectual disabilities was a complex clinical challenge for a number of reasons, including that standard assessment instruments were not valid for use in this population.[40]

4.51 National Disability Services agreed that there were particular challenges when assessing people with an intellectual disability for dementia:

> While the diagnosis of dementia in someone with an intellectual disability should follow the same process as for other people,

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[37] Ms Cate Young, Tangentyere Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 25.

[38] Ms Stephanie Walters, Kimberley Aged and Community Services, *Official Committee Hansard*, Broome, 13 November 2012, p. 9. See also: p. 8.

[39] CDAMS, *Submission 39*, p. 8.

[40] Dr Jennifer Torr, *Submission 73*, pp. 1 and 3.

> special challenges arise from the fact that people with intellectual disability have pre-existing difficulties with tasks that involve thinking, remembering and daily living skills. They, therefore, do not perform well on the standard tests used for the general population.[41]

4.52 Dr Torr and CDAMS called for the identification of best practice guidelines for assessing people with intellectual disabilities for dementia.[42]

4.53 MDAG recommended the promotion of the use of standardised cognitive screening instruments, as have been evaluated by the Commonwealth funded Dementia Outcomes Measurement Suite (DOMS).[43]

Committee comment

4.54 The Committee notes there are a range of screening tools available to medical practitioners to assist in making a diagnosis of dementia. It is clear that the application of these tests is not an exact science, and at times this testing can produce either a false diagnosis, or fail to diagnose someone who is later found to have dementia. All screening tests and assessment processes have their strengths, weaknesses, and limitations.

4.55 It is not the Committee's intention to offer an exhaustive list of available screening tools for dementia in this report, or to offer a judgement on the effectiveness of each tool.

4.56 The Committee understands that best practice dictates that screening tools be used as only one step of the assessment process. Ideally, a diagnosis of dementia should be obtained through the results of a suitable screening test, a GP's clinical judgment, information gathered from the patient and/or their families, and a referral to geriatricians or other specialists, if required.

4.57 The Committee heard there are challenges associated with achieving an accurate diagnosis in some population groups, such as people with an intellectual disability, people from CALD backgrounds and Aboriginal and Torres Strait Islander people, where English is a second language. Further, the Committee heard standard cognitive testing is invalid for people with intellectual disabilities.

4.58 Alternate tools have been developed which may be more useful for people of CALD or Indigenous backgrounds. However, the Committee was told

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[41] National Disability Services, *Submission 43*, p. 2.

[42] Dr Torr, *Submission 73*, pp. 1 and 3; CDAMS, *Submission 39*, p. 8.

[43] MDAG, *Submission 48*, p. 9. See also: Dementia Collaborate Research Centres, *Dementia Outcomes Measurement Suite,* <http://www.dementia-assessment.com.au/> viewed 7 June 2013.

there is no 'one size fits all' screening test, and tests need to be adapted to suit a particular community's needs.

4.59 Cultural sensitivity and understanding, as well as flexibility in assessment processes, is necessary when undertaking assessments for dementia for people from CALD backgrounds, and Indigenous people for whom English is a second language.

4.60 Where necessary, interpreters should be utilised to assist with the screening process. Unfortunately, the Committee heard that finding an appropriate interpreter to assist Indigenous communities is difficult, given the range of languages spoken across different communities. Further, hospital or medical staff members may not be alert to some of the language barriers and the availability of interpreters to assist in the screening processes.

4.61 In its submission to the Committee, MDAG referred to the development of the Dementia Outcomes Measurement Suite (DOMS), a project commissioned under the Australian Government's National Dementia Initiative (administered through the Department of Health and Ageing). The DOMS aims to develop a standard suite of instruments to be circulated throughout Australia to encourage clinicians to 'talk the same language', by using the same instruments as much as possible.[44]

4.62 The Committee supports this project and encourages the dissemination of standardised best practice guidelines for the assessment and diagnosis of dementia, including separate guidelines for assessment of people from CALD backgrounds.

4.63 The Committee also notes the work of the National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) in consulting with Alzheimer's Australia to develop principles to underpin best practice, to improve services and support for Aboriginal and Torres Strait Islander communities. Presumably this includes best practice principles for diagnosis.

4.64 It appears from the evidence that the diagnostic needs of people with disabilities, particularly those with intellectual disabilities, have not yet been considered in the development of best practice principles, as a population group with special needs.

4.65 The Committee is of the view that the development of best practice guidelines for diagnosis of dementia for people with an intellectual disability should be prioritised.

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[44] Dementia Collaborate Research Centres, *Dementia Outcomes Measurement Suite,* <http://www.dementia-assessment.com.au/> viewed 7 June 2013.

Recommendation 3

4.66 **The Australian Government, through the Dementia Outcomes Measurement Suite, develop best practice guidelines for diagnosis of people with intellectual disability.**

Targeted screening for dementia?

4.67 Over the course of the inquiry, there were wide-ranging discussions regarding whether targeted screening for dementia should be undertaken at an age when individuals are most at risk of developing dementia.

4.68 Specifically, discussion canvassed whether cognitive screening should form part of health assessments undertaken for people over 75 years of age, which are free to patients through the Medicare Benefits Schedule (MBS).

4.69 A health assessment for people aged 75 and over (a '75-plus health assessment') provided under the MBS involves an 'assessment of a patient's health and physical, psychological and social function for the purpose of initiating preventive health care and/or medical interventions as appropriate'.[45] The assessment may be undertaken once every 12 months, with a consultation time of up to one hour, and must include:

- measurement of the patient's blood pressure, pulse rate and rhythm;
- an assessment of the patient's medication;
- an assessment of the patient's continence;
- an assessment of the patient's immunisation status for influenza, tetanus and pneumococcus;
- an assessment of the patient's physical function, including the patient's activities of daily living, and whether or not the patient has had a fall in the last 3 months;
- an assessment of the patient's psychological function, including the patient's cognition and mood; and
- an assessment of the patient's social function, including the availability and adequacy of paid and unpaid help, and

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[45] DoHA, *Medicare Benefits Schedule*, 'Note A29', <http://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&q=A29&qt=NoteID> viewed 7 June 2013.

> whether the patient is responsible for caring for another person.[46]

4.70 Alzheimer's Australia argued that the MBS be strengthened to emphasise the assessment of cognitive issues, as well as for physical issues.[47]

4.71 The wider use of the MBS items by GPs is discussed further in Chapter 5, in the context of considering the barriers for primary practitioners in making a timely diagnosis.

4.72 Dr Robert Prowse, of ANZSGM, considered that 75 years of age was a sensible point in time to screen people for dementia:

> One of the problems with screening … is that we probably do not want to screen people at 60 or 65, when the incidence is about one per cent in the population. It goes up quite rapidly from there.
>
> Perhaps 75-plus, we thought, would not be a bad time to do a screen, because by then it is sufficiently common that you might be picking up things. Of course, with a screening test you will still pick up all sorts of things that we have already talked about—depression, sleep apnoea—but they in themselves still need treatment. So, if someone has a cognitive problem that is not just due to normal ageing, then that is the time at which making a diagnosis might be helpful.[48]

4.73 Dr Lyndon Bauer, of Health Promotion Central Coast, was of the view that targeted screening of people over 75 would likely lead to an increase in false positive results:

> … you will find that a surprisingly high number of patients, if you randomly select them from your practice without them having any sort of underlying problem, will come up positive. There are number of different reasons why this might be: the stress around taking the test, their literacy levels et cetera, and because the tests are not so good. Many of the tests have weaknesses. If we then take that percentage of people—it is a large number; let's say it is 35 per cent but I am only guessing—and put that pressure on

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[46] DoHA, *Medicare Benefits Schedule*, 'Note A29', <http://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&q=A29&qt=NoteID> viewed 7 June 2013.

[47] Alzheimer's Australia (National Office), *Submission 44*, p. 15. See also: Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 1; Ms Kathryn Cunningham, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 18; Alzheimer's Australia (National Office), *Submission 44.1*, p. 2.

[48] Dr Robert Prowse, ANZSGM, *Official Committee Hansard*, Sydney, 22 June 2012, p. 22.

> them, 'Gee, you've come up positive for dementia,' that can be very damaging.[49]

4.74 Some individuals and organisations advocated for a 'case-finding' approach to diagnosis, triggered when a person presents to a doctor with relevant symptoms, rather than a targeted approach where all individuals were screened once they reached a certain age.

4.75 MDAG explained that while the 'case-finding' approach to diagnosis was widely accepted, targeted screening was also recommended by many:

> Targeted screening followed by more detailed assessment for individuals at high risk of dementia is recommended by many, e.g. people over 75 in general practice, older people admitted to hospital. Case-finding is recommended by all, i.e. once concerns or symptoms are voiced, comprehensive assessment is mandatory.[50]

4.76 NSW Health favoured the case-finding approach and did not support targeted screening:

> NSW Health does not support population-level universal dementia screening of older individuals as the sensitivity and specificity the screening tools available would lead to many false positives, causing undue distress and unnecessary follow-up assessment costs. Instead, a 'case-finding approach' is recommended where the General Practitioner acts on concerns raised or on symptom presentation. [51]

4.77 An alternative model of targeted screening was to screen people over a certain age when they were admitted to hospital. Associate Professor Yates explained:

> Simple screening of the over 65 population in all hospitals (where our estimates put the prevalence at 30%) using validated tools usable by medical, nursing and allied health staff with simple education such as the MMSE, AMTS or miniCOG would rapidly improve awareness of patients at risk.[52]

4.78 Ms Marianne Cummins, from the Australian Association of Gerontology (AAG), told the Committee that in Alice Springs, for example, it would not be appropriate to undertake mandatory screening of people admitted to hospital, as this would likely lead to false diagnosis:

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[49] Dr Bauer, Health Promotion Central Coast, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 31.

[50] MDAG, *Submission 48*, p. 1.

[51] NSW Health, *Submission 95*, p. 2.

[52] Associate Professor Yates, *Submission 13*, p. 1. See also: Dr Leslie Bolitho, RACP, *Official Committee Hansard*, Sydney, 22 June 2012, p. 22.

> As a nurse working in the hospital we already have people, as Cate said, that are identified as having dementia and are labelled with dementia because of a whole range of things. They may be delirious and acutely unwell. That is really the common cause. It is the most common cause of people's confusion, and it is on top of their chronic illnesses. It is well-known that if you have a chronic illness and you become acutely unwell then you can become delirious. There are a lot of risk factors. Sometimes it is actually about the hospital not then going down the track of making sure that that acute illness is treated. That would be the most disastrous thing I think because they have a lot of people that that is an issue for.[53]

Committee comment

4.79 Currently, there are unacceptable delays in the average time taken for an individual to receive a diagnosis of dementia. The Committee has considered how the screening of dementia might contribute to these unacceptable delays, and how this might be addressed.

4.80 The Committee heard conflicting evidence regarding whether targeted or population-based screening of dementia was an appropriate means of improving capacity to detect dementia early.

4.81 Some evidence suggested that cognitive screening should form a more significant part of the annual health assessment that a person over the age of 75 can access through Medicare (‘the 75-plus health assessment’). It was argued that targeted screening of people over the age of 75 would help increase the rates of early diagnosis.

4.82 The Committee accepts that targeted screening for people at most risk of developing dementia would likely result in higher levels of diagnosis, and in many cases, in earlier diagnosis. This goal is to be commended.

4.83 On the other hand, the Committee heard that targeted screening could lead to more false positives, and the costs of administering this screening for patients who were not experiencing symptoms of cognitive decline may outweigh the ultimate benefits of the screening.

4.84 The Committee is of the view that cognitive screening should not be included in a 75-plus health assessment as a specific item of assessment. The 75-plus health assessment aims to assess a person’s ‘physical, psychological and social function for the purpose of initiating preventive

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[53] Ms Marianne Cummins, Australian Association of Gerontology, *Official Committee Hansard*, Alice Springs, 30 January 2013, pp. 29-30.

health care and/or medical interventions as appropriate'.[54] Emphasising cognitive screening over other important basic health assessments would likely defeat the intended purpose of the assessment.

4.85 The Committee notes that the 75-plus health assessment can include an assessment of the patient's psychological function, and appears to allow a General Practitioner to provide a person with a referral for a cognitive screen or specialist assessment, if appropriate.

4.86 Rather than extend the 75-plus health assessment to allow for cognitive screening, it may be more appropriate to promote the use of other existing MBS items which allow for cognitive screening, or review the need to create additional MBS items. The use of MBS items is discussed further in Chapter 5.

4.87 The Committee supports the promotion of a 'case-finding' approach to diagnosis. This approach supports the timely assessment of an individual who has reported symptoms relevant to dementia to their doctor or other medical practitioner.

4.88 This view is in keeping with evidence provided in this inquiry, suggesting that there is no 'one size fits all' approach to screening for dementia. Targeted screening may encourage inaccurate screening which does not recognise a person's background or individual needs.

4.89 As discussed earlier in this chapter, a diagnosis of dementia should not result from one screening test alone. A diagnosis should be formed by undertaking a comprehensive assessment based on a GP's clinical judgment, screening test results, information gathered from the patient and/or their families, and an assessment by an appropriately trained specialist, if required.

Future planning

4.90 One of the benefits of early or timely diagnosis of dementia is the ability for a person to plan for their own future, including:

- Planning their financial future;
- Planning their future care, including advance care directives; and
- Organising their legal affairs.

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[54] DOHA, *Medicare Benefits Schedule*, 'Note A29', <http://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&q=A29&qt=NoteID> viewed 7 June 2013.

4.91 Early diagnosis provides a greater opportunity for a person with dementia to engage with important legal issues and arrange legal instruments necessary to give effect to their wishes for the future, while they have the capacity to do so.[55]

4.92 Early diagnosis of dementia assists a person to make decisions about their preferences for their care when their condition progresses. As Professor Kichu Nair submitted:

> Advance care planning is important in dementia; often without this patients are subjected to invasive and futile medical interventions. There should be clear-cut instructions regarding this in patients who are admitted to nursing homes.[56]

4.93 Planning for the future has been identified as one means of assisting people with dementia to retain their independence. The NSW Department of Health recommended that 'Planning for the future and putting mechanisms in place should be encouraged as a normal practice as we grow older.'[57]

4.94 Kate Swaffer stated that diagnosing dementia early allows people to consider their future care needs and resolve financial and legal issues:

> Early diagnosis for people with the symptoms of dementia is essential as they may still have the ability to think logically, even though their powers of reasoning may have started to be impaired. They will still be able to discuss the implications of the illness and how it will affect them and their families now and in the future, and it is the time when decisions regarding future care needs and financial and legal issues must be considered, while the person with dementia is still legally competent.[58]

4.95 The Committee heard that a lack of awareness across the community about future planning options prevented people with a diagnosis of dementia from seeking advice early. This lack of awareness extends to some health and legal professionals, meaning that many people do not receive accurate future planning information and advice, if they receive advice at all. Those who have made advance care directives at times do not have their wishes implemented. Further, the legislative steps required to secure financial and legal matters are complex and differ between the states, adding to the difficulty of future planning.

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[55] Law Council of Australia, *Submission 56*, p. 3. See also: DoHA, *Submission 89*, p. 10.

[56] Professor Kichu Nair, *Submission 108.*

[57] NSW Department of Health, *Submission 95*, p. 11. See also, Financial Services Council Ltd, *Submission 71,* p. 2.

[58] Ms Kate Swaffer, *Submission 77*, p. 7.

4.96 The barriers which prevent or delay a person planning for their future with dementia, including legal barriers and lack of awareness, are discussed further below.

Legal barriers

4.97 There are a number of legal barriers which prevent people with dementia from organising their legal affairs early in the dementia journey. Primarily, these barriers relate to the complex legislative framework covering issues such as capacity, guardianship, advance care planning and directives, wills and powers of attorney.

4.98 Woy Woy Community Aged Care told the Committee that there are a number of processes and documents a person must understand to successfully plan for their future:

> It is very complicated and time consuming for the person with dementia and their family/carer to know the difference between Power of Attorney, Enduring Guardianship, ACAT assessment, bonds/accommodation fees as well as Advance Care Plans.[59]

4.99 All adults, regardless of disability, are entitled to make their own decisions, unless it is found that they do not have, or have lost, the capacity to make certain decisions.[60]

4.100 The Law Council of Australia (the Law Council) considered how early diagnosis provided greater opportunities to consider the implications of a future loss of capacity:

> Early diagnosis and intervention provides individuals with a greater opportunity to consider the implications of a loss of capacity, to seek information and to engage in discussions with their families, carers and friends regarding their wishes. It is important that dementia sufferers are encouraged to make decisions in relation to lifestyle, medical and financial matters and take the necessary steps to execute any necessary legal instruments, before a loss of capacity precludes them from being able to validly do so.[61]

4.101 To retain control over their future medical care, living arrangements, finances and guardianship, a person must engage with a number of processes while they have capacity, including:

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[59] Woy Woy Community Aged Care, *Submission 102*, p. 4.

[60] Office of the Public Advocate, Victoria, *Guardianship*, <http://www.publicadvocate.vic.gov.au/file/Guardianship%20290909[1].pdf> viewed 7 June 2013.

[61] Law Council of Australia, *Submission 56*, p. 5.

- The making of valid powers of attorney;
- The making of a valid will; and
- The making of valid advance care directives.

4.102 Where a person is deemed not to have capacity to make certain decisions, and they have not made valid legal documents advising of their decisions, guardianship[62] laws may come into play.

Capacity

4.103 Capacity generally refers to the cognitive ability required to make a legally valid decision.[63] The onset of dementia can have significant implications on the future capacity of a person to make legally valid decisions relating to important matters such as medical care, financial and legal matters.

4.104 A person's capacity to make decisions about their future care, as well as organise their own legal and financial affairs, is influenced by the timeliness of diagnosis. As the Law Council explained:

> The issue of capacity is particularly important in the context of the execution of wills and the appointment of substitute decision makers; as such decisions can only be validly made where an individual has legal capacity. Capacity therefore has significant implications for an individual's autonomy and ability to make important decisions about their life.[64]

4.105 Ms Colleen Pearce, Public Advocate in Victoria, told the Committee that capacity was a vexed issue:

> There are different tests of capacity in law for things such as marriage, wills or guardianship, so capacity is really very vexed. For people with dementia, as John said, capacity fluctuates. Can a person remain at home and manage their own purse—the day-to-day? Perhaps they can. Can they enter into a contract to sell their house? Perhaps they cannot. Capacity is not an all-or-nothing; it is very situational. We say it really depends on the decision that needs to be made and people should be able to make as many

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[62] Guardianship is 'the appointment of a person (a 'guardian') to make decisions for an adult with a disability (the 'represented person') when they are unable to do so.' See Office of the Public Advocate, Victoria, *Guardianship*, <http://www.publicadvocate.vic.gov.au/file/Guardianship%20290909[1].pdf>, viewed 7 June 2013.

[63] Law Council of Australia, *Submission 56*, p. 4. See also: Victorian Law Reform Commission, *Guardianship*: *Final report 24*, 2012, <http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf>, pp. 98-116 viewed 7 June 2013.

[64] Law Council of Australia, *Submission 56*, p. 5.

> decisions for themselves for as long as possible—but the law is a blunt instrument.[65]

4.106 HammondCare considered that a major barrier to people planning their future was in the confusion surrounding the definition of 'legal capacity' or competence. HammondCare submitted:

> A major impediment to effective planning at the moment is the confusion around legal capacity or competence, which varies from state to state. With the exception of Queensland, there are no legal definitions of capacity in Australia so a number of tests are used to assess capacity. If the definition of capacity was expressed more clearly and consistently, it would assist people with dementia and their families to make critical plans about future legal, financial and care decisions.[66]

4.107 The Victorian Law Reform Commission (VLRC) investigated issues of capacity and incapacity in detail, in its 2012 report for the review of the *Guardianship and Administration Act 1986* (Vic). The report noted that different capacity standards apply for different activities, such as entering into contracts, getting married, or making a will. These legal rules have developed over time and without coordination.[67]

4.108 The report noted that the Victorian guardianship laws drew a sharp distinction between those people who had capacity, and those people who did not. It did not cater for different levels of cognitive functioning. Accordingly, the VLRC recommended that the way in which guardianship law described and assessed incapacity be clarified, and that the guardianship laws become sufficiently flexible to accommodate different levels of cognitive ability and decision-making needs.[68]

4.109 The Committee received evidence advocating for recognition of 'contextual capacity', to avoid a person being shut out of all decision-making after being diagnosed with dementia:

> Legally recognise 'contextual capacity' for decision-making (similar to Europe) to ensure individuals living with a dementia

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[65] Ms Colleen Pearce, Office of the Public Advocate, Victoria, *Official Committee Hansard*, 14 June 2013, p. 37.

[66] HammondCare, *Submission 86*, p. 4.

[67] Victorian Law Reform Commission, *Guardianship*: *Final report 24*, 2012, <http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf>, pp. 98-116 viewed 7 June 2013.

[68] Law Council of Australia, *Submission 56*, p. 4. See also: Victorian Law Reform Commission, *Guardianship*: *Final report 24*, 2012, <http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf>, pp. 98-116 viewed 7 June 2013.

> [diagnosis are] not deemed 'incompetent' for all decisions and choices with each decision being assessed for its appropriateness for an individual living with a dementia to make.[69]

Committee comment

4.110 The Committee strongly supports any means of assisting people with dementia to retain their independence for as long as possible.

4.111 One way in which people can maintain their independence is to make decisions regarding their future care, living, legal and financial arrangements while they still have capacity to do so, and record these decisions through valid legal documents such as an enduring power of attorney, a will and advance care directives.

4.112 The Committee notes that the law regarding a person's capacity to make certain decisions about their life, including care, financial or legal matters, has developed over time, and in a range of different contexts. While this report considers capacity in the context of people who have dementia, the Committee notes the wider application of capacity in various other areas of the law. This law also varies across each state and territory.

4.113 The assumption of capacity is the axis around which future planning must revolve. The Committee therefore supports all efforts to ensure that the recognition of capacity is assumed until proven otherwise, whether by clinical or legal means.

4.114 The Committee supports the development of a national standard definition of capacity, as it relates to a person's ability to make decisions about their care, or financial or legal matters. As advocated by the Victorian Law Reform Commission, this definition should acknowledge 'contextual capacity' and support the concept that a person may have capacity for some aspects of decision-making, while perhaps not having capacity for others.

Recommendation 4

4.115 **The Australian Government collaborate with the state and territory governments, through the Standing Council on Law and Justice, to develop uniform definitions and guidelines relating to capacity.**

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[69] Traynor, Devries, Fares and Pilkington, *Submission 70*, p. 4.

Complexity of legal processes

4.116 The Committee was told that there was unnecessary complexity in some of the legal instruments and processes that would allow a person to successfully plan for their future, including advance care directives and powers of attorney. This complexity also extended to guardianship laws.

4.117 State and territory governments are responsible for making the laws governing issues such as guardianship, advance care directives, wills and powers of attorney. The Office of the Public Advocate, Victoria, explained that these laws varied across the different states and territories:

> Unfortunately, laws vary significantly in each State and Territory as to the requirements for creation, execution and registration of enduring instruments and operation of advance care directives. Although there have been discussions in the Standing Committee of Attorneys-General (now the Standing Council on Law and Justice) about uniformity or harmonization of these instruments, such discussions have not resulted in actual reform.[70]

4.118 Dr John Chesterman, of the Office of the Public Advocate, Victoria, advised that the guardianship systems in place across the states and territories were comparable, although slightly different. Dr Chesterman considered the benefits of uniformity in guardianship laws and practices:

> It makes sense for guardianship systems to be organised at the state and territory level because service provision and accommodation options for people with cognitive impairments and/or mental ill health are normally provided at the state and territory level. Having said that, there would be many benefits if we had greater interjurisdictional consistency in our guardianship laws and practices.[71]

4.119 An advance care directive is based on 'respect for personal autonomy and is intended to ensure that a person's preferences can be honoured during any period of temporary or permanent impaired decision-making capacity, not only at the end of life.'[72]

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[70] Australian Guardianship and Administration Council, *Submission 76*, p. 30.

[71] Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 30.

[72] An Advance Care Directive (ACD) is a written advance care plan which is recognised by either common law or through legislation, which has been completed and signed by a competent adult. See The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives*, September 2011, <http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf>, p. 5 viewed 29 May 2013.

4.120 The types of advance care directives available in Australia varied between the states and territories and include the ability to:

- allow directions to be recorded, but not appoint a substitute decision maker;
- appoint or allow the appointment of a substitute decision maker, but not record directions for treatment; and
- allow directions to be recorded and the appointment of a substitute decision maker.[73]

4.121 Dr Chesterman advised that the laws around enduring powers of attorney were even more complicated:

> Each of Australia's states and territories has its own laws around enduring powers of attorney. They are all slightly different. Some of them require registration; some do not. Some cover the three fields that ours cover in Victoria; some do not.[74]

4.122 The Law Council of Australia advised the Committee that there were a number of problems with substitute-decision making laws:

> The legislative framework for substitute decision makers varies across jurisdictions, and in some cases may be distributed across a number of legislative instruments. This is problematic as it makes it difficult for individuals to understand their options in relation to substitute decision makers and the actions that they need to take to appoint a substitute decision maker. Differences between jurisdictions and across instruments within jurisdictions may also lead to uncertainty and confusion regarding the validity of a substitute decision maker appointment and the scope of their roles and responsibilities.[75]

Moves towards uniformity

4.123 In 2011 the Productivity Commission published a report titled *Caring for Older Australians*.[76] The Commission found that there were difficulties arising from jurisdictional differences in legislation relating to advance

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[73] The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives*, September 2011, p. 10.

[74] Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 31.

[75] Law Council of Australia, *Submission 56*, p. 5.

[76] Productivity Commission, *Caring For Older Australians*, Productivity Commission Inquiry Report, Vol. 2. No.53, June 2011.

care directives, powers of attorney and enduring guardianship legislation.[77]

4.124 Recognising the need for a standardised national format for advance care directives, the *National Framework for Advance Care Directives* was published by the Australian Health Ministers' Advisory Council (AHMAC) in September 2011. The Framework consists of a national terminology, a code for ethical practice and best practice standards for advance care directives.[78]

4.125 Some of the objectives that underpinned the creation of the National Framework are:

- To have mutual recognition of advance care directives across all states and territories;
- That a person's preferences can be known and respected after the loss of decision-making capacity;
- That decisions by substitute decision-makers chosen and appointed under advance care directives will be respected and will reflect the preferences of the person;
- That they be recognised and acted upon by health and aged care professionals, and will be part of routine practice;
- That clinical care and treatment plans written by health care professionals will be consistent with the person's expressed values and preferred outcomes of care as recorded in their advance care directive.[79]

4.126 The Law Council told the Committee that it supports the adoption and implementation of the guidelines and principles outlined in the *National Framework for Advance Care Directives*, as endorsed by AHMAC.[80]

4.127 In its report, the Productivity Commission recommended that other 'onerous duplicate or inconsistent regulations' such as powers of attorney or guardianship rules, be identified and removed.[81]

4.128 In its report titled *Older people and the law*, the House of Representatives Standing Committee on Legal and Constitutional Affairs recommended:

> Recommendation 26 (paragraph 3.183)

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[77] Productivity Commission, *Caring For Older Australians*, Productivity Commission Inquiry Report, Vol. 2. No.53, June 2011. p. 460.

[78] DoHA, *Submission* 89, p. 11.

[79] The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives*, September 2011, p.1.

[80] Law Council of Australia, *Submission 56*, p. 3.

[81] Productivity Commission, *Caring For Older Australians*, Productivity Commission Inquiry Report, Vol. 2. No.53, June 2011. p. 463.

- The Committee notes that the third Key Priority of the National Framework for Action on Dementia 2006-2010 proposes that the jurisdictions refer the issue of legislative barriers regarding Guardianship, advance care planning, advance care directives, wills, and powers of attorney to the Australian Government and to the State and Territory Attorneys-General Departments.
- The Committee recommends that the Australian Government place the third Key Priority of the National Framework for Action on Dementia 2006-2010 on the agenda of the Standing Committee of Attorneys-General.

Recommendation 28 (paragraph 3.200)

- The Committee recommends that the Australian Government encourage the Standing Committee of Attorneys-General to work towards the implementation of nationally consistent legislation on guardianship and administration in all states and territories.[82]

4.129 In April 2006, the Australian Health Ministers' Conference endorsed the *National Framework for Action on Dementia 2006-2010* (the Framework).[83] One of the priorities for action identified in the Framework was to refer the legislative barriers regarding guardianship, advance care planning and advance care directives, wills and powers of attorney to the Australian Government, State and Territory Attorneys-General Departments.[84]

4.130 The Committee questioned why, given the consensus regarding creating uniform laws, there was not yet uniformity in the laws. The Public Advocate for Victoria outlined some possible reasons:

> It is two things. Firstly, political will. Secondly, it is very difficult to get national uniform legislation. The Australian Council on Guardianship and Administration put forward a proposal at one stage to try and harmonise the laws: if we cannot get national laws, can we get harmony in the laws at a state level? But you have got to have the political will to do that and have it high on the agenda. I think the enduring power of attorney laws have been on the attorney-generals committee but that has fallen off the agenda. So it has to be on the agenda and be a priority.[85]

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[82] Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 31. See also: House of Representatives Standing Committee on Legal and Constitutional Affairs, *Older people and the law*, September 2007, <http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=laca/olderpeople/report.htm> viewed 7 June 2013.

[83] The Framework is discussed in more detail in Chapter 2.

[84] DoHA, *Submission 89*, pp. 10-11.

[85] Ms Colleen Pearce, Office of the Public Advocate, Victoria, *Official Committee Hansard*, 14 June 2013, p. 34.

4.131 Dr Chesterman expanded:

> One of the politically contentious aspects of this concerns not the most frequently used enduring power of attorney—which is the financial one—but others regarding medical treatment and the ability of people to appoint others to, for instance, refuse medical treatment. That creates some political consternation among the various jurisdictions, so it is hard to get uniformity on that issue. That is a significant impediment.[86]

Committee comment

4.132 From the evidence before the Committee in this inquiry, the Committee is of the view that there is merit in simplifying the laws relating to guardianship, advance care planning, wills and powers of attorney, so that there is uniformity across the states and territories.

4.133 The Committee has heard that creating uniformity and simplicity could make it easier to raise general awareness and educate people about the laws, and what it means for them, or their patients. The issue of awareness regarding future planning is discussed further below.

4.134 The Committee supports the steps taken by government thus far, towards creating uniformity in these laws. The Committee notes, for example, the *National Framework for Advance Care Directives* endorsed by AHMAC.

4.135 The Committee is of the view that if the creation of uniform legal instruments and legislation will assist people with dementia plan for their future and retain some control over the major decisions in their lives, then this goal should be supported.

Recommendation 5

4.136 **The Australian Government collaborate with the state and territory governments, through the Standing Council on Law and Justice, to develop uniform definitions and guidelines relating to powers of attorney.**

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[86] Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 34.

Awareness about future planning

4.137 There is concern within the legal and medical community about what is perceived to be a lack of awareness regarding the significant implications that dementia may have on an individual's ability to plan for their future.[87]

4.138 The Office of the Public Advocate in Victoria outlined a number of statistics which showed the lack of awareness about future planning:

> When we add our guardianship clients with dementia to our clients with acquired brain injuries and mental ill health, we find that more than half of our guardianship clients are people who once had capacity to make their own decisions. This has important implications for the promotion of alternatives to guardianship, in particular enduring powers of attorney…
>
> … Most of our clients could have avoided the need for a guardianship order if they themselves had appointed someone to make their key decisions for them.[88]

4.139 Dr Chesterman continued:

> … One of the key challenges I imagine for this inquiry will be to ascertain how we might improve the general public's knowledge of and uptake of enduring powers of attorney.[89]

4.140 The Australian Guardianship and Administration Council (AGAC) considered that the appointment of a responsible enduring attorney or enduring guardian following an early diagnosis of dementia could avoid the need for an application to a guardianship tribunal to be made, whereby a statutory authority of 'last resort' such as the Public Advocates/Guardians or the Public Trustees was appointed:

> Sadly, many people put off consideration of appointment of an attorney or guardian until well after a diagnosis has been made, because it can be emotionally difficult, may involve the expense of consulting a trustee company or a legal practitioner or is administratively demanding. Often people do not consider it necessary until the stage at which the person with dementia is admitted to a nursing home. At that stage, the person's dementia

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[87] Law Council of Australia, *Submission 56*, p. 3.

[88] Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 30.

[89] Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 31.

> may be so advanced that they are incapable of executing a valid instrument.[90]

4.141 While discussion about planning for the future may often focus on legal matters or accommodation, the medical profession and allied services and industries also play a critical role in assisting those with an early diagnosis of dementia. As the RACGP stated:

> The GP is well placed to inform the patient and family not only about the condition, diagnosis and prognosis but also about the consideration of legal and financial matters, available support, and care options. Early intervention allows for future planning of more complex areas such as financial planning and future care, to simpler issues such as driving capacity and daily activity.[91]

4.142 The Australian Government Department of Health and Ageing explained that GPs reported feeling reluctant about providing advice regarding future planning:

> General Practitioners report uncertainty as well as reluctance about their role in relation to legal matters arising in dementia care, e.g. enduring power of attorney, advance care plans. This uncertainty is also a cause of frustration and confusion for the person with dementia and their carer.[92]

4.143 The NSW Department of Health has advised the Committee that:

> …eliciting preferences about future care in the event they can no longer make decisions should be normalised as part of routine health checks. Consumers expect their health professionals to raise Advance Care Planning with them.[93]

4.144 The Consumers Health Forum of Australia was advised that awareness within the health sector about advance care directives was at times variable:

> Consumers have told CHF that awareness of the option of an advance care plan is dependent on their care location and care provider. In other words, it is dependent on 'luck'…[94]

4.145 Mr Tim Tierney, of Tierney Law in Tasmania, submitted that more practical training was needed for lawyers and health professionals on dealing with capacity issues.[95]

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[90] Australian Guardianship and Administration Council (AGAC), *Submission 76*, p. 2.

[91] RACGP, *Submission 83*, pp. 6-7.

[92] DoHA, *Submission 89*, p. 7.

[93] NSW Department of Health, *Submission 95*, p. 13.

[94] Consumers Health Forum of Australia, *Submission 31*, p. 3.

4.146 Dr Chesterman submitted that creating uniformity in the laws regarding powers of attorney would assist in attempts to educate the public about future planning:

> If we had national laws around enduring powers of attorney, we could then engage in a national education program which would encourage people to have the conversation with family and friends, and say, 'In the event that I am not able to make my own decisions, I want such and such to make those decisions for me.' By doing that you obviate the need for public guardianship.[96]

4.147 The Committee heard that one resource which was effective in helping people understand the definition and implications of capacity was the NSW Capacity Toolkit, developed by the NSW Attorney-General's Department. This toolkit has since been adapted for use in Tasmania.[97]

4.148 CDAMS submitted:

> Clearer guidelines and education regarding the assessment of capacity are required for the legal profession, health workers and for those that are able to act as witnesses. The NSW Capacity toolkit is a good example of this.[98]

Committee comment

4.149 A major barrier to a person retaining their independence following a diagnosis of dementia is the lack of awareness about available future planning options.

4.150 Achieving greater rates of early diagnosis of dementia would be futile if a person is not made aware of the options available to them to achieve greater independence, or provided with the tools necessary to plan for their future care and support.

4.151 Accordingly, the Committee takes the view that along with the move towards uniform laws regarding future planning, there is also a need to educate and inform the public, as well as the medical and legal community, about the importance of future planning, and the options available to a person.

4.152 As part of this education, the Committee supports the development of a national 'toolkit', such as the one developed by the NSW Attorney-General's Department, which provides guidance on the issue of capacity

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[95] Mr Tim Tierney, *Submission 16*, p. 1.

[96] Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 31.

[97] Alzheimer's Australia Tasmania, *Submission 37*, p. 6.

[98] CDAMS, *Submission 39*, p. 10.

and its implications. This toolkit could be expanded to include broader information relevant to a person who has received a diagnosis of dementia and their family or carers, including general information on advance care directives, powers of attorney, wills and other processes relevant to their future care or financial and legal arrangements.

4.153 The Committee discusses the need for contextualised practice guidelines for GPs to provide people with advice on local pathways, including future planning options, in Chapter 6.

Recommendation 6

4.154 **The Australian Government collaborate with the state and territory governments to develop a toolkit or guidelines to assist medical/legal professionals, or a person diagnosed with dementia and their carer understand future planning options.**

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My deepest regret is that we lost so much time during the first years of her illness. Time wasted by repetitive misdiagnosis by all her doctors. I am sad about all our unnecessary fear, struggle, anger, my poor mother must have felt so misunderstood and abandoned at times, when we did not believe her. In addition, I have lost precious years when I could have been studying about dementia and actively assisting my mother, instead of becoming emotionally and mentally ill in my caring role.[1]

Barriers to diagnosis

5.1 As discussed in Chapter 4, a diagnosis of dementia can take an average of three years from the time a person starts experiencing symptoms of cognitive decline or memory loss.[2]

5.2 The Committee was told that part of this delay is due to a lack of awareness and the stigma attached to dementia. Other barriers exist within the health system itself.

5.3 The Committee heard countless stories from carers and individuals, telling of lengthy delays in receiving a diagnosis of dementia. A delay in diagnosis denies a person the opportunity to receive beneficial treatment to enhance their quality of life and maintain their independence by making plans for their future care. The benefits of receiving an early diagnosis are outlined in more detail in Chapter 4.

5.4 There are four main types of barriers to receiving an early or timely diagnosis of dementia:

- Consumer level barriers;
- Primary care provider level barriers;

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[1] Danielja, *Submission 8*, p. 2.

[2] Alzheimer's Australia (National Office), *Submission 44*, p. 3. See also: Alzheimer's Australia (National Office), *Submission 44.1*, p. 1.

- Health system level barriers; and
- Service context barriers.[3]

5.5 Consumer level barriers to diagnosis, such as lack of awareness and stigma about dementia, are discussed in Chapter 3.

5.6 The barriers which exist to prevent medical professionals from making an early or timely diagnosis of dementia, including barriers within the health care system, are discussed below.

Who can make a diagnosis of dementia?

5.7 Dementia may be diagnosed in a number of different medical settings:

- By a medical professional in a primary care setting (for example, a General Practitioner (GP) or Nurse Practitioner (NP));
- By a specialist, such as a neurologist, geriatrician, gerontologist, psychogeriatrician, psychiatrist, or neuropsychologist;
- By a medical practitioner in an acute care setting such as a hospital; or
- Through a service operated by a multi-disciplinary team, such as an Aged Care Assessment Team (ACAT) or memory clinic.[4]

5.8 The barriers to achieving early diagnosis in the above settings are discussed further below.

Barriers to diagnosis in primary care

5.9 A GP is often the first point of contact when a person is concerned about possible memory loss. Approximately 83 per cent of Australians consulted with a GP at least once a year, with 73 per cent of people aged over 75 years of age consulting with a GP four or more times during 2010-11.[5]

5.10 The Royal Australian College of General Practitioners (RACGP) told the Committee that as a person's main health care provider, GPs had an important role in recognising, assessing, diagnosing and managing dementia.[6]

5.11 Professor Henry Brodaty, of the Minister's Dementia Advisory Group (MDAG), told the Committee that primary care was the key to obtaining

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[3] Alzheimer's Australia (National Office), *Submission 44*, p. 10.

[4] Alzheimer's Australia Victoria, *Submission 35*, p. 3.

[5] Royal Australian College of General Practitioners (RACGP), *Submission 83*, p. 4.

[6] RACGP, *Submission 83*, p. 4.

early diagnosis of dementia, and the 'corner shop' where people went for assessment and management of dementia.[7]

5.12 The Australian General Practice Network (AGPN) explained the benefits of using general practice teams in the assessment of dementia:

> General practice teams, particularly the GP and practice nurse (PN), who often have established relationships with patients and are commonly the first professionals to whom patients present for medical assistance, are well placed to recognise the symptoms and signs of early dementia and to trigger diagnostic evaluations.[8]

5.13 Mr Glenn Rees, of Alzheimer's Australia, told the Committee that over 90 per cent of Australians would approach their GP first, if they were concerned about their memory. Accordingly, the knowledge and skills of a GP often determined how early a diagnosis was made:

> So the GPs are the gatekeepers for the system. Depending on whether the gatekeeper, the GP, is familiar with dementia and knows what to look for, the process for the person can be good, as it was reasonably good in Jane's case. If the GP is not familiar with it or regards it as just a question of ageing, the person will be sent on their way until the concern becomes so great that the dementia becomes very obvious, in which case a diagnosis is very late.[9]

5.14 Mr Rees outlined the best practice approach to a GP making a diagnosis of dementia:

> The best practice, really, is for the GP or the practice nurse to screen the person, do the simple tests, and if they are convinced that there is a problem to then refer them to a specialist, whether that is a neurologist or a geriatrician or some other speciality. Obviously it depends on what the doctor thinks is the problem. From that point, the person probably comes back to the GP, gets the diagnosis and then—this is the second critical point—gets a referral to services.[10]

5.15 Mrs Elizabeth Rand, of Cognitive Dementia and Memory Services (CDAMS), told the Committee that while a GP could take many people

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[7] Professor Henry Brodaty, Minister's Dementia Advisory Group (MDAG), *Official Committee Hansard*, Canberra, 8 February 2013, p. 15.

[8] Australian General Practice Network (APGN), *Submission 87*, p. 9.

[9] Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 3.

[10] Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 3.

through the entire assessment process, there were some cases where a GP should refer the person for a specialist assessment:

> Once they do present to their GPs that GP needs to recognise the significance of the problems and whether they then need to go on to have a more specialist assessment to determine whether it is a dementia and what can be done about it. A percentage of people can be managed well by GPs and in general practice but people that are presenting quite early need perhaps a bit more detailed assessment, such as what can be provided through memory clinics, to work out whether it is dementia and what type of dementia it is.[11]

5.16 Dr Lynne Barnes, a General Practitioner, advised that she would normally refer a person with memory issues to a specialist for thorough testing:

> The patient would come to see the doctor, or often a family member will come to the doctor beforehand and say, 'Look, I am having trouble with this relative.' It might be mum or dad or whoever, and then you get the patient in. I then take their history, examine the patient and look for any other sorts of medical problems and then, if I thought the patient had dementia, I would start to check for any screening tests that might be done for treatable causes for that. I would then probably refer them to one of the services we have here…
>
> … I could either refer to the dementia support worker or the psychogeriatric service. They are both based at the same place…
>
> Then we would get the visiting geriatrician to see the person.[12]

5.17 Despite GPs being the first point of contact for most people experiencing memory issues, the Committee heard there were many barriers to GPs providing a timely diagnosis of dementia.

5.18 These barriers include:

- System-level barriers/operation of the primary health care system:
  - ⇒ Medicare Benefits Schedule (MBS) item numbers;
  - ⇒ Poor remuneration; and
  - ⇒ Perceived or actual lack of available services.
- Attitudes of GPs:
  - ⇒ Nihilistic attitudes; and

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[11] Mrs Elizabeth Rand, Cognitive Dementia and Memory Services (CDAMS), *Official Committee Hansard*, Canberra, 21 August 2012, p. 2.

[12] Dr Lynne Barnes, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 31.

  - ⇒ False negative diagnoses ('it's just old age').
- Knowledge and skills of GPs:
  - ⇒ Lack of awareness about the signs of memory loss and other cognitive symptoms.[13]

5.19 The knowledge and skills of GPs regarding dementia diagnosis and treatment are discussed further in Chapter 3.

Barriers for General Practitioners

5.20 There were a number of system-level barriers cited to the Committee which were said to prevent or delay a GP's ability to diagnose dementia. These barriers included remuneration for undertaking an assessment for dementia and limitations around consultation times.

5.21 Associate Professor Mark Yates, of MDAG, told the Committee of the nature of the Medicare system, as it related to remuneration (using geriatrics as an example):

> I think the reality of the Medicare system is that you get paid well if you stick something in, through or up someone but not if you think deeply about them. That is not unique to geriatrics; that is unique to a number of the subspecialty areas such as rheumatology, infectious diseases and endocrinology, for that matter, with diabetes. Medicare has been modified to meet some of that with the additional item numbers for geriatricians; I think that has grown the number of geriatricians and that will happen over time.[14]

5.22 The AGPN observed that there was no remuneration available through Medicare for primary health care teams to consult with the carer of a person with cognitive issues such as dementia, unless the carer was seeking their own medical assistance.[15]

5.23 CDAMS supported the revision of the MBS to ensure GPs were adequately remunerated for the additional time required for the assessment, diagnosis and ongoing support of people (and their carers) with dementia. CDAMS believed this support should include

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[13] MDAG, *Submission 48*, p. 2; AGPN, *Submission 87*, pp. 9-11.

[14] Associate Professor Mark Yates, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, p. 19.

[15] AGPN, *Submission 87*, p. 11. See also: Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 1.

remuneration for the additional support provided to families, sometimes independently of patient visits.[16]

5.24 Regarding limited consultation times under Medicare, the AGPN stated:

> Assessment processes for dementia, and often provision of the comprehensive dementia management support required, cannot effectively be undertaken within the time period associated with the shorter consultation that can be claimed through the Medicare Benefits Schedule (MBS) item. Whilst there are avenues to claim longer consultations under the MBS, for both patient flow and business viability reasons, many practice systems are structured around shorter consultations. Some practices are also not aware of how to effectively use available MBS items to support longer consultations for people with dementia.[17]

5.25 Dr Catherine Yelland, of the Royal Australasian College of Physicians (RACP), said diagnosing dementia was time-consuming and did not fit well within a brief general-practitioner consultation.[18]

5.26 NSW HACC Issues Forum told the Committee that GPs had limited opportunities to monitor a person’s cognitive capacity on an ongoing basis, due to the nature of consultations:

> GPs have limited opportunities to monitor peoples’ cognitive capacity on an ongoing basis. GP consultation times are brief, and often do not give GPs the opportunity to pick up on signs and symptoms of dementia. People experiencing memory loss, confusion or behavioural change may be hesitant to report these experiences to their GP, or may mask these symptoms during consultations. Symptoms of dementia can thus go medically undetected for quite some time.[19]

5.27 Ms Helga Merl, of Hunter Medicare Local, told the Committee that a formal assessment for dementia could take at least an hour and a half, which was prohibitive in a primary care setting:

> The issue is that that type of assessment takes at least an hour and a half. Within primary care there are just not the funds or reimbursements to recompense somebody for spending that

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[16] Cognitive Dementia and Memory Services (CDAMS), *Submission 39*, p. 7. See also: RACGP, *Submission 83*, p. 7; Alzheimer’s Australia (National Office), *Submission 44*, p. 15.

[17] AGPN, *Submission 87*, pp. 10-11.

[18] Dr Catherine Yelland, Royal Australasian College of Physicians (RACP), *Official Committee Hansard*, Sydney, 22 June 2012, p. 20. See also: CDAMS, *Submission 39*, p. 1 and p. 7; and RACGP, *Submission 83*, p. 6.

[19] NSW HACC Issues Forum, *Submission 85*, p. 3.

> amount of time in primary care in a busy practice. When there are the pressures of a waiting room full of other people, being able to spend an hour and a half with someone is a luxury we just do not have.[20]

5.28 The Australian Government Department of Health and Ageing (DoHA) outlined the number of MBS items which could be utilised as part of an assessment process:

- health assessments provided for people aged 75 and older that can be undertaken annually – MBS items 701-707;
- comprehensive medical assessments in residential aged care facilities that can be provided annually;
- people of any age, with suspected or diagnosed dementia, are eligible for longer consultations using the standard General Practitioner attendance items – Level C attendance item - lasting at least 20 minutes, and the Level D attendance item - lasting at least 40 minutes.[21]

5.29 Despite the MBS items available to support diagnosis of dementia, DoHA acknowledged that many GPs were unaware of the MBS items available to assist in dementia assessment and diagnosis, and required further education in this regard:

> So there is some work to be done around how to switch GPs more on to what is available to support them in not only diagnosing someone, but also coordinating their care. I know that we have provided some information to the minister's group around what potential items on the MBS could be available for that purpose. For example, there is an annual health check for people over the age of 75, but there are also the chronic disease items which actually enable not only that sort of care coordination with a GP, but also then access and referral on to allied health services and the like.[22]

5.30 Ms Kathryn Cunningham, of Alzheimer's Australia in South Australia, agreed that the wider use of MBS items for the assessment of dementia symptoms should be promoted:

> We promote wider use of existing MBS items for the assessment and management of dementia symptoms by GPs and aged-care nurse practitioners. We recommend review of existing MBS items and, where necessary, revision or creation of new items to ensure

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[20] Ms Helga Merl, Hunter Medicare Local, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 7.

[21] Australian Government Department of Health and Ageing (DoHA), *Submission 89*, pp. 7-8.

[22] Ms Rosemary Huxtable, Deputy Secretary, DoHA, *Official Committee Hansard*, Canberra, 8 February 2013, p. 12. See also: p. 18.

> effective payment to support identification, assessment and management of dementia in primary care, we recommend the creation of financial incentives to support cognitive screening as part of the 75-plus health assessment, and we encourage dementia related GP consultation in residential aged care.[23]

5.31 The Committee was told that a proposal was made for the funds earmarked to achieve timely diagnosis through the *Living Longer. Living Better.* aged care reforms to be used for the development, piloting and national dissemination of a training resource package for health professionals including GPs, NPs and practice nurses. The proposed training package would be implemented through Medicare Locals and include education on the use of MBS items for cognitive assessment and management of dementia.[24]

5.32 Alzheimer's Australia commented on the move:

> This is good progress but it has been much more difficult to identify Medicare Benefit Items that could be used by doctors to ensure that they are compensated for time required for diagnosis, assessment and referral of patients to services. Further work is to be done but it is clear that a "Business Plan" is needed for GPs to ensure they are able to the extent possible to use the MBS items to achieve timely diagnosis.[25]

Committee comment

5.33 At a systems level, one the main barriers to individuals receiving a timely diagnosis of dementia through their GP relates to the use of MBS Items.

5.34 The Committee heard proposals that the use of MBS items for dementia diagnosis be reviewed in consideration of the following issues:

- The need to provide adequate remuneration for the lengthy time required to undertake a diagnosis of dementia (including time to undertake a screening test);
- The need to better inform GPs about the use of MBS items for cognitive assessment and diagnosis of dementia;
- The need to provide an MBS item for carers or family members to consult with a GP or other practitioner about an individual they are concerned with regarding cognitive issues;

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[23] Ms Kathryn Cunningham, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 18.

[24] Alzheimer's Australia (National Office), *Submission 44.1*, p. 2.

[25] Alzheimer's Australia (National Office), *Submission 44.1*, p. 2.

- The need to promote the use of a multi-disciplinary team in dementia assessment and diagnosis; and
- The possibility of expanding the use of the 75-plus assessment to include or support cognitive assessment.

5.35 The Committee comments in detail on the use of the 75-plus assessment for cognitive assessment in Chapter 4. The use of a multi-disciplinary team in dementia diagnosis is discussed later in this chapter.

5.36 The Committee notes the work already being undertaken through MDAG and DoHA to educate primary care practitioners about the use of MBS items for dementia diagnosis and assessment, as part of a broader program to achieve better rates of timely diagnosis of dementia. The Committee supports the use of the funds available through the *Living Longer. Living Better.* scheme to encourage the wider use of MBS items for dementia assessment and diagnosis, and wider training for GPs in dementia diagnosis and intervention (this is discussed further in Chapter 3).

5.37 As indicated in Chapter 4, the Committee considers there is a need to review the usefulness of existing MBS items for dementia diagnosis and assessment, to determine whether expansion of existing items is necessary, or whether further items are required to support early and timely diagnosis of dementia.

Recommendation 7

5.38 **The Australian Government Department of Health and Ageing undertake a comprehensive review of the use of existing MBS items to determine whether it is necessary to expand existing items or create new items to support identification, assessment and management of dementia in primary care.**

Barriers to specialist diagnosis

5.39 Although GPs are often the first point of contact for a person experiencing memory loss or cognitive decline, GPs or individuals often refer patients to specialists in dementia diagnosis, to assist in complex cases or to conduct a thorough assessment.

5.40 There are a number of specialists who are able to make a diagnosis of dementia. These include (but are not limited to):

- A Gerontologist – a doctor who studies old age, its diseases and phenomena;
- A Geriatrician - a doctor who specialises in the care of older people;
- A Psychogeriatrician - a doctor who specialises in mental disorders affecting older people;
- A Neurologist - a doctor who specialises in the diagnosis and treatment of disorders of the nervous system, including the brain, spinal cord and nerves;
- A Neuropsychologist - a psychologist who specialises in disorders of the brain and how they affect memory, thinking and behaviour;[26] or
- A Psychiatrist - a doctor who specialises in the diagnosis and treatment of mental disorders, emotional disturbances and thought disorders.[27]

5.41 The RACP and Australian and New Zealand Society for Geriatric Medicine (ANZSGM) explained that specialist medical care was essential at the time of diagnosis:

> Specialist medical care is especially required at the time of diagnosis; when medical acuity and/or behavioural and psychological symptoms of dementia (BPSD) increase (frequently at the midpoint of the disease); and at end of life. Geriatricians, general physicians, psychogeriatricians and neurologists are skilled at making a complete and accurate diagnosis of dementia.[28]

5.42 Associate Professor Mark Yates, of MDAG, told the Committee of the important link between medical practitioners in primary care and specialists in the diagnostic process:

> Again, going back to this concept of the connection between primary care and specialist services, when it is more complicated—which is the very early stage, as opposed to timely—with all the comorbidities that are perhaps associated with someone with a memory problem, GPs have to have somewhere nationally where someone is putting up their hand and saying, 'If you've got a problem as a GP with someone who is worried about their memory and you can't sort it out, we can do

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[26] For information on diagnosis via a psychologist/neuropsychologist, see Australian Psychological Society, *Submission 50*, p. 4; Leo, *Official Committee Hansard*, Launceston, 27 July 2012, pp. 1-2; Leo (Tas), *Submission 12*.

[27] Alzheimer's Australia, *Early Diagnosis of Dementia*, Paper 10, March 2007, p. 3; Macquarie Dictionary 'WordGenius 4.3', February 2006 [W32], Fourth Edition.

[28] RACP and Australian and New Zealand Society for Geriatric Medicine (ANZSGM), *Submission 22*, p. 6.

> it.' To make primary healthcare work well, they have to have a means by which they can have specialist help.[29]

5.43 A number of barriers to achieving a diagnosis of dementia in specialist settings were outlined to the Committee. These barriers include limited access to specialist care in regional, rural and remote areas of Australia.

Specialist diagnosis in rural, regional and remote communities

5.44 The Committee heard a number of stories from people living in rural, regional or remote communities, advising of the lack of access to medical specialists to assist in making a diagnosis of dementia.

5.45 The National Rural Health Alliance (NRHA) told the Committee:

> Poor access to primary care generally in country areas, including shortages of medical specialists and allied health professionals of any kind, let alone those that specialise in dementia, mean there is less likelihood of early diagnosis and treatment for people in those areas.[30]

5.46 The Committee heard that the only gerontologist available to see people in Moree was based in Tamworth and visited Moree approximately once every six to eight weeks.[31]

5.47 Cecilia, from Moree, who cared for her mother with Alzheimer's Disease, advised that she took her mother to see a geriatrician in Toowoomba (some 300km away), who undertook the necessary assessments and made a diagnosis of dementia. [32]

5.48 NRHA considered that innovative approaches to dementia care, such as telehealth[33] initiatives, would be required to facilitate early diagnosis and treatment of dementia in regional, rural and remote communities:

> Innovative approaches to team dementia care, such as outreach services, telehealth consultations with specialists and other work

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[29] Associate Professor Mark Yates, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, p. 17.

[30] National Rural Health Alliance Inc. (NRHA), *Submission 36*, p. 4.

[31] Mrs Bernadette Mary Meppem, Fairview Retirement Village, *Official Committee Hansard*, Moree, 27 August 2012, p. 2. See also: Mr Mark Howland, Hunter New England Local Health District (Tablelands, Mehi and McIntyre Clusters), *Official Committee Hansard*, Moree, 27 August 2012, p. 18.

[32] Cecilia, *Submission 100*, p. 1.

[33] Telehealth is an initiative through Medicare which provides financial incentives to eligible health professionals and aged care services that help patients have a video consultation with a specialist, consultant physician or consultant psychiatrist. For further information, see <http://www.medicareaustralia.gov.au/provider/incentives/telehealth/>, viewed 7 June 2013.

> to complement the work of local health professionals, will be an important part of this strategy.[34]

5.49 Mrs Judy Ratajec, of Uniting Church Frontier Services, said the use of telehealth initiatives may be useful in the diagnostic process:

> You can use telehealth to help with the diagnosis—you can have with the person a clinician who has done all of the assessments and all the pathology and they can talk to a specialist to pull that together and have a conversation.[35]

5.50 Dr Robert Prowse, President of ANZSGM, told the Committee that telehealth initiatives could address the gap in care available to Australians with dementia living in regional, rural and remote locations:

> In some rural areas there is a visiting geriatrician or psychogeriatrician who goes to that place regularly and sees patients. I do that myself in Port Augusta, in South Australia. But it is a once-a-month visit. The demand is bigger than the service can provide. I am aware that there are many other places that do not have that service, that do not have a geriatrician visiting. We, I think, struggle to find people who feel they can give their time to the disruption that that causes to clinical practice back in the city. The telehealth initiatives, which are well developed in Queensland… would provide the opportunity for people to do at least some of the assessment from home. They can easily, and it has been shown that they can effectively, allow assessment and diagnosis with a general practitioner or another person with the patient at their home site and with the specialist observing from the city base.[36]

5.51 The Pharmacy Guild of Australia submitted that local pharmacies could assist in providing access to telehealth services:

> Access to telehealth will also assist in addressing some of the barriers to accessing dementia related medical services for patients in rural, regional and outer metropolitan areas. It should be recognised that in many circumstances, particularly in regional and remote Australia, the local community pharmacy may be the only available or most appropriate health service for conducting telehealth consultations. The Guild strongly believes that community pharmacy should be viewed as an 'other health care

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[34] NRHA, *Submission 36*, p. 5.

[35] Mrs Judy Ratajec, Uniting Church Frontier Services, *Official Committee Hansard*, Broome, 13 November 2012, p. 26.

[36] Dr Robert Prowse, ANZSGM, *Official Committee Hansard*, Sydney, 22 June 2012, p. 20.

> facility' in which a patient can access telehealth and video conference to a specialist at another location.[37]

5.52 The Australian Nursing Federation (ANF) also saw the potential of utilising telehealth to improve access to specialists, and recommended it also use telephone link-ups where videoconferencing was not an option:

> The ANF considers there is huge potential for the use of telehealth to improve access to specialist gerontology and/or support services for people in remote, rural and regional areas requiring cognitive assessment and dementia care. However, we believe this facility should be extended beyond use of videoconferencing techniques, to enable Medicare reimbursement to health professionals for utilising telephone link-up, where this is the only communication facility available in remote sites (or the only reliable service available).[38]

5.53 NSW Health suggested that telehealth could be utilised as part of a wider multi-disciplinary strategy in regional, rural or remote communities of Australia:

> Integrated models would need to be appropriate for rural settings and provide access for culturally and linguistically diverse and Aboriginal populations through interpreter time, outreach and liaison. In rural areas, the model would be dependent on improved access to these Medical Specialist positions, either through increasing the number of positions particularly in rural areas or improving access through recent tele-health initiatives.[39]

Committee comment

5.54 Lack of access to specialists equipped to make a diagnosis of dementia is likely to inhibit early and timely diagnosis in regional, rural and remote communities of Australia. Distance is often a significant barrier to achieving access to early and timely diagnosis of dementia in these communities.

5.55 While GPs may be equipped to make a diagnosis of dementia, GPs and other primary care practitioners may require specialist advice before a diagnosis can be made, particularly in complex cases, or where a person is young, or presenting at the early stages of the condition.

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[37] Pharmacy Guild of Australia, *Submission 57*, p. 3.

[38] Australian Nursing Federation (ANF), *Submission 79*, p. 7.

[39] NSW Health, *Submission 95*, p. 6.

5.56 The Committee has heard stories of individuals who travelled hundreds of kilometres away from their home to obtain a diagnosis of dementia from a specialist. Others waited several months to see a visiting specialist.

5.57 There is a clear need to ensure that regional, rural and remote communities of Australia are equipped with appropriate access to specialist medical practitioners and diagnostic services, to encourage timely diagnosis and support for dementia.

5.58 The best way of gaining access to specialist services would be to encourage medical practitioners specialising in dementia diagnosis and treatment to work in rural and remote areas of Australia. However, the Committee recognises that this is often not a viable option.

5.59 Another model of care would be for primary care practitioners to work in collaboration with a visiting specialist (such as a gerontologist or geriatrician), with additional specialist support provided via telehealth.

5.60 Such collaboration could form part of a multi-disciplinary team providing diagnosis, management and support services for dementia. These multi-disciplinary teams could be coordinated through Medicare Locals, or otherwise at a local level.

5.61 The Committee notes that through the *Living Longer. Living Better.* aged care reforms, the Commonwealth will allocate $58.5 million to promote 'better practice and partnerships' and remove barriers for people with particular needs, including Aboriginal and Torres Strait Islander people and those living in rural and remote areas. This includes increasing multi-disciplinary care and introducing telehealth trials.[40]

5.62 The Committee supports the trialling of multi-disciplinary teams of care, including the use of telehealth initiatives, as a means of encouraging early diagnosis and intervention of dementia in regional, rural and remote communities of Australia.

5.63 Multi-disciplinary care is discussed further below, and in Chapter 6.

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[40] Australian Government, *Living Longer. Living Better.,* April 2012, p. 20.

Recommendation 8

5.64 **The Australian Government Department of Health and Ageing implement early and timely diagnosis in regional, rural and remote communities where access to specialist diagnosis is limited by coordinating multi-disciplinary teams comprising primary health care practitioners and visiting medical specialists, supplemented by primary or specialist assessment provided via telehealth facilities.**

The need for multi-disciplinary teams should be assessed at a local level, via Medicare Locals, or other such local health networks.

Diagnosis in a multi-disciplinary practice

5.65 A number of individuals and organisations advocated for a multi-disciplinary system of diagnosis, treatment and management of dementia in Australia.[41] How a multi-disciplinary approach to diagnosis would operate is discussed below. How such an approach would operate post-diagnosis is discussed in Chapter 6.

5.66 The RACP and the ANZSGM support a shared-care approach to dementia diagnosis, which would involve GPs, medical specialists, nurses, pharmacists and other allied health professionals (as needed):

> A network of specialist, multidisciplinary clinics and services should be systematically resourced and comprehensively established across Australia to undertake assessment and diagnosis of cognitive impairment and dementia. It is preferable that the clinic be led by a medical specialist who will usually be a geriatrician (or geriatric trainee) and include, at a minimum, a specialist dementia nurse, social worker and/or occupational therapist and neuropsychologist/ psychologist. Currently, different memory clinic models are in operation across Australian jurisdictions.[42]

5.67 RACP and ANZSGM considered that the Victorian Government's Cognitive, Dementia and Memory Services (CDAMS) clinics represented the best model to inform a national, systematic approach to the diagnosis of dementia.[43] CDAMS provides clients (and their families and carers)

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[41] For example, see Alzheimer's Australia Victoria, *Submission 35*, p. 5.

[42] RACP and ANZSGM, *Submission 22*, p. 2.

[43] RACP and ANZSGM, *Submission 22*, p. 2.

> with access to specialist multi-disciplinary assessment and diagnosis, advice, referral and education.[44]

5.68 Mrs Elizabeth Rand, of CDAMS, called for the wider introduction of memory-clinic style models as a means of supporting GPs in diagnosis:

> We feel that the introduction of memory-clinic-style services more broadly would provide an engine room for supporting primary care and GPs, as GPs remain the first port of call for most people when they first develop symptoms and are wondering what is going on, and they also remain the central figure in coordinating all of a person's health care. So CDAMS can support them in that role with regard to cognition and dementia.[45]

5.69 Mrs Rand explained the usual process of diagnosis in CDAMS:

> With the CDAMS model, when they get referred to us generally they have an initial assessment by a community nurse or an OT or a social worker that goes and sees them in their home…
>
> … Generally that is a face-to-face appointment that might take an hour and a half to two hours. Following that they come in and see one of the medical specialists; that might be a neurologist or a geriatrician or a psychiatrist, depending on what their presentation is. They will spend about an hour and a half with them doing some cognitive testing, a physical examination and a bit more history taking. After that, if it is still not clear what is going on, in our service we have neuropsychologists and they can do some very detailed testing…[46]

5.70 Dr John Ward, a Geriatrician, also advocated for the introduction of a shared-care system for dementia diagnosis and intervention across Australia, based on the model operating in the Hunter/Newcastle area of NSW. Dr Ward submitted:

> It is a shared-care program with general practitioners, designed around locally based Community Dementia Nurses (CDNs) who work within ACATs, together with a Geriatrician who has responsibility for that community as part of the workload…
>
> …The Geriatrician sees people referred by GPs while the CDN sees people with cognitive impairment referred to ACAT or directly to her from any source. The CDN assists the Geriatrician with the clinic which allows patients and families to be interviewed separately and also provides more complex cognitive

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[44] CDAMS, *Submission 34*, pp. 3-4.

[45] Mrs Elizabeth Rand, CDAMS, *Official Committee Hansard*, Canberra, 21 August 2012, p. 1.

[46] Mrs Elizabeth Rand, CDAMS, *Official Committee Hansard*, Canberra, 21 August 2012, p. 2.

> assessments e.g. RUDAS, Adas-Cog, ACE-R, etc. The CDN is available to follow-up clinic clients via home visits to complete the assessment and to provide education, information and carer support in a more family-friendly environment.[47]

5.71 Dr Ward noted that as part of the multi-disciplinary model, the CDN and Geriatrician worked closely with GPs, providing feed-back on assessments, management plans and case management.[48]

5.72 NSW Health considered that GPs and practice nurses could be supported through integrated multi-disciplinary care models where dementia health experts, such as CDNS and/or allied health professionals could undertake a comprehensive assessment, with access to medical specialists if diagnosis was unusual or difficult.[49]

5.73 Mrs Sharyn Bannister, from the Central Coast Local Health District, explained the purpose of their memory screening service:

> Our memory screening service was set up to support local GPs with the diagnosis of dementia. The service goes into a home and completes cognitive screens such as the Addenbrooke Frontal Assessment Battery, anxiety and depression scales, the carer stress screening tool, and functional assessment and histories. All information is documented in a report and sent to the GP. We do this because we know GPs are extremely time-poor, and diagnosing dementia is difficult. It is not like other diseases. The indicators for dementia are varied, and all other diseases must be considered and ruled out.[50]

5.74 Associate Professor George Razay established the Launceston Memory Disorders Clinic. Associate Professor Razay believes that a memory disorders clinic is the most cost effective way to provide early diagnosis and treatment for individuals:

> These have contributed greatly not only to raising the awareness of the community about memory problems and dementia but also to changing the stigma about dementia in general and Alzheimer's disease in particular. This has led to patients with memory disorders and carers seeking early diagnosis and treatment. It is

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[47] Dr John Ward, *Submission 5*, pp. 1-2.

[48] Dr John Ward, *Submission 5*, p. 2.

[49] NSW Health, *Submission 95*, pp. 5-6. For 'good practice' examples of multi-disciplinary models in the Central Coast region, see NSW Health Central Coast District, *Submission 106*, pp. 1-2.

[50] Mrs Sharyn Bannister, Central Coast Local Health District, NSW Health, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 42.

> reflected in our data, which shows that about 50 per cent of my patients in the memory clinic have mild cognitive impairment.[51]

Committee comment

5.75 A multi-disciplinary approach to dementia care has been advocated to encourage early diagnosis, as well as to facilitate early and appropriate treatment, management and support once a diagnosis is made.

5.76 The Committee notes the numerous explanations of multi-disciplinary memory clinics and other multi-disciplinary teams who provide diagnostic services and support for people experiencing symptoms of memory loss or cognitive decline.

5.77 The following features exist within the multi-disciplinary teams evidenced before the Committee:

- Clear and established links of communication and referrals between the specialist memory clinic and GPs;
- Visability, which promotes greater awareness of dementia and encourages people to undertake assessments early;
- Utilising Nurse Practitioners or other health professionals to undertake a comprehensive assessment, including comprehensive screening, preferably at a person's home;
- Access to specialist review and assessment, when required; and
- The ability to make referrals to ongoing treatment and support services such as Alzheimer's Australia.

5.78 The Committee considers there is merit in exploring a nation-wide multi-disciplinary system of dementia diagnosis and intervention, noting that the system would need flexibility, to ensure the model provided appropriate services and support to individual communities around Australia.

5.79 A multi-disciplinary approach, encompassing diagnosis, treatment and support of dementia is discussed further in Chapter 6.

Specialist nurses

5.80 As discussed above, the Committee heard that a specialist nurse, such as a Community Dementia Nurse (CDN) or Clinical Nurse Specialist was considered an essential member of any multi-disciplinary team tasked with dementia assessment and care.[52]

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[51] Associate Professor George Razay, Launceston General Hospital, *Official Committee Hansard*, Launceston, 27 July 2012, pp. 13-14.

[52] For discussion on specialist nurses, see Royal College of Nursing, *Submission 61*.

5.81 Professor Brodaty suggested that one way to address the time-consuming nature of diagnosis was for specialist nurses to assist GPs:

> Most GPs have a practice nurse who could do a lot of the screening. They could be supported by a clinical nurse specialist. So, there could be a network at primary level which would lead to earlier diagnosis.[53]

5.82 Alzheimer's Australia echoed this view:

> 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.[54]

5.83 Ms Helga Merl, a Transitional Nurse Practitioner, told the Committee of her role within the Hunter Medicare Local, in the assessment process for dementia:

> My role is to take referrals from GPs and practice nurses of people they feel are at risk of dementia, people who have identified with early symptoms, and they are thinking, 'I am really not sure what to do, or I do not have that time, so I would like to refer over for someone to be able to do one of those complex assessments.' I would be able to do those assessments, including a physical exam and making recommendations for the pathology, the blood tests required to look at reversible causes.[55]

5.84 Ms Merl advised that specialist nurses were able to guide practice nurses and GPs through the diagnosis process and proposed that a NP in dementia operate at each of the Medicare Locals across Australia.[56]

5.85 The ANF indicated that the NP role was growing within the aged care sector and could be utilised effectively in dementia diagnosis:

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[53] Professor Henry Brodaty, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, pp. 20-21.

[54] Alzheimer's Australia (National Office), *Submission 44*, pp. 15-16. See also, Kathryn Cunningham, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 18.

[55] Ms Helga Merl, Hunter Medicare Local, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 7.

[56] Ms Helga Merl, Hunter Medicare Local, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 8 and p. 10.

> The expertise of these clinicians enables them to identify and diagnose early stage dementia, and to prescribe the appropriate treatment modalities. This also applies to Nurse Practitioners in the mental health field.[57]

5.86 Ms Pauline Armour, of UnitingCare Ageing (NSW and ACT), envisaged practice nurses taking a lead role in engaging with people in health assessments for people over 70 years of age. Ms Armour recommended that the number of NP trained with a cognition focus be increased.[58]

5.87 Mrs Kylie Wood, a specialist occupational therapist appearing in a private capacity, considered that one way to promote early diagnosis and intervention was to develop opportunities to extend the scope and role of nursing and allied health professionals to be able to diagnose dementia:

> Nurse practitioner positions in dementia specific roles is an achievable option to overcome GP reluctance and ability to diagnose accurately and rule out all differential diagnoses which would have possibly reversible symptoms and different disease prognoses.[59]

Committee comment

5.88 It is clear from evidence provided throughout this inquiry that specialist nurses, such as CDNs, NPs, and Clinical Nurse Consultants, play a crucial role in the timely diagnosis and ongoing management of dementia.

5.89 The Committee heard there was an opportunity to expand the use of dementia care specialist nurses (whether NPs or other specialist nurses), via an accredited training program or other such workforce development program. The Committee supports this proposal and agrees that expanding the use of multi-disciplinary teams in dementia diagnosis, treatment and support is an important step in encouraging early diagnosis and intervention of dementia.

5.90 The Committee will discuss the further engagement of specialist nurses as a case manager for people with dementia and their carers, in Chapter 6.

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[57] ANF, *Submission 79*, p. 5.

[58] Ms Pauline Armour, UnitingCare Ageing, New South Wales and ACT, *Official Committee Hansard*, Sydney, 14 June 2012, p. 13. See also, The College of Nursing, *Submission 28,* regarding the potential to create specific dementia training courses for nurses.

[59] Mrs Kylie Wood, *Official Committee Hansard*, Launceston, 27 July 2012, p. 6. See also: Denise Chaston and Kylie Wood, *Submission 52;* Alzheimer's Australia (National Office), *Submission 16*, pp. 8-9.

Recommendation 9

5.91 **The Australian Government, in consultation with Health Workforce Australia, develop an accredited training and support program to increase capacity for specialist nurses to provide dementia assessment and diagnosis in primary care settings, as part of multi-disciplinary teams.**

Barriers to diagnosis in acute care

5.92 In a report produced by the Australian Institute of Health and Welfare (AIHW), it was noted that identification and reporting of dementia was often poor in hospitals. The following reasons were cited for this under-identification:

- Difficulties of detection and diagnosis of dementia, given the presentation of other medical conditions;
- The brevity of interactions between doctors and patients;
- The potential inability of people with dementia to report symptomatic behaviour as a result of cognitive impairments; and
- Clinical and administrative issues.[60]

5.93 Ms Merl considered that it would be difficult to provide a diagnostic service within a hospital, because of the presentation of acute conditions:

> Often it is a delirium that people will have in hospital and, of course, that can be misdiagnosed—when we are talking about misdiagnosis—as a dementia. But a delirium is because there is something wrong with you, an illness that is causing your brain to not function well. Once you get rid of that cause—and the most common cause of delirium in older women is a urinary tract infection; in hospitals it will be surgeries, it will be falls, it will be lots of things—then often there is no dementia underneath that…[61]

5.94 Dr Stephen Brady, of Alice Springs Hospital, told the Committee that access to the appropriate diagnostic tools was not always available in a hospital setting, in areas such as Alice Springs:

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[60] Australian Institute of Health and Welfare 2013, *Dementia care in hospitals: costs and strategies*, Catalogue no. 72, p. 9.

[61] Ms Helga Merl, Hunter Medicare Local, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 12. See also: Associate Professor Mark Yates, *Submission 13*, p. 1.

> In terms of early diagnosis, the earlier you try to diagnose the better your tools need to be, and access to complex diagnostic procedures and personnel is not always available. Doing complex psychometric testing in a younger person who you think may be demonstrating early signs is not always available. An MRI scan is not available here—we have to send people 1,500 kilometres away. For the younger patients we are often talking about people who may have mixed morbidity diseases, which may be causing memory impairment, and that expertise is not always easily available.[62]

5.95 Ms Julie Johnston, of Kimberley Aged and Community Services, advised that there were processes and evidence-based guidelines (in the Kimberley region) within which medical and allied health teams could work to diagnose and treat dementia in hospitals. However, the use of these processes was inconsistent and depended on the level of staff knowledge and experience. She noted the application of these protocols was more consistent in regional hospitals, than in smaller hospitals.[63]

5.96 As the focus in hospital care was on getting people well and getting them home again, Dr Brady advised that follow up with patients was limited, once they were discharged from hospital. Dr Brady told the Committee:

> We are aware that, when we are getting them home, we are often getting them home to somewhere that is a long way away and without a lot of resources. We try to do what we can but we do have a very limited window in which we can do it. We would like to be able to hand on things to be done in the community but it does not always happen. For example, yesterday I saw a gentleman of 85 who had been admitted from one of the communities in South Australia with acute confusion. We had looked after him three months ago with an acute confusional episode, which was recovering. We wanted a dementia assessment when he returned to the community in that three months. It did not get done.[64]

5.97 Ms Johnston said that she knew of instances where a diagnosis of dementia was made in an acute hospital setting without undertaking any pre-work:

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[62] Dr Stephen Brady, Alice Springs Hospital, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 6.

[63] Ms Julie Johnston, Kimberley Aged and Community Services, *Official Committee Hansard*, Broome, p. 9.

[64] Dr Stephen Brady, Alice Springs Hospital, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 8.

> … often, when a client comes into an acute hospital, a diagnosis may be made for dementia without any prework. It is a diagnosis that is put on when it could be a lot of other things. It could be delirium…
>
> … with something else, quite acutely ill. But a diagnosis is made of dementia without any substantiation of it.[65]

5.98 Ms Johnston advised that the ideal referral process within a hospital setting involved a formal assessment (with geriatrician or psychogeriatrician input) to confirm the diagnosis, before referring the individual on to the best placed community-care service provider.[66]

Committee comment

5.99 The Committee was told that a hospital is often the first health setting where a person presents with cognitive issues. However, due to the nature of acute care, a diagnosis of dementia is often overlooked.

5.100 There are a number of barriers which prevent a diagnosis of dementia being made in hospitals. These barriers include the limited interactions between a patient and medical practitioners, limited hospital resources, and a lack of connection between the hospital, the community and primary care services.

5.101 It is vital that medical practitioners within hospitals are appropriately educated and resourced to identify symptoms of dementia in a hospital or acute setting when they present, and make appropriate referrals for follow-up assessment and treatment once a person is discharged.

5.102 It was proposed to the Committee that all hospitals have Clinical Nurse Specialists in dementia to provide staff education, carer support and important links into the community for the person with dementia on discharge.[67] This proposal is discussed further in Chapter 6.

5.103 Wider issues of awareness and education regarding dementia are discussed in Chapter 3.

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[65] Ms Julie Johnston, Kimberley Aged and Community Services, *Official Committee Hansard*, Broome, p. 9.

[66] Ms Julie Johnston, Kimberley Aged and Community Services, *Official Committee Hansard*, Broome, p. 9.

[67] Associate Professor Mark Yates, *Submission 13*, p. 1.

6

What do I need to do? How am I going to understand what Deb's condition is about? What does it mean? What does it mean for both of us? What support do we need? What intervention do we need? Where can I get it? How much does it cost?[1]

Post-diagnosis

6.1 As discussed in Chapter 4, early or timely diagnosis is the key to improving the quality of life, independence and social engagement of a person with dementia, and supporting those who care for them.

6.2 However, the Committee was told that without timely intervention, there is no benefit to early diagnosis of dementia.[2] Diagnosis must be seen as a first step that connects people to support and services which help them to live with their condition.[3] As HammondCare submitted:

> It is crucial that any strategy or policy to promote early diagnosis of dementia be matched by an equal effort to provide timely and appropriate assistance and guidance.[4]

6.3 Baptcare considered that a person's quality of life and independence could be improved greatly if dementia treatment and support was provided in a timely, person-centred way, involving a collaboration between health care providers:

> Quality of life and independence can be considerably enhanced if an early diagnosis is achieved and treatment commenced in a timely manner. However this needs to be undertaken in a person-

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[1] Mr Fred Tanner, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 20.

[2] See Professor Jillian Krill, *Submission 6*, p. 1; Tasmanian Government Department of Health and Human Services, *Submission 41*, p. 7.

[3] HammondCare, *Submission 86*, p. 2.

[4] HammondCare, *Submission 86*, p. 2. See also, Dr Paul Goldstraw, *Submission 94*.

> centred holistic context. The current approach to dementia care is still quite fragmented with diagnosis, treatment and service provision often undertaken separately and without any collaboration between health care providers.[5]

6.4 The Committee heard that once a diagnosis of dementia was made, the pathway to accessing appropriate treatment and support could be complex, confusing and frustrating. A diagnosis was often met with shock and confusion about what the future held for a person with dementia and their family. Mr Fred Tanner, a carer, outlined some of the questions raised by a diagnosis:

> … How am I going to understand what Deb's condition is about? What does it mean? What does it mean for both of us? What support do we need? What intervention do we need? Where can I get it? How much does it cost? Can I continue to work? Do I go and become a full-time carer, as a number of my very close friends have done in similar positions? How long will I do this for? I did not know. I was not even 50 at the time. So all those sorts of things were there, and then there was the question of cost. I do not just mean financial costs; I mean emotional costs, social costs—all those sorts of things. And also, more importantly, from my perspective, there was more about my wife. How was she coping with all this? How was Deb coping? She is a pretty strong woman, but this, I think, created lots of dilemma.[6]

6.5 A person's post-diagnosis experience will undoubtedly shape their quality of life, level of independence, and ability to remain engaged with their community.

6.6 This chapter discusses the post-diagnosis pathway for people with dementia and their carers, with a focus on how early intervention of dementia may assist to:

- Improve a person's quality of life and help them remain independent for as long as possible; and
- Increase their opportunities for continued social engagement and community participation.

Committee comment

6.7 From the evidence before the Committee, it is evident that the pathway from diagnosis to treatment of dementia varies according to a person's

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[5] Baptcare, *Submission 58*, p. 3.

[6] Mr Fred Tanner, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 20.

individual needs and the resources and services available to them (and their carers).

6.8 This chapter illustrates some of the experiences and common issues associated with life following a diagnosis of dementia, as shared during the course of the inquiry.

6.9 The Committee has not attempted to cover the field of issues associated with pathways of care for people with dementia and their carers. The Committee acknowledges that each person's experience of the aged/disability care system and the pathway from diagnosis to treatment and support is different.

6.10 The focus of the inquiry is how early diagnosis and intervention can improve the quality of life of a person with dementia and their family. Discussion in this chapter is therefore limited to the predominant issues experienced at the early stages of treatment for dementia, in cities and in regional, rural and remote areas. The nature of residential care or palliative care is not discussed in any detail, as this is outside of the terms of reference.

Referral pathways

6.11 The pathway from diagnosis to appropriate care and support must be timely and user-friendly for early or timely diagnosis to be beneficial. As a person's care and support needs change, additional or alternate services must be available and accessible, to meet that person's changing needs.

6.12 The Committee was told that people had difficulty navigating and accessing the referral pathway, due to a lack of coordination between services, and a lack of assistance and information about available services and support.

Navigating the pathway

6.13 Both consumers and service-providers told the Committee that the pathway from diagnosis to care and support was complex and varied nationally, which made it difficult to identify consistent referral pathways.[7]

6.14 Benetas submitted that information about available dementia services was often provided at the time of diagnosis, making the information difficult

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[7] Cognitive Dementia Memory Services (CDAMS), *Submission 39*, p. 3. See also, Silver Chain Nursing Association Inc., *Submission 68*, p. 5.

to process. They suggested that best practice would be to schedule a follow up meeting after diagnosis:

> Too often information about dementia is given at the same time of the diagnosis, but we have found that people often cannot take in this information as they are still shocked by the diagnosis. As a result health professionals need to ensure another consultation is arranged where they can sit with the person with dementia and family and provide the necessary information about dementia. An excellent model for this approach is that of the Cognitive and Dementia Memory Services (CDAMS) where a follow up meeting is arranged approximately four weeks after the initial diagnosis to discuss future planning.[8]

6.15 CDAMS noted that people who have been diagnosed at an earlier stage are sometimes not ready for, or in need of services at the point of diagnosis. Rather, they need to be linked in with services at an appropriate time in the future:

> …with earlier diagnosis clients and families are often not ready for or in need of services at the point of diagnosis apart from some initial education and information. This group is perhaps more at risk than those that are diagnosed further along the dementia pathway and linked to the service system at the point of diagnosis. They often tend to manage alone initially and, apart from some possible contact with their GP, are not connected to the service system. Information, provided at the time of diagnosis, about available supports and contacts, can be lost during this time and they often remain outside the service system until a crisis occurs.[9]

6.16 Alzheimer's Australia (Victoria) advised of the difficulties a consumer had in processing information once a diagnosis was made:

> (Robyn, cares for her mother with Alzheimer's Disease):
> Once diagnosed she was dismissed. I was given an A4 envelope of about 100 brochures and we were shown the door. It did turn out that some of those brochures were important – like the one introducing us to AAV (Alzheimer's Australia (Victoria)), but it looked like a pile of junk mail so I 'filed' it. It also took me about 2 more years to find out there were services that specialized in dementia care and also about HACC (Home and Community Care), CACPs (Community Aged Care Package) etc.[10]

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[8] Benetas, *Submission 25*, p. 6.

[9] CDAMS, *Submission 39,* p.9.

[10] Alzheimer's Australia (VIC), *Submission 35*, p. 5.

6.17 Mrs Helen Little, a carer, agreed that she did not know what to do or where to turn, once a diagnosis was given to her husband:

> Having had the diagnosis I was in the same situation. When you are given the diagnosis, what do you do? Where do you go? What services are available to you? There is really nothing that is on a bit of paper that says, 'Well, you could have this, this and this.' Largely I found that the things I came to know were just from word of mouth or somebody saying to me, 'Have you thought of ringing these people, contacting this agency?' I contacted Alzheimer's. I found Carers ACT were extremely helpful.
>
> As I speak to you, I am still not completely sure what is out there. I guess, in a sense, I feel it would be useful for people in my situation to have something that was more straightforward put to them as to the number of services that are available. [11]

6.18 Another carer, Mrs Joy Whitehorn, told the Committee that it took six years to obtain an ACAT[12] assessment for her husband, which was needed to access certain services. She said the paperwork required to access services was onerous and daunting:

> In the end there were tears on my behalf and begging. I badly needed assistance with night-time care. I am eligible for six weeks, but I could not get that without an ACAT; I could not get the ACAT. So you are in no-man's land. I eventually got the ACAT. When the paperwork came out, according to them I had been waiting for 12 months, so something was not quite right there. Looking at residential care, we badly need paperwork to be standardised. It is a jungle. Every facility appears to have different needs in paperwork; there are different forms. This is so time-consuming. A carer is so time poor and, in a lot of cases, sleep deprived. To be told that we need to put our names down in probably 10 different places to try and get into residential care is so daunting, especially with the paperwork.[13]

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[11] Mrs Helen Little, *Official Committee Hansard*, Canberra, 11 September 2012, p. 3.

[12] The Aged Care Assessment Team (ACAT) is outlined in Chapter 2.

[13] Mrs Joy Whitehorn, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 4. See also, Mr Garry Leith, Mrs Raelene Schilling and Mrs Joy Whitehorn, *Submission 111*; Mrs Raelene Schilling, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 4; and Mr Fred Tanner, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 20; and Home Instead Senior Care, *Submission 9*, p. 2.

Committee comment

6.19 The Committee acknowledges that when people first receive a diagnosis of dementia, it is a difficult time, both for them, and their family or close friends.

6.20 A diagnosis may come as a shock, which may make it difficult for a person to digest information about what services they can access for care and support.

6.21 For others, who are diagnosed in the early stages of dementia, the need for services may not be immediate. There is a risk these people will not be followed up at an appropriate time, when they are in need of support.

6.22 The Committee heard that once a diagnosis is given, information is often provided to a person in a passive way, by a General Practitioner (GP) or other service handing a person (or their carer) a number of brochures or fact sheets informing a person where they might receive further treatment and support.

6.23 The Committee notes that as part of the *Living Longer. Living Better.* aged care reforms, $198.2 million is to be allocated to build a gateway to aged care services. This includes the launch of a 'My Aged Care' website (www.agedcare.gov.au) and national call centre to give people one main entry point into the aged care system and access to all of the information they need.

6.24 These proposed reforms will likely assist in providing a clearer access point for dementia care services.

6.25 To avoid people falling through the cracks of accessing services, the Committee is of the view that there should be system in place whereby people are followed up, from the point of diagnosis and throughout progression of the condition.

6.26 The Committee heard evidence from a number of individuals with dementia and their carers, regarding the need for a 'real person' to provide face-to-face case management throughout the course of their condition. This proposal is discussed in more detail below. The need for follow up is discussed in that context.

Referral process

6.27 The Committee was told that one of the barriers to receiving appropriate dementia care and support was the lack of referral from GPs to specialists or community care, once a diagnosis was given.

6.28 Mr Glenn Stoll, of ECH Inc, an aged care service provider, considered that an integrated approach to dementia care was needed to guide people through the referral pathways:

> We need a more integrated approach so when people come into that system, as fragmented as it is now, it may be a little bit more connected so that we would be referring across or linking people together into a pathway of service, as opposed to it being a little bit ad hoc and indiscriminate, as it is at the moment.[14]

6.29 The Committee was told that GPs and other health professionals needed clear practice guidelines and information about local pathways to assist them to direct people to appropriate support and care, following a diagnosis.

6.30 Alzheimer's Australia submitted that one means of achieving this was to create contextualised clinical practice guidelines, utilising Medicare Locals or the Australian General Practice Network (AGPN) to develop and promote the pathways.[15]

6.31 The AGPN agreed there was a lack of clear guidelines available for GPs to provide appropriate referrals:

> Evidence suggests that many GPs are not aware of diagnostic guidelines for dementia and that in many cases there are not clearly established care pathways relevant to the local context. Associated with this is often poor integration of general practice with other relevant primary health care and specialist services and limited awareness amongst GPs and PNs of locally-available support services and resources. This can mean that care provided does not follow best practice care pathways and may be poorly coordinated, with patients and their carers missing out on needed or potentially beneficial care and support.[16]

6.32 It was noted that the single guideline created for the management of dementia in general practice was out-of-date and not widely used.[17]

6.33 Alzheimer's Australia noted in a subsequent submission that the guidelines are being revised through a project funded by the Dementia Collaborative Research Centre (DCRC) for Assessment and Better Care.[18] The DCRCs are discussed in more detail in Chapter 7.

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[14] Mr Andrew Stoll, ECH Inc, *Official Committee Hansard*, Adelaide, 8 June 2012, p. 27.

[15] Alzheimer's Australia, *Submission 44*, pp. 18-19.

[16] Australian General Practice Network (AGPN), *Submission 87*, p. 11.

[17] Alzheimer's Australia, *Submission 44*, p. 18.

[18] Australian Government, *Dementia Collaborative Research Centres,* <http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&view=dcrc&layout=project&Itemid=101&research_topic=0&researcher=0&research_type=0&year=0&population=0&centre=0&keywords=&searchtype=&pid=43&search=true_> viewed 31 May 2013.

Committee comment

6.34 The Committee notes evidence suggesting that one barrier to achieving early intervention of dementia is the lack of referrals provided by GPs to specialists or other pathways of care, following a diagnosis. Another major barrier, the lack of awareness regarding dementia, is discussed in Chapter 3.

6.35 One means of assisting GPs make appropriate referrals following a diagnosis of dementia is to provide GPs with clear practice guidelines, which are relevant to the local context.

6.36 The Committee notes a project currently underway through the DCRC to update the dementia guidelines for general practice.

6.37 The Committee supports this project and proposes that the Commonwealth, in consultation with Medicare Locals or other local health care networks, ensure that the guidelines are contextualised to provide relevant information on local pathways.

Recommendation 10

6.38 **The Australian Government Department of Health and Ageing complete and promote practice guidelines for the care of dementia in general practice (or primary care). In consultation with Medicare Locals or other such local health networks, these guidelines should be contextualised and provide information on local dementia care pathways, including information on future planning services, such as legal services.**

Coordinating pathways

6.39 The Committee heard there was a lack of coordination between the diagnostic services or medical professionals who made a diagnosis of dementia, and the service providers who delivered treatment and support once a diagnosis was made.[19] There was a call to establish clearer pathways for people to access appropriate support and care in a timely way, following a diagnosis.

6.40 Associate Professor Scott Whyte, of Central Coast Local Health Network, told the Committee that people were often not linked in with services once they were given a diagnosis:

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[19] See for example, Darabin Council, *Submission 64*, p.

> I think the real issue and problem with dementia, particularly with young people, is that they get sent down to Sydney for a diagnosis and that is where it stops. We pick them up years later as everything fails. They have not been linked in with local services. One really important thing is to keep people on the coast, and not just to give them a diagnosis but to link them up with the community services.[20]

6.41 The Committee was told that one method of better coordinating local pathways of care would be to utilise Medicare Locals.

6.42 The Department of Health and Ageing (DoHA) advised that Medicare Locals were improving the coordination and integration of primary health care in local communities and helping people navigate the local system, by better linking local GPs, nursing, allied health and other health professionals, hospitals and aged care, and maintaining up to date local service directories.[21]

6.43 Ms Lisa Rollinson, of the Brotherhood of St Laurence, asserted that Medicare Locals could be used effectively to coordinate and manage dementia services in the primary care sector:

> Medicare Locals are well placed to facilitate and coordinate dementia care in the primary health arena, with partnerships with local experts in the community field. Currently dementia diagnosis and referral is managed through the acute and subacute sectors by a specialised memory clinic and ACAT. Clients and carers will be much better served through the service coordination and primary health focus to be provided through the Medicare Locals and the community health sector.[22]

6.44 AGPN agreed that Medicare Locals, or other existing primary health care networks charged with regional primary health care coordination, were well placed to facilitate greater integration and networking of local primary and specialist health services, and social care and support services. AGPN submitted that this networking would ensure people living with dementia and their families accessed comprehensive and well-coordinated care that optimised the potential benefit of local services.[23]

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[20] Associate Professor Scott Whyte, Central Coast Local Health District, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 14. See also, Townsville Health Services District, *Submission 27*, p. 2.

[21] Department of Health and Ageing (DoHA), *Submission 89*, p. 8.

[22] Ms Lisa Rollinson, Brotherhood of St Laurence, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 2.

[23] AGPN, *Submission 87*, p. 13. See also, MDAG, *Submission 48*, p. 4.

6.45 Mr Rees considered how Medicare Locals might be used to link people in to services once they obtained a diagnosis:

> It is, firstly, important to establish the principles that should govern the system. What should you look for across Australia in terms of the main characteristics of any system? That is important. But given the diversity of service provision in Australia, it would be very hard to have a very consistent system view across Australia. I would go back to one of the points that I made at the outset that, whether it is through Medicare Locals or through some other system, we would look to develop regional or local pathways that local professionals could follow. They might be quite different from area to area, depending on health infrastructure. That is where we got to with our stakeholder group and that seems to me to be the sort of approach that one should take.[24]

6.46 Mr Mark Booth, of DoHA, explained how Medicare Locals were already being utilised to develop local pathways in dementia care:

> … Medicare Locals are tasked with looking at two things. One is that care coordination work to ensure that, from a patient perspective, patients can have an easy journey through care. The second one is really that notion of looking at the health needs of the community that they cover. So they do work on going out, consulting, doing analysis and seeing what the particular issues are in the communities that they cover. The first tranche of Medicare Locals have started doing that. They have done interim needs assessment reports, and we have good examples of Medicare Locals that have identified dementia issues as a particular issue and have put in place pathways.[25]

6.47 Ms Carolyn Smith, of DoHA, explained how the Medical Local structure could be used to create effective pathways of care that suited local circumstances, and highlight effective models of care:

> We are going to be working with the Medicare Local structure in terms of adapting those local pathways to suit local circumstances, but also how we can actually share good work that is happening. I think one of the frustrations in some of these areas is that there are lots of really good models of practice occurring around the country, and how do we actually learn about all of the good stuff

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[24] Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September, 2012, p. 4.

[25] Mr Mark Booth, DoHA, *Official Committee Hansard*, 8 February 2013, Canberra pp. 10-11.

> that is happening and develop it into tools that can then be applied more broadly. We are going to be working very closely with lead Medicare Locals and also the Medicare Local Alliance in terms of how we can imbed those models of care and pathways into a broader setting.[26]

A multi-disciplinary approach

6.48 Many stakeholders submitted to the Committee that a multi-disciplinary approach to providing dementia care and support was another means of creating a clearer pathway of care for a person with dementia.

6.49 A multi-disciplinary approach to diagnosis is considered in Chapter 5.

6.50 It was submitted that the use of a multi-disciplinary team would ensure that a person's complex care needs were met appropriately, to improve a person's quality of life and assist them to remain independent for as long as possible.

6.51 Aged Care Association Australia Ltd submitted:

> An early diagnosis, supported by multi-disciplinary dementia care teams – (comprising doctors, specialists, counsellors, family members, communities etc.) could see an:
>
> - Improved understanding of the disease for all those impacted
> - Improved levels of involvement in advanced care planning, particularly for those individuals/families uncertain what the future holds post diagnosis
> - Improved approach toward management and self-determination, rather than just treatment.[27]

6.52 Mercy Health stated that as with all chronic diseases, people with dementia would benefit from a multi-disciplinary approach to care:

> Mercy Health would urge that attention be given to supporting an increased involvement of other health providers in the care of people with dementia, including gerontologists, neurologists, registered nurses, social workers, nutritionists, health and behavioural psychologists, speech pathologists, and occupational and physiotherapists, in order that a comprehensive, integrated and quality program of care can be provided to this group who are experiencing one of the most disabling conditions and who are in most need our support.[28]

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[26] Ms Carolyn Smith, DoHA, *Official Committee Hansard*, 8 February 2013, Canberra p. 11.

[27] Aged Care Association Australia Ltd, *Submission 84*, p. 1.

[28] Mercy Health, *Submission 81*, p. 4.

6.53 Dr Leslie Bolitho, of the Royal Australasian College of Physicians (RACP), explained that an integrated and multi-disciplinary model of care was needed to meet the needs of people with dementia (and their carers):

> Adequately responding to the needs of people with dementia and their carers over time will require an adapted and integrated healthcare system and aged-care delivery driven by new and improved models of care and service delivery involving multidisciplinary teams of professionals providing care, particularly outside hospitals, and in the primary and ambulatory settings, and particularly with residential aged-care facilities where over 50 per cent of the residents have a diagnosis of dementia.[29]

6.54 The RACP and the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) submitted that people with dementia and their carers should have easy and timely access to coordinated multi-disciplinary care over the course of the condition. Such an approach would involve a shared-care model involving (as required) the GP, specialist dementia nurse, medical specialist, pharmacist and allied health professional(s)[30] who provide continuity of care and smooth transitions across acute, sub-acute, transitional, community, primary and palliative care settings. It was submitted that for such a model to exist across Australia, consideration was needed regarding:

- Education and training of the multi-disciplinary team;
- Workforce requirements;
- Adequate financial arrangements and incentives;
- Examples of good practice; and
- Opportunities presented through emerging technologies and the health and aged care reform process.[31]

Committee comment

6.55 The Committee heard there was a need for greater coordination of services and clearer referral pathways, to address concerns about the lack of linkages between services and duplication of other services.

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[29] Dr Leslie Bolitho, RACGP, *Official Committee Hansard*, Sydney, 22 June 2012, p. 18. See also, RACP and ANZSGM, *Submission 22*.

[30] There were a number of submissions which advocated for the benefits of health professionals such as speech pathologists, to be part of any multi-disciplinary team. See for example, Speech Pathology Australia, *Submission 74*; Margaret Pozzebon, *Submission 97*; Ms Kim Torresi, Dr Bronwyn Moorhouse and Dr Amanda Scott, *Submission 98*.

[31] RACP and ANZSGM, *Submission 22*, pp. 12-13.

6.56 A number of suggestions were made to the Committee on how to achieve better coordination and clearer pathways. These include:

- Utilising Medicare Locals or other established primary care networks to streamline and coordinate localised care pathways in a user-friendly way for people with dementia and their carers; and
- Utilising a multi-disciplinary approach to dementia care, by using a range of health professionals trained to treat and assist people with dementia.

6.57 The Committee notes that policy development within the area of dementia diagnosis and post-diagnostic care and support, is moving at a rapid rate. Stakeholders are likely very familiar with the call for better coordination of services, as outlined above.

6.58 The Committee understands that a range of initiatives which have the aim of making care pathways more user-friendly and efficient for people with dementia and their families are already in progress under the auspice the DoHA, the Minister's Dementia Advisory Group (MDAG), DCRCs and Alzheimer's Australia. For example, the Committee notes that MDAG is currently exploring the barriers and opportunities for improving care, including avenues available through Medicare Locals.[32]

6.59 The Committee joins with these stakeholders in recommending that government facilitate initiatives which will assist in smoothing the post-diagnosis pathway of care for people with dementia, their families and for health care providers. Noting the Committee's comments in Chapter 4, integration of services should also extend to services available for people to obtain a diagnosis of dementia.

Recommendation 11

6.60 **The Australian Government establish clear and streamlined local referral pathways for dementia diagnosis, treatment and support, through Medicare Locals, localised primary health care networks, or other specialist dementia networks such as Memory Clinics.**

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[32] DoHA, *Submission 89*, p. 12.

Recommendation 12

6.61 **The Australian Government Department of Health and Ageing, in collaboration with the Minister's Dementia Advisory Group, Alzheimer's Australia and Health Workforce Australia, evaluate the creation of a nation-wide multi-disciplinary approach to dementia diagnosis, treatment and support.**

Such an approach should build upon the existing workforce and localised infrastructure, such as Medicare Locals and/or Memory Clinics.

Dementia link worker

6.62 While health practitioners and consumer groups called for clear pathways and better coordination of care, consumers called for information to be provided from a real person who could manage their case and link them in with the appropriate services.[33] This person is referred to as a Dementia Link Worker (DLW).

6.63 Mr Glenn Rees, Chief Executive Officer of Alzheimer's Australia, called for clear local pathways to allow medical professionals to refer people to community support and information on an ongoing basis. Mr Rees relayed the call from consumers for a key link worker to assist in the referral process:

> One of the things that consumers stress over and over again as important is having key link workers who focus on providing ongoing advice as and when it is needed.[34]

6.64 Dr Jane Thompson, a carer, echoed the call for a 'key worker' to assist people in navigating the system of care, telling the Committee of the difficulties she experienced finding appropriate services:

> I felt I was told, 'Well, here it is. You go home and deal with it.' In fact it is very much up to the individual to work out where to go for help and what sorts of services you are going to need, and it does require considerable resourcefulness, I think, to negotiate that system. I think, again, I would support Glenn's comments about the benefits that we might have gained from having a key worker

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[33] Alzheimer's Australia (National Office), *Submission 44*, p. 22.

[34] Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 1.

> or a case manager to help us just negotiate our way through the transitions that are required in care needs.[35]

6.65 The proposed role of a dementia link worker was outlined to the Committee:

> 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.[36]

6.66 NSW Health envisaged that a key worker would be a person with a nursing or allied health qualification, skilled in dementia care, who worked closely with the person's GP or Aboriginal Medical Service, proactively following up after diagnosis and building a continuing relationship. The key worker would case manage a person's care needs as they increased or became complex, and would assist the person to remain independent for as long as possible.[37]

6.67 Alzheimer's Australia outlined how the DLW program could be implemented as part of the current aged care reforms, and integrated into existing models of primary care:

- A DLWcould be recruited from a variety of professional backgrounds, including nursing or allied health fields (with backgrounds in areas such as social work, psychology or occupational therapy);[38]
- The worker would have specialised training and experience in dementia care, and extensive knowledge of local services;
- Implementation of the program would require the development and endorsement of an accreditation program with appropriate competencies and professional development requirements; and

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[35] Dr Jane Forbes Thompson, *Official Committee Hansard*, Canberra, 11 September 2012, p. 2. See also, NSW Health, *Submission 95*, p. 4, p. 6.

[36] Alzheimer's Australia (National Office), *Submission 44*, p. 21.

[37] NSW Health, *Submission 95*, p. 6. See also, RACP and ANZSGM, *Submission 22*, p. 2, p. 14.

[38] For further discussion on nurses as coordinators, see Royal College of Nursing, *Submission 61*, pp. 1-2.

- The program could be delivered by 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.[39]

6.68 Alzheimer's Australia South Australia has already implemented a DLW program. The program was outlined to the Committee in Adelaide:

> …we have what we call dementia link workers who work throughout South Australia and we positioned one of our dementia link workers with Craig in Repat [the Repatriation General Hospital] and this has proved to be a really successful. Our organisation's aim is to try and get people on diagnosis, so when they walk out of the memory clinic they walk straight into one of our workers who can provide relevant information and then work with them and the family throughout that journey.[40]

6.69 Ms Marie Alford, of Alzheimer's Australia South Australia, said that those people who had access to a DLW were more likely to be supported through their dementia journey, than those people who received a passive referral, by being given written information. This was particularly important for people who were living alone:

> I think one of the biggest barriers is around people who live alone who develop dementia: how do we access this particular cohort? If they do not have family members like Fred who will make that connection it is important to have that immediate connection either through the GP or the specialist. What we know is that passive referral where people are given a piece of information, whether it is by the GP or specialist, may lead to a referral but those clients who have direct access to a worker on the ground either at the QEH [Queen Elizabeth Hospital] or at the Repat [Repatriation General Hospital] or potentially through a GP clinic are more likely to be supported through their journey and have an increased quality of life through that early intervention.[41]

6.70 Mrs Fiona Young, a Clinical Nurse Consultant in Tasmania, was part of Community Dementia Service that offered consultation, assessment, information and the provision of direct care to people with dementia

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[39] Alzheimer's Australia (National Office), *Submission 44*, pp. 22-23.

[40] Ms Kathryn Cunningham, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 23. See also Professor Craig Whitehead, South Australia Health Statewide Older People Clinical Network, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 17.

[41] Ms Marie Alford, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 22.

living in the community. The service considered that following up with people after diagnosis of dementia was important. Within the service, follow up was provided to people in a number of ways:

> Depending on the individual client and on family needs, the follow up ranged from phone calls to the client or carer, contact with other services already involved in the client's care or admission to either the Community Dementia Service or the Community Options Service, which is also part of Primary Health North, for ongoing care provision and case management.[42]

6.71 It was submitted that post-diagnostic support promoted a feeling of independence for a person with dementia, and assisted them to maintain control over their life.[43]

Committee comment

6.72 It is clear to the Committee that the pathway from diagnosis to receiving ongoing treatment and support is complex and difficult to navigate. Evidence called for a case management approach to assist people with dementia and their carers, following diagnosis. This will ensure that a person's care and support needs, and those of their carers, are met in a timely and appropriate way.

6.73 The Committee heard that there is a need to give people with dementia access to a 'real person' who can coordinate their care from the point of diagnosis and throughout progression of the condition.

6.74 Carers may also have discrete support needs and may require case management in their own right.

6.75 As noted earlier in this chapter, some people do not require immediate access to services, particularly when diagnosis is received at an early stage. A case management approach that includes proactive follow up will ensure these people are not forgotten and receive services when they are needed.

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[42] Mrs Fiona Young, Community Dementia Service, Tasmanian Health Organisation North, *Official Committee Hansard*, Launceston, 27 July 2012, p. 18.

[43] Community Dementia Service Primary Health North, *Submission 14*, p. 3.

Recommendation 13

6.76 **The Australian Government Department of Health and Ageing examine the case for establishing a Dementia Link Worker program to assist in the ongoing case management of people with dementia and their carers.**

A proactive case management approach, utilising a Dementia Link Worker, should include regular scheduled follow up from the time of diagnosis through the progression of the condition.

How dementia care services can improve quality of life

6.77 For early intervention of dementia to be successful, the Committee understands that services must be dementia friendly, flexible and accessible. Unfortunately, the Committee heard that this is not always the case.

Dementia management in acute care

6.78 In its report, *Dementia care in hospitals costs and strategies*, the Australian Institute of Health and Welfare (AIHW) found that the identification and recording of dementia as a diagnosis in hospital records was often poor. This could impact on the treatment of individuals with dementia:

> The identification and recording of dementia as a diagnosis in hospital records is often poor. … there are a number of potential reasons for this, including the time constraints on the interactions between patients and doctors, clinical coding practices, the challenges associated with differential diagnosis and cognitive impairment of dementia patients and the systemic limitations and issues with documentation and classification practices...
>
> … Under-identification of dementia in hospital data sets has an impact on both the reliability of information and statistics and on the approaches and practices used within the hospital. Ultimately, under-identification has potential negative consequences for patient outcomes.[44]

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[44] AIHW, *Dementia care in hospitals costs and strategies*, 2013, p. 15. For statistics on dementia diagnosis in hospitals, see p. ix and pp. 67-80.

6.79 Despite the large numbers of people with dementia being admitted for some form of acute care, the Committee heard that hospital care was often not 'dementia friendly'. As explained by RACP and ANZSGM:

> Currently, hospitals are daunting places for people with dementia in terms of both quality of care and quality of the environment with higher likelihood of poor outcomes including disability and death. People with dementia tend to have longer hospital stays and an increased number of complications including polypharmacy, undernutrition, skin tears, pressure areas and fall-related injuries. People with dementia can find hospitals unfamiliar, confusing and disorienting and there is risk of sensory overload from a busy, time-pressured ward.[45]

6.80 It was submitted that despite dementia being 'core business' for hospital staff, dementia often went overlooked in hospital settings:

> Diagnosis of cognitive impairment, specifically of dementia and delirium, is often overlooked when older people are admitted for medical or surgical reasons to emergency departments or acute hospital wards. Yet dementia is associated with longer length of stay, behavioural complications, higher rates of falls and fractures and more expensive admissions than non-demented patients with same conditions.
>
> Management of people with dementia in hospitals can be sub-optimal if health professionals are not aware of the limitations of cognitively impaired patients in even seemingly simple matters such as filling in menus or adhering to treatment regimens.[46]

6.81 The Committee heard that in some hospital settings there was insufficient recognition by staff of patients who had dementia, particularly when the patients were admitted to hospital for a particular acute condition.[47]

6.82 Associate Professor Mark Yates explained that some families of hospital patients with cognitive impairment believed that cognitive impairment was not recognised by hospital staff:

> Our research has shown us that on any day 30% of patients in hospital have cognitive impairment and that families believe that in 20% of admissions the hospital are unaware of their loved ones cognitive impairment.[48]

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[45] RACP and ANZSGM, *Submission 22*, p. 20.

[46] MDAG, *Submission 48*, pp. 6-7. See also, Associate Professor Mark Yates, *Submission 13*.

[47] Dr Stephen Brady, Alice Springs Hospital, *Official Committee Hansard*, Alice Springs, Wednesday 30 January, 2013, p.10. See also, Gloria (NSW), *Submission 18*.

[48] Associate Professor Mark Yates, *Submission 13*.

6.83 Given the prevalence of dementia within the acute care system, it was submitted that one means of meeting the needs of these patients was to place Clinical Nurse Specialists in dementia at all hospitals, to assist patients who had dementia. Associate Professor Yates recommended this course of action:

> I would also recommend that all hospitals have Clinical Nurse Specialists in Dementia. It is surprising to me that almost all hospitals have a Diabetes Nurse when the in-patient prevalence of this condition is 11.1%... and an asthma nurse when is it estimated that asthma represents just 0.5% of separations…but not have a Dementia Nurse Specialist who can provide staff education, carer support and important links for the person with dementia into the community on discharge.[49]

6.84 Mrs Judy Buckley, who cared for her mother with dementia, advised that there needed to be some way to alert staff within hospitals that a patient had dementia:

> … when someone is, for example, in hospital for some other reason, there needs to be some sort of indication that that person has dementia. We have signage for disability in car parks and things that we are all familiar with and that is usually around the hospital bed somewhere. But there is nothing to indicate to staff that that person has some form of dementia. I think it can lead to lots of misunderstanding and lots of confusion for the person who is in hospital. I guess they are the main issues for me.[50]

6.85 Associate Professor Yates advocated for the nationalisation of a program implemented in Victoria to improve awareness and communication with people with dementia within hospitals:

> In Victoria the Dementia Care in Hospitals Program has been rolled out to 22 public hospitals and is now being trialled in the private sector. It is a program to improve the awareness of and communication with people with dementia and their families linked to a visual bedside alert called the Cognitive Impairment Identifier. The program has led to improvement in staff and carer satisfaction with the care of those with Cognitive Impairment. I would recommend to the Inquiry that this program be made

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[49] Associate Professor Mark Yates, *Submission 13*.

[50] Mrs Judy Buckley, Alzheimer's Australia NT Inc., *Official Committee Hansard*, Alice Springs, 30 January 2013.

> national as one element in the improved care and early diagnosis of those with cognitive impairment.[51]

6.86 Another perspective however was presented by Mrs Marianne Cummins, from the Northern Territory Division of the Australian Association of Gerontology. Mrs Cummins was concerned that using an identifier for patients with cognitive impairment may lead to misdiagnosis in some instances:

> As a nurse working in the hospital we already have people …that are identified as having dementia and are labelled with dementia because of a whole range of things. They may be delirious and acutely unwell. That is really the common cause. It is the most common cause of people's confusion, and it is on top of their chronic illnesses. It is well-known that if you have a chronic illness and you become acutely unwell then you can become delirious. There are a lot of risk factors. Sometimes it is actually about the hospital not then going down the track of making sure that that acute illness is treated. That would be the most disastrous thing I think because they have a lot of people that that is an issue for.[52]

6.87 MDAG considered that early diagnosis of dementia, combined with training of hospital health professionals on how best to assist patients with cognitive impairment, could assist in reducing complications of care for a person’s primary reason for admission and decrease their length of stay.[53]

6.88 To address the under-identification and awareness of dementia in hospitals, MDAG recommended that hospital health professionals and other front-line professionals undertake awareness training and education about the importance of recognising cognitive impairment.[54]

Committee comment

6.89 For a number of reasons outlined above, the identification and awareness of dementia within hospital settings is low. This undoubtedly effects a person’s health outcomes and the quality of care that person receives.

6.90 As part of the *Living Longer. Living Better.* aged care reforms, $39.2 million has been allocated to improve acute care services for people with dementia. The reforms as outlined by DoHA, are:

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[51] Associate Professor Mark Yates, *Submission 13*.

[52] Ms Marianne Cummins, Australian Association of Gerontology, *Official Committee Hansard*, Alice Springs, 30 January 2013, pp. 29-30.

[53] MDAG, *Submission 48*, pp. 6-7.

[54] MDAG, *Submission 48*, p. 9.

> People with dementia will be identified and better coordinated and supported systems will be developed and trialled to enable safe and appropriate hospital services. People with dementia will benefit through early identification of cognitive impairment, improved assessment, and access to specialist dementia programs. This will assist in achieving better outcomes for people, including reduced falls, shorter stays, improved nutrition, and fewer setbacks.[55]

6.91 It is further noted that these improved support services will take into account people with dementia with specialised needs, including people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people and people with Younger Onset Dementia (YOD).[56]

6.92 In implementing reforms to acute care settings to improve treatment and services for people with dementia, the Committee recommends consideration of the following suggestions from experienced stakeholders specialising in dementia care:

- The feasibility of introducing Clinical Nurse Specialists in dementia into hospital settings, to address the needs of dementia patients in acute care;
- The feasibility of introducing a Cognitive Impairment Identifier into hospital settings; and
- The training and education of hospital health professionals in dementia assessment, treatment and care.

6.93 In addition, the Committee recommends that to improve management of dementia in an acute care setting, a protocol be established regarding the identification of cognitive issues at the point of triage.

6.94 Training and education of hospital health professionals in dementia assessment, treatment and care is dealt with in the discussion regarding awareness of health professionals in Chapter 3.

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[55] Australian Government Department of Health and Ageing, *Living Longer. Living Better.*, 'Tackling dementia', <http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/tackling-dementia#2> viewed 3 June 2013.

[56] Australian Government Department of Health and Ageing, *Living Longer. Living Better.*, 'Tackling dementia', <http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/tackling-dementia#2> viewed 3 June 2013.

Recommendation 14

6.95 **The Australian Government Department of Health and Ageing, as part of the *Living Longer. Living Better.* reforms and through the Council of Australian Governments, trial the following initiatives to investigate their capacity to assist in improving dementia care in acute hospital settings, with a view to these initiatives being implemented nationally:**

- **The introduction of Clinical Nurse Specialists in dementia in hospitals;**
- **The introduction of a Cognitive Impairment Identifier in hospitals; and**
- **The introduction of a protocol for the identification of cognitive issues at the point of triage.**

Accessible and flexible services

6.96 The Committee received a significant volume of evidence addressing the issue of care services for people with dementia, and emphasising the specific needs of particular population groups.[57]

6.97 The following section is not intended to be a comprehensive discussion of the dementia care requirements for all population groups with specific needs. Rather it is intended to be illustrative of the need for services that are accessible and flexible enough to accommodate the different care requirements of diverse populations.

6.98 As explained by Life Care, a South Australian community aged care service provider, each individual has different care needs and, as dementia is progressive, these needs are likely to change over time:

> An individual with dementia has a very individual path as they move from early diagnosis to moderate and advanced stages. Irrespective of age, there needs to be flexible models of support in both community and residential settings to meet their needs. For example, an 80 year old with some early signs of cognitive decline, will not find a program for individuals with advanced dementia stimulating or appropriate. Service providers must have flexible management of programs and the skills to identify and address each individual's needs. Their models of care are often restricted

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[57] See for example, Central Coast Local Health District, *Submission 103.*

> due to funding and staffing constraints, rather than individual care needs.[58]

6.99 The need for accessible and flexible dementia care services is considered with reference to the following population groups:

- People with YOD;
- People with intellectual disabilities;
- People from culturally and linguistically diverse (CALD) backgrounds;
- Indigenous Australians; and
- People living in regional, rural and remote areas.

6.100 Discussing issues relating to dementia care services for people with YOD, the NSW HACC Forum submitted:

> People with younger onset dementia can be at a very different life stage than older people with dementia. They may be in full-time employment, with caring responsibilities for children, may be physically fit and active, and have a number of interests. As support for dementia is mostly funded and provided in the aged care sector, people with younger onset dementia do not necessarily identify with needing the types of care or support available for people with dementia.[59]

6.101 It was submitted that younger patients with dementia needed access to age-appropriate services, rather than services targeted towards older people.[60] Ms Kate Swaffer, who was diagnosed with dementia at age 49, noted that there were a number of factors that needed to be taken into account when considering the appropriateness of care and support services for people with YOD. These factors included that a person with YOD was more likely to be still in paid employment when the diagnosis came, and have dependent children. [61]

6.102 In relation to residential care facilities, HammondCare noted the distinct care needs of people with YOD:

> Younger people with dementia have a different set of needs as they are heavily involved in complex professional and family relationships. They tend to be much more physically active than older people with more conventional forms of dementia and are more likely to have a form of dementia that is associated with higher levels of behaviours of concern, such as fronto-temporal

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[58] Life Care, *Submission 110*, pp. 2-3.

[59] NSW HACC Issues Forum, *Submission 85*, p. 5. See also, Jenie (SA), *Submission 15*.

[60] See for example, Baptistcare Inc, *Submission 33*, pp. 2-3.

[61] Ms Kate Swaffer, *Submission 77*, p. 10.

> lobe dementia. This means that traditional residential aged care services are not well-equipped to support younger people with dementia.[62]

6.103 According to evidence presented by Dr Jennifer Torr, people with intellectual disabilities and dementia have particular problems with accessing appropriate services. In relation to this, Dr Torr commented:

> … people [with intellectual disabilities] living in group homes are seriously disadvantaged and refused access to a range of allied health services that would be provided to someone with dementia living at home. Have group homes been confused with aged care facilities which are required to provide these services? Group homes provide accommodation support, not health care.[63]

6.104 Dr Torr called for greater clarity on how eligibility criteria for accessing dementia care services applies to people with an intellectual disability following a diagnosis of dementia, observing that:

> The failure to provide adequate support within family home, or group homes can only result in premature placement in an aged care facility.[64]

6.105 The Australian Nursing Federation submitted that there was a need to educate the health and aged care workforce on culturally sensitive, acceptable and specific approaches to the dementia care for people from CALD backgrounds, noting:

> Flexibility in models of dementia care must be supported to accommodate preferences for intervention for people from culturally and linguistically diverse backgrounds. Initiatives are required to be adopted that build cultural awareness and cultural competence of the health and aged care workforce. Dementia care resources need to include models that support cultural liaison.[65]

6.106 Mercy Health echoed the call for more training for service providers around the social and spiritual needs of people with CALD backgrounds, noting that differences in language and culture could create challenges for service providers:

> Consistent with population changes indicating that between one quarter and one third of Australians were born in a country other than Australia, the current and future needs of ageing migrant and

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[62] HammondCare, *Submission 86*, p. 2. See also, Ms Kate Swaffer, *Submission 77*, p. 13; Mrs Jacinta Robertson, Life Care, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 3.

[63] Dr Jennifer Torr, *Submission 73*, p. [6].

[64] Dr Jennifer Torr, *Submission 73*, p. [6].

[65] Australian Nursing Federation, *Submission 79*, p. 8.

> CALD communities needs to be an increased priority. For those living with dementia and their families, particularly in the urban centres of Australia, linguistic and cultural diversity assumes great significance. Social isolation, reversion to 'first' language, confusion exacerbated by unfamiliarity with prevailing Western cultural mores, and other factors pose unique and major challenges for communication with and assessment of such individuals.[66]

6.107 The Committee also received evidence indicating a shortage of dementia care services which address the specific needs of Indigenous Australians, particularly those living in remote communities.[67]

6.108 Professor David Atkinson, Medical Director with the Kimberley Aboriginal Medical Services Council, explained that accessibility of services was a major issue in remote Indigenous communities:

> The big issue is that services are provided in the towns but most of the people actually do not live in the big towns and, therefore, patients do not really have access to them. The system is not sufficiently flexible to deliver services in communities.[68]

6.109 Professor Atkinson considered that communities needed to have input into how the services were to be delivered:

> … The thing that would work for remote communities would be to have funding that is put together and communities having a say in what services they need. If they have two young people with disabilities and five or six old people, maybe one person can contribute to all of those people's care. That would be more efficient. They can employ local people. As it is, we have visiting services coming in for an hour or two and then going away again, and that is clearly a waste of resources and probably not that productive.[69]

6.110 Ms Wilma Gibson, who manages aged and disability services within the Central Desert Shire Council in the Northern Territory, advised that when providing dementia care services to remote Indigenous communities,

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[66] Mercy Health, *Submission 81*, p. 5. See also, SA Department for Communities and Social Inclusion, *Submission 91*, p. 13.

[67] See for example: Mrs Nicole O'Connor, Alzheimer's Australia (NT), *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 2.

[68] Professor David Atkinson, Kimberley Aboriginal Medical Services Council, *Official Committee Hansard*, Broome, 13 November 2012, p. 3. See also, Kimberley Aged and Community Services, *Submission 107.*

[69] Professor David Atkinson, Kimberley Aboriginal Medical Services Council, *Official Committee Hansard*, Broome, 13 November 2012, p. 3.

there was a need to consider the cultural differences in how dementia was perceived and how care could be provided:

> There are two different realms here: how we would actually perceive dementia and work with dementia, and then what is it to an Indigenous community and culture around that and how do you work with that, and then how do you go on a much closer scale within that household environment to work with that person, because maybe something has happened and you have got a fear that has developed because some safety issue has taken place. There are a lot of other things that need to be considered as to how we really make that workable on community because it is becoming quite demanding. That is pretty much the challenge in and around that.[70]

6.111 Ms Nina Bullock, who similarly managed aged care services at MacDonnell Shire Council, considered that providing appropriate care to remote Indigenous communities required forming partnerships between the person, their extended families, and the relevant agencies:

> Culturally safe services, information and activities are often hard to come by. This community alone has lost 14 members in the last two months. Yet the community has access to hidden assets: the support of a wide network of family members who reside on community, on a country that they know intimately; a history of resilience; a living language; and ideas about how to move forward and to where. Thus it is critical to a client's wellbeing and independence that plans for their care are undertaken in true partnership with the extended family and relevant agencies.[71]

6.112 Shortages of dementia care services in remote, rural and regional communities represents a major barrier to accessing appropriate interventions for people with dementia living outside of Australia’s metropolitan centres.[72]

6.113 Mr Terry Mehan, of Queensland Health, told the Committee of the advantages and disadvantages faced by people in rural communities, in relation to the provision of aged care services:

> Your advantage is that whole sense of community, flexibility and responsive. Your disadvantage is that you will not be able to

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[70] Ms Wilma Gibson, Central Desert Shire Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 37.

[71] Ms Nina Bullock, MacDonnell Shire Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 36.

[72] See for example, Jill (NSW), *Submission 101.*

> sustain specialist services because of your low numbers. You do not have small country towns with specialist geriatricians. What you could have is a nurse in that hospital that has extended skills in aged care. You have to tailor the package of services to meet your community needs but you have a fair degree of flexibility.
>
> In my observation there is a strong sense of community and responsiveness, but the disadvantage is that if you have an acute condition and you need specialised care you have to travel long distances. The distance of travel is usually an hour or two in New South Wales but is usually four to six hours in Queensland, so it is the distances of travel and the convenience and affordability of air travel. You are dislocated from those specialist services.[73]

6.114 The National Rural Health Alliance advised the Committee that:

> Poor access to primary care generally in country areas, including shortages of medical specialists and allied health professionals of any kind, let alone those that specialise in dementia, mean there is less likelihood of early diagnosis and treatment for people in those areas. The smaller aged care services with fluctuating numbers, that struggle to be sustainable in rural and remote communities, are also less likely to have the capacity to provide specialised dementia care – although the more flexible care arrangements possible can contribute to more personalised care for local people with dementia.[74]

Committee comment

6.115 Dementia is not a condition that is exclusive to 'old age' or limited to people from a specific background. People with dementia vary in age, and come from diverse cultural backgrounds and have a range of life experiences. People with dementia may live in the city, or they may live in regional, rural and remote communities. They may have a large extended family, or they may live alone. Further, a person's care needs will likely change over time.

6.116 Navigating the maze of services to determine what services might be available following a diagnosis of dementia is one of the most significant challenges that people with dementia and their families face. However, it is not the only challenge. To be beneficial to people with dementia and

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[73] Mr Terry Mehan, Queensland Health, *Official Committee Hansard*, Brisbane, 1 August 2012, pp. 30-31. See also, National Rural Health Alliance (NRHA), *Submission 36*, p. 3.

[74] NRHA, *Submission 36*, p. 3. See also, Mrs Kylie Wood, *Official Committee Hansard*, Launceston, 27 July 2012, p. 6.

their families, the Committee understands that dementia care services must be accessible to those that need them and sufficiently flexible to meet the differing care needs of diverse population groups.

6.117 There are several factors that may affect a person's ability to access dementia care services. For example, the Committee heard there is a need to increase the accessibility of dementia care services, particularly in regional, rural and remote areas. Regional, rural and remote areas often face particular challenges accessing community care services. Services may simply not be available locally. Equally, restrictive eligibility criteria, and inconsistency or confusion around the application of eligibility criteria, can also limit access for some population groups. This is illustrated by the challenges accessing dementia care services facing people with YOD and intellectual disability.

6.118 The Committee also recognises that there is a need for greater flexibility within dementia care services. As noted earlier, people with dementia (and their families and carers) are not a homogenous group. The Committee agrees that services should be structured in such a way that they have the capacity to adapt to a person's individual needs, rather than requiring the person to adapt to the service they are accessing. For example, services may need to have the capacity to adapt to and account for differences in a person's age, cultural identity and life experiences.

6.119 The Committee understands that the issues raised in relation to accessibility and flexibility of community-based and residential care services for people with dementia reflect long-standing concerns with these systems. The Committee notes that these issues were examined and reported on in 2011 in an Australian Government commissioned report, *Dementia services pathways – an essential guide to dementia services planning.*[75]

6.120 The Committee also notes that as part of the *Living Longer. Living Better.* reforms, funding has been approved to support the following actions:

- Improved support for people with YOD ($23.6 million);
- Ensuring older people from diverse backgrounds can access aged care services that are specific to their needs ($24.4 million);
- Ensuring sexual diversity does not act as a barrier to receiving high quality aged care ($2.5 million);
- More assistance for older people who are homeless or at risk of homelessness ($7.3 million);

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[75] DoHA, *Dementia Services Pathways,* <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-dementia-services-pathways-2011-toc.htm> viewed 5 June 2013.

- Ensuring culturally appropriate quality aged care services are available for Aboriginal and Torres Strait Islander people ($43.1 million); and
- Ensuring the sustainability of aged care services in regional, rural and remote areas ($108 million).[76]

6.121 In implementing these initiatives, the Committee emphasises that frameworks should have sufficient flexibility to empower specific population groups and communities to structure services according to specific and local needs. The Committee encourages the Australian Government to consult regularly with stakeholders, including state and territory governments (where relevant), providers of services and users of services (people with dementia and their families). Furthermore the Committee believes that robust partnerships with local communities and stakeholder groups will be essential to effective implementation, if dementia care services are to be structured to ensure the needs of specific population groups and communities are met.

6.122 The Committee also notes that much of the evidence regarding the ability of dementia care services to meet the needs of people from diverse backgrounds relates to the need to better educate and train health professionals. This issue has been addressed separately in Chapter 3.

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[76] Australian Government, *Living Longer. Living Better.* April 2012.

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> *It is about educating the whole community to be aware and conscious that there are people living amongst them who have various forms of confusion. It is about the care sector, yes, but it is also about the schools, the banks, the shops, the pubs, the police and the emergency services, and helping everybody through education to understand that there are people in their communities who are living with this challenge.*[1]

A dementia friendly future

7.1 The focus of the report so far has been on what needs to be done to ensure that people with dementia receive a timely diagnosis, and improve access to the appropriate supports and services for people living with dementia, and their families and carers.

7.2 In this final chapter of the report the Committee considers what can be done to reduce the future impact of dementia and to create a future that is 'dementia friendly'. The ideal would be a future in which dementia could be prevented or cured. Although not currently a reality, advances in understanding of the risk factors and protective factors associated with dementia offer hope for the future.

7.3 The chapter considers the potential for healthy lifestyle choices, combined with continued mental activity and social engagement, to reduce the risk of developing dementia and to slow progression of the condition in people already affected. The chapter also reviews the potential dementia research to improve dementia diagnosis, treatment and management.

7.4 The chapter concludes by examining the concept of dementia friendly communities and considering how this might be applied to create a

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[1] Mr Andrew Larpent, Southern Cross Care (SA & NT), *Official Committee Hansard*, Adelaide, 4 March 2013, p. 9.

society that is more inclusive and supportive of people living with dementia, their families and carers.

Preventing dementia

7.5 Although over the years there has been progress in understanding the risk factors and protective factors associated with dementia, as yet there is no certainty that dementia can be prevented. While the relative importance of individual risk factors will vary for the different forms of dementia, the main risk factor for most forms is advancing age. Clearly advancing age is a factor that cannot be modified. However a great deal remains to be learnt about the precise triggers for the development of dementia, which will likely involve a complex interaction between genetic, lifestyle and environmental factors.

7.6 Although not yet conclusive, there is also a growing body of evidence which suggests that particular interventions may delay the onset of dementia or slow progression of the condition. Over the course of the inquiry the Committee received a significant volume of evidence which consistently identified the influence of following factors on dementia onset and progression:

- Lifestyle factors;
- Mental activity; and
- Social engagement.

7.7 The importance of each of these three factors was summarised by Mr Glenn Rees of Alzheimer's Australia when he told the Committee that:

> The critical elements of [dementia] prevention are physical activity, doing things that are good for your heart. … Also, mental activity, social activity, avoiding head injury, avoiding drugs and alcohol. Social activity is also very important. What we really say to people is that they have to look for activities that hopefully combine physical, mental and social activities if they want to reduce the risk of dementia.[2]

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[2] Mr Glenn Rees, Alzheimer's Australia, *Official Committee Hansard*, 1 August 2012, p. 8.

Lifestyle factors

7.8 A large number of submissions noted that dementia more often occurs in association with other diseases or conditions. These so called co-morbidities include a range of chronic health conditions usually associated with a sub-optimal lifestyle, such as cardio-vascular diseases, some cancers and Type 2 Diabetes.[3]

7.9 Lifestyle factors which reduce the risk of developing these chronic health conditions are well documented, and include:

- A healthy and balanced diet;
- Regular physical exercise;
- Cessation of smoking; and
- Responsible patterns of alcohol consumption.

7.10 While acknowledging that the evidence is not yet definitive, evidence to the inquiry indicates that there is a growing body of clinical and research evidence which suggests that that lifestyle factors have powerful influences on the development of dementia in many patients.[4] For example, the submission from the Commonwealth Scientific and Industrial Research Organisation (CSIRO) states:

> Evidence for lifestyle effects on risk factors for cardiovascular disease are well established from randomised controlled trials. For example significant and sometimes substantial blood [pressure] reductions have been shown with weight reduction, increased physical activity, alcohol moderation, vegetarian diets, non-vegetarian diets increasing fruit and vegetable consumption and decreasing saturated fat intake, increased dietary fish or protein or fibre or combinations of the above. The ability for exercise, weight control and various dietary changes to favourably influence serum

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[3] See for example: Professor Philip Morris, *Official Committee Hansard*, Brisbane, 1 August 2012, p. 13.

[4] See for example: Dr Leah Collins, Australian Psychological Society (APS), *Official Committee Hansard*, Melbourne, 14 June 2012, p. 19; Mr Mark Howland, Dementia (Community Health), Hunter New England Local Health District, *Official Committee Hansard*, Newcastle, 27 August, 2012, p. 21; Mr Joseph Cidoni, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 1; Professor Scott Whyte, Central Coast Local Health, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 16.

> lipids, insulin resistance and circulating inflammatory markers is also well established. Many of the behaviours influencing the risk of cardiovascular disease also affect the risk of other chronic disorders such as some common cancers, diabetes mellitus, chronic lung diseases and dementia.[5]

7.11 Similarly, Dr Leah Collins of the Australian Psychological Society (APS), observed:

> Recent prevention campaigns are very much likening preventing dementia to preventing heart disease. We have all come to terms with the idea of exercising the heart and we understand that we need to exercise, lower our saturated fat intake and stay active in our community. That is definitely the message we are getting now with dementia: heart health almost equals brain health.[6]

7.12 The Royal Australian College of General Physicians (RACGP) also pointed to the growing body of evidence relating to the potential influence of lifestyle factors, stating:

> While large randomised controlled trials are still being run, there is growing evidence that activities such as exercise and a healthy diet can delay the onset of dementia or slow down progression. Monitoring and management of cardiovascular risk factors (e.g. hypertension, obesity, high cholesterol) is also important and may slow down onset or prevent dementia.[7]

7.13 The National Stroke Foundation suggested that existing and proven methods of chronic disease prevention based on interventions to improve lifestyle choices could provide cost-effective opportunities for delaying the onset of dementia or slowing its progression:

> When it comes to prevention and improving quality of life and delaying onset of disease, addressing common risk factors across these major vascular disease groups can be highly cost-effective, with large population health benefits across the vascular disease groups. This approach is critical as the population ages and more

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[5] Commonwealth Scientific and Industrial Research Organisation (CSIRO), *Submission 34 (Attachment B)*, p. 17.

[6] Dr Leah Collins, Australian Psychological Society (APS), *Official Committee Hansard*, 14 June 2012, p. 19.

[7] The Royal Australian College of General Physicians (RACGP), *Submission 83*, p. 8.

> people are at risk of developing devastating and costly vascular diseases.[8]

7.14 Dr Lyndon Bauer of Health Promotion Central Coast, also suggested that a community wide approach could also provide best value for money, telling the Committee:

> … I think primary prevention is best served by community actions which address smoking cessation, overweight, obesity, diabetes et cetera and are delivered to the whole community. For bang for your buck, that is probably the best way to go. With the diagnosis of dementia, particularly if it is done earlier, there are secondary aspects whereby people can work hard at improving vascular risk et cetera and reduce the progression of the disease. From the health promotion side, for bang for your buck you must address the whole community, particularly around smoking, weight reduction, physical activity et cetera.[9]

7.15 The means of promoting prevention-focussed lifestyle advice varies greatly. RACGP suggested:

> GPs are well placed to take action in these areas and advise people about the activities that can prevent dementia.[10]

7.16 The submission from DoHA also notes that the Australian Government already takes a significant role in implementing preventive health initiatives and promoting healthy lifestyle messages to the Australian community.[11]

Mental activity and social engagement

7.17 Evidence to the inquiry indicated consensus among health professionals, researchers, carers and those living with dementia itself that mental activity and social engagement, so called psychosocial interventions, are often powerfully effective in maximising health and well-being generally, and in maintaining cognitive function.[12]

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[8] National Stroke Foundation, *Submission 88*, p. 2. See also: Life Activities Clubs Victoria Inc., *Submission 10*, p. 2.

[9] Dr Lyndon Bauer, Health Promotion Central Coast, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 30.

[10] RACGP, *Submission 83*, p. 8.

[11] Department of Health and Ageing (DoHA), *Submission 89*, p. 16.

[12] See for example: Centre for Ageing and Pastoral Studies, *Submission 26*; Coralie (Tas), *Submission 30*.

7.18 The positive effects of mental activity, broadly understood as mental activity or exercise for the brain, and social engagement was described by the CSIRO as follows:

> A growing body of research supports the protective effects of late-life intellectual stimulation on incident dementia. Recent research from both human and animal studies indicates that cognitive stimulation, physical activity and socialization in old age are an important predictor of enhancement and maintenance of cognitive functioning. An engaged lifestyle during adulthood has been shown to be correlated with a variety of benefits, including enhanced longevity, reduced risk of dementia, enhanced cognitive resilience in the face of brain pathology, and enhanced mental flexibility.[13]

7.19 Professor Scott Whyte, Director of Neurosciences at the Central Coast Local Health District, emphasised the importance of the social environment for cognitive function, noting:

> The people who have some of the most rapid progressions in their dementia are people who are isolated and living alone, and they are a very difficult group to get to, because we rely upon the carers and the family to start taking over the functions of the person with dementing illness. …We like to keep people at home, and with community services and things like that I think that is good. But at times, if they are isolated, that is not a good thing for people to do. We should be putting them into enriching environments. A lot of people improve once they get into hostels.[14]

7.20 Unfortunately, for some a diagnosis of dementia results in a deterioration of their social networks. As explained by Community Care Services-Central Coast Ltd:

> The benefits of developing and maintaining friendships & social connectedness (improved overall health & well-being etc.) are well documented, as have the consequences of social isolation (anxiety, depression, anger and poorer physical health). Unfortunately, equally well documented is how the impact of a diagnosis of dementia takes its toll on social relationships, with, friends and/or family members withdrawing and 'disappearing' because they can no longer bear to see the changes that are taking place in their

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[13] CSIRO, *Submission 34 (Attachment B)*, p. 24.

[14] Professor Scott Whyte, Central Coast Local Health District, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 17.

> diagnosed friend or relative and further adding to the person's feelings of depression, abandonment and otherness.[15]

7.21 Noting that married people have a reduced risk of developing dementia Professor Phillip Morris, a private practitioner working in the field of dementia, suggested that this could be a result of a complex interplay of social and economic factors:

> Socioeconomic background seems to be a protective factor to some degree. It may be that being in a relationship means that the person is engaged in conversation and social and other activities, and that is a protective factor. No-one has really worked that out. It is a bit of a curious finding, but it is a finding that has been shown in a number of studies. The reasons for it, I think, are less clear…Diet, and probably those people who are married are less likely to be drinking heavily, and this, that and the other thing, so it may have indirect effects.[16]

7.22 Also noting the potential interplay between psychosocial interventions, Alzheimer's Australia Tasmania observed that educational opportunities available to those living with dementia often assist with providing a much needed source of social contact as well, saying:

> When we hold educational courses for persons living with dementia and their carers, we find that one of the most positive things to occur is the bonding between people participating in the courses. Often, people have not met another person experiencing dementia, or had the opportunity to speak with another carer of a person with dementia. Although the learning from the courses is greatly appreciated and beneficial, this opportunity to meet with others experiencing dementia is life-changing in terms of the recognition for people that they are not alone in their suffering. We find that people bond very quickly with others in our groups, and that they find support in hearing each other's stories.[17]

7.23 Evidence to the inquiry included reference to a diverse range of programs and activities that enhance mental activity and social engagement.[18] While

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[15] Community Care Services-Central Coast Ltd, *Submission 104*, p. 2.

[16] Professor Philip Morris, *Official Committee Hansard*, Brisbane, 1 August 2012, p. 13.

[17] Alzheimer's Australia Tasmania, *Submission 37*, p. 5.

[18] See for example: Benetas, *Submission 25*, p. 7; National Rural Health Alliance Inc, *Submission 36*, p. 8; Blue Care, *Submission 51*, p. 10; Alzheimer's Australia, NSW, *Submission 92*, p. 2; NSW Department of Health, *Submission 95*, p. 10; Ms Kate Swaffer, *Official Committee Hansard*, Adelaide, 8 June 2012, p. 33; Mr Peter McCloskey and Mrs Marilyn Cassin, Community Care Services-Central Coast Ltd, *Official Committee Hansard*, Terrigal, 12 October 2012, pp. 27-29.

some activities target older Australians generally (e.g. Meals on Wheels, Men's Sheds etc.), others cater to the particular needs of people living with dementia and their carers.

7.24 In broad terms the types of activities referred to include:

- Opportunities for formal and informal education and learning;
- Physical and creative activities (e.g. group exercise programs, music, dance, drama, art, woodwork etc.); and
- Social activities (e.g. visits to galleries, dementia friendly cafés and restaurants etc.).

7.25 A number of submissions suggested that more could be done to improve mental activity and social engagement for people with dementia in residential aged care facilities.[19]

7.26 While initiatives to promote mental activity and social engagement were widely supported, evidence from Ms Anna Le Deux provided insight on a different perspective. Based on personal experience with her father who has dementia, Ms Le Deux cautioned that some people with dementia could find well intentioned actions to promote mental activity and social engagement stressful.[20]

Committee comment

7.27 The Committee appreciates that interventions which are likely to delay the onset of dementia or slow progression of the condition will have significant benefits. Such interventions have the potential to benefit individuals, allowing them to enjoy the best possible quality of life for as long as possible. Families and communities also stand to benefit through a lessening of the financial and social costs associated with caring for those affected by dementia.

7.28 Although interventions that are proven to prevent or cure dementia are not as yet a reality, medical thinking and practice is increasingly focussed on a preventive approach. Evidence linking dementia to a number of co-morbidities, including some chronic conditions strongly linked to lifestyle choices, suggests that a preventive approach could usefully be applied to dementia.

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[19] See for example: Benetas, *Submission 25*, pp. 7-8; Reliance Medical Practice and Reliance GP Super Clinic, *Submission 105*, p. 4.

[20] Ms Anna Le Deux, Alzheimer's Australia Vic, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 23.

7.29 The Committee believes that the consistent evidence linking healthy lifestyle choices to improved brain health offers ready opportunities for dementia prevention to take advantage of existing approached to disease prevention more generally. In this regard Australia is fortunate to have a well-established foundation of policies and programs devoted to preventive medicine.

7.30 The Australian Government already seeks to promote healthy lifestyle choices, principally through DoHA and the Australian National Preventive Health Agency (ANPHA).[21] There are a range of national initiatives and public health awareness campaigns which target diet and exercise (e.g. *Swap it, don't stop it*[22]), smoking cessation (e.g. *Quit now*[23]) and responsible consumption of alcohol (National Alcohol Strategy[24]).

7.31 The Committee also notes evidence linking mental activity and social engagement with delayed onset of dementia and slower disease progression. The Committee understands that environments which promote these activities can add a great deal to the quality of life of those living with dementia. Furthermore, these same activities may also help carers by facilitating social engagement in a supportive environment.

7.32 Australia already has a wide range of educational institutions, government and non-government service providers, and community-based support groups that offer opportunities for older people to engage in learning and social activities. Furthermore, the Committee is aware that in 2012 under the Chronic Disease Prevention and Service Improvement Fund, the Australian Government supported Alzheimer's Australia to establish *Your Brain Matters: A guide to healthy hearts and minds* initiative.[25]

7.33 Under the *Your Brain Matters* initiative Alzheimer's Australia has established a website which provides information on the links between maintaining good physical health and healthy brain function, as well as advice on activities that can be built into everyday life to improve brain health and reduce dementia risk. Information and advice on keeping the brain active through mental activity and social engagement is also

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[21] Australian National Preventive Health Agency (ANPHA), *Promoting a Healthy Australia*, <http://anpha.gov.au/internet/anpha/publishing.nsf/Content/home-1> viewed 31 May 2013.

[22] Australian Government, *Swap it don't stop it,* <http://swapit.gov.au/> viewed 31 May 2013.

[23] Australian Government, *Quit now*, <http://www.quitnow.gov.au/> viewed 31 May 2013.

[24] Australian Government Department of Health and Ageing, *National Alcohol Strategy*, <http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/nas-06-09> viewed 31 May 2013.

[25] Alzheimer's Australia, *Your Brain Matters*, <http://www.yourbrainmatters.org.au> viewed 21 May 2013.

available. The website provides access to a suite of resources including a series of help sheets (available in 21 languages); the 'BrainyApp'; and information on the Brain Health Program, which is based on promoting health and lifestyle decisions associated with healthy brain function and the reducing the risk of developing dementia. [26]

7.34 Together these initiatives constitute a formidable national resource. However, the Committee would like to see messages on brain health and the potential for healthy lifestyle choices to reduce the risk of dementia embedded in all national initiatives and campaigns which promote the health benefits of diet, exercise, smoking cessation and responsible consumption of alcohol.

7.35 While acknowledging the potential of existing healthy lifestyle awareness campaigns, including the brain health specific campaign, *Your Brain Matters*, the Committee considers that mental activity and social engagement should feature more prominently.

Recommendation 15

7.36 **The Australian Government should ensure that messages on brain health and dementia prevention are included in all relevant national initiatives and public health awareness campaigns which promote healthy lifestyle choices through diet, exercise, smoking cessation and responsible consumption of alcohol.**

Key messages to be included in any future campaigns with relevance to brain health should also promote the importance of mental activity and social engagement.

Dementia research

7.37 The importance of dementia research is uncontested. As noted earlier, there is as yet no way to prevent or to cure dementia. Research provides the way forward, and hope that in the future the goal of dementia prevention will be realised.

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[26] Alzheimer's Australia, *Your Brain Matters*, <http://www.yourbrainmatters.org.au> viewed 21 May 2013.

7.38 In relation to this the RACGP submitted:

> Investment in research must be a key plank of a comprehensive and effective long-term dementia strategy. Research will build knowledge about the causes of dementia and possible preventative measures. It will provide evidence about the efficacy and suitability of diagnostic and screening tools, pharmacological and non-pharmacological interventions, and dementia specific service design and delivery. It is through research that major improvements in the health and wellbeing of people with dementia and their carers can be realised.[27]

7.39 Dementia research in Australia, and internationally, is conducted in a range of different settings including educational and medical research institutions, health services and community settings. While much of the dementia research effort is supported by Government, some aspects, particularly research and development of pharmacological products, draws investment from the pharmaceutical industry.[28]

7.40 Dementia research covers a vast field of disparate areas, ranging from basic biomedical research to improve diagnosis and treatment, through to research into biological, social and behavioural risk and protective factors, and applied research to improve health services and management of the condition.[29]

7.41 Evidence to the inquiry included calls for Australia to increase its dementia research effort. In the words of The Australian Association of Gerontology:

> Increased funding for ageing research, including dementia research, is essential if Australia is to develop the evidence-base required for the development and implementation of effective and efficient dementia care services that allow people to remain independent for as long as possible, promote social engagement for people with dementia, and help people with dementia and their carers plan for the future.[30]

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[27] RACGP, *Submission 22*, p. 3.

[28] See for example: Cooperative Research Centre for Mental Health, *Submission 40*; Pfizer Australia, *Submission 49*; Eli Lilly Australia, *Submission 54*.

[29] See for example: CSIRO, *Submission 34*, pp. 3-4; National Ageing Research Institute (NARI), *Submission 59*, pp. 1-3; Mental Health Research Institute (MHRI), *Submission 94*, pp. 1-4; Professor Ralph Martins, Edith Cowan University and McCusker Alzheimer's Research Foundation, *Official Committee Hansard*, Perth, 12 November 2012, pp. 14-20;

[30] The Australian Association of Gerontology Inc. (AAG), *Submission 67*, p. 2.

7.42 Similarly, Alzheimer's Australia submitted that research into dementia is underfunded relative to research funding available for other chronic conditions. Alzheimer's Australia also observed that Australia's investment in dementia research does not compare well with international investments.[31] In a supplementary submission to the Committee, Alzheimer's Australia identified addition funding for dementia research as one of its key aspirations, calling for:

> Commitment of $200 million additional [dementia research] funding (over and above current NHMRC investment) over 5 years to 2018.[32]

7.43 According to the National Health and Medical Research Council (NHMRC), Australia's major source of funding for health and medical research[33], Australia's investment in dementia research is not insignificant. The general activities of the NHMRC were described by the CEO, Professor Warwick Anderson, as follows:

> Our general approach to supporting the discovery of the knowledge we need to help people with health problems and to make sure that they are delivered can be summarised in three ways. Firstly, research that is itself discovering new knowledge, and we really do need it in this area. Secondly, translating research—that is, trying to bridge that gap between what we know and what happens in the health system in prevention, policy and clinical practice. And, thirdly, building capacity to do research, so looking at the future and bringing along the next generation of researchers. All our funding is provided through a peer review process…We get the best people we can to judge what is the most valuable research and fund it on that basis.[34]

7.44 In a supplementary submission the NHMRC provided data on the allocation of funding for dementia research relative to funding for research on other chronic conditions (Table 3.1). The NHMRC also advised that of the research funds awarded each year, an average of three per cent was awarded to dementia research.[35]

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[31] Alzheimer's Australia (National Office), *Submission 44*, p. 27.

[32] Alzheimer's Australia (National Office), *Supplementary Submission 44.2*, p. 27.

[33] Government funding for research is also available from the Australian Research Council and also from the Australian Government Department of Health and Ageing, notably through the flexible funds initiatives.

[34] Professor Warwick Anderson, National Health and Medical Research Council (NHMRC), *Official Committee Hansard*, Canberra, 12 February 2013, p. 2.

[35] Department of Health and Ageing (DoHA), *Supplementary submission* (NHMRC) 89.1, p. 2.

Table 3.1 NHMRC funding of applications for awards, 2003-2013

	Total funds awarded between 2003-2013	**Percentage of total funds awarded between 2003-2013**
Cancer	$1,451,594,253	23.44%
Cardio-vascular disease	$902,347,534	14.57%
Diabetes Mellitus	$543,157,882	8.77%
Mental Health	$463,967,983	7.49%
Obesity	$258,027,923	4.17%
Arthritis and Musculoskeletal	$239,083,848	3.86%
Dementia	$190,510,431	3.08%
Asthma	$173,625,347	2.80%
HIV/AIDS	$119,380,570	1.93%

Source DoHA, *Supplementary submission* (NHMRC) 89.1, p. [2].

7.45 Professor Anderson explained that the allocation of research funding for dementia was to some extent influenced by the relatively small number of applications received, telling the Committee:

> One of the points that I really would emphasise and which is very much on our minds is that the number of applications we get in the area of dementia is surprisingly small. To give you an example, in 2012 in all the research areas except fellowships—projects, programs and so on—we had nearly 4,000 applications for all areas of health and medical research and only 82 of those were for dementia research. … So that is about two or three per cent of total applications. You are not going to get 20 per cent of the funding if there are only two per cent of applicants.[36]

7.46 In view of the limited number of applications for funding of dementia research, Professor Anderson suggested increasing dementia research capacity was a priority. Professor Anderson also highlighted the role of the three NHMRC funded Dementia Collaborative Research Centres (DCRC) in developing this research capacity.[37]

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[36] Professor Warwick Anderson, NHMRC, *Official Committee Hansard*, Canberra, 12 February 2013, p. 2.

[37] The Dementia Collaborative Research Centres (DCRC) undertake research, as well as translating the outcomes of that research into practice. Each Centre has a specific focus: Early Detection and Prevention; Assessment and Better Care Outcomes; and Carers and Consumers.

7.47 The need to develop research capacity in the area of ageing and dementia research was emphasised by the Australian Association of Gerontology, which observed:

> … this research capacity should be invested in both academic and service sectors and should facilitate effective collaborations, skill sharing and knowledge transfer. Such partnerships ensure a well-educated ageing research workforce that is capable of undertaking timely and relevant dementia research around the needs of an ageing population.[38]

7.48 While the intrinsic merit of the dementia research was not questioned in evidence, there was a range of perspectives on dementia research priorities. In her submission Dr Barbara Horner of the Centre for Ageing Research in Western Australia took a broad view of the need for research across all aspects of dementia, saying:

> Funding for research must be available for the whole spectrum of the disease: while prevention, diagnosis and intervention are important and a cure would be wonderful, there will continue to be hundreds of thousands of people 'living' with the disease, part of families and communities, being cared for by unpaid carers; need funding for evaluation and innovation.[39]

7.49 The scope of dementia research was raised in the submission from the RACGP, which submitted:

> Research must continue to go beyond formal clinical trials into causes, treatment and interventions to include monitoring, evaluation and economic analysis of dementia service models. Research can develop and identify models of care that can provide high quality, safe and effective care, and do so in a sustainable and cost-effective manner. Funding for esteemed and effective research and evaluation centres, such as the Dementia Collaborative Research Centres, should be maintained and expanded.[40]

7.50 The Australian Nurses Federation submitted:

> That the Australian Government fund research targeted to:
>
> - early identification of dementia,
> - commencement of appropriate evidence-based dementia care interventions from the findings,

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[38] AAG, *Submission 67*, pp. [3-4].

[39] Dr Barbara Horner, *Submission 109*, p 2.

[40] RACGP, *Submission 22*, p. 18.

- on-going refinement of models of dementia care which can be adapted to differing communities, and
- quality use of medicines in dementia care.[41]

7.51 Professor Dimity Pond, a general practitioner and Professor of General Practice at the University of Newcastle, told the Committee:

> From my perspective as a clinician and, to some extent, a health services researcher, I see that it is easier to get money in the basic sciences than it is to get money in the delivering of clinical services and looking at how services should fit together. How services should fit together does not score very highly at all on research grants. There also needs to be more money spent on primary healthcare research more generally.[42]

7.52 The Australian Association of Gerontology argued that research funding in Australia tends to place too much emphasis on academic publications and too little on practical outcomes and input into health policy:

> Presently, there is an overemphasis by the NHMRC and other funding bodies on publications being the primary outcome of research, rather than a focus on practical implementation of research … there is a need for translating ageing research into meaningful policy and practice outcomes. This requires funding to be built into the grant application process to allow researchers to engage with relevant stakeholders, including consumers, service providers, practitioners, researchers and policy makers, to identify key areas of research and models of best practice, as well as incorporating mechanisms for disseminating and translating research findings effectively to increase the uptake and application of knowledge by policy makers and health care professionals.[43]

7.53 Emphasising the importance of a multi-disciplinary approach to research, the submission from CSIRO refers to the Australian Imaging Biomarkers and Lifestyle Study of Ageing (AIBL), a collaborative longitudinal study to improve understanding of the causes and diagnosis of Alzheimer's disease. CSIRO commented:

> Where inroads have been made, success has come from multidisciplinary approaches to the identification of the key biological signatures for the early development of that disease. It is unlikely that any one discipline is able to achieve this, and that a

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[41] Australian Nursing Federation, *Submission 79*, p. 11.

[42] Professor Dimity Pond, *Official Committee Hansard,* Newcastle, 8 November 2012, p. 44.

[43] AAG, *Submission 67*, pp. 2-3.

> combination of integrated clinical sciences, biological sciences, physical sciences and mathematical sciences offers the way forward.[44]

7.54 CSIRO further highlighted the need for a coordinated and cohesive research approach to achieve translation of research outcomes:

> The fundamental emphasis must be upon a translational approach to the development of early detection and intervention. The integration of traditional health and medical research with a translational approach requires high level priority setting and coordination of a whole of systems and whole of government approach. In some cases, this may require a fundamental change to the way health and medical research is funded and managed. What must be avoided is fragmentation, subcritical approaches and lack of coordination in areas of research in dementia for early detection and intervention.[45]

Committee comment

7.55 The Committee acknowledges that support for dementia research dementia is vitally important to promote positive ageing, and reduce the future impact of dementia on individuals and the wider community. The importance of dementia research is acknowledged with the NHMRC identifying dementia as one of its own research priority areas[46], and with the Australian Government, which in 2012 designated dementia as the ninth National Health Priority Area (NHPA).[47]

7.56 Dementia research is part of a much wider biomedical research environment. While the Committee understands the premise for seeking additional funding for dementia specific research, the need to support research into a whole range of diseases and conditions presents challenges for funders in allocating limited resources across worthy but competing areas of interest.

7.57 However, it should be noted that those living with dementia stand to benefit not only from dementia specific research, but also from advances made by research into a range of other areas (e.g. cardiovascular disease, diabetes, mental health etc). Therefore, funding for research in one area of

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[44] CSIRO, *Submission 34*, pp. 2-3.

[45] CSIRO, *Submission 34*, pp. 2-3.

[46] NHMRC, *National Health Priority Areas*, <http://www.nhmrc.gov.au/grants/research-funding-statistics-and-data/national-health-priority-areas-nhpas> viewed 7 June 2013.

[47] Standing Committee on Health, Communiqué, 10 August 2012, p.1.

medicine may also provide benefits to the wider community, not least those with diverse co-morbidities as occurs often in the case of people living with dementia.

7.58 Developing dementia research capacity, by expanding the dementia research workforce and enhancing their knowledge, skills and experience, was identified as a priority. In addition to the scholarships and fellowships available through people support schemes, the NHMRC identified the importance of DCRCs in this regard.

7.59 During the course of the inquiry the Committee was consistently impressed by evidence presented which demonstrates Australia's role in supporting world class, innovative dementia research. A good example of this is provided by the AIBL study, which also benefited from a collaborative and multidisciplinary approach.

7.60 However, as with all endeavours there are challenges associated with research. Timeframes can be lengthy, and even then, positive outcomes are not guaranteed. For example, research into the underlying disease mechanisms or to develop pharmacological interventions may take many years or even decades. Although a long-term investment, the rewards can be significant. Equally, the benefits of applied research, such as research to develop clinical best-practice and evidence-based models of care, can be significant in improving the quality of life for people living with dementia, their families and carers.

7.61 The Committee notes concern expressed by some suggesting that the current allocation of research funding for dementia is too heavily skewed toward basic biomedical research, with insufficient priority given to applied clinical or health services research, particularly occurring outside of academic institutions (e.g. in primary healthcare settings). In addition, the Committee is of the view that research into psychosocial interventions could be encouraged.

Recommendation 16

7.62 **The Australian Government Department of Health and Ageing and/or the National Health and Medical Research Council initiate targeted research into the influence of psychosocial interventions on brain health and the implications for the risk of developing dementia.**

7.63 While appreciating the valuable contribution of dementia researchers generally, the Committee recognises the need for an appropriate balance of research areas, such that research into all aspects of dementia is adequately supported.

7.64 A coordinated research approach, which brings together multi-disciplinary teams, were identified as important factors to improve translation of research outcomes into evidence based best practice. The Committee also notes evidence regarding the need to develop a research approach that improves translation of research outcomes into practical improvements in dementia diagnosis, treatment, clinical care and management.

7.65 The Committee understands that supporting translation of research outcomes is an important function for the NHMRC. Over the last decade the NHMRC has supported a range of initiatives to promote research translation, including:

- Centres of Clinical Research Excellence;
- Partnerships for Better Health - Partnership Projects and Partnership Centres;
- Clinical Program Grants; and
- Translating Research Into Practice Fellowships.[48]

7.66 In relation to dementia, the Committee understands that supporting research translation is an important and integral aspect of the DCRCs. Furthermore, in August 2012 the NHMRC launched a major strategic initiative to support research translation, establishing the Research Translation Faculty (RTF). The RTF aims to provide a key advisory body to 'support more effective and accelerated translation of health and medical research into improved policy and practice in Australia'.[49] The RTF will do this by:

> … focus[sing] on the key activity of identifying the most significant gaps between research evidence and health policy and practice in NHMRC's Major Health Issues [including dementia], and developing a compelling case for NHMRC on how to address those gaps. Possible actions on how to address a gap might

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[48] NHMRC, *Research Translation Faculty Symposium: A vision for research translation at NHMRC*, <http://www.nhmrc.gov.au/media/newsletters/ceo/2012/research-translation-faculty-symposium-vision-research-translation-nhmrc> viewed 3 June 2013.

[49] NHMRC, *Research Translation Faculty*, <http://www.nhmrc.gov.au/research-translation/research-translation-faculty> viewed 3 June 2013.

> include advice to government about health policy, clinical or public health guidelines, or opportunities to collaborate with strategic partners.[50]

7.67 The RTF held its inaugural symposium in October 2012. The symposium provided a forum to identify key priority areas and articulate a plan for action. The Committee provides it full support for initiatives such as the DCRCs and the RTF.

Dementia friendly communities

7.68 Although aspiring to a future where dementia is preventable or curable, the current reality is that over the next few decades as the population ages more people will be affected by dementia, either directly or by association. In view of this, further consideration has to be given to creating communities that are not only more understanding and tolerant, but which in a social and physical environment are better adapted to accommodate the needs of people living with dementia.

7.69 In determining how to best engage the wider community in learning about dementia and supporting people with dementia to retain their independence and improve their quality of life, the Committee has considered the concept of ‘dementia friendly communities’.

7.70 A dementia friendly community is premised on ‘educating the whole community to be aware and conscious that there are people living amongst them who have various forms of confusion’.[51]

7.71 Alzheimer’s Australia defines a dementia friendly society as a ‘cohesive system of support that recognises the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way.’ Initiatives to support individuals to remain engaged in everyday life are categorised under ‘social environment’ and ‘physical environment’.[52]

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[50] NHMRC, *Research Translation Faculty*, <http://www.nhmrc.gov.au/research-translation/research-translation-faculty> viewed 3 June 2013.

[51] Mr Andrew Larpent, Southern Cross Care (SA & NT), *Official Committee Hansard*, Adelaide, 4 March 2013, p. 9.

[52] Alzheimer’s Australia, *Dementia friendly societies: the way forward*, Paper 31, May 2013, p. 6 <http://www.fightdementia.org.au/common/files/NAT/Paper_31_web.pdf> viewed 16 May 2013

7.72 A number of witnesses raised the possibility of creating dementia friendly cities or dementia friendly communities in Australia, following in the footsteps of regions such as the United Kingdom. The Committee was told that South Australia was attempting to emulate the idea that had been implemented in York in the United Kingdom.[53]

7.73 As explained by Mr Andrew Larpent, Chief Executive Officer, Southern Cross Care (SA & NT), the concept of dementia friendly communities extended to all facets of society, rather than being limited to the health or aged care sectors:

> It is about the care sector, yes, but it is also about the schools, the banks, the shops, the pubs, the police and the emergency services, and helping everybody through education to understand that there are people in their communities who are living with this challenge. For example, banks are encouraged to think beyond chip and PIN—if you have a PIN you cannot remember what are we going to do about that? The banks are being challenged with this, and we should do the same here in Australia to come up with something like that.[54]

7.74 Professor Henry Brodaty of the Minister's Dementia Advisory Group (MDAG) also outlined the concept explaining that community awareness was at the heart of dementia friendly communities:

> You make the whole community dementia friendly. You have signage, you have people aware of it. You have the bank tellers aware of it, you have people at the golf club willing to tolerate somebody who cannot keep count of their strokes, and it is not just somebody who is cheating! I have had patients who have been excluded because they could not manage how to play bowls or how to play golf and it ruined their lives. Community awareness is central to that.[55]

7.75 Ms Lisa Astete, of the Brotherhood of St Laurence, advised that the environment that people with dementia lived in was important to consider, whether in aged care facilities or within the wider community:

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[53] Mr Andrew Larpent, Southern Cross Care (SA & NT), *Official Committee Hansard*, Adelaide, 4 March 2013, p. 9. See also: Southern Cross Care (SA & NT), *Submission 122*, p. 2, and Joseph Rowntree Foundation, *Dementia without Walls*, <http://www.jrf.org.uk/work/workarea/dementia-without-walls> viewed 16 May 2013.

[54] Mr Andrew Larpent, Southern Cross Care (SA & NT), *Official Committee Hansard*, Adelaide, 4 March 2013, p. 9.

[55] Professor Henry Brodaty, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, pp. 15-16.

> I would like to highlight that the environment is extremely important for people with dementia and you need to have people in an appropriate environment that is going to be—we touched on this—dementia friendly. That is definitely something that needs to be considered when we are setting up facilities or services or even looking out into the community and seeing how we set up our communities so that people with dementia are able to continue to participate and be active members of the community, especially in the early stages ...[56]

7.76 The Brotherhood of St Laurence expanded on the idea in their submission to the Committee:

> When thinking about dementia, particularly early onset dementia, social inclusion is an important concept in relation to people maintaining their independence, status and rights to the many benefits of citizenship. As dementia has become more common, a social inclusion approach is required to ensure that people with dementia and their carers are not excluded from productive lives, including engaging in all aspects of social, civic, learning and work participation opportunities.[57]

7.77 Ms Kate Swaffer submitted that a dementia friendly environment was pivotal to social engagement, outlining international examples of where the concept has been implemented:

> … Alzheimer's UK has launched a program to promote Dementia friendly communities; villages, towns, cities and organisations working to challenge misunderstandings about dementia, seeking to improve the ability of people with dementia to remain independent for longer with choice and control over their own lives. Dementia friendly communities have the potential to transform the quality of life of hundreds of thousands of people, supporting their independence and reducing pressure on the medical and social systems. Endorsed by the World Health Organisation, Belgium has commenced with the Healthy Cities program, and was officially accredited in March 2011 as member of the Network of European National Healthy Cities Networks in Phase V. This has been successfully implemented in 25 cities in

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[56] Ms Lisa Astete, Brotherhood of St Laurence, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 4.

[57] Brotherhood of St Laurence, *Submission 53*, p. 5.

> Belgium, and the Belgium Alzheimer's Association is helping to draft the Dementia Friendly Charter.[58]

Committee comment

7.78 A dementia friendly community involves taking a holistic approach to dementia care, treatment and support. Extending beyond the health and aged care sectors, it involves all facets of society taking responsibility to support and encourage people living with dementia to maintain their independence and quality of life.

7.79 In dementia friendly communities, people living with dementia are able to access all of the services and participate in ordinary day-to-day activities without hindrance and with appropriate support and sensitivity. The Joseph Rowntree Foundation calls this concept 'Dementia without Walls', with an aim to:

- Challenge attitudes, understanding and behaviours;
- Inspire local communities to be more aware and understanding of dementia; and
- Support the collective behaviour of people with dementia.[59]

7.80 The Committee strongly supports the concept of dementia friendly communities, and sees this as an opportunity to increase awareness and understanding of dementia within Australia.

7.81 The Committee notes that Alzheimer's Australia has recently released a report titled *Dementia friendly societies: the way forward*. The report outlines a number of localised initiatives which are already underway to increase opportunities for people with dementia to remain socially engaged and independent. Alzheimer's Australia calls for the adoption of dementia friendly communities throughout Australia, such as has occurred in other areas of the world, such as in the UK.[60]

7.82 As noted by Mr Larpent, the British Prime Minister Mr David Cameron MP supported the creation of dementia friendly cities as part of his dementia challenge, calling for up to 20 cities and villages to sign up as

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[58] Ms Kate Swaffer, *Submission 77,* p. 13.

[59] Joseph Rowntree Foundation, 'Dementia without Walls' <http://www.jrf.org.uk/work/workarea/dementia-without-walls> viewed 16 May 2013.

[60] Alzheimer's Australia, *Dementia friendly societies: the way forward*, Paper 31, May 2013, p. 15 <http://www.fightdementia.org.au/common/files/NAT/Paper_31_web.pdf> viewed 16 May 2013.

dementia champions by 2015, and for local businesses to provide support for this concept.[61]

7.83 From the evidence provided to the Committee and the report produced from Alzheimer's Australia, the development of the concept of dementia friendly communities within Australia is still in its early developmental stages.

7.84 The Committee supports the steps proposed by Alzheimer's Australia to work towards having dementia friendly communities, by working with the Australian Local Government Association to consider and develop a strategic approach that could fit in each local and physical environment.[62]

7.85 The Committee is of the view that the development of a set of flexible values and standards for dementia friendly communities should be supported and directed from a Commonwealth level, in partnership with Alzheimer's Australia.

Recommendation 17

7.86 **The Australian Government collaborate with Alzheimer's Australia to develop a set of flexible values and standards which would inform the creation of dementia friendly communities around Australia.**

Ms Jill Hall MP
Chair

18 June 2013

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[61] Alzheimer's Australia, *Dementia friendly societies: the way forward*, Paper 31, May 2013, p. 4 <http://www.fightdementia.org.au/common/files/NAT/Paper_31_web.pdf> viewed 16 May 2013; Mr Andrew Larpent, Southern Cross Care (SA & NT), *Official Committee Hansard*, Adelaide, 4 March 2013, p. 7.

[62] Alzheimer's Australia, *Dementia friendly societies: the way forward*, Paper 31, May 2013, p. 15 <http://www.fightdementia.org.au/common/files/NAT/Paper_31_web.pdf> viewed 16 May 2013.

A

Appendix A – List of submissions

001	Greypath Pty Ltd
002	Mr Em Isle
003	Office of the Public Advocate (Vic)
004	Professor Philip Morris
005	Associate Professor John Ward
006	Professor Jillian Kril
007	Frontline Care Solutions
008	Ms Danijela Hlis
008.1	Ms Danijela Hlis *(Supplementary)*
009	Home Instead Senior Care
010	Life Activates Clubs Victoria Inc
011	Ms Dianne Stewart
012	Mr Leo White
013	Associate Professor Mark Yates
014	Primary Health North
015	Ms Jenie Aikman
016	Mr Tim Tierney
017	DutchCare Ltd
018	Ms Gloria Medo
019	Mr Bob Page
020	Ms Jenny Potter
021	MAC.ART
022	Royal Australasian College of Physicians & Royal Australian and New Zealand Society for Geriatric Medicine

022.1	Royal Australasian College of Physicians & Royal Australian and New Zealand Society for Geriatric Medicine *(Supplementary)*
023	Queensland Health
024	Multicultural Communities Council SA
025	benetas
026	Centre for Ageing and Pastoral Studies, Charles Sturt University
027	Townsville Health Service District
028	The College of Nursing
029	Life Care
030	Ms Coralie Verralls
031	Consumers Health Forum of Australia
032	National Cross Cultural Dementia Network
033	Baptistcare
034	CSIRO
035	Alzheimer's Australia Vic
036	National Rural Health Alliance Inc
037	Alzheimer's Australia Tasmania
038	Australian Women's Health Network and Community Vision
039	Cognitive Dementia & Memory Services Vic
040	CRC for Mental Health
041	Department of Health and Human Services Tasmanian Government
042	Confidential
043	National Disability Services
044	Alzheimer's Australia ACT
044.1	Alzheimer's Australia ACT *(Supplementary)*
045	The Royal Australian & New Zealand College of Psychiatrists
045.1	The Royal Australian & New Zealand College of Psychiatrists *(Supplementary)*
046	Dr Fiona Bardenhagen
047	Aged and Community Services Australia
048	Minister's Dementia Advisory Group
049	Pfizer Australia Pty Ltd
050	Australian Psychological Society
051	Blue Care

051.1	Blue Care *(Supplementary)*
052	Ms Kylie Wood and Ms Denise Chaston
053	Brotherhood of St Laurence
054	Eli Lilly Australia
055	ECH Inc, Resthaven Inc and Eldercare Inc
056	Law Council of Australia
057	The Pharmacy Guild of Australia
058	Baptcare
059	National Ageing Research Institute
060	La trobe University
061	Royal College of Nursing Australia
062	Ethnic Communities' Council of Victoria Inc
063	KinCare
064	Darebin Council
065	Assoc Prof George Razay
066	Dr Ross Colquhoun
067	The Australian Association of Gerontology Inc
068	Silver Chain Nursing Association Inc
069	Australian Institute of Health and Welfare
070	Associate Professsor Victoria Traynor, Ms Loren Devries and Ms Jenny Fares
071	Financial Services Council
072	Fronditha Care
073	Monash University
074	Speech Pathology Australia
075	Doutta Galla Community Health
076	Australian Guardianship and Administration Council
077	Ms Kate Swaffer
078	Royal District Nursing Service Limited
079	Australian Nursing Federation
080	Carers Australia
081	Mercy Health and Australian Catholic University / Mercy Health
082	COTA Australia
083	The Royal Australian College of General Practitioners

084	Aged Care Association Australia Ltd
085	The Council of Social Service of NSW
085.1	The Council of Social Service of NSW *(Supplementary)*
086	HammondCare
087	Australian General Practice Network
088	National Stroke Foundation
089	Australian Government Department of Health and Ageing
089.1	National Health and Medical Research Council *(Supplementary)*
090	Australian Government Department of Veterans' Affairs
091	Department for Communities and Social Inclusion
092	Alzheimer's Australia NSW
093	Dr Carmel Lum
094	James Cook University
095	NSW Government Department of Health
096	The University of Melbourne
097	Ms Margaret Pozzebon
098	Kym Torresi, Dr Bronwyn Moorehouse and Dr Amanda Scott
099	East Lake Macquarie Dementia Service Inc
100	Miss Cecilia Donohoe
101	Mrs Jill Malone
102	Woy Woy Community Aged Care
103	Central Coast Local Health District
104	Community Care Services - Central Coast Ltd
105	Reliance Medical Practice & Reliance GP Super Clinic
106	Dementia Care Services
107	Kimberley Aged and Community Services
108	Professor Balakrishnan (Kichu) Nair
109	Curtin University
110	Life Care
111	Mr Garry Leith, Mrs Raelene Schilling and Mrs Joy Whitehorn
112	Southern Cross Care (SA & NT)

B

Appendix B – List of exhibits

01 *Are younger people with Dementia and their Carers being informed and supported appropriately at the time of diagnosis?*

Provided and prepared by Alison Easton, The Ella Centre.

02 *A National Roll-out of the Cognitive Impairment Bedside Alert and Education Program to Australian Hospitals – Program roll-out justification and roll-out strategy.*

Provided and prepared by Associate Professor Mark Yates, Ballarat Health Services.

03 *Shifting the Care Paradigm – Introducing a Cognitive Impairment Bedside Alert and Education Program to Victorian Hospitals.*

Provided and prepared by Associate Professor Mark Yates, Ballarat Health Services.

04 *Government Funded Clinical Neuropsychological Services,* (February 2012).

Provided by The Australian Psychological Society.

05 *Meant to care about culturally relevant dementia care: empowering, informing, resourcing,* Policy Discussion paper, volume 1, number 2, (2011).

Provided by Ethnic Communities' Council of Victoria Inc.

06 Questionnaire: *Mind Check Inventory - Self Report.*

Provided by Dr Ross Colquhoun, Addiction Treatment and Psychology Services.

07 Information paper: *Psychological Assessment and Treatment of Dementia*

Provided by Dr Ross Colquhoun, Addiction Treatment and Psychology Services.

08 *Advance care planning: rights and responsibilities*, article from The Australian Health Consumer, number 2, 2005-2006.

Provided by Ms Denise Chaston, North West Area Health Service.

09 Document containing information on ways of understanding test scores – false positive.

Provided by Leo.

10 *Blood Pressure, Dementia and Alzheimer's Disease: The OPTIMA Longitudinal Study,* (31 July 2009).

Provided by Associate Professor George Razay.

10.1 *A community-based exercise program to improve functional ability in people with Alzheimer's disease: a randomized controlled trial,* (2011).

Provided by Associate Professor George Razay.

10.2 *A prospective study of ventriculo-peritoneal shunting for idiopathic normal pressure hydrocephalus,* (2009).

Provided by Associate Professor George Razay.

10.3 *Obesity, Abdominal Obesity and Alzheimer Disease,* (14 July 2006).

Provided by Associate Professor George Razay.

10.4 *The Metabolic Syndrome and Alzheimer Disease,* (2007).

Provided by Associate Professor George Razay.

10.5 Diagrams: Brain MRI – patient with normal pressure hydrocephalus; and Brain CT scan – showing a shunt in brain.

Provided by Associate Professor George Razay.

11 Draft Area Submitting Proposal for Central Coast Area Health Service to recruit a 12 month temporary dementia intake project officer.

Provided by Associate Professor Scott Whyte, Central Coast Local Health District.

12 Background Information about Sue Mann Nursing and Community Service and client statistics.

Provided by Sue Mann Nursing and Community Service.

13 Form: *Medical Orders Life Sustaining Treatment – Medical Summary*; and Questionnaire: *"Planning What I Want" Advance Care Directive*.

Provided by Dr Lyndon Bauer, Health Promotion Central Coast.

14 Booklets: *In our words, Younger Onset Dementia* (A collection of very personal stories); and *Quality Dementia Care: Understanding Younger Onset Dementia*.

Provided by Alzheimer's Australia (Vic)

14.1 Paper prepared by Professor Henry Brodaty AO: *Six Reasons Why Diagnosis of Dementia Does Not Occur and Ten Reasons Why It Is Important*.

Provided by Alzheimer's Australia (Vic)

14.2 Alzheimer's Disease International, *World Alzheimer Report 20121, The benefits of early diagnosis and intervention*, Executive Summary, (September 2011).

Provided by Alzheimer's Australia (Vic)

15 Submission to the Production Commission, Draft Report of Caring for Older Australians

Provided by Australian Psychological Society Ltd

16 DVD: *Take control – a film about powers of attorney and guardianship*; and Booklet: *Take control – a kit for making powers of attorney and guardianship*

Provided by Officer of the Public Advocate Victoria

17 Information Kit for Carers; and *Information and Project Plan 2011-2015*, Central Coast Primary Dementia Care Network.

Provided by Ms Sharyn Bannister, Dementia Care Services.

18 MAC Summary Response to the Productivity Commission Inquiry – *Caring for Older Australians: CaLD Perspectives.*

Provided by Ms Debbie Boock, Multicultural Aged Care.

19 *Norman News*, volume 4, issue 3, (June 2012).

Provided by Mr Tim Horsnell, Life Care Inc.

20 Information on Resthaven's development initiatives to support people with dementia living independently in the community.

Provided by Ms Sue McKechnie, Resthaven Inc.

21 Background paper: *Dementia – Chronic Disease Management Approach.*

Provided and prepared by Professor Philip Morris.

22 Australian Institute for Primary Care, *Review of the Cognitive, Dementia and Memory Service Clinics, Final Report*, (January 2003); and Cognitive Dementia and Memory Service Practice Guidelines, (May 2006)

Provided by Cognitive Dementia and Memory Service

23 McLean Care – Community Client Assessment.

Provided by Jill

24 Survey: Evaluation of service provided to GPs and patients undertaken by the Memory Screening Assessment Service.

Provided by Dementia Care Services

25 DVD: *The Long Goodbye.*

Provided by Mrs Myrlene Hauser.

26 *Targeting Brain, Body and Heart for Cognitive Health and Dementia Prevention*, paper 29, (September 2012).

Provided by Mrs Sally O'Loughlin, The Hunter Dementia Memory Resource Centre, Alzheimer's Australia NSW.

27 Draft Clinical Pathway for Diagnosis, Management and Referral – Early Stage Dementia, (October 2012).

Provided by Ms Helga Merl, Hunter Medicare Local.

27.1 Medical Local Hunter, *Nurse Practitioner Scope of Practice.*

Provided by Ms Helga Merl, Hunter Medicare Local.

28 DVD: *Strong Old People – Strong Communities*, Kimberley Aged and Community Services, WA Department of Health.

Provided by Kimberley Aged and Community Services.

29 Dementia Service Coordination in Aboriginal Communities in Central Australia, (September 2012); and Abridged Guidelines for Dementia Assessment and Care of Aboriginal people living in remote communities, (September 2012).

Provided by Ms Marianne Cummins.

29.1 Diagrams: Action plan following a KICA assessment in the Northern Territory; Pathways to diagnosis for people with Dementia living in Aboriginal communities; and Care plan for older people living in Aboriginal communities.

Provided by Ms Marianne Cummins.

C

Appendix C – List of public hearings

Friday, 8 June 2012 - Adelaide

Individuals

Jenny

Mrs Carol Bielak

Ms Kate Swaffer

Churches of Christ Life Care Inc.

Mr Tim Horsnell, General Manager, Community Care

ECH Inc.

Ms Katherine Elding, Program Consultant, Restorative Program

Mr David Kemp, Cheif Executive's Adviser

Mr Andrew Stoll, General Manger, Community Services

Multicultural Aged Care Inc.

Ms Debbie Boock, Training Officer

Resthaven Inc.

Ms Sue McKechnie, Executive Manager, Community Services

Thursday, 14 June 2012 - Melbourne

Individuals

Dr Jennifer Torr

Alzheimer's Australia Victoria

Ms Dianne Biermann, Policy Officer, Strategic Initiatives

Ms Anna Le Deux, Volunteer, Consumer Advisory Committee

Mr Jack Sach, General Manager, Strategic Initiatives

Australian Psychological Society

Dr Leah Collins, Policy Officer, Professional Practice

Mr Bo Li, Senior Policy Advisor, Professional Practice

Mr David Stokes, Executive Manager, Professional Practice

Baptcare

Mrs Judith Basile, Program Manager, Northern Metropolitan Community Packages

Mrs Rhonda Craig, Program Manager, Northern Metropolitan Community Packages

Benetas

Mrs Barbara Donaldson, Dementia Consultant

Mr Alan Gruner, Manager, Research and Development

Brotherhood of St Laurence

Ms Lisa Astete, Senior Manager, Day and Respite Programs

Ms Lisa Rollinson, Senior Manager, Community Aged Care

Office of the Public Advocate, Victoria

Dr John Chesterman, Manager, Policy and Education

Ms Colleen Pearce, Public Advocate

Dr Claire Spivakovsky, Policy and Research Officer

Friday, 22 June 2012 - Sydney

Alzheimer's Australia NSW

Mr Brendan Moore, General Manager, Policy, Research and Information

Australian and New Zealand Society for Geriatric Medicine

Dr Robert Prowse, President

Council of Social Service of NSW

Ms Rashmi Kumar, Senior Policy Officer

Eli Lilly Australia Pty Ltd

Dr Katarina Kelin, Medical Fellow

Mr Chris Miskel, General Manager, Australia and New Zealand

Financial Services Council

Ms Eve Brown, Senior Policy Manager, Trustees

Mr Ross Ellis, Trustee Services Consultant

Illawarra Forum Inc.

Ms Simone Dallow, HACC Development Officer

Perpetual Private

Mr Peter Whitehead, Senior Manager, Fiduciary and Legal

Royal Australasian College of Physicians

Dr Leslie Bolitho AM, President

Dr Catherine Yelland, Fellow

UnitingCare Ageing, NSW and ACT

Ms Pauline Armour, Community Care Development Manager

Friday, 27 July 2012 - Tasmania

Individuals

Coralie

Danijela

Leo

Dr Fiona Bardenhagen

Mrs Denise Chaston

Mrs Kylie Wood

Alzheimer's Australia Tasmania

Adjunct Associate Professor Sally Garratt, Board Member

Dr Tamara Jones, Counsellor

Launceston General Hospital

Associate Professor George Razay, General Physician and Geriatrician

Tasmanian Health Organisation North

Ms Fiona Young, Clinical Nurse Consultant, Community Dementia Service

Wednesday, 1 August 2012 - Brisbane

Individuals

Professor Philip Morris

Blue Care

Mrs Denise Edwards, Memory Support Advisor

Mrs Glenys Webby, Director, Strategy and Service Planning

Frontline Care Solutions

Dr Drew Dwyer, Principal Consultant, Gerontology

Home Instead Senior Care

Mr Martin Warner, Director

Mrs Sarah Warner, General Manager

Queensland Health

Mr Graham Kraak, Director, Older People's Health and Extended Care Unit, System, Policy and Performance Division

Mr Terry Mehan, Deputy Director-General, System, Policy and Performance Division

Tuesday, 21 August 2012 - Canberra

Grampians Region Cognitive, Dementia and Memory Service

Associate Professor Mark Yates, Consultant Physician in Geriatric Medicine, Ballarat Health Services

State-wide Dementia and Memory Service Coordinator Group, Victoria

Mrs Elizabeth Rand, Chairperson, and Manager, Cognitive, Dementia and Memory Service, Caulfield Hospital, Alfred Health Service

Monday, 27 August 2012 - Moree

Individuals

Cecilia

Jill

Fairview Retirement Village

Mr Brett Arthur, Chief Executive Officer

Mrs Bernadette Meppem, Director of Care

Hunter New England Local Health District (Tablelands, Mehi and McIntyre Clusters)

Mr Mark Howland, Clinical Nurse Consultant, Dementia (Community Health)

Tuesday, 11 September 2012 - Canberra

Individuals

Mrs Helen Little

Dr Jane Thompson

Alzheimer's Australia Inc.

Dr Christopher Hatherly, National Research Manager

Mr Glenn Rees, Chief Executive Officer

Tuesday, 18 September 2012 - Canberra

CSIRO

Professor Lynne Cobiac, Director, Preventative Health Flagship

Dr Lance Macaulay, Theme Leader, NeuroHealth

Friday, 12 October 2012 - Terrigal

Individuals

Dr Rodney Beckwith

Mr Joseph Cidoni

Central Coast Local Health District

Dr John Dobrohotoff, Clinical Director, Specialist Mental Health Services for Older People

Dr Sunil Gupta, Clinical Director, Rehabilitation and Aged Care, and Staff Specialist Geriatrician

Associate Professor Scott Whyte, Director of Neurosciences

Central Coast Local Health District, NSW Health

Mrs Sharyn Bannister, Nurse Unit Manager, Dementia Care Services

Mr Mark Kane, Clinical Nurse Consultant, Dementia Care Services

Community Care Services, Central Coast Ltd

Mrs Marilyn Cassin, Manager, Programs

Mr Peter McCloskey, Chief Executive Officer

Health Promotion Central Coast

Dr Lyndon Bauer, Administrator

Sue Mann Nursing and Community Care

Mrs Lorraine Williams, Regional Manager

Woy Woy Community Aged Care

Mrs Jennifer Eddy, Chief Executive Officer

Ms Kathy Murphy, Assistant Care Manager Hostel

Thursday, 8 November 2012 - Newcastle

Individuals

Ms Jennifer Campbell

Ms Myrle Hauser

Professor Balakrishnan (Kichu) Nair

Professor Constance Pond

Alzheimers Australia, NSW Hunter Dementia Memory Resource Centre

Mrs Sally O'Loughlin, Regional Manager

East Lake Macquarie Dementia Service Inc.

Ms Glynis Butler, Manager

Mr Richard Delbridge, Treasurer

Mrs Jennifer Webb, Chairperson

Hunter Medicare Local

Ms Helga Merl, Transitional Nurse Practitioner Dementia, Mobile Memory Clinic

Hunter New England Local Health District

Acting Professor Dr John Ward, Clinical Director, Greater Newcastle Cluster

Royal Australian and New Zealand College of Psychiatrists

Dr Roderick McKay, Chair, Faculty of Psychiatry of Old Age

Monday, 12 November 2012 - Perth

Community Vision

Ms Wilma Dougherty, Manager, Aged Care Services

Ms Jean Garratt-Reed, Executive Manager, Community Services

Ms Jenni Werner, Chief Executive Officer

Curtin University

Professor Barbara Horner, Director, Centre for Research on Ageing

McCusker Alzheimer's Research Foundation

Dr Judy Edwards, Manager, Special Projects

Prof Ralph Martins, Director of Research

Melbourne Health, Royal Park Campus

Associate Professor Dina LoGiudice, Geriatrician

WA Centre for Health and Ageing, University of Western Australia

Winthrop Professor Leon Flicker, Professor of Geriatric Medicine

Dr Kate Smith, Research Assistant Professor

Tuesday, 13 November 2012 - Broome

Individuals

Ms Madeleine Jadai

Ms Sue Urquhart

Kimberley Aboriginal Medical Services Council Inc.

Professor David Atkinson, Medical Director

Dr Stephanie Trust, Deputy Medical Director

Kimberley Aged and Community Services

Ms Penelope Houghton, Aged Care Assessment Team Coordinator

Ms Julie Johnston, Manager

Ms Cheryl Vacchini, Team Leader, West Kimberley

Mrs Stephanie Waters, Older Patient Coordinator

United Church Frontier Services

Mrs Sharon Davis, Regional Manager NT

Mrs Judy Ratajec, Manager, Professional Development

Wednesday, 30 January 2013 - Alice Springs

Individuals

Dr Lynne Barnes

Alice Springs Hospital

Dr Stephen Brady, Head, Department of Medicine

Alzheimer's Australia NT Inc.

Mrs Judy Buckley, Board Member

Mrs Nicole O'Connor, Family Support Coordinator

Australian Association of Gerontology

Ms Marianne Cummins, Member and Treasurer, NT Division

Central Desert Shire Council

Ms Wilma Gibson, Manager, Aged and Disability Services

Frontier Services, Commonwealth Respite and Carelink Centre

Ms Lowell Wood, Carelink Officer, Frontier Services

Frontier Services

Miss Rose Lovell, Quality Coordinator

Frontier Services Community Care Central

Ms Bronwyne Arnold, Coordinator

Frontier Services, Hetti Perkins Home for the Aged

Mrs Jacqueline Garrard, Acting Director of Care

Mrs Flora Mpofu, Clinical Nurse Manager

MacDonnell Shire Council

Ms Nina Bullock, Manager, Aged Care

Northern Territory Government Department of Health

Mrs Janice Diamond, Manager, Aged Care Unit, Darwin and NT Clinical Leader, ACAT

Dr Michael Lowe, Community Geriatrician

Tangentyere Council

Ms Cate Young, Coordinator, Tangentyere Aged and Community Services

Ms Sarah Miller

Uniting Church of Australia Frontier Services, Old Timers

Mrs Mary Miles, Director of Nursing

Uniting Church of Australia Frontier Services, ROST Central

Ms Jane Paige, Team Leader

Miss Emma Rossi, Coordinator

Friday, 8 February 2013 - Canberra

Australian Government Department of Health and Ageing

Mr Mark Booth, First Assistant Secretary, Primary and Ambulatory Care Division

Ms Fifine Cahill, Acting First Assistant Secretary, Medical Benefits Division

Mr Russell de Burgh, Assistant Secretary, Ageing and Workforce Program Branch, Ageing and Aged Care Division

Dr Susan Hunt, Senior Nurse Adviser, Office of Aged Care Quality and Compliance

Ms Rosemary Huxtable, Deputy Secretary

Ms Carolyn Smith, First Assistant Secretary, Ageing and Aged Care Division

Dr Bernie Towler, Principal Medical Adviser

Minister's Dementia Advisory Group

Professor Henry Brodaty, Member

Dr Christopher Hatherly, National Research Manager, Alzheimer's Australia

Dr Susan Koch, Meeting Chair

Ms Sue Pieters-Hawke, Co-Chair

Professor Dimity Pond, Member

Dr Ronald Sinclair, Member

Mrs Wendy Venn, Member

Associate Professor Mark Yates, Member

Office of the Coordinator General for Remote Indigenous Services

Mr Brian Gleeson, Coordinator General for Remote Indigenous Services

Tuesday, 12 February 2013 - Canberra

National Health and Medical Research Council

Professor Warwick Anderson, Chief Executive Officer

Ms Virginia Hart, Executive Director, Research Programs Branch, Research Group

Monday, 4 March 2013 - Adelaide

Individuals

Mrs Raelene Schilling

Mrs Joy Whitehorn

Alzheimer's Australia South Australia

Ms Marie Alford, General Manager

Ms Kathryn Cunningham, Chief Executive Officer

Mr Fred Tanner, Consumer

Department of Rehabilitation and Aged Care Repatriation, General Hospital

Dr Owen Davies, Consultant Geriatrician

Life Care

Mrs Deborah Muldoon, Manager Service Development

Mrs Jacinta Robertson, Manager Respite Service

Mr Peter Salotti, Family carer and volunteer, Norman House

SA Health Statewide Older People Clinical Network

Ms Louise Heuzenroeder, Network Development Manager

Professor Craig Whitehead, Chair

Southern Cross Care (SA & NT) Inc.

Mr Andrew Larpent, Chief Executive Officer