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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, p. 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.**