7

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

---

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]

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

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

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]

---

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

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

---

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.

---

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

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.

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]

---

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]

---

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]

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,

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

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

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

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]

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:

---

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

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

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

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.