

*What do I need to do? How am I going to understand what Deb's condition is about? What does it mean? What does it mean for both of us? What support do we need? What intervention do we need? Where can I get it? How much does it cost?*<sup>1</sup>

## Post-diagnosis

- 6.1 As discussed in Chapter 4, early or timely diagnosis is the key to improving the quality of life, independence and social engagement of a person with dementia, and supporting those who care for them.
- 6.2 However, the Committee was told that without timely intervention, there is no benefit to early diagnosis of dementia.<sup>2</sup> Diagnosis must be seen as a first step that connects people to support and services which help them to live with their condition.<sup>3</sup> As HammondCare submitted:

It is crucial that any strategy or policy to promote early diagnosis of dementia be matched by an equal effort to provide timely and appropriate assistance and guidance.<sup>4</sup>

- 6.3 Bapcare considered that a person's quality of life and independence could be improved greatly if dementia treatment and support was provided in a timely, person-centred way, involving a collaboration between health care providers:

Quality of life and independence can be considerably enhanced if an early diagnosis is achieved and treatment commenced in a timely manner. However this needs to be undertaken in a person-

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1 Mr Fred Tanner, *Alzheimer's Australia South Australia, Official Committee Hansard*, Adelaide, 4 March 2013, p. 20.

2 See Professor Jillian Krill, *Submission 6*, p. 1; Tasmanian Government Department of Health and Human Services, *Submission 41*, p. 7.

3 HammondCare, *Submission 86*, p. 2.

4 HammondCare, *Submission 86*, p. 2. See also, Dr Paul Goldstraw, *Submission 94*.

centred holistic context. The current approach to dementia care is still quite fragmented with diagnosis, treatment and service provision often undertaken separately and without any collaboration between health care providers.<sup>5</sup>

- 6.4 The Committee heard that once a diagnosis of dementia was made, the pathway to accessing appropriate treatment and support could be complex, confusing and frustrating. A diagnosis was often met with shock and confusion about what the future held for a person with dementia and their family. Mr Fred Tanner, a carer, outlined some of the questions raised by a diagnosis:

... How am I going to understand what Deb's condition is about? What does it mean? What does it mean for both of us? What support do we need? What intervention do we need? Where can I get it? How much does it cost? Can I continue to work? Do I go and become a full-time carer, as a number of my very close friends have done in similar positions? How long will I do this for? I did not know. I was not even 50 at the time. So all those sorts of things were there, and then there was the question of cost. I do not just mean financial costs; I mean emotional costs, social costs – all those sorts of things. And also, more importantly, from my perspective, there was more about my wife. How was she coping with all this? How was Deb coping? She is a pretty strong woman, but this, I think, created lots of dilemma.<sup>6</sup>

- 6.5 A person's post-diagnosis experience will undoubtedly shape their quality of life, level of independence, and ability to remain engaged with their community.
- 6.6 This chapter discusses the post-diagnosis pathway for people with dementia and their carers, with a focus on how early intervention of dementia may assist to:
- Improve a person's quality of life and help them remain independent for as long as possible; and
  - Increase their opportunities for continued social engagement and community participation.

### Committee comment

- 6.7 From the evidence before the Committee, it is evident that the pathway from diagnosis to treatment of dementia varies according to a person's

5 Baptcare, *Submission 58*, p. 3.

6 Mr Fred Tanner, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 20.

- individual needs and the resources and services available to them (and their carers).
- 6.8 This chapter illustrates some of the experiences and common issues associated with life following a diagnosis of dementia, as shared during the course of the inquiry.
- 6.9 The Committee has not attempted to cover the field of issues associated with pathways of care for people with dementia and their carers. The Committee acknowledges that each person's experience of the aged/disability care system and the pathway from diagnosis to treatment and support is different.
- 6.10 The focus of the inquiry is how early diagnosis and intervention can improve the quality of life of a person with dementia and their family. Discussion in this chapter is therefore limited to the predominant issues experienced at the early stages of treatment for dementia, in cities and in regional, rural and remote areas. The nature of residential care or palliative care is not discussed in any detail, as this is outside of the terms of reference.

## Referral pathways

- 6.11 The pathway from diagnosis to appropriate care and support must be timely and user-friendly for early or timely diagnosis to be beneficial. As a person's care and support needs change, additional or alternate services must be available and accessible, to meet that person's changing needs.
- 6.12 The Committee was told that people had difficulty navigating and accessing the referral pathway, due to a lack of coordination between services, and a lack of assistance and information about available services and support.

## Navigating the pathway

- 6.13 Both consumers and service-providers told the Committee that the pathway from diagnosis to care and support was complex and varied nationally, which made it difficult to identify consistent referral pathways.<sup>7</sup>
- 6.14 Benetas submitted that information about available dementia services was often provided at the time of diagnosis, making the information difficult

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7 Cognitive Dementia Memory Services (CDAMS), *Submission 39*, p. 3. See also, Silver Chain Nursing Association Inc., *Submission 68*, p. 5.

to process. They suggested that best practice would be to schedule a follow up meeting after diagnosis:

Too often information about dementia is given at the same time of the diagnosis, but we have found that people often cannot take in this information as they are still shocked by the diagnosis. As a result health professionals need to ensure another consultation is arranged where they can sit with the person with dementia and family and provide the necessary information about dementia. An excellent model for this approach is that of the Cognitive and Dementia Memory Services (CDAMS) where a follow up meeting is arranged approximately four weeks after the initial diagnosis to discuss future planning.<sup>8</sup>

- 6.15 CDAMS noted that people who have been diagnosed at an earlier stage are sometimes not ready for, or in need of services at the point of diagnosis. Rather, they need to be linked in with services at an appropriate time in the future:

...with earlier diagnosis clients and families are often not ready for or in need of services at the point of diagnosis apart from some initial education and information. This group is perhaps more at risk than those that are diagnosed further along the dementia pathway and linked to the service system at the point of diagnosis. They often tend to manage alone initially and, apart from some possible contact with their GP, are not connected to the service system. Information, provided at the time of diagnosis, about available supports and contacts, can be lost during this time and they often remain outside the service system until a crisis occurs.<sup>9</sup>

- 6.16 Alzheimer's Australia (Victoria) advised of the difficulties a consumer had in processing information once a diagnosis was made:

(Robyn, cares for her mother with Alzheimer's Disease):  
Once diagnosed she was dismissed. I was given an A4 envelope of about 100 brochures and we were shown the door. It did turn out that some of those brochures were important - like the one introducing us to AAV (Alzheimer's Australia (Victoria)), but it looked like a pile of junk mail so I 'filed' it. It also took me about 2 more years to find out there were services that specialized in dementia care and also about HACC (Home and Community Care), CACPs (Community Aged Care Package) etc.<sup>10</sup>

8 Benetas, *Submission 25*, p. 6.

9 CDAMS, *Submission 39*, p.9.

10 Alzheimer's Australia (VIC), *Submission 35*, p. 5.

- 6.17 Mrs Helen Little, a carer, agreed that she did not know what to do or where to turn, once a diagnosis was given to her husband:

Having had the diagnosis I was in the same situation. When you are given the diagnosis, what do you do? Where do you go? What services are available to you? There is really nothing that is on a bit of paper that says, 'Well, you could have this, this and this.'

Largely I found that the things I came to know were just from word of mouth or somebody saying to me, 'Have you thought of ringing these people, contacting this agency?' I contacted Alzheimer's. I found Carers ACT were extremely helpful.

As I speak to you, I am still not completely sure what is out there. I guess, in a sense, I feel it would be useful for people in my situation to have something that was more straightforward put to them as to the number of services that are available.<sup>11</sup>

- 6.18 Another carer, Mrs Joy Whitehorn, told the Committee that it took six years to obtain an ACAT<sup>12</sup> assessment for her husband, which was needed to access certain services. She said the paperwork required to access services was onerous and daunting:

In the end there were tears on my behalf and begging. I badly needed assistance with night-time care. I am eligible for six weeks, but I could not get that without an ACAT; I could not get the ACAT. So you are in no-man's land. I eventually got the ACAT. When the paperwork came out, according to them I had been waiting for 12 months, so something was not quite right there. Looking at residential care, we badly need paperwork to be standardised. It is a jungle. Every facility appears to have different needs in paperwork; there are different forms. This is so time-consuming. A carer is so time poor and, in a lot of cases, sleep deprived. To be told that we need to put our names down in probably 10 different places to try and get into residential care is so daunting, especially with the paperwork.<sup>13</sup>

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11 Mrs Helen Little, *Official Committee Hansard*, Canberra, 11 September 2012, p. 3.

12 The Aged Care Assessment Team (ACAT) is outlined in Chapter 2.

13 Mrs Joy Whitehorn, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 4. See also, Mr Garry Leith, Mrs Raelene Schilling and Mrs Joy Whitehorn, *Submission 111*; Mrs Raelene Schilling, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 4; and Mr Fred Tanner, *Alzheimer's Australia South Australia*, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 20; and Home Instead Senior Care, *Submission 9*, p. 2.

## Committee comment

- 6.19 The Committee acknowledges that when people first receive a diagnosis of dementia, it is a difficult time, both for them, and their family or close friends.
- 6.20 A diagnosis may come as a shock, which may make it difficult for a person to digest information about what services they can access for care and support.
- 6.21 For others, who are diagnosed in the early stages of dementia, the need for services may not be immediate. There is a risk these people will not be followed up at an appropriate time, when they are in need of support.
- 6.22 The Committee heard that once a diagnosis is given, information is often provided to a person in a passive way, by a General Practitioner (GP) or other service handing a person (or their carer) a number of brochures or fact sheets informing a person where they might receive further treatment and support.
- 6.23 The Committee notes that as part of the *Living Longer. Living Better.* aged care reforms, \$198.2 million is to be allocated to build a gateway to aged care services. This includes the launch of a 'My Aged Care' website ([www.agedcare.gov.au](http://www.agedcare.gov.au)) and national call centre to give people one main entry point into the aged care system and access to all of the information they need.
- 6.24 These proposed reforms will likely assist in providing a clearer access point for dementia care services.
- 6.25 To avoid people falling through the cracks of accessing services, the Committee is of the view that there should be system in place whereby people are followed up, from the point of diagnosis and throughout progression of the condition.
- 6.26 The Committee heard evidence from a number of individuals with dementia and their carers, regarding the need for a 'real person' to provide face-to-face case management throughout the course of their condition. This proposal is discussed in more detail below. The need for follow up is discussed in that context.

## Referral process

- 6.27 The Committee was told that one of the barriers to receiving appropriate dementia care and support was the lack of referral from GPs to specialists or community care, once a diagnosis was given.
- 6.28 Mr Glenn Stoll, of ECH Inc, an aged care service provider, considered that an integrated approach to dementia care was needed to guide people through the referral pathways:

We need a more integrated approach so when people come into that system, as fragmented as it is now, it may be a little bit more connected so that we would be referring across or linking people together into a pathway of service, as opposed to it being a little bit ad hoc and indiscriminate, as it is at the moment.<sup>14</sup>

- 6.29 The Committee was told that GPs and other health professionals needed clear practice guidelines and information about local pathways to assist them to direct people to appropriate support and care, following a diagnosis.
- 6.30 Alzheimer's Australia submitted that one means of achieving this was to create contextualised clinical practice guidelines, utilising Medicare Locals or the Australian General Practice Network (AGPN) to develop and promote the pathways.<sup>15</sup>
- 6.31 The AGPN agreed there was a lack of clear guidelines available for GPs to provide appropriate referrals:
- Evidence suggests that many GPs are not aware of diagnostic guidelines for dementia and that in many cases there are not clearly established care pathways relevant to the local context. Associated with this is often poor integration of general practice with other relevant primary health care and specialist services and limited awareness amongst GPs and PNs of locally-available support services and resources. This can mean that care provided does not follow best practice care pathways and may be poorly coordinated, with patients and their carers missing out on needed or potentially beneficial care and support.<sup>16</sup>
- 6.32 It was noted that the single guideline created for the management of dementia in general practice was out-of-date and not widely used.<sup>17</sup>
- 6.33 Alzheimer's Australia noted in a subsequent submission that the guidelines are being revised through a project funded by the Dementia Collaborative Research Centre (DCRC) for Assessment and Better Care.<sup>18</sup> The DCRCs are discussed in more detail in Chapter 7.

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14 Mr Andrew Stoll, ECH Inc, *Official Committee Hansard*, Adelaide, 8 June 2012, p. 27.

15 Alzheimer's Australia, *Submission 44*, pp. 18-19.

16 Australian General Practice Network (AGPN), *Submission 87*, p. 11.

17 Alzheimer's Australia, *Submission 44*, p. 18.

18 Australian Government, *Dementia Collaborative Research Centres*, <[http://www.dementia.unsw.edu.au/index.php?option=com\\_dcrc&view=dcrc&layout=project&Itemid=101&research\\_topic=0&researcher=0&research\\_type=0&year=0&population=0&centre=0&keywords=&searchtype=&pid=43&search=true\\_](http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&view=dcrc&layout=project&Itemid=101&research_topic=0&researcher=0&research_type=0&year=0&population=0&centre=0&keywords=&searchtype=&pid=43&search=true_)> viewed 31 May 2013.

## Committee comment

- 6.34 The Committee notes evidence suggesting that one barrier to achieving early intervention of dementia is the lack of referrals provided by GPs to specialists or other pathways of care, following a diagnosis. Another major barrier, the lack of awareness regarding dementia, is discussed in Chapter 3.
- 6.35 One means of assisting GPs make appropriate referrals following a diagnosis of dementia is to provide GPs with clear practice guidelines, which are relevant to the local context.
- 6.36 The Committee notes a project currently underway through the DCRC to update the dementia guidelines for general practice.
- 6.37 The Committee supports this project and proposes that the Commonwealth, in consultation with Medicare Locals or other local health care networks, ensure that the guidelines are contextualised to provide relevant information on local pathways.

## Recommendation 10

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

## Coordinating pathways

- 6.39 The Committee heard there was a lack of coordination between the diagnostic services or medical professionals who made a diagnosis of dementia, and the service providers who delivered treatment and support once a diagnosis was made.<sup>19</sup> There was a call to establish clearer pathways for people to access appropriate support and care in a timely way, following a diagnosis.
- 6.40 Associate Professor Scott Whyte, of Central Coast Local Health Network, told the Committee that people were often not linked in with services once they were given a diagnosis:

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<sup>19</sup> See for example, Darabin Council, *Submission 64*, p.

I think the real issue and problem with dementia, particularly with young people, is that they get sent down to Sydney for a diagnosis and that is where it stops. We pick them up years later as everything fails. They have not been linked in with local services. One really important thing is to keep people on the coast, and not just to give them a diagnosis but to link them up with the community services.<sup>20</sup>

- 6.41 The Committee was told that one method of better coordinating local pathways of care would be to utilise Medicare Locals.
- 6.42 The Department of Health and Ageing (DoHA) advised that Medicare Locals were improving the coordination and integration of primary health care in local communities and helping people navigate the local system, by better linking local GPs, nursing, allied health and other health professionals, hospitals and aged care, and maintaining up to date local service directories.<sup>21</sup>
- 6.43 Ms Lisa Rollinson, of the Brotherhood of St Laurence, asserted that Medicare Locals could be used effectively to coordinate and manage dementia services in the primary care sector:
- Medicare Locals are well placed to facilitate and coordinate dementia care in the primary health arena, with partnerships with local experts in the community field. Currently dementia diagnosis and referral is managed through the acute and subacute sectors by a specialised memory clinic and ACAT. Clients and carers will be much better served through the service coordination and primary health focus to be provided through the Medicare Locals and the community health sector.<sup>22</sup>
- 6.44 AGPN agreed that Medicare Locals, or other existing primary health care networks charged with regional primary health care coordination, were well placed to facilitate greater integration and networking of local primary and specialist health services, and social care and support services. AGPN submitted that this networking would ensure people living with dementia and their families accessed comprehensive and well-coordinated care that optimised the potential benefit of local services.<sup>23</sup>

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20 Associate Professor Scott Whyte, Central Coast Local Health District, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 14. See also, Townsville Health Services District, *Submission 27*, p. 2.

21 Department of Health and Ageing (DoHA), *Submission 89*, p. 8.

22 Ms Lisa Rollinson, Brotherhood of St Laurence, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 2.

23 AGPN, *Submission 87*, p. 13. See also, MDAG, *Submission 48*, p. 4.

- 6.45 Mr Rees considered how Medicare Locals might be used to link people in to services once they obtained a diagnosis:

It is, firstly, important to establish the principles that should govern the system. What should you look for across Australia in terms of the main characteristics of any system? That is important. But given the diversity of service provision in Australia, it would be very hard to have a very consistent system view across Australia. I would go back to one of the points that I made at the outset that, whether it is through Medicare Locals or through some other system, we would look to develop regional or local pathways that local professionals could follow. They might be quite different from area to area, depending on health infrastructure. That is where we got to with our stakeholder group and that seems to me to be the sort of approach that one should take.<sup>24</sup>

- 6.46 Mr Mark Booth, of DoHA, explained how Medicare Locals were already being utilised to develop local pathways in dementia care:

... Medicare Locals are tasked with looking at two things. One is that care coordination work to ensure that, from a patient perspective, patients can have an easy journey through care. The second one is really that notion of looking at the health needs of the community that they cover. So they do work on going out, consulting, doing analysis and seeing what the particular issues are in the communities that they cover. The first tranche of Medicare Locals have started doing that. They have done interim needs assessment reports, and we have good examples of Medicare Locals that have identified dementia issues as a particular issue and have put in place pathways.<sup>25</sup>

- 6.47 Ms Carolyn Smith, of DoHA, explained how the Medical Local structure could be used to create effective pathways of care that suited local circumstances, and highlight effective models of care:

We are going to be working with the Medicare Local structure in terms of adapting those local pathways to suit local circumstances, but also how we can actually share good work that is happening. I think one of the frustrations in some of these areas is that there are lots of really good models of practice occurring around the country, and how do we actually learn about all of the good stuff

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24 Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September, 2012, p. 4.

25 Mr Mark Booth, DoHA, *Official Committee Hansard*, 8 February 2013, Canberra pp. 10-11.

that is happening and develop it into tools that can then be applied more broadly. We are going to be working very closely with lead Medicare Locals and also the Medicare Local Alliance in terms of how we can imbed those models of care and pathways into a broader setting.<sup>26</sup>

## A multi-disciplinary approach

6.48 Many stakeholders submitted to the Committee that a multi-disciplinary approach to providing dementia care and support was another means of creating a clearer pathway of care for a person with dementia.

6.49 A multi-disciplinary approach to diagnosis is considered in Chapter 5.

6.50 It was submitted that the use of a multi-disciplinary team would ensure that a person's complex care needs were met appropriately, to improve a person's quality of life and assist them to remain independent for as long as possible.

6.51 Aged Care Association Australia Ltd submitted:

An early diagnosis, supported by multi-disciplinary dementia care teams – (comprising doctors, specialists, counsellors, family members, communities etc.) could see an:

- Improved understanding of the disease for all those impacted
- Improved levels of involvement in advanced care planning, particularly for those individuals/families uncertain what the future holds post diagnosis
- Improved approach toward management and self-determination, rather than just treatment.<sup>27</sup>

6.52 Mercy Health stated that as with all chronic diseases, people with dementia would benefit from a multi-disciplinary approach to care:

Mercy Health would urge that attention be given to supporting an increased involvement of other health providers in the care of people with dementia, including gerontologists, neurologists, registered nurses, social workers, nutritionists, health and behavioural psychologists, speech pathologists, and occupational and physiotherapists, in order that a comprehensive, integrated and quality program of care can be provided to this group who are experiencing one of the most disabling conditions and who are in most need our support.<sup>28</sup>

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26 Ms Carolyn Smith, DoHA, *Official Committee Hansard*, 8 February 2013, Canberra p. 11.

27 Aged Care Association Australia Ltd, *Submission 84*, p. 1.

28 Mercy Health, *Submission 81*, p. 4.

6.53 Dr Leslie Bolitho, of the Royal Australasian College of Physicians (RACP), explained that an integrated and multi-disciplinary model of care was needed to meet the needs of people with dementia (and their carers):

Adequately responding to the needs of people with dementia and their carers over time will require an adapted and integrated healthcare system and aged-care delivery driven by new and improved models of care and service delivery involving multidisciplinary teams of professionals providing care, particularly outside hospitals, and in the primary and ambulatory settings, and particularly with residential aged-care facilities where over 50 per cent of the residents have a diagnosis of dementia.<sup>29</sup>

6.54 The RACP and the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) submitted that people with dementia and their carers should have easy and timely access to coordinated multi-disciplinary care over the course of the condition. Such an approach would involve a shared-care model involving (as required) the GP, specialist dementia nurse, medical specialist, pharmacist and allied health professional(s)<sup>30</sup> who provide continuity of care and smooth transitions across acute, sub-acute, transitional, community, primary and palliative care settings. It was submitted that for such a model to exist across Australia, consideration was needed regarding:

- Education and training of the multi-disciplinary team;
- Workforce requirements;
- Adequate financial arrangements and incentives;
- Examples of good practice; and
- Opportunities presented through emerging technologies and the health and aged care reform process.<sup>31</sup>

### Committee comment

6.55 The Committee heard there was a need for greater coordination of services and clearer referral pathways, to address concerns about the lack of linkages between services and duplication of other services.

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29 Dr Leslie Bolitho, RACGP, *Official Committee Hansard*, Sydney, 22 June 2012, p. 18. See also, RACP and ANZSGM, *Submission 22*.

30 There were a number of submissions which advocated for the benefits of health professionals such as speech pathologists, to be part of any multi-disciplinary team. See for example, Speech Pathology Australia, *Submission 74*; Margaret Pozzebon, *Submission 97*; Ms Kim Torresi, Dr Bronwyn Moorhouse and Dr Amanda Scott, *Submission 98*.

31 RACP and ANZSGM, *Submission 22*, pp. 12-13.

- 6.56 A number of suggestions were made to the Committee on how to achieve better coordination and clearer pathways. These include:
- Utilising Medicare Locals or other established primary care networks to streamline and coordinate localised care pathways in a user-friendly way for people with dementia and their carers; and
  - Utilising a multi-disciplinary approach to dementia care, by using a range of health professionals trained to treat and assist people with dementia.
- 6.57 The Committee notes that policy development within the area of dementia diagnosis and post-diagnostic care and support, is moving at a rapid rate. Stakeholders are likely very familiar with the call for better coordination of services, as outlined above.
- 6.58 The Committee understands that a range of initiatives which have the aim of making care pathways more user-friendly and efficient for people with dementia and their families are already in progress under the auspice the DoHA, the Minister's Dementia Advisory Group (MDAG), DCRCs and Alzheimer's Australia. For example, the Committee notes that MDAG is currently exploring the barriers and opportunities for improving care, including avenues available through Medicare Locals.<sup>32</sup>
- 6.59 The Committee joins with these stakeholders in recommending that government facilitate initiatives which will assist in smoothing the post-diagnosis pathway of care for people with dementia, their families and for health care providers. Noting the Committee's comments in Chapter 4, integration of services should also extend to services available for people to obtain a diagnosis of dementia.

### **Recommendation 11**

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

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32 DoHA, *Submission 89*, p. 12.

## Recommendation 12

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

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

### Dementia link worker

- 6.62 While health practitioners and consumer groups called for clear pathways and better coordination of care, consumers called for information to be provided from a real person who could manage their case and link them in with the appropriate services.<sup>33</sup> This person is referred to as a Dementia Link Worker (DLW).
- 6.63 Mr Glenn Rees, Chief Executive Officer of Alzheimer's Australia, called for clear local pathways to allow medical professionals to refer people to community support and information on an ongoing basis. Mr Rees relayed the call from consumers for a key link worker to assist in the referral process:

One of the things that consumers stress over and over again as important is having key link workers who focus on providing ongoing advice as and when it is needed.<sup>34</sup>

- 6.64 Dr Jane Thompson, a carer, echoed the call for a 'key worker' to assist people in navigating the system of care, telling the Committee of the difficulties she experienced finding appropriate services:

I felt I was told, 'Well, here it is. You go home and deal with it.' In fact it is very much up to the individual to work out where to go for help and what sorts of services you are going to need, and it does require considerable resourcefulness, I think, to negotiate that system. I think, again, I would support Glenn's comments about the benefits that we might have gained from having a key worker

33 Alzheimer's Australia (National Office), *Submission 44*, p. 22.

34 Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 1.

or a case manager to help us just negotiate our way through the transitions that are required in care needs.<sup>35</sup>

6.65 The proposed role of a dementia link worker was outlined to the Committee:

The primary role of a Dementia Link Worker would be to provide support, advice and advocacy for the person with dementia and their family. The goal is to link people to support and services early in diagnosis before they may actively seek out formal supports and to provide a continuity of support throughout the dementia journey. Individuals with dementia and their families would be referred to a Dementia Link Worker soon after diagnosis. The Dementia Link Worker would then assist in linking the person with dementia and their families to support groups, education and information. The Dementia Link Workers may also provide information and support about advanced care planning, carer stress, and access to services such as respite.<sup>36</sup>

6.66 NSW Health envisaged that a key worker would be a person with a nursing or allied health qualification, skilled in dementia care, who worked closely with the person's GP or Aboriginal Medical Service, proactively following up after diagnosis and building a continuing relationship. The key worker would case manage a person's care needs as they increased or became complex, and would assist the person to remain independent for as long as possible.<sup>37</sup>

6.67 Alzheimer's Australia outlined how the DLW program could be implemented as part of the current aged care reforms, and integrated into existing models of primary care:

- A DLW could be recruited from a variety of professional backgrounds, including nursing or allied health fields (with backgrounds in areas such as social work, psychology or occupational therapy);<sup>38</sup>
- The worker would have specialised training and experience in dementia care, and extensive knowledge of local services;
- Implementation of the program would require the development and endorsement of an accreditation program with appropriate competencies and professional development requirements; and

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35 Dr Jane Forbes Thompson, *Official Committee Hansard*, Canberra, 11 September 2012, p. 2. See also, NSW Health, *Submission 95*, p. 4, p. 6.

36 Alzheimer's Australia (National Office), *Submission 44*, p. 21.

37 NSW Health, *Submission 95*, p. 6. See also, RACP and ANZSGM, *Submission 22*, p. 2, p. 14.

38 For further discussion on nurses as coordinators, see Royal College of Nursing, *Submission 61*, pp. 1-2.

- The program could be delivered by existing community aged care providers, health provider organisations or community organisations such as Alzheimer's Australia or Medicare Locals, and should build on existing networks.<sup>39</sup>

6.68 Alzheimer's Australia South Australia has already implemented a DLW program. The program was outlined to the Committee in Adelaide:

...we have what we call dementia link workers who work throughout South Australia and we positioned one of our dementia link workers with Craig in Repat [the Repatriation General Hospital] and this has proved to be a really successful. Our organisation's aim is to try and get people on diagnosis, so when they walk out of the memory clinic they walk straight into one of our workers who can provide relevant information and then work with them and the family throughout that journey.<sup>40</sup>

6.69 Ms Marie Alford, of Alzheimer's Australia South Australia, said that those people who had access to a DLW were more likely to be supported through their dementia journey, than those people who received a passive referral, by being given written information. This was particularly important for people who were living alone:

I think one of the biggest barriers is around people who live alone who develop dementia: how do we access this particular cohort? If they do not have family members like Fred who will make that connection it is important to have that immediate connection either through the GP or the specialist. What we know is that passive referral where people are given a piece of information, whether it is by the GP or specialist, may lead to a referral but those clients who have direct access to a worker on the ground either at the QEH [Queen Elizabeth Hospital] or at the Repat [Repatriation General Hospital] or potentially through a GP clinic are more likely to be supported through their journey and have an increased quality of life through that early intervention.<sup>41</sup>

6.70 Mrs Fiona Young, a Clinical Nurse Consultant in Tasmania, was part of Community Dementia Service that offered consultation, assessment, information and the provision of direct care to people with dementia

39 Alzheimer's Australia (National Office), *Submission 44*, pp. 22-23.

40 Ms Kathryn Cunningham, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 23. See also Professor Craig Whitehead, South Australia Health Statewide Older People Clinical Network, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 17.

41 Ms Marie Alford, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 22.

living in the community. The service considered that following up with people after diagnosis of dementia was important. Within the service, follow up was provided to people in a number of ways:

Depending on the individual client and on family needs, the follow up ranged from phone calls to the client or carer, contact with other services already involved in the client's care or admission to either the Community Dementia Service or the Community Options Service, which is also part of Primary Health North, for ongoing care provision and case management.<sup>42</sup>

- 6.71 It was submitted that post-diagnostic support promoted a feeling of independence for a person with dementia, and assisted them to maintain control over their life.<sup>43</sup>

### Committee comment

- 6.72 It is clear to the Committee that the pathway from diagnosis to receiving ongoing treatment and support is complex and difficult to navigate. Evidence called for a case management approach to assist people with dementia and their carers, following diagnosis. This will ensure that a person's care and support needs, and those of their carers, are met in a timely and appropriate way.
- 6.73 The Committee heard that there is a need to give people with dementia access to a 'real person' who can coordinate their care from the point of diagnosis and throughout progression of the condition.
- 6.74 Carers may also have discrete support needs and may require case management in their own right.
- 6.75 As noted earlier in this chapter, some people do not require immediate access to services, particularly when diagnosis is received at an early stage. A case management approach that includes proactive follow up will ensure these people are not forgotten and receive services when they are needed.

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42 Mrs Fiona Young, Community Dementia Service, Tasmanian Health Organisation North, *Official Committee Hansard*, Launceston, 27 July 2012, p. 18.

43 Community Dementia Service Primary Health North, *Submission 14*, p. 3.

### Recommendation 13

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

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

## How dementia care services can improve quality of life

6.77 For early intervention of dementia to be successful, the Committee understands that services must be dementia friendly, flexible and accessible. Unfortunately, the Committee heard that this is not always the case.

## Dementia management in acute care

6.78 In its report, *Dementia care in hospitals costs and strategies*, the Australian Institute of Health and Welfare (AIHW) found that the identification and recording of dementia as a diagnosis in hospital records was often poor. This could impact on the treatment of individuals with dementia:

The identification and recording of dementia as a diagnosis in hospital records is often poor. ... there are a number of potential reasons for this, including the time constraints on the interactions between patients and doctors, clinical coding practices, the challenges associated with differential diagnosis and cognitive impairment of dementia patients and the systemic limitations and issues with documentation and classification practices...

... Under-identification of dementia in hospital data sets has an impact on both the reliability of information and statistics and on the approaches and practices used within the hospital. Ultimately, under-identification has potential negative consequences for patient outcomes.<sup>44</sup>

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44 AIHW, *Dementia care in hospitals costs and strategies*, 2013, p. 15. For statistics on dementia diagnosis in hospitals, see p. ix and pp. 67-80.

- 6.79 Despite the large numbers of people with dementia being admitted for some form of acute care, the Committee heard that hospital care was often not 'dementia friendly'. As explained by RACP and ANZSGM:

Currently, hospitals are daunting places for people with dementia in terms of both quality of care and quality of the environment with higher likelihood of poor outcomes including disability and death. People with dementia tend to have longer hospital stays and an increased number of complications including polypharmacy, undernutrition, skin tears, pressure areas and fall-related injuries. People with dementia can find hospitals unfamiliar, confusing and disorienting and there is risk of sensory overload from a busy, time-pressured ward.<sup>45</sup>

- 6.80 It was submitted that despite dementia being 'core business' for hospital staff, dementia often went overlooked in hospital settings:

Diagnosis of cognitive impairment, specifically of dementia and delirium, is often overlooked when older people are admitted for medical or surgical reasons to emergency departments or acute hospital wards. Yet dementia is associated with longer length of stay, behavioural complications, higher rates of falls and fractures and more expensive admissions than non-demented patients with same conditions.

Management of people with dementia in hospitals can be sub-optimal if health professionals are not aware of the limitations of cognitively impaired patients in even seemingly simple matters such as filling in menus or adhering to treatment regimens.<sup>46</sup>

- 6.81 The Committee heard that in some hospital settings there was insufficient recognition by staff of patients who had dementia, particularly when the patients were admitted to hospital for a particular acute condition.<sup>47</sup>

- 6.82 Associate Professor Mark Yates explained that some families of hospital patients with cognitive impairment believed that cognitive impairment was not recognised by hospital staff:

Our research has shown us that on any day 30% of patients in hospital have cognitive impairment and that families believe that in 20% of admissions the hospital are unaware of their loved ones cognitive impairment.<sup>48</sup>

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45 RACP and ANZSGM, *Submission 22*, p. 20.

46 MDAG, *Submission 48*, pp. 6-7. See also, Associate Professor Mark Yates, *Submission 13*.

47 Dr Stephen Brady, Alice Springs Hospital, *Official Committee Hansard*, Alice Springs, Wednesday 30 January, 2013, p.10. See also, Gloria (NSW), *Submission 18*.

48 Associate Professor Mark Yates, *Submission 13*.

- 6.83 Given the prevalence of dementia within the acute care system, it was submitted that one means of meeting the needs of these patients was to place Clinical Nurse Specialists in dementia at all hospitals, to assist patients who had dementia. Associate Professor Yates recommended this course of action:

I would also recommend that all hospitals have Clinical Nurse Specialists in Dementia. It is surprising to me that almost all hospitals have a Diabetes Nurse when the in-patient prevalence of this condition is 11.1%... and an asthma nurse when it is estimated that asthma represents just 0.5% of separations...but not have a Dementia Nurse Specialist who can provide staff education, carer support and important links for the person with dementia into the community on discharge.<sup>49</sup>

- 6.84 Mrs Judy Buckley, who cared for her mother with dementia, advised that there needed to be some way to alert staff within hospitals that a patient had dementia:

... when someone is, for example, in hospital for some other reason, there needs to be some sort of indication that that person has dementia. We have signage for disability in car parks and things that we are all familiar with and that is usually around the hospital bed somewhere. But there is nothing to indicate to staff that that person has some form of dementia. I think it can lead to lots of misunderstanding and lots of confusion for the person who is in hospital. I guess they are the main issues for me.<sup>50</sup>

- 6.85 Associate Professor Yates advocated for the nationalisation of a program implemented in Victoria to improve awareness and communication with people with dementia within hospitals:

In Victoria the Dementia Care in Hospitals Program has been rolled out to 22 public hospitals and is now being trialled in the private sector. It is a program to improve the awareness of and communication with people with dementia and their families linked to a visual bedside alert called the Cognitive Impairment Identifier. The program has led to improvement in staff and carer satisfaction with the care of those with Cognitive Impairment. I would recommend to the Inquiry that this program be made

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49 Associate Professor Mark Yates, *Submission 13*.

50 Mrs Judy Buckley, Alzheimer's Australia NT Inc., *Official Committee Hansard*, Alice Springs, 30 January 2013.

national as one element in the improved care and early diagnosis of those with cognitive impairment.<sup>51</sup>

- 6.86 Another perspective however was presented by Mrs Marianne Cummins, from the Northern Territory Division of the Australian Association of Gerontology. Mrs Cummins was concerned that using an identifier for patients with cognitive impairment may lead to misdiagnosis in some instances:

As a nurse working in the hospital we already have people ... that are identified as having dementia and are labelled with dementia because of a whole range of things. They may be delirious and acutely unwell. That is really the common cause. It is the most common cause of people's confusion, and it is on top of their chronic illnesses. It is well-known that if you have a chronic illness and you become acutely unwell then you can become delirious. There are a lot of risk factors. Sometimes it is actually about the hospital not then going down the track of making sure that that acute illness is treated. That would be the most disastrous thing I think because they have a lot of people that that is an issue for.<sup>52</sup>

- 6.87 MDAG considered that early diagnosis of dementia, combined with training of hospital health professionals on how best to assist patients with cognitive impairment, could assist in reducing complications of care for a person's primary reason for admission and decrease their length of stay.<sup>53</sup>
- 6.88 To address the under-identification and awareness of dementia in hospitals, MDAG recommended that hospital health professionals and other front-line professionals undertake awareness training and education about the importance of recognising cognitive impairment.<sup>54</sup>

### Committee comment

- 6.89 For a number of reasons outlined above, the identification and awareness of dementia within hospital settings is low. This undoubtedly effects a person's health outcomes and the quality of care that person receives.
- 6.90 As part of the *Living Longer. Living Better.* aged care reforms, \$39.2 million has been allocated to improve acute care services for people with dementia. The reforms as outlined by DoHA, are:

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51 Associate Professor Mark Yates, *Submission 13*.

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

53 MDAG, *Submission 48*, pp. 6-7.

54 MDAG, *Submission 48*, p. 9.

People with dementia will be identified and better coordinated and supported systems will be developed and trialled to enable safe and appropriate hospital services. People with dementia will benefit through early identification of cognitive impairment, improved assessment, and access to specialist dementia programs. This will assist in achieving better outcomes for people, including reduced falls, shorter stays, improved nutrition, and fewer setbacks.<sup>55</sup>

- 6.91 It is further noted that these improved support services will take into account people with dementia with specialised needs, including people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people and people with Younger Onset Dementia (YOD).<sup>56</sup>
- 6.92 In implementing reforms to acute care settings to improve treatment and services for people with dementia, the Committee recommends consideration of the following suggestions from experienced stakeholders specialising in dementia care:
- The feasibility of introducing Clinical Nurse Specialists in dementia into hospital settings, to address the needs of dementia patients in acute care;
  - The feasibility of introducing a Cognitive Impairment Identifier into hospital settings; and
  - The training and education of hospital health professionals in dementia assessment, treatment and care.
- 6.93 In addition, the Committee recommends that to improve management of dementia in an acute care setting, a protocol be established regarding the identification of cognitive issues at the point of triage.
- 6.94 Training and education of hospital health professionals in dementia assessment, treatment and care is dealt with in the discussion regarding awareness of health professionals in Chapter 3.

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55 Australian Government Department of Health and Ageing, *Living Longer. Living Better.*, 'Tackling dementia', <<http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/tackling-dementia#2>> viewed 3 June 2013.

56 Australian Government Department of Health and Ageing, *Living Longer. Living Better.*, 'Tackling dementia', <<http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/tackling-dementia#2>> viewed 3 June 2013.

## Recommendation 14

- 6.95 **The Australian Government Department of Health and Ageing, as part of the *Living Longer. Living Better.* reforms and through the Council of Australian Governments, trial the following initiatives to investigate their capacity to assist in improving dementia care in acute hospital settings, with a view to these initiatives being implemented nationally:**
- **The introduction of Clinical Nurse Specialists in dementia in hospitals;**
  - **The introduction of a Cognitive Impairment Identifier in hospitals; and**
  - **The introduction of a protocol for the identification of cognitive issues at the point of triage.**

## Accessible and flexible services

- 6.96 The Committee received a significant volume of evidence addressing the issue of care services for people with dementia, and emphasising the specific needs of particular population groups.<sup>57</sup>
- 6.97 The following section is not intended to be a comprehensive discussion of the dementia care requirements for all population groups with specific needs. Rather it is intended to be illustrative of the need for services that are accessible and flexible enough to accommodate the different care requirements of diverse populations.
- 6.98 As explained by Life Care, a South Australian community aged care service provider, each individual has different care needs and, as dementia is progressive, these needs are likely to change over time:

An individual with dementia has a very individual path as they move from early diagnosis to moderate and advanced stages. Irrespective of age, there needs to be flexible models of support in both community and residential settings to meet their needs. For example, an 80 year old with some early signs of cognitive decline, will not find a program for individuals with advanced dementia stimulating or appropriate. Service providers must have flexible management of programs and the skills to identify and address each individual's needs. Their models of care are often restricted

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57 See for example, Central Coast Local Health District, *Submission 103*.

due to funding and staffing constraints, rather than individual care needs.<sup>58</sup>

- 6.99 The need for accessible and flexible dementia care services is considered with reference to the following population groups:
- People with YOD;
  - People with intellectual disabilities;
  - People from culturally and linguistically diverse (CALD) backgrounds;
  - Indigenous Australians; and
  - People living in regional, rural and remote areas.
- 6.100 Discussing issues relating to dementia care services for people with YOD, the NSW HACC Forum submitted:

People with younger onset dementia can be at a very different life stage than older people with dementia. They may be in full-time employment, with caring responsibilities for children, may be physically fit and active, and have a number of interests. As support for dementia is mostly funded and provided in the aged care sector, people with younger onset dementia do not necessarily identify with needing the types of care or support available for people with dementia.<sup>59</sup>

- 6.101 It was submitted that younger patients with dementia needed access to age-appropriate services, rather than services targeted towards older people.<sup>60</sup> Ms Kate Swaffer, who was diagnosed with dementia at age 49, noted that there were a number of factors that needed to be taken into account when considering the appropriateness of care and support services for people with YOD. These factors included that a person with YOD was more likely to be still in paid employment when the diagnosis came, and have dependent children.<sup>61</sup>
- 6.102 In relation to residential care facilities, HammondCare noted the distinct care needs of people with YOD:

Younger people with dementia have a different set of needs as they are heavily involved in complex professional and family relationships. They tend to be much more physically active than older people with more conventional forms of dementia and are more likely to have a form of dementia that is associated with higher levels of behaviours of concern, such as fronto-temporal

58 Life Care, *Submission 110*, pp. 2-3.

59 NSW HACC Issues Forum, *Submission 85*, p. 5. See also, Jenie (SA), *Submission 15*.

60 See for example, Baptistcare Inc, *Submission 33*, pp. 2-3.

61 Ms Kate Swaffer, *Submission 77*, p. 10.

lobe dementia. This means that traditional residential aged care services are not well-equipped to support younger people with dementia.<sup>62</sup>

- 6.103 According to evidence presented by Dr Jennifer Torr, people with intellectual disabilities and dementia have particular problems with accessing appropriate services. In relation to this, Dr Torr commented:

... people [with intellectual disabilities] living in group homes are seriously disadvantaged and refused access to a range of allied health services that would be provided to someone with dementia living at home. Have group homes been confused with aged care facilities which are required to provide these services? Group homes provide accommodation support, not health care.<sup>63</sup>

- 6.104 Dr Torr called for greater clarity on how eligibility criteria for accessing dementia care services applies to people with an intellectual disability following a diagnosis of dementia, observing that:

The failure to provide adequate support within family home, or group homes can only result in premature placement in an aged care facility.<sup>64</sup>

- 6.105 The Australian Nursing Federation submitted that there was a need to educate the health and aged care workforce on culturally sensitive, acceptable and specific approaches to the dementia care for people from CALD backgrounds, noting:

Flexibility in models of dementia care must be supported to accommodate preferences for intervention for people from culturally and linguistically diverse backgrounds. Initiatives are required to be adopted that build cultural awareness and cultural competence of the health and aged care workforce. Dementia care resources need to include models that support cultural liaison.<sup>65</sup>

- 6.106 Mercy Health echoed the call for more training for service providers around the social and spiritual needs of people with CALD backgrounds, noting that differences in language and culture could create challenges for service providers:

Consistent with population changes indicating that between one quarter and one third of Australians were born in a country other than Australia, the current and future needs of ageing migrant and

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62 HammondCare, *Submission 86*, p. 2. See also, Ms Kate Swaffer, *Submission 77*, p. 13; Mrs Jacinta Robertson, *Life Care, Official Committee Hansard*, Adelaide, 4 March 2013, p. 3.

63 Dr Jennifer Torr, *Submission 73*, p. [6].

64 Dr Jennifer Torr, *Submission 73*, p. [6].

65 Australian Nursing Federation, *Submission 79*, p. 8.

CALD communities needs to be an increased priority. For those living with dementia and their families, particularly in the urban centres of Australia, linguistic and cultural diversity assumes great significance. Social isolation, reversion to 'first' language, confusion exacerbated by unfamiliarity with prevailing Western cultural mores, and other factors pose unique and major challenges for communication with and assessment of such individuals.<sup>66</sup>

6.107 The Committee also received evidence indicating a shortage of dementia care services which address the specific needs of Indigenous Australians, particularly those living in remote communities.<sup>67</sup>

6.108 Professor David Atkinson, Medical Director with the Kimberley Aboriginal Medical Services Council, explained that accessibility of services was a major issue in remote Indigenous communities:

The big issue is that services are provided in the towns but most of the people actually do not live in the big towns and, therefore, patients do not really have access to them. The system is not sufficiently flexible to deliver services in communities.<sup>68</sup>

6.109 Professor Atkinson considered that communities needed to have input into how the services were to be delivered:

... The thing that would work for remote communities would be to have funding that is put together and communities having a say in what services they need. If they have two young people with disabilities and five or six old people, maybe one person can contribute to all of those people's care. That would be more efficient. They can employ local people. As it is, we have visiting services coming in for an hour or two and then going away again, and that is clearly a waste of resources and probably not that productive.<sup>69</sup>

6.110 Ms Wilma Gibson, who manages aged and disability services within the Central Desert Shire Council in the Northern Territory, advised that when providing dementia care services to remote Indigenous communities,

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66 Mercy Health, *Submission 81*, p. 5. See also, SA Department for Communities and Social Inclusion, *Submission 91*, p. 13.

67 See for example: Mrs Nicole O'Connor, *Alzheimer's Australia (NT)*, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 2.

68 Professor David Atkinson, Kimberley Aboriginal Medical Services Council, *Official Committee Hansard*, Broome, 13 November 2012, p. 3. See also, Kimberley Aged and Community Services, *Submission 107*.

69 Professor David Atkinson, Kimberley Aboriginal Medical Services Council, *Official Committee Hansard*, Broome, 13 November 2012, p. 3.

there was a need to consider the cultural differences in how dementia was perceived and how care could be provided:

There are two different realms here: how we would actually perceive dementia and work with dementia, and then what is it to an Indigenous community and culture around that and how do you work with that, and then how do you go on a much closer scale within that household environment to work with that person, because maybe something has happened and you have got a fear that has developed because some safety issue has taken place. There are a lot of other things that need to be considered as to how we really make that workable on community because it is becoming quite demanding. That is pretty much the challenge in and around that.<sup>70</sup>

- 6.111 Ms Nina Bullock, who similarly managed aged care services at MacDonnell Shire Council, considered that providing appropriate care to remote Indigenous communities required forming partnerships between the person, their extended families, and the relevant agencies:

Culturally safe services, information and activities are often hard to come by. This community alone has lost 14 members in the last two months. Yet the community has access to hidden assets: the support of a wide network of family members who reside on community, on a country that they know intimately; a history of resilience; a living language; and ideas about how to move forward and to where. Thus it is critical to a client's wellbeing and independence that plans for their care are undertaken in true partnership with the extended family and relevant agencies.<sup>71</sup>

- 6.112 Shortages of dementia care services in remote, rural and regional communities represents a major barrier to accessing appropriate interventions for people with dementia living outside of Australia's metropolitan centres.<sup>72</sup>

- 6.113 Mr Terry Mehan, of Queensland Health, told the Committee of the advantages and disadvantages faced by people in rural communities, in relation to the provision of aged care services:

Your advantage is that whole sense of community, flexibility and responsive. Your disadvantage is that you will not be able to

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70 Ms Wilma Gibson, Central Desert Shire Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 37.

71 Ms Nina Bullock, MacDonnell Shire Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 36.

72 See for example, Jill (NSW), *Submission 101*.

sustain specialist services because of your low numbers. You do not have small country towns with specialist geriatricians. What you could have is a nurse in that hospital that has extended skills in aged care. You have to tailor the package of services to meet your community needs but you have a fair degree of flexibility.

In my observation there is a strong sense of community and responsiveness, but the disadvantage is that if you have an acute condition and you need specialised care you have to travel long distances. The distance of travel is usually an hour or two in New South Wales but is usually four to six hours in Queensland, so it is the distances of travel and the convenience and affordability of air travel. You are dislocated from those specialist services.<sup>73</sup>

6.114 The National Rural Health Alliance advised the Committee that:

Poor access to primary care generally in country areas, including shortages of medical specialists and allied health professionals of any kind, let alone those that specialise in dementia, mean there is less likelihood of early diagnosis and treatment for people in those areas. The smaller aged care services with fluctuating numbers, that struggle to be sustainable in rural and remote communities, are also less likely to have the capacity to provide specialised dementia care – although the more flexible care arrangements possible can contribute to more personalised care for local people with dementia.<sup>74</sup>

### Committee comment

6.115 Dementia is not a condition that is exclusive to ‘old age’ or limited to people from a specific background. People with dementia vary in age, and come from diverse cultural backgrounds and have a range of life experiences. People with dementia may live in the city, or they may live in regional, rural and remote communities. They may have a large extended family, or they may live alone. Further, a person’s care needs will likely change over time.

6.116 Navigating the maze of services to determine what services might be available following a diagnosis of dementia is one of the most significant challenges that people with dementia and their families face. However, it is not the only challenge. To be beneficial to people with dementia and

73 Mr Terry Mehan, Queensland Health, *Official Committee Hansard*, Brisbane, 1 August 2012, pp. 30-31. See also, National Rural Health Alliance (NRHA), *Submission 36*, p. 3.

74 NRHA, *Submission 36*, p. 3. See also, Mrs Kylie Wood, *Official Committee Hansard*, Launceston, 27 July 2012, p. 6.

their families, the Committee understands that dementia care services must be accessible to those that need them and sufficiently flexible to meet the differing care needs of diverse population groups.

- 6.117 There are several factors that may affect a person's ability to access dementia care services. For example, the Committee heard there is a need to increase the accessibility of dementia care services, particularly in regional, rural and remote areas. Regional, rural and remote areas often face particular challenges accessing community care services. Services may simply not be available locally. Equally, restrictive eligibility criteria, and inconsistency or confusion around the application of eligibility criteria, can also limit access for some population groups. This is illustrated by the challenges accessing dementia care services facing people with YOD and intellectual disability.
- 6.118 The Committee also recognises that there is a need for greater flexibility within dementia care services. As noted earlier, people with dementia (and their families and carers) are not a homogenous group. The Committee agrees that services should be structured in such a way that they have the capacity to adapt to a person's individual needs, rather than requiring the person to adapt to the service they are accessing. For example, services may need to have the capacity to adapt to and account for differences in a person's age, cultural identity and life experiences.
- 6.119 The Committee understands that the issues raised in relation to accessibility and flexibility of community-based and residential care services for people with dementia reflect long-standing concerns with these systems. The Committee notes that these issues were examined and reported on in 2011 in an Australian Government commissioned report, *Dementia services pathways - an essential guide to dementia services planning*.<sup>75</sup>
- 6.120 The Committee also notes that as part of the *Living Longer. Living Better.* reforms, funding has been approved to support the following actions:
- Improved support for people with YOD (\$23.6 million);
  - Ensuring older people from diverse backgrounds can access aged care services that are specific to their needs (\$24.4 million);
  - Ensuring sexual diversity does not act as a barrier to receiving high quality aged care (\$2.5 million);
  - More assistance for older people who are homeless or at risk of homelessness (\$7.3 million);

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75 DoHA, *Dementia Services Pathways*, <<http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-dementia-services-pathways-2011-toc.htm>> viewed 5 June 2013.

- Ensuring culturally appropriate quality aged care services are available for Aboriginal and Torres Strait Islander people (\$43.1 million); and
- Ensuring the sustainability of aged care services in regional, rural and remote areas (\$108 million).<sup>76</sup>

6.121 In implementing these initiatives, the Committee emphasises that frameworks should have sufficient flexibility to empower specific population groups and communities to structure services according to specific and local needs. The Committee encourages the Australian Government to consult regularly with stakeholders, including state and territory governments (where relevant), providers of services and users of services (people with dementia and their families). Furthermore the Committee believes that robust partnerships with local communities and stakeholder groups will be essential to effective implementation, if dementia care services are to be structured to ensure the needs of specific population groups and communities are met.

6.122 The Committee also notes that much of the evidence regarding the ability of dementia care services to meet the needs of people from diverse backgrounds relates to the need to better educate and train health professionals. This issue has been addressed separately in Chapter 3.

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<sup>76</sup> Australian Government, *Living Longer. Living Better*. April 2012.

