5

My deepest regret is that we lost so much time during the first years of her illness. Time wasted by repetitive misdiagnosis by all her doctors. I am sad about all our unnecessary fear, struggle, anger, my poor mother must have felt so misunderstood and abandoned at times, when we did not believe her. In addition, I have lost precious years when I could have been studying about dementia and actively assisting my mother, instead of becoming emotionally and mentally ill in my caring role.[1]

Barriers to diagnosis

5.1 As discussed in Chapter 4, a diagnosis of dementia can take an average of three years from the time a person starts experiencing symptoms of cognitive decline or memory loss.[2]

5.2 The Committee was told that part of this delay is due to a lack of awareness and the stigma attached to dementia. Other barriers exist within the health system itself.

5.3 The Committee heard countless stories from carers and individuals, telling of lengthy delays in receiving a diagnosis of dementia. A delay in diagnosis denies a person the opportunity to receive beneficial treatment to enhance their quality of life and maintain their independence by making plans for their future care. The benefits of receiving an early diagnosis are outlined in more detail in Chapter 4.

5.4 There are four main types of barriers to receiving an early or timely diagnosis of dementia:

- Consumer level barriers;
- Primary care provider level barriers;

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1 Danielja, *Submission 8*, p. 2.

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

- Health system level barriers; and
- Service context barriers.[3]

5.5 Consumer level barriers to diagnosis, such as lack of awareness and stigma about dementia, are discussed in Chapter 3.

5.6 The barriers which exist to prevent medical professionals from making an early or timely diagnosis of dementia, including barriers within the health care system, are discussed below.

Who can make a diagnosis of dementia?

5.7 Dementia may be diagnosed in a number of different medical settings:

- By a medical professional in a primary care setting (for example, a General Practitioner (GP) or Nurse Practitioner (NP));
- By a specialist, such as a neurologist, geriatrician, gerontologist, psychogeriatrician, psychiatrist, or neuropsychologist;
- By a medical practitioner in an acute care setting such as a hospital; or
- Through a service operated by a multi-disciplinary team, such as an Aged Care Assessment Team (ACAT) or memory clinic.[4]

5.8 The barriers to achieving early diagnosis in the above settings are discussed further below.

Barriers to diagnosis in primary care

5.9 A GP is often the first point of contact when a person is concerned about possible memory loss. Approximately 83 per cent of Australians consulted with a GP at least once a year, with 73 per cent of people aged over 75 years of age consulting with a GP four or more times during 2010-11.[5]

5.10 The Royal Australian College of General Practitioners (RACGP) told the Committee that as a person's main health care provider, GPs had an important role in recognising, assessing, diagnosing and managing dementia.[6]

5.11 Professor Henry Brodaty, of the Minister's Dementia Advisory Group (MDAG), told the Committee that primary care was the key to obtaining

3 Alzheimer's Australia (National Office), *Submission 44*, p. 10.

4 Alzheimer's Australia Victoria, *Submission 35*, p. 3.

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

6 RACGP, *Submission 83*, p. 4.

early diagnosis of dementia, and the 'corner shop' where people went for assessment and management of dementia.[7]

5.12 The Australian General Practice Network (AGPN) explained the benefits of using general practice teams in the assessment of dementia:

> General practice teams, particularly the GP and practice nurse (PN), who often have established relationships with patients and are commonly the first professionals to whom patients present for medical assistance, are well placed to recognise the symptoms and signs of early dementia and to trigger diagnostic evaluations.[8]

5.13 Mr Glenn Rees, of Alzheimer's Australia, told the Committee that over 90 per cent of Australians would approach their GP first, if they were concerned about their memory. Accordingly, the knowledge and skills of a GP often determined how early a diagnosis was made:

> So the GPs are the gatekeepers for the system. Depending on whether the gatekeeper, the GP, is familiar with dementia and knows what to look for, the process for the person can be good, as it was reasonably good in Jane's case. If the GP is not familiar with it or regards it as just a question of ageing, the person will be sent on their way until the concern becomes so great that the dementia becomes very obvious, in which case a diagnosis is very late.[9]

5.14 Mr Rees outlined the best practice approach to a GP making a diagnosis of dementia:

> The best practice, really, is for the GP or the practice nurse to screen the person, do the simple tests, and if they are convinced that there is a problem to then refer them to a specialist, whether that is a neurologist or a geriatrician or some other speciality. Obviously it depends on what the doctor thinks is the problem. From that point, the person probably comes back to the GP, gets the diagnosis and then—this is the second critical point—gets a referral to services.[10]

5.15 Mrs Elizabeth Rand, of Cognitive Dementia and Memory Services (CDAMS), told the Committee that while a GP could take many people

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7 Professor Henry Brodaty, Minister's Dementia Advisory Group (MDAG), *Official Committee Hansard*, Canberra, 8 February 2013, p. 15.

8 Australian General Practice Network (APGN), *Submission 87*, p. 9.

9 Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 3.

10 Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 3.

through the entire assessment process, there were some cases where a GP should refer the person for a specialist assessment:

> Once they do present to their GPs that GP needs to recognise the significance of the problems and whether they then need to go on to have a more specialist assessment to determine whether it is a dementia and what can be done about it. A percentage of people can be managed well by GPs and in general practice but people that are presenting quite early need perhaps a bit more detailed assessment, such as what can be provided through memory clinics, to work out whether it is dementia and what type of dementia it is.[11]

5.16 Dr Lynne Barnes, a General Practitioner, advised that she would normally refer a person with memory issues to a specialist for thorough testing:

> The patient would come to see the doctor, or often a family member will come to the doctor beforehand and say, 'Look, I am having trouble with this relative.' It might be mum or dad or whoever, and then you get the patient in. I then take their history, examine the patient and look for any other sorts of medical problems and then, if I thought the patient had dementia, I would start to check for any screening tests that might be done for treatable causes for that. I would then probably refer them to one of the services we have here…
>
> … I could either refer to the dementia support worker or the psychogeriatric service. They are both based at the same place…
>
> Then we would get the visiting geriatrician to see the person.[12]

5.17 Despite GPs being the first point of contact for most people experiencing memory issues, the Committee heard there were many barriers to GPs providing a timely diagnosis of dementia.

5.18 These barriers include:

- System-level barriers/operation of the primary health care system:
  - ⇒ Medicare Benefits Schedule (MBS) item numbers;
  - ⇒ Poor remuneration; and
  - ⇒ Perceived or actual lack of available services.
- Attitudes of GPs:
  - ⇒ Nihilistic attitudes; and

11 Mrs Elizabeth Rand, Cognitive Dementia and Memory Services (CDAMS), *Official Committee Hansard*, Canberra, 21 August 2012, p. 2.

12 Dr Lynne Barnes, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 31.

- ⇒ False negative diagnoses ('it's just old age').
- Knowledge and skills of GPs:
  - ⇒ Lack of awareness about the signs of memory loss and other cognitive symptoms.[13]

5.19 The knowledge and skills of GPs regarding dementia diagnosis and treatment are discussed further in Chapter 3.

Barriers for General Practitioners

5.20 There were a number of system-level barriers cited to the Committee which were said to prevent or delay a GP's ability to diagnose dementia. These barriers included remuneration for undertaking an assessment for dementia and limitations around consultation times.

5.21 Associate Professor Mark Yates, of MDAG, told the Committee of the nature of the Medicare system, as it related to remuneration (using geriatrics as an example):

> I think the reality of the Medicare system is that you get paid well if you stick something in, through or up someone but not if you think deeply about them. That is not unique to geriatrics; that is unique to a number of the subspecialty areas such as rheumatology, infectious diseases and endocrinology, for that matter, with diabetes. Medicare has been modified to meet some of that with the additional item numbers for geriatricians; I think that has grown the number of geriatricians and that will happen over time.[14]

5.22 The AGPN observed that there was no remuneration available through Medicare for primary health care teams to consult with the carer of a person with cognitive issues such as dementia, unless the carer was seeking their own medical assistance.[15]

5.23 CDAMS supported the revision of the MBS to ensure GPs were adequately remunerated for the additional time required for the assessment, diagnosis and ongoing support of people (and their carers) with dementia. CDAMS believed this support should include

13 MDAG, *Submission 48*, p. 2; AGPN, *Submission 87*, pp. 9-11.

14 Associate Professor Mark Yates, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, p. 19.

15 AGPN, *Submission 87*, p. 11. See also: Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 1.

remuneration for the additional support provided to families, sometimes independently of patient visits.[16]

5.24 Regarding limited consultation times under Medicare, the AGPN stated:

> Assessment processes for dementia, and often provision of the comprehensive dementia management support required, cannot effectively be undertaken within the time period associated with the shorter consultation that can be claimed through the Medicare Benefits Schedule (MBS) item. Whilst there are avenues to claim longer consultations under the MBS, for both patient flow and business viability reasons, many practice systems are structured around shorter consultations. Some practices are also not aware of how to effectively use available MBS items to support longer consultations for people with dementia.[17]

5.25 Dr Catherine Yelland, of the Royal Australasian College of Physicians (RACP), said diagnosing dementia was time-consuming and did not fit well within a brief general-practitioner consultation.[18]

5.26 NSW HACC Issues Forum told the Committee that GPs had limited opportunities to monitor a person's cognitive capacity on an ongoing basis, due to the nature of consultations:

> GPs have limited opportunities to monitor peoples' cognitive capacity on an ongoing basis. GP consultation times are brief, and often do not give GPs the opportunity to pick up on signs and symptoms of dementia. People experiencing memory loss, confusion or behavioural change may be hesitant to report these experiences to their GP, or may mask these symptoms during consultations. Symptoms of dementia can thus go medically undetected for quite some time.[19]

5.27 Ms Helga Merl, of Hunter Medicare Local, told the Committee that a formal assessment for dementia could take at least an hour and a half, which was prohibitive in a primary care setting:

> The issue is that that type of assessment takes at least an hour and a half. Within primary care there are just not the funds or reimbursements to recompense somebody for spending that

16 Cognitive Dementia and Memory Services (CDAMS), *Submission 39*, p. 7. See also: RACGP, *Submission 83*, p. 7; Alzheimer's Australia (National Office), *Submission 44*, p. 15.

17 AGPN, *Submission 87*, pp. 10-11.

18 Dr Catherine Yelland, Royal Australasian College of Physicians (RACP), *Official Committee Hansard*, Sydney, 22 June 2012, p. 20. See also: CDAMS, *Submission 39*, p. 1 and p. 7; and RACGP, *Submission 83*, p. 6.

19 NSW HACC Issues Forum, *Submission 85*, p. 3.

> amount of time in primary care in a busy practice. When there are the pressures of a waiting room full of other people, being able to spend an hour and a half with someone is a luxury we just do not have.[20]

5.28 The Australian Government Department of Health and Ageing (DoHA) outlined the number of MBS items which could be utilised as part of an assessment process:

- health assessments provided for people aged 75 and older that can be undertaken annually – MBS items 701-707;
- comprehensive medical assessments in residential aged care facilities that can be provided annually;
- people of any age, with suspected or diagnosed dementia, are eligible for longer consultations using the standard General Practitioner attendance items – Level C attendance item - lasting at least 20 minutes, and the Level D attendance item - lasting at least 40 minutes.[21]

5.29 Despite the MBS items available to support diagnosis of dementia, DoHA acknowledged that many GPs were unaware of the MBS items available to assist in dementia assessment and diagnosis, and required further education in this regard:

> So there is some work to be done around how to switch GPs more on to what is available to support them in not only diagnosing someone, but also coordinating their care. I know that we have provided some information to the minister's group around what potential items on the MBS could be available for that purpose. For example, there is an annual health check for people over the age of 75, but there are also the chronic disease items which actually enable not only that sort of care coordination with a GP, but also then access and referral on to allied health services and the like.[22]

5.30 Ms Kathryn Cunningham, of Alzheimer's Australia in South Australia, agreed that the wider use of MBS items for the assessment of dementia symptoms should be promoted:

> We promote wider use of existing MBS items for the assessment and management of dementia symptoms by GPs and aged-care nurse practitioners. We recommend review of existing MBS items and, where necessary, revision or creation of new items to ensure

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20 Ms Helga Merl, Hunter Medicare Local, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 7.

21 Australian Government Department of Health and Ageing (DoHA), *Submission 89*, pp. 7-8.

22 Ms Rosemary Huxtable, Deputy Secretary, DoHA, *Official Committee Hansard*, Canberra, 8 February 2013, p. 12. See also: p. 18.

> effective payment to support identification, assessment and management of dementia in primary care, we recommend the creation of financial incentives to support cognitive screening as part of the 75-plus health assessment, and we encourage dementia related GP consultation in residential aged care.[23]

5.31 The Committee was told that a proposal was made for the funds earmarked to achieve timely diagnosis through the *Living Longer. Living Better.* aged care reforms to be used for the development, piloting and national dissemination of a training resource package for health professionals including GPs, NPs and practice nurses. The proposed training package would be implemented through Medicare Locals and include education on the use of MBS items for cognitive assessment and management of dementia.[24]

5.32 Alzheimer's Australia commented on the move:

> This is good progress but it has been much more difficult to identify Medicare Benefit Items that could be used by doctors to ensure that they are compensated for time required for diagnosis, assessment and referral of patients to services. Further work is to be done but it is clear that a "Business Plan" is needed for GPs to ensure they are able to the extent possible to use the MBS items to achieve timely diagnosis.[25]

Committee comment

5.33 At a systems level, one the main barriers to individuals receiving a timely diagnosis of dementia through their GP relates to the use of MBS Items.

5.34 The Committee heard proposals that the use of MBS items for dementia diagnosis be reviewed in consideration of the following issues:

- The need to provide adequate remuneration for the lengthy time required to undertake a diagnosis of dementia (including time to undertake a screening test);
- The need to better inform GPs about the use of MBS items for cognitive assessment and diagnosis of dementia;
- The need to provide an MBS item for carers or family members to consult with a GP or other practitioner about an individual they are concerned with regarding cognitive issues;

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23 Ms Kathryn Cunningham, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 18.

24 Alzheimer's Australia (National Office), *Submission 44.1*, p. 2.

25 Alzheimer's Australia (National Office), *Submission 44.1*, p. 2.

- The need to promote the use of a multi-disciplinary team in dementia assessment and diagnosis; and
- The possibility of expanding the use of the 75-plus assessment to include or support cognitive assessment.

5.35 The Committee comments in detail on the use of the 75-plus assessment for cognitive assessment in Chapter 4. The use of a multi-disciplinary team in dementia diagnosis is discussed later in this chapter.

5.36 The Committee notes the work already being undertaken through MDAG and DoHA to educate primary care practitioners about the use of MBS items for dementia diagnosis and assessment, as part of a broader program to achieve better rates of timely diagnosis of dementia. The Committee supports the use of the funds available through the *Living Longer. Living Better.* scheme to encourage the wider use of MBS items for dementia assessment and diagnosis, and wider training for GPs in dementia diagnosis and intervention (this is discussed further in Chapter 3).

5.37 As indicated in Chapter 4, the Committee considers there is a need to review the usefulness of existing MBS items for dementia diagnosis and assessment, to determine whether expansion of existing items is necessary, or whether further items are required to support early and timely diagnosis of dementia.

Recommendation 7

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

Barriers to specialist diagnosis

5.39 Although GPs are often the first point of contact for a person experiencing memory loss or cognitive decline, GPs or individuals often refer patients to specialists in dementia diagnosis, to assist in complex cases or to conduct a thorough assessment.

5.40 There are a number of specialists who are able to make a diagnosis of dementia. These include (but are not limited to):

- A Gerontologist – a doctor who studies old age, its diseases and phenomena;
- A Geriatrician - a doctor who specialises in the care of older people;
- A Psychogeriatrician - a doctor who specialises in mental disorders affecting older people;
- A Neurologist - a doctor who specialises in the diagnosis and treatment of disorders of the nervous system, including the brain, spinal cord and nerves;
- A Neuropsychologist - a psychologist who specialises in disorders of the brain and how they affect memory, thinking and behaviour;[26] or
- A Psychiatrist - a doctor who specialises in the diagnosis and treatment of mental disorders, emotional disturbances and thought disorders.[27]

5.41 The RACP and Australian and New Zealand Society for Geriatric Medicine (ANZSGM) explained that specialist medical care was essential at the time of diagnosis:

> Specialist medical care is especially required at the time of diagnosis; when medical acuity and/or behavioural and psychological symptoms of dementia (BPSD) increase (frequently at the midpoint of the disease); and at end of life. Geriatricians, general physicians, psychogeriatricians and neurologists are skilled at making a complete and accurate diagnosis of dementia.[28]

5.42 Associate Professor Mark Yates, of MDAG, told the Committee of the important link between medical practitioners in primary care and specialists in the diagnostic process:

> Again, going back to this concept of the connection between primary care and specialist services, when it is more complicated—which is the very early stage, as opposed to timely—with all the comorbidities that are perhaps associated with someone with a memory problem, GPs have to have somewhere nationally where someone is putting up their hand and saying, 'If you've got a problem as a GP with someone who is worried about their memory and you can't sort it out, we can do

26 For information on diagnosis via a psychologist/neuropsychologist, see Australian Psychological Society, *Submission 50*, p. 4; Leo, *Official Committee Hansard*, Launceston, 27 July 2012, pp. 1-2; Leo (Tas), *Submission 12*.

27 Alzheimer's Australia, *Early Diagnosis of Dementia*, Paper 10, March 2007, p. 3; Macquarie Dictionary 'WordGenius 4.3', February 2006 [W32], Fourth Edition.

28 RACP and Australian and New Zealand Society for Geriatric Medicine (ANZSGM), *Submission 22*, p. 6.

> it.' To make primary healthcare work well, they have to have a means by which they can have specialist help.[29]

5.43 A number of barriers to achieving a diagnosis of dementia in specialist settings were outlined to the Committee. These barriers include limited access to specialist care in regional, rural and remote areas of Australia.

Specialist diagnosis in rural, regional and remote communities

5.44 The Committee heard a number of stories from people living in rural, regional or remote communities, advising of the lack of access to medical specialists to assist in making a diagnosis of dementia.

5.45 The National Rural Health Alliance (NRHA) told the Committee:

> Poor access to primary care generally in country areas, including shortages of medical specialists and allied health professionals of any kind, let alone those that specialise in dementia, mean there is less likelihood of early diagnosis and treatment for people in those areas.[30]

5.46 The Committee heard that the only gerontologist available to see people in Moree was based in Tamworth and visited Moree approximately once every six to eight weeks.[31]

5.47 Cecilia, from Moree, who cared for her mother with Alzheimer's Disease, advised that she took her mother to see a geriatrician in Toowoomba (some 300km away), who undertook the necessary assessments and made a diagnosis of dementia. [32]

5.48 NRHA considered that innovative approaches to dementia care, such as telehealth[33] initiatives, would be required to facilitate early diagnosis and treatment of dementia in regional, rural and remote communities:

> Innovative approaches to team dementia care, such as outreach services, telehealth consultations with specialists and other work

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29 Associate Professor Mark Yates, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, p. 17.

30 National Rural Health Alliance Inc. (NRHA), *Submission 36*, p. 4.

31 Mrs Bernadette Mary Meppem, Fairview Retirement Village, *Official Committee Hansard*, Moree, 27 August 2012, p. 2. See also: Mr Mark Howland, Hunter New England Local Health District (Tablelands, Mehi and McIntyre Clusters), *Official Committee Hansard*, Moree, 27 August 2012, p. 18.

32 Cecilia, *Submission 100*, p. 1.

33 Telehealth is an initiative through Medicare which provides financial incentives to eligible health professionals and aged care services that help patients have a video consultation with a specialist, consultant physician or consultant psychiatrist. For further information, see <http://www.medicareaustralia.gov.au/provider/incentives/telehealth/>, viewed 7 June 2013.

> to complement the work of local health professionals, will be an important part of this strategy.[34]

5.49 Mrs Judy Ratajec, of Uniting Church Frontier Services, said the use of telehealth initiatives may be useful in the diagnostic process:

> You can use telehealth to help with the diagnosis—you can have with the person a clinician who has done all of the assessments and all the pathology and they can talk to a specialist to pull that together and have a conversation.[35]

5.50 Dr Robert Prowse, President of ANZSGM, told the Committee that telehealth initiatives could address the gap in care available to Australians with dementia living in regional, rural and remote locations:

> In some rural areas there is a visiting geriatrician or psychogeriatrician who goes to that place regularly and sees patients. I do that myself in Port Augusta, in South Australia. But it is a once-a-month visit. The demand is bigger than the service can provide. I am aware that there are many other places that do not have that service, that do not have a geriatrician visiting. We, I think, struggle to find people who feel they can give their time to the disruption that that causes to clinical practice back in the city. The telehealth initiatives, which are well developed in Queensland… would provide the opportunity for people to do at least some of the assessment from home. They can easily, and it has been shown that they can effectively, allow assessment and diagnosis with a general practitioner or another person with the patient at their home site and with the specialist observing from the city base.[36]

5.51 The Pharmacy Guild of Australia submitted that local pharmacies could assist in providing access to telehealth services:

> Access to telehealth will also assist in addressing some of the barriers to accessing dementia related medical services for patients in rural, regional and outer metropolitan areas. It should be recognised that in many circumstances, particularly in regional and remote Australia, the local community pharmacy may be the only available or most appropriate health service for conducting telehealth consultations. The Guild strongly believes that community pharmacy should be viewed as an 'other health care

34 NRHA, *Submission 36*, p. 5.

35 Mrs Judy Ratajec, Uniting Church Frontier Services, *Official Committee Hansard*, Broome, 13 November 2012, p. 26.

36 Dr Robert Prowse, ANZSGM, *Official Committee Hansard*, Sydney, 22 June 2012, p. 20.

> facility' in which a patient can access telehealth and video conference to a specialist at another location.[37]

5.52 The Australian Nursing Federation (ANF) also saw the potential of utilising telehealth to improve access to specialists, and recommended it also use telephone link-ups where videoconferencing was not an option:

> The ANF considers there is huge potential for the use of telehealth to improve access to specialist gerontology and/or support services for people in remote, rural and regional areas requiring cognitive assessment and dementia care. However, we believe this facility should be extended beyond use of videoconferencing techniques, to enable Medicare reimbursement to health professionals for utilising telephone link-up, where this is the only communication facility available in remote sites (or the only reliable service available).[38]

5.53 NSW Health suggested that telehealth could be utilised as part of a wider multi-disciplinary strategy in regional, rural or remote communities of Australia:

> Integrated models would need to be appropriate for rural settings and provide access for culturally and linguistically diverse and Aboriginal populations through interpreter time, outreach and liaison. In rural areas, the model would be dependent on improved access to these Medical Specialist positions, either through increasing the number of positions particularly in rural areas or improving access through recent tele-health initiatives.[39]

Committee comment

5.54 Lack of access to specialists equipped to make a diagnosis of dementia is likely to inhibit early and timely diagnosis in regional, rural and remote communities of Australia. Distance is often a significant barrier to achieving access to early and timely diagnosis of dementia in these communities.

5.55 While GPs may be equipped to make a diagnosis of dementia, GPs and other primary care practitioners may require specialist advice before a diagnosis can be made, particularly in complex cases, or where a person is young, or presenting at the early stages of the condition.

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37 Pharmacy Guild of Australia, *Submission 57*, p. 3.

38 Australian Nursing Federation (ANF), *Submission 79*, p. 7.

39 NSW Health, *Submission 95*, p. 6.

5.56 The Committee has heard stories of individuals who travelled hundreds of kilometres away from their home to obtain a diagnosis of dementia from a specialist. Others waited several months to see a visiting specialist.

5.57 There is a clear need to ensure that regional, rural and remote communities of Australia are equipped with appropriate access to specialist medical practitioners and diagnostic services, to encourage timely diagnosis and support for dementia.

5.58 The best way of gaining access to specialist services would be to encourage medical practitioners specialising in dementia diagnosis and treatment to work in rural and remote areas of Australia. However, the Committee recognises that this is often not a viable option.

5.59 Another model of care would be for primary care practitioners to work in collaboration with a visiting specialist (such as a gerontologist or geriatrician), with additional specialist support provided via telehealth.

5.60 Such collaboration could form part of a multi-disciplinary team providing diagnosis, management and support services for dementia. These multi-disciplinary teams could be coordinated through Medicare Locals, or otherwise at a local level.

5.61 The Committee notes that through the *Living Longer. Living Better.* aged care reforms, the Commonwealth will allocate $58.5 million to promote 'better practice and partnerships' and remove barriers for people with particular needs, including Aboriginal and Torres Strait Islander people and those living in rural and remote areas. This includes increasing multi-disciplinary care and introducing telehealth trials.[40]

5.62 The Committee supports the trialling of multi-disciplinary teams of care, including the use of telehealth initiatives, as a means of encouraging early diagnosis and intervention of dementia in regional, rural and remote communities of Australia.

5.63 Multi-disciplinary care is discussed further below, and in Chapter 6.

40 Australian Government, *Living Longer. Living Better.,* April 2012, p. 20.

Recommendation 8

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

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

Diagnosis in a multi-disciplinary practice

5.65 A number of individuals and organisations advocated for a multi-disciplinary system of diagnosis, treatment and management of dementia in Australia.[41] How a multi-disciplinary approach to diagnosis would operate is discussed below. How such an approach would operate post-diagnosis is discussed in Chapter 6.

5.66 The RACP and the ANZSGM support a shared-care approach to dementia diagnosis, which would involve GPs, medical specialists, nurses, pharmacists and other allied health professionals (as needed):

> A network of specialist, multidisciplinary clinics and services should be systematically resourced and comprehensively established across Australia to undertake assessment and diagnosis of cognitive impairment and dementia. It is preferable that the clinic be led by a medical specialist who will usually be a geriatrician (or geriatric trainee) and include, at a minimum, a specialist dementia nurse, social worker and/or occupational therapist and neuropsychologist/ psychologist. Currently, different memory clinic models are in operation across Australian jurisdictions.[42]

5.67 RACP and ANZSGM considered that the Victorian Government's Cognitive, Dementia and Memory Services (CDAMS) clinics represented the best model to inform a national, systematic approach to the diagnosis of dementia.[43] CDAMS provides clients (and their families and carers)

41 For example, see Alzheimer's Australia Victoria, *Submission 35*, p. 5.

42 RACP and ANZSGM, *Submission 22*, p. 2.

43 RACP and ANZSGM, *Submission 22*, p. 2.

with access to specialist multi-disciplinary assessment and diagnosis, advice, referral and education.[44]

5.68 Mrs Elizabeth Rand, of CDAMS, called for the wider introduction of memory-clinic style models as a means of supporting GPs in diagnosis:

> We feel that the introduction of memory-clinic-style services more broadly would provide an engine room for supporting primary care and GPs, as GPs remain the first port of call for most people when they first develop symptoms and are wondering what is going on, and they also remain the central figure in coordinating all of a person's health care. So CDAMS can support them in that role with regard to cognition and dementia.[45]

5.69 Mrs Rand explained the usual process of diagnosis in CDAMS:

> With the CDAMS model, when they get referred to us generally they have an initial assessment by a community nurse or an OT or a social worker that goes and sees them in their home…
>
> … Generally that is a face-to-face appointment that might take an hour and a half to two hours. Following that they come in and see one of the medical specialists; that might be a neurologist or a geriatrician or a psychiatrist, depending on what their presentation is. They will spend about an hour and a half with them doing some cognitive testing, a physical examination and a bit more history taking. After that, if it is still not clear what is going on, in our service we have neuropsychologists and they can do some very detailed testing…[46]

5.70 Dr John Ward, a Geriatrician, also advocated for the introduction of a shared-care system for dementia diagnosis and intervention across Australia, based on the model operating in the Hunter/Newcastle area of NSW. Dr Ward submitted:

> It is a shared-care program with general practitioners, designed around locally based Community Dementia Nurses (CDNs) who work within ACATs, together with a Geriatrician who has responsibility for that community as part of the workload…
>
> …The Geriatrician sees people referred by GPs while the CDN sees people with cognitive impairment referred to ACAT or directly to her from any source. The CDN assists the Geriatrician with the clinic which allows patients and families to be interviewed separately and also provides more complex cognitive

44 CDAMS, *Submission 34*, pp. 3-4.

45 Mrs Elizabeth Rand, CDAMS, *Official Committee Hansard*, Canberra, 21 August 2012, p. 1.

46 Mrs Elizabeth Rand, CDAMS, *Official Committee Hansard*, Canberra, 21 August 2012, p. 2.

> assessments e.g. RUDAS, Adas-Cog, ACE-R, etc. The CDN is available to follow-up clinic clients via home visits to complete the assessment and to provide education, information and carer support in a more family-friendly environment.[47]

5.71 Dr Ward noted that as part of the multi-disciplinary model, the CDN and Geriatrician worked closely with GPs, providing feed-back on assessments, management plans and case management.[48]

5.72 NSW Health considered that GPs and practice nurses could be supported through integrated multi-disciplinary care models where dementia health experts, such as CDNS and/or allied health professionals could undertake a comprehensive assessment, with access to medical specialists if diagnosis was unusual or difficult.[49]

5.73 Mrs Sharyn Bannister, from the Central Coast Local Health District, explained the purpose of their memory screening service:

> Our memory screening service was set up to support local GPs with the diagnosis of dementia. The service goes into a home and completes cognitive screens such as the Addenbrooke Frontal Assessment Battery, anxiety and depression scales, the carer stress screening tool, and functional assessment and histories. All information is documented in a report and sent to the GP. We do this because we know GPs are extremely time-poor, and diagnosing dementia is difficult. It is not like other diseases. The indicators for dementia are varied, and all other diseases must be considered and ruled out.[50]

5.74 Associate Professor George Razay established the Launceston Memory Disorders Clinic. Associate Professor Razay believes that a memory disorders clinic is the most cost effective way to provide early diagnosis and treatment for individuals:

> These have contributed greatly not only to raising the awareness of the community about memory problems and dementia but also to changing the stigma about dementia in general and Alzheimer's disease in particular. This has led to patients with memory disorders and carers seeking early diagnosis and treatment. It is

47 Dr John Ward, *Submission 5*, pp. 1-2.

48 Dr John Ward, *Submission 5*, p. 2.

49 NSW Health, *Submission 95*, pp. 5-6. For 'good practice' examples of multi-disciplinary models in the Central Coast region, see NSW Health Central Coast District, *Submission 106*, pp. 1-2.

50 Mrs Sharyn Bannister, Central Coast Local Health District, NSW Health, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 42.

> reflected in our data, which shows that about 50 per cent of my patients in the memory clinic have mild cognitive impairment.[51]

Committee comment

5.75 A multi-disciplinary approach to dementia care has been advocated to encourage early diagnosis, as well as to facilitate early and appropriate treatment, management and support once a diagnosis is made.

5.76 The Committee notes the numerous explanations of multi-disciplinary memory clinics and other multi-disciplinary teams who provide diagnostic services and support for people experiencing symptoms of memory loss or cognitive decline.

5.77 The following features exist within the multi-disciplinary teams evidenced before the Committee:

- Clear and established links of communication and referrals between the specialist memory clinic and GPs;
- Visability, which promotes greater awareness of dementia and encourages people to undertake assessments early;
- Utilising Nurse Practitioners or other health professionals to undertake a comprehensive assessment, including comprehensive screening, preferably at a person's home;
- Access to specialist review and assessment, when required; and
- The ability to make referrals to ongoing treatment and support services such as Alzheimer's Australia.

5.78 The Committee considers there is merit in exploring a nation-wide multi-disciplinary system of dementia diagnosis and intervention, noting that the system would need flexibility, to ensure the model provided appropriate services and support to individual communities around Australia.

5.79 A multi-disciplinary approach, encompassing diagnosis, treatment and support of dementia is discussed further in Chapter 6.

Specialist nurses

5.80 As discussed above, the Committee heard that a specialist nurse, such as a Community Dementia Nurse (CDN) or Clinical Nurse Specialist was considered an essential member of any multi-disciplinary team tasked with dementia assessment and care.[52]

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51 Associate Professor George Razay, Launceston General Hospital, *Official Committee Hansard*, Launceston, 27 July 2012, pp. 13-14.

52 For discussion on specialist nurses, see Royal College of Nursing, *Submission 61.*

5.81 Professor Brodaty suggested that one way to address the time-consuming nature of diagnosis was for specialist nurses to assist GPs:

> Most GPs have a practice nurse who could do a lot of the screening. They could be supported by a clinical nurse specialist. So, there could be a network at primary level which would lead to earlier diagnosis.[53]

5.82 Alzheimer's Australia echoed this view:

> GPs work under time and financial constraints, and are in short supply in many parts of the country, particularly in rural and regional areas. As such, there is both a need and an opportunity to do more to improve identification, assessment and management of dementia by facilitating the involvement of appropriately trained and experienced nurses and other allied health professionals. This is also important because nurses and allied health professionals are often amongst the first to encounter people with early signs of dementia.[54]

5.83 Ms Helga Merl, a Transitional Nurse Practitioner, told the Committee of her role within the Hunter Medicare Local, in the assessment process for dementia:

> My role is to take referrals from GPs and practice nurses of people they feel are at risk of dementia, people who have identified with early symptoms, and they are thinking, 'I am really not sure what to do, or I do not have that time, so I would like to refer over for someone to be able to do one of those complex assessments.' I would be able to do those assessments, including a physical exam and making recommendations for the pathology, the blood tests required to look at reversible causes.[55]

5.84 Ms Merl advised that specialist nurses were able to guide practice nurses and GPs through the diagnosis process and proposed that a NP in dementia operate at each of the Medicare Locals across Australia.[56]

5.85 The ANF indicated that the NP role was growing within the aged care sector and could be utilised effectively in dementia diagnosis:

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53 Professor Henry Brodaty, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, pp. 20-21.

54 Alzheimer's Australia (National Office), *Submission 44*, pp. 15-16. See also, Kathryn Cunningham, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 18.

55 Ms Helga Merl, Hunter Medicare Local, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 7.

56 Ms Helga Merl, Hunter Medicare Local, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 8 and p. 10.

> The expertise of these clinicians enables them to identify and diagnose early stage dementia, and to prescribe the appropriate treatment modalities. This also applies to Nurse Practitioners in the mental health field.[57]

5.86 Ms Pauline Armour, of UnitingCare Ageing (NSW and ACT), envisaged practice nurses taking a lead role in engaging with people in health assessments for people over 70 years of age. Ms Armour recommended that the number of NP trained with a cognition focus be increased.[58]

5.87 Mrs Kylie Wood, a specialist occupational therapist appearing in a private capacity, considered that one way to promote early diagnosis and intervention was to develop opportunities to extend the scope and role of nursing and allied health professionals to be able to diagnose dementia:

> Nurse practitioner positions in dementia specific roles is an achievable option to overcome GP reluctance and ability to diagnose accurately and rule out all differential diagnoses which would have possibly reversible symptoms and different disease prognoses.[59]

Committee comment

5.88 It is clear from evidence provided throughout this inquiry that specialist nurses, such as CDNs, NPs, and Clinical Nurse Consultants, play a crucial role in the timely diagnosis and ongoing management of dementia.

5.89 The Committee heard there was an opportunity to expand the use of dementia care specialist nurses (whether NPs or other specialist nurses), via an accredited training program or other such workforce development program. The Committee supports this proposal and agrees that expanding the use of multi-disciplinary teams in dementia diagnosis, treatment and support is an important step in encouraging early diagnosis and intervention of dementia.

5.90 The Committee will discuss the further engagement of specialist nurses as a case manager for people with dementia and their carers, in Chapter 6.

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57 ANF, *Submission 79*, p. 5.

58 Ms Pauline Armour, UnitingCare Ageing, New South Wales and ACT, *Official Committee Hansard*, Sydney, 14 June 2012, p. 13. See also, The College of Nursing, *Submission 28,* regarding the potential to create specific dementia training courses for nurses.

59 Mrs Kylie Wood, *Official Committee Hansard*, Launceston, 27 July 2012, p. 6. See also: Denise Chaston and Kylie Wood, *Submission 52;* Alzheimer's Australia (National Office), *Submission 16,* pp. 8-9.

Recommendation 9

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

Barriers to diagnosis in acute care

5.92 In a report produced by the Australian Institute of Health and Welfare (AIHW), it was noted that identification and reporting of dementia was often poor in hospitals. The following reasons were cited for this under-identification:

- Difficulties of detection and diagnosis of dementia, given the presentation of other medical conditions;
- The brevity of interactions between doctors and patients;
- The potential inability of people with dementia to report symptomatic behaviour as a result of cognitive impairments; and
- Clinical and administrative issues.[60]

5.93 Ms Merl considered that it would be difficult to provide a diagnostic service within a hospital, because of the presentation of acute conditions:

> Often it is a delirium that people will have in hospital and, of course, that can be misdiagnosed—when we are talking about misdiagnosis—as a dementia. But a delirium is because there is something wrong with you, an illness that is causing your brain to not function well. Once you get rid of that cause—and the most common cause of delirium in older women is a urinary tract infection; in hospitals it will be surgeries, it will be falls, it will be lots of things—then often there is no dementia underneath that… [61]

5.94 Dr Stephen Brady, of Alice Springs Hospital, told the Committee that access to the appropriate diagnostic tools was not always available in a hospital setting, in areas such as Alice Springs:

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60 Australian Institute of Health and Welfare 2013, *Dementia care in hospitals: costs and strategies*, Catalogue no. 72, p. 9.

61 Ms Helga Merl, Hunter Medicare Local, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 12. See also: Associate Professor Mark Yates, *Submission 13*, p. 1.

> In terms of early diagnosis, the earlier you try to diagnose the better your tools need to be, and access to complex diagnostic procedures and personnel is not always available. Doing complex psychometric testing in a younger person who you think may be demonstrating early signs is not always available. An MRI scan is not available here—we have to send people 1,500 kilometres away. For the younger patients we are often talking about people who may have mixed morbidity diseases, which may be causing memory impairment, and that expertise is not always easily available.[62]

5.95 Ms Julie Johnston, of Kimberley Aged and Community Services, advised that there were processes and evidence-based guidelines (in the Kimberley region) within which medical and allied health teams could work to diagnose and treat dementia in hospitals. However, the use of these processes was inconsistent and depended on the level of staff knowledge and experience. She noted the application of these protocols was more consistent in regional hospitals, than in smaller hospitals.[63]

5.96 As the focus in hospital care was on getting people well and getting them home again, Dr Brady advised that follow up with patients was limited, once they were discharged from hospital. Dr Brady told the Committee:

> We are aware that, when we are getting them home, we are often getting them home to somewhere that is a long way away and without a lot of resources. We try to do what we can but we do have a very limited window in which we can do it. We would like to be able to hand on things to be done in the community but it does not always happen. For example, yesterday I saw a gentleman of 85 who had been admitted from one of the communities in South Australia with acute confusion. We had looked after him three months ago with an acute confusional episode, which was recovering. We wanted a dementia assessment when he returned to the community in that three months. It did not get done.[64]

5.97 Ms Johnston said that she knew of instances where a diagnosis of dementia was made in an acute hospital setting without undertaking any pre-work:

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62 Dr Stephen Brady, Alice Springs Hospital, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 6.

63 Ms Julie Johnston, Kimberley Aged and Community Services, *Official Committee Hansard*, Broome, p. 9.

64 Dr Stephen Brady, Alice Springs Hospital, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 8.

> … often, when a client comes into an acute hospital, a diagnosis may be made for dementia without any prework. It is a diagnosis that is put on when it could be a lot of other things. It could be delirium…
>
> … with something else, quite acutely ill. But a diagnosis is made of dementia without any substantiation of it.[65]

5.98 Ms Johnston advised that the ideal referral process within a hospital setting involved a formal assessment (with geriatrician or psychogeriatrician input) to confirm the diagnosis, before referring the individual on to the best placed community-care service provider.[66]

Committee comment

5.99 The Committee was told that a hospital is often the first health setting where a person presents with cognitive issues. However, due to the nature of acute care, a diagnosis of dementia is often overlooked.

5.100 There are a number of barriers which prevent a diagnosis of dementia being made in hospitals. These barriers include the limited interactions between a patient and medical practitioners, limited hospital resources, and a lack of connection between the hospital, the community and primary care services.

5.101 It is vital that medical practitioners within hospitals are appropriately educated and resourced to identify symptoms of dementia in a hospital or acute setting when they present, and make appropriate referrals for follow-up assessment and treatment once a person is discharged.

5.102 It was proposed to the Committee that all hospitals have Clinical Nurse Specialists in dementia to provide staff education, carer support and important links into the community for the person with dementia on discharge.[67] This proposal is discussed further in Chapter 6.

5.103 Wider issues of awareness and education regarding dementia are discussed in Chapter 3.

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65 Ms Julie Johnston, Kimberley Aged and Community Services, *Official Committee Hansard*, Broome, p. 9.

66 Ms Julie Johnston, Kimberley Aged and Community Services, *Official Committee Hansard*, Broome, p. 9.

67 Associate Professor Mark Yates, *Submission 13*, p. 1.