

Quality Dementia Care :

**No time like
the present:
the importance
of a timely
dementia
diagnosis**

Acknowledgements

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Quality Dementia Care Standards: No time like the present: the importance of a timely dementia diagnosis

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Foreword

The first step in addressing the health care needs of individuals with dementia is to provide an accurate and timely diagnosis. Unfortunately a timely diagnosis is not the experience of many people with dementia, their families and carers, and improving the capacity of the current primary care system to do better is a high priority for consumers.

Market research commissioned by Alzheimer's Australia indicates that over 90% of Australians say they would be likely to visit their GP if concerned about their memory. For that reason, an important part of the advocacy of Alzheimer's Australia in recent years has been to urge the Federal government and stakeholders in primary care to take action to better support GPs in the diagnosis, assessment and ongoing management of dementia. While individuals will vary in the choices they make, most people concerned about their memories and their families take the view that early intervention is necessary if they are going to be able to properly plan their finances, lives and care for the future.

To have effective primary health care for dementia, attention needs to be focused on adequate incentives and training for GPs and practice nurses to secure an appropriate response to those presenting with cognitive impairment, be that independently or through referral from family or other health care providers. Primary care should be able to address the chronic disease elements of dementia such as counselling, access to community base support, medical management of emergent disorders and legal and driving issues.

Alzheimer's Australia is working to ensure that these issues are properly addressed between stakeholders and the Federal government. Meanwhile, this publication is a step towards assisting GPs in achieving the important goal of timely diagnosis.

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Lastly, I should like to thank the authors of this report for writing this publication.



Glenn Rees
Alzheimer's Australia



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Introduction

The purpose of this paper is to outline the steps involved in the diagnosis of dementia and to promote timely diagnosis. This paper is aimed at general practitioners, practice nurses, other health professionals, policy makers, academics and those people concerned about their memory or that of a family member or friend. This paper updates and extends the Alzheimer's Australia paper, Early Diagnosis of Dementia (March, 2007).



What is dementia?

Dementia is an umbrella term for a range of conditions (see 'Types of dementia'). It is characterised by loss of memory, and impairments in thinking and problem-solving capabilities. Features may include impairment in language, memory, perception, and cognitive skills. These may result in loss of intellect, personality, rationality, social skills and normal emotional reactions [1-3]. Dementia results from degeneration of nerve pathways and the conditions associated with it are typically progressive [1,3].

Types of dementia

There are many different causes and, thus, types of dementia. The most common is Alzheimer's disease, which is associated with distinctive changes in the brain tissue in the form of 'tangles' and 'plaques'. While Alzheimer's disease can develop in younger people, it is most common after the age of 65 years. It accounts for at least 50 per cent of cases [1].

Vascular dementia is thought to be the second most common form of dementia and is associated with problems of blood circulation in the brain. It may account for up to 20 per cent of cases [1].

Mixed dementia, which contains elements of both vascular dementia and Alzheimer's disease, is also common. Elements of Alzheimer's disease and vascular dementia are often both present upon autopsy [2].

'Dementia with Lewy bodies' accounts for about 15 per cent of all dementias [1] and is marked by fluctuating alertness and attention, hallucinations, falls and Parkinsonism or slowing of, and increased stiffness of, movement.

Frontotemporal dementia typically occurs between the ages of 45 and 65 years and can involve profound personality and behavioural changes and/or language impairment. It accounts for approximately 5 per cent of cases [1].

There are many other possible causes of dementia including alcohol-related dementia, Parkinson's disease, Huntington's disease and Creutzfeldt-Jacob disease. An accurate diagnosis helps to maximise benefits from appropriate treatment, and enhance understanding about prognosis and symptoms.

A person complaining of memory loss or other cognitive changes, which are present on testing but not severe enough to have dementia, may be classified as having a Mild Cognitive Impairment (MCI). MCI is a relatively new concept and more research is needed to understand the relationship between MCI and later development of dementia. MCI does not always lead to dementia and can improve, even reverting to normal. Regular monitoring of memory and thinking skills is recommended in individuals with this diagnosis.

Common symptoms^a

The symptoms of dementia are not always obvious to the person or their family and friends. The early symptoms can include memory problems, difficulties in word finding and thinking processes, changes in personality or behaviour, a lack of initiative, and changes in day to day function at home, at work or in taking care of oneself. Symptoms will differ according to the type of dementia. As the condition progresses, symptoms may become more obvious and could include:

- increased memory loss
- decreased ability to perform routine tasks
- impaired judgement and ability to understand concepts or follow a plot
- learning and concentration difficulties
- altered sleeping patterns
- eating disturbances
- disorientation to time and space, and getting lost in familiar places
- focal neurological signs
- muscle rigidity [1].

How common is dementia?

In Australia, the number of new cases of dementia (incidence) is estimated to increase from 75,000 in 2010 to 385,000 in 2050 [1]. The total number of people with dementia in Australia (prevalence) is projected to increase from 257,000 in 2010 to over one million in 2050 [4]. Dementia prevalence is strongly age-related and, with an ageing population, it is estimated that the number of cases of dementia will more than double to around 565,000 over the next 20 years [4].

According to the Australian Bureau of Statistics (ABS) [5], dementia and Alzheimer's disease was the third leading cause of death in 2008, having risen from sixth in 2003, and from seventh in 1999.

The ABS reports the number of deaths due to dementia and Alzheimer's disease to have increased 138 per cent from 3,427 in 1999 to 8,171 in 2008.

^a This paper does not include detailed information about all of the warning signs and it is recommended that consumers consult other sources for this information. Visit the Alzheimer's Australia website at www.alzheimers.org.au for comprehensive information about dementia and care and available education and training.



Risk factors associated with dementia

Many risk factors have been associated with dementia. Some are firmly established, while others remain unconfirmed and are the subject of ongoing research [1]. Drawing on a comprehensive literature review, Woodward et al. [6] presented the following risk factors for Alzheimer's disease:

| WELL ESTABLISHED | LIKELY | LESS LIKELY |
|---|--|--|
| Old age | Hypothyroidism | Depression |
| Genetic factors: <ul style="list-style-type: none">- Down Syndrome- Apolipoprotein E status- Genetic mutations (rare)- Family history of Alzheimer's disease | Vascular risk factors: <ul style="list-style-type: none">- Smoking currently- High blood pressure- Diabetes (generally Type 2)- Atrial fibrillation- Obesity in mid life | Elevated homocysteine (a by-product of chemical reactions in the body) Fatty diet |
| | Head injury (especially more severe) | |
| | Low level of education | |
| | Low birth weight for gestational age | |

The risk factors for vascular dementia include many of the above plus male gender, cardiac disease or major cardiac surgery, obesity, stroke, family history of vascular disease and elevated cholesterol. As yet, no amenable risk or protective factors for dementia with Lewy bodies and frontotemporal dementia have been identified [6].

Protective factors associated with dementia

According to Woodward et al. [6], actions that may reduce the risk of developing dementia include control of the following factors:

- **Nutrition** – moderate to high intake of polyunsaturated and monounsaturated fats is associated with reduced risk for dementia. It is not yet clear whether B12 or folate supplementation reduces the risk, but it is prudent to check for and treat any deficiencies of these vitamins [6]. While there is no convincing evidence that antioxidants prevent dementia, it does not mean they are ineffective, rather there is currently a lack of evidence. Some studies suggest that omega-3 fatty acids (for example, fish oil) may reduce risk of dementia [7], as could mild to moderate alcohol consumption^b[8]. A high intake of saturated fat is a risk factor for Alzheimer's disease and vascular dementia [6].
- **Activity** – several observational studies have found an association between physical activity in mid to late life and a lower risk of cognitive decline and dementia. Physical activity has numerous health benefits and may reduce cardiovascular risk factors, improve blood flow to the brain and possibly stimulate nerve cell growth and survival [6]. Cumulative activities over a day, are found to be protective, and include those that involve socialising, mental activity and leisure such as: walking for pleasure or excursion; going to the cinema or to a restaurant, sporting venue, club, or church; community or volunteer work; visiting relatives or friends, and having visitors ; going to classes; reading, watching TV, listening to the radio; knitting, music or other hobbies. Woodward et al. [6] also note that numerous studies suggest a high level of education is associated with a lower risk. It seems

that complex mental activity throughout all stages of life may reduce the likelihood of developing dementia [11].

- **Vascular risk factors** – high blood pressure in mid-life has been identified as a risk factor . Treatment of high blood pressure appears to reduce the risk of cognitive decline and dementia. Diligent reduction of high blood pressure and regular monitoring are recommended throughout mid and later life [6]. High cholesterol and type 2 diabetes in mid-life are also risk factors for dementia [12,13]. Regular monitoring of blood cholesterol and blood sugar levels from mid-life and effective treatment of hypercholesterolaemia and diabetes are also recommended. Current smoking is a risk factor [14] and more research is needed to clarify to what extent smoking cessation reduces the risk of dementia.

Some doctors suggest that further research into the limitations of existing studies is needed before any recommendations on interventions to reduce dementia risk can be made [15]. However, others highlight there is good evidence that preventative strategies including physical, mental and social activity together with good nutrition and control of vascular risk factors may reduce the risk or delay the onset of dementia [16]. Encouraging people of all ages, and particularly those in their forties and fifties, to reduce their risk of dementia will enhance physical health as well as brain health and can do no harm. Further information about the risk factors for dementia, including helpful advice about what might be done to reduce risk, is available from Alzheimer's Australia's Mind your Mind[®] program^c.

^bAlcohol intake associated with a lower risk of dementia appears to range from 1 up to 4 standard drinks per day [9,10].

^cInformation and resources on dementia risk reduction are available from the Alzheimer's Australia website at www.alzheimers.org.au



Treatment of dementia

There is currently no cure for dementia. However, better understanding of the changes that occur at the molecular and cellular levels has led to the development of drug treatments that can slow the worsening of the symptoms of Alzheimer's disease [3,17,18]. In Australia, four drugs are approved for the treatment of Alzheimer's disease. Donepezil, rivastigmine and galantamine are cholinesterase inhibitors that make more of the neurotransmitter acetylcholine available at brain synapses, and help to enhance memory function [19]. Memantine acts on the neurotransmitter glutamate and can relieve symptoms in middle and later stages of Alzheimer's disease [20].


Medical comorbidities such as diabetes and hypertension must also be managed. Preventative primary care through vaccination, personal hygiene, restful sleep, hydration, nutrition, and dental care is important [16].

Psychosocial treatments and support are also beneficial. People with dementia need emotional and practical support. Their safety must be ensured, for example, by providing support for those who live alone, supervising their medication doses, and preventing wandering or driving if necessary. Care to assist them with functional losses in daily activities will eventually be required. Physical, mental and social activity and stimulation should be encouraged and maintained to avoid de-conditioning [16]. Dementia carers also require support, especially education about dementia and its progression. They need professional support in providing activities, overseeing medication, managing crises and handling problem behaviours, all of which require availability and input from dementia care professionals [16].



Diagnosing dementia

Obtaining a diagnosis of dementia can be a difficult, lengthy and intensive process. While circumstances differ from person to person, everyone has the right to:

- A thorough and prompt assessment by medical professionals
 - Sensitive communication of a diagnosis with appropriate explanation of symptoms and prognosis
 - Sufficient information to make choices about the future
 - Maximal involvement in the decision-making process
 - Ongoing maintenance and management
 - Access to support and services.
- 



What are the benefits of a timely diagnosis?

- Checking concerns about cognition – changes in memory and thinking ability can be very worrying. Symptoms similar to dementia can be caused by several different diseases and conditions, some of which are treatable and reversible, including infections, depression, medication side-effects or nutritional deficiencies. The sooner the cause of these symptoms is identified, the sooner treatment can begin. A medical review of any symptoms and identification of the cause of symptoms can bring relief.
- Planning and assistance – timely diagnosis enables persons with dementia and their families to receive help in understanding and adjusting to the diagnosis of dementia, and allows them to prepare for the future. This might include making legal and financial arrangements, changing living arrangements, and finding out about aids and services that will enhance quality of life for the person with dementia and their family and friends. Timely diagnosis can give the person an active role in decision-making and planning, while family members can educate themselves about the disease and learn effective ways of interacting with the person with dementia.
- Treatment – timely diagnosis allows for prompt access to medications and medical attention. There is evidence that the currently available medications for Alzheimer's disease may be more beneficial if given early in the disease process. In some people, these medications can help to maintain daily function and quality of life as well as stabilise cognitive decline. However, they do not help everyone and they are not a cure.

- Health management – general practitioners need to remember the possibility of dementia in people with multisystem disease. Early stage dementia can be overlooked when the patient seeks consultation for other conditions. A diagnosis can also help in the management of other symptoms that may accompany the early stages of dementia, such as depression or irritability. Factors that might exacerbate cognitive problems can be checked for and treated. For example, vascular risk factors, poor nutrition, lack of stimulation and activity and some medications can contribute to cognitive impairment.
- Medication review – a person with dementia needs to have a medication review. Some medications, such as anticholinergics, can exacerbate dementia symptoms. Memory problems may interfere with a person remembering to take important medications such as those for diabetes, heart disease or high blood pressure. A Webster pack can help to simplify administration of medication.

Current practice in diagnosing dementia

In specialist practice, the diagnosis can be made at a syndromal level – that is, there is dementia – and at a disease, or aetiological level e.g. there is Alzheimer's disease or Lewy body dementia. The accuracy of the diagnosis of dementia syndrome is very high, with doubt only occurring in a small percentage of cases usually at the borderline of normal, or MCI. The diagnosis of aetiology, even in specialist clinics, is about 90% accurate against post-mortem confirmation – though this is improving with new biomarkers identified [21]. However, in primary care diagnosis is more challenging. Findings from a variety of sources and tests

must be pooled before a diagnosis can be made, and the process can be complex and time consuming. Even then, early in the course of the disease, uncertainty may still remain, and the diagnosis is often conveyed as “possible” or “probable”.

Practitioners involved in diagnosing dementia may include:

- The General Practitioner (GP) – is usually the first contact when concerns about thinking or memory arise. The GP takes a medical history, may carry out a brief test of memory and concentration, and organise further investigation.
- Specialist Geriatrician/ Memory Clinic – the GP may refer to this service in many cases.
- Clinical Nurse Specialist in Dementia – a nurse who undertakes assessments for the detection of dementia.
- The Practice Nurse (PN) – a nurse who works in a General Practice and whose role includes identification and assistance in the assessment processes (such as aged care health assessments), support for patients and carers, and networking with community services.

If the person is still concerned about his or her thinking or memory after a GP consultation, a referral to a specialist for evaluation is appropriate. It is important to remember that the choice is up to the patient, who can ask the GP for a referral.

Specialists involved in diagnosing dementia may include:

- Geriatrician – a medical practitioner who specialises in the care of older people.
- Old Age Psychiatrist (Psychogeriatrician) – a psychiatrist who deals with mental

health issues in people aged from 65 years, and people younger than 65 years with age-related mental health problems, such as younger onset dementia.

- Neurologist – a medical practitioner who specialises in the diagnosis and treatment of disorders of the nervous system, including the brain, spinal cord and nerves.
- Clinical neuropsychologist – a psychologist who specialises in the assessment, diagnosis and treatment of disorders associated with conditions affecting the brain.
- Psychiatrist – a medical practitioner who specialises in the diagnosis and treatment of mental disorders, emotional disturbances and thought disorders.

Such specialists have a detailed knowledge of the memory and behaviour changes associated with dementia. They may perform or arrange for in-depth assessments, brain scans and blood tests.

In Australia, a specialist medical practitioner must confirm the diagnosis of Alzheimer’s disease for a patient to be eligible for subsidised Alzheimer’s medications.

Other assessment options may include:

- Aged Care Assessment Teams (ACATs) - multidisciplinary teams often comprised of social workers, occupational therapists and physiotherapists, nurses and doctors. ACATs are usually based in hospitals or regional community health centres. ACATs assess the health needs of ageing individuals, put the individual in contact with relevant services, make recommendations about the level of care required, and approve eligibility for certain services.
- Memory clinics - incorporate a range of specialists in the diagnosis of dementia.



While they provide diagnostic services for all types of dementia, they may also offer specialist services for younger onset or rare forms of dementia. Memory clinics are known as Cognitive Dementia and Memory Services (CDAMS) in Victoria.

Web-based cognitive tests are becoming available. There are ethical and professional issues relating to the use of these tests. For example, are the instructions understood? How should scores be interpreted? Have the tests been validated? Useful information about dementia symptoms may be available on quality websites, but diagnosis remains a process that must be undertaken by a qualified health professional.

The process of diagnosis

The first step is to assess symptoms with a thorough medical history, physical examination, and evaluation of memory and thinking abilities. Other causes of dementia-like symptoms must be ruled out through laboratory tests and in some cases, brain scans. Conditions that can produce dementia-like symptoms include:

- Neurological problems such as stroke, brain tumour, head injury
- Mental disorders such as depression, delirium
- Abnormal function of liver, kidney, thyroid, hormonal system
- Nutritional deficiencies and anaemia
- Other causes such as poor eyesight or hearing, severe constipation, side effects of medication, diabetes or infections.

If these conditions are ruled out and symptoms meet the criteria for a dementia, a later step in the process is to determine the cause of the dementia. Common causes include Alzheimer's disease,

vascular dementia, dementia with Lewy bodies or frontotemporal dementia.

Medical History

A complete medical and family history is required along with details of current problems. Questions will be asked about forgetfulness, orientation, problem solving, coping with everyday life, mood, alcohol consumption and medication usage. It needs to be established when the change in function was first noticed, whether the change was sudden or gradual and whether the person's difficulties are getting worse. Determining the onset and progression of symptoms can help to differentiate types of dementia. Descriptions of the person's difficulties from family members, obtained if the person consents, are vital in the diagnosis process.

Medical Testing

Medical tests sometimes used in the diagnosis of dementia include blood, urine and genetic tests, and brain scans. Blood or urine tests can exclude other causes of dementia symptoms by testing for infections, vitamin and nutrient levels, as well as kidney, liver and thyroid function. Genetic testing is only performed in rare cases where there is a family history of younger onset dementia, and is currently not a common practice in the diagnosis of dementia. Although researchers have identified some more common genes, such as ApoE 4, that increase the risk of developing Alzheimer's disease, these genes do not cause the disease. Currently available genetic tests for ApoE 4 do not reliably aid in predicting who will develop Alzheimer's disease, so are not routinely conducted.

Investigations

Brain scans can be used to detect brain abnormalities such as tumour, stroke or brain haemorrhage, brain shrinkage (atrophy) and increased pressure of fluid in the brain. Routine brain scans, which include computerised tomography (CT) scans and magnetic resonance imaging (MRI)^d, are relatively non-invasive procedures that produce an image of the brain. Brain scans do not always show abnormalities in people diagnosed with dementia, as sometimes there are no visible changes in the brain. Sometimes, brain scans can be used to help determine the type of dementia. A person with vascular dementia might show evidence of strokes or other vascular changes in the brain, whereas a person with Alzheimer's disease might show evidence of brain shrinkage in certain regions.

Other types of brain scans are used in specialist or research settings. Positron Emission Tomography (PET) is a type of functional brain imaging^e. Single Photon Emission Computed Tomography (SPECT) is a brain scanning technique that can show changes in blood flow. Functional Magnetic Resonance Imaging (fMRI) provides information about brain function as well as structure and is typically used in research studies. It is likely that these will become more commonly used in diagnosis in the future.

Psychological Evaluation

Mood can influence cognition and the symptoms of depression can often be mistaken for dementia. Consequently, tests of mental wellbeing may be included in the diagnosis process. These may involve interviews or questionnaires to ask about the presence of symptoms of depression or anxiety.

Cognitive Evaluation And Screening Tests

Tests of cognitive functioning are obviously very important in the diagnosis process. These tests are used to determine the extent of any memory or thinking problems and can be used to track progression over time.

Initial dementia screening tests can be quite brief and simple, such as the person giving the date, copying a diagram, learning a short list of words, or naming common objects. Common brief assessments include the Mini-Mental State Examination (MMSE) and the Brief Cognitive Rating Scale. These screening tests may also include gaining information about the person from their carer or support person. Currently, the MMSE is used for determining whether someone is eligible for subsidised prescriptions of medications for treating Alzheimer's disease. The Dementia Outcomes Measurement Suite (DOMS) provides more information about these and other tests [22].

^dCT scanning involves use of specialised x-rays to generate a 3-D image of brain structure and is useful to rule out other causes of symptoms. MRI uses a strong magnetic field and radio waves instead of x-rays to produce a 3-D image. MRI can be used to rule out other causes, find characteristic patterns of brain damage, and differentiate between types of dementia.

^eFor further information see the podcast from Austin Health in which Professor Chris Rowe discusses PET and detection of cognitive decline in our aging population: www.austin.org.au/podcasts



Recently developed screening tests include:

- The General Practitioner Assessment of Cognition (GPCOG) – a quick, valid, and efficient test for dementia screening in primary care that can use informant information if necessary [23]. Brodaty and colleagues also note that the GPCOG scores appeared to be independent of the patient's Geriatric Depression Scale (GDS) score, a popular test for diagnosis of depression in the elderly.
- The Rowland Universal Dementia Assessment Scale (RUDAS) – a simple screening tool that tests multiple cognitive domains and appears unaffected by gender, years of education and seems culturally fair. It was developed using culturally diverse study populations and advisory groups [24].
- The Kimberley Indigenous Cognitive Assessment - includes several subsections including a cognitive assessment section (KICA-Cog) and a briefer cognitive screen (KICA-Screen) that can be used in conjunction with carer input (KICA-Carer) [25]. It is a valid dementia test for older rural and remote dwelling Indigenous Australians that does not appear to be affected by educational level.
- The Montreal Cognitive Assessment (MoCA) – a brief cognitive screening test which also has a high sensitivity and specificity for detecting Mild Cognitive Impairment (MCI) [26].
- The MiniCOG – composed of a three item recall and clock drawing. It has been established as an effective routine screening test for use in primary care practice [27].

Brief screening tests can be followed up by more detailed neuropsychological tests (for example, the Cambridge Cognitive Examination – CAMCOG), which explore different areas of function such as memory, language, reasoning, calculation and ability to concentrate [28]. Some people perform well on brief screening tests but memory and thinking impairments may be found with more comprehensive testing. In other cases, people who have performed more poorly on brief tests may be found not to suffer from dementia on more detailed screening. The more detailed tests are able to distinguish between different patterns of decline and are therefore important in helping to identify the type of dementia affecting the person^f. There are also tests used in drug trials, such as the Alzheimer's Disease Assessment Scale Cognitive test (ADAS-Cog), which are not used for screening.

^fFor more information about different types of dementia, please see the Alzheimer's Australia web page on Types of Dementia at www.alzheimers.org.au



Experiencing a diagnosis of dementia

A diagnosis of dementia is an emotional time for both the person with the illness and for those caring for them. Bamford and colleagues [29] found that following disclosure, studies reported feelings of shock, anger and fear and negative effects on self-esteem and confidence, whilst non-disclosure (or a vague or possible diagnosis) was confusing, upsetting and difficult to understand. Positive impacts from disclosure, such as an end to uncertainty and confirmation of suspicions, were also reported.





Recent research conducted by Pond et al. [30] captured benefits and disadvantages of diagnosis for both the person with the dementia diagnosis and their carer or support person. An excerpt from this project revealing carers' experiences is shown below:

An important benefit is early access to medication which may delay the progression of the disease:

"And I know there is medication that can be put into place if you catch it early" (10LR).

Early awareness of a person's diagnosis was important for carers. This knowledge allowed them to prepare for the future management of caring for the person with significant memory problems:

"I would much rather know that there are medical issues or possible you know Alzheimer's issues or dementia or something along that line so that we can get up to speed get things in place and be pro-active in dealing with it... for a whole range of reasons more to do with myself than anything else" (28TB).

The participant above indicated that timely and relevant information on issues such as support networks and dementia services was also important. However, like this participant, other carers reported difficulty accessing information. It was suggested that a central information point to direct people to the appropriate service was essential:

"I'm just sort of finding that there's no kind of system that I could go to, an information session or get a briefing as to now that we've transitioned to this level and you're sort of the primary support person, these are the sort of things that you might need to consider and these are the services that

are available and here's how you qualify for them. Like an information package" (28TB).

Not everyone appreciated the benefits of receiving a diagnosis. A carer perceived that she had to shield her husband from the negative connotations of dementia. Consequently, using the term "memory loss" was preferable to "Alzheimer's":

"He's still got his wits about him in a lot of ways. And I just didn't want to present him with the word Alzheimer's. Because it has connotations that you know, ah are not particularly nice so I thought well we'll just leave it that he's got a memory loss problem and, and leave it at that" (27PM).

Findings from this project also provided insight into how carers perceived the experience of caring for the person with dementia [30]:

Carers reported providing more or less care, depending on the progression of the dementia. At a minimum, and where the carer believed the dementia to be mild or even non-existent, a carer might provide "emotional support" or care that was "very basic at this stage." In this instance, a stepdaughter provided: daily phone contact, transport, financial/money management, medication management and some assistance with household cleaning.

Carers also emphasised the need for vigilance, particularly in relation to monitoring/ surveillance of a person with dementia:

"Well, I won't let him go anywhere on his own. We always go out together, come home together" (3.MT.W).

"I just feel I've got to watch him" (8.JL.W).

"I've got to keep any eye on things when she's cooking the lunch; when she puts things on the griller; she's got a habit of leaving the griller turned on and walking away. She turns the gas off at the main, but then next time she comes to turn the stove on the gas is still on and she can't smell the gas and so, one of these days she'll probably blow herself up" (62 IW).

Despite a person experiencing early stage dementia, there were carers who were adversely affected by the person's memory impairment. For example, fearful for what his wife may or may not do if he left her alone for a long period of time, the carer below restricted his leisure time:

"Well I've got to be around a bit. I do leave her and I, I'm confident. Like I go and have a game of golf occasionally and play a game of bowls and I can go down the street, go and see a mate. ... she doesn't mean to be molly coddled if that's what you mean and I don't need to be there twenty four hour service, but I wouldn't leave her on her own for any length of time, I think she'd forget to take her medicine I'd reckon" (9.JF).

If constant visual contact was not possible, some carers developed strategies to address the problem. A daughter described the systems she had put into place to monitor her mother:

"Well actually, she lives in a little rumpus room about two metres away, across like a patio and then it's the house, so she's got a room like that. And we have a baby monitor, because we used to have a door bell and she used to forget to ring the door bell for help and so now we've got a baby monitor and we can hear every movement almost (chuckle)" (40.HS).

Local and overseas research suggests that there are significant delays from symptom onset to diagnosis of dementia. For instance, in Europe the average time to diagnosis after the caregiver first noticed symptoms was 20 months, with caregivers waiting, on average, 47 weeks before bringing the affected person to the attention of a physician [31]. In Australia, families first notice symptoms of dementia an average of 1.9 years before the first health professional consultation and there was an average of 3.1 years before a firm diagnosis was made, which was consistent with other overseas studies [32]. The consequence of this delay is a lost opportunity for earlier medical and social interventions for those suffering dementia and their families [32].

Barriers to diagnosis

Speechly et al. [32] identified two areas of delay in diagnosis: prior to, and following, the first consultation with a health professional. Some carers initially arranged support instead of seeking medical advice. The stigma associated with dementia and the misinterpretation of symptoms also contributed to the delay. Some carers perceived that their concerns raised in the initial consultation with a health professional were dismissed, symptoms not acted upon, or referral delayed. Recent research has explored this latter aspect [33].

Paterson and Pond [33] conducted an extensive literature review to identify the most frequently cited barriers to diagnosis and disclosure of dementia. These included:

- GP limitations - difficulties in differentiating normal ageing from dementia; a perceived lack of need to determine a specific diagnosis; GP lack of confidence or training; and risk of misdiagnosis.



- Practical limitations – a paucity of specialist diagnostic services, especially in rural areas; lack of a recognised, quick-to-administer screening tool; limited consultation time; and the patient’s impaired ability, which hinders an accurate history and participation in self-care.
- Negative attitude to dementia – the stigma associated with dementia; doubts about the efficacy of medications; a perception of the patient as unable to comprehend or cope with the diagnosis, and the risk of detriment to the doctor-patient relationship.

Their research also suggested that involving the practice and community nurses in the diagnostic process may overcome some of the barriers and improve detection rates.

The GP’s perceptions of barriers to timely diagnosis of dementia have also been explored [34]. It seems that in the consultation context, patients and GPs often have competing health priorities, and that GPs are reactive and rely on patients to alert them to their issues [34]. This can be problematic for dementia sufferers who may lack insight into the problems they are experiencing. Often the carer or family member of the patient is the person who alerts the GP to possible dementia. Consequently, should someone live alone, the absence of this information from a carer or family member can hinder the diagnostic process. Also, diagnosis is particularly difficult in carers who develop cognitive impairment themselves, as consultations often focus on their caring responsibilities. Furthermore, GPs become used to treating existing illnesses and do not look for new emerging pathology. Patients and carers may value being perceived as coping with their situation more than they desire diagnosis or treatment – a reflection of the value placed on stoicism in our culture.

For some people, other barriers to diagnosis, especially to a timely diagnosis, include the belief that memory problems are a normal part of ageing, the perceived stigma attached to dementia, the lack of a cure, and fear about the future. Timely diagnosis and awareness about dementia are the first steps in designing management strategies. As more effective treatments become available in the future, timely diagnosis will become even more important.

Pond et al. continue to conduct research into barriers to the process of disclosure regarding dementia diagnosis. An excerpt from research in progress appears below:

“You’re not really seeing what’s going on.”(GP)

The GP consultation occurs in a time limited context which is not conducive for identifying dementia – *“it’s really difficult to do on someone you’ve never met before in a 15 minute interview ... if they’re in the early stages of it, you can’t possibly know”* (GP#9) – *“unless they behave erratically in the room”* (GP#17). Furthermore, other health concerns may cloud the issue: *“if there is something like anxiety or depression coexisting...[it] makes it difficult for us... you do only see them in that...brief little time they come in with their...scripts”* (GP#7).

“The patients mask it particularly well.”

People with early dementia may perceive their memory decline as part of the normal ageing process and not as a health issue. They may hold negative connotations of becoming old and forgetful and try to present themselves in the best possible way; they want to be seen to be coping. Nonetheless, *“the hardest thing is if ...*

the person's got obvious memory loss and they either, or their family, have chosen to significantly ignore it...Then trying to bring it up...it makes it harder" (GP#8).

"Giving bad news... no one likes [to do it]"

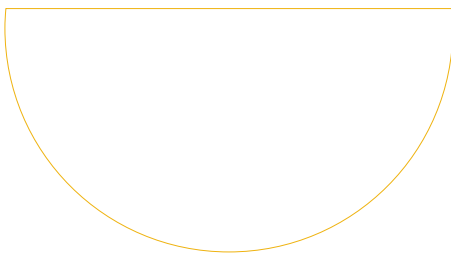
Most GPs considered that patients were often *"fearful of the diagnosis"* (GP#7), *"they don't want to be told that. No. Memory problem, no. Alzheimer's, please don't tell me that"* (GP#5). However, disclosure was largely deemed essential – *"Patients rights come to the fore...to know ... as with any condition"* (GP#15). In the main, GPs favoured conveying the diagnosis to the patient with the patient's family/carer(s) present.

"I find it better to do so with other family members there."

When patients were accompanied by family/carer(s), often the family/carer(s) would be the focus for information so that they could understand the disease. In turn, this knowledge would help them support the patient. A diagnosis of dementia has *"implications for the patient and the family"* (GP#15) *"and most... carers actually really ...want to know what they can do about it"* (GP#6). It was important for the carer to be informed and understand about dementia to help them cope with the consequences of the disease: *"The best piece of advice... is to actually explain why they're doing that and they're not actually lying, that they don't have that piece of information, so they're filling it in with something else. Once the carer understands why they're saying what they're saying and doing what they're doing.... that seems to help the carers*

more than anything" (GP#11). However, informing about dementia was further complicated by *"the unpredictability of the decline"* (GP#21). *"Everyone can fluctuate. One day they're quite good, another day they're terrible"* (GP#5).

Multiple factors interplayed when disclosing the diagnosis of dementia. Communicating the diagnosis sensitively suggested the underlying stigma attached to the 'dementia' label. The GPs appeared sensitive to the negative connotations the word 'dementia' implied and tended to couch their disclosure of the diagnosis in other phrases: *"I don't mind disclosing the diagnosis, because I don't disclose it as dementia, I disclose it more as memory impairment"* (GP#10); *"I don't think you necessarily need to use the words dementia or Alzheimer's disease.... words like 'memory loss' or 'memory not working as well as it used to' are euphemisms that are quite useful"* (GP#13); *"Memory impairment or cognitive decline seems to be a bit safer.... There is some stigma, there's also.... a lot of fear associated with dementia"* (GP#21). Overall, disclosure was *"about maybe confirming people's fears, then trying to give them a constructive way to move on"* (GP#19).



Solutions to the barriers

Professor Henry Brodaty [35, p.1-2] identified six reasons why early diagnosis does not occur and suggested possible solutions⁹. These are summarised in the table below:

| OBSTACLES TO A DIAGNOSIS OF DEMENTIA | POSSIBLE SOLUTIONS: |
|--|---|
| Personal unawareness. | Increase awareness about dementia and the significance of memory impairment. |
| Personal reluctance to seek help. | Raise public awareness. Reduce stigma in the community and dispel the myths surrounding dementia. |
| A belief that memory loss is an inevitable part of ageing – and training at least half of the people presenting to their GP with memory loss do not receive a diagnosis of dementia – it's just 'old age'. | More education for GPs. |
| Non referral for specialist opinion. Reasons may include: lack of awareness by GP, unavailability of specialist services, financial impediments. | May include: more education for GPs, improved relationships between GPs and specialists, better access to specialist services (e.g. telepsychiatry for rural or remote services), improved communications/ links between health practitioners and organisations involved in the diagnosis and management of dementia. |
| Lack of management plans. | Education for health practitioners, for patients and families about the availability of management possibilities. |
| Medication not prescribed – GPs' lack of awareness of antidementia medication, or a lack of conviction of their efficacy. | Education about the use of medication, advocacy for reimbursement for antidementia medication. |

⁹For a good review of the benefits of timely diagnosis, please see "Six reasons why timely diagnosis of dementia does not occur and ten reasons why it should" by Professor Henry Brodaty [35].

After the diagnosis

Timely diagnosis of dementia is the first step in understanding and managing the condition. Communicating a diagnosis of dementia can allow for planning to begin. Although many people with early stage dementia will initially feel 'shattered' by the diagnosis, many also say they feel a sense of relief that the cause of their difficulties is identified, and knowing the diagnosis can increase their sense of independence and enable an active role in planning for their future. It can be difficult to take in information at the time of diagnosis, so scheduling another GP consultation time to talk about the diagnosis, possible benefits of medication and side effects, and referral to support services is important. Should the person with dementia have a support person, it will generally be helpful for them to be involved and attend these consultations. The carer can be an important source of information about changes in behaviour and other concerns, and can help the person with dementia to gather information.

It is important to encourage persons with dementia and their families and carers to consider using the information and support services offered by organisations such as Alzheimer's Australia. Both parties will need ongoing sources of support as the condition progresses and behaviours change. The GP may be well placed to monitor the mental and physical health of the person and their family carers as the care burden increases. Similarly, the GP may encourage planning around ceasing driving and use of alternative transport as functional deficits and driving risk increases.

If the GP is concerned about any tension between privacy considerations and the care relationship, the Office of the Privacy Commissioner is available to provide advice.

Life doesn't stop with a diagnosis. Quality of life can be maintained, as there are many available sources of support, which can help the person with dementia as well as their family and friends. Alzheimer's Australia provides assistance and support.



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