



Diagnosing Dementia

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Foreword

I would like to thank the National Ageing Research Institute and the University of Melbourne for undertaking this reference paper on Diagnosing Dementia at the request of the Alzheimer's Association Australia.

The Alzheimer's Association Australia as part of its new strategic plan has set the objective of greatly increasing the priority given to policy work. We believe this reference paper will be helpful in promoting a better understanding among consumers and those working in the health and aged care industry of the issues surrounding the diagnosis of Dementia.

The Association is grateful to Janssen-Cilag for their willingness to fund papers of this kind.

Dr Robert Yeoh
President
Alzheimer's Association Australia
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Executive Summary

Dementia is the word commonly used to describe problems such as forgetfulness or confusion, and it is usually thought of as a problem of old age. Although many definitions of dementia exist, most include impairment of cognition, social and occupational functioning and performance in activities of daily living. The many advances in the understanding of dementia and related disorders are contributing to improved methods of assessment and diagnosis of those with cognitive impairment. Dementia is usually chronic and progressive, with various stages of severity. There are more than 70 diseases that cause dementia, although Alzheimer's disease (AD), vascular dementia (VaD), dementia with Lewy bodies (DLB) and combinations of these account for between 80-90% of cases. Although younger people can have dementia, it more commonly occurs in later life with the prevalence doubling every five years between age 60 and 85. Due to the increasing population in older age groups, the number of people with dementia in Australia is expected to triple between 1999 and 2041.

Alzheimer's Association Australia commissioned the National Ageing Research Institute to develop this summary of the current research and clinical evidence of diagnosing dementia. This paper aims to provide some practical information about the complexity of diagnosing dementia. This will be helpful for people who may want to seek a diagnosis, for health professionals and others working in the aged care field, and for Government.

Early diagnosis

The accurate and early diagnosis of the cause of cognitive impairment and dementia has many benefits. There are a number of potentially treatable conditions, including depression and delirium, that can resemble dementia or coexist with dementia. It is important that these conditions are identified and treated to either reverse the cognitive impairment or improve the prognosis and progression of dementia. Early diagnosis also has many other benefits for people with dementia, their families and carers, including sharing the problem with an expert and understanding the reasons for behaviours. Early diagnosis can maximise the possibility that families and carers receive counselling and support in the early stages of the disease progression. It can help people plan for the future and make decisions relating to power of attorney and future living arrangements and can facilitate access to medical treatment. There are a number of medications that can relieve symptoms and lead to improvements in thinking, performance of daily tasks and reduce hallucinations and delusions for some people with mild to moderate dementia.

Although there are many benefits for identifying dementia early, the diagnostic process is complex and usually involves a combination of tests and investigations to assess change over time and the presence of other conditions, such as depression and delirium. There are a number of screening tests, such as the Mini-Mental Status Examination (MMSE), which can determine whether someone may have cognitive impairment and therefore require a comprehensive assessment to investigate possible underlying causes. There are a number of diagnostic criteria that aim to assist clinicians and researchers in assessing cognitive impairment. The aim of these criteria is to identify a set of characteristics that must be present or absent to determine whether dementia or a specific disease that causes dementia is probable. The information that carers

and families can provide about the person's behaviour and memory, are an essential element of an assessment and usually the only way of discovering changes over time.

Specific assessments

Other aspects of a diagnosis can include assessments of behaviour, function, and cognition. A functional assessment involves consideration of what daily tasks a person can undertake and how to increase independence in these tasks. Neuropsychological assessments consider aspects of cognition, including memory, recognition and concentration. These tests are usually paper-based or computerised questionnaires and help to determine which part of the brain may be affected and which disease is causing dementia. These tests can provide a baseline from which to measure change and progression of the disease over time. Behavioural tests can vary in nature but can include depression, hallucinations, delusions, apathy, anxiety, anger, aggression, agitation and sleeping disorders. Care needs to be taken when interpreting many of these tests as they can have biases in relation to education level and cultural background.

X-rays and other investigations

Radiology also plays an important role in the diagnostic process. Computed Tomography (CT) is a relatively quick and non-invasive process where soft tissue in the brain is scanned to produce three-dimensional images of the brain. It is used primarily to rule out other conditions, such as strokes and tumours. Magnetic Resonance Imaging (MRI) provides greater detail than CT and appears to be able to assist in the differentiation of mild cognitive impairment from AD. It also has a role in eliminating other conditions. Many new techniques involving radiology, electroencephalography, blood and cerebrospinal fluid may prove beneficial as assessment techniques of the future. At present genetic testing is in its infancy and is appropriate for only a very small number of people with dementia. Genetic testing presents serious ethical implications for families and clinicians. At present autopsy is the most accurate means of confirming a diagnosis of dementia.

The team approach

An accurate assessment, which also has useful outcomes for people with dementia, their family and carers, needs to combine a number of methods. A multidisciplinary team, such as those within memory clinics, ensures that a comprehensive assessment is undertaken and provides an effective way of managing the testing and diagnostic processes. Alzheimer's Association, General Practitioners (GPs) and Aged Care Assessment Teams (ACATs) can also play key roles in the provision of information, initial assessment and ongoing management of dementia, and in ensuring that the needs of the person with dementia, their family and carers are met throughout the course of the disease.

There are other important issues relevant to diagnosing dementia. For instance, what is the best way to tell people with dementia their diagnosis? There is increased complexity and often greater impacts associated with younger onset dementia, especially when the person with dementia is in paid employment and has dependent children. Accurate measurement of the progression of dementia has become more significant with the introduction of cholinesterase inhibitor drugs for treatment of mild to moderate stages of AD and the eligibility

requirements for subsidised prescriptions. The need for more culturally sensitive and appropriate assessment and management of dementia is also evident.

Summary

An accurate and early diagnosis of dementia is both complex and important. Future research may potentially enable delayed onset, slower progression, prevention or even cure of dementia as our understanding of the disease processes increases. However, current medication, behavioural, environmental and social support strategies are important for promoting independence and quality of life for people with dementia as well as their families and carers. The move towards a more positive public awareness reflects the next stage of encouraging the community to view dementia with more optimism and hope. This is a document that will contribute to this increased awareness.

1. Introduction

Dementia is the word commonly used to describe problems such as forgetfulness or confusion, and it is usually thought of as a problem of old age. Although many definitions of dementia exist, most include impairment of cognition, social and occupational functioning and performance in activities of daily living [1]. Dementia is caused by numerous brain disorders and is usually chronic and progressive [1]. As definitions usually imply a decline from previous levels of function (including intellectual, emotional and cognitive), diagnosis needs to determine *change in* rather than just *present level* of function [2]. Changes in behaviour can also provide indicators for differentiating which condition is the cause of dementia.

There are more than 70 diseases that can cause dementia [3, 4], although Alzheimer's disease (AD), vascular dementia (VaD), dementia with Lewy bodies (DLB) and combinations of these account for between 80-90% of cases [5]. When diagnosing, it is just as important to eliminate non-dementia conditions as to determine which disease or diseases are present. Different types of dementia have different treatment strategies [4].

Due to the nature of dementia and the large number of diseases that cause dementia, diagnosis can be a difficult and slow process. At present the accuracy and sensitivity of diagnosis of AD using careful assessment of clinical presentation, signs and symptoms, is in the range of 80-90% [6]. A definite diagnosis of the cause of dementia is not possible without autopsy.

Dementia has a major impact on the lives of people with dementia, their families and carers. Dementia, with its progressive nature, can be viewed as a series of stages from mild to severe. Each stage presents new challenges and requires families and carers to learn and adapt to new situations [7]. The extent to which help is needed from community and social support services varies, as does the need for residential care options.

Dementia mainly affects older people, although some people may develop symptoms in early middle age. The prevalence of dementia increases with age, doubling every five years between age 60 and 85, so that over 20% of people over 80 years of age have some form of the disease. Due to the increasing proportion of the population in the older age groups, the prevalence of dementia in Australia is expected to increase from 148,000 in 1999 to 258,000 in 2021 and 450,000 in 2041 [8]. Although few studies on incidence rates in Australia have been carried out, one study found that for mild dementia in the 75-79 year age group, 43 people per 1000 are diagnosed with dementia each year compared to 170 people per 1000 90 years and over [9]. Findings from the mid-term review of the National Action Plan for Dementia Care, indicate that 45% of people with moderate to severe dementia are living in residential aged care facilities and that three quarters of those living in the community live with others [3].

This paper focuses on the complex issue of diagnosing dementia. It considers the importance and beneficial aspects of early diagnosis, the different techniques that may be used during an assessment and who is likely to carry out these assessments. A number of important ethical issues in assessing

dementia are briefly discussed in later sections. This paper aims to provide some practical information about the complexity of diagnosing dementia for people who may want to seek a diagnosis, for health professionals and others working in the aged care field, and for Government. It also highlights some areas that require further investigation. Before these topics are addressed, the main conditions that cause dementia are briefly described.

1.1 Description of the different types of dementia

Dementia is an organic brain syndrome characterised by loss of intellectual ability. These abilities commonly include memory and language skills, social interaction, reasoning, planning, decision-making and emotional responses. Many symptoms are shared by a number of different types of dementia. In addition to those detailed below, depression, acute brain syndrome, psychotic disorders, progressive supranuclear palsy (PSP), Huntington's disease, Creutzfeldt-Jakob disease, a range of encephalopathies, and many other conditions, have symptoms that overlap with the major types of dementia. Since some of these are treatable conditions, it is important that they are differentiated from dementia. There are several forms of dementia, distinguished from each other with varying degrees of diagnostic accuracy on the basis of a complex array of functional, clinical and pathological factors.

Studies exploring the prognosis of dementia vary considerably ranging from 3.3 to 9.3 years with the disease [10]. Determining a prognosis for any one individual is difficult due to the range of diseases that cause dementia and the difficulty in establishing when the dementia began. As dementia also increases in prevalence in the older age groups, differences in life expectancies between people who have dementia and those who don't may be very small [10]. Many therapies can be used that focus on the abilities that people with dementia still have, improving their quality of life and that of their families and carers. The following sections provide an overview of the main types of dementia. Before this, however, Mild Cognitive Impairment, which is often a precursor to dementia, will be briefly described.

Mild Cognitive Impairment (MCI) is often defined as a cognitive state in the transition from normal ageing to dementia [11]. Although this definition implies a continuum of cognitive decline, this is not always the case and some people with apparent MCI will never develop dementia. Some possible causes of MCI include physiological changes of ageing, the functional consequence of depression or drug induced states, degeneration of the brain or early AD [11]. Its presence is usually established through evidence of memory impairment relative to age, preservation of general cognitive and functional abilities, and absence of dementia [12]. Ability to carry out activities of daily living is not significantly influenced by the presence of MCI [13]. Many studies of MCI consider its relationship to AD with the aim of determining the likelihood of MCI developing into AD. Detecting AD in its early stages has gained greater importance as treatments that have been found to be beneficial for mild and moderate stages of AD are becoming available (refer to section 3.3). A number of studies have found that 10-15% of people with MCI develop AD per year [11, 12]. There is sufficient data to recommend the evaluation and clinical monitoring of persons with MCI due to their increased risk for developing dementia [14].

Alzheimer's disease (AD) accounts for about 60% of people with dementia [15]. Usually developing after the age of 65 years, AD is an insidious and progressive disease causing a gradual decline of mental abilities including memory, judgement, abstract thinking and other intellectual functions [16]. Personality changes may appear as the first symptoms in the early stages, with behavioural and cognitive changes developing as the disease progresses. In later stages, people with AD may become totally mute - inattentive, unresponsive and dependent on families and carers. Diagnosis is essentially a clinical one that involves, taking a history, using a range of psychometric and behavioural measures and brain imaging techniques. Although it is important to exclude any conditions that may mimic AD, the pattern of symptoms is characteristic. Definitive diagnosis can only be confirmed by post-mortem presence of characteristic plaques and tangles in the brain tissue. What causes AD is still not fully understood although some contributing factors have been elucidated. As there is no apparent single cause, it is better regarded as a syndrome for which a number of possible risk factors have been proposed. These include genetic factors (see 2.9), ethnicity, education and intelligence levels, lifestyle and environmental factors.

Vascular dementia (VaD), formerly referred to as multi-infarct dementia, accounts for 10-20% of those with dementia. VaD is caused by infarction or "strokes" (sudden loss of blood supply to regions of the brain), cardiovascular disease, cerebrovascular diseases and haemorrhage. Unlike AD, it usually progresses in a fluctuating stepwise manner after an abrupt onset triggered by specific cerebral damage. In the case of small vessel dementia (one of several subtypes), however, the disease can be insidious and progressive. It is commonly accompanied by other neurological disorders such as weakness in limbs, exaggerated deep reflexes, abnormality in eating patterns, hypertension, partial one-sided paralysis, sensory defects (for example visual deficits), loss of voluntary motor control, depression and mood changes. Diagnosis of VaD is somewhat easier than of AD because generally the clinical and pathological symptoms are clearer. Brain imaging techniques are effective in localising areas of damage, and clinical symptoms provide a basis for differentiating VaD from other dementias [17]. VaD often coexists with AD and in these cases the condition is usually referred to as a 'mixed dementia'. In mixed dementia, VaD is thought to promote the clinical expression of AD. The relationship between the two is an area that requires further study [18].

Dementia with Lewy bodies (DLB) accounts for almost 10% of dementia diagnoses. It is a form of dementia associated with the growth in the brain of intracellular bodies (Lewy bodies) that are not completely understood. Clinical features include rapid onset and progression of socially and occupationally debilitating cognitive decline over a 1-4 year period. It is marked by fluctuating cognition, visual and auditory hallucinations and motor features in common with those of Parkinson's disease [19]. Other features include frequent falling, syncope (sudden loss of blood pressure leading to swoons or unconsciousness), sensitivity to neuroleptic drugs, delusions and memory impairment. The pathology of DLB is difficult to differentiate from that of AD as it shares common features. Nonetheless the sometimes diffuse growth of Lewy bodies in cortical and/or subcortical structures is a primary component of the

pathology. Accurate clinical diagnosis is made according to criteria established only in the last decade. Further refinement of these criteria is needed to improve diagnostic procedures generally. The potential for brain imaging methods in DLB diagnosis is yet to be convincingly demonstrated.

Frontotemporal dementia (FTD) typically occurs earlier than AD and VaD, commonly occurring between 45 and 65 years of age. Approximately 50% of people with FTD have a family history of dementia in a first-degree relative (e.g. parent). Some cases of FTD are associated with genetic abnormality in the tau protein gene on chromosome 17. The major differentiating clinical features of FTD include profound personality changes and a diverse range of dysfunctional social behaviours. Mood and emotional disorders typically foreshadow behavioural and cognitive decline in which speech becomes less frequent, eventually leading to mutism. Severe impairment of information processing, planning and organisation takes place together with increasing inflexibility in both mental activity and daily routine. Repetitive behaviours, wandering, deteriorating personal care and hygiene and inappropriate actions are characteristic of FTD. These symptoms result from atrophy (degeneration) of neural tissue in the frontal and anterior temporal regions of the cortex [20]. Such degeneration in some cases may be detected using modern brain-imaging methods capable of localising the areas of damage. The clinical behaviours differ to some extent according to the precise area of atrophy.

It is thought that **excess alcohol consumption** may play a role in the onset of dementia, although it is not a common outcome [21]. There are other well-known cognitive impairments associated with alcoholism, such as Wernicke-Korsakoff syndrome, which to some extent may be reversible with abstinence and by addressing nutritional deficiencies (e.g. thiamine).

1.2 The importance of early diagnosis of dementia

Diagnosing dementia is a complex task. At its core there are two key elements involved:

- ensuring that other conditions that show similar symptoms are identified or eliminated; and
- differentiating which disease(s) is (are) causing dementia.

There are many factors that make diagnosis complex. For example, multiple diseases that cause dementia can co-exist and non-dementia conditions, such as depression, can occur concurrently with dementia. Other conditions such as hypertension or diabetes may exacerbate cognitive impairment and, therefore, optimum management of these conditions is desirable.

Cognitive impairment can be a result of dementia, delirium, depression or other underlying conditions such as intellectual disability. In comparison to dementia, the likelihood of treating and alleviating delirium or depression is greater [22]. With this in mind, the accurate identification of factors that lead to cognitive impairment is particularly important to ensure that conditions or symptoms that can be treated are.

1.2.1 Depression

Depression can be difficult to differentiate in a person with dementia as the two often coexist. In standardised clinical studies, an average of 20% of memory clinic patients with dementia also have depression [23]. Identifying a past history of depression may help the diagnostic process [4].

1.2.2 Delirium

Delirium can be confused with dementia because it has a similar impact on cognitive functions including orientation, attention, memory, planning and organisation skills. Although the presentation of delirium is the same whether or not dementia is present, the key to its diagnosis is the fluctuating and acute onset [24]. For example, an older person with an acute medical problem such as a urinary tract infection may also present with confusion, memory and other cognitive problems. Sometimes delirium can persist after removal of the organic cause. Delirium is often the result of multiple causes with between 2-6 factors present in any case. Age, pre-existing cognitive impairment, severe illness and multiple medications are all strong predictors of delirium [24].

Recognition of delirium, depression and other potentially treatable disorders is often neglected when coexisting with a primary dementia. It is important, however, to identify and treat these disorders as they can affect the prognosis and progression of dementia [4].

1.2.3 Early diagnosis

There are important benefits of an accurate and early diagnosis of dementia and its causes. Despite this, people with dementia, their families and carers often wait many years before seeking a diagnosis [25]. One study found that spouse carers were reluctant to get a diagnosis of dementia because they believed:

- there was a stigma associated with dementia;
- there was no cure for dementia;
- little could be done to help; or
- memory problems were a normal part of ageing. [26]

Some of the difficulties that people with dementia, their families and carers experience when trying to obtain a diagnosis include: misdiagnosis, dismissal of concerns by General Practitioners (GPs) and other health professionals, and lack of information. These difficulties can lead to ineffective and inappropriate treatments. Misdiagnosis can easily occur when a person with dementia presents themselves well to their doctor. General social and language skills are often maintained in the early stages so it is possible for people to present as having no problems if conversation is at a superficial level or with someone who does not know the person well. Particularly for those living alone, impairment may not be discovered until a crisis occurs. There is also the problem that an early diagnosis can be difficult to make and not all health practitioners are experienced in this area. There are also strong societal attitudes that, somewhat inappropriately, attribute any memory or cognitive decline to 'normal ageing'.

A diagnosis of dementia can be a stressful experience that brings the realisation of a progressive and incurable disease that impacts on the person's social standing and perceptions of themselves [25]. There are also the potentially negative impacts of being 'labelled' as having dementia and the implications for

everyday activities such as driving and social relationships [27]. Despite this, there are many benefits of an accurate and early diagnosis.

A diagnosis of dementia can have some initial positive emotional benefits such as relief to someone whose problem has now been identified and recognised [25]. People with dementia, their families and carers may also feel that their reports of difficulties are now acknowledged. The involvement of a professional who can share and understand concerns can also provide relief to all involved [25]. A diagnosis can enable families and carers to have a better understanding of their relatives' behaviours. Strategies can be introduced to reduce negative reactions that the person with dementia may encounter [25]. Early diagnosis can maximise the possibility that families and carers receive counselling and support in the early stages of the disease progression [3]. Education and its potential benefits can be maximised with the early detection of dementia. There is evidence to suggest that programs that aim to alleviate the difficulties associated with being a carer of a person with dementia can improve their health related quality of life [28] and delay institutional care [29]. Early intervention appears to increase a carer's use of strategies in coping [30] and can also assist the person with dementia to maintain independence and quality of life.

Early diagnosis has many practical benefits such as enabling people with dementia and their families and carers to plan for the future and organise their financial affairs [25]. Decisions relating to power of attorney and planning for future living arrangements can be made [31]. Detection of dementia influences decisions relating to rehabilitation programs and provision of aids and services [27].

The process of determining a diagnosis of dementia usually involves a number of assessments that also aid adjustment. Assessment of function by an occupational therapist is not only useful for informing the diagnostic outcome, but enables identification of strategies to reduce risks, maximise independence in daily tasks and identify necessary modifications of the home environment to maximise function [31]. Assessment of driving ability is also important and diagnosis can allow preparation for the eventual or more immediate cessation of driving privileges [31].

A diagnosis of dementia can also facilitate access to medical treatment. Although no cures have been developed for most causes, there are a number of medications that can relieve symptoms of dementia. Treatment with newer medications has been found to show improvements in clear thinking, daily tasks and reducing hallucinations and delusions for some people with mild to moderate dementia [32]. There are also medications available for managing secondary symptoms such as depression and difficulties in sleeping.

2. Current practice for diagnosing dementia

The following sections describe the different mechanisms and tests that may be carried out during an assessment of suspected dementia. A diagnosis of dementia may not require all the various types of assessments to be completed and in the clinical setting this would rarely occur. However, it is important that the diagnostic process is comprehensive and includes a combination of assessments to improve the accuracy of diagnosis [33]. There are a few key elements, including carer report and tests of cognition, that every person should have. The identification of family and carers' needs is also an essential element of an assessment.

As there are a large number of paper based tests used for diagnosing dementia in Australia, the aim here has not been to identify individual tests but to highlight the key aims of assessment, what is likely to be involved and some of the limitations of these assessments. Some general points about tests of cognition, function in daily activities, behaviour and depression are described briefly. It is important that these tests are valid (measure what they are supposed to measure) and reliable (measure this in a consistent way). It is also important that bias in relation to education, cultural background and age have been identified and accounted for. It has been argued that many cognitive tests are not appropriate for older people due to the length of time they take to complete, their reliance on speed and their content [34]. There are also many tests for which age standardised norms have not been developed. The content of tests often reflect Western society values and norms, increasing the likelihood of poor performance for different cultural groups that do not relate to or recognise these characteristics. Education level and intellectual ability are also important factors as low scores may reflect low education levels rather than brain damage [4, 34]. An individual test score needs to be interpreted rather than used in a rigid way to classify a person as having dementia or not.

Research using a variety of biological techniques and approaches has expanded our knowledge and understanding of dementia. Some techniques have made a useful contribution to diagnostic procedures, others have little to contribute to diagnosis at this stage but have important research applications. These are described in sections 2.7 –2.10.

2.1 Who diagnoses dementia?

An assessment of dementia has two key processes, firstly to determine the condition causing the symptoms (whether to rule out dementia, or determine which disease is causing dementia) and secondly to assess the needs of the person with dementia and their family and carers [33].

The GP is usually the first health professional an older person will consult when they need assistance [3] and will often play a key role in the diagnostic process and ongoing care of the person with dementia, their family and carers. Since November 1999, GPs have been able to claim Medicare rebates for completing health assessments of Australians aged 75 years and over and of Aboriginal and Torres Strait Islander people over 55 through the Enhanced Primary Care Initiative (EPCI). These assessments aim to enhance the role of general practice

in the primary health system. These comprehensive assessments go beyond a routine physical examination and have a health promotion focus. They also include a screen for dementia. It has been argued, however, that the time used to complete these screens for dementia could be more usefully spent gathering patient history [35]. There are also “concerns regarding the training that GPs have been provided in the use and interpretation of the assessment tools required by the EPCI” [36]. Nevertheless, the detailed health assessment process can be a useful way for GPs to undertake a more comprehensive review of the health of an older person.

Aged Care Assessment Teams (ACATs) are multidisciplinary teams that are located in public hospitals and community health centres on a regional basis across Australia. They generally include a combination of a Geriatrician, Registered Nurse, Social Worker, Occupational Therapist and Physiotherapist [3]. ACATs focus on the assessment of the physical, medical, psychological and social needs of older people, including those with dementia, and their families and carers, linking them to appropriate support services [33]. ACATs also play a key role in approving eligibility for admission to residential care and access to Community Aged Care Packages (CACPs). ACATs vary in their composition and a diagnosis of the presence or type of dementia would generally occur where a specialist geriatrician or psychiatrist is part of the team [37]. Regardless of the composition of the team, ACATs should have the expertise to identify someone who needs further assessment regarding possible dementia – and refer them to an appropriate specialist.

The complexity in reaching a diagnosis of dementia and determining which disease is causing dementia requires the completion of various assessments. Management of these assessments is best suited to a multidisciplinary team that has a broad range of the necessary skills. Memory clinics are an efficient solution to co-ordinating these assessments and interpreting the large quantity of information obtained [38]. Although GPs are often the first contact for people with dementia and their families and carers, they are often not equipped to carry out the more comprehensive psychometric screening nor have the skills to diagnose the early stages of dementia or complex and unusual dementias [25].

Memory clinics were first developed to provide outpatient diagnostic, treatment and advice for people with milder forms of dementia [39]. They recognised that memory impairment was an important early sign of dementia [40]. A number of memory clinics operate in Australia and some State Governments provide funding for these services.

In Victoria, fourteen regional Cognitive Dementia and Memory Services (CDAMS) have been developed as a result of the state’s Ministerial Taskforce completed in 1997 [41]. These services aim to provide a multidisciplinary assessment of dementia, counselling and information. Referrals to CDAMS can come from health professionals or directly from people in the community that may have concerns about themselves or someone they care for. The Taskforce reported that all CDAMS should comprise at least a:

- specialist geriatrician or psychogeriatrician; and a
- clinical nurse consultant, allied health professional or social worker.

In addition, these core personnel should have access to:

- neuropsychologists;
- clinical psychologists;
- psychiatrists;
- counsellors with expertise in behaviour management;
- specialist allied health professionals. [25]

The Taskforce stated that CDAMS "...should apply an holistic philosophy in which assessment focuses equally on the positive and remaining capacities of the person, as well as their deficits, identifying strategies to strengthen the coping skills of the person and their carer" [25]. The most important consideration is that diagnosis of dementia requires specialist assessment and preferably input from a multidisciplinary team.

2.2 Carer reports

A person with suspected dementia is likely to have difficulties providing a reliable history. Further, in the early stages of dementia social conversational ability is usually preserved and the person may, superficially at least, present very well. Obtaining information from other sources, including case notes and carer reports becomes an important aspect of determining whether dementia is diagnosed. A relative or friend close to the person with cognitive impairment is a key source for diagnosing or ruling out dementia. Key informants should be reliable, know well the person about whom they are providing information, and have close contact with the person [1]. Family members are often able to identify and monitor changes in their relative's ability to perform daily tasks. This information can signal decline in cognitive function where a standard cognitive screening tool may not indicate an impairment [42].

Developing a history may include consideration of:

- cognitive symptoms;
- the onset, progression and pattern of symptoms;
- past medical history;
- coexisting medical conditions;
- depression;
- alcohol;
- family history; and
- symptoms of behavioural and psychological disturbance. [4]

The onset, progression and pattern of symptoms can be useful for differentiating different types of dementia. For example, VaD is typically characterised by sudden onset, stepwise progression and development of a fragmented pattern of symptoms of cognitive deficit. However, this information on its own can be misleading as 30% of people with VaD, have a clinical course similar to that of AD [4]. It is also important to distinguish between sudden onset and sudden realisation. For example, sudden realisation by families and carers may occur with the death of a spouse who may have been covering up their partner's symptoms for an extended period of time.

Considering past and present medical conditions is another important aspect of diagnosing dementia and can help to rule out delirium. Abnormality in many of

the major body systems can be associated with cognitive impairment. Medication use also needs to be reviewed and could be the underlying cause of confusion or delirium. Past history of depression can point towards a diagnosis of depression, however, as dementia often coexists with depression it needs to be determined whether one or both are present [4]. Alcohol excess tends to be under-reported by people with dementia, their families and carers. Family history may be important for determining particular genetic dementias, including the rare case of familial AD [4].

2.3 Screening tests

Screening tests for dementia are short cognitive assessments, usually taking less than ten minutes to administer, that can alert the tester that something may be wrong and indicate that further testing is necessary [42]. They require some training to use, are inexpensive to administer and are used in a variety of settings. They are not, on their own, able to diagnose dementia as they test limited domains of cognition, providing a global index of cognitive impairment [43, 44]. Some of the commonly used tests in Australia include:

- Hodkinson's Abbreviated Mental Test Score (AMTS) [45]; and
- Folstein's Mini-Mental Status Examination (MMSE) [46].

The MMSE is one of the most widely used brief measures of cognitive function. The maximum score for this test is 30 with a score below 23 suggesting the presence of cognitive impairment, and often dementia [47]. It is however, poor at detecting very mild dementia and has biases in relation to culture and education [44].

Although these screens are relatively simple to use, there can be wide variations in the way they are administered and scored. For example, evidence from the UK suggests that psychiatrists and geriatricians do not complete the AMTS in a consistent manner with an average of only 7-8 items completed of the total 10 items. Only 16% of 104 doctors were able to obtain the correct score in a case study, with only one doctor scoring each individual item correctly [43]. This suggests that training is indeed necessary to improve outcomes in screening.

More recently, screening tests that require responses from someone close to the person with suspected dementia have been developed. These include the Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE) [48]. There has been mixed evidence as to the usefulness of these tests, although they do appear to be unbiased towards education. Using a combination of short cognitive tests with these informant tests has been recommended based on evidence that using both can increase the rate of diagnosis for those who have dementia and reduce the likelihood of falsely diagnosing dementia [27].

There are also a number of semi-structured diagnostic interviews that are sometimes used as a more comprehensive alternative to the AMTS and MMSE. Two such diagnostic instruments include the Cambridge Mental Disorders of the Elderly Examination (CAMDEX) and the Consortium to Establish a Registry for Alzheimer's Disease (CERAD). The advantages of these approaches over the shorter screens are that they cover a wider range of cognitive functions, detect mild levels of impairment and avoid ceiling effects [2]. They are not completed as a standard practice as they are lengthy and can be time consuming to

administer. In some specialist settings, such as memory clinics, however, they may be used on a more routine basis. There are other instruments, including the Alzheimer's Disease Assessment Scale (ADAS) of which one section ADAS-Cog, evaluates the primary cognitive functions affected in AD including memory, language and praxis [49]. This tool has been predominately used in medication trials but more recently is required for assessment of those seeking subsidised access to cholinesterase inhibitor medications.

2.4 Neuropsychological assessment

Neuropsychological tests are either paper based or computerised questionnaires that aim to test different cognitive aspects such as memory, concentration and recognition. The purpose of performing a neuropsychological assessment is to determine whether memory and/or cognitive dysfunction are present to inform diagnosis, treatment and management of dementia. It also provides a baseline from which to monitor change over the progression of disease [34, 50] with high reproducibility between raters [50]. Instruments used during assessment are particularly useful for localising impairment and assessing dementia [34].

To determine subtle cognitive impairment and to determine which disease is causing dementia, tests that assess each major cognitive domain need to be included [51]. For example, a battery of tests could consider: memory, language, visuospatial ability and apraxia. Apraxia includes difficulties carrying out tasks that are learnt and patterns of movement, such as putting clothes on the correct way. The focus on specific domains of cognition distinguishes neuropsychological assessment instruments from the broad cognitive screening instruments described in the previous section [2].

When completing these tests, assessors need to consider factors that influence test performance including: sensory impairments, depression and anxiety about completing the tests. It is essential, therefore, that the examiner minimises these barriers as much as possible [22, 34]. Anxiety can be minimised by informing the person about the length of time the tests will take, what will be involved, and that questions range from simple to very difficult. Generally a neuropsychological assessment will take 45 minutes to 2 hours and will tend to take longer for people with mild dysfunction where a more thorough investigation might be necessary. If someone is over-anxious or angry about completing the tests it may be beneficial to have a break, try another test or even discontinue the assessment [34].

Computerised instruments have become a popular alternative to paper based instruments as they enable more accurate recording of time taken to complete tasks and require less assessor time. The degree to which people being assessed are familiar and comfortable with the use of computers needs to be taken into consideration.

2.5 Behavioural assessment

Behavioural assessment considers the non-cognitive aspects of dementia which include:

- personality, eg apathy and disengagement;
- mood, eg depression, anxiety and anger;
- psychotic symptoms, eg delusions and hallucinations and misidentifications;
- behaviours of concern, eg agitation, wandering, verbal and physical aggression, noisiness; and
- sleep, eating and sexual disorders.[52]

These “non-cognitive” characteristics can be used to improve diagnostic accuracy and to distinguish different causes of dementia [52]. There are many ways in which behaviours can be assessed, including: direct observation, semi-structured or open-ended interviews, specially designed questionnaires and case notes. Interviews and questionnaires can be completed by the person with cognitive decline, or by their family and carers who have been able to observe changes in behaviour. The use of these instruments in a clinical setting depends on individual clinician’s preferences.

There are many instruments used for measuring **depression**, including the Geriatric Depression Scale (GDS) and the Cornell Depression Scale (CDS). Other tests that incorporate feedback from key informants and clinical examination, however, may be more useful for measuring depression in people with dementia. Techniques for measuring depression in people with severe dementia, however, appear to be inadequate [53].

Delusions and **hallucinations** are disorders of thought content and perception and have to be present for longer than seven days to eliminate delirium as their cause [53]. Three brief, validated instruments, which rely on informant reports, are the Behavioural Pathology in Alzheimer’s Disease (BEHAVE-AD) [54], the Columbia University Scale for Psychopathology in Alzheimer’s Disease (CUSPAD) [55] and the Neuropsychiatric Inventory (NPI) [56]. It has been argued that instruments for assessing these disorders have not been adequately tested; that the boundaries between hallucinations and delusions are unclear; and that delusions and confabulations are difficult to distinguish [53]. Despite this, the tests appear to be clinically useful.

A clear definition of what is a **behaviour of concern** is difficult and often relies on the subjective experiences of families and carers. There is some evidence to suggest that behaviours of concern are the most stressful aspect of caring for someone who has dementia [57]. These behaviours may be influenced (made better or worse) by the carer’s responses to the person displaying these behaviours and can sometimes be improved with a range of medication, behavioural and environmental strategies [57]. A number of instruments that assess behaviour have been criticised for their focus on aggressive behaviours and that they are generally developed in one setting and sometimes for only one type of dementia. They are only suitable, therefore, when these conditions are present [53]. The Dysfunctional Behaviour Rating Instrument (DBRI) overcomes some of these limitations as it has been found to be reliable and valid for people with cognitive impairment living in the community [57]. It is completed by the caregiver and includes a broad range of behaviours including repetitiveness,

aggression, agitation, wandering, suspiciousness and inappropriate behaviour [57]. It has the advantage of not only asking how frequently behaviour occurs but also how much the caregiver perceives the behaviour to be a problem.

2.6 Functional assessment

Everyday tasks are often referred to as activities of daily living (ADL) and include everything from washing, eating and dressing to leisure or social activities. Personal activities of daily living (PADL), such as washing, eating and dressing, are generally learnt in childhood and thus can be performed habitually and relatively free from cultural influences [2]. Instrumental ADL (IADL) refers to tasks that require a higher level of functioning due to greater complexity and include housekeeping and budgeting. IADLs are more likely to be affected earlier than PADL in the progress of dementia and are influenced not only by function but also by the environment, social expectations and motivation. They are also more likely to be influenced by gender, profession, culture and education than PADL. In dementia, safety issues are important, particularly for IADL which includes assessing whether someone is safe to continue driving a car or living alone [42].

A functional assessment aims to determine the person's ability to successfully complete activities of daily living (PADL and IADL) and live in their physical, social and cultural environment. As a significant feature of dementia is functional decline, these assessments are important for establishing diagnosis, monitoring the progression of disease, determining the need for services and evaluating the effectiveness of different therapies and treatments [42]. A functional assessment aims to address issues of safety, promote independence and quality of life, and minimise or identify the need for assistance or assistive devices [58].

Tests can seek to measure whether a task is successfully completed or measure the type and amount of assistance needed to complete the task. One approach is to examine the processes underlying function, including: attention, organisation, planning, sequencing, motivation and concentration. This assumes that if a process, such as sequencing is dysfunctional in one activity, such as dressing, that sequencing in cooking may also be an area of difficulty. There is some evidence that assessment of process is more useful for identifying milder levels of dementia than assessment of motor skills [59].

A functional assessment can either be a self-report, a caregiver report or an observation of performance. People with dementia, however, have been found to exaggerate their ability to complete PADL and IADL when compared to caregiver reports [42]. For this reason, caregiver reports or direct observation are generally preferred. Caregiver reports may be more efficient than completing an observation assessment. Where a caregiver is not available, or is not able to provide an unbiased report or the assessor feels that performance under standardised conditions is needed, an observation of performance may be completed. As people with dementia are more likely to perform well in a familiar setting an observation assessment is most effective within the person's home environment [42]. Occupational therapists can provide specialist functional assessment. Other team members may also make a contribution to functional assessment.

2.7 Blood screening

Blood tests are routinely used in dementia diagnosis mainly to exclude other, possibly reversible, causes of cognitive disorder. A full blood investigation is used to detect infections. Other tests seek to exclude hyperthyroidism, hypothyroidism, B12 deficiency, renal and liver failure and to record folate, glucose, calcium and cholesterol levels.

2.8 Radiology

2.8.1 Computed Tomography (CT)

CT is a relatively inexpensive, quick and non-invasive technique used to scan soft tissue [60]. Repeated passes of a narrow X-ray beam through the brain yields data that can be used to produce three dimensional images of brain structures such as the grey matter, white matter, cerebrospinal fluid cavities and blood vessels. These images also reveal the presence of tumours, lesions and other abnormalities. The role of CT imaging in the diagnosis of dementia is primarily one of exclusion [61]. When, for example, AD is one of a number of possible diagnoses, CT is used to confirm or eliminate other causes. When all other explanations have been discounted, a clinical diagnosis of AD can be made with more confidence. Since there is some overlap between AD and normal ageing, CT data on its own does not provide a sufficiently robust basis for diagnosis. Recent evidence based guidelines indicate that structural neuroimaging with either CT or MRI scan is appropriate in the routine initial evaluation of patients with dementia [6].

2.8.2 Magnetic Resonance Imaging (MRI)

MRI is a structural neuroimaging method that provides three-dimensional images of the brain and other anatomical structures. An MRI is done with patients placed in a lying position in a magnetic chamber. Using a magnetic field and radio signals, MRI techniques provide exceptionally well-defined images of the brain, with greater levels of detail than CT. A combination of measures is used to provide the best differentiation of anatomical structures and pathologies. Numerous scans are made of different planes and sections of the brain. MRI has generated images of unprecedented detail, precision and contrast. It is less invasive than CT as it employs a non-ionising form of radiation and it lends itself well to both qualitative (visual interpretation) and quantitative (especially volumetric) methods of analysis [62].

Studies using MRI have demonstrated that medial temporal lobe (MTL) atrophy is highly predictive of AD and that it is associated with neuropsychological and post-mortem data. It appears to be able to differentiate AD and mild cognitive impairment (MCI) and track MCI progression to AD [61]. The application of MRI has progressed from the identification of characteristic neurological changes in AD to more specifically predictive and diagnostic investigations. Like CT, MRI has value in excluding other possible diagnoses and supplying confirmatory data to clinical diagnoses, however, MRI is more expensive than CT and is less available. In rural areas, it is more likely for CT to be available than MRI.

A further development of MRI methods - **functional Magnetic Resonance Imaging (fMRI)** - is so called because, in addition to imaging brain structures, it provides information about brain function. This is possible because it has the capacity to detect changes in blood flow through the brain - an index of function that is particularly sensitive to the changes that occur in dementia. Currently,

functional MRI is used for research and *structural* MRI is used as an aid to diagnosis.

2.8.3 Single Proton Emission Computed Tomography (SPECT)

SPECT is another functional neuroimaging method. It monitors changes in cerebral blood flow and can also be used to evaluate the functional status of junctions (synapses) between neurons. SPECT has been used in many studies of dementia and has confirmed some of the physiological mechanisms that underlie the progression of AD [61], although findings of this type have not contributed to a routine diagnostic role for SPECT. It is mainly a research tool as other non-invasive clinical measures have been shown to be just as useful. Nonetheless, where neuropsychological assessments are unavailable, SPECT is the preferred investigation in early differentiation of frontal dementias from dementia of the Alzheimer's type [63].

2.8.4 Other tests used in research

A number of tests that are currently research based are discussed briefly.

Positron Emission Tomography (PET) is a functional imaging method that, when used in conjunction with a structural imaging technique such as MRI, has the potential to correlate biological processes with clinical/behavioural symptoms of dementia [64]. As with MRI and SPECT, it intercepts radioactive particles emitted from the brain after infusion of radioisotopes. Recent studies have shifted from a diagnostic focus to imaging functional responses to cognitive tasks in order to profile what happens in the brain during cognitive performance [61]. It is anticipated that PET research will increasingly focus on developing the capacity for presymptomatic prediction of AD since at least one measure has indicated that impaired metabolism is predictive of cognitive decline early in MCI subjects [61]. At present PET presents many practical difficulties limiting its use in a clinical setting.

Neuronal signals in the brain have two central aspects - biochemical and electrical. **Electroencephalography (EEG)** is a technique that records this electrical activity allowing it to be analysed by a variety of methods that yield information about the functional status of the brain. Conventional EEG, in which the electrical activity is presented as a continuous trace on paper or computer screen, is comparatively inexpensive and can differentiate some disorders. However, its use in diagnosis of dementia is very limited. Quantitative analysis of the EEG (qEEG), Evoked Potentials (EP), Event Related Potentials (ERP) and EEG-coherence analysis are more complex procedures that facilitate a highly detailed examination of brain electrical activity. A number of changes in EEG activity are associated with AD, however these findings do not yet constitute a basis for the use of EEG as a diagnostic tool [65]. In a research context, EEG is inexpensive and non-invasive and lends itself well to investigations involving a variety of cognitive tasks. Research in recent years has moved towards using EEG measures in conjunction with other neuroimaging methods.

Cerebrospinal fluid (CSF), the fluid that surrounds the brain and spinal cord, contains several biomarkers that may be implicated in the onset of AD.

Biomarkers may serve firstly to represent generalised brain injury. The **tau protein** is a possible biomarker for AD. Secondly, some biomarkers may prove to be specific to certain diseases. For example, CSF levels of **A Beta 1-40** may prove to be specific to AD [66]. A recent investigation has shown that CSF tau

protein differentiates AD from normal ageing and depression very early in the disease process and may therefore have diagnostic applications early in the onset when symptoms are vague and diagnosis particularly difficult [67]. Although disappointing to date [68], the search for specific biomarkers of AD has indicated that both CSF tau protein and A Beta are likely to have future value in predicting who is at risk of AD [66]. Other potential biomarkers include neuronal thread protein, apolipoprotein A1 (ApoA1) and hemeoxygenase. These have shown some significant differences between AD and healthy subjects but need much more testing to establish a positive diagnostic value.

2.9 Genetic testing

A number of genes have been implicated in the onset of AD. Studies of familial **early-onset AD** which accounts for less than 1% of all AD cases, have identified mutations in three genes [69] that account for up to 50% of such cases. Mutations in the amyloid precursor protein gene (APP) and in the presenilin 1 (PS1) gene account for many early onset familial AD cases. Mutations in the presenilin 2 gene (PS2) are also implicated, but rare. Currently, genetic testing for early-onset AD should be performed in a research context rather than as a screening device. In **late-onset AD**, (accounting for over 90% of all AD patients) it has been discovered that several structural variants (polymorphisms) of the apolipoprotein E gene (APOE) constitute a risk factor [69]. Subject to further validation, tests to detect the presence of APOE ϵ 4 form of the gene may improve upon conventional clinical diagnosis but at this stage, their clinical value has not been established. Indeed, at the clinical level it has been necessary to exercise caution in the use of the genetics of dementia as there is insufficient evidence for an unequivocal diagnostic or predictive evaluation of patients. Using genetic information has serious ethical implications for families and clinicians. Future research is likely to find more genetic actions implicated in dementia [70]. The interaction between genetic susceptibility and presence of risk factors is still unclear. As more is learned, it is reasonable to suggest that even more complex processes will come to light, and that the possibility of a single, simple underlying genetic factor will become more improbable.

2.10 Neuropathology at autopsy

AD is essentially a disease of the central nervous system, although recent research suggests that it is also linked to abnormalities in peripheral blood elements [71]. Autopsy is still the most accurate means of confirming diagnosis in people with dementia, and although death is usually due to secondary (commonly respiratory) causes, autopsy is primarily concerned with identifying changes in the brain that are established pathological indicators of dementing illnesses. In general, brain weight is reduced by loss of neuronal tissue especially in the cerebral hemispheres rather than the lower structures such as the brain stem. Brain size is reduced through atrophy and ventricles are enlarged. At the microscopic level, autopsy seeks to establish the presence of plaques and neurofibrillary tangles, the most common lesions associated with AD. Autopsy examines many other abnormalities and continues to be a significant means of research. An accurate diagnosis can be important and help to identify possible genetic associations and risk factors that family members should be aware of. In appropriate situations, discussions of the benefits of autopsy may be made sensitively at some stage of ongoing management of a person with dementia and their family.

2.11 Diagnostic criteria

The diagnosis of dementia and its different causes is complex, and therefore various diagnostic criteria have been developed to assist clinicians and researchers in the assessment of those with possible cognitive impairment. The aim of these criteria is to identify a set of characteristics that must be present or absent to determine whether dementia or a specific disease that causes dementia is possible or probable. A set of characteristics can include any combinations of the assessments previously described in this paper. Ones developed in the last decade for AD, VaD and DLB have incorporated neuroimaging findings to support a diagnosis, although they are not considered a fundamental part of the diagnosis. Common criteria are those included in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV), International Classification of Diseases, 10th revision (ICD-10) classifications and others. These have different sets of criteria for different causes of dementia.

The extent to which these criteria lead to a diagnosis that is consistent with detailed clinical assessment varies considerably. While criteria for AD appear to be reasonably accurate, those used for VaD and dementia in general appear to be less successful. Criteria also appear poor in identifying the presence of mixed dementias [15].

The National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer's Disease and Related Disorders Association (NINCDS ADRDA) criteria are often used for diagnosing AD and have been found to be 80% accurate in ruling out AD in healthy people. These criteria also produce consistent diagnoses between assessors and can therefore be used between trained assessors with some confidence in the clinical setting [15].

Criteria for assessing dementia in general tend to under diagnose dementia suggesting that milder levels of dementia are not identified. For example, a study of older people in Canada found that clinical consensus identified 21% of the sample as having dementia compared to only 14% using the DSM-IV criteria and 3% using the ICD-10 criteria [72].

The four most common clinical criteria for the diagnosis of VaD are not interchangeable because of important differences in the composition of the criteria, leading to different prevalence rates [73]. Consensus criteria for the diagnosis of dementia with lewy bodies (DLB) require further research to understand the relationship with Parkinson's disease [15].

Further development and testing is needed to improve the use of diagnostic criteria for identifying milder levels of dementia and for improving differentiation of mixed dementias.

3. Issues in diagnosing dementia

3.1 To tell or not to tell?

Should people with dementia be told their diagnosis? This is a common question for families and health professionals. A survey of 281 GPs in the UK found that only 39% would inform their patients of a diagnosis of dementia, compared to 95% who would inform their patients of a diagnosis of terminal cancer [74].

In summary, the arguments against informing people they have dementia include:

- emotional distress for the person with dementia and their family and carers, which may precipitate dementia-related symptoms, including functional decline, depression, and paranoia;
- some people are unable or unwilling to assimilate this distressing information;
- diagnosis can not be made with absolute certainty and therefore a wrong diagnosis can be avoided by not telling;
- the negative impact of the stigma attached to dementia;
- person would not understand the diagnosis;
- no benefit for the person knowing; and
- request of the carer.

Although the initial awareness of the diagnosis can cause emotional reactions, there is no evidence that this information has long term negative effects [75].

One of the difficulties in not telling someone they have dementia is the influence of family members who know the diagnosis. Sometimes family members do not want their relative told of the diagnosis, even though they may state that they would want to know if they were the one with dementia [76]. This is contrary to other reports where carers indicated that there were no benefits in hiding the information from the person with dementia and that they would find out for themselves anyway. Knowledge of the diagnosis also enabled them to explain why they could not remember things [77].

In summary, the arguments for informing people they have dementia include:

- the person's right to know about their own health;
- better planning for the future;
- power of attorney, wills and future living arrangements can be considered;
- facilitate access to services;
- sense of relief about reasons for behaviours and symptoms;
- strengthen communication and rapport between health professionals and the person with dementia and their family and carers;
- knowing what to expect has potential benefits for quality of life [26];
- adaptation to progressive changes;
- to help families learn strategies for managing behavioural problems; and
- facilitating access to medical treatments.

Withholding information about a diagnosis should be avoided as people have a right to know about their health and possible outcomes [78]. From a medical professional's viewpoint: "Although we cannot make the diagnosis of progressive dementia with absolute certainty, we can be truthful with our patients about what we think is happening and about the certainty on which this opinion is based" (p 949) [79]. The arguments for informing someone they have dementia will become stronger as further improvements in management and treatment occurs.

Although there are many advantages to an early diagnosis of dementia, evidence suggests that many families wait for a number of years before seeking medical evaluation of memory loss [26, 80]. This may relate to a reluctance to confirm suspected dementia or to the time consuming and perceived stressful nature of the assessment process. For some caregivers the most difficult part of the diagnostic process was the insensitive manner in which the diagnosis was disclosed and the time consuming and expensive nature of the process [26]. This points to the need for a sensitive delivery of the diagnosis with sufficient information and appropriate supports to enable people with dementia and their families and carers to act positively and use the information to improve quality of life.

In a clinical setting, discussion of a diagnosis of dementia with a patient and their family requires individual consideration, including issues that may arise for those from culturally and linguistically diverse backgrounds.

3.2 Diagnosing younger onset dementia

Young onset dementia (onset before the age of 65) is rare with estimates of 53 in 100,000 people aged 45-64 having dementia [81]. The most common causes of younger onset dementia are AD (usually the rarer dominantly inherited type), VaD, FTD, alcohol-related dementia and Huntington's disease. Diagnosing dementia for people under 65 is more complex than for older people. The impact of a diagnosis is also likely to have a number of additional difficulties as younger people with dementia are more likely to:

- be in paid employment;
- have school aged children at home;
- have heavier financial commitments;
- have an inheritable dementia and thus have concerns for their children;
- experience difficulty obtaining a diagnosis; and
- experience difficulty integrating with mainstream services designed for older people [82].

An Australian study of younger people with dementia found that 71% of carers reported that the diagnostic process was problematic [83]. Health professionals' lack of knowledge was the most commonly reported difficulty followed by long distances to travel and misdiagnosis. On average, 2.8 professionals were consulted to obtain a diagnosis, most frequently a GP.

3.3 Medication access and diagnosis

Cholinesterase inhibitor drugs are now available in Australia for treatment of mild to moderate stages of AD. Clinical trials have indicated that these drugs can provide modest symptomatic benefits for almost half the people who try them [32]. These prescription drugs have subsidised access through the Pharmaceutical Benefits Schedule (PBS) for people who meet a range of eligibility requirements, but can also be purchased at full cost. Prior to obtaining these medications a specialist/consultant physician (including a psychiatrist) must confirm a diagnosis using the MMSE or the Alzheimer's Disease Assessment Scale, cognitive sub-scale (ADAS-Cog). Up to six months of treatment can be supplied but for continuing use the person must have improved on various criteria including improvement in MMSE and ADAS-Cog scores [84]. The problem with this requirement is that it presumes that only cognitive improvement can be considered a positive feature of treatment. For people with AD, however, symptomatic improvement of the disease can have a positive influence on quality of life for themselves and their family and carers. One study has noted beneficial effect of using cholinesterase inhibitor drugs for those with DLB [85], but the PBS only accepts dementia caused by AD for subsidised rates.

Other difficulties with the requirement of an improvement on one of two measures relate to the limitations of tests including biases in regard to education levels and cultural background. The importance of showing an improvement may also increase stress for the person performing the test, thereby increasing the likelihood of poor test performance. Relying on the ADAS-Cog or MMSE only recognises the cognitive aspects of dementia and fails to recognise that improvement in other non-cognitive domains, including behaviour and carer burden can be beneficial [86]. There is ongoing review of the criteria for receipt of these drugs though subsidised programs.

3.4 Issues in diagnosing dementia for people from culturally and linguistically diverse backgrounds

The way in which dementia is defined and understood varies between cultures. It is strongly suspected that people from culturally and linguistically diverse (CALD) backgrounds are more likely to be diagnosed later on in the process of the illness or be misdiagnosed [33]. The consequences of misdiagnosis can be severe if treatable but serious conditions are not identified. One study found that of the people assessed at a memory clinic as having dementia, people from CALD backgrounds presented with more advanced dementia than those from non-CALD backgrounds [80]. Barriers to diagnosing dementia for people from CALD backgrounds include:

- communication difficulties that are likely to occur where the assessor and person being assessed speak different languages;
- cultural misunderstandings;
- lack of available interpreters and bilingual staff;
- culturally inappropriate assessment tools; and
- reluctance to seek assessment due to difficulties communicating with health professionals, believing that nothing can be done or believing that they should manage without outside assistance. [33, 87].

With the onset of dementia, skills learnt earlier in life are more likely to be retained

than more recently acquired skills. This means that some people with dementia, who may have been speaking English for many years, may revert to their first language. This can be distressing for children who have not learnt their parent's first language [87]. It can also present challenges for those trying to assess language skills who may not know whether to test in the person's first language or English.

There are many limitations to cognitive tests due to the influence of cultural norms and meanings. Many cognitive tests are culturally biased as they have been developed in the USA or in Western societies and thus are based on Western values, norms and meanings. As a result test items can have a different meaning or be unfamiliar to people of different CALD backgrounds, thus increasing the likelihood of a poor test score [33]. This bias may explain why people from CALD backgrounds appear to have more advanced dementia when presenting to a memory clinic. Alternatively, it could be that they delay presenting to their GP or a memory clinic.

Direct translations can sometimes change the meaning of the question or the nature of the task. For example, one word may translate into two or three words, increasing the complexity of the original task. An assessor's actions and manner can be interpreted by someone from a different CALD background as disinterest or impatience. This can influence a person's performance and increase test anxiety. It is important that a test situation allows people to achieve the best test results possible. Generating test averages based on specific CALD communities (ie normative data) can allow a person's score to be compared with a group of people from a similar background, thereby reducing the likelihood of a poor score resulting in a misdiagnosis of dementia. These averages should also be generated with a sample of people within a similar age group and educational level. Unfortunately, few tests have generated normative data for the large number of CALD groups living in Australia.

3.4.1 Issues specific to diagnosing dementia for Aboriginal and Torres Strait Islander people

Cultural and language differences also complicate the assessment of dementia for Australian Aboriginal and Torres Strait Islander people. Assessments and issues relating to assessment are also likely to vary considerably depending on where in Australia Aboriginal and Torres Strait Islander people live. The limited evidence available suggests that the prevalence of dementia in Aboriginal and Torres Strait Islander communities for the 65+ population is similar to the mainstream Australian prevalence for the 80+ population, reflecting the generally poorer health status and lower life expectancies in these communities [88]. Seeking a diagnosis is unlikely and may require permission from traditional healers. Even when outside assistance is sought services are difficult to access, particularly in rural and remote areas, and mainstream services are often culturally inappropriate. There may also be a reluctance to answer questions due to previous negative experiences with mainstream institutions and health services [88].

While some assessments may be inappropriate due to educational and cultural biases, the process is further complicated for Aboriginal and Torres Strait Islander communities by factors such as diversity in languages, few written languages and lack of formal schooling. Informant history may also be difficult to obtain as there is often a reluctance to speak about others, especially in relation to embarrassing or inconsiderate behaviours. Structured interviews are usually inappropriate in these communities [88]. Further investigation is needed to develop less threatening and more appropriate ways for assessing dementia and for developing appropriate support services for people with dementia, their families and carers in these communities.

4. The future

The diagnosis of dementia can be a complex, time consuming process, which often requires the involvement of a range of health professionals. The clinical assessment of a person with cognitive impairment entails detailed gathering of information from the person and key informants, medical examination and a number of investigations to determine presence and type of dementia and exclude other complicating factors such as delirium or depression. A holistic approach to the ongoing care of a person with dementia and their family and carers, taking into consideration the individual's cultural and social background, is required.

An early and accurate diagnosis of the cause(s) of dementia is important for providing individuals with dementia, their families and carers time to adjust and plan for the future. Timely intervention with education, provision of services, including respite, and use of medications (to delay progression of the disease, or treat ancillary symptoms of dementia) will prepare the person with dementia, their family and carers to better cope with the changes experienced through the pathway of dementia. The growth in diagnostic and support service provision will need to parallel the increase in dementia prevalence.

GPs and other health professionals need to be attuned to early signs of dementia, and the potential benefits of accurately and promptly diagnosing dementia. The availability of medications for early to moderate stages of AD has increased the importance of early identification. GPs are often the initial contact for those in earlier stages of dementia and they play a vital role in referral to specialised services and support services. There is much potential for assisting GPs to attend more effectively to the needs of people at this vulnerable stage. The diagnosis and management of the ever-changing face of dementia is time consuming and complicated and ongoing support for the GP will be required. This is particularly so for GPs who may not have the benefits of access to specialised services such as memory clinics or geriatricians, for example, in some rural regions. New initiatives such as teleconferencing may provide support for GPs who are more isolated.

As more is uncovered about the causative factors that lead to dementia, the potential for prevention is becoming more evident (e.g. VaD) and is likely to impact on the focus of dementia policies. Other issues such as potential benefits of treating those with MCI or strong family history of AD with a preventive approach are still unknown. Ongoing medication trials to determine usefulness of treating those with non AD dementia and MCI are underway. Well conducted trials are being performed to assess the benefits of drug treatments on the behavioural and psychological symptoms of those with dementia, including those living in residential care. Non-medication trials assessing the effectiveness of behavioural management skills and specific service delivery models have commenced but require further assessment. Research and development is needed to address the specific needs of those with early onset dementia and the implications for future provision of appropriate management and care for the person and their family. Currently there is limited research evidence on which to base medical management of dementia.

The potential for other forms of diagnostic tools and treatments is increasing. The expanding knowledge of mechanisms which may underlie the formation of amyloid plaques is leading the way to potentially new exciting forms of treatment aimed at reversing neuronal damage or preventing disease (e.g. amyloid therapies and secretase inhibitors). Tools that may add to the accuracy of diagnosis are being developed and tested e.g. skin tests to assess peripheral amyloid activity and computerised screening tools for cognitive testing.

Many ethical and legal issues are being raised which need to be addressed by the community at large. Driving capabilities, financial capacities and end of life decisions are examples of complex matters that require ongoing discussion and leadership by Government, peak agencies, the health care system and members of the community. Assessment of a person's capacity to decide personal care issues, advanced directives and living wills are topics for further exploration.

There has been much focus on the families and carers of those with dementia and their needs. In recent times there has been increased awareness of the requirements of the person with dementia particularly in relation to early assessment, involvement in planning for future care and improvement of quality of life. A holistic approach to the care of a person with dementia is imperative, and issues considering self determination and spirituality are recent areas of interest.

The awareness of dementia and its implications for individuals and the community has grown significantly over recent years as a result of Government policy, increasing research into causes and treatments of dementia and ongoing efforts of community advocates such as Alzheimer's Association nationally. The move towards a more "positive public awareness" reflects the next stage of encouraging the community to view dementia with more optimism and hope.

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