
Early Diagnosis of Dementia

Alzheimer's Australia

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Promoting early diagnosis of dementia

Introduction

The purpose of this paper is to outline the steps involved in the diagnosis of dementia and to promote early diagnosis. This paper may be helpful to people who have concerns about dementia or to those who are concerned about their family members or friends.

The early symptoms of dementia can include memory problems, difficulties in word finding and thinking processes, changes in personality or behaviour, a lack of initiative or changes in day to day function at home, at work or in taking care of oneself. This paper does not include detailed information about all of these warning signs, so it is recommended that you seek other sources of information¹. If you notice signs in yourself or in a family member or friend, it is important to seek medical help to determine the cause and significance of these symptoms.

Obtaining a diagnosis of dementia can be a difficult, lengthy and intensive process. While circumstances differ from person to person, Alzheimer's Australia believes that 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, and
- Access to support and services.

For some people, there may be barriers to diagnosis, especially to an early diagnosis. These 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. However, there are many reasons why early diagnosis is important, some of which are detailed within this paper². Early diagnosis and awareness about dementia are the first steps in designing management strategies. As more effective treatments become available in the future, early diagnosis will become even more important.

¹ A checklist of the early warning signs of dementia is contained in the '*Worried about your memory?*' brochure, available from Alzheimer's Australia on request or online at: http://www.alzheimers.org.au/upload/Early_Signs_brochure_web.pdf.

² For a good review of the benefits of early diagnosis, please see *Six reasons why early diagnosis of dementia does not occur and ten reasons why it should* by Professor Henry Brodaty. Full reference can be found at the back of this paper.

What are the benefits of early diagnosis?

- **Early planning and assistance:** Early diagnosis enables a person with dementia and their family to receive help in understanding and adjusting to the diagnosis and to prepare for the future in an appropriate way. This might include making legal and financial arrangements, changes to living arrangements, and finding out about aids and services that will enhance quality of life for people with dementia and their family and friends. Early diagnosis can allow the individual to have an active role in decision making and planning for the future while families can educate themselves about the disease and learn effective ways of interacting with the person with dementia.
- **Checking Concerns:** Changes in memory and thinking ability can be very worrying. Symptoms of 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 dementia symptoms is identified, the sooner treatment can begin. Asking a doctor to check any symptoms and to identify the cause of symptoms can bring relief to people and their families.
- **Treatment:** There is evidence that the currently available medications for Alzheimer's disease may be more beneficial if given early in the disease process. These medications can help to maintain daily function and quality of life as well as stabilise cognitive decline in some people; however, they do not help everyone and they are not a cure. Early diagnosis allows for prompt access to medications and medical attention.
- **Health management:** Receiving a diagnosis can also help in the management of other symptoms which may accompany the early stage of dementia, such as depression or irritability. Also reviewing management of other medical conditions is critical, as memory problems may interfere with a person remembering to take important medications such as for diabetes, heart disease or high blood pressure.

Current practice in diagnosing dementia

The remainder of this paper will provide an overview of the diagnosis process and a guide to what happens after diagnosis.

It is important to remember that there is no definitive test for diagnosing Alzheimer's disease or any of the other common causes of dementia. 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, uncertainty may still remain, and the diagnosis is often conveyed as "possible" or "probable". Despite this uncertainty, a diagnosis is accurate around 90% of the time.

People with significant memory loss without other symptoms of dementia, such as behaviour or personality changes, may be classified as having a Mild Cognitive Impairment (MCI). MCI is a relatively new concept and more research is needed to understand the relation between MCI and later development of dementia. However, MCI does not necessarily lead to dementia and regular monitoring of memory and thinking skills is recommended in individuals with this diagnosis.

Specialist doctors involved in dementia diagnosis

Geriatrician - a doctor who specialises in the care of older people.

Psychogeriatrician - a doctor who specialises in mental disorders affecting older people.

Neurologist - a doctor who specialises in the diagnosis and treatment of disorders of the nervous system, including the brain, spinal cord and nerves.

Neuropsychologist - a psychologist who specialises in disorders of the brain and how they affect memory, thinking and behaviour.

Psychiatrist - a doctor who specialises in the diagnosis and treatment of mental disorders, emotional disturbances and thought disorders.

Who diagnoses dementia?

- The General Practitioner (GP) is usually the first contact when concerns about thinking or memory arise. The GP will take a medical history and may carry out a brief test of memory and concentration. If the GP is concerned about the possibility of dementia, the person may be referred to a specialist or specialist memory centre. It is important to remember that the choice of doctor is up to you – so if after your visit you are still concerned and wish a referral to a specialist, you may wish to ask for a second opinion.
- Specialists such as neurologists, geriatricians, psychogeriatricians, psychiatrists, and neuropsychologists have a more detailed knowledge of the memory and behaviour changes associated with dementia and may

perform or arrange in-depth assessments, brain scans and blood tests. In Australia, a specialist must confirm the diagnosis of Alzheimer's disease in order for you to be eligible for subsidised Alzheimer's medications.

- Aged Care Assessment Teams (ACATs) are multidisciplinary teams often comprised of social workers, occupational and physiotherapists, as well as 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 involved in the diagnosis of dementia. While they provide diagnostic services for all types of dementia, they often 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 tests are becoming available. There are ethical and professional issues relating to the use of unsupervised online testing by people who may be cognitively impaired. For example, are the instructions understood? How should scores be interpreted? Have the tests been validated? Whilst useful information about dementia symptoms is available on quality websites, diagnosis remains a process that must be undertaken by a qualified health professional.

The diagnosis process

The first step in the diagnosis process is to assess symptoms through 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. The next step is to determine the cause of the dementia, most commonly Alzheimer's disease, vascular dementia, Lewy body dementia or frontotemporal dementia.

Medical history

The doctor will obtain a complete medical and family history. Questions will be asked about forgetfulness, orientation, problem solving, coping with everyday life, alcohol consumption and medication usage. The doctor needs to establish 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.

Conditions that can produce dementia-like symptoms

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

Medical testing

- Medical tests, including blood, urine and genetic tests, as well as brain scans, are sometimes used in the diagnosis of dementia.
- Blood or urine tests are carried out to 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, which increases 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.

- Brain scans can be used to detect brain tumours, strokes or brain haemorrhages, brain shrinkage and increased pressure of fluid in the brain. Routine brain scans include computerised tomography (CT) scans and magnetic resonance imaging (MRI). These procedures produce an image of the brain, allowing the identification of abnormal changes. These scans are relatively non-invasive and are only used for diagnosis in certain cases.
- CT 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.
- 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 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 either brain shrinkage or no changes at all.
- Other types of brain scans are used primarily in research studies. SPECT (Single Photon Emission Computed Tomography) is a brain scanning technique used primarily in research studies that can show functional changes in brain activity. fMRI (Functional Magnetic Resonance Imaging) also provides information about brain function as well as structure and is typically used in research studies. PET (Positron Emission Tomography) is another type of functional brain imaging, typically used in a research setting.

Psychological evaluation

Tests of mental functioning are 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 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), the Brief Cognitive Rating Scale and Alzheimer's Disease Assessment Scale - Cognitive (ADAS-Cog). Some people perform well on brief screening tests but memory and thinking impairments may be found with more comprehensive testing. Additionally, some tests have been shown to have educational, social and cultural biases.

Brief screening tests can be followed up by more detailed tests of mental function. These tests are known as neuropsychological tests and examine different areas of function such as memory, language, reasoning, calculation and ability to concentrate.

These tests are able to distinguish between different patterns of decline and are therefore important in helping to identify the type of dementia affecting the individual.

Types of Dementia

There are many different causes of dementia. The most common is Alzheimer's disease, which is associated with distinctive changes in the brain. While Alzheimer's disease can develop in younger people, it is most common after the age of 65 years. Vascular dementia is thought to be the second most common form of dementia and is associated with problems of blood circulation in the brain. However, mixed dementia containing elements of vascular dementia and Alzheimer's disease is also common.

Other causes of dementia include Dementia with Lewy Bodies and Frontotemporal dementia. Dementia with Lewy Bodies is marked by a fluctuating mental state, hallucinations and motor problems, while Frontotemporal dementia typically occurs between 45 and 65 years of age and involves profound personality and behavioural changes.

There are many other possible causes of dementia including Huntington's disease, Creutzfeld-Jacob Disease, Alcohol-related dementia and Parkinson's disease. It is important to obtain an accurate diagnosis to maximise benefits from treatment and understand more about prognosis and symptoms³.

Future directions in diagnosis research

Considerable research effort is being put into the development of better tools for accurate and early diagnosis. Research continues to provide new insights that in the future may promote early detection and improved diagnosis of dementia, including:

- *Better dementia assessment tests that are suitable for people from diverse educational, social, linguistic and cultural backgrounds.*
- *New computerised cognitive assessment tests which can improve the delivery of the test and simplify responses.*
- *Improved screening tools to allow dementia to be more effectively identified and diagnosed by GPs.*
- *The development of blood and spinal fluid tests to measure Alzheimer's related protein levels and determine the risk of Alzheimer's disease.*
- *The use of sophisticated brain imaging techniques and newly developed dyes to directly view abnormal Alzheimer's protein deposits in the brain, yielding specific tests for Alzheimer's disease.*

³ For more information about different types of dementia, please see Alzheimer's Australia web page on Types of Dementia at <http://www.alzheimers.org.au>

After the diagnosis

Early diagnosis of dementia is the first step in understanding and managing the condition. Communicating a diagnosis of dementia can allow for planning to begin. Increasingly early diagnosis of dementia means that in the vast majority of cases, it is appropriate for people to be told about their diagnosis, as they have a right to information about their health.

In the past, some people argued against telling a person of their diagnosis because of the belief that there is no benefit in knowing, the fear of provoking distress, and that the diagnosis would be difficult for the person to understand. However, although many people with early stage dementia will initially feel 'shattered' by the diagnosis, many also say that 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 time to talk to the doctor is important. Take time and ask as many questions as you like. It may also be helpful to have someone supportive with you at the time of diagnosis. You may want to ask your doctor about the possible benefits of medication and side effects.

Life doesn't stop with a diagnosis. There are many available sources of support, which can help you, as well as families and friends. Alzheimer's Australia can assist you and your family and put you in touch with others in your situation.

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Further Reading Material

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A Memory Concerns Brochure is available from Alzheimer's Australia or online at: http://www.alzheimers.org.au/upload/Early_Signs_brochure_web.pdf

Alzheimer's Australia has a range of publications, information and help sheets that may be helpful to you. An index of all Alzheimer's Australia help sheets is available at:

<http://www.alzheimers.org.au/upload/HelpSheetsIndex2005.pdf> or by phoning the National Dementia Helpline. Help sheets which may be of interest include: Diagnosing dementia, Early planning, Next steps, Tests used in diagnosing dementia and Mild Cognitive Impairment.

Visit the Alzheimer's Australia website at

www.alzheimers.org.au

for comprehensive information about

- dementia and care
- information, education and training
- other services offered by member organisations

Otherwise, for further information and advice contact:
the **National Dementia Helpline** on **1800 100 500**

