

Diagnosis and assessment

If you are close to someone who is feeling confused, agitated or forgetful, you may like to suggest that the person see their general practitioner (GP). They may wish to accompany them on their visit.

'Dementia' describes a group of symptoms caused by the physical impact of disease or injury on the brain. There are a number of different conditions which lead to dementia, including Alzheimer's disease, vascular disease (including stroke) and dementia with Lewy bodies.

Each person will experience dementia in his or her own individual way, but there will usually be:

- A decline in memory, reasoning and communication skills
- A gradual loss of the skills needed to carry out daily activities
- Confusion.

Why get a diagnosis?

It is important to get a proper diagnosis of dementia. A diagnosis is essential to:

- Rule out other conditions that may have symptoms similar to dementia and that may be treatable. These include depression, chest and urinary infections, severe constipation, vitamin and thyroid deficiencies and brain tumours.
- Rule out other possible causes of confusion, such as poor sight or hearing, emotional changes and upsets, such as moving or bereavement, or the side-effects of certain drugs or a combination of drugs.
- Get access to advice, information and support from social services, voluntary agencies and support groups.
- Allow the person with dementia to plan and make arrangements for the future.

Identifying the type of dementia is becoming increasingly important as drugs for treating different conditions become available. For example, drugs are already available to treat some people with Alzheimer's disease. These drugs are ineffective in the treatment of Pick's disease, another form of dementia, and may actually worsen symptoms. Please see the Society's information sheet *Drug treatments for Alzheimer's disease - Aricept, Exelon, Reminyl and Ebixa* for further information.

Making a diagnosis

Making a diagnosis of dementia is often difficult, particularly in the early stages. A definite diagnosis of the cause may only be confirmed after death, at post mortem, or in very rare instances through a brain biopsy. The time it takes to make a diagnosis can vary. If scans and other investigations are required, it could be four to 12 weeks, depending on waiting lists. If the person is in the early stages of dementia, a six to 12 month period of monitoring may be required before a diagnosis can be made.

The first step - assessment by a GP

The GP is the first person to consult if you are concerned about someone close to you.

Home or surgery

You may see the GP in their surgery or they may prefer to make a home visit. If dementia is suspected it is often easier to assess and observe the person's behaviour in the home. It then becomes clearer just what the problems are.

Background information

You can expect the GP to spend some time talking to you and the person you are concerned about, to try to establish some of the symptoms. The GP will look at the medical history of the person they are examining and the medical history of other members of the family.

Physical examinations and tests

The GP will normally carry out a physical examination and may perform a number of tests, such as blood and urine tests, to identify other conditions that may be causing confusion.

Mental tests

The GP may ask a series of questions designed to test thinking and memory.

Ability to cope

The GP will have access to some services such as community nursing. If there is a probable diagnosis of dementia or you are experiencing difficulties in managing, the GP can refer you to the social services.

Communication

At the end of the assessment the GP should communicate their findings in an appropriate way and discuss what action needs to be taken. They may feel able to make a diagnosis or they may wish to wait a certain length of time to make sure. In some cases they may want to refer the person to a specialist for a fuller assessment.

Referral to a specialist

The GP is the usual person to refer someone to a specialist. You are entitled to ask for a referral to a specialist for a second opinion or for support and access to services that such a referral may give. Press for a referral if you feel it would be helpful and the GP does not suggest it.

Specialist referral

A consultant will have more specialised knowledge and experience of dementia and will have access to more specialised investigations, such as brain scans.

Your GP will refer the person being diagnosed to a consultant in a particular specialty. The specialty may depend on the age of the person concerned, their symptoms and what is available in your particular area.

Types of consultant

Neurologist

A neurologist is a doctor specialising in disorders of the brain and nerve pathways. Some neurologists have particular experience in diagnosing dementia.

Geriatrician

A geriatrician specialises in the physical illnesses and disabilities associated with old age and in the care of older people. If the person being diagnosed has reached retirement age they may be referred to a geriatrician to see whether their symptoms are due to a physical illness or to find out whether they are suffering from a physical illness as well as dementia.

General adult psychiatrist

A general adult psychiatrist specialises in diagnosing and treating a wide range of mental health problems. A younger person may be referred to a psychiatrist to assist in the diagnosis.

Old age psychiatrist

An old age psychiatrist, sometimes known as a psychogeriatrician, is a psychiatrist who has further specialised in the mental health problems of older people, including dementia. They may sometimes also offer support to younger people with dementia.

The specialist team

The consultant usually works with a number of fully qualified doctors at various stages of further training in that particular speciality. Although you may not always see the consultant, he or she is responsible for your case and will discuss it with the doctor concerned.

The consultant also usually works with other professionals, including nurses, psychologists, occupational therapists and social workers. They will all contribute their own knowledge, skills and advice.

Assessment

Location

Assessment may take place in the home, in outpatients, in a day hospital over several weeks or, very occasionally, as a hospital inpatient.

Background information

As with the GP, an assessment is likely to include time spent talking to the person being diagnosed and those close to them.

Physical examination and tests

A physical examination and/or tests will be undertaken, if they have not already been carried out by the GP.

Memory tests

The person being diagnosed may see a psychologist for a detailed assessment. Time may be spent observing their behaviour and assessing their ability to cope.

Scans

The person with suspected dementia might be given a brain scan. A brain scan can identify conditions such as strokes, brain tumour and hydrocephalus (a build-up of fluid inside the brain).

There are several types of brain scan:

- CT or CAT (computerised axial tomography) scans are a way of taking pictures of the brain using X-rays and a computer.
- MRI (magnetic resonance imaging) scans also use a computer to create an image of the brain but, instead of X-rays, they use radio signals produced by the body in response to the effects of a very strong magnet contained within the scanner.
- SPECT (single photon emission computerised tomography) scans look at the blood flow through the brain, rather than at the structure of the brain.

After the assessment the consultant will send a report to the GP. CT and MRI scans may show brain shrinkage (atrophy) and SPECT and PET scans show areas of loss of function; the pattern of these changes helps to diagnose the cause of the dementia. A scan that shows no unexpected changes in the brain does not rule out conditions such as Alzheimer's disease because in the early stages of the disease the changes can be difficult to distinguish from normal ageing. The consultant may discuss their findings or may refer the person back to the GP for this information. In some cases the consultant may wish to see the person again after some months to observe any changes before making a diagnosis.

Getting the most from a consultation

If you are supporting the person being diagnosed, it may be useful to:

- Write down any questions or worrying signs beforehand to ask the GP or specialist. It can be difficult to remember everything you want to say during a consultation.
- Write down any important points the doctor makes during the consultation.
- Ask a doctor, or any other professional, to explain words or phrases if you do not understand.
- Ask a doctor to write down any medical terms, particularly if English is not your first language.

Explaining the diagnosis

Doctors will differ in their views on what to tell their patients about a diagnosis of dementia. They may:

- Feel that patients who can understand have a right to know, particularly if this gives them the opportunity to put their affairs in order.
- Feel that the knowledge that they have dementia will be too much for the person to cope with.
- Use a term such as 'memory problems' if they feel this is more easily understood or more appropriate.
- Be prepared to give a diagnosis of dementia, but only if the patient asks or seems to want to know.

Most doctors will inform those close to the person concerned of the diagnosis of dementia or possible dementia. In some cases it may be left to the relatives or friends to decide whether to tell the person that they have dementia. In this case the carer will probably be guided by the kind of relationship they have with the person and what they feel they would want to know.

If you feel that the doctor is avoiding the issue, you should press them to explain.

Ongoing assessment

The GP:

- Should arrange to see the person with dementia from time to time to assess changes and discuss any problems.
- May refer the person with dementia to a specialist for help in assessing changes and for advice on ways to deal with specific difficulties.
- Is responsible for the general health of the person with dementia.

The GP and a hospital specialist will usually jointly prescribe any drugs for Alzheimer's disease. The arrangement will depend upon the person's situation, where they live, and what medication they are taking.

Carers should not feel afraid to seek help from their GP or from local support groups if they feel that they need it. The Society's information sheet Next steps provides information about where carers and people with dementia can get support and further advice once a diagnosis has been made.

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