Diagnosis and assessment

Anybody who is worried because of feeling confused, agitated or forgetful should consider visiting their GP. The GP may be able to organise a referral to a specialist, offer advice or carry out tests in order to make a diagnosis. It may be helpful if a friend or relative accompanies the person to their GP.

‘Dementia’ describes a group of symptoms caused by the physical effects of disease or injury on the brain. Dementia is not a single specific disease. There are a number of different conditions that lead to dementia, including Alzheimer’s disease, vascular disease (including stroke), dementia with Lewy bodies and fronto-temporal dementia (Pick’s disease). Please see the Alzheimer’s Society’s information sheet What is dementia? for further information.

Each person experiences dementia in his or her own individual way, but there is usually:

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

Most causes of dementia are degenerative, which means the symptoms will gradually get worse.

Why get a diagnosis?

It is important to get a proper diagnosis of dementia. A diagnosis is essential in order 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, brain haemorrhages and brain tumours.
- Rule out other possible causes of confusion. These include poor sight or hearing; emotional upset caused by a life-changing event such as a house move or bereavement; the side-effects of medication, and the combination of certain 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

If a person is worried about their health or the health of a friend or relative, the GP is the first person to consult.

Home or surgery

GPs can make home visits as well as seeing people by appointment in their surgery. If dementia is suspected it is often easier for them to assess and observe the person’s behaviour in the home.

Background information

The GP will spend some time talking to the person to try to establish some of their symptoms. He or
she will also 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 if the person or their carer is having difficulty managing, the GP can refer them to social services.

**Communication**
At the end of the assessment the GP should explain his or her findings clearly to the person and their carer, and discuss with them what to do next. The GP may be able to make a diagnosis or may want to wait for a certain length of time to make sure. In many cases, the GP will 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. Any GP patient can ask for a referral to a specialist for a second opinion or for further support and access to services.

If a person feels that a referral would be helpful they should ask for this even if 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.

The 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 the 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 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 the person being diagnosed may not always see the consultant, the consultant is responsible for the 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 all contribute their own knowledge, skills and advice.

**Assessment**

**Location**
Assessment may take place in the person’s home, in a hospital outpatients department or in a day hospital, over several weeks. Very occasionally, a person is assessed as a hospital inpatient.

**Background information**
An assessment will include time spent talking to the person being diagnosed and to their relatives and/or friends.

**Physical examination and tests**
A physical examination and/or tests will be carried out, 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. This may be called a
‘cognitive assessment’, ‘memory tests’ or ‘neuropsychological tests’. The psychologist will spend some time observing the person’s 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 stroke, 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)** or **PET (positron emission tomography)** scans look at the activity of the brain or blood flow through the brain, rather than 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
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. It helps to bring a list of medications that the person is taking, as well as details of any previous medical problems.

- 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.

- Ask whether the doctor will be sending you a copy of his/her letter to the GP.

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 person will not be able to cope with the knowledge that they have dementia.

- 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.

Further reading
We can provide a list of further reading on request. Please contact the librarian at the Alzheimer’s Society national office on 020 7306 0606 or email library@alzheimers.org.uk