If you are worried that you are getting more forgetful, or you have been feeling confused, anxious or low for a while, it is a good idea to visit your GP. If you are concerned that someone close to you has been experiencing these difficulties, or has been behaving out of character, you may like to suggest that they visit their GP and that you accompany them for the appointment.

This factsheet outlines the process and benefits of assessing someone for possible dementia and then making and sharing a diagnosis.

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Assessment and diagnosis

If you are worried that you are getting more forgetful, or you have been feeling confused, anxious or low for a while, it is a good idea to visit your GP. These changes may be caused by several conditions, but they may also be an indication of dementia. The term ‘dementia’ describes a set of symptoms that occur when the brain is damaged by certain diseases, such as Alzheimer’s disease or a series of small strokes.

Each person will experience dementia differently, but there will usually be problems with:

- day-to-day memory
- concentrating, planning or organising
- language (for example, struggling to find the right word)
- judging distances and seeing objects properly (not caused by poor eyesight)
- orientation (for example, confusion about the day or month, or where they are).

These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. For example, the person or their family may notice that they now struggle to use the phone or regularly forget to take their medicine.

A person with dementia may also experience changes in their mood or behaviour. For more information about dementia, see factsheet 400, What is dementia?

Assessment for possible dementia is not a single step but a process that takes time. It often starts with the person or family members realising that there is something wrong. Assessment proceeds through various stages and tests, and ends with sharing of the diagnosis. For the person and those close to them, this journey is often an uncertain, anxious and emotional one.
Why get a diagnosis?

A thorough and timely assessment for possible dementia is essential, in order to:

- rule out other conditions that may have similar symptoms and may be treatable, including depression, chest and urinary tract infections, severe constipation, and vitamin and thyroid deficiencies
- rule out other possible causes of confusion (for example, poor sight or hearing), emotional changes and upsets (for example, moving house or bereavement), or the side effects of certain drugs or combinations of drugs
- provide a person with dementia with an explanation for their symptoms, removing uncertainty and allowing them to begin to adjust
- allow a person with dementia to access treatment as well as information, advice and support (emotional, practical, legal and financial)
- allow a person with dementia to plan and make arrangements for the future.

If the outcome of the assessment is a diagnosis of dementia, it is important that the type (for example, Alzheimer’s disease or vascular dementia) is also diagnosed. Knowing the dementia type will help to understand symptoms, predict how the dementia might progress, and suggest how best to manage it. For example, certain drugs will be prescribed for Alzheimer’s disease (but not vascular dementia), although these do not cure the condition.

Making a diagnosis

Making a diagnosis of dementia is often difficult, particularly in the early stages. This is because there is no one simple test and early symptoms can be similar to those of lots of other common conditions, as mentioned above. A thorough assessment (as detailed below) will often accurately diagnose the type of dementia, and people will usually be told the type, though this may only be confirmed after death if a post-mortem is done.
There is more than one way that someone might end up being assessed for possible dementia. Most people start by visiting the GP because of their symptoms, as described in steps 1–4 below.

In some cases an assessment starts in hospital. This is because anyone over 75 who is admitted urgently to hospital should now be assessed for confusion and memory problems.

Similarly, GPs may now ask certain patients who are at increased risk of dementia whether they are concerned about their memory. This includes people with Parkinson’s disease or those who are over 60 and have diabetes or a heart condition, or have had a stroke. The GP may ask such patients about memory problems even if they are visiting them about something else.

In either of these situations, if dementia is suspected the person will have further assessment and will generally be referred to one of the specialists listed below.

**Step 1: Assessment by a GP**

In the case of suspected dementia, the first person to consult is the GP. A person may see the GP in their surgery, or the GP may prefer to make a home visit. If they suspect the person has dementia, it is often easier to assess and observe their behaviour in their home. The exact problems then become clearer, as the person is in a familiar environment. The GP will assess the person through the following procedures:

- **Taking a ‘history’** – The GP will spend some time talking to the person and someone who knows them well. (The doctor may contact a family member by phone if they cannot attend in person.) They will ask about how and when the symptoms started and how they are affecting the person’s life. The GP will look at the person’s medical history and those of other family members. They will also review the medicines the person is taking.
Physical examinations and tests – The GP may carry out a physical examination, particularly if a stroke or Parkinson’s disease is suspected. They will also take samples (blood and possibly urine) to send off for tests. These may identify other conditions that are causing the symptoms.

Tests of mental abilities – The GP will ask the person a series of questions or give them a short pen-and-paper test. These are designed to test thinking, memory and orientation.

At the end of the assessment, the GP should explain their findings and discuss what action needs to be taken. Depending on their expertise and training, they may feel able to make a diagnosis at this stage, although this is uncommon. If it is dementia, the GP is more likely to be able to diagnose this if the condition is more advanced or the dementia is a common type such as Alzheimer’s.

More often, the GP will decide that further assessment is needed to make sure. In such cases they will generally refer the person to a memory assessment service, memory clinic or other specialist service within a community mental health team. These services all have teams of different professionals, and are set up to assess people with memory problems, especially those with suspected dementia.

Step 2: Referral to a specialist

The GP is the usual person to make a referral to a specialist. If the person or their carer feels that a referral would be helpful and the GP does not suggest it, they should ask about it. A specialist such as a consultant will have more knowledge and experience of dementia than a GP. They will have more time allocated for the appointment and access to more specialised investigations, such as brain scans and in-depth mental testing. After referral, the person should have to wait no longer than 4–6 weeks to see a specialist.

The GP will make the referral to a consultant working in a particular specialty. Which specialty they refer them to may depend on the age of the person, their symptoms, and what is available in the area they live in. The main types of consultant are explained below.
Old age psychiatrists are psychiatrists who specialise in the mental health of older people, including dementia. They may sometimes also offer support to younger people with dementia.

General adult psychiatrists specialise in diagnosing and treating a wide range of mental health problems. A younger person (under 65) may be referred to such a psychiatrist to help with the diagnosis.

Geriatricians specialise in physical illnesses and disabilities associated with old age, and in the care of older people. If the person being assessed is frail or in poor general health, they may be referred to one of these specialists to see whether their symptoms are due to a physical illness. They may have a physical illness as well as dementia.

Neurologists specialise in diseases of the brain and nervous system. Some neurologists have particular experience in diagnosing dementia. They tend to see younger people and those with less common types of dementia.

The consultant usually works in a specialist team, alongside a number of doctors at various stages of training in that particular specialty. Although the person may not always see their consultant, they are ultimately responsible for the case and will discuss it with the doctor the person has seen. The consultant also usually works with other professionals, including mental health nurses, psychologists, occupational therapists, social workers and dementia advisers (professionals who provide information, advice and guidance to people with dementia and their carers).

Step 3: Assessment

An assessment for possible dementia can be confusing and daunting, and a diagnosis of dementia is life-changing. Many memory services offer people who are about to go through assessment and diagnosis the chance to talk things over with a professional beforehand.

This pre-diagnostic counselling will help the person (and those close to them) understand why they have been referred, learn about the assessment process, give consent (or not) to go ahead, and prepare them for the possible outcomes. It is also an opportunity for the person and those supporting them to share what they already know about dementia, express their feelings and raise any concerns.
Assessment and diagnosis

Assessment may take place in the home, in an outpatient’s department at a hospital, in a day hospital over several weeks or, very occasionally, while the person stays in hospital as an inpatient. The specialist will carry out their assessment via the following steps:

- **Taking a history** – As with the GP, the specialist will talk to the person being assessed and those close to them for up to 90 minutes.

- **Physical examinations and tests** – A physical examination and/or tests will be undertaken, if they have not already been carried out by the GP. In many cases the blood tests will already have been done before referral.

- **Tests of mental abilities** – The person will have a more detailed assessment of memory and other thinking processes. This assessment consists of a range of pen-and-paper tests and questions. These will test things like memory, orientation, language and visuospatial skills (for example, copying shapes). These tests can be very good at helping to determine the type of problem a person may have, particularly in the early stages. The assessment can also be used as a baseline to measure any changes over time, which can help with making a diagnosis. The test is often given by a trained professional such as a mental health nurse or occupational therapist. In more complicated cases the person will be assessed by a clinical psychologist or neuropsychologist (professionals whose specialty includes the diagnosis of mental health problems).

- **Scans** – The person might be sent for a brain scan. Depending on where they live, this may involve a wait of several weeks. There are several types of brain scan:
  - CT (computerised tomography), CAT (computerised axial tomography) and MRI (magnetic resonance imaging) scans are widely used. They all show structural changes to brain tissue.
  - SPECT (single photon emission computerised tomography) and PET (positron emission tomography) scans are less widely used. They show changes in brain activity.

CT and MRI scans can identify conditions with similar symptoms to dementia such as a brain bleed, tumour or build-up of fluid inside the brain. If the person has dementia, these scans may show that the brain
has shrunk in certain areas. MRI in particular may also show changes caused by diseased blood vessels in the brain, indicating stroke or possible vascular dementia. A scan showing no unexpected changes in the brain does not rule out conditions such as Alzheimer’s disease. This is because in the early stages of the disease the changes can be difficult to distinguish from those seen in normal ageing.

SPECT and other more specialised scans can show areas where brain activity (blood flow or metabolism) is reduced. These scans are mostly used if the diagnosis of dementia type is still unclear after a CT or MRI scan.

To make the diagnosis, the consultant will bring together all the information from the history, symptoms, physical exam, tests and any scans. The combined picture will often allow a diagnosis to be made. If the diagnosis is dementia, the consultant should also be able to determine the type.

In some cases the consultant may diagnose mild cognitive impairment rather than dementia, especially if the symptoms are mild or could indicate depression. Mild cognitive impairment is when the person has problems with memory or thinking but these are not severe enough to be diagnosed as dementia. The specialist may then discharge the person back to their GP and ask the GP to re-refer them if they are significantly worse after a further 6–12 months. Sometimes the brain scan will not show any significant changes and a further scan is arranged. For more information see factsheet 470, What is mild cognitive impairment (MCI)?

Tips: Getting the most from a consultation
If possible, someone who knows the person being assessed well should go with them to the consultation. Whether you are attending the appointment for yourself or for someone you are supporting, it may be useful to do the following:

- Write down any questions or worrying symptoms beforehand to bring up with the GP or specialist. Try to include details of when symptoms first started. It can be difficult to remember everything you want to say during a consultation.
During the consultation, write down any important points the doctor makes.

Ask the doctor (or any other professional) to explain any words or phrases you do not understand.

Ask the doctor to write down any medical terms, especially if English is not your first language.

If a professional refers to ‘memory problems’ when giving a diagnosis, and you’re unclear what they mean, you might want to ask, ‘Do you mean I have dementia?’ or ‘Is that the same as Alzheimer’s?’, for example. Make sure you are clear what type of dementia has been diagnosed.

A specialist should offer to send you a copy of the letter they will write to the GP. This letter will include details of the diagnosis. You can ask them to provide a more personalised letter, containing clear information about the diagnosis and care needs.

**Step 4: Receiving the diagnosis**

At the end of a consultation the doctor will explain if they can make any tentative diagnosis based on the information they have so far. When all the test results are known, a separate appointment will usually be made for the consultant, and often other professionals in the team, to give the final diagnosis. Very occasionally, the consultant will send a report to the person’s GP, who will then give the diagnosis.

A diagnosis of dementia should be communicated sensitively but honestly, in a way that is tailored to the needs of the individual. The person being assessed has the right to be told their diagnosis and should be asked if they wish to know the outcome. (Very occasionally, a person chooses not to know; this is their right too.) If relevant, the doctor should also ask the person if they are happy for the person attending with them to be told, although this question should already have been raised in any pre-diagnostic counselling. It is usually in everyone’s interests for the diagnosis to be shared with those close to the person.

Occasionally the doctor will decide not to tell the person with dementia their diagnosis. It may be that the doctor thinks that the person would not understand the diagnosis, perhaps because the dementia is at a late
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stage. Or the doctor may feel that the person would find this knowledge too distressing. For example, they may be struggling with a very serious illness, have had a recent bereavement, or already been very upset by the assessment process so far. The doctor should discuss what is in the person’s best interests with anyone supporting the person.

To make the diagnosis, the consultant will bring together all the information from the history, symptoms, physical exam, tests and any scans. The combined picture will often allow a diagnosis to be made. If the diagnosis is dementia, the consultant should also be able to determine the type.

Doctors differ in how they communicate a diagnosis of dementia and the words they use. Some doctors will refer to ‘memory problems’ instead of using the word ‘dementia’. What is important is that the doctor uses language that the person understands and takes things at a pace that works for them. Professionals should answer any questions the person has in a sensitive but honest and straightforward way.

Following a diagnosis of dementia there is lot to adjust to and a great deal of information to take in. The final diagnosis meeting will usually cover how the dementia is likely to progress and any treatments (drug or non-drug) as part of a care plan.

Most memory services also offer sessions, running for several weeks after diagnosis, at which the person and those close to them can talk through the next steps in more detail and receive further written information. These sessions usually cover medication, living well, driving, benefits, local support services, planning ahead and more.

For more information on these topics see booklet 872, The dementia guide.
Step 5: Ongoing assessment

Once a diagnosis of dementia is confirmed, any medication has been started, and any post-diagnostic sessions have been completed, the person will generally be discharged from the memory service back to their GP. (An exception may be that there is a need for ongoing specialist support for specific symptoms or behaviours.) As the dementia progresses, the GP may refer the person with dementia back to a specialist for help in assessing changes, and for advice on ways to deal with certain difficulties such as changes in behaviour. The GP remains responsible for the general health of the person with dementia.

Prescription of drugs for Alzheimer’s disease will be started by the specialist and then routine prescribing will usually transfer to the GP. A review of these drugs is generally carried out every six months by the specialist or GP.

Someone diagnosed with dementia can seek support from their GP, or local support groups, if they feel they need it. For information about where to get support and further advice once a diagnosis has been made, see booklet 872, The dementia guide.

Further reading

For more information on different types of dementia, see the following Alzheimer’s Society factsheets:

- What is dementia? (400)
- What is Alzheimer’s disease? (401)
- What is vascular dementia? (402)
- What is dementia with Lewy bodies (DLB)? (403)
- What is frontotemporal dementia (FTD)? (404)

If you are having memory problems that you think may be associated with dementia, you may find the leaflet, Worried about your memory? helpful.


Other useful organisations

British Psychological Society
St Andrews House
48 Princess Road East
Leicester LE1 7DR

0116 254 9568
enquiries@bps.org.uk
www.bps.org.uk

Provides access to a list of clinical and counselling psychologists who offer private therapy services.

Carers UK
20 Great Dover Street
London SE1 4LX

0808 808 7777 (advice line, Monday–Friday 10am–4pm)
adviceline@carersuk.org
www.carersuk.org

Provides information and advice about caring, alongside practical and emotional support for carers.
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Reviewed by: Dr John-Paul Taylor, Senior Clinical Lecturer, Institute for Neuroscience, Honorary Consultant in Old Age Psychiatry, Tyne and Wear NHS Trust; Dr Sophia Bennett, specialty trainee in Old Age Psychiatry, Tyne and Wear NHS Trust; Dr Steve Iliffe, Professor of Primary Care for Older People, UCL Dept of Primary Care & Population Health
This factsheet has also been reviewed by people affected by dementia.
A list of sources is available on request.

Alzheimer’s Society National Dementia Helpline
England, Wales and Northern Ireland:
0300 222 1122
9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

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