



Alzheimer Scotland
Action on Dementia

Getting help from your doctor

- a **guide** for people worried about their
memory, people with dementia and carers



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Introduction

This booklet is for you if you are worried you might have dementia or if your doctor has told you that you have dementia. It will help you to find out how doctors and other health workers can help you. The information in this booklet will also help relatives or carers of people with dementia, and there is a section especially for them starting on page 22.

Talk to your doctor if you are worried

Summary

- **Lots of things can cause memory problems, not just dementia.**
- **See your doctor if you are worried.**
- **There might be treatment to help you.**

Forgetfulness or getting muddled about things can make people worry about dementia. There are good reasons why you should talk to your doctor:

- to find out what is causing your symptoms (the diagnosis)
- to get any treatment that might help you, whether the problem is dementia or something else.

Many people think that memory problems are just a sign of old age and not a medical condition that could benefit from drug treatment or other advice and support. Or that their problems aren't important enough to 'bother the doctor' about. But if the problem is affecting your life, you should take it seriously, and so should your family and your doctor. It may not turn out to be anything to worry about. See your family doctor (general practitioner) if you have noticed a change, gradual or sudden, from what is normal for you, or if your symptoms are causing you problems in your life.

Some possible causes of forgetfulness and confusion:

- stress, for example, after a bereavement
- anxiety
- depression
- tiredness
- an infection, for example a chest or a bladder infection
- other illnesses such as vitamin deficiency or thyroid disorder
- the side effects of drugs
- long-term overuse of alcohol or some tranquillisers
- the menopause
- the normal ageing process (which causes mild forgetfulness or difficulty finding words)
- dementia

When you visit your doctor, take a list of what you want to ask, and a notepad to write down what he or she says. You can also take a friend or relative with you, who could tell the doctor what changes he or she has noticed and help you remember what the doctor says.



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What will the doctor do?

Summary

- **Take someone with you to help you tell the doctor what's happening to you.**
- **The doctor will ask you questions about what you are usually like and what has changed.**
- **Tell the doctor what problems you are having.**

Your doctor will want to know what has changed for you, so he or she needs to know how you normally manage. Unless he or she knows you very well, you will need to answer some questions about how you used to live day to day before your problems began, and what's happening now. Your relative or friend may be able to give more information about any change from your normal self. It is useful if you write down some examples of what's worrying you.

Some common early problems:

- forgetting appointments
- losing things more than usual
- difficulty with familiar names or with words
- problems handling money
- difficulties with work
- problems with driving
- feeling unsure in familiar places
- poor concentration
- lack of confidence or feeling low.

Having some or all of these problems does not necessarily mean you have dementia - but you should see your doctor to find out what's causing your difficulties.

Examination

Summary

- **There is no simple test to say if you have dementia or not.**
- **The doctor will examine you and ask questions to test your memory.**
- **The doctor won't be able to tell you what is wrong right away.**
- **The doctor may want you to see a specialist or go to a memory clinic.**
- **You have a right to information about your illness and about any treatment.**
- **The doctor should not tell your diagnosis to anyone else without your permission.**

The doctor will then examine you and do some tests. There is no simple test for dementia. The examination may include a general physical examination, but he or

she will also want to test how well your brain is working. This will include memory tests but also how well your brain is taking things in, and your mental abilities. He or she will look for any problems in your ability to communicate and to carry out tasks. You might do a standard set of tests such as the 'Mini Mental State Examination'. Or the doctor may ask you to do a task like drawing a clock face.

Although some of the tests may seem odd, they are trying to test all the different things that your brain does, in the simplest possible way.

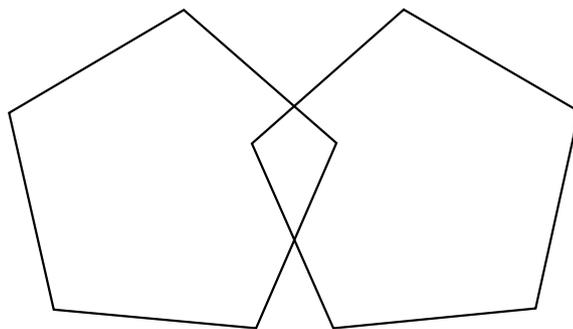


The doctor will then examine you and do some tests.

Mini Mental State Examination

This is an example of a memory test which may show that there is a possible problem. This test does not diagnose dementia.

- 1a What date/month/year/season is it?
Maximum score 5
- 1b What town/country/building/floor is this?
Maximum score 5
- 2 Remember three objects eg apple/table/penny
Maximum score 3
- 3 Keep subtracting 7 from 100 ie 100 ... 93 ... 86 ... 79 ... 72 ... 65
Maximum score 5
- 4 Repeat words from question 2
Maximum score 3
- 5 Name two objects shown to you eg watch & pencil
Repeat sentence: 'No ifs, ands or buts.'
Maximum score 3
- 6 Read and obey this instruction: 'Close your eyes'
Write a sentence
Maximum score 2
- 7 Obey verbal instruction, 'take this paper in your right hand, fold it in half, put it on the floor.'
Maximum score 3
- 8 Copy this drawing
Maximum score 1



Adapted from Folstein MF et al (1975) Journal of Psychiatric Research 12:189

The reason for the physical examination is to find out whether your symptoms are due to something other than dementia. For the same reason he or she will want to do blood tests, and might want to check your heart with an ECG or do a chest x-ray. (In some areas these tests may be done at the memory clinic.) It is important to distinguish between dementia and temporary confusion which has a physical cause (for example an infection or a side-effect of drugs). This type of confusion usually starts much more suddenly than dementia and the symptoms are more variable. The doctor should also check for signs of depression, since depression can lead to poor concentration and memory, which can be mistaken for dementia.

Don't expect the doctor to be able to give you a definite diagnosis after your first visit. He or she will have to wait for the results of tests and may want you to see a specialist or go to a memory clinic. Once the doctor has all the information he or she will tell you as much as possible about what is wrong.

You have a right to information about your illness and about any treatment. You also have a right to confidentiality. The doctor should not tell your diagnosis to anyone else - such as a relative - without your permission.

The diagnosis

Summary

- **The doctor might tell you that you don't have dementia.**
- **If you do have dementia, it means your brain isn't working as well as it used to.**
- **There are lots of kinds of dementia, and the doctor will tell you which kind he or she thinks you have.**
- **You can call the Dementia Helpline on 0808 808 3000 (24 hours) for more information and to talk things over.**

The doctor may be able to tell you that you do not have dementia. He or she will either be confident that you are simply showing the mild changes that are common in old age, or that you have some other condition, which the doctor will offer you treatment for.

What does a diagnosis of dementia mean?

If the doctor has decided that you do have dementia, he or she is saying that your brain is beginning not to manage to do some of the things it should. Dementia is the overall term for this problem. There are many causes of dementia, each of which is a different illness. What they have in common is that they damage brain cells and the very complicated connections between them. Alzheimer's disease is the name of the most common type of dementia, but there are many others.

The doctor should explain that he or she thinks that your problems are because of dementia and also which type of dementia he or she thinks it is. Unfortunately, it is hard to be 100% definite. Many doctors use terms like 'possible dementia' or 'probable Alzheimer's'. There is no definite test for any of these conditions, and some people have a mixture of more than one.

You can get more information about the different kinds of dementia from the **Dementia Helpline (0808 808 3000)** or on the internet at **www.alzscot.org**.

Types of dementia

- **Alzheimer's disease** - progressive damage to certain types of brain cell
- **vascular dementia** - connected with arteriosclerosis or 'hardening of the arteries' in the brain (including multi-infarct dementia, which is due to repeated small strokes)
- **Lewy body dementia** - which damages cells in the same way as Parkinson's disease, but affects the whole brain rather than one small area and often causes hallucinations or visions and mild signs like Parkinson's
- **alcohol-related dementia** (including **Korsakoff's syndrome**, which causes problems especially with recent memory)
- **frontal lobe dementia** or **Pick's disease** - only part of the brain is affected; the memory may be quite good but there are changes in the ability to control feelings or behaviour
- **AIDS-related dementia**
- **Creutzfeld-Jacob disease (CJD)** - the human form of BSE or 'mad cow' disease
- **medical conditions causing reversible dementia**

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Benefits of early diagnosis

Summary

- **It is a good idea to know as early as possible if you have dementia.**
- **If you know you have dementia, you can get information and plan for the future.**
- **You can get support to cope with your illness.**
- **You can choose people now to help you later on. They can help if you need someone to look after your money or take other decisions for you.**

It is important that if you have dementia you are diagnosed as early as possible. This means that you have the best opportunity to:

- benefit from any appropriate treatments
- understand what the future holds for you
- talk about your diagnosis and your feelings with friends and family
- get information, for example about welfare benefits and support available
- get support such as counselling or join a support group
- choose someone to handle your financial or affairs or take welfare and health care decisions for you if you can't in the future (powers of attorney) - call the Dementia Helpline on 0808 808 3000 to get a booklet about this, or see a solicitor
- make other decisions for the future, such as making an advance directive or living will about what treatments you would or would not want
- get other affairs in order (for example, write your will).

Seeing a specialist

Summary

- **Your doctor might send you to see a specialist at the hospital or to a memory clinic.**
- **There are several different kinds of specialists who can help with dementia.**
- **The specialist will do more tests to see what is wrong.**
- **Sometimes the specialist might send you for a brain scan but not everyone needs one.**

Your doctor should refer you to a hospital specialist if you:

- need more detailed tests and examinations for diagnosis or assessment
- need treatment that has to be prescribed by a specialist (for example, drugs to treat Alzheimer's disease)
- ask for a second opinion
- need to go into hospital for assessment or short-term care or to attend a day hospital.

You will be referred to one of the following:

- old age psychiatrist (also known as psycho-geriatrician)
- geriatrician (specialist in the medicine of old age)
- psychiatrist
- neurologist
- clinical psychologist (who specialises in memory, language and other tests)
- memory clinic.

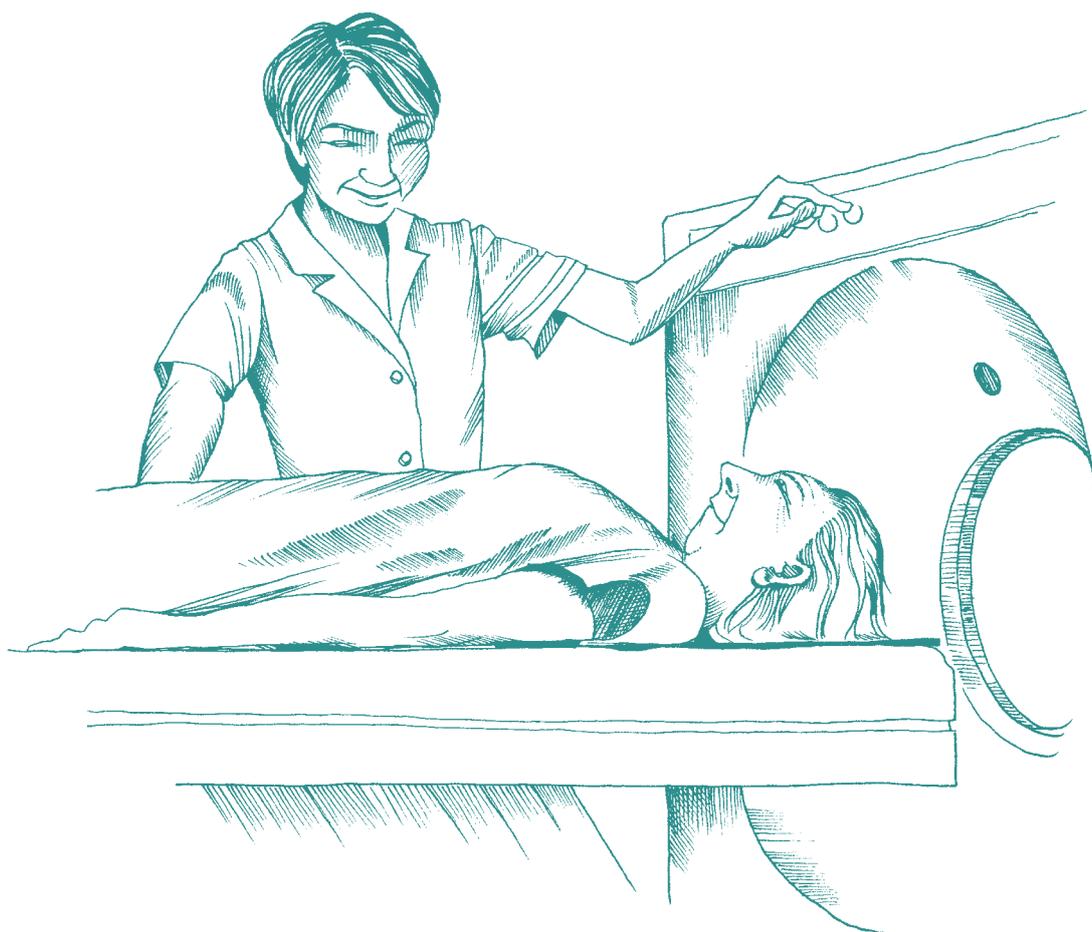
Early on, the specialist will want to look for potentially reversible causes. Such disorders are rare but many can be checked by simple blood and urine tests.

Brain scans

Brain scans can help to distinguish between Alzheimer's disease and vascular dementia. They can also help to identify the much rarer hydrocephalus or brain tumours. However, they are expensive, so the doctor will only arrange a scan if there is a good reason for it.

Types of brain scan

- **CT** (computerised tomography) - the most commonly-used scan, which uses X-rays to show the details of the structure of the brain
- **MRI** (magnetic resonance imaging) - a different technique, which is likely only to be recommended if there are difficulties in diagnosis
- **SPECT** (single proton emission computerised tomography) - another technique which can give information about how the brain is working; for example, whether there is poor blood flow to particular areas



Brain scans can help to distinguish between Alzheimer's disease and vascular dementia or other conditions

Memory clinics

In some areas, you may be referred to a memory clinic. At the clinic, your symptoms will be investigated, and any appropriate treatment prescribed. Some memory clinics are special centres for diagnosis. Others concentrate on treatments for dementia. Some do both.

Treatment

Drugs to treat dementia

Summary

- **Drug treatments can help some people with some kinds of dementia.**
- **There are three drugs which might help for early Alzheimer's disease or Lewy body dementia. These are Aricept, Exelon and Reminyl.**
- **There is one drug which might help later in the illness: Ebixa.**
- **There is a lot of research going on to find new treatments.**

There is no cure for Alzheimer's or the other common forms of dementia yet, but there are drug treatments which can help some people.

If you are in the early stages of Alzheimer's, or have Lewy body dementia, there are three possible drugs which the specialist (or in some areas your own GP) may prescribe. These are:

- Aricept (donepezil)
- Exelon (rivastigmine)
- Reminyl (galantamine).

These three drugs all help damaged nerve cells work a little better for a time, and so may slow down the effects of the illness. Like all drugs, they are not suitable for everyone, and there can be side effects. Your progress will be carefully checked - your doctor will not just give you a prescription and leave you to get on with it.

For people in the middle to later stages of Alzheimer's (and perhaps vascular dementia), a different type of treatment called Ebixa (memantine) can sometimes help for a while.

For more information on any of these drugs, call the Dementia Helpline (0808 808 3000).

Unfortunately, not everyone is helped by these drugs, but there is a lot of research going on to find new treatments for dementia. Call the Dementia Helpline for information on current Scottish research.

Drugs to treat the effects of dementia

Summary

- **Some people with dementia might get depression, anxiety or feel very restless.**
- **Some people might have hallucinations.**
- **Your doctor can help with these problems.**
- **Your doctor will only give you drugs for these problems if other ways of helping don't work.**

Some people who have dementia may be troubled by symptoms such as depression, anxiety, restlessness or hallucinations (visions). Many of these problems are an understandable reaction to having the illness, and the doctor will help you get the necessary assistance to deal with them, such as support from a community nurse or other local professionals. However, sometimes drug treatment may be necessary; but the doctor should only think of this if other forms of help are not going to work.

It is very unlikely that you will need these drugs for more than a short time. Go back to the doctor to check if they are still necessary.

Call the Dementia Helpline (0808 808 3000) for more information on these drugs.

Prescriptions

Summary

- Ask the doctor all about any drug he or she prescribes for you.
- Make sure the doctor knows if you are taking any other medicines, including ones you bought from the chemist without a prescription.
- Ask the chemist for special packs to help you to remember to take your pills at the right time.

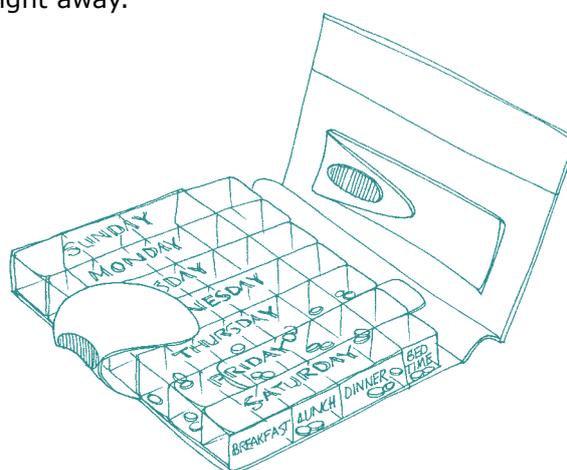
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Any drug you are given should be for a very specific reason. If the doctor gives you a prescription, ask for clear information about what each drug is for and how it should be taken. Ask the doctor what the effect of each drug should be, how long it is likely to be before it begins to work and what the side-effects might be. Make sure the doctor knows if you are taking any other medicines, whether over the counter or prescribed, since the combination of certain drugs can produce unpleasant and sometimes dangerous results. Find out too if it is safe to drink any alcohol when taking the drugs.

You may need help with reminders to take the medication. The pharmacist can help by providing special packs with compartments marked with the days of the week as a reminder of when to take the pills.

In general, older people need lower dosages of drugs because their metabolism works more slowly than when they were young. If any drug does seem to be having a bad effect, contact the doctor straight away.

The pharmacist can help by providing special reminder packs with compartments



Getting help

Talking about it

Summary

- You will probably feel shocked if your doctor tells you that you have dementia.
- If you forget what the doctor says, you can go back again.
- Ask for written information.
- The doctor should put you in touch with people who can give you information and support.
- The Dementia Helpline (0808 808 3000) can send you free booklets.

Your GP or specialist will be the first person to tell you definitely if you have dementia. This can of course come as a great shock, and you will need some time to come to terms with it and start thinking positively about your future. Don't worry if you don't take in what the doctor says - you can go back and ask again. Ask for written information or factsheets.

The doctor will start the process of talking over all the implications of the diagnosis but will want to put you in touch with others who can help. There may be a special service for advice and support for people in the early stages of dementia in your area, or you may see a community nurse or other local professionals.

There are two booklets which may help you. Both are free from the Dementia Helpline (0808 808 3000):

- *Don't make the journey alone* - written by people with dementia for people who have just had a diagnosis
- *Facing dementia* - about practical ways to cope.



Your family and friends

Summary

- It is usually best to make sure your family and friends know about your dementia so that they can help.
- They might find it hard to cope with at first, but they can get support too.

The doctor will usually want to discuss the diagnosis with those closest to you, because even more than most illnesses, dementia will affect them too. It is of course up to you how much your family and friends are involved, but remember that it will be very difficult for you to cope with all the effects of dementia alone. You are likely to need their help, and putting them in the picture early is usually easier. And if your memory is getting worse they can help you fill in the gaps.

Sometimes relatives or friends have very different ideas from the person with dementia about how serious the illness is or what help is needed. It's best to discuss these differences before they cause any difficulties in your relationship. The doctor can help or suggest someone else who can.

Remember also that your illness is likely to be quite distressing for your relatives and friends, so they may need help and support themselves.

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The doctor will usually want to discuss the diagnosis with those closest to you

Community care

Summary

- You can get help with day-to-day living when you start to need it.
- Your local social work department can give you a 'community care assessment' to see what help you need.
- The social worker will give you a 'care plan' showing what services you can get.

As time goes on, you will probably need more help with day-to-day living. The services available to help people with dementia and their carers vary from area to area. Community care services can help you cope in your own home for as long as possible and maintain your quality of life.

You are entitled to a **community care assessment** from the social work department. Your GP, health visitor or nurse can arrange this, or you can contact the social work department directly (the number is in your local phonebook under the name of the council).

The assessment is to work out what you need. It will usually be done by a social worker. He or she will talk to you, your carer if you have one, your doctor and, if appropriate, other people who can have information about what might help.

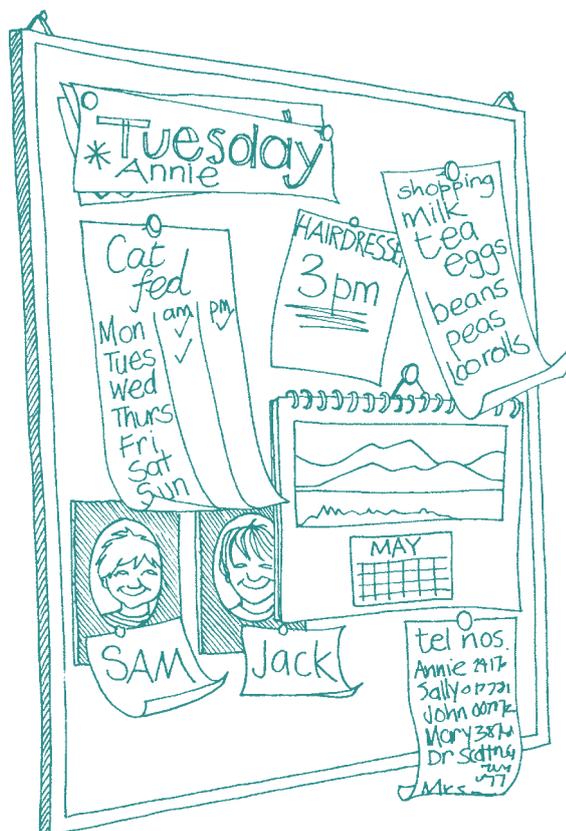
The social worker will then produce a **care plan** for you, showing what services you can get to help you.



You are entitled to a community care assessment from the social work department

Some services which may help are:

- home support - for help with personal care or day-to-day tasks and to help you be safe in your home
- home adaptations and memory aids
- meals on wheels
- day centres - for enjoyable and sociable activities
- short or respite breaks - to give your carer time for him or herself.



Memory aids can help you manage better

Health services

Summary

- **Your doctor can put you in touch with other professionals who can help.**

Other health professionals besides doctors can help. Part of the GP's role is to put you in touch with their expert help. They will be able to help you with finding services and support for yourself and your carer. You can contact them directly at your GP surgery, or your GP or hospital specialist may refer you. They include:

- Community psychiatric nurse (CPN) - can visit you at home, providing information about the illness, practical advice on how to cope with dementia and the difficulties it can cause and emotional support both for you and for your carer and family

- District or community nurse - can visit to help with nursing needs such as bathing or continence problems
- Health visitor - can advise you on any health issues. Some areas have specialist dementia health visitors
- Continence adviser or practice nurse - can help if you have problems with continence.

Your GP or hospital specialist may also refer you to a day hospital for assessment, diagnosis or care.



A community psychiatric nurse can visit you at home

Benefits

Summary

- **Your doctor or nurse can help you make sure you get all the welfare benefits you are entitled to.**

Your GP or, more often, your practice nurse, health visitor or district nurse, may be the first person to tell you about benefits such as Attendance Allowance, Disability Living Allowance and Council Tax discounts. They may not be experts on welfare benefit matters, but will be able to suggest where you can get help with making a claim. The welfare rights officer at the social work department, or your local Citizens Advice Bureau can help with benefits advice.

Planning ahead

Summary

- You can choose who you want to handle your affairs for you if you can't do it yourself in the future. This is called a power of attorney.
- You can only do this if you are mentally fit enough - ask your doctor if you are not sure.
- See a solicitor to make a power of attorney.

Because you have dementia, you will find that you gradually have more difficulty managing, or making important decisions. You can prepare for the future by giving someone you trust the ability to handle your affairs for you. This is called a power of attorney. You can have a power of attorney for your financial affairs or for your welfare and health care or for both. You will need to see a solicitor to do this, but you should check with your doctor if you or the solicitor have any doubts about whether you are mentally fit enough to sign.

Dementia Helpline

Summary

- The Dementia Helpline, freephone 0808 808 3000, is open 24 hours a day.
- You can call at any time for support and for information on anything to do with dementia and how to cope.
- The Helpline can send you free information.

The Dementia Helpline, freephone 0808 808 3000, is open 24 hours a day. You can call at any time for emotional support and for information on dementia, coping with problems, getting help, benefits and anything else to do with dementia. Trained Helpline volunteers and staff are always there to listen and can send you free information and publications, including guides to local services. The Dementia Helpline has a panel of professional advisors and consultants who can help with information on more complex questions.



Keeping well

Summary

- **Make sure you look after your health.**
- **Getting ill can make you feel more confused.**

It is important to look after your general health. This can help you avoid getting illnesses which can make your symptoms worse.

- Ask your GP, health visitor, practice nurse or community nurse for advice on improving your diet.
- Try to exercise regularly.
- Avoid drinking too much alcohol.
- Try to stop or cut down on smoking, especially if you have vascular dementia.
- Check with your GP to make sure you are not taking medicines you don't need.
- Drink plenty of fluids - 8 glasses a day.



Try to exercise regularly

When you should see the doctor again

Summary

- **Stay in touch with your doctor so that he or she knows how you are doing.**
- **If you are over 75 the doctor will offer a check-up every year.**
- **See your doctor if you get symptoms of another illness or problems with your eyesight or hearing**
- **Many conditions can make you more confused until you are treated.**
- **It is a good idea for your carer or family and friends to know when to make sure you see the doctor.**

It is important to keep in touch with the doctor so that he or she can monitor your progress. The doctor may see you in person or give responsibility to a health visitor, district nurse or community psychiatric nurse. Whoever has the main responsibility, the doctor will want to see you regularly to reassess you. This may involve re-testing to measure the progress of any illness.

Doctors must, as part of their contract, offer a yearly check-up to all patients aged 75 and over. You can choose whether to go into the surgery or be visited at home. The doctor may delegate the check-up to a practice nurse or a health visitor. The check-up will include assessing your mental abilities.

Even if you have dementia it doesn't mean you can't also get other illnesses. If you have aches or pains, or feel depressed, for example, you need treatment. It is important to see your doctor if you get symptoms of another illness. You should let your doctor know if you are having problems with your eyesight or hearing; such problems are not part of dementia. Many conditions, such as constipation or chest and urinary infections, can make you more confused. If you are treated, you will improve. There may be times when illness makes you get confused and you may not realise something is wrong. Because of this, it is a good idea for your carer or family and friends to know when to make sure you see the doctor.

You should *always* see your doctor if:

- you get symptoms of an infection - for example a bladder infection that gives you pain when you urinate, or a bad chest infection that doesn't settle quickly
- you are constipated
- you develop hallucinations
- you have problems with your eyesight or hearing
- you are not managing to eat or drink enough
- you fall - or if you have cuts or bruises even though you don't remember falling
- you are feeling depressed.

The doctor will also need to be involved if you are having difficulty making decisions about treatment, money matters or getting help. No-one can take away your power to make decisions for yourself unless you have had a proper medical examination which shows that you need someone else to take decisions for you, and there has been a formal legal process.

If you are not satisfied

Summary

If you are not satisfied with your doctor you can:

- **Talk to him or her about the problem**
- **Try another GP in the practice**
- **Make a complaint**
- **Change to a doctor in another practice.**

A good doctor can be a tower of strength and the gatekeeper for a wide range of useful services. However, some people have had problems with their doctors, such as poor diagnosis, insensitive advice or failure to refer to services. Some doctors seem more interested in and sympathetic to the problems of people with dementia and carers than others.

If you are not satisfied with your doctor, talk to him or her about the problem if you can. If that doesn't solve the problem you could try another GP in the practice. You have a right to make a complaint or to change to a doctor in another practice if you wish.

Every GP has a complaints procedure and must give you information about it if you ask. You can call the Dementia Helpline on 0808 808 3000 for more information on complaining or to talk over the issues before you decide whether to complain. Your Local Health Council can support you in making a complaint - call the Dementia Helpline for their details.

You do not need permission to change doctor, and you don't need to tell your old doctor or say why. Just ask another GP to put you on his or her list. If you can't find another GP the health board must allocate you to one.

Research

Summary

- **You can take part in research if you want, but you don't have to.**
- **Make sure you understand what the research is about and what you will have to do.**
- **You can stop at any time if you change your mind.**

Some memory clinics and other doctors carry out research; for example, drug trials or trials of other types of treatment. Research is important, but may involve some inconvenience to you; for example, returning regularly for tests. You do not have to take part if you prefer not to. If you are asked to take part in a research study, ask for clear information about it:

- What is the purpose of the study?
- How long will it last?
- What would I have to do?
- If it is a drug trial, would I know whether I am receiving the drug or a placebo (dummy pill)?
- What are the possible side effects or other risks?

Even if you agree to take part in research, if you change your mind, you can pull out at any time.

Information for relatives and carers

What to do if you are worried

Summary

- **Speak to the person first about changes you have noticed.**
- **If something is wrong, the person should see the doctor.**
- **Don't delay in seeking help. You know your partner, relative or friend best, so you will know when something has changed.**

Sometimes it is family and friends who first notice that something is wrong. You may notice changes in the person that worry you, such as memory lapses, mood changes, or difficulty doing everyday tasks. See page 4 for a list of some common early problems.

It is best to speak to the person about what you have noticed. It may be that he or she is also worried, or has already seen the doctor. It may be that there is something else wrong. Page 8 describes why it is important that anyone worried sees the GP.

You may feel awkward speaking about the problems you are facing. Remember that the doctor will have talked to many people in similar situations before. Dementia is an illness and nobody is to blame. Remember also that thousands of people in Scotland face similar problems.

Don't delay in seeking help. You are likely to know your partner, relative or friend better than anyone else, so you will know best when something has changed.



Sometimes it is family and friends who first notice that something is wrong

Going to the doctor

Summary

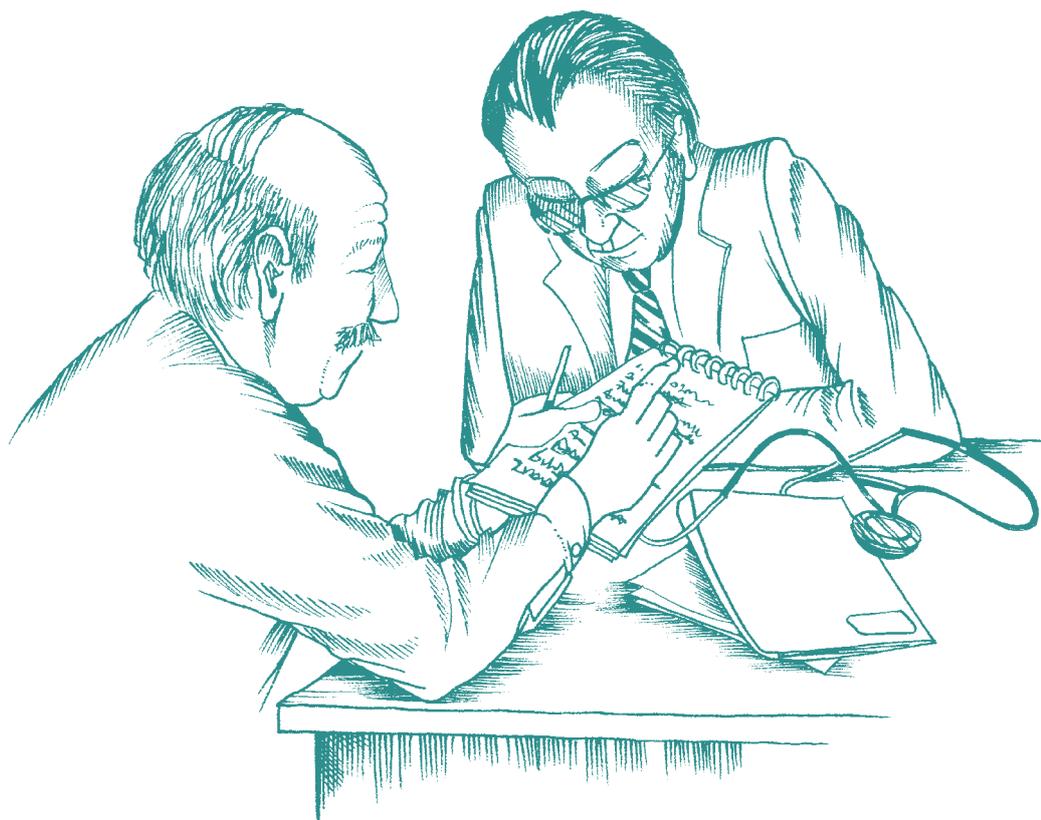
- **If possible, go with the person to see the doctor.**
- **The person has a right to confidentiality, but can give the doctor permission to talk to you.**
- **If the person does not realise anything is wrong, you can still tell the doctor of your concerns.**
- **If it's hard to give the doctor the full picture in front of the person, see the doctor separately to make sure he or she has the full story.**

If the person is willing, you should go together to the GP. That way the GP will get all the information, and you will be fully informed. Alternatively, the person could see the doctor alone, but give permission for the doctor to tell you what is wrong. However, everyone has a right to confidentiality, so without permission, doctors will not usually be able to give you information about the person.

Unfortunately, sometimes people in the early stages of dementia don't realise there is a problem and do not want to see the doctor at all. It is still possible for you to talk to the doctor about your worries, but the doctor may not be able to do very much unless he or she can see the person and persuade him or her to seek help. The doctor may have to wait until the next time he or she sees the person, for example at the annual check-up for people over 75.

It is important that the doctor gets the full picture, especially if the person isn't aware of some of the problems or is forgetful. It is quite common for someone with dementia to seem to put on a special show for the doctor and to deny the existence of the problems you describe.

You may find it difficult to talk to the doctor in front of your partner, relative or friend. If so, ask for an appointment at another time to go over the problems in more detail. If you feel you will need more time it may be possible to book a double appointment. Book the appointment in the person's name so that the doctor will have all the appropriate notes ready. Try to make sure it is with the doctor who knows the person best. Before seeing the doctor, make a list of symptoms and the questions you want to ask. You can see the person's doctor even if you have a different doctor, perhaps in a different practice.



Before seeing the doctor, make a list of symptoms and the questions you want to ask

How the doctor can help

Summary

- **The doctor will make a diagnosis or refer the person to a specialist.**
- **It is almost always best that the person is told the diagnosis, so that he or she can understand what is wrong and plan for the future.**
- **There are treatments for some kinds of dementia and for some of the other difficulties dementia can cause.**
- **The doctor can also help you to consider questions such as the person's fitness to drive, whether he or she should give up work and when to get legal advice.**
- **The doctor can refer you for a carer's assessment to help you get support.**

The first important job that the GP has to do is to make a diagnosis or to refer the person on to a specialist for a diagnosis. See page 4 for more information.

Some people worry about what will happen if the person finds out he or she has dementia. You may even have thought that it would be better not to tell. However, not sharing the diagnosis can cause a lot of problems. If the person doesn't know what's wrong, he or she can't understand the situation and can't make any plans for the future. There will inevitably be a communication barrier between you. The doctor can make the process of sharing the diagnosis easier.

After making the diagnosis, the doctor will help if there are any problems - for example:

- depression
- apathy (not wanting to do anything)
- agitation
- hallucinations
- repeated questions
- aggression
- wandering.

There are treatments for some kinds of dementia and for some of the other difficulties dementia can cause - see page 11 for more information.

The doctor can also help you to consider questions such as the person's fitness to continue driving, whether he or she should give up work and when to get legal advice. Often the person with dementia may be more likely to take advice from the doctor than from you or other friends or relatives - for example, on when to give up driving.

The GP can refer you to the social work department for a carer's assessment, to look at what help you might need to support you as a carer.

Follow up

Summary

- **Keep in touch with the person's doctor.**
- **Most GPs will also give advice over the telephone.**

Keep in touch with the person's doctor. See page 20 for information on when it is particularly important that the person sees the doctor. Most GPs are also happy to give advice over the telephone - ask the surgery when the best times are. If the person you care for gets agitated in the waiting room, request the first appointment to avoid a wait or ask the doctor to visit.

Medical decisions

Summary

- **Carers should be consulted about medical decisions.**
- **Welfare attorneys with authorisation to make medical decisions must be consulted under all reasonable circumstances.**

If the person you care for is having difficulty making health care and treatment decisions, then the doctor should make an assessment and consult with you. If the person has given you welfare power of attorney including authorisation to make medical decisions, then the doctor must consult with you under all reasonable circumstances. There is more information about medical decision making in *Dementia: money and legal matters*, which is free to carers from the Dementia Helpline (0808 808 3000) or on www.alzscot.org.

Support for yourself

Summary

- **It can be difficult to cope with some of your feelings about caring for the person with dementia.**
- **Don't try to cope alone with your feelings.**
- **Speak to your doctor, or call the Dementia Helpline on 0808 808 3000 for emotional support.**

Looking after someone with dementia is often very stressful. One of the things you may find hardest is living with your feelings about caring for the person with dementia. Most carers will experience a variety of emotions such as sadness, guilt, anger and fear. Tiredness and tension are also common. Some of these feelings come as no surprise. You might expect to be sad if you feel you are slowly losing someone you love. Anger can be more of a shock. You may be alarmed at how angry you can get and how quickly you come to the end of your tether, even over minor upsets.

You may need help to come to terms with these emotions, at all stages of the illness. When the person is first diagnosed, you will need to cope together with the implications for the future and the changes that will be required.

As the disease progresses you will have to learn how to deal with various problems. The whole family may need the chance to talk things through, as caring for someone with dementia may be affecting everyone's life. Some families find it helpful to arrange special group discussions to talk over difficulties. Problems can arise, for example, when teenagers are having their own problems at the same time as a member of the family has dementia, or when a parent of young children develops the illness. Later in the illness, you may need to consider residential care. This can be a difficult time for everyone.

Don't try to cope alone with your feelings. Speak to your doctor, or call the Dementia Helpline on 0808 808 3000 for emotional support.

Your GP may not have enough time to provide all these kinds of advice and support him or herself. However, he or she can refer you to specialist agencies or a carers' support group.

Your health

Summary

- **Make sure you look after your own health too.**
- **Call the Helpline for a free booklet, *Looking after yourself*.**

Caring can affect your mental and physical health. Make sure you look after your own needs too. Remember, the most common reason for people with dementia to go into long stay care is that the carer can no longer cope due to ill health. Use your GP to make sure you stay as healthy as possible. Use community care services (see page 15) to try to make sure you get some time off caring. Look after yourself - make sure your diet is as healthy as possible and that you get regular exercise and enough sleep. Call the Dementia Helpline (0808 808 3000) for a free copy of the booklet *Looking after yourself - for carers of people with dementia*.



Conclusion

Summary

- **Make full use of your GP to maintain your physical and mental health.**

The GP is a vital resource for people with dementia and for carers, and is the gateway to getting many other kinds of help. It is important that both people with dementia and carers make full use of their GPs to maintain both physical and mental health. Don't worry about consulting the doctor if you are at all concerned; that's his or her job.

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www.alzscot.org

This booklet is for you if you are worried you might have dementia or if your doctor has told you that you have dementia. It will help you to find out how doctors and other health workers can help you. The information will also help relatives or carers of people with dementia, and there is a section especially for them.

The booklet covers:

- how dementia is diagnosed
- treatments
- how to get help and support
- how you can keep yourself as well as possible
- when you should see the doctor again.

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