

Alzheimer's disease

Introduction

This information sheet is for people with early Alzheimer's disease who want to know more about their illness, and for carers of people at any stage of the illness. It includes medical information about the diagnosis and treatment of Alzheimer's disease, and practical information for carers.

If you require information about other issues regarding dementia call the freephone **Dementia Helpline** on **0808 808 3000**, or see our website at www.alzscot.org.

What is Alzheimer's disease?

Alzheimer's disease is an illness of the brain which causes dementia. Dementia is the general term for a gradual progressive decline in a person's memory and other mental abilities. There are many different illnesses which can cause dementia, but Alzheimer's disease is the most common. It is estimated that, out of the 61,000 people in Scotland who have dementia, 55% have Alzheimer's disease, which means that there are approximately 33,550 people with Alzheimer's disease in Scotland. Most people with Alzheimer's disease are over 70 years old. It is uncommon for people to develop it under 60 and it is very rare under the age of 50.

Alzheimer's disease slowly and progressively destroys brain cells and their connections. This affects how an individual copes with everyday tasks. Each person will be affected in different ways and it is not possible to predict which symptoms someone will develop.

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The illness is likely to last for anywhere between 5 and 15 years and it is eventually fatal - although as it mainly affects older people, it is often another illness, such as pneumonia, which eventually causes the person's death. However, with the right help and support, people with Alzheimer's disease can enjoy a good quality of life for many years.

What causes Alzheimer's disease?

Scientists still do not fully understand what causes Alzheimer's disease. Age is the only known risk factor. Research is ongoing and factors which might be important in determining why certain people develop dementia are being looked into. Factors such as the environment, diet, drugs, education levels and genetics are all being researched.

Symptoms

The onset of Alzheimer's disease is usually gradual. The person will often start to become more forgetful than is normal for him or her, for example mislaying things around the house or forgetting appointments. As the illness develops, usually the person will suffer from more severe memory loss, language skills will deteriorate, practical abilities will decline and he or she will have increasing difficulty making judgements and maintaining standards. Some people may behave in ways which are uncharacteristic for them or lose some of their normal control over their emotions.

A person with Alzheimer's disease may have 'good' and 'bad' days. He or she can be coping well one day, remembering where things are or how to get dressed, but the next day may not be able to cope with these tasks. Tiredness, other health problems, depression or emotional state can have an impact on the person's day-to-day coping abilities.

Listed below is a more comprehensive list of possible symptoms broken down into three probable stages. Remember that **not everyone will have all of these symptoms** and **the symptoms do not necessarily**

appear in this order. If you or the person you care for has any symptoms you find hard to cope with or have difficulty understanding, seek help.

(See section 'Who can help you').

Possible symptoms during the early stages of Alzheimer's disease

In the early stages, the person may begin to have some difficulty with various everyday activities and abilities such as:

- remembering names, recent events and conversations, keeping appointments and remembering where things are kept
- managing money, remembering to pay bills
- everyday tasks like cooking and shopping
- finding his or her way around less familiar places
- coping with the complexities of a job or leisure interests
- making decisions, especially complicated ones
- coping with social situations.

However, he or she should be able to maintain independence with the help of memory aids and some support from family or friends.

Possible symptoms during the middle stages of Alzheimer's disease

In the middle stages, the problems get more severe, and the person will need more help.

- The person will have more severe memory loss.
- He or she will find it increasingly difficult to communicate, with problems understanding what others are saying and problems in expression. There will also be problems with reading, writing and understanding numbers.
- He or she will gradually need more help with personal care including dressing, washing and going to the toilet.
- There will be increasing difficulty in recognising family and friends leading the person to misidentify people.
- There will be increasing difficulty in recognising even familiar places, so that

the person is at risk of getting lost - and he or she may lose road sense.

- The person may have difficulty understanding how to use common objects - for example knives and forks.
- Some people may have mistaken beliefs, such as accusing people of taking things that they have mislaid.
- The person's emotional life and personality may begin to decline or change.
- Some people become more restless or agitated for example in the evenings, and there may be other problems with the person's behaviour. These problems can include loss of 'social graces', irritability and changes in how the person relates to people socially or sexually.
- Some people have continence problems, usually only urinary.

Not all people with Alzheimer's disease will suffer from all or even most of these problems. With the right support and help, the person should be able to continue to enjoy a good quality of life through the middle stages of Alzheimer's disease.

Possible symptoms during the late stages of Alzheimer's disease

Eventually, in the late stages, the disease affects wider areas of the brain. The difficulties with memory and everyday activities become more severe and the disease will affect every area of the person's functioning, including physical activities.

- Communication may become very difficult.
- The person may become unable to recognise familiar people, places and objects.
- The illness will increasingly affect the person's physical abilities so that he or she will have more and more difficulty with walking, self-care, eating and drinking and going to the toilet.
- The person may lose weight even if he or she is eating.

What happens in the brain

The brain does its work of receiving and storing information and organising all our actions by an unbelievably complicated pattern of connections between billions of microscopic nerve cells.

When Dr Alois Alzheimer first described the pathological changes in the brains of people dying of this disease in the early 1900s he saw that each patient's brain had shrunk in size. It is this shrinkage which shows up in a scan test of the brain. Dr Alzheimer understood that the shrinkage was because huge numbers of nerve cells were dead or dying. Under the microscope he saw unusual 'plaques' which were partly made up of the dead cells, and 'tangles' inside the dying cells.

In the 1970s scientists looked in more detail at the changes brought about by Alzheimer's disease, using more modern techniques. They found that certain areas of the brain had shrunk more than others, and that particular types of nerve cells were most likely to be damaged. The temporal lobes at the side of the brain, which are important in storing recent memories, are the most damaged areas. In these areas there are a lot of cells that pass their messages by a chemical transmitter called acetyl choline (this discovery led on to the new treatments for Alzheimer's which are described below). The question which needs to be solved is why these particular areas and cells are damaged in Alzheimer's disease. We now have bits of the answer, but not the whole answer.

It seems most likely that the damage occurs because some important complex chemicals, whose normal job is to protect the membrane (outer surface) of the tiny nerve cells, may become poisonous to those cells. This can happen either by too much of the chemical being produced or the wrong type of the chemical being produced.

The plaques which Dr. Alzheimer found in the areas of the brain used for memory and other

cognitive (thinking and understanding) functions contain, along with dead bits of cells, one of the chemicals thought to be the cause of the damage, called beta-amyloid. Beta-amyloid is a fragment taken from a larger protein called amyloid precursor protein (APP) which is found in the membrane of the nerve cells.

But it does not seem to be the amyloid alone that causes the damage. Another chemical, called apolipoprotein, is also involved somehow.

In people who have Down's syndrome too much of some of these chemicals are produced and this can lead to them developing Alzheimer's in middle age.

So it is now generally thought that Alzheimer's disease is caused by abnormalities in the amyloid protein or associated chemicals, leading to damage and death of particular sorts of nerve cells. The 'neurofibrillary tangles' described by Dr Alzheimer consist of abnormal collections of twisted threads of a protein called 'tau' inside the nerve cells. They are probably signs of the damage to the cells and lead to a problem of communication between the nerve cells.

It has also been found that people with Alzheimer's disease have less of some brain chemicals which carry messages between the brain cells ('neurotransmitters'). The drugs currently available for the disease aim to increase the amount of these chemicals available and so help messages be transmitted.

Genetics

Hereditary and risk factors

It is important to distinguish between a hereditary condition which is passed directly from parent to child, and a genetic risk factor where having a particular gene increases or reduces the likelihood of suffering from a particular condition, but is not actually the cause of the condition.

Hereditary Alzheimer's disease

There are some very rare families who have hereditary Alzheimer's disease which is passed from an affected parent to roughly half their children, over many generations. It is important to stress that this only occurs in early onset dementia (where people develop the disease before the age of 65). It is extremely uncommon, in fact less than 5% of all people with Alzheimer's disease. These families pass the illness through a faulty gene which causes a pathological form of the normal nerve cell chemicals. This kind of inherited Alzheimer's disease is only likely to be the cause in families where at least three people have developed Alzheimer's disease before 65 and at around the same age as each other. If this is the case in your family, you can talk to your GP about whether genetic testing is appropriate.

Genetic risk factors

In the vast majority (over 95%) of cases of Alzheimer's disease, and in all cases which start in late life, we do not fully understand why particular individuals are affected by the illness, as it is not hereditary. But there are some hints.

One of the chemicals associated with Alzheimer's disease is apolipoprotein. There are three types of this protein, called e2,3 and 4. Which one you have depends on your genetic makeup. If someone has e4 they are somewhat more likely to get Alzheimer's disease, and if they have e2 they are somewhat less likely – so e4 is a 'risk factor' and e2 is a 'protective factor'. Since we each have two sets of chromosomes and the genes on them, some people will have two e4 genes and some will have two e2s, with every possible combination in between. People with two e4 genes are at quite a high risk of getting Alzheimer's, but it is not by any means a 100% link. However, having e4 does not tell you for certain whether someone will develop the disease, and nor does it tell you when. Many people with e4 live to very old age with no sign of Alzheimer's disease. For

this reason, at present many specialists say that there is no point in having a test, because:

- the result does not show whether or not someone will get Alzheimer's disease, and
- at present, there is no preventive treatment that someone could take.

Diagnosis

A friend of mine is concerned about her relative who is showing signs of dementia. They do not want to bother the doctor and I think it is very difficult for them to face the thought that it may be Alzheimer's disease.
Carer

If you suspect that you or someone you know may be displaying signs of Alzheimer's disease it is very important that you contact your doctor as soon as possible.

Who to contact

The doctor (general practitioner) is the first person to contact. Make sure that you or the person you are concerned about has a proper diagnosis. Tell the doctor about any changes you have noticed. The doctor may suggest referring on to a specialist, or you can ask for this yourself. The specialist might be an old-age psychiatrist or a general psychiatrist, a physician in geriatric medicine or a neurologist. In some areas you are likely to be referred to a special memory clinic. Alzheimer Scotland has a booklet which might help: *Getting Help From Your Doctor*.

If you are a carer or relative it is important that you discuss your problems too. For instance if you are anxious, upset or exhausted you should seek help. The GP is also the person to ask about health services which might be needed now or in the future.

How the diagnosis is made

It is very hard to give a 100% accurate diagnosis of this disease. However by a process of elimination specialists can usually be more than 90% certain whether someone is likely to have Alzheimer's disease or not.

The doctor will give the person concerned a full physical examination and a blood test. The person's memory will be assessed, usually with questions about recent events and past memories. If there is cause for concern, the person may be seen by a psychologist who will assess their memory and thinking skills. Further tests may be required including a CT scan¹ or a magnetic resonance imaging scan (MRI)². The different types of scans allow specialists to examine the brain and reveal any areas damaged by the disease.

The GP or specialist will advise on whether the drug treatments available for mild to moderate Alzheimer's disease might be suitable. There is also a new drug which is for people with moderately severe to severe dementia. (See below for more details of these drug treatments). At present the treatments will only help some people, and they are not a cure, but research is continuing.

Why is early diagnosis important

There are various reasons why it is so important to receive an early diagnosis. Early diagnosis of Alzheimer's disease will:

- allow you to learn about the illness, so that you and your family and friends can come to terms with the huge changes that the illness will bring over time, and learn how to cope with those changes and get appropriate help in good time
- allow access to drugs which may help to delay or improve the symptoms of the illness, especially in early to middle stages of the disease
- give you or the person you care for time to discuss future plans – you can:
 - discuss money matters
 - discuss legal issues and draw up legal documents; including wills and powers of attorney
 - discuss future care and medical support.

¹ CT scans or CAT scans use x-rays but show more detail and allow the specialist to see inside the brain.

² MRI scans use radio waves and a strong magnetic field to give a clear and detailed picture of the brain.

Making decisions

Remember that people with early dementia can make their own decisions about important issues such as who they would like to manage their affairs in the future when they become unable to, what medical treatment they would or would not want, and about future care.

I had discussed with my wife what might happen as the dementia progressed. We both agreed that when I couldn't care for her at home, I would find a good care home for her. She is now in a lovely care home and seems content. Discussing this when we could make these decisions together helped.

Carer

Other conditions which may cause the same symptoms as Alzheimer's disease

There are many conditions which are treatable or reversible, which could be causing symptoms which are similar to those of Alzheimer's disease. Always consult your doctor as the sooner they are treated the better.

Some of the conditions which could account for the symptoms are:

- depression or grief
- urinary tract or other infections
- side effects of medications
- excessive alcohol use
- vision or hearing loss
- chronic stress or fatigue.

Drug treatment

For mild to moderate Alzheimer's disease

Aricept (donepezil), Exelon (rivastigmine) and Reminyl (galantamine)

While there are no drugs that can cure Alzheimer's disease there are drugs which can help alleviate some of the symptoms for some people with Alzheimer's disease and improve their quality of life. The three drugs are: Aricept (donepezil), Exelon (rivastigmine) and Reminyl (galantamine). These drugs are for people with mild to moderate Alzheimer's disease. The drugs have the potential to help

over 11,000 of those with mild to moderate Alzheimer's disease in Scotland.

These drugs prevent the breakdown of acetylcholine, a chemical which carries messages between brain cells. This means that there is more acetylcholine available to transmit messages. This may temporarily improve or stabilise the symptoms of the disease. However, these drugs do nothing to stop the death of the nerve cells in the long run, so they will not bring a permanent cure.

For moderately severe to severe Alzheimer's disease

Ebixa (memantine)

Ebixa (memantine) which was launched in 2002 is licensed for the treatment of moderately severe to severe Alzheimer's disease, but it is still not widely available on the NHS. It is different from the other drugs available in the UK for Alzheimer's disease because they are all licensed for the mild to moderate stages. Ebixa is not claimed to be a cure for Alzheimer's disease. It treats only the symptoms and there is no evidence to show that it could halt or reverse the process of cell damage that causes Alzheimer's disease. Alzheimer Scotland believes that the drug should be made available across Scotland because of the evidence of its benefits both for people with moderate to severe Alzheimer's disease and for their carers.

Drugs for related conditions

There are also drugs which can help control symptoms such as problems with sleeping, agitation, wandering, anxiety and depression. Speak to your GP for advice on which treatments might be appropriate.

Further detailed information on drugs is available on information sheets produced by Alzheimer Scotland:

- *Drugs used during dementia – sleeping tablets, tranquillizers and anti-depressants*
- *Drug treatment for Alzheimer's disease - Ebixa or memantine*

- *Drug treatment for Alzheimer's disease: Aricept or donepezil hydrochloride*
- *Anti-inflammatory drugs and Alzheimer's disease – current research*
- *Drug treatments for Alzheimer's disease: Exelon or rivastigmine*

Call the Dementia Helpline (0808 808 3000) for a free copy of these sheets, or see them on www.alzscot.org in full text.

Research

As more information becomes available through research our knowledge of how the disease develops and possible causes expands. There are many different research projects looking into cures, causes, possible drug treatments and preventative measures which might stop Alzheimer's disease developing. Alzheimer Scotland has produced an information sheet: *Current Scottish Research*. Call the Dementia Helpline for a free copy or visit our website: www.alzscot.org.

Who can help you

Information and support for people with Alzheimer's disease

If you are coping alone with Alzheimer's disease do try to find support from someone. Contact your GP for support, advice and information. Find out about local services which may be able to provide the help you need. Contact the Dementia Helpline (0808 808 3000) for emotional support and information on local services. Speak to the CPN or any other health professionals you are in contact with. Alzheimer Scotland has various publications which may help, such as *Don't make the journey alone* and *Facing Dementia* - call the Helpline for a free copy.

For those with access to the internet there is an organization called Dementia Advocacy and Support Network International (DASNI). This is a web-based network at www.dasninternational.org of people diagnosed with dementia. There are members from the United States, Canada, UK, Australia and elsewhere. It provides a supportive

network and a place to exchange information through its website. There is an email group and a twice-daily hosted web chat room.

Information and support for carers

There are many coping strategies which can help you cope with your caring role. Try to work out what help you do need and then find out what services are available in your area. Speak to your GP, social worker and call the Dementia Helpline (0808 808 3000) for support and to get more information about local services and what help is available. You can ask for an independent carer's assessment from the social work department, which will allow you to discuss your needs in relation to your caring role. Alzheimer Scotland has produced a booklet for carers called *Looking after yourself*. There are also many information sheets and leaflets which you might find useful. All the information sheets, booklets and leaflets are on the website: www.alzscot.org or you can get copies by phoning the Helpline.

Carers' groups can offer information, advice, support and a place where you know that the carers will understand what you are going through.

I have had a lot of support from carers in the group I go to. Even though my wife is now in a care home I still go to the group, as I feel it is important to support other carers and pass on information I have. I also find it very distressing visiting my wife in the care home and still feel the need for support even though I am not caring for her in my own home anymore.

Carer

Alzheimer Scotland runs courses for carers on subjects they would like to know more about. Contact your local Alzheimer Scotland service for information on these courses.

Services

We received so much help from local Alzheimer Scotland services. Day care and home support were particularly appreciated. My wife didn't like going away for short breaks but coped well with day care which gave me a break too.

Carer

Services which may be useful include home support, day services, community opportunities and short-breaks. Social workers and occupational therapists will be able to provide useful information, support and advice. To find out more about services in your area contact your local Alzheimer Scotland service, your social worker or the Alzheimer Scotland Helpline for information.

Sometimes someone with dementia will refuse help, maybe because he or she is not comfortable with the person providing the help or the care setting or perhaps because it is just not be right time. If one type of service doesn't suit the person with dementia try out other options.

Dementia Helpline

Alzheimer Scotland runs the freephone 24 hour Dementia Helpline - 0808 808 3000. Call anytime for confidential information and emotional support on any issue to do with dementia.

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