Information Sheet



Alzheimer's disease

What is Alzheimer's disease?

Alzheimer's disease is a disease of the brain which causes dementia. The word dementia describes a group of symptoms that may include memory loss, difficulties with planning, problem-solving or language and sometimes changes in mood or behaviour.

There are many different illnesses which can cause dementia, but Alzheimer's disease is the most common. Around 90,000 people in Scotland have dementia and it is estimated that 66% of them have Alzheimer's disease.

Most people with Alzheimer's disease are over 70 years of age. It is uncommon for people to develop it under 60 and it is very rare under the age of 50. It slowly breaks down brain cells and their connections, affecting how a person copes with everyday tasks. Each person will be affected in different ways so it is not possible to accurately predict the symptoms someone will develop.

At present there is no cure; however with the right help and support, people can live well with the disease for many years.

What causes Alzheimer's disease?

The cause of Alzheimer's disease is not fully understood, but research in this area is ongoing. At present, age is the only confirmed risk factor. Other possible factors being explored are: physical inactivity, sight loss, social connectivity, depression, hypertension, head injury, smoking and alcohol consumption, education levels and genetics.

Symptoms

The onset of Alzheimer's disease is usually gradual. The person may start to become more forgetful than usual, for example misplacing things around the house or forgetting appointments. As the disease develops the person will experience more severe memory loss, their language skills will deteriorate, practical abilities will decline and they will find it harder to make judgements. Some people may behave in ways which are uncharacteristic for them or lose some control over their emotions.

Someone 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 may not be able to cope the following day. Tiredness, other health problems, depression or emotional state can also have an impact on the person's day-to-day coping abilities.

Diagnosis

If you suspect that you – or someone you know – may be displaying signs of Alzheimer's disease it is important that you seek help as soon as possible.

Who to contact

A doctor (usually a GP) is the first person to contact. Tell the doctor about any changes you have noticed. Make sure that you or the person you are concerned about receives a proper diagnosis. The doctor may recommend referral to a specialist, or you can request this yourself. The specialist might be a psychiatrist, a physician in geriatric medicine, or a neurologist. In some areas the person may be referred to a specialist memory clinic.

How is a diagnosis made?

The GP will generally carry out a physical examination, including blood tests, to eliminate other possible causes of your symptoms. The doctor will also look at your medical history and, if you have a partner or other close family, may ask them about any changes they have noticed. The doctor will assess your cognitive ability and memory and may refer you to a specialist doctor or memory clinic for further assessment. It might be necessary to carry out a scan of your brain which will allow the specialist to determine if there are any areas which appear to be damaged by disease.

Why is early diagnosis important?

Early diagnosis of Alzheimer's disease will:

- allow the person to learn about the illness, so that they can come to terms with the changes that will happen over 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 the person time to discuss future plans, including money matters, legal issues and documents, and future care or medical support

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.

Drug treatment options

While Alzheimer's disease is incurable, there are drugs which can help alleviate some of the symptoms and improve quality of life.

Drug treatment for mild to moderate Alzheimer's disease

The drugs available for people with mild to moderate Alzheimer's disease are: Aricept (donepezil), Exelon (rivastigmine) and Reminyl (galantamine). These drugs prevent the breakdown of a chemical (Cholinesterase) which carries messages between brain cells. This can temporarily improve or stabilise the symptoms of the disease.

Another drug, Lecanemab, has been approved by the organisation which regulates medicine in the UK (the MHRA).

Though not a cure, Lecanemab has been shown to slow the progress of disease and give people with Alzheimer's a better quality of life for longer. However, it is not yet clear whether Lecanemab is more effective at slowing memory changs than existing drugs such as donepezil.

The Scottish Medicine Consortium will consier the evidence and decide whether Lecanemab will be prescribed on the NHS in Scotland.

Drug treatment for moderately severe to severe Alzheimer's disease

Ebixa (memantine) is the only drug licenced for later stage 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.

Drugs for related conditions

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

Who can help?

Information and support for people with Alzheimer's disease

If you are coping with Alzheimer's disease alone, please try to find support from someone. Contact your GP for advice or information on support services.

The Scottish Government has guaranteed a year's post-diagnostic support for everyone diagnosed with dementia. In many areas this is provided by Alzheimer Scotland's Dementia Link Workers on behalf of the NHS. In other areas post-diagnostic support is provided by NHS staff.

Contact the Dementia Helpline **(0808 808 3000)** to find out if there is a Dementia Link Worker or other post-diagnostic support in your area. You can also use the Helpline to find out about other local services and the information available from Alzheimer Scotland.

Speak to the community psychiatric nurse (CPN) or any other health professionals you are in contact with.

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Information and support for carers

If you are a carer or relative it is important that you discuss your own challenges too. For example, if you are anxious, upset or exhausted you should seek help. Ask your GP about health services which you may need now or in the future.

There are many coping strategies which can help you in 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 and social worker for support, and call the Dementia Helpline (0808 808 3000) for more information and to find out 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 number of publications for carers. 'Coping with demetia: A guide for Carers' might be particularly useful. All of the information sheets, booklets and leaflets are on the website: **www.alzscot.org** or by phoning the helpline.

Carers' groups can offer information, advice, support and a place where you know that the other carers will understand what you are going through. Alzheimer Scotland runs courses for carers on a range of subjects that carers have indicuated they would like to know more about. Contact your local Alzheimer Scotland service for information on these courses.