Where can I find out more?

Alzheimer Scotland exists to help people with dementia and their carers. We provide information, support and a network of services and carers’ support groups around Scotland.

Our confidential Dementia Helpline offers 24 hour information and emotional support. Call anytime to talk things over or for our free information pack.

The Dementia Helpline can give you information about the services we offer in your area and signpost you to other sources of support. You can also find information on our website at www.alzscot.org.

Support after diagnosis

Anyone in Scotland receiving a diagnosis of dementia is entitled to a minimum of one year’s post-diagnostic support from a named and trained person, called a Dementia Link Worker (or similar job title). The Link Worker works with the person with dementia and his or her partner and family to help them understand the diagnosis, learn to cope with symptoms and live well with dementia, now and in the future.

What is dementia?

The good news is that treatments are available which may help some people with the symptoms of some forms of dementia, particularly Alzheimer’s disease, and research is progressing all the time.

What can I do?

If you or someone you know has dementia, it may be hard to come to terms with the illness. Talk to someone about how you feel and what you can do. You can call the 24 hour Dementia Helpline free on 0808 808 3000 at any time or email helpline@alzscot.org.

- Share your feelings with other members of the family or friends. Give them this leaflet and other information.
- Tell the doctor about any changes.
- Find out what services are available. Try to get as much help as you can.
- Find out about benefits and claim them.
- Talk to other people with dementia or families and carers who are facing similar problems.
- Try to make life as full and enjoyable as possible. Both people with dementia and carers should try to get out and about and keep in touch with friends.
- Don’t just put up with new difficulties. Ask for information, help and advice to cope with problems.

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What is dementia?

Dementia is the progressive loss of the powers of the brain. There are many kinds of dementia but the most common is Alzheimer’s disease. Other kinds of dementia include vascular dementia, Lewy body dementia, frontotemporal dementias (including Pick’s disease) and alcohol-related dementias. It is also possible to have more than one type of dementia, for example Alzheimer’s disease and vascular dementia. What all these diseases have in common is that they damage and kill brain cells, so that the brain cannot work as well as it should.

In Scotland, over 90,000 people have dementia. It is most common in older people but can affect people in their 40s or 50s or even younger.

What causes dementia?

We do not yet know exactly what causes dementia. Medical researchers all over the world are working to find causes and develop treatments.

Alzheimer’s disease damages individual brain cells one by one, so that the brain can’t work as well as it used to. A protein called amyloid builds up in deposits, called plaques, and tiny filaments in the brain cell form tangles. Much current research is trying to find out why these changes happen and what can be done to stop them.

Some rare kinds of Alzheimer’s disease affecting people under 65 can be inherited. Faulty genes may cause the build up of the amyloid protein. Recent research seems to show that there may also be a genetic factor in other cases of Alzheimer’s disease. However, this does not mean that someone whose parent had Alzheimer’s will automatically develop the disease.

In the vascular dementias, there are problems with the blood supply to brain cells. For example, some people have tiny strokes (or infarcts) which damage small areas of the brain.

In frontotemporal dementias the parts of the brain responsible for decision-making, control of behaviour and emotion and language are affected. It is not fully known how this happens but there seems to be an abnormal growth of some types of proteins in the brain cells. In around 30–50% of cases of frontotemporal dementia, the person may have a family history.

Dementia with Lewy bodies is caused by small round clumps of protein that build up inside nerve cells in the brain. The protein clumps damage the way brain cells work and communicate with each other. The nerve cells affected by Lewy bodies control thinking and movement.

What are the symptoms of dementia?

Every person with dementia is different. How their illness affects them depends on which areas of their brain are most damaged.

One of the most common symptoms of dementia is memory loss. Everyone forgets things sometimes and most people’s memory gets worse as they get older. But when someone has dementia, they may forget the names of family members, not just of strangers. They may burn pans because they have forgotten them or forget whether they have eaten lunch. They may repeat the same question again and again and not know they are doing it.

People with dementia may lose their sense of time, losing awareness of which day it is or of the time of day. They may lose track of where they are, and get lost even in a familiar place. They may fail to recognise people they know well.

People with dementia may often be confused. Their ability to think, to reason and to calculate can all be affected. They may make odd decisions and find it hard to solve problems. Handling money may become difficult as they find it harder to work out their change or lose their sense of the value of money.

Dementia can also cause personality and behaviour changes. Someone who was active and energetic may become listless, someone pleasant and well-mannered may become rude and aggressive. These changes can be particularly distressing to relatives and friends as they lose the person they knew.

Gradually, over a period of years, most functions of the brain will be affected. Eventually, people with dementia will probably need help with even simple daily activities, such as dressing, eating or going to the toilet.

What should I do if I’m worried?

It is very important not to jump to conclusions. Confusion or forgetfulness does not mean someone has dementia, nor is dementia an inevitable part of growing older. Many other conditions, such as infections, depression or the side effects of medicines can cause similar problems. If you are worried, see your doctor.

If your doctor finds no reason for the symptoms, he or she may want to refer you or your relative to see a hospital specialist. The specialist can do further tests. Dementia can only be diagnosed by ruling out other possible causes of the symptoms. This is why a full medical assessment is important.

The earlier a person gets a diagnosis of dementia, the sooner he or she can start to come to terms, make plans for the future, and access services that can help.