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**things you
should know
about dementia**



**Alzheimer
Scotland**
Action on Dementia

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**Dementia is
not a natural
part of ageing**

Dementia is not a normal part of ageing. It is caused by diseases which lead to changes to the structure and chemistry of the brain.

When someone becomes forgetful or confused, friends and family are often quick to say that this is just 'what happens when you get older'. Some of us do struggle with our memory as we get older or during times of stress or illness. But dementia is different. Lots of people momentarily forget a friend's name but people with dementia may forget ever having met them. They usually experience a range of other symptoms alongside memory problems and will begin to struggle with daily life as the illness progresses.

Dementia doesn't just affect older people. Over 3,000 people in Scotland under the age of 65 have some form of dementia. This is often referred to as early-onset or young-onset dementia.

Help and support

If you are worried about your memory, or about someone else, the first step is to make an appointment to see the GP. The GP can help rule out other conditions that may cause symptoms similar to dementia and that may be treatable. These include depression, chest and urinary tract infections, severe constipation, vitamin and thyroid deficiencies, side effects of medication, and brain tumours. The earlier you seek help, the sooner you can get the information, advice and support you need.

Around 90,000 people in Scotland have dementia

The chance of developing dementia increases with age. One in 14 people over 65 – and one in six people over 80 – has dementia

Dementia is more common among women than men

Researchers now suggest that one in three babies born in 2015 will go on to develop dementia in their lifetime, unless a cure or a vaccine can be found

For more information on the help and support available, visit www.alzscot.org or phone our 24 hour freephone Dementia Helpline on 0808 808 3000.

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**Dementia is
caused by
diseases of
the brain**

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.

What causes dementia?

Dementia occurs when the brain is damaged by disease. There are many known causes of dementia. The most common is Alzheimer's disease. This changes the chemistry and structure of the brain, causing brain cells to die. The first sign is usually short-term memory loss.

Other common types of dementia include vascular dementia, dementia with Lewy Bodies and frontotemporal dementias (including Pick's disease). It is also possible to have more than one type of dementia at the same time, such as Alzheimer's disease and vascular dementia.

Each of these diseases affects the brain in slightly different ways. For example, Alzheimer's disease tends to start slowly and progress gradually, while vascular dementia following a stroke or mini-stroke often progresses in a stepped way, with symptoms worsening suddenly after another stroke occurs.

Everyone's dementia is different

Whatever type of dementia a person has, everyone will experience the condition in their own way. How it affects a person over time is also unique to the individual – their own attitude, relationships with others, other health conditions, and their environment will all have an impact.

For more information, visit www.alzscot.org/information_and_resources

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**Dementia is
not just about
losing your
memory**

People often associate dementia with memory loss, and it does often start by affecting a person's short-term memory. Someone with dementia might repeat themselves and have problems recalling things that happened recently – although some people easily remember things from a long time ago. But dementia can also affect the way people think, speak, perceive things, feel and behave. These symptoms can be very distressing for the person and the family.

Common symptoms

Dementia often causes difficulties with concentration, planning and thinking things through. Some people will struggle with familiar daily tasks, like following a recipe or using a bank card. Dementia also makes it harder to communicate. For example, a person with dementia might have trouble remembering the right word or keeping up with a conversation. Many people have problems judging distances even though their eyes are fine. Mood changes and difficulties controlling emotions are common too. Someone might become unusually sad, frightened, angry or easily upset. They could lose their self-confidence and become withdrawn.


As dementia progresses

Dementia is progressive, which means that symptoms gradually get worse over time. How quickly this happens varies from person to person – and many people stay independent for years.

There is no known cure for dementia, but there are ways to help with symptoms and make life better at every stage. The more we understand about the condition, the more we can do to help people stay independent and live the life they want for as long as possible.

For more information on how you can help people with dementia stay independent and live well in their local community, visit

www.dementiafriendsscotland.org

A middle-aged man with thinning hair and blue eyes is shown from the chest up. He is wearing a dark blue blazer over a light blue and white plaid shirt. He is holding an open book with both hands and looking slightly upwards and to the right. The background is a library or study area with bookshelves filled with books, a clock on the wall, and a red bag hanging on a bulletin board.

'I have dementia but it does not define me.
My actions and hopes and dreams define me.'
Henry, who has a diagnosis of vascular
dementia

Living with dementia

“I was glad to get my diagnosis. It’s not that I was glad to have dementia. I was just so relieved to finally know what was wrong. It meant I could start doing something about it. Everyone with dementia should have that right.”

Anne, who lives with dementia

“If I had the chance to do this all again, I would definitely have done things differently. I would have talked more openly with my parents about what was happening, especially in the early stages. It might have meant that my mum got a diagnosis earlier, or that my dad would have considered and accepted help.”

Diane, whose mother had dementia

“When I was told that I had dementia, I really closed down, I didn’t want to do anything as I was in shock. I didn’t go out for two weeks. It wasn’t until I had a visit from a worker from Alzheimer Scotland that I could understand what was happening to me and how to deal with the situation – she was fantastic. When she mentioned about getting involved with the Scottish Dementia Working Group (a national campaigning group run by people with dementia) I jumped at the chance.

The Group is about people with dementia working to improve the lives of people with dementia. It’s not just about helping us now but helping improve the lives of the next generation with dementia. A lot of the time we laugh at each other’s experiences, like forgetting things, and we all end up in hysterics. I think this is very healthy because if we can laugh about dementia then we can laugh about anything that life throws at us”.

My attitude is: I have dementia..... but dementia has not got me.”

Archie, who lives with dementia

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**It's possible to
live well with
dementia**

Scientists and researchers are working hard to find a cure or effective treatments for dementia. In partnership with people with dementia and their families, they are also looking into its causes, how it might be prevented and diagnosed earlier, and how to improve quality of life for people living with the condition.

Until we find a cure, there are drugs and other therapies that can help with some of the symptoms, so people can lead active, healthy lives and continue to do the things that matter to them most. Unfortunately, the drugs don't work for everyone but there are things you can do to keep as well as possible with dementia.

Drug treatments

There are medications available that may help some people with some types of dementia and stop symptoms progressing for a while. This is one reason why it's important to go to the doctor as soon as you suspect there's a problem. It can feel like a big step to take, but a diagnosis can open up many opportunities to help overcome problems and find better ways of coping. Getting your symptoms checked out is also important in case it isn't dementia but another, treatable, condition.

People with dementia can also benefit from approaches that don't involve drugs.

Non-drug therapies

Just as important are things like staying mentally, socially and physically active, and eating a healthy diet. Meeting other people in the same situation at peer support groups or in Dementia Cafes can also help people with dementia and their partners and family members realise they are not alone.

Many people derive great benefit and pleasure from taking part in therapeutic and group activities such as singing, walking or sporting reminiscence activities where the person is encouraged to share their experiences and memories, or cognitive stimulation, which might involve doing word puzzles or discussing current affairs.

Find out more about the support groups and activities provided by Alzheimer Scotland at www.alzscot.org/services_and_support

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**There's more
to the person
than their
dementia**

There is no getting away from it – living with dementia is hard. When someone is diagnosed, their plans for the future might have to change. But dementia doesn't change who they are or what their history is.

"I like to keep the garden looking nice so I work on it when needed. But most of all I do art. I have good days and bad days. Some paintings don't turn out as well as I'd like, but often they do. When a painting turns out well, it gives me a lift and encourages me to press on. I'm really lucky to have my art because it's the thing that keeps me going."

John, who lives with dementia

"My mum can't remember what she ate for lunch half an hour ago, but she can remember the words and tunes of hundreds of songs from her young days. But it's not just her remembering the songs that's so great, it's how hearing the music seems to make her so happy. Her face lights up and she taps along, mouthing the words."

Alison, whose mother has dementia

With the right support, it is possible for people with dementia to carry on doing the things they enjoy, or even finding new things to enjoy, to get the best out of life.

See page 15 for details of help and support available.

"My family and friends have been wonderful – they support me in so many ways and I'm glad I can talk openly to them. Nobody should have to face dementia alone. Never be afraid to ask: ask people, ask questions and ask for help".

Anne, who lives with dementia

"It's great to be able to talk to people in the same situation as you and share the load. I can't imagine doing this alone".

Nancy, whose husband has dementia

Let's talk
about
dementia

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dementia

**Alzheimer
Scotland is
here for you**



National services:

These are available wherever you live in Scotland

Dementia Helpline – 0808 808 3000

Our freephone Dementia Helpline is there 24 hours a day, every day, for anyone who needs information or someone to talk to about dementia. Everyone on the Helpline is fully trained and supported by staff at Alzheimer Scotland and has a particular interest in dementia. You can also contact the Helpline by e-mail at helpline@alzscot.org

You can also find information about dementia and the services and activities we offer on our website at www.alzscot.org

Local services:

Our specialist dementia services provide personalised support designed around each individual's abilities and interests:

Our **day care** and **day opportunities** services give people with dementia a stimulating and sociable environment with a high ratio of staff and volunteers to people with dementia. In many areas we provide a one-to-one **home support service**, providing the person with dementia with care and stimulation while the carer is free to go out

In many parts of Scotland, people recently diagnosed with dementia can benefit from a minimum of one year's support after their diagnosis from one of our **Dementia Link Workers**. Our **Dementia Advisors** provide a local point of contact for people with dementia and their families at all stages of their journey, from diagnosis through to end-of-life care. They also support communities to become more dementia-friendly.

Our **community activities**, such as dementia cafes, singing groups, sporting reminiscence groups, walking groups and cinema clubs, are a great way to meet other people, benefit from mutual support and talk to staff about any issues relating to dementia. We support carers and people with dementia with information, support groups, and carer education.

Alzheimer Scotland – Action on Dementia is Scotland’s leading specialist dementia charity, providing direct care services, therapeutic activities and support to people with dementia and their families and carers from more than 60 sites around Scotland. We also campaign to improve public policies and services for people with dementia and their partners, families and carers.

We provide information and support to people with any form of dementia and their carers through our publications, our national Dementia Helpline, and our website.

How you can help

We need £15,000 every day to provide our networks of Dementia Advisors and Dementia Nurses across Scotland, our 24-hour Dementia Helpline, the Alzheimer Scotland Dementia Research Centre, and our Reminiscence Networks.

You can support our work by:

- donating regularly with a monthly gift, enabling us to plan ahead with confidence
- taking part in our fun events held throughout the year in Scotland, or hold your own event. See our Fundraising Toolkit at www.my.alzscot.org/
- becoming a member and adding strength to our campaigning voice
- leaving us a legacy or setting up a tribute fund
- becoming a Dementia Friend – www.dementiafriendsscotland.org.

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