

About Young Onset Dementia

Dementia is an illness that affects the brain and a person's ability to manage everyday activities. It can affect all aspects of thinking and feeling, and can cause changes in behaviour.

It is most common in older people, but around 3,000 people in Scotland under the age of 65 will have dementia, including people in their 40s and 50s, or even younger.

When this happens to someone under 65 it is usually called young onset or early onset dementia.

People with learning disabilities such as Down's syndrome can also develop dementia. They are more likely to develop dementia in their 40s and 50s than the general population.

Dementia in younger people is often not recognised and the needs of younger people with dementia can be very different from those of older people. Younger people and their families are more likely to:

- » be in work, and therefore to need support to continue working or help when employment ends
- » have financial commitments including supporting children or young adults
- » need emotional support to cope with the diagnosis
- » have difficulties obtaining an accurate diagnosis
- » have one of the rarer forms of dementia

About dementia

There are many kinds of dementia, the most common being Alzheimer's disease, vascular dementia, frontotemporal dementia, and Lewy body dementia.

Younger people can have these forms of dementia but are also more likely to have rarer kinds. Dementia can also be present in other conditions such as motor neurone disease (MND), Parkinson's disease, and multiple sclerosis.

What are the symptoms of dementia?

Each person with dementia will experience it differently. The symptoms depend on which areas of the brain are affected.

Some of the most common symptoms include memory difficulties and confusion about time and place.

The ability to think, reason, and make judgements can also be affected. Handling money and calculating may also become more difficult.

Conditions such as frontotemporal dementia cause early changes in personality and behaviour, although the person's memory may not be badly affected.

What causes dementia?

We do not know exactly what causes dementia. Some forms of dementia, such as Huntington's disease, are inherited. Younger people are more likely to have inherited forms of dementia but these are rare.

Most forms of dementia will be caused by a combination of genes and environment but the exact cause in any individual is very difficult to identify.

Alzheimer's disease

Alzheimer's disease damages individual brain cells, 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. With Alzheimer's disease there is usually a slow, steady progression of the illness.

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.

Frontotemporal dementia (FTD)

This form of dementia is thought to be the second most common form of dementia in younger people.

Frontotemporal dementia (FTD) is a complex condition and difficult to diagnose. It is sometimes called 'Pick's disease' although this name is used less often today.

It is not fully understood how this type of dementia develops. There seems to be an abnormal growth of some types of proteins in the brain cells affecting those parts of the brain responsible for decision making, emotion, language and control of behaviour.

In around 30% –50% of cases there may be a family history of this illness.

Vascular dementia

A problem with the blood supply to the brain can cause some people to have strokes which damage areas in the brain and can cause dementia.

Vascular dementia progresses in 'steps' and it is difficult to predict how it will develop. CADASIL is a rare inherited form of vascular dementia that affects younger people.

Information and support for younger people with dementia and their carers.

Any person who is newly diagnosed with dementia should receive support from a named individual such as a healthcare worker or worker from a voluntary sector organisation for at least one year.

Alzheimer Scotland and NHS Health Scotland have produced a booklet and DVD called "Younger people with dementia: Living well with your diagnosis", designed to give useful information to younger people and their families.

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People with dementia and their carers were involved in the making of the DVD and can be seen talking about their experiences and offering suggestions on how to live well with dementia. Areas covered include: keeping well and connected; health; money; and work.

Copies of the DVD can be ordered through the NHS GG & C Public Health Resource Directory at:

<http://www.phrd.scot.nhs.uk/HPAC/Search>.

Film clips from the DVD are also available on the NHS Health Scotland YouTube channel, at:

https://www.youtube.com/playlist?list=PLdtTilZi8S7_w71ZJv2ajj80NePtlwLa7

Work

If you are still employed you might want to discuss your diagnosis with your employer.

Dementia counts as a disability under the Equality Act 2010, giving you legal protection at work.

You have more rights once you have told your employer about your diagnosis. By law your employer must:

- » Make 'reasonable adjustments' to help you stay in work
- » Assess what risks you face because of your health
- » Put adequate measures in place to reduce risk

The booklet can be viewed and downloaded as a PDF file at: <http://www.healthscotland.com/documents/22313.aspx>

Services for younger people with dementia

In Glasgow there are specialist services for younger people with dementia and these include:

Glasgow Younger Persons Support Service (GYPSS)

Alzheimer Scotland

Glasgow Younger Persons Support Service (GYPSS)

81 Oxford Street

Glasgow

G5 9EP

This service provides a range of supports including:

- » Link Workers who will maintain regular contact with the person with dementia and their family and who can provide information and emotional support.
- » A counsellor providing person centred counselling to the person with dementia and/or their carers.
- » Group work – groups supporting people with dementia including time limited therapeutic groups, carers groups and carer education.
- » A home support service offering one-to-one support for the person with dementia in his or her own home or in the community
- » Day services – a small group of people with dementia supported on a Tuesday and a Friday from the Oxford Street premises.

Young Onset Dementia Service (NHS Greater Glasgow & Clyde)

It is recognised that younger people with dementia may have more complex needs than others and require additional support. Within NHS Greater Glasgow & Clyde, younger people may be referred, by their Community Mental Health Team, to a specialist service (the Young Onset Dementia Service) which has been set up to provide additional input for patients under 65 years of age, and /or their family members or carers.

Advice and guidance on all aspects of dementia is available to anyone through Alzheimer Scotland's 24 hour Freephone Dementia Helpline on **0808 808 3000**, and from local Alzheimer Scotland services.

This leaflet has been prepared to provide information for people with dementia, and for their carers.