



About dementia: some facts and figures

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Introduction

This information sheet aims to provide introductory information for people who are interested in finding out about dementia, such as people with a diagnosis of dementia and their families, students, journalists and health care professionals.

What is dementia?

Dementia is an umbrella term for a range of illnesses and disease symptoms, which primarily or secondarily affect the brain. Alzheimer's disease and vascular dementia are the most frequently occurring illnesses. In Alzheimer's disease brain cells deteriorate through the build-up of a protein, vascular dementia is caused by problems in the supply of blood to brain cells. Many cases of dementia are caused by a mix of vascular damage and Alzheimer's disease. Lewy body dementia is the next most frequently occurring illness, with fronto-temporal dementia then more commonly occurring in younger people¹.

¹ Onset of illness occurring before the age of 65

What are the symptoms?

Although there are many different forms of dementia, the thing they all have in common is that they progressively damage the brain. In most cases, the key symptom of dementia is serious memory loss, but others include losing track of the time, getting lost in familiar places and changes in behaviour. Additionally, people with dementia are likely to lose their ability to reason clearly, and may find making decisions very hard. Dementia can also cause personality changes, which can be particularly distressing for those who care for a person with the illness.

Most types of dementia progress gradually, and, with the right help and support, most people with dementia can go on living at home and enjoy a good quality of life for a long time.

Early on in the illness, many people may need help such as reminders and memory aids, and help with managing money or making decisions. Later, the person will need increasing amounts of help with their daily activities. In the later stages of the illness, people with dementia are likely to need a lot of help with ordinary everyday activities such as eating, washing, dressing and going to the toilet.

Many people worry about memory loss, and fear that it is the start of dementia. However, in many cases, there may be another cause. Illnesses and infections, as well as depression, anxiety, bereavement, tiredness and the side effects of some prescribed medications can all cause memory problems which can be treated.

It is important that anyone concerned sees his or her doctor.

What is the impact of dementia?

In almost every case, dementias are progressive and degenerative. The care needs of people with dementia increase as the disease progresses.

The lived experience of dementia will be unique to each individual and dependent on a number of factors². Generally, the progress of the disease is broken into three stages; mild, moderate and severe.

- In mild dementia, a person might have difficulty making decisions, coping with complexities in their work or hobbies, and may have problems remembering to pay bills or attend appointments.
- At a moderate stage, the person with dementia may have increasing difficulty recognising family, friends or familiar places, may need more help with everyday activities such as reading or dressing, and their behaviour may change.
- In the later stages of dementia, the disease affects more functions of the brain, and problems of memory and everyday activity become more severe. Communication can become very challenging, and the illness is likely to increasingly affect the person's physical abilities.

Although there are no cures, much can be done to ease the impact of the illness, and to maintain the best possible quality of life for those affected. It is important for people with dementia that their interests, skills, and normal life are supported and maintained for as long as possible, and that their capacity to make choices, even if this is limited, and their rights are recognised. In addition, remembering other health and wellbeing

² This includes the person's general health, individual responses to illness and social context.

issues, such as hearing, eyesight, and depression is vital.

Who is affected?

In 2013, there are an estimated 86,000³ people with dementia in Scotland. Age is the greatest risk factor for dementia. However, there are around 3,000 people with dementia aged under 65.

Overall, 67% of people with dementia are female. This is as a result of longer life expectancy and higher dementia prevalence rates in the older age groups for women.

The number of people with dementia is increasing, because the population is getting older. Based on current dementia prevalence rates, the number of people with dementia is set to double within the next 25 years.

Who develops dementia?

Some people are more at risk of developing dementia than others.

People with Down's syndrome are more likely than people in the general population to develop Alzheimer's disease, and the onset of the illness is likely to be earlier.

There are some rare forms of dementia which are hereditary, caused by inheriting a faulty gene, but there are only a few families affected by these. All of these hereditary types of Alzheimer's disease are 'early onset', which means that they occur before the age of 65.

For anyone not in these few families, having a close relative with Alzheimer's disease increases your own risk of developing the disease only slightly.

The main 'risk factor' for dementia is age – it is more common in older people and the risk

³ Based on EuroCoDe (2009) and Harvey (1998) dementia prevalence rates – for further information go to: <http://www.alzscot.org/campaigning/statistics>

increases with age. But most people over 90 will not develop dementia.

Who cares for people with dementia?

Most people with dementia live at home. The majority of care and support for people with dementia is provided informally, by family and friends

Caring for a person with dementia can be very stressful and complex, and research has consistently shown that carers suffer from high levels of stress and anxiety. Because dementia is degenerative, carers often find themselves taking on more and more tasks in order to support the increasing needs of the person with dementia. This can cause considerable problems for carers, whose own health and wellbeing may be jeopardised.

Treatment and research

Research into the causes of dementia is difficult, especially as human brain cells can only be studied after death. However, research into the causes, care and treatment of dementia are now the focus of a great deal of research worldwide.

There are only four drug treatments developed specifically for Alzheimer's disease. These treat the symptoms of the illness, as opposed to tackling the cause.

The symptoms of dementia are largely experienced in a social way. The main treatment for dementia is human care and treatment.

What services do people with dementia need?

People with dementia have a right to live their lives as normally as possible. A range of services should be provided to enable people with dementia to do so for as long as possible.

Diagnosis and assessment

Timely diagnosis in dementia is important as people in the early stages of dementia are

better able to make decisions about their future. Diagnosis is also important to enable people to gain access to drug treatments and services.

Post-diagnostic support

This includes therapeutic responses such as drug treatments and rehabilitation. It also includes support and education, such as counselling, carer education and training, information on welfare benefits and financial advice, access to advocacy and assistance to help plan for the future e.g. powers of attorney. Research has demonstrated that early intervention can delay – or even prevent – the person moving into a care home.

From April 2013, anyone in Scotland newly diagnosed with dementia will be entitled to at least a year's worth of post-diagnostic support, coordinated by a named Link Worker.

Community support

This includes home support, day services, community opportunities, short-breaks, crisis response services, assistive technology and carer support. The objective of community support is to enable people with dementia to remain at home for as long as they wish to.

Continuing care

Government policy is working to shift the balance of care for people with dementia, as well as for other groups, away from hospital care and care homes, to care in the person's own home. However, care homes will continue to be an important part of providing long term care for people with dementia.

Palliative and end of life care

The final stages of dementia can be very prolonged and difficult and, as with any other illness, people may need pain control, help with nutrition and fever management, for example.

Further reading

For detailed estimates of the number of people with dementia (by age and by local authority or health board) see

www.alzscot.org/campaigning/statistics

See **Alzheimer Scotland**'s website (www.alzscot.org) and publication list (from the website, or from our Helpline on **0808 808 3000**) for details of our full range of publications



Dementia Alzheimer Scotland
Action on Dementia

Helpline **24**
HOUR

Freephone **0808 808 3000**
Email: helpline@alzscot.org

Alzheimer Scotland

22 Drumsheugh Gardens, Edinburgh EH3 7RN

Telephone: 0131 243 1453

Email: info@alzscot.org

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