



# 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 a term for a range of illnesses. The most common type is Alzheimer's disease, in which brain cells deteriorate through the build up of a protein. Vascular dementia is the second most common type of dementia and is caused by problems in the supply of blood to brain cells. About 75% of people who are diagnosed with dementia will have either Alzheimer's or vascular dementia, or a combination of the two. There are other forms of dementia which are less common. They include dementia with Lewy bodies, fronto-temporal dementias (including Pick's disease), Huntington's disease, alcohol-related dementias, and HIV/AIDS-related dementia.

## 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, they 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.

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.

It is estimated that 30% of people with dementia have mild dementia, 42% are at a moderate stage, and 28% have severe dementia<sup>1</sup>.

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

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<sup>1</sup> Roth et al. (1998) *CAMDEX, the Cambridge Examination for Mental Disorders of the Elderly*. Cambridge University Press

rights are recognised. In addition, remembering other health and wellbeing issues, such as hearing, eyesight, and depression is vital.

### Who is affected?

We estimate that, in 2010, there will be around 71,000<sup>2</sup> people with dementia in Scotland. Dementia is more common among older people, but can also affect younger people, even (very rarely) those in their thirties. Some forms of dementia (such as fronto-temporal dementias, and alcohol-related dementias) are more likely to affect those who are younger. Around 2,300 people with dementia in Scotland are under 65.

Overall, 67% of people with dementia are female. However, the proportion varies with age group: women account for 45% of people with dementia between 65 and 69, but 79% of people with dementia aged 90 and above. This is due to a combination of higher dementia prevalence rates for men up until the age of 75, and the longer life expectancy of women.

The number of people with dementia is increasing, because the population is getting older; the number of people with dementia is set to double within the next 25 years.

Year	Estimate of number of people with dementia in Scotland
2010	71,000
2031	127,000

### 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

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<sup>2</sup> Based on the midpoint between Dementia UK and EuroCoDe dementia prevalence rates – for further information go to: <http://www.alzscot.org/pages/statistics.htm>

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

### **Who cares for people with dementia?**

Contrary to perception, most people (over 60%) with dementia live at home, often supported by a range of community and health care services<sup>3</sup>. Around 70% of people with dementia living in the community live with their carer. Research shows that most carers are the spouse/partner or daughter of the person with dementia.

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.

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<sup>3</sup> see Alzheimer Scotland (2000) *Planning Signposts for Dementia Care Services*, Edinburgh and HDL(2004)44 *The planning, organisation and delivery of joined up services for those with dementia and their carers.*

### **Treatment and research**

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

People develop dementia as a result of degeneration and death of brain cells. In the case of Alzheimer's disease, a protein called amyloid builds up in deposits in the brain (known as plaques) and tiny filaments in brain cells form what are known as tangles.

In the last few years drugs have been developed which can sometimes delay the progress of the symptoms of Alzheimer's disease.

In particular, there is a group of drugs known as 'cognitive enhancers', which work by preventing the breakdown of acetylcholine, a chemical which carries messages between brain cells. This may temporarily improve or stabilise the symptoms of the disease, but, since these drugs cannot stop the death of the brain cells, they are not a permanent cure. Unfortunately, these drugs do not work for everyone who has Alzheimer's disease. They seem to help about half of all people in the mild to moderate stages of the disease.

In 2002, a drug called memantine – which may help people in the moderate to severe stages of Alzheimer's – was licensed for use in the UK (although it is not widely available through the NHS). As with the cognitive enhancers, memantine cannot cure Alzheimer's, but may improve the symptoms.

### **What services do people with dementia need?**

People with dementia are entitled 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

Early diagnosis has become easier, and 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 Diagnosis 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 indicates that early intervention can reduce depression in people with dementia, reduce levels of carer stress, and can delay – or even prevent – institutionalisation.

### Community care services

These include home support, day services, community opportunities, short-breaks, crisis response services, assistive technology and carer support. The objective of community care 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 the institutional care of hospitals and care homes to care in the person's own home. However, many people with dementia will at some stage need long term care, usually in a care home.

### Palliative 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 more information on the drug treatments for Alzheimer's disease:

#### Donepezil:

[www.alzscot.org/pages/info/aricept.htm](http://www.alzscot.org/pages/info/aricept.htm)

#### Rivastigmine:

[www.alzscot.org/pages/info/exelon.htm](http://www.alzscot.org/pages/info/exelon.htm)

#### Galantamine:

[www.alzscot.org/pages/info/reminyl.htm](http://www.alzscot.org/pages/info/reminyl.htm)

#### Memantine:

[www.alzscot.org/pages/info/ebixa.htm](http://www.alzscot.org/pages/info/ebixa.htm)

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

[www.alzscot.org/pages/statistics.htm](http://www.alzscot.org/pages/statistics.htm)

See **Alzheimer Scotland's** website ([www.alzscot.org](http://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

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