

What is it?

Dementia is a word to describe a group of illnesses. These illnesses affect a person's brain and how it works. These illnesses get worse over time.

What causes dementia?

Scientists are working to find out more about what causes the brain changes that give rise to dementia. Different illnesses cause different brain changes.

Some examples are:

Alzheimer's Disease

Alzheimer's Disease causes changes in the chemistry and structure of the brain and brain cells die. It starts slowly and then gradually declines over the years.

Vascular dementia is caused by problems with the blood supply to the brain. Blood brings food and oxygen to the brain to allow it to work, so disruption to the blood supply leads to damage to brain cells. It is like a small stroke that the person may not notice. It gets worse in steps, sometimes quite suddenly.

Dementia with Lewy bodies

This is caused by very small proteins that build up in the brain and disrupt how it works. The person's abilities may fluctuate. They may see things that are not there.

Fronto-temporal dementia

This type of dementia affects certain parts of the brain which help us with making decisions, controlling our behaviour, our emotions and our ability to communicate.

Alzheimer's disease is the most common type of dementia, followed by vascular dementia. There are many others. A person can have more than one type of dementia. For example sometimes people with Alzheimer's Disease may have vascular dementia too.

Dementia mainly affects older people but it can affect younger people too.





How does dementia develop?

New discoveries are being made all the time. We do know a little about what makes some people more likely to develop dementia:

- Alzheimer's Disease is more common in women
- Vascular dementia is more common in men
- Untreated blood pressure problems or high cholesterol can be linked to dementia
- The older you are the more likely you are to develop dementia
- People with Down's Syndrome are at particular risk of developing dementia

Things which may reduce the chances of developing dementia

- Eating well
- Avoiding drinking excess alcohol
- Drinking alcohol in small amounts
- Not smoking or stopping smoking

Is it hereditary?

There is research happening all the time about whether genes have a role in the development of dementia. For some dementias there is a tendency for family members to also develop dementia. This is called familial disease. Some types of early-onset dementia are an example of this. However this does not mean it is hereditary as such. Huntington's disease (a rare condition that can cause dementia) is hereditary with someone having a 50:50 chance of inheriting the disease from a parent who has it.





Dementia affects the brain which is the control centre for everything that we do. It can cause:

- & Loss of memory e.g. forgetting where something is, forgetting names or faces
- © Communication difficulties e.g. difficulty with understanding things, difficulty with finding the right words
- Disorientation e.g. being muddled about the time, day or date, mistaking people for others, difficulty with finding the way to places or remembering where they are
- Mood changes
- Seeing or hearing things that aren't there

Everyone is different so dementia affects everyone differently. Also certain parts of the brain have certain functions. If one part of the brain is affected by the illness it can cause certain types of difficulties.

The difficulties that dementia causes affect the person's ability to cope with everyday life and manage the things that they need or want to do. They may:

- Repeat themselves when talking
- Repeat actions or tasks
- Forget to look after themselves e.g. forgetting to wash, change clothes or eat
- Become distressed or angry

Early signs and symptoms

In the earlier stages the person may have an understanding of what is happening to them. The person may feel vulnerable or anxious and need reassurance and support. They may want to do things for themselves. They may seem:

- Unwilling to try new things
- Less interested in hobbies or activities
- Slow to understand complicated information / ideas
- More self-centred
- Willing to blame others for things e.g. for stealing items that have been lost or misplaced
- Uninterested in things



What is not dementia?

There are lots of illnesses or difficulties that are not dementia that can affect someone's memory and other brain functions. For some of these illnesses the person can get better with the correct treatment, so it is important to talk to a doctor. Some examples of things illnesses that can cause dementia-like symptoms are:

- Feeling unwell due to physical illness e.g. this might be due to an infection, a problem with the thyroid, a combination of medication or a lack of vitamins
- Feeling depressed (feeling low all the time) can cause symptoms such as poor concentration and forgetfulness, loss of interest in things and poor sleep or appetite
- Feeling confused due to acute confusion, which is something that comes on very quickly. It might be caused by an illness such as pneumonia, a heart condition, an infection or the side effects of some medication

It is very important to get medical advice for these, especially if there has been a sudden change in how the person is.

What if someone is worried about their memory?

Speaking to family and friends about it may help. The person should see their doctor if they are worried about changes in their memory, if their memory has been getting worse gradually over time, if they are having difficulty managing familiar tasks. The doctor can talk to the person about it and get further information. They may wish to refer on to a specialist service for help, further tests and advice. This might be a specialist doctor or nurse, perhaps at a memory clinic.

What can help?

Support and treatment

Although there is no cure for dementia, with the right support and treatment it is possible to live well with dementia. Early identification and diagnosis are important because it gives the person and their family time to come to terms with the illness. The person may be able to start treatment. Having a diagnosis as early as possible means the person is able to plan for the future. It is important that they have information and support to do this.

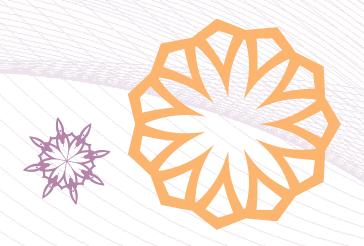
The Person-centred approach

Seeing the person first and focusing on the things that the person can still do is very important. This is a person-centred approach. It aims to maintain emotional and social wellbeing. It recognises that we are all unique. Dementia affects each person differently and everyone will have their own way of responding to the illness. Knowing about the person, their background, likes and dislikes etc., helps to support him or her in a positive way. It is important for people to understand that the illness is affecting the person's brain and that they don't have control over the difficulties that this causes them. Trying to understand how the person might be feeling can help with giving them the right support and knowing how to respond.

Dementia can cause difficulties with communication, for example repeating words or phrases, a difficulty with finding the right words, difficulty with understanding others, difficulty reading or writing. It is important to try to find the best ways of communicating with that person. Paying attention to facial expressions and body language is important. Also, making sure that the person has the correct aids for their sight or hearing e.g. glasses, hearing aid. The environment can affect communication e.g. lots of background noise might be difficult for the person, light levels may also affect whether faces can be seen. The way of talking is important as well as the words we use, so that the person understands.

Some things that might help with communicating with a person with dementia are:

- Allow time for the person to understand
- Allow time for a reply
- Keep calm
- Use short sentences
- Give clues to help the person to understand what you mean e.g. point to things, think about the gestures you use
- Make sure you have the person's attention
- Avoid asking questions that test memory
- Avoid arguing with the person
- Focus on what the person can do



Sometimes a person with dementia might behave in a way which is confusing to others. Knowing about the person and trying to find out what might make them act in a certain way can help. What someone does is a way of communicating. For example, a person may feel frightened, may be in pain or may feel they are losing their independence and that might mean they behave in a certain way. Trying to understand the feelings behind the behaviour may help others to respond in a helpful way. For example if the person is frightened, giving them reassurance might help.

A person with dementia may find these things helpful:

- **&** Keeping routines and habits that are helpful
- Keeping as active as possible doing things they find enjoyable and meaningful
- **Exercise**
- Practical help to carry on doing the things they need or wish to do
- Eating well
- The environment can be very important in helping the person. Familiar environments are best and things like lighting, noise levels and design can be important. A relaxing environment can be important
- For some types of dementia and for some people there are drug treatments that help to slow down the deterioration of the illness
- Memory aids e.g. calendar or noticeboard
- © Cognitive Stimulation Therapy. This is a special programme of activities done in a group which helps with stimulating memory and communication
- Life story work talking about and recording interesting and important things that have happened in the person's life e.g. a life story book or a box of objects that are special

It is important to note that everyone is different and the illness affects everyone differently. Different people will have different ways of coping and might need different types of support. Support for the person and their carers / family is very important.



What support is available?

The person with dementia and their family and friends may have lots of questions and may be worried or fearful. They have a right to information and support to help them. This might come from Health Services, Social Services or voluntary or charitable organisations. The exact type of services and support available may vary from place to place. This might include:

- Memory clinics
- Community Mental Health Teams e.g. community psychiatric nurses (CPNs)
- GP and other health professionals
- Social workers or care managers, support workers
- Home care services (people visiting to provide support with practical tasks at home), day care
- Telecare / technology which can help to keep people independent and help with safety (such as an emergency alarm to let others know when the person needs help e.g. if they have fallen)
- Benefits (welfare rights)
- Support groups for people and their carers

The person has a right to have an assessment of their situation and needs and to have support for those needs.





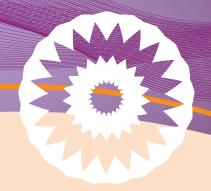
Caring for people with dementia

Carers are people who help someone with coping with everyday life and with emotional support. A carer might be a family member, a neighbour or a friend. They may provide different types of help, for example emotional support, or help with practical tasks such as shopping, meals or dressing. They may help the person now and then, or help regularly. They may live with the person and provide help 24 hours a day, 7 days per week.

Carers are very important in the lives of people with dementia. Caring for someone with dementia can be very rewarding however it can lead to emotional, psychological and physical problems. Carers can be tired, worried and feel isolated or under stress. It is important for carers to know that they are not alone and that support is available.

Carers have a right to an assessment of their needs called a Carer's Assessment. This is to make sure the carer has the support they need to help the person with dementia. This might be practical help, for example people called homecarers to help the person with dementia to dress. It might be help to give the carer a rest or allow them some time to do other things. It might be emotional support too, and some carers find having someone to talk to or meeting others in a similar situation is very helpful. There might be carer support groups in the area that can offer this.





There are lots of organisations that can provide information and support to carers. There are some useful organisations to contact listed below.

Further information

Dementia Services Development Centre www.dementia.stir.ac.uk | 01786 467740

Alzheimer's Scotland www.alzscot.org | Helpline 0808 808 3000

The Charter of Rights for People with Dementia and their Carers in Scotland (2009) Cross Party Group on Alzheimer's, Alzheimer's Scotland www.dementiarights.org

The Scottish Dementia Working Group (an independent group run by and for people with dementia) **www.sdwg.org.uk**

Scotland's National Dementia Strategy (2010) Scottish Government www.scotland.gov.uk/Resource/Doc/324377/0104420.pdf

Care Information Scotland

www.careinfoscotland.co.uk | Telephone 08456 001 001

NHS Inform www.nhsinform.co.uk | Telephone 0800 22 44 88

The Princess Royal Trust for Carers www.carers.org/home | 0141 221 5066

