



Information for Family & Friends

What is Dementia?

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is a broad term which describes a loss of memory, intellect, social skills and usual emotional reactions.

For a long time, the person may look healthy, but on the inside, their brain is not working properly.

Some people mistakenly think that dementia is "going nuts" when in fact the brain is being affected by a disease by progressive cell death.

There are a number of forms of dementia. The best known is Alzheimer's disease. This is also the most common accounting for between 50% to 70% of all cases. Alzheimer's disease is a progressive, degenerative disease that affects the brain.

Memory Loss

One of the main symptoms of dementia is memory loss. We all forget things from time to time, but the loss of memory with dementia is different. It is persistent and progressive, not just occasional. It may affect the ability to continue to work, or carry out familiar tasks.

It may mean having difficulty finding the way home. Eventually it may mean forgetting how to dress or bathe, or who the person's relatives or friends are. An example of normal forgetfulness is walking into the kitchen and forgetting what you went in there for, or misplacing the car keys. A person with dementia, however, may lose the car keys and then forget what they are used for.

Who gets Dementia?

Dementia can happen to anyone but it is much more common after the age of 65. For people 85 years and over, 1 in 4 have dementia. In some cases, it may affect people in their 30's, 40's and 50's.

Can dementia be inherited?

This depends on the cause of the dementia. About a third of people with Alzheimer's have a close relative (parent, brother or sister) who has, or has had, dementia. However, in many cases it occurs when there is no family history.



How does dementia progress?

The situation of every person with dementia is unique. Their abilities may change from day to day, or even within the same day. What is certain is that the person's abilities will deteriorate, sometimes rapidly, and in other cases, more slowly over a number of years.

Is there a cure for dementia?

At present, there is no cure for most causes of dementia. However, medications and alternative treatments have been found to relieve some of the symptoms for some people for a period of time.

How does dementia affect people?

Initially, there may be only slight changes in personality or behaviour. They may become less motivated to do things that previously interested them or are reluctant to part from familiar surroundings or routines.

They may have difficulty finding the right words or may repeat themselves.

As the disease progresses, the changes become more marked. Concentration, understanding and the ability to reason and respond may deteriorate.

People with dementia can suffer confusion, distress, mood changes and aggression as they struggle with the frustrations of everyday life.

The importance of family and friends

Family and friends play an important part in the lives of people affected by dementia. They provide valuable links to past experiences and enable a person with dementia to continue to be a loved and valued member of a family and circle of friends.

Family and friends can also provide support for carers. Many studies confirm high rates of depression, anxiety and even physical illness in families where someone has dementia. Unfortunately, many people with dementia and their carers find that family and friends stay away from them after dementia has been diagnosed. Some people are frightened or embarrassed by dementia. Some are afraid of saying or doing the wrong thing.



Ways to help

Family and friends can support people affected by dementia in a variety of ways

- Learning about dementia is always a good starting point. This includes understanding that while outwardly the person may look fine, inwardly they have a disease of the brain that is NOT contagious. This may cause the person to act irrationally.
- Encouraging family members and carers to have a break or just a change of scenery.
- Being available for a chat from time to time.
- Bringing a meal, or helping with gardening or shopping.
- Supporting the person with dementia to do the kind of things that they enjoyed doing before dementia was diagnosed can be helpful. Outings to football, fishing, walks or drives in the country may all be activities that can still be enjoyed.
- Remember that many people with dementia do not enjoy crowds or noisy environments.
- Activities may need to be adapted but it is important to keep doing them for as long as possible.
- Enjoyment does not require memory, so it is important to remember even if an outing is soon forgotten it can still be worthwhile.
- Ask about specific ways you can help. Be aware though that many people are reluctant to admit they need help until the need becomes desperate.

Communicating

Losing the ability to communicate can be one of the most frustrating problems for people with dementia and can also add to the difficulty of maintaining friendships for family and friends.

Remember that people retain their feelings and emotions even though they may not understand what is being said, so it is important to always maintain their dignity and self esteem. Use touch to keep the person's attention and to communicate a feeling of worth and affection.

It is helpful to talk in a gentle, matter of fact way and to keep sentences short, focussing on one idea at a time. Always allow plenty of time for what you have said to be understood. Silence can give time to think and respond.

Remember – the best way of all to help someone with dementia is to stay interested, stay in touch and let them know that they are loved.