

Information for family and friends

This Help Sheet is designed for people with dementia and their families to provide information to friends, neighbours and others about dementia. It explains what dementia is, how it affects people and ways to help.

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 that 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.

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

Memory loss

Not everyone experiences memory loss, but it is one of the main symptoms of Alzheimer's disease, the most common type of dementia. 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, and to carry out familiar tasks. It may mean having difficulty finding the way home. Eventually it may mean forgetting how to dress or bathe, or recognising family and friends.

An example of normal forgetfulness is walking into the kitchen and forgetting what you went there for, or misplacing your 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 as people get older, the chances of developing dementia are higher. For people aged 70 to 74, approximately 1 person in 30 has dementia, while for people aged 90 to 94 it is 1 person in 3. In some cases, it can 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 disease 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. What is certain though, 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 forms of dementia. However, some 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 only be slight changes in personality or behaviour. They may become less motivated to do the things that previously interested them, or reluctant to part from familiar surroundings or routines.

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

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

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

National Dementia Helpline **1800 100 500**

dementia.org.au

The importance of family and friends

Family and friends play an important part in the lives of people with 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 those providing assistance to a person with dementia. Many studies confirm high rates of depression, anxiety and even physical illness in families where someone has dementia.

Unfortunately, many people with dementia, their family and carers, find that some people stay away from them after the dementia has been diagnosed. Some are frightened or embarrassed by dementia. Others are afraid of saying or doing the wrong thing.

How can you 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, they have a condition of the brain that is deteriorating. This may cause the person to act irrationally at times
- Encouraging family 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 kinds of things that they enjoyed doing before dementia was diagnosed. Outings to the 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 they are enjoyed
- Enjoyment does not require memory, so it is important to remember that even if an outing is soon forgotten it is still worthwhile
- Ask about specific ways that you can help. Be aware though that many people may be reluctant to admit that 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 add to the difficulty of maintaining friendships.

Remember that people with dementia 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 feelings of worth and affection.

Talk in a gentle, matter-of-fact way, keep sentences short, focusing on one idea at a time. Allow plenty of time for what you have said to be understood. Silence can give time to think and respond.

Where appropriate, use body language to demonstrate and reinforce your verbal message eg wave when saying goodbye.

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.

FURTHER INFORMATION

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at dementia.org.au



For language assistance phone the Translating and Interpreting Service on **131 450**