

# Information for family and friends

Approximately 353,800 Australians have dementia. All of these people have family, friends, neighbours and acquaintances. It can be difficult to explain about dementia if you, or someone close to you, has the condition. This help sheet is designed for people with dementia and their families to provide information to 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, understanding, 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. Alzheimer's disease is the most common and accounts for about two-thirds of all cases. Alzheimer's disease damages the brain and the person's ability to think clearly, communicate and remember.

## Memory Loss

For many people with dementia the main symptom 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. This means it is always there and will get worse no matter what you do. It will eventually affect the ability to continue to work and to carry out tasks a person knows well. It may mean having difficulty finding the way home. Eventually it may mean forgetting how to dress or wash, 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 keys are used for.

### **Who gets dementia?**

Dementia can happen to anybody, but it is much more common after the age of 65. For people between 70 to 74 approximately 1 in 30 has dementia while people over 90 it is 1 person in 3.

In some cases, it can affect people even in their 30's, 40's and 50's or even younger if the dementia is caused by substance misuse. A study in the Kimberly region of Australia showed that Aboriginal people are up to 5 times more likely to develop dementia and at an earlier age than non Aboriginal people and the Koorie Growing Old Well study in NSW showed Aboriginal people were up to 3.5 times more likely to develop dementia.

### **Can dementia be inherited?**

This depends on the cause of the dementia, but most dementias are not inherited. About a third of people with Alzheimer's disease have a close relative (parent, brother or sister) who has, or has had, dementia, but this does not mean that it is inherited. In most cases it occurs when there is no family history.

### **How does dementia progress?**

Each person with dementia will experience things differently. Their abilities may change from day to day. What the person is able to do will get less and less over time, sometimes quite quickly, but often slowly over a number of years.

### **Is there a cure for dementia?**

At present there is no cure for most dementias. 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?**

In the beginning there may only be slight changes in personality or behaviour. They may become less likely to do the things that they used to be interested in, or reluctant to be away from familiar surroundings or routines. They may have difficulty finding the right words, or may repeat themselves.

As the illness progresses, the changes become easier to see. Concentration, understanding and the ability to reason and respond usually get worse.

People with dementia may experience 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 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 and some get upset by not being recognised anymore by the person with dementia.

## 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 cannot be passed onto others but may cause the person to act strangely at times
- Encouraging family and carers to have a break, or just a change of scenery
- Being available for a yarn 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 or helping them to be involved in cultural activities may be things 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 for others 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 do not like 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 keep 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. Don't forget that as dementia affects mainly older people they often deserve a certain amount of respect as an Elder regardless of their illness.

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.

## 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](http://dementia.org.au)



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