

INFORMATION ABOUT DEMENTIA FOR YOUNG PEOPLE

This Help Sheet is written especially for young people and answers some questions they frequently ask about dementia.

What is dementia?

Dementia is the name used to describe the symptoms of a large group of illnesses which cause a progressive decline in the way a person functions.

People with dementia may have memory loss and difficulty communicating. They may also have problems with thinking, recognising people and will sometimes forget what things are used for. They may also act in ways that are different to how they acted before.

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

Is dementia a mental illness?

No, it is a condition of the brain. Our brain is our control centre and it controls everything we do and say and think. When the brain is sick we have problems with all our actions including remembering, speaking, understanding and learning new skills.

Is dementia something all older people get?

No. We all forget things from time to time especially if we get stressed. Someone who does not have dementia may forget where they have put the car keys. A person with dementia may forget what the keys are used for.

As people get older the chances of developing dementia are higher. Dementia is not a normal part of ageing and not all older people will develop it. For people aged 70 to 74, approximately 1 person in 30 is likely to have dementia, while for people aged 90 to 94, it is 1 person in 3.

Can younger people get dementia too?

Sometimes people in their 30's, 40's and 50's can get dementia, but this is not as common.

What problems do people with dementia have?

- Increasing forgetfulness
- Not able to learn new information or follow directions

- Repeating the same story over and over and asking the same question many times
- Difficulty finding the right words or completing a sentence; jumbling words and phrases and not making sense
- Losing, hiding possessions or blaming others for stealing them
- Confusion about the time of day, where they are or who other people are
- Fear, nervousness, sadness, anger and depression
- Forgetting how to do everyday things like cooking a meal or taking a bath
- Changes to behaviour, possible aggression or agitation
- Trouble with visual awareness

How do doctors know someone has dementia?

There is not just one test. Several different tests must be performed as well as collecting information from people who know the person well. There are some illnesses which might seem like dementia, but are treatable. If these are ruled out the doctor may then be able to say that the person has a particular type of dementia.

How long does it last?

Some people can live up to 20 years after they show signs of dementia, but everyone is different.

What causes dementia?

There is a lot of research happening throughout the world. We now know that dementia causes changes to a person's brain that results in cell death. The death of cells is responsible for the gradual loss of a person's abilities.

Is there a cure?

At the moment there is no treatment that can cure dementia. There are some medications that may help the person with dementia to think more clearly, but they do not cure the person.

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How will dementia affect me?

If someone in your family has dementia, you and your family may be impacted even if you don't live in the same house as the person with dementia. It can be very upsetting and stressful. You may experience some confusing feelings and not want to believe that this is happening. This is very normal.

You may feel upset that your relative with dementia, whom you love very much, has become like a different person.

If your relative with dementia lives in your house, it may mean that you miss out on some attention or that you may be asked to take on other jobs and responsibilities. You may no longer feel like a normal family. You may feel angry and resentful that people in your family are busier and no longer have as much time for you.

Caring for someone with dementia is very stressful and can make people tired and worried. Sometimes that can make them cranky or short-tempered with you. Try to understand what your parents are feeling too.

You may not want to have friends over to your house any more because you are embarrassed by the behaviour of the person with dementia. If you are able to learn more about the condition you can explain it to your friends.

Are there things that young people can do to help a person with dementia?

Yes. Safe, simple and quiet activities that involve repetition are best. Many people with dementia can remember things from long ago, but not things from a few minutes ago. You might look at a family photo album with them or play music that they might remember. A person with dementia may have trouble understanding you. Keep sentences short, be patient and try not to argue.

A person with dementia may only be able to concentrate for a short time. Stop or change what you're doing if they become anxious or distracted. Even though they might not recognise you, your love and understanding can be a great comfort. Give them a cuddle, a kiss or stroke their arm. The best help you can give is reassurance and letting them know that you care about them.

What can young people do to make life easier for a person with dementia?

- Learn all you can about the illness
- Talk to family and friends about the situation

- Help your friends understand about dementia
- Be loving
- Be calm and patient
- Be involved
- Be understanding
- Treat the person with dementia with dignity
- Don't correct what they are saying even if it is wrong or mixed up
- Help around the house

What about my feelings?

Remember that all feelings you have are normal and okay. It is very hard to watch someone you love, and who loves you, forget things and change and lose their independence. You must remember that even if the person becomes angry, cries a lot or does strange things, they have a brain condition and cannot help what they are doing. Don't blame them, and don't blame yourself for their behaviour.

Talk to someone you trust about how you're feeling. This might be a parent, another trusted adult, a school teacher or Alzheimer's Australia. Kids Helpline is a telephone and online counselling service specifically for young people aged between 5 and 25. For free and confidential support call **1800 55 1800**, or visit their website on kidshelp.com.au.

Support for families, carers and kids

Any family member can ring the National Dementia Helpline on **1800 100 500** to obtain practical information and emotional support. An appointment can also be arranged with a counsellor for any family member, including children.

Alzheimer's Australia in each State and Territory has an extensive collection of books and videos for loan, including some specifically for children.

FURTHER INFORMATION

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



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