

Information for young people

This help sheet is especially for young people and answers frequently asked questions about dementia. It also includes information for parents and grandparents about discussing dementia with young people.

If someone in your family has dementia, you may have lots of questions about the condition.

Below are some frequently asked questions to help you learn more about dementia, what changes may be happening for your loved one and how you can help.

What is dementia?

Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease.

Someone with dementia may look healthy on the outside for a long time, but on the inside, their brain is not working properly.

People with dementia may have:

- memory loss
- difficulty communicating
- problems with their thinking
- difficulties recognising people.

They will sometimes forget what things are used for. As an example, anyone can forget where they put the car keys. But a person with dementia may forget what the car keys are used for.

Dementia changes the way people think, feel and act.

Is dementia a mental illness?

No, dementia is not a mental illness. When someone has dementia, they have a disease of the brain which damages part of it and stops those parts working the way they should.

Is dementia something all older people get?

No, dementia is not a normal part of getting older. Not everyone will get it.

As people get older, the risk of developing dementia is higher.

- Over the age of 65, dementia affects almost one person in 10.
- Over the age of 85, dementia affects three people in 10.

Can younger people get dementia too?

Yes. It's not as common, but people in their 30s, 40s and 50s can get dementia. This is called younger onset dementia.

What kind of changes happen to people with dementia?

The person may experience some, or all, of the following changes:

- becoming increasingly forgetful
- an inability to learn new information or follow directions
- repeating the same story over and over, or asking the same question many times
- having difficulty finding the right words or finishing a sentence; jumbling words and phrases and not making sense
- losing possessions, hiding them or blaming others for taking them
- confusion about time of day, where they are or who other people are
- fear, nervousness, sadness, anger and depression
- forgetting how to do everyday things like cook a meal or have a shower
- differences to their behaviour, possible aggression or agitation
- inability to make sense of what they see, such as not being able to judge the depth of a puddle.

No two people experience the same changes. The symptoms will depend on the cause of dementia and the parts of the brain affected.

How do doctors know someone has dementia?

Several different tests are carried out and the doctors may also get information by talking with family and friends.

How long does it last?

Dementia is a disease that affects more and more of the brain as time passes. It can progress over a number of years. The rate at which any form of dementia gets worse varies from person to person.

Doctors can't tell how long it will take for these changes to happen.

Is there a cure?

There is currently no cure for dementia. Some medications may help with symptoms, but they do not cure the person.

How will dementia affect me?

If someone in your family has dementia, it can make you feel emotional. This is very normal.

At times, you may feel confused and not want to believe it is happening to someone in your family.

You may be upset that someone you love has become like a different person.

If your relative with dementia lives in your house, people in your family might become busier and not have as much time for you. You may miss out on some attention or be asked to take on extra jobs. That could make you feel angry and resentful. This is normal and understandable. Big changes are happening for you.

Caring for someone with dementia can make people feel tired, stressed, or worried. Sometimes that can lead to them being cranky or short-tempered with you. Know that most likely, all family members are struggling with how they are feeling.

You might not want to have friends over anymore, because you are embarrassed by the behaviour of the person with dementia. Learning more about the condition may help you understand the person's behaviour and you can explain it to your friends.

What can I do to support a person with dementia?

The best help you can give is reassurance and letting them know that you care about them.

Your love and understanding can be a great comfort.

Spending time with your loved one is very important, even if the person is unable to recognise you or hold a conversation.

Ways to spend time together:

- If they like it, you could give the person a cuddle, a kiss or stroke their arm.
- Many people with dementia can remember things from long ago. You could look through a photo album together or play music they might remember.

Ways you can help:

- Learn all you can about dementia.
- Be loving, calm and patient.
- Be involved, offering to help around the house.
- Be understanding; avoid correcting the person when what they say seems wrong or mixed up.

Who can I talk to about my feelings?

It can help to talk to someone about your feelings, especially if things seem tough. There are no 'right' or 'wrong' feelings. All feelings are normal.

Sometimes feelings might show in ways we don't expect. For example, you might:

- find it hard to pay attention at school
- feel tired more often
- get into arguments with people
- have trouble sleeping
- not enjoy activities you usually like.

If you can, talk to someone about how you're feeling. They might be:

- someone in your family

- a friend, even an adult
- a teacher or school counsellor
- National Dementia Helpline: call 1800 100 500
- Kids Helpline: call 1800 551 800.

Information for parents and grandparents

There are many ways young people may be impacted when a person they are close to has dementia. Below is advice for parents and grandparents about discussing dementia with young people.

Talking with young people

The most important way to help young people understand dementia is to talk openly and be willing to listen. They need to be able to ask questions and express their feelings in a free manner.

Don't be surprised if they do not initiate discussion. Watch for clues in their behaviour that something is on their mind and then try to talk openly.

Some young people may find it difficult talking with their parents because they don't want to worry them or are afraid of making them sad or being an extra burden. They may prefer to talk to people their own age or to a counsellor.

Consider

Young people will react differently depending on:

- their age and stage of development
- their personality
- how important the person with dementia is in their lives
- the quality of their relationship and how often they interact with the person with dementia.

Questions young people may ask:

- What's happening to the person with dementia and why is it happening?
- Why can't medicine make it better?
- Will I get it too?
- Will they die?
- What can I do to make it better?
- Who will take care of me?
- Why is everyone always so sad and angry?
- Why can't things be the way they were?

Emotional reactions:

Young people express emotions differently to adults.

Depending on their age, they may:

- seem irritable, clingy, anxious and fearful more than usual
- change their eating and sleeping habits
- be easily distracted or forgetful
- retreat to introverted or solo activities, and seem quiet and distant
- appear happy or unaffected, despite feeling grief or sadness
- show strong emotions such as anger, guilt, resentment or rejection
- seek to take on more adult responsibilities
- seem embarrassed and may conceal what is happening in their family life from friends.

What to try:

- Let the young person know that they are cared for.
- Acknowledge the impact dementia is having on them directly.
- Encourage open and honest conversations: don't be afraid of their feelings, or yours.
- Help them confront and deal with their worst fears. Sometimes these fears may be unrealistic, but they are certainly very real to the child.
- Maintain as much family structure as possible. This will give everyone a feeling of security and self-confidence.
- Spend some time with them each day, making them the focus of your attention.
- Make family plans and carry them out. Try to persist, even if family members lack enthusiasm.
- Use respite care to give everybody a break.
- Encourage teenagers to continue with their own daily routines, social activities and making plans.
- Address conflicts and concerns.
- Set aside special times when the family can discuss responsibilities and concerns, but try not to make 'helping' the overriding purpose.
- Notify the child's teacher or school counsellor that someone in the family has dementia. Schedule regular check-ins to monitor wellbeing.
- Encourage learning about dementia in the school environment. Contact Dementia Australia to find out about appropriate resources.
- Make time to look after yourself, especially if you find yourself being a primary carer for the person with dementia and also your family unit.

Additional reading and resources

- **Dementia in my family**
A website developed for children and young people to learn about dementia. Visit: dementiainmyfamily.org.au
- Dementia Australia library service
Visit: dementia.org.au/library
- Dementia Australia counselling
Visit: dementia.org.au/support/counselling
- Family and friends matter
Visit: dementia.org.au/family-and-friends-matter

Further information

Dementia Australia offers support, information, education and counselling.

National Dementia Helpline: 1800 100 500

For language assistance: 131 450

Visit our website: dementia.org.au