

Information for family and friends

This help sheet is designed for family and friends to learn about dementia, how it affects people and ways to help.

If you know someone living with dementia, learning about the condition will help you understand the impact it may have on the person. While dementia may cause some things to change over time, one thing that will not change is their need to be a valued member within a family or circle of friends.

About dementia

- Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease.
- Alzheimer's disease is the most common form of dementia.
- No two people experience dementia in the same way.
- People often lead active and fulfilling lives for many years after their diagnosis.

How dementia may affect someone

Dementia can affect thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with someone's family, social and working life.

The changes you may notice in your family member or friend will depend on the form of dementia diagnosed.

Some common symptoms may include:

- memory loss, particularly remembering the day, date, or recent events
- increasing confusion
- reduced concentration
- personality or behaviour changes

- apathy and withdrawal, or depression
- difficulty following conversations, particularly in groups
- losing interest in activities they usually enjoy
- difficulty doing things previously done well, such as driving, managing finances or their family role
- loss of ability to do everyday tasks.

Common questions about dementia

When you learn that someone has dementia, it is understandable to have questions.

Below are some frequently asked questions. The answers will help you understand the condition and how it may affect the person who has been diagnosed.

Who gets dementia?

Dementia can happen to anyone, but the risk of developing dementia increases with age. Research shows it depends on a combination of age, genes, health and lifestyle.

- Over the age of 65, dementia affects almost one person in 10.
- Over the age of 85, dementia affects three people in 10.
- People under the age of 65 can develop dementia, but it is less common. This is called younger onset dementia.

Can dementia be inherited?

Dementia can be hereditary, but this is quite rare.

Your risk depends on the cause of the dementia. About a third of people with Alzheimer's disease have a close relative (parent or sibling) diagnosed with dementia. However, in many cases, it occurs when there is no family history of the condition.

How does dementia affect people?

Everyone experiences dementia differently.

In mild or early-stage dementia, there might be some changes in thinking and memory skills, but minimal need for support. They may repeat themselves or have difficulty finding the right words. The person may become less motivated to do things that previously interested them, or reluctant to change familiar surroundings or routines.

In moderate or middle-stage dementia, changes are more obvious and have a greater impact on the person's abilities and independence. They may need support with daily activities in the home and in the community. There may be deterioration in the person's ability to concentrate, understand, reason and respond. Some people may forget how to dress or bathe, or to recognise family and friends. They may experience confusion, distress, mood changes and aggression.

In severe or late-stage dementia, someone is likely to be fully dependent on the care and supervision of others.

How does dementia progress?

Dementia progresses differently in everyone. Someone's abilities may change from day to day. However, their abilities will deteriorate, sometimes rapidly, or sometimes slowly, across many years.

Is there a cure for dementia?

Currently, there is no cure for dementia. Medications and alternative treatments may be used to relieve symptoms for some people, depending on the form of dementia diagnosed.

Family and friends are important

Family and friends provide invaluable links to someone's past. They can enable someone living with dementia to continue to be a loved and valued member of their family or circle of friends.

Connection with others is important. You can help the person maintain a sense of identity and worth. How you behave towards them can be a powerful reminder to the person of their role in your life and the value of that role to you.

How you can help

The best way to help someone living with dementia is to stay interested, stay in touch and let them know that they are loved.

- Learning about dementia is a good starting point. Someone may look fine, but at times experience changes in mood or behaviour due to dementia.
- Plan outings together. Enjoyment does not require memory; even if an outing is not remembered, it is still worthwhile.
- Make yourself available for a chat from time to time.
- Encourage family and carers to take a break by offering to spend time with the person they care for.

You may offer practical support, such as:

- delivering a meal
- helping with gardening or shopping
- doing things together, such as hobbies or activities
- asking about specific ways to help.

When you offer practical support, be aware that someone may be reluctant to admit to needing help.

Communication and connection

For many people living with dementia, language skills and vocabulary can diminish as the condition progresses. But their desire to communicate does not.

Communication is essential for maintaining our identity and connecting us to others. People continue to want to understand and be understood. It is important to always maintain someone's dignity and self-esteem.

You can keep the communication going, even when it feels one-sided.

Some tips for talking with people with dementia:

- Talk to the person, not the carer, family member or friend.
- 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, allowing silence to give time for someone to think and respond.
- Use touch to keep the person's attention and to communicate feelings of worth and affection.
- Where appropriate, use body language to demonstrate your verbal message, such as waving when saying goodbye.

Additional reading and resources

- Dementia Australia library service
Visit: dementia.org.au/library
- Dementia Australia support
Visit: dementia.org.au/support
- Dementia Australia education
Visit: dementia.org.au/education
- 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