

# About you: Talking about the diagnosis

**This help sheet suggests what to consider when talking about your diagnosis.**

If you have been diagnosed with dementia, you may be thinking about who among your family and friends to tell, what information to share and when to tell them.

Some people find these decisions very straightforward and decide quickly. Others may need a lot more time to consider options.

As your dementia progresses, the support of people who know and understand you will become increasingly important. Some relationships might be tested, but others are likely to become stronger.

## Coming to terms with the diagnosis

One of the steps in discussing your diagnosis with others is coming to terms with the information yourself.

It is normal to experience a range of emotions after a dementia diagnosis. Understanding how you are feeling can help you adjust to your diagnosis and decide the next steps.

## Making the decision to discuss the diagnosis

You may be considering a number of questions:

- Who do I tell?
- Do I have to tell anyone?
- How and when should I raise it?
- What information should I share, such as the diagnosis, my symptoms, or both?
- How will people respond to me after I tell them?
- If I tell people, do I want them to keep it confidential?

There are no right or wrong answers.

You may have concerns about how you will be treated if others know of your diagnosis or how people may react to your news.

You might start telling close, trusted family members or friends who held concern for your health and wellbeing prior to you receiving a diagnosis. Or you might choose to tell a broader group of people.

It can be helpful to discuss your options and concerns with someone outside the family who can listen to your views, such as:

- your doctor
- a social worker
- a Dementia Australia counsellor
- the National Dementia Helpline.

What is important is to respect your own needs for privacy, while also acknowledging the value of allowing selected others to know of your diagnosis.

## **Telling family and friends about your diagnosis**

When you decide to tell people about your diagnosis, you could write them a letter or email, rather than talking face-to-face or on the phone. Choose the way that makes you feel most comfortable.

Family and friends often want information that helps them to understand dementia and ways they can support you.

Discussing your diagnosis means that you and your family can work together to learn more about support options to help you live well, and maintain your independence and wellbeing.

## **How family and friends may react**

The people you tell may have a range of reactions. Some people may seem angry, afraid or surprised. Others may seem relieved there is an explanation for your symptoms. You can't always predict how people will respond to your news.

Some people may question or trivialise your diagnosis. They may find it difficult to accept because they have a limited knowledge of dementia. Often family and friends who live far away, or who you don't see regularly, are less likely to understand or accept your diagnosis.

Try to be patient with any of these responses. Some people might need time before they become more supportive.

Sometimes family members may share your diagnosis without your consent. This can lead to mixed feelings: perhaps anger that you were not in charge, or maybe relief that it was done for you. Consider that your family will also need their own support in this process and sometimes need to share the diagnosis so that they can receive assistance. In times of change, most people want to know they can find care and support.

## **Additional reading and resources**

- Help sheet: Informing family and friends  
Visit: [\*\*dementia.org.au/help-sheets\*\*](https://dementia.org.au/help-sheets)
- Dementia Australia library service  
Visit: [\*\*dementia.org.au/library\*\*](https://dementia.org.au/library)
- Dementia Australia support  
Visit: [\*\*dementia.org.au/support\*\*](https://dementia.org.au/support)
- Dementia Australia education  
Visit: [\*\*dementia.org.au/education\*\*](https://dementia.org.au/education)

## **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\*\*](https://dementia.org.au)**