



Section 2

Understanding your diagnosis

The Dementia Guide is for anyone who has been impacted by any form of dementia. The information in this guide is divided into sections. Each section relates to a particular stage of your dementia journey.

It is important to remember that everyone living with dementia is unique. The content in this guide is general in nature and we recommend you seek professional advice in relation to any specific concerns or issues you may have.

While we strive to keep content accurate and up-to-date, information can change over time. For updates, please visit dementia.org.au or call the **National Dementia Helpline** on **1800 100 500**.

Web: dementia.org.au/the-dementia-guide



“

Initially it was a shock but, in some ways, a relief to me as it had a name, I could identify what was going on for me. ”

Natalie, a Dementia Advocate who lives with younger onset dementia and primary progressive aphasia

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Dementia can only be diagnosed with certain medical examinations.

This could involve:

- physical examinations to test sensory, movement, heart and lung function
- blood, urine and spinal fluid tests
- cognitive or neuropsychological tests to assess memory, language, attention and problem-solving
- scans to check brain structure and rule out anomalies
- asking about medical history, including current medical problems, medications being taken, and family medical history
- psychiatric assessment to check for treatable disorders and manage symptoms that can occur alongside dementia.

Your doctor will likely refer you to different medical specialists for these examinations.

Recognising your feelings

It is normal to experience a range of emotions after your diagnosis.

You may feel:

- anger
- fear
- loss
- shocked
- disbelief
- denial
- sadness
- anxiety
- isolated
- a sense of relief.

It is important to recognise your emotions.

This will help you adjust to your diagnosis.

Try to share your feelings with family and friends.

Writing your thoughts in a journal can be helpful. You can also get help from:

- support groups for people with dementia
- your doctor or nurse
- trained counsellors.

Learn about support groups, counselling and other services available to you by calling the **National Dementia Helpline** on **1800 100 500**.

Learning more about dementia

Learning about dementia might be daunting or uncomfortable. But understanding the changes you may experience is an important first step towards living well with dementia.

Learning more about dementia can help you:

- adjust to your diagnosis
- talk to your doctor about treatment and support

- identify your priorities and goals for the future
- access support and coping strategies
- make financial and legal plans
- make plans for your care in the coming years
- learn to live well with dementia.

You do not need to learn everything at once. If you start feeling overwhelmed, give yourself time to get used to the new information.

Dementia Australia provides a range of information resources online at dementia.org.au and education sessions and programs at dementia.org.au/education.

You can also call the **National Dementia Helpline** on **1800 100 500** for more information.

Telling people about your diagnosis

When you decide to tell people about your diagnosis, you might start with close family and friends. Or you might choose to tell a broader group of people.

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.

The people you tell may have a range of reactions. They may seem angry, afraid or surprised. They may even seem relieved there is an explanation for your symptoms.

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.

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

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.

If you are finding it difficult to talk about your diagnosis and need support to tell other people, you can call the **National Dementia Helpline** on **1800 100 500**.