Call the National Dementia Helpline on 1800 100 500
2 Understanding your diagnosis

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Key Points: Diagnosis

A number of conditions can result in similar symptoms to dementia. For that reason, a thorough medical examination by a GP must take place so all other possible causes can be ruled out before a diagnosis of dementia is given. Assessment by a specialist in the area is then the best way to diagnose some form of dementia.

After being diagnosed with dementia, people are bound to experience a number of different emotions including anger, fear or a sense of loss. Sometimes, people even feel relieved at being given an explanation for the symptoms they have been experiencing.

It is important to find ways to deal with whatever emotions you are experiencing at the time. Taking care of your emotional needs will help you come to terms with your diagnosis.

Educating yourself about your condition is also important. While learning more about dementia and the changes you may experience can be daunting, this is an important step in helping you make vital decisions now and in the future.
You will also need to decide who to share details of your diagnosis with. Some people will confide only in their closest family and friends. Others will share the news more broadly. Everyone is different, and it is important to identify the approach that works best for you.

When sharing your diagnosis, don’t be surprised if responses vary from person to person. Allow people whatever time they need to digest your news, so you can all move forward in a positive way. While some relationships might be tested, others will likely be strengthened.

Often when family and friends are told of a diagnosis, they are keen to understand what they can do to best support the person with dementia. It is important to let others know how they can help.
How dementia is diagnosed

There are many conditions that have similar symptoms to dementia. A diagnosis of dementia therefore requires a thorough psychological and medical examination, so that other reasons for the person’s symptoms can be ruled out. These reasons might include strokes, depression, alcoholism, infections, hormone disorders, nutritional deficiencies and brain tumors. Many of these conditions can be treated.

Consult your GP at an early stage; your GP will likely refer you to a private specialist or one of the public Cognitive Dementia and Memory Services clinics for further detailed assessment.

An assessment may include the following:

**Medical history** Discussion of past and current medical problems, family medical history and any medications being taken, as well as the specific problems with memory, thinking or behaviour that are causing concern.

**Physical examination** Testing of the senses and movement function, as well as heart and lung function, to help rule out other conditions.

**Laboratory tests** A variety of blood and urine tests to identify any possible conditions that could be responsible for the symptoms. In some cases, a small sample of spinal fluid may also be collected for testing.

**Neuropsychological or cognitive testing** Tests to assess thinking abilities including memory, language, attention and problem solving. This can help identify specific problem areas, the underlying cause or the type of dementia.

**Brain imaging** Scans look at the structure of the brain to rule out brain tumors or blood clots as the reason for symptoms. By detecting patterns of brain tissue loss and the levels of activity in certain parts of the brain, they can also help determine the type of dementia.

**Psychiatric assessment** Identifying treatable disorders such as depression, and managing any psychiatric symptoms such as anxiety or delusions that might occur alongside dementia.

Remember, at any time during the process you can request a second opinion or referral to a specialist, if your GP has not already done so.
Feelings after diagnosis

If you have recently been diagnosed with dementia, you may experience a range of emotions.

• anger, fear or a sense of loss
• denial and avoidance
• depression and anxiety (If these feelings persist, talk to your doctor about treatment options)
• feelings of isolation – you may feel like no one understands what you are going through and you may lose interest in maintaining relationships
• a sense of relief – a diagnosis can validate your concerns and provide an explanation for your symptoms

Understanding your emotions will help you move forward and discover ways to live a positive and fulfilling life.

If you would like to speak to somebody about the services available that will help you cope with your emotions following diagnosis, call the National Dementia Helpline on 1800 100 500, or speak to your primary care team, doctor or practice nurse.

See Help Sheet, Information for people with dementia 6: Feelings and adjusting to change. Available at dementia.org.au

Looking after your emotional needs

Try to find ways to deal with your emotions. In recognising and taking care of your emotional needs, you may find it becomes easier to face your diagnosis.

You can work through your feelings in a number of ways:

• Use a journal to write down your thoughts and feelings.
• Share your feelings with family and friends, and don’t be afraid to be honest.
• Develop a strong support network. This could include people in similar situations. Support groups and social events specifically for people with dementia and their family and friends do exist.
• Share any concerns you have about your emotional health with your doctor or practice nurse. They may be able to suggest treatments, if appropriate.

• Speak to a trained counsellor about your emotions. This may help you understand what you are feeling and why. Counselling can be arranged through Dementia Australia.

• Talk to family and friends about their own emotions when it comes to your diagnosis.

• For more information on the support available, call the National Dementia Helpline on 1800 100 500.

Educating yourself about your condition

Taking steps to learn more about dementia and the changes you may experience can be daunting. But doing so can help you decide how to move forward.

You may come across information that is difficult to deal with. Try to learn about your diagnosis at your own pace and have realistic expectations about the information you are able to process.

Knowing about dementia can help you:
• come to terms with your diagnosis
• plan for your future and the future of your family
• explain your diagnosis to other people
• re-evaluate your priorities
• set goals and identify things you would like to accomplish
• make your own legal, financial and long-term care plans
• discuss available treatment and medications with your doctor
• adapt to the changes you are experiencing
• develop coping strategies

Dementia Australia offers a broad range of information, resources and programs, delivered in many different formats. To find out more, visit dementia.org.au
Sharing your diagnosis

“Friends in your life are like pillars on your porch. Sometimes they hold you up... sometimes it’s just enough to know they’re standing by.”

**Ralph Waldo Emerson**

As your dementia progresses, the support of people who know and understand you will become increasingly important. Sharing your feelings with family and friends can help you cope with changes.

While some relationships might be tested, others may be strengthened. When sharing details of your diagnosis, it is normal to be worried or uncomfortable. But talking openly with people you trust will encourage them to offer support and will help educate them about dementia.

Some people will decide to share their diagnosis only with their closest family and friends. Others will share the news with a broader network. Everyone is different, so identify your own comfort level and take the approach that works best for you.

Responses to your diagnosis

Consider how you felt after hearing your diagnosis for the first time. The people you choose to share details of your dementia with are likely to experience similar reactions including anger, fear, disbelief or even relief at being given an explanation for your symptoms.

Denial is a common response when disclosing a serious illness to family and friends. You may also encounter some negative reactions based on stigma or misconceptions. These reactions could be a sign the person or people in question need some extra time and more information before they can respond helpfully to your situation.

**Sharing this guide with your family, friends and carers may help them to understand your diagnosis.** Allow the people you share your news with all the time they need to digest the information, so you can all move forward in a positive way. And remember, those people who feel unable to be part of your support network straight away might join later, once they have had time to adjust to the news of your diagnosis.