The Dementia Guide

For people with dementia, their families and carers
This guide is for anyone who has been impacted by dementia. This could be Alzheimer’s disease, vascular dementia, frontotemporal dementia, Lewy body disease, mixed dementia or any of the various other types.

If you have been diagnosed with dementia, there are people who understand what you are going through, and help is available. There are lots of things you can do in the early stages to prepare for the changes ahead.

This guide will also be useful to the friends, families and carers of people living with dementia, as it contains information for anyone taking on a caring role.

It will also help people to understand more about dementia and the treatments, support and services available. It includes information about living well with dementia and about making plans for the future.

How to use the guide

You might choose to read the whole guide, or you might focus on the parts that seem most relevant to your situation. Each part begins with key points for those who prefer to read an overview rather than the whole section.

You will find a checklist on page 148. It lists some of the things discussed in this guide that you can do to help you live well now and plan for the future.
Your feelings

A diagnosis of dementia can cause a range of emotions. It can also have a big impact on family and friends.
If you, or somebody close to you, has recently been diagnosed with dementia you might feel angry, annoyed, frustrated, worried, fearful, sad, embarrassed, lonely, guilty or even relieved at being given an explanation for the issues or symptoms you have been experiencing. Everyone is different, but all these reactions are normal. How you feel may change from day to day.

If you can, talk to family and friends about how you are feeling. Other people want to understand what you are going through. They might be finding things difficult too, so talking can help you and them. There are also various professionals you can talk to for support.

Your plans for the future might change in light of your diagnosis, but dementia doesn’t change who you are. It doesn’t mean you need to stop doing the things you enjoy, but you might have to do them in a different way.

Support

You will find a list of Alzheimer’s Australia Vic services on page 141 and other useful organisations that may be able to provide information or support are listed throughout this guide.

If you would like to talk about the information in this guide or any questions or concerns you might have, please call the Alzheimer’s Australia National Dementia Helpline on 1800 100 500.

The Helpline is open across Australia between 9.00am and 5.00pm, Monday to Friday excluding national public holidays. A message bank service is provided for after-hours enquiries, which will be responded to the next working day.

Trained helpline advisers will provide you with information, support, guidance, and access to other organisations and support services.

Throughout this guide you will see suggestions for Alzheimer’s Australia Help Sheets. They provide advice, common sense approaches and practical strategies on the issues most commonly associated with dementia. You can view them and order printed versions online at fightdementia.org.au
You are not alone

Following a diagnosis of dementia, it is important to know that you are not alone – as of 2016, we estimate there to be more than 350,000 Australians living with dementia.

Additionally, an estimated 1.2 million people are involved in the care of a person living with dementia. Without a medical breakthrough the number of people with dementia in Australia is expected to reach almost 900,000 by 2050. If you would like to read a breakdown of key dementia statistics and facts, visit vic.fightdementia.org.au/vic/about-us/media/key-facts-and-statistics

Please note, all contact details listed in this guide are correct at the time of printing. For updates, please visit fightdementia.org.au/vic, helpwithdementia.org.au or call the National Dementia Helpline on 1800 100 500.

To order printed copies of this guide go to fightdementia.org.au/vic, call Alzheimer’s Australasia Vic Client Services on 03 9815 7800 or email alzvic@alzheimers.org.au
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This guide can be downloaded from our website at fightdementia.org.au/vic

Sources are available on request.

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

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Foreword

People who use our services often tell us that a diagnosis of dementia is completely overwhelming. Emotions are running high, there is a great deal of information to take in and there are many decisions that need to be made.

Alzheimer’s Australia Vic has created The Dementia Guide as a resource for anyone who has recently been told they have dementia, as well as their families, friends and carers. It will help the reader understand more about the condition, the treatments and support services available.

The content of this guide is based on a similar resource produced by the Alzheimer’s Society in the UK, which was well-received locally by people affected by dementia. We have worked with a number of Victorians living with dementia and carers to ensure the information included is as relevant and meaningful as possible.

This guide is important for a number of reasons. First and foremost, it is a handy source of information that is easy to understand. It offers ideas and information on the many things you can do to continue living well following diagnosis, and also in the early stages to prepare for the future.

We also hope it helps to reassure people that they are not alone, that there are people who understand what they are going through, and that support is available.

The information in this guide is divided into parts that are specific to the different stages of dementia. People with dementia are encouraged to keep a copy and refer to it throughout their experience, share it with family and friends, and use the information as and when it is needed.

If at any stage you would like additional information, support or to talk to somebody who understands what you are going through, please call the National Dementia Helpline on 1800 100 500. We are here for you.

Maree McCabe
CEO Alzheimer’s Australia Vic
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# About dementia

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- Disease progression
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Key points: About dementia

Dementia occurs when the brain is affected by a disease. It is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in the person’s functioning. It is not a normal part of ageing.

Dementia affects everyone differently and can result in a wide range of symptoms including problems with memory, thinking, concentration, language or social skills. People may become confused or struggle with how they perceive things. Dementia can also cause changes in mood or emotions and can affect how a person behaves.

Because dementia has a slow onset and is a progressive disease, symptoms begin gradually and worsen over time. This means that many people with dementia lead active and fulfilling lives for many years following their diagnosis.

There are many different types of dementia. The most common are Alzheimer’s disease and vascular dementia. These two conditions sometimes occur at the same time. This is known as mixed dementia. Other dementia types include Lewy body disease and frontotemporal dementia.

There are also some rarer conditions that cause dementia. Together, they account for only about five percent of all people living with dementia.

Various factors increase a person’s risk of developing dementia. Ageing, genes, health and lifestyle all play a part.

There are a few very rare forms of inherited dementia. However, even if several members of the same family are affected, this does not usually mean the dementia is inherited.

Dementia is most common in people aged 65 and over, but it does also affect younger people. The term ‘younger onset dementia’ is used to describe any form of dementia that develops in people under the age of 65.

Some people experience what is known as mild cognitive impairment. This is a condition that results in significant memory loss, but does not result in the loss of other cognitive functions.

While people with mild cognitive impairment are more likely to develop dementia than other people in the same age group, mild cognitive impairment does not always lead to dementia or can take many years to do so.
What is dementia?

The word dementia describes a group of symptoms that may include memory loss, difficulties with planning, problem-solving or language, and sometimes changes in mood, personality or behaviour. It is a progressive illness, meaning symptoms gradually worsen over time. The medical term for dementia is Major Neurocognitive Disorder.

Dementia isn’t a natural part of ageing. It occurs when the brain is affected by a disease.

There are many known types of dementia – probably more than 100. The most common type is Alzheimer’s disease. To find out more, see Types of dementia on page 19.

About dementia:

- As of 2016, we estimate there to be more than 353,800 Australians living with dementia.
- The chance of developing dementia increases significantly with age. Three in ten people over the age of 85 and almost one in ten people over the age of 65 have dementia. It is more common among women than men.
- There are approximately 25,100 Australians aged 65 and under currently living with younger onset dementia.

No two people experience dementia in the same way. Many factors can affect a person’s experience including age, the type of dementia, cultural or religious background, and the presence of other health conditions.

What are the symptoms?

While every person’s experience of dementia is different, some common symptoms are listed below.

Memory loss:

- problems recalling things that happened recently (although some people easily remember things from a long time ago)
- repeating yourself (such as asking the same question a number of times)

Difficulty thinking things through and planning:

- issues concentrating, following a series of steps, grasping new ideas or solving problems
- struggling with familiar daily tasks, such as following a recipe or using a debit or credit card

Problems communicating:

- difficulty finding the right words, struggling to follow a conversation or misinterpreting things

Being confused about time or place:

- losing track of the time, date or season
- not knowing where you are, even in a place you know well

Sight and visual difficulties:

- difficulty judging distances
- misinterpreting patterns or reflections in mirrors

Mood changes or difficulties controlling emotions:

- becoming unusually sad, frightened, angry or upset
- losing interest in things and becoming withdrawn
- losing initiative
- lacking self-confidence

Personality or behaviour changes:

- disinhibition
- aggression
- repetitive behaviour

For more information see Help Sheet, About dementia 2: Diagnosing dementia. Available at fightdementia.org.au
Changes over time

Dementia is generally progressive, which means symptoms gradually worsen over time. How quickly it progresses varies greatly from person to person. A lot of people with dementia can maintain their independence for many years.

In the middle and later stages of dementia, people will need more support with activities like cooking, or personal care such as washing and dressing. Dementia does shorten life expectancy, although some people live with it for many years. It is now the second leading cause of death in Australia.

At each stage there will be ways to make life better. To find out more, see Living well on page 53, Services for people with dementia on page 91 and Support for carers on page 101.

What are the causes?

Dementia is caused by physical changes in the brain. As dementia progresses, the structure and chemistry of the brain changes, leading to the damage and gradual death of brain cells.

Damage to different parts of the brain will have different effects. For example, in one area it might affect short-term memory, while in another it might affect a person’s ability to organise things.

To find out more about changes to the brain, see Types of dementia on page 19.

If you would like to watch a short video about the causes of dementia, visit helpwithdementia.org.au

Why do some people get dementia?

Dementia can happen to anybody. Scientists are still researching why some people get it. Most now believe it depends on a combination of age, genes, health and lifestyle.

While dementia most commonly occurs in people aged over 65, it can also affect younger people. This is known as younger onset dementia.

Dementia can sometimes be hereditary, but this is quite rare. The vast majority of dementia cases are not caused by genetics. Dementia is so common that having several close relatives with the disease is not evidence of a genetic link.

Sometimes, gene variations exist that do not inevitably lead to a person developing dementia, but they can increase the risk of developing it. These are known as susceptibility or risk genes. For more information, speak to your GP or medical specialist.

Importantly, scientific research suggests that living a brain healthy life, particularly during mid-life, may reduce a person’s risk of developing dementia.

Your Brain Matters™ is an Alzheimer’s Australia program that guides people on how to look after their brain health. Being brain healthy is relevant at any age, whether you’re young, old or in between.

For more information visit our website yourbrainmatters.org.au

While a brain healthy lifestyle can reduce a person’s risk of developing dementia, there are no guarantees. Sometimes, people who follow the principles of a brain healthy lifestyle will still develop dementia.

Types of dementia

There are many known types of dementia. Around 95 per cent of people with a diagnosis will have one of the four main types – Alzheimer’s disease being the most common, and vascular dementia (or a combination of these two conditions, known as mixed dementia), Posterior Cortical Atrophy and Lewy body disease or frontotemporal dementia – all described on the following pages.

For more information see Help Sheet, About dementia 1: What is dementia? Available at fightdementia.org.au
**Alzheimer’s disease**

**Inside the brain**

Abnormal proteins known as ‘plaques’ and ‘tangles’ build up in the brain, disrupting how nerve cells work and communicate with each other. The affected nerve cells eventually die.

There is also a shortage of some important chemicals in the brain when someone has Alzheimer’s disease. Reduced levels of these chemicals mean messages don’t travel around the brain as well as they should.

**Early symptoms**

Alzheimer’s disease usually begins gradually with mild memory loss. This is because the first changes are often in the part of the brain that controls memory and learning. A person with Alzheimer’s disease might repeat what they have previously said, or forget where they have put things. They might also have problems with language, such as finding the right word or forgetting people’s names.

Other early symptoms include feeling confused or finding it hard to follow what is being said. Some everyday activities might seem challenging, and some people might become more withdrawn and/or experience mood swings.

For more information see Help Sheet, About dementia 13: Alzheimer’s disease. If you would like to watch a short video about Alzheimer’s disease, visit helpwithdementia.org.au

**Vascular dementia**

**Inside the brain**

The word ‘vascular’ relates to blood vessels. Vascular dementia results from problems with the blood supply to the brain. Without enough blood, brain cells can die.

There are several types of vascular dementia. One type is caused by stroke (called stroke-related dementia). Another is caused by poor blood supply to deep parts of the brain often due to narrowing of the arteries supplying blood to the brain (called subcortical vascular dementia).

Strokes happen when a blood clot blocks the flow of blood to part of the brain, or when a blood vessel in the brain bursts. Vascular dementia sometimes follows a large stroke. However, more often it occurs after a number of small strokes (called multi-infarct dementia).

**Early symptoms**

The symptoms of vascular dementia will depend on which part of the brain has been damaged. Some people might experience physical weakness on one side due to a stroke. Other changes could include difficulty thinking quickly or concentrating, and short periods of confusion. Some people might also become depressed or anxious. Memory loss isn’t always a common early symptom of vascular dementia.

Vascular dementia usually progresses in stages. A person’s abilities will deteriorate following one stroke before stabilising until another stroke occurs. If further strokes do not occur, abilities may not continue to decline, or they might improve. However, these improvements may not last.

On average, people with vascular dementia decline more rapidly than people with Alzheimer’s disease.

For more information see Help Sheet, About dementia 16: Vascular dementia. Available at fightdementia.org.au If you would like to watch a short video about vascular dementia, visit our website helpwithdementia.org.au

**Lewy body disease**

**Inside the brain**

This form of dementia gets its name from tiny structures called Lewy bodies that sometimes develop inside brain cells. Similar to the plaques and tangles associated with Alzheimer’s disease, these structures disrupt the way the brain functions, reducing levels of chemical messengers and causing cells to die.

For more information see Help Sheet, About dementia 17: Lewy body disease. Available at fightdementia.org.au If you would like to watch a short video about Lewy body disease, visit our website helpwithdementia.org.au

**Mixed dementia**

Some people may have more than one form of dementia. This is called mixed dementia. It might contain elements of Alzheimer’s disease with vascular dementia, or Alzheimer’s disease with Lewy body disease.
Lewy bodies are also found in people with Parkinson’s disease. In Parkinson’s disease, the deeper parts of the brain responsible for controlling movement are affected initially by the Lewy bodies. Conversely, with Lewy body disease, these structures start in the surface part of the brain, and cause problems with thinking.

It is possible that people with Parkinson’s disease may develop a type of dementia known as Parkinson’s disease dementia, which occurs when a person has been living with Parkinson’s disease for several years.

**Early symptoms**

People who have Lewy body disease might find it hard to remain alert and have problems planning ahead, reasoning and solving problems. These symptoms can vary a lot from one day to the next.

People might also experience problems with how they see things. It might be hard to judge distances or they might mistake one object for another. Some people see things that aren’t really there (visual hallucinations) and disturbed sleep patterns are also common.

However, if someone has Lewy body disease, their memory will often be affected less than someone with Alzheimer’s disease.

Many people that have Lewy body disease also develop symptoms similar to those associated with Parkinson’s disease, including tremors, stiffness and difficulties moving around. These occur as the Lewy bodies spread to the deeper parts of the brain.

For more information see Help Sheet, About dementia 20: Lewy body disease. Available at fightdementia.org.au. If you would like to watch a short video about Lewy body disease, visit our website helpwithdementia.org.au

**Frontotemporal dementia**

**Inside the brain**

The term frontotemporal dementia covers a range of conditions. Although it does affect older people, frontotemporal dementia is more likely to affect people in their 40s, 50s and 60s (younger than most people who get Alzheimer’s disease or vascular dementia).

It is caused by damage to areas of the brain called the frontal and temporal lobes. These areas control behaviour, emotional responses and language skills. Abnormal proteins collect within brain cells in each of these lobes and cause the cells to die. Important chemicals that carry messages around the brain are also affected.

There are many different forms of frontotemporal dementia. The most common forms include behavioural variant, semantic dementia and progressive non-fluent aphasia. There are also a number of other syndromes that overlap with frontotemporal dementia.

**Early symptoms**

With behavioural variant frontotemporal dementia, changes in personality or behaviour are often noticed first. The person might seem withdrawn or not to care as much about other people. They might make socially inappropriate remarks. They may also become obsessive or impulsive.

When someone has semantic dementia their speech is usually fluent, but they lose their understanding of some words. Language is also affected in progressive non-fluent aphasia. Speech is often slow and requires a lot of effort.

People in the early stages of frontotemporal dementia often don’t experience day-to-day memory loss.

For more information see Help Sheet, About dementia 17: Frontotemporal dementia. Available at fightdementia.org.au. If you would like to watch a short video about frontotemporal dementia, visit our website helpwithdementia.org.au

**Posterior Cortical Atrophy**

**Inside the brain**

Posterior Cortical Atrophy is a progressive condition involving the loss and dysfunction of brain cells particularly at the back (or posterior) of the brain. Consequently, brain tissue in the outer layer shrinks.

In the majority of cases, this loss of brain cells is associated with the same brain changes seen in Alzheimer’s disease, namely ‘plaques’ and ‘tangles’. In other words, Posterior Cortical Atrophy is generally considered to be an unusual variant of Alzheimer’s disease.
Early symptoms

Despite being caused by the same disease process, the effects of Posterior Cortical Atrophy and Alzheimer’s disease on behaviour and thinking can be very different.

Alzheimer’s disease is most commonly associated with deterioration in memory, language, perception and other abilities. People living with Posterior Cortical Atrophy, however, tend to have well preserved memories and language skills, but instead show a progressive decline in visual processing and/or literacy and numeracy skills such as spelling, writing and arithmetic.

For more information on Posterior cortical atrophy see Help Sheet, About dementia 22: Posterior cortical atrophy. Available at fightdementia.org.au

Dementia in younger people (younger onset dementia)

There are currently over 25,000 Australians under the age of 65 living with dementia. The term ‘younger onset dementia’ is used to describe their diagnosis. People under the age of 65 may develop any type of dementia, but the most common form amongst this group is Alzheimer’s disease. Some of the other types of dementia commonly diagnosed in people with younger onset dementia are:

- vascular dementia
- frontotemporal dementia
- Posterior Cortical Atrophy
- alcohol-related dementia
- Parkinson’s disease with dementia
- Lewy body disease
- Huntington’s disease
- multiple sclerosis
- HIV associated dementia
- Creutzfeldt-Jacob disease
- dementia after head injury
- dementia in Down syndrome

In some cases, younger onset dementia has been found to have a genetic link. This is known as Familial Alzheimer’s disease. If a parent has a mutated gene that causes Familial Alzheimer’s disease, each of their children will have a 50% chance of inheriting it. The presence of this gene means the person will eventually develop Alzheimer’s disease, usually in their 40s or 50s. This form of Alzheimer’s disease affects an extremely small number of people – probably no more than 100 across Australia at any one time.

People with younger onset dementia often struggle to get a diagnosis, with the disease frequently misdiagnosed as a psychiatric condition. The person will receive psychiatric treatment until it is discovered they have dementia.

While many of the symptoms between younger and older people with dementia are similar, people with younger onset dementia will often have very different support needs.

They are more likely to be strong and healthy physically, in full time employment, raising a family and perhaps looking after elderly parents. Many will have a mortgage or other financial commitments, and may have planned a future based on retiring at the age of 65. Younger onset dementia can therefore have significant financial and lifestyle implications. In addition, people with the condition may encounter misunderstanding, as many people do not expect to see dementia in younger people.

People with younger onset dementia might also have different interests and expectations of how they can continue to live well with dementia. Accessing some supports and services may prove to be a challenge because of their age.

For information on the support services available to people living with younger onset dementia, see Services for people with younger onset dementia on page 97.

For more information see Help Sheet, About dementia 21: Younger onset dementia. Available at fightdementia.org.au
Rarer causes of dementia

A wide range of other conditions can lead to dementia. These are rare, and together account for only about five per cent of all people with dementia.

These diseases include:
- Parkinson’s disease
- corticobasal degeneration
- Creutzfeldt-Jakob disease
- HIV-related cognitive impairment
- Huntington’s disease
- alcohol-related brain damage and Korsakoff’s syndrome
- multiple sclerosis
- Niemann-Pick disease type C
- normal pressure hydrocephalus
- Progressive Supranuclear Palsy
- Chronic Traumatic Encephalopathy (from repeated head injuries)
- Down syndrome

Disease progression

By learning what to expect as dementia progresses, you can develop strategies to help you manage potential future challenges.

Symptoms and disease progression vary between individuals. No two cases are the same.

But despite the variations between different types and symptoms of dementia, most dementias have a gradual onset, are progressive in nature and are irreversible.

The course of dementia is often characterised as occurring in three stages:
- In mild or early-stage dementia there might be problems with memory, but the person can still function with minimal support.
- In moderate or middle-stage dementia difficulties become more obvious and severe, and increasing levels of support are required to help the person maintain their functioning in the home and community.
- Severe or late-stage dementia is characterised by almost total dependence on care and supervision by others.

Mild cognitive impairment

Mild cognitive impairment is generally defined as significant memory loss without the loss of other cognitive functions. People with mild cognitive impairment have more memory problems than would usually be found in people of a similar age, are able to function independently and do not show other signs of dementia.

Typical symptoms associated with mild cognitive impairment include trouble remembering names or the flow of a conversation, and a greater tendency to misplace things. People with mild cognitive impairment can usually accomplish all of their daily tasks, but often compensate for their memory problems by relying on prompts such as reminder notes or calendars.

It is currently estimated that people with mild cognitive impairment are three to five times more likely to develop dementia than other people in the same age group. However, mild cognitive impairment does not always lead to dementia or can take many years to do so.

There is currently no medical treatment for mild cognitive impairment. However, cognitive training such as exercising the mind and memory can help reduce the symptoms, or the risk of developing mild cognitive impairment in the first place. It is important to maintain a healthy diet, take regular physical exercise and maintain good general health, particularly when it comes to controlling blood pressure and cholesterol levels, and stopping smoking.

In most cases a person diagnosed with mild cognitive impairment will not undergo any medical treatment, but will be monitored for changes in their memory. Counselling may assist people with mild cognitive impairment to find ways of adjusting to changes and to learn about ways to compensate for their memory difficulties.

The medical term for mild cognitive impairment is Minor Neurocognitive Disorder.
Understanding your diagnosis

In this part

Key points: Diagnosis
- How dementia is diagnosed
- Feelings after diagnosis
- Looking after your emotional needs
- Educating yourself about your condition
- Sharing your diagnosis
- Responses to your 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 or 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.

Key Points: Diagnosis

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.

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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.

For more information see Help Sheet, Information for people with dementia 6: Feelings and adjusting to change. Available at [fightdementia.org.au](http://fightdementia.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 Alzheimer’s Australia Vic.

• 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

Alzheimer’s Australia Vic offers a broad range of information, resources and programs, delivered in many different formats. To find out more, visit vic.fightdementia.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.
3 Treatments

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Key Points: Treatments

There is no known cure for dementia, but there are drugs and other therapies that can help with some of the symptoms. With the right combination, lots of people can live well with dementia for many years.

Developing a strong relationship with your doctor is an important step in managing your illness. Your GP can also be a valuable source of information and support.

As your dementia progresses, you may rely on medical experts in a variety of different areas including geriatricians, neurologists and psychiatrists. Your GP will refer you to see each of these people when appropriate during the course of your dementia (this could be right at the start for assessment and confirmation of diagnosis, right through to treatment).

Allied health clinicians will form an integral part of your healthcare team. They will provide support at different stages of the disease to help you maintain your quality of life and independence. These may include counsellors, dental therapists, dieticians, occupational therapists, optometrists, psychologists and social workers.

Your pharmacist can also play an important role in helping you manage your medication by offering a variety of support services.

A number of drugs have been developed that can lessen the symptoms of Alzheimer’s disease for a while in some people. Sometimes they are also given to people with mixed dementia or Lewy body disease. However, they are not suitable for people with frontotemporal dementia, who may be given other drugs for some of their symptoms.

A person with vascular dementia will usually be prescribed drugs to treat any underlying conditions, such as high blood pressure or heart problems.

People with dementia can also benefit from approaches that don’t involve drugs, such as counselling or cognitive behavioural therapies. Reminiscence therapy, which involves talking about things from the past, using prompts such as photos or music can also be helpful. Staying mentally active, for instance doing word puzzles or discussing current affairs, is important, as is remaining socially connected and continuing to be engaged in enjoyable activities.

Depression or anxiety are commonly experienced by people with dementia. The symptoms of withdrawal, apathy and agitation are sometimes put down to dementia, and consequently it may be some time before depression is recognised and treated.
Working together with your doctor

Developing a strong relationship with your doctor is important to effectively manage your condition. General practice and primary care teams play a vital role in supporting people living with dementia, their families and carers, from identification and diagnosis, through to ongoing management and care.

Help your doctor and practice nurses get to know you, and be open and honest with them. Answer all questions truthfully and, if you don’t know the answers, let them know. This will help them understand how your dementia is affecting your brain, health and relationships, as well as what referrals and treatments are appropriate.

Often a family member or carer has a unique insight into your needs, preferences and symptoms. Include them in discussions with your doctor about diagnosis and care management. Doctors and nurses can also provide valuable support to carers themselves.

When preparing for an appointment, it may be helpful to make a list of questions you would like to ask, as it can sometimes be more difficult to remember these things during the appointment itself.

Consider booking a longer appointment than usual, so that you have time to discuss everything in detail.

Make a list of all the medications, vitamins and supplements you take, including dosages, and keep a log of any changes you or your family and friends have noticed.

Take a family member or friend into the appointment with you. They may ask questions that you hadn’t thought of and could write things down to help you remember anything you forget or explain anything you don’t understand. This can also provide a way of helping those around you understand your condition.

Discuss a treatment plan. Ask your doctor about the medications or treatment options available to you, as well as the associated benefits and risks. You can also discuss whether you would be an appropriate candidate to participate in clinical studies. For more information, visit dementiaresearchfoundation.org.au

Ask about the support services available that will help you live well with the disease, for as long as possible.

Make sure you take notes, ask for information to take away with you, and request written details of your condition so that you can refer back to these later.

For more information see Help Sheet, Information for people with dementia 9: Talking with your doctor. Available at fightdementia.org.au

Your multidisciplinary team

During the different stages of dementia, you may be treated by a number of different health professionals. Together, they will make up what is known as your multidisciplinary team.

Your doctor will arrange for you to see different experts relevant to different aspects of your care. Medical specialists such as geriatricians, neurologists and psychiatrists, as well as allied health clinicians such as nurses, social workers, psychologists, occupational therapists, physiotherapists and counsellors might all be involved in your treatment at some stage.

Make sure you know the different roles and functions of each health professional involved in the ongoing care and management of your condition.

Medical specialists

A geriatrician is a medical doctor who specialises in the diagnosis, treatment and prevention of disease and disability in older adults.

A psychogeriatrician is a medical doctor who specialises in diagnosing and treating mental and emotional disorders in older adults.

A neurologist is a medical doctor who specialises in the detection, diagnosis and treatment of people with neurological conditions i.e. abnormalities of the brain and central nervous system.

A neuropsychiatrist is a medical doctor who has trained in the field of psychiatry and has a special interest in the behavioural and psychological effects of neurological diseases or injury to the brain.
A **psychiatrist** is a medical doctor who has obtained additional qualifications to become a specialist in the diagnosis, treatment and prevention of mental illness and emotional problems.

It is important to keep looking until you find the medical specialists for you. Make sure you feel comfortable with them and they are a good fit for you and your family. Your doctor will help you keep looking until you find the right specialists.

**Getting a second opinion**

At any time, you can request a second opinion or referral to a specialist, if your GP has not already done so. Don’t worry about offending your doctor. Most medical professionals understand the benefit of a second opinion, and should be happy to refer you to another doctor.

**Allied health clinicians**

Allied health clinicians form an integral part of your multidisciplinary healthcare team. They provide support at all different stages of the disease and work with others health professionals to help you maintain your quality of life, independence, self care and mobility, while helping to reduce the risk of complications due to other conditions or injuries.

**Counsellors and Dementia Consultants** can help maintain your wellbeing by talking to you about adjusting to change and feelings such as loss and grief.

An **occupational therapist** can focus on the things you do in everyday life such as eating, dressing and showering, as well as things like driving and socialising. They can help you identify your skills and abilities, and what help you might need to continue to do the things you want to do.

A **psychologist** can provide counselling and help you and those around you cope with feelings and adjustments to change.

A **neuropsychologist** will work with you and your family to help find strategies to cope with the changes in behaviour that might happen as a result of the changes in your brain.

A **social worker** can provide emotional support during times of stress and practical support with things like money, accessing support services and appointing powers of attorney.

A **physiotherapist** can help you improve your strength, balance and the way you move around.

**Dental therapists, dental hygienists and oral health therapists** work alongside dentists to help keep your mouth, teeth and gums in good condition.

A **dietitian** can focus on the relationship between your health and the food you eat, providing advice and strategies for maintaining a nutritious diet.

A **diversional therapist** can design leisure and recreation programs appropriate for your tastes and abilities, by getting to know about your history, interests and culture.

An **exercise physiologist** can work with you to improve your fitness, strength and balance.

A **music therapist** can help improve your health, functioning and wellbeing using music.

An **optometrist** can check your eyesight and monitor for any eye conditions.

An **osteopath** can offer treatment and advice to help improve mobility, circulation and balance.

A **podiatrist** can check and help maintain the health of your feet.

A **speech pathologist** can help you find ways to communicate with others if speaking has become difficult.

These professionals are found in both private and public health care settings. Speak to your doctor for advice on how to access these services as part of your dementia care plan.
Partnering with your pharmacist

The cognitive issues associated with dementia mean people living with the condition are more likely to have problems managing their medication. Appropriate medication management is important to ensure you receive the greatest benefit from your treatment, while minimising the risk of harm.

Your pharmacist can play an important role in supporting you and your carer, by offering a variety of services, including:

• packing and organising drugs on your behalf
• providing simplified administration instructions, including verbal, written and visual material
• minimising the generic substitution of brand-named drugs
• managing the maintenance of current scripts
• conducting telephone follow-ups
• providing dose administration boxes, with the days of the week marked on them
• using ‘reminder’ pill packaging
• providing dose-dispensing units of medication and medication charts
• offering appointment and prescription refill reminders
• providing memory aids including planners or calendars, and medication or pill box timers

Drugs to treat dementia

Currently, there is no known cure for dementia. Scientists around the world are involved in research to try and find one.

However, there are drugs that can help to improve some of the symptoms or stop them progressing for a while, depending on the type of dementia.

All drug treatment information was correct at the time of printing.

Non-drug treatments and support after diagnosis (such as information, advice and counselling) are also valuable.

And remember, it is important to maintain other areas of your general health. See Looking after your general health on page 69.

Alzheimer’s disease

Four drugs have been developed to tackle some of the physical changes in the brain that cause Alzheimer’s disease.

Donepezil, rivastigmine and galantamine

People who have mild to moderate Alzheimer’s disease may be prescribed donepezil (e.g. Aricept), rivastigmine (e.g. Exelon, Exelon Patch) or galantamine (e.g. Reminyl, Galantyl). The names in brackets are the common brand names of these drugs. People who have mixed dementia in which Alzheimer’s disease is the main cause may also be prescribed these drugs.

These drugs are usually initially prescribed to a person living with Alzheimer’s disease by a specialist such as a neurologist, geriatrician or psychiatrist. The person’s doctor will generally then take over routine prescribing.

These three drugs all work in a similar way and offer similar benefits. They increase the amount of a chemical called acetylcholine, which helps messages travel around the brain and assists us to make memories. People with Alzheimer’s disease have a shortage of this chemical.

Possible benefits

Some people find these drugs lessen their symptoms for a while. Possible benefits include improvements in motivation, anxiety levels, confidence, daily living, memory and thinking.

Possible side effects

Side effects are usually minor and can include loss of appetite, nausea, vomiting, diarrhea and vivid dreams. Lowered heart rate is another possible side effect, meaning an ECG is sometimes recommended before a person trials these drugs. They can also be problematic for people with asthma. If one of these drugs causes problematic side effects, it may be possible to try another.
Memantine
People who have moderate Alzheimer’s disease but are unable to take any of the three drugs listed on page 45, might be offered memantine (e.g. Ebixa, APO-Memantine, Memanxa). It is also becoming more common to be offered memantine in the later stages of Alzheimer’s disease when symptoms become more severe.

Memantine works by protecting brain cells from the harmful effects of a natural substance called glutamate. People with Alzheimer’s disease often have damagingly high levels of glutamate in their brains.

Possible benefits
Memantine can temporarily slow down the progression of symptoms in people in the middle and later stages of Alzheimer’s disease. It may also help with agitation or aggressive behaviour, and may improve language and communication.

Possible side effects
Memantine usually has fewer side effects than the other three drugs, although it can still cause dizziness, headaches, tiredness, increased blood pressure and constipation.

Memantine is only available under the Pharmaceutical Benefit Scheme (PBS) for moderately severe dementia. Speak to your doctor to find out whether you are eligible for this drug.

For more information see Help Sheet, About dementia 9: Drug treatments and dementia. Available at fightdementia.org.au

Vascular dementia
The four drugs described in the previous section aren’t recommended for vascular dementia unless this is part of mixed dementia with Alzheimer’s disease.

It may be possible to slow down the progression of vascular dementia by taking drugs that treat the underlying conditions. A doctor will often prescribe drugs for people with vascular dementia who are at risk of having a stroke or heart attack by treating high blood pressure, high cholesterol, diabetes or heart problems.

Other dementias

Lewy body disease
A person living with Lewy body disease might be offered one of the three anti-Alzheimer’s disease drugs (donepezil, rivastigmine or galantamine). In particular, they may benefit if they have distressing symptoms, such as seeing things that aren’t there (hallucinations) or believing things that aren’t true (delusions).

Drugs that are used to treat Alzheimer’s disease are not available under the Pharmaceutical Benefit Scheme (PBS) for Lewy body disease. However, they may be prescribed if Alzheimer’s disease cannot be excluded. Speak to your doctor to find out whether you are eligible for these drugs.

Frontotemporal dementia
Existing drugs for treating Alzheimer’s disease haven’t been shown to offer any benefits to people with frontotemporal dementia and it is thought they might even be harmful.

Often people with behavioural variant frontotemporal dementia are prescribed psychiatric medications to reduce the associated problematic behaviours, or an antidepressant if they are experiencing depression.

Possible questions to ask your doctor about medications
- Are there any medications that can help me?
- Why are you offering me this medication?
- How do I take this medication?
- What happens if I miss a dose?
- Can I still take my other medication?
- Can I drink alcohol?
- Can I still drive my car?
- Will it impact my work?
- What are the pros and cons of this medication?
  - How will it help me?
Non-drug treatments for dementia

Living well

Dementia can be difficult to live with at times. Fortunately, there are lots of ways to maintain a good quality of life following diagnosis.

Keeping the body and mind active is essential, while people who remain engaged with their day-to-day activities, interests and social groups often feel more satisfied and fulfilled. Research suggests that exercise and eating well can be beneficial and may even slow down changes in the brain.

For more information see Living Well on page 53.

Information, support and counselling

People who have been diagnosed with dementia, their families and friends usually benefit from information that helps them understand the diagnosis and what they can expect as the dementia progresses.

There is a range of useful resources and programs available that offer up-to-date information in an accessible way.

• vic.fightdementia.org.au includes Help Sheets on a variety of topics
• livingwellwithdementia.org.au includes personal stories, resources, information and tips on how to make the most of life with dementia
• Educational programs like the Alzheimer’s Australia Living With Dementia program

Counselling can also be helpful, and is available specifically for the person with dementia individually or in conjunction with a partner or family members. Alzheimer’s Australia Vic’s staff are specifically trained to provide dementia-related support, tailored to the needs of the particular person or group.

Counselling might include discussions about reactions to the diagnosis, ways to live well with dementia, strategies to deal with role changes and changes to relationships, or planning for the future.

To access any of the support outlined above, contact the National Dementia Helpline on 1800 100 500.

Other approaches

There are a number of other approaches that may assist the person with dementia as their condition progresses.

Reminiscing and life story work

Reminiscing involves talking about events from the past, using prompts such as photos, familiar objects or music.

In some dementia cases, people experience memory loss associated with recent events, but are still able to recall events that occurred earlier in their lives. Reminiscing with a person who has dementia can therefore help them to feel connected, engaged and valued.

Life story work is a shared experience between the person with dementia and a family member, friend or support worker. A scrapbook, photo album or some form of digital media is used to develop a physical record of the person’s life experiences, values and beliefs.

There is evidence to suggest that reminiscing and life story work can improve mood, wellbeing and some cognitive abilities such as memory. Call the National Dementia Helpline on 1800 100 500 for details.

Complementary therapies

The term complementary therapies refers to a broad range of treatments used to prevent or treat illness and promote wellbeing. They are not the same as conventional medicines.
Some complementary therapies that may help people with dementia include aromatherapy, acupuncture, massage, bright light therapy, herbal medicines and listening to preferred music.

While there have been many indications that complementary therapies can impact positively on the overall wellbeing of a person living with dementia, there is no definitive evidence to suggest that complementary therapies can be used to effectively treat symptoms such as memory loss.

Practitioners of complementary therapies should not be viewed as a substitute for your doctor. A good practitioner of complementary therapies should encourage continued input from your doctor during any program of treatment, and many even liaise directly with them.

To find out more about complementary therapies, speak to your GP or visit the The National Institute of Complementary Medicine website at nicm.edu.au

For more information see Help Sheet, Caring for someone with dementia 2: Therapies and communication approaches. Available at fightdementia.org.au

Treating depression and anxiety

People with dementia, their families and carers may experience depression or anxiety, particularly in the early stages.

Non-drug treatments

There are ways to treat depression and anxiety that don’t involve drugs. These include talking therapies such as counselling, reminiscence activities and life story work. See Other approaches on page 49.

Other simple things that can help with depression and anxiety include keeping active, engaging in enjoyable activities and talking to friends and family. Maintaining a healthy diet and not having too much alcohol or caffeine can also help.

Drug treatments

Drugs are just one approach when it comes to treating depression and anxiety.

Antidepressant drugs work by correcting the levels of some chemicals in the brain. It can take several weeks for someone to notice the benefits of taking an antidepressant. It is important to discuss your options with your doctor.

Many people experience some side effects to begin with, but these usually lessen after a week or two.

A doctor might advise people to try different antidepressants, at different doses, to find out what works best.

Things to consider

- Are you clear about the questions you will ask your doctor when discussing your treatment plan?
- What are some things you would like your doctor to know about you?
- Would some additional written or online information, support or counselling assist you at this time? If so, have you called the National Dementia Helpline on 1800 100 500?
- Have you considered the possibility of group counselling with your family and carers?
- Would you consider collecting photographs and memorabilia from your past to assist reminiscence?
- What activities have you always enjoyed doing that you would like to continue with?
4 Living well

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Key points: Living well

If you’ve been diagnosed with dementia, there are lots of things you can do that will help you live as well as possible.

To help you cope with memory problems you could try using a large diary, perhaps keeping it next to a calendar clock. Also, try keeping important items, such as keys or glasses, together in the same place.

Try to make your home safer. Remove things that are easy to trip over and install assistive technologies such as carbon monoxide detectors and smoke alarms. You could also get automatic timers for plugs, lights and heaters.

Many people with dementia can continue to live on their own during the early stages of the disease, by making simple adjustments, taking extra safety precautions and calling on support from families, friends and others.

A diagnosis of dementia does not mean you should stop travelling, particularly if this is something you have always enjoyed. When people living with dementia are away from home, some careful planning will ensure the safety, comfort and enjoyment of everyone involved.

Try to stay active and social. This can help you retain skills and memory, as well as improving your self-esteem, sleep and wellbeing. Wherever possible, keep doing what you enjoy, even if you have to do it differently. Ask an occupational therapist (a health professional who supports people to maintain everyday skills) for advice on appropriate activities.

Having dementia doesn’t mean you should feel unwell. It is important to take steps to remain fit and healthy. Regular exercise and eating a balanced diet can help. If you smoke, try to stop.

Arrange regular check-ups with your doctor, as well as regular dental, eye and hearing checks. Get the annual flu vaccine and see your doctor promptly if you feel unwell.

Because dementia affects many parts of your brain, you may need to develop new ways of communicating with people. Simple modifications such as talking slowly, finding a quiet place to talk, and being more descriptive when you can’t remember a specific word will help you continue to communicate effectively.

Symptoms of dementia can affect relationships with family and friends. It is important to be open and honest about these changes, talk them through and ask for help wherever it is needed. Seeking counselling from a professional can help.
A positive outlook

"If you can’t change your fate, change your attitude." Amy Tan

Living with dementia is challenging and you may feel angry or frustrated about what is happening to you.

Your plans for the future might change, but dementia doesn’t change who you are. It doesn’t mean that you need to stop doing the things you enjoy, but you might have to do them in a different way.

There are some practical things you can do to help you live as well as possible following a diagnosis of dementia. Focus on the things you can and want to do, and try not to become isolated. Keeping busy with activities you enjoy and staying socially connected with friends and family may help you to feel more confident.

To discover some examples of measures that have helped people with dementia to live happy and fulfilled lives, visit livingwellwithdementia.org.au

Coping with changes

The changes that occur with dementia can be frustrating, distressing and may undermine your confidence. You will probably notice changes in your abilities to do the things you usually do. When you or your family and friends notice these changes, it is time to adapt your daily routine.

Changes might include memory loss, problems with thinking and planning, difficulties communicating, confusion about time or place, sight and visual difficulties, apathy and withdrawal.

There are lots of practical things you can do to help you cope with these changes.

- Keep a notebook or large diary. Write down things you want to remember, such as names, phone numbers, social engagements or appointments. Keep the diary next to something you use a lot like the kettle or phone, so that you get used to referring to it.
- Consider writing down important ideas and information. This can provide a helpful memory aid. Written information can be easily shared with others.
- Consider positioning a whiteboard in a prominent place to record and display important information.
- Put labels or pictures on cupboards to remind you where things are.
- Reduce clutter around the home to make things easier to find.
- Place useful telephone numbers by the phone.
- If you find it helps, put a note on the door or by your bed to remind yourself to lock up at night.
- Ask your pharmacist about putting your pills in a dosage box or pack with the days of the week marked.
- Consider using a medication or pill box timer to help remind you when to take your medication.

Call the National Dementia Helpline on 1800 100 500
• Keep a note of your address, family contact details and written instructions explaining how to get home, whenever you go out.
• Get support from family, friends and services in the community to help you keep doing the things that you want or need to be able to do.
• Make sure you continue to exercise, within your ability. This will improve the way you think and feel.
• Exercise your mind. Keep learning, thinking, and doing a variety of activities.
• Remain socially engaged.
• Make sure family and friends know to gently reassure you if you become confused about the time or place.
• Place way finding symbols and instructions on how to operate certain equipment around the home.
• Use contrasting colours. For instance, if your toilet bowl is white, consider a contrasting toilet seat to make sure it stands out.

There are also a number of technological aids can help you cope with changes.
• Reminder messages. Whenever you go in or out of the house, a recorded voice reminds you to pick up your keys or lock the front door.
• Calendar clocks. These show the date and the day of the week. Keeping the clock next to a diary or weekly planner can help you orientate yourself when checking appointments and other commitments. It can also be useful to keep a clock next to a medication dosage box for the same reason.
• Locator devices. These help you find frequently mislaid items such as keys. You attach a small electronic tag to the item, and you can then click a button on the locator device to make the tag beep.
• Automatic timers and switches. These will automatically turn off lights, irons and stoves if they have been left on too long.

For more information on technological aids that can help you, see Keeping safe at home on page 61.

Daily coping strategies

“Courage does not always roar. Sometimes courage is that quiet voice at the end of the day saying, “I will try again tomorrow.”

Mary Anne Radmacher

Things you once found easy like maintaining your schedule or managing your money may become increasingly difficult as your dementia progresses. Developing coping methods can reduce stress by making things as easy as possible and can help you remain engaged and active, and overcome challenges that inhibit your independence and wellbeing.

Identify

Make a list of tasks that have become more challenging, with a focus on the activities that are most important in your daily life.

Prioritise

Determine whether each task is necessary. For the more difficult and important tasks, consider asking for help from family and friends, or local service providers.

Strategise

Develop a regular daily routine and approach one task at a time.

Reduce stress

Living with dementia can be overwhelming and frustrating. Stress can further affect your health and ability to function. Taking steps to reduce stress can help improve your concentration, decision-making ability and overall quality of life.

To help reduce stress:
• identify sources of stress in your life and remove yourself from these situations whenever possible;
• establish boundaries and let others know what you are willing to tolerate and what you are not;
• take a break and find a quiet place to relax, if you’re in an environment that has too much noise or other stimulation;
• keep things straightforward by simplifying your routine and daily tasks to make them more manageable;
• consider asking for help with the tasks that become too difficult for you, or consider putting them off until later;
• break each task down into a step-by-step process. Give yourself plenty of time and take things at a slower pace if you need to;
• perform tasks with other people, for instance, cooking, shopping, housekeeping, exercising and paying bills.

Getting support
Support from family, friends and service providers in the community can help you keep doing the things that you want or need to do.

Make sure you let people around you know how they can help. If you can get support, you’ll have more energy to do the things you enjoy the most. You may be able to get some help with tasks around the house like cooking, cleaning, shopping or showering. There are support services available that can provide assistance.

Some useful ways to get information, support and referral to services include:

My Aged Care – a website and telephone service established by the Australian government to help you navigate the aged care system. Visit myagedcare.gov.au or call 1800 200 422.

The National Dementia Helpline – call 1800 100 500 to access support services and get advice on developing effective coping strategies.

Dementia-friendly environments
The physical environment can have a major impact on a person living with dementia. There are lots of practical things you can do to create an environment that will maximise your engagement and wellbeing at home:
• Improve lighting by replacing current globes with brighter ones, position seating such as chairs and couches by windows to take advantage of sunlight, and consider installing sensor lighting to reduce the risk of falls at night time.
• Ensure personal items and photos are on display to provide opportunities for reminiscence to reduce stress and anxiety.
• Place regularly used items in line of sight and group common items together to make them easier to find.
• Use labels to help locate and identify items.
• Make sure hot/cold indicators are clearly identified on taps, to avoid confusion.
• If you ever need to replace an appliance, make sure you do so with a familiar and recognisable model.
• Have distinctive coloured doors with contrasting door frames to help with orientation.

For more information see our series of Help Sheets, The environment and dementia, or refer to enablingenvironments.com.au for practical suggestions on each area of the home.

Keeping safe at home
Dementia can increase the risk of a person having an accident around the home, but there are measures you can take that will help keep you safe.

A broad range of assistive technologies and dementia-friendly products exists to improve the safety and wellbeing of people living with dementia, their families and carers by:
• reducing the risk of accidents in and around the home
• supporting independence and choice
• reducing premature entry into residential and hospital care
• reducing carer stress

The term ‘assistive technology’ refers to any device or system that allows an individual to safely perform a task they would otherwise be unable to undertake.

Assistive technology can range from high-tech solutions to simple equipment such as personal alarms and timers that switch off electrical items, calendar clocks, touch lamps and walking sticks.

These types of technologies can be easier to get used to if you adopt them early on, rather than introducing them after an emergency or crisis has already occurred, and in the more advanced stages of dementia.
Alzheimer’s Australia provides advice on a range of assistive technology equipment suitable for dementia care. You can find out more by visiting bit.ly/vicassistivetech or calling the National Dementia Helpline on 1800 100 500.

Here are some other measures you can take to keep yourself safe at home:
- Arrange for somebody to regularly check smoke alarms and carbon monoxide detectors.
- Ask your local fire service about a free home fire safety visit.
- An occupational therapist can give advice on items that could improve safety in the home.
- A physiotherapist can provide guidance on appropriate exercises that will reduce the risk of falls. Speak to your doctor for advice.

The Independent Living Centre in each state and territory provides information about smoke detectors, hot water services, temperature regulators and monitoring services. Advice is also available on home modifications and home design.

Contact numbers for Independent Living Centres can be obtained by calling the National Dementia Helpline on 1800 100 500, or by visiting ilcaustralia.org.au

Living alone with dementia
Many people with dementia continue to live on their own during the early stages of the disease. Making simple adjustments, taking extra safety precautions and calling on others for support can help enable this.

Safety
There are a number of safety issues to consider that, if addressed, will help you maintain your independence and allow you to live at home for longer.

Allied health clinicians can also provide support at home to help you maintain your quality of life, independence, self-care and mobility, while helping to reduce the risk of complications due to other conditions or injuries.

See Allied health clinicians on page 42.

Falls
Some people with dementia experience changes in their balance, which increases the risk of falls. Changes in your sensitivity to light, the contrast between colours, or depth perception might affect your navigation skills. Falls can be particularly dangerous if there is nobody around to assist.
- Help prevent falls by making sure the house is well lit, removing trip hazards such as rugs, and having handrails fitted on the stairs or in the bathroom.
- Keep a personal alarm with you at all times, so you can alert somebody if you fall.
- A physiotherapist can provide guidance on appropriate exercises that will reduce the risk of falls. Speak to your doctor for advice.

Accessing your property
It may be that memory loss causes you to become locked out of your home at some stage. Make sure you leave a set of house keys with a neighbor you trust, and keep their telephone number with you at all times. Alternatively, consider fitting a key-lock safe outside your property, with a spare key.

Looking after yourself
Changes in thinking might result in you paying less attention to your self-care, personal hygiene and household chores. Additionally, your risk of malnutrition or dehydration may increase.

Plan ahead to ensure your basic needs are met.
- Organise to have your groceries delivered, or arrange home delivered meals.
- Consider engaging a cleaning service.
- Arrange for family, friends or a paid worker to help you with housekeeping, meals, transportation and daily chores.
- Make arrangements for help with paying bills. You can give a trusted person the legal authority to handle money matters, or speak with your bank or service provider about automatic payments.
- Establish a system for medication reminders.
Isolation and loneliness

Establish a routine that encourages you to stay connected with family and friends. You can also take advantage of programs and services that involve other people in the early stages of dementia. Support groups and events organised specifically for people living with dementia and their family and friends do exist.

To find out more, call the National Dementia Helpline on 1800 100 500. You can also connect with other Australians in similar circumstances by joining the online forum at helpwithdementia.org.au

Driving

At some point, everyone with a diagnosis of dementia will need to stop driving. This will reduce the risk to themselves and others due to a decline in their cognitive or sensory abilities. Giving up driving can be a big adjustment for anybody to make, but for a person who lives alone, this change can be even more significant.

Make sure you plan how you will get around once driving becomes an issue. Consider taxis, public transport and lifts from family and friends.

For more information, see Driving, page 81.

Health care services

People who live alone rely on their own perceptions of when they need care and support. A diagnosis of dementia means you might be less likely to recognise when you need to use health care services.

There is support available that will help you assess your health and care needs, and programs that can help you meet those needs. For more information, visit myagedcare.gov.au or call the National Dementia Helpline on 1800 100 500.

See Help Sheet, Information for people with dementia 05: Living alone. Available at fightdementia.org.au

Keeping safe when you travel

Just because you have been diagnosed with dementia does not mean that you can’t still experience the joys of travel. You may even have a list of places to visit while you are still able.

When people living with dementia are travelling away from home, some careful planning will ensure the safety, comfort and enjoyment of everyone involved.

• Pick your travel companions wisely. Make sure they are not only good company, but also understand your condition and are able to ease stress by looking after the logistical aspects of your trip.
• Reduce anxiety by selecting travel options based on your needs and abilities, while also considering comfort and safety.
• Allow plenty of time for rest in your schedule. Don’t try and do too much.
• If you are flying, taking a cruise or staying in a hotel, inform staff of any specific needs so they can be prepared to assist if necessary.
• If you have other health issues, plan trips where emergency health services and pharmacies are easily accessible.
• Be aware that changes in environment can trigger moments of confusion. Ensure your travel companions and other significant people (such as hotel staff) are also aware of this.
• Buy travel insurance if you have booked flights or hotels, to ensure you don’t lose out financially if things change. Call the insurance company before taking the policy, to get an understanding of any exclusions relating to a diagnosis of dementia.
• Create an itinerary that includes details of each place you will be staying and the dates you will be there. Give copies to family members, friends or your emergency contacts at home.
• Keep a list of your emergency contacts and telephone numbers with you at all times, in case you get lost.
• If you are travelling overseas, ensure your trip is registered with the Department of Foreign Affairs and Trade. You can do this through the smartraveller.gov.au website.
“As carer for my husband with dementia, I made sure we had time travelling together in our motorhome. By this time he was unable to drive and his mobility had declined, but he was able to enjoy the changing scenery, while being reassured that our living environment remained the same.”

For more information see Help Sheet, Caring for someone with dementia 8: Travelling. Available at fightdementia.org.au

Staying active

Keeping as active as possible – physically, mentally and socially – offers great benefits. It can help you meet new people, retain skills and memory, boost your self-esteem, improve the quality of your sleep and avoid depression.

You might find that activities take you longer than they used to. You may need to make changes to the way you do things, or have some support to do them. For example, if you enjoy cooking but are having trouble preparing a meal, you may still be able to do some elements of it, such as peeling the vegetables, setting the table or serving.

Try to adapt and make these changes, rather than giving up an activity that you enjoy altogether, or not pursuing an activity that could improve your wellbeing.

Keeping your mind active

You can exercise your mind by doing things you find challenging. Keep learning and thinking. Keeping your mind active can help you feel good and think more clearly. Try reading, singing, playing games, talking with others, doing crossword puzzles and learning new skills.
Remaining physically active

Physical activity is essential for keeping fit. It can also improve the way you think and feel.

National Physical Activity Guidelines recommend we do at least 30 minutes of physical activity every day. If this is difficult, start with less activity and increase it over time. People of all ages and abilities should do a few activities every day to improve fitness, strength, flexibility and balance. Examples include walking, dancing, Tai Chi, gardening, lawn bowls and exercise classes, including low intensity and water exercises.

For more information see Help Sheet, Information for people with dementia 7: Keeping involved and active. Available at fightdementia.org.au

Looking after your general health

Ensure you follow up any health concerns you may have with your doctor. Other conditions such as urinary tract or respiratory infections can make the symptoms of dementia more severe.

- Try to eat a balanced diet and drink plenty of fluids.
- Take regular physical exercise.
- If you enjoy having the occasional alcoholic drink, keep doing this (unless your doctor advises you not to).
- If you smoke, consider stopping.
- Get enough sleep.
- If you find yourself regularly feeling low, anxious or irritable, you may be depressed. This can be treated, so talk to somebody close to you and consider discussing it with your doctor.
- Have the flu vaccine each year and ask your doctor about the pneumonia vaccine for over-65s, if this is appropriate.

Maintaining a healthy diet

Eating well and staying hydrated will improve your overall health and energy levels so you can remain active. It can also help you to think better.

You need a variety of nutritious foods to stay healthy including vegetables, fruit, whole grains, lean protein (e.g. fish, beans, chicken) and low fat dairy. You should also limit some foods including sugary foods and drinks, high fat foods, salty foods and alcohol.

For convenience, you can arrange to have healthy meals delivered to your home. For information on how to arrange meal delivery, visit myagedcare.gov.au/help-home/meals

Nutritional supplements, such as Souvenaid, are also available. Speak to your doctor about your options.

Check-ups

Visiting your doctor regularly means any other health problems that could make the symptoms of your dementia more severe should get picked up quickly. This is especially important if you have diabetes, or heart or breathing problems.

In addition, have regular sight and hearing checks, dental check-ups, pay attention to foot care and make sure your shoes fit well.

For more information see Help Sheet, Information for people with dementia 3: Looking after yourself. Available at fightdementia.org.au
Effective communication

“If I occasionally lose track of what we’re talking about, give me the time to remember, and if I can’t, don’t be nervous, impatient or arrogant. Just know in your heart that the most important thing for me is to be with you.” Sergio Cadena

Because dementia affects many parts of your brain, you may need to develop new ways of communicating with people.

Communication is a crucial way of letting people know what you think, feel or need. It also forms an important part of maintaining your relationships with family and friends.

Most people have good days and bad days. On bad days, you may experience some of the following changes:

- struggling to find the right words or losing your train of thought.
- repeating words, stories or questions a number of times.
- getting words confused or saying them in the incorrect order.
- problems with spelling or writing.
- problems with understanding what other people are saying.

Some approaches to consider when modifying how you communicate include:

- slowing down and taking more time to speak
- finding a quiet place to talk where you will not become distracted
- letting people know when you are finding it difficult to speak or understand
- describing the person, place or thing if you cannot recall its name.

Because the disease affects each person differently, try different combinations of these approaches until you find what works best for you.
Have a conversation with family and friends about whether you want to be prompted, reminded or helped if you are struggling to find a word or are repeating yourself. And make sure you provide feedback about how their communication style is working for you.

In cases where English is spoken as a second language, people with dementia may revert to their first language as their illness progresses. This may have an impact on future care, particularly if the person with dementia reverts to a language that is not familiar to the person or people caring for them.

In these instances, caregivers may need to start looking out for more visual cues, or use word/picture cards to aid communication. Non-verbal communication such as body language and use of gestures will become even more important.

It is vital that the person with dementia has a doctor who understands their first language and cultural heritage.

**Changed relationships**

Symptoms of dementia, such as memory loss and changed behaviours, can affect relationships with family and friends.

When you share news of your diagnosis with family and friends, they will probably experience a range of emotions. See Responses to your diagnosis on page 35.

You may feel that you need to rely on family and friends more than you would like to. Unwanted help can feel overbearing or intrusive, leading to feelings of frustration, guilt or resentment.

**Remember – at some point in their lives, everybody will need help from others.**

Talk to your family and friends about what type of support you need and how they may be able to provide it. Accepting help will ensure you can remain independent for as long as possible, and accepting support from people close to you may help them to feel useful.

**Role changes**

Many people with dementia will experience a sense of losing their independence, as their roles or responsibilities are passed on to somebody else.

Others may find family members starting to have conversations as if they are not in the room, or making plans for the future without their presence or input.

Feelings of concern may result from the guilt associated with ‘burdening’ others with caregiving roles or the responsibilities you once managed.

Talking to others and sharing your feelings may help. Doing so will also help make your family and friends aware of how you are feeling and can help them modify their behaviour appropriately.

Alzheimer’s Australia Vic offers counselling for couples, families and groups. This can help during periods of change and adjustment. For more information, call the National Dementia Helpline on 1800 100 500 or visit fightdementia.org.au/vic

**Keeping your relationships positive**

Learning to be completely open with your family and friends about how you are feeling can be difficult, but this is important to ensure you get the support you need.

Share your experiences of living with the disease with family and friends, and encourage them to share how they are feeling, too. Don’t let dementia become a topic that is ignored. Try to understand that your family and friends might sometimes want to talk about their feelings to other people and seek advice from external sources.

Be honest with each person in your life about how you would like your relationships to continue, and how you would like them to treat you. Make sure you focus your energy on your most supportive and comforting relationships, and show your gratitude to the people who are there for you.

If your family and friends sometimes become frustrated, try to remember they are frustrated with the disease and not with you.
Intimacy and sexuality

If you have a sexual partner, openness about sexual changes will help maintain closeness.

Dementia may affect sexual feelings and behaviour over time. Discuss your needs and expectations at each stage of the disease, including what you would like to happen in the future, and allow your partner to do the same. If you can be completely honest with each other, there is likely to be less confusion, blame, resentment, guilt or lowering of self-esteem.

You may experience uncertainty, frustration or reduced confidence because you are unable to do some of the things you were able to manage previously. This may lead to stress and changes in feelings towards your partner.

Remember, your partner may be experiencing some of these feelings as well. They may need to make adjustments if there is uncertainty about your levels of comfort with sexual contact or activities that you no longer enjoy.

Depression can lead to a loss of interest in sex, while some medications may have side effects that alter your sexual desire. As your dementia progresses, you may experience significant increases or decreases in your sexual expression and need for intimacy. Speak to your doctor if any of these changes are causing physical or emotional distress.

You may want to explore new methods of intimacy. This may include non-sexual touching or sharing special memories. Have an open dialogue with your partner and work together to find approaches that you both find satisfying and comfortable.

Things to consider

- What are the important things in your life that you would like to continue doing?
- What would it take for you to continue living a happy, fulfilling life?
- What strategies might you or your family and friends be able to employ to enable this to happen?
- What would you like people to do when you are having problems communicating?
- What changes could you make to your home to create a more dementia-friendly environment?
- Have you booked regular check-ups with your doctor and dentist?
- Do you have a partner? If so, have you discussed the potential changes in your relationship with them? Would you consider counselling as a couple?
- How would you like to be supported by friends and family?
Planning for the future

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"Planning is bringing the future into the present so that you can do something about it now."
Alan Lakein
Key points: Planning for the future

Following diagnosis, dedicate some time to making sure your financial and other affairs are in order.

There are things you can do to make managing your money easier. Organising an enduring power of attorney will allow someone else, nominated by you, to make decisions about matters relating to your finances. An enduring power of attorney can also be appointed for other matters, including making medical decisions on your behalf, once you no longer have the capacity to do so.

You and your carer may be entitled to a range of benefits. If you have dementia you may be eligible for an aged or disability payment, dependent on your situation. Your carer may also be eligible for carer allowance and/or carer payment. You can contact Centrelink for advice on eligibility.

Now is the time to plan ahead and talk to others about your future. If you are able, try to do this as soon as you can. Make sure you have an up-to-date Will, so you can choose who inherits your money and possessions after you die.

To have a say in your future medical care, you can set up an advance care plan. Talk to your doctor or solicitor about this, or for more information visit advancecareplanning.org.au

If you drive, you must legally tell your local road and traffic authority about your diagnosis. You will find their contact details on page 81. You must also tell your vehicle insurance company. If you wish to continue driving, you can organise to sit a test that will determine your ability to do so safely.

If you are still working when you are diagnosed with dementia, you may choose to carry on doing so. Talk to your employer after taking advice on your rights, entitlements, working conditions and health issues. Advice is available from a range of places, including your doctor, the human resources department at your place of work, your trade union if you have one, a lawyer or anti-discrimination advocate.

If you stop working or reduce your hours, you may be eligible for some further benefits.
Financial matters

Once you have had a chance to adjust to your diagnosis, take some time to ensure your financial and legal affairs are in order, making sure all your essential documents can be found easily.

Things to think about include: details of your bank accounts, tax, benefits, pensions and superannuation, shares, trusts, mortgage or rent documents, insurance policies, powers of attorney and your Will.

It may become more difficult for you to make decisions or choices about financial or legal matters as time goes on, but there are lots of things you can do now to make sure you get to choose how you live now and in the future. Make these plans as early as you can with a trusted friend, family member or professional.

You may wish to elect different people to help you with different elements of this planning. Choose those who are likely to be able to offer you continued support as time goes on.

Direct debits

If they aren’t already in place, consider setting up direct debits for regular payments such as phone or power bills. That way they will get paid automatically.

Bank accounts

Think about your banking needs and how they might be impacted following your diagnosis. If you need or want somebody else to be able to manage your account, you can arrange an enduring power of attorney. Banks will require original copies of the enduring power of attorney, so it is helpful to talk to your branch manager and keep them informed about your decisions.

Talk to a financial advisor or solicitor about the best options for your circumstances. For some couples with joint accounts, setting up separate accounts during the later stages of dementia can make things simpler. Benefits and pensions, for example, can be paid directly into the account of the person living with dementia. In addition, any means-testing for benefits or aged care costs will be more straightforward, if the accounts are separate.

If you need or want somebody else to deal with your account, see Enduring power of attorney on page 87 for more information.

Debit and credit cards

If you have memory problems, you may find it difficult to remember PIN numbers for debit or credit cards. Talk to your bank about alternatives, such as a ‘chip and signature’ card.

Trusts

If you have property or savings, you might want to consider setting up a trust. This will ensure things are managed the way you have chosen, now and in the future. Seek advice from your solicitor, financial adviser and accountant.

For more information see Help Sheet, About dementia 7: Early planning. Available at fightdementia.org.au

Driving

People living with dementia can remain safe and competent drivers, particularly in the early stages of the condition. However, as dementia progresses it can have serious effects on memory, reactions, perception and the ability to perform tasks. At some point, all people with dementia will need to stop driving in order to reduce risk to themselves and others.

If you have a driving licence, the law says you must inform VicRoads promptly after being diagnosed with dementia. They can be contacted on 131 171.

Often, the doctor who gives a diagnosis of dementia will use their professional discretion to determine whether they need to notify VicRoads themselves from a duty of care perspective.

If you are interested in continuing to drive, you can undergo a medical review. This is likely to involve a driving test conducted by an occupational therapist. You must also tell your vehicle insurance company about your diagnosis.
For more information see Help Sheet, Information for people with dementia 04: Driving and dementia. Available at fightdementia.org.au

**Changed Conditions Ahead** is a guide by Alzheimer’s Australia Vic and RACV for the carers, family members and friends of a person living with dementia who is driving. The kit can be downloaded at bit.ly/vicdrivinganddementia

Many people with dementia choose to stop driving voluntarily, because they begin to feel less confident or find themselves becoming confused, even on familiar routes.

Stopping driving can be a difficult adjustment, but there can be some benefits. These include reduced stress and saving money on insurance, fuel, registration and maintenance. These savings may be used to fund alternate transport (e.g. public transport and taxis, for which half price concession may be available. Ask your GP for more information).

**Working**

Some older adults and people diagnosed with younger onset dementia are often still employed at the time of their diagnosis. In many cases it is possible to continue working after a diagnosis of dementia. Some people find working helps them feel better physically and emotionally. Others might feel that stopping is for the best.

Likewise, many carers are still working and may require access to support and advice when it comes to balancing work and care. For more information see Support for carers on page 101.

**Getting help**

Consider taking advice on your rights, entitlements, working conditions and health issues before talking to your employer. Advice is available from a range of places, including your doctor, the Human Resources department at your place of work, your trade union if you have one, a lawyer or anti-discrimination advocate.

**Assessing the work situation**

Allow yourself time to absorb your diagnosis and don’t rush into making any decisions. Take time to thoroughly consider any possible implications of work-related decisions.

Things to consider include:
- the possible safety risks associated with dementia symptoms
- access to staff counselling
- the size of the company you work for and its ability to provide support
- your relationships with peers and management
- whether it may be possible to change or reduce duties, or put in place supports that may assist you in carrying out your role
Talking to your employer

Deciding whether or not you tell your employer about your diagnosis of younger onset dementia can be complex. For many people it will depend on the extent to which symptoms affect their ability to do their job, as well as the support that may be required from the employer.

You might feel anxious about telling your employer about your diagnosis, but doing so will help give you protection under the law. Once your employer knows, they are required to make ‘reasonable adjustments’ so that you can keep working, if you are able to do so safely.

In some occupations you are legally obliged to tell your employer about your diagnosis, so you will need to check your contract. If you drive or operate machinery as part of your job, you should let your employer know straight away.

It may be helpful to speak to the Human Resources advisor at your workplace, and have a support person including a family member, friend, colleague or advocate involved in any discussions.

Once your employer has been informed, regularly monitor the employment situation and the effect dementia symptoms are having on your work duties, particularly if your symptoms are progressing.

Leaving work

At some stage, you might decide to leave work or retire early. This decision should only be made after appropriate consultation has taken place with immediate family, advocates and your employer.

Use your current sick leave entitlements before leaving the workforce due to health reasons. An employee is entitled, on the production of a medical certificate, to utilise unused sick leave before resigning.

Before you leave the workforce, seek advice from your insurance company, superannuation fund or financial planner on entitlements such as Total and Permanent Disability (TPD) and income protection.

After leaving the workforce, check that any annual leave and long service leave has been paid out at the correct amount.

A lawyer, your superannuation advisor or Centrelink representative can offer advice about your superannuation and pension options. Contact details for Centrelink can be found at humanservices.gov.au/customer/dhs/centrelink

If conflict arises during the termination process, use support networks such as family, unions, work place advocates, or other sources of legal support.

Medical testing

Depending on the nature of your work, some employers might require you to undergo a medical test. If you are found to be unable to perform the duties required in your existing role, you may be asked to consider changing to a different, more suitable role within the organisation. Alternatively, you might be asked to consider retirement, or working reduced hours.

For more information see Help Sheet, Information for people with dementia 10: Making employment decisions or Younger onset dementia 6: Employment. Available at fightdementia.org.au

Benefits

People with dementia and their carers may be entitled to a range of benefits. Some are means-tested, so they depend on income or assets, including savings. Accessing them can seem complicated, but there is support available through Centrelink who can advise on what to claim for and how to complete the forms.

Visit the Centrelink Payment Finder online at bit.ly/CentrelinkPaymentFinder to discover what benefits might be available to you. If you would prefer to speak to somebody over the phone, call 132 300 to discuss benefits for the person living with dementia or 132 717 to discuss carer benefits.
Carer payment and carer allowance

Carer payment is an income support payment for people who provide constant care at home to somebody with a severe disability, medical condition, or who is aged. To receive this, the carer must meet the Centrelink income and assets test.

Carer allowance is an income supplement for carers who provide additional daily care and attention. This allowance is not currently means-tested.

It is possible to receive one or both of these benefits. Speak to Centrelink for more information. Contact details can be found at humanservices.gov.au/customer/dhs/centrelink

Companion Card

The Companion Card is issued to people with a significant, permanent disability, who can demonstrate they are unable to access most community activities and venues without attendant care support.

The card can be presented when booking or purchasing tickets, provided the cardholder requires attendant care support to participate in that particular activity. Participating organisations will then issue the cardholder with a second ticket for their companion at no charge.

This is a great way to encourage friends and family to accompany a person with dementia during leisure activities. It can also be used when paying for public transport.

For more information, visit companioncard.gov.au

Making decisions for the future

Everyone needs to make decisions from time to time about their health, care and finances. As dementia progresses, it will become harder for you to do this. If you are able to, think about your future, talk to others and plan ahead as soon as possible. You can make decisions and plans to ensure your future care and finances are handled in a way that reflects your wishes. These choices could range from how your money is managed to how you want to be cared for at the end of your life.

If you have dementia, the law protects your right to do the following:

• Make your own decisions and be involved in any decision making that affects you.
• Get support with making decisions about the future.
• Put plans in place in case you are unable to make decisions in the future.
• Appoint a person or people to make decisions in your best interests, if you are unable to.

Wills

Everyone should make a Will. It allows you to choose who inherits your money and your possessions after you die. Talk to a solicitor about making or updating your Will. If you are living with dementia, you can still make or change your Will, as long as you understand the decisions you are making and the implications of any changes. A solicitor can offer advice.

Enduring power of attorney

An enduring power of attorney is a legal document that allows an individual to appoint another person or people to make decisions for them regarding financial and personal matters.

There are various types of powers of attorney, including supported, financial and medical.

It is important to note that the person who makes the appointment must have the decision making capacity to do so, and trust the person or people they appoint to manage their affairs. The power then ‘endures’, meaning it continues once the person loses capacity to make decisions for themselves.

Visit the Office of the Public Advocate website at bit.ly/PublicAdvocateEnduringPowerOfAttorney or speak to your lawyer, accountant and/or financial advisor for more information on powers of attorney.

The book ‘Take Control’ includes information on how to appoint powers of attorney, and is available in hard copy from Alzheimer’s Australia Vic, the Office of the Public Advocate or online at bit.ly/PublicAdvocateTakeControl
Make sure you lodge financial or medical powers of attorney with all relevant bodies, including Medicare, your banks, Centrelink and the Department of Veterans’ Affairs.

**Advocacy**

Sometimes, an individual with dementia might need a professional to advocate on their behalf, particularly when it comes to planning for the future and liaising with health care, housing, welfare and financial service providers. In these instances, the following agencies may be able to assist.

- **The Office of the Public Advocate** 1300 309 33
- **Seniors Rights Victoria** 1300 368 821
- **The National Aged Care Advocacy Line** 1800 700 600
- **Elder Rights Advocacy** 03 9602 3066 or 1800 700 600

**Advance care planning**

Advance care planning is when a person discusses their preferences for future medical treatment and personal care with family, friends and medical professionals. Preferences might include the treatment and type of care they want.

These discussions should happen while the person still has capacity to make these kinds of decisions. Ideally, everybody should have a discussion about their future medical treatment, whether they have a diagnosis of dementia or not.

A written advance care plan helps people to accurately remember what you want and makes it easier to communicate these wishes to doctors and nurses who do not know you.

To make a written advance care plan, the person with dementia discusses and documents their wishes. These are known as advance care directives. They then appoint somebody to be their substitute decision maker by making an enduring power of attorney. The instructions (or advance care directives) within the plan can then be used by the appointed attorney to inform their decision-making.

Advance care planning usually involves ongoing discussions, as the wishes of a person might change as their circumstances change.

While the law does not require a lawyer to be involved with advance care planning, you should discuss it with your doctor to ensure your decisions are made based on good information. Your doctor can also help you complete the necessary document. Take a copy of your advance care plan with you every time you go to the doctor or to hospital.

**Start2Talk**

The Start2Talk website contains information and practical advance care planning worksheets that you can fill out.

For more information, visit [start2talk.org.au](http://start2talk.org.au)

**Advance Care Planning Australia**

The Advance Care Planning Australia website contains information about how to make an advance care plan, relevant to each state and territory.

For more information, visit [advancecareplanning.org.au](http://advancecareplanning.org.au)

**Things to consider**

- What are some of the things you would like help making decisions about?
- Who do you trust to make decisions on your behalf?
- What do you need to take care of now to ensure your wishes for the future are recognised?
- Have you taken care of powers of attorney, and made your advance care plan and will?
- What things are important to you about your future care?
- Do you know what financial assistance you are eligible for?
- If you drive, have you notified your local driving authority about your diagnosis?
- How will you know when it’s time to stop driving?
Support and services for people with dementia

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Key points: Support and services

There is a wide range of social care and support services that exist to help people with dementia live as well as possible, throughout the various stages of the illness. While some services are free, you may have to contribute to the costs of others, depending on your income and savings.

The key point of contact for people aged over 65 to access dementia services is My Aged Care. Alzheimer’s Australia Vic, the Dementia Behaviour Management Advisory Service (DBMAS), local councils, GPs and private care agencies can also offer valuable support.

Services for people with dementia have often been developed around the needs of older people, and in some cases are unavailable to people diagnosed with dementia when they are below the age of 65. Even where services are available to people with younger onset dementia, they may not necessarily be appropriate. For that reason, Alzheimer’s Australia Vic provides tailored advice and information through its Younger Onset Dementia Key Worker Program. You may also be eligible for the National Disability Insurance Scheme (NDIS).

Full, up-to-date details of the services available for people living with dementia, their families and carers can be found by contacting the National Dementia Helpline on 1800 100 500.
Where to go for support

A diagnosis of dementia can be daunting and raises many questions about the future. Asking for help can feel difficult, particularly if you have always been independent. You might not feel like you need it straightaway, but it can be useful and comforting to know about the wide range of information and support available.

Most people will know how to contact their doctor for healthcare. But you might not know as much about the social care and support services offered in your local area. Some services are free, but you may have to contribute to the costs of others, depending on your income and savings.

Services for people with dementia over 65 years of age

The main sources of information and support for people living with dementia who are aged over 65 are My Aged Care, Alzheimer’s Australia Vic, local Councils, the Dementia Behaviour Management Advisory Service, your GP and some private agencies.

My Aged Care

My Aged Care is the main entry point to the aged care system in Australia. It was established by the Australian government to help people navigate the aged care system and is designed to give people more choice, control and easier access to a full range of aged care services.

Through its website and contact centre, My Aged Care can provide information on aged care for yourself, a family member, friend or someone you are caring for.

The service provides information and advice on the different types of aged care services available, your eligibility and the associated costs. It helps you understand your aged care needs, provides information on the local services available that will meet those needs, and allows you to select your own service provider.

Determining the appropriate next steps might involve referring you for a home support assessment with the Regional Assessment Service, or a comprehensive assessment with an Aged Care Assessment Service.

To find out more about My Aged Care, visit myagedcare.gov.au or call 1800 200 422.

Alzheimer’s Australia Vic

Alzheimer’s Australia Vic is the state’s peak body and charity representing people with all forms of dementia in Victoria. The organisation supports people with dementia, their families and carers in a range of ways, including information resources, counselling, support, education sessions and social support programs.

To contact Alzheimer’s Australia Vic, call the National Dementia Helpline on 1800 100 500 or visit fightdementia.org.au/vic

Local councils

Your local council will offer a variety of programs and support services, including:
- senior citizen groups and centres
- Planned Activity Group (PAG) programs – exercise, gardening, crafts, games
- shopping assistance
- meal delivery
- home and garden maintenance
- home and personal care services
- respite care
- community transport
- accessible arts and recreational programs

To find out more about services provided by your local council, visit myagedcare.gov.au

Call the National Dementia Helpline on 1800 100 500

For more information visit fightdementia.org.au
Home Care Packages
A Home Care Package provides a package of services tailored to meet your specific care needs. It can help you stay in your own home as you get older and give you choice and flexibility in the way your care and services are provided to you at home.

The types of services you receive under a Home Care Package will depend on your needs. Your service provider will work with you to identify these needs and your personal goals. They will also work with you to co-design the best ways to deliver those services so you can live a more active and independent life.

The services that can be provided in a Home Care Package include, but are not limited to:

- support services, such as help with washing and ironing, house cleaning, gardening, basic home maintenance, home modifications related to your care needs, and transport to help you with shopping, visiting your doctor or attending social activities
- personal care, such as help with showering or bathing, dressing and mobility
- nursing, allied health and other clinical services, such as hearing and vision services

For more information on eligibility and how to apply for a Home Care Package, visit myagedcare.gov.au/aged-care-services/home-care-packages

Dementia Behaviour Management Advisory Service
Dementia Behaviour Management Advisory Service is a nationwide service funded by the Australian government. The program provides clinical support to the carers of people living with dementia, where behavioural and psychological symptoms are impacting on the care provided, at home or in an aged care facility.

The organisation works to improve the dementia care capacity of professional and family carers, and service providers. Clinicians conduct individual assessments and care planning to assist carers in their roles and establish links to appropriate support networks.

For more information, visit dbmas.org.au or call 1800 699 799.

General practitioner
Your doctor is a good resource for the ongoing monitoring of your health and treatment of your dementia. They can provide referrals to private and public specialists such as geriatricians, neurologists and psychiatrists.

Private care agencies
A wide range of private companies offer care and support services at home for people with dementia. Somebody with dementia might pay for a care assistant using their own money, or engage these services using government funding, if they are eligible for a Home Care Package. For more information, see the details on Home Care Packages on page 96.

Services for people with younger onset dementia
If you have been diagnosed with dementia and are under the age of 65, you may have very different interests, and care and support needs from someone diagnosed in their 70s, 80s or 90s.

For example, people with younger onset dementia are more likely to be working (or have a partner who is), have dependent children and possibly dependent parents. They are also likely to have multiple financial commitments, such as a mortgage.

In some cases, services for people with dementia have often been developed around the needs of older people, and sometimes access is restricted to those aged over 65. Even when a service is open to people with younger onset dementia, the type of care and support provided may not always be appropriate or flexible enough to meet individual needs.
However, the number of services suitable for people with younger onset dementia is growing. Your Cognitive Dementia and Memory Service, consultants, doctor, or Alzheimer’s Australia Vic can provide information on the support available.

Depending on your geographical location, you may be eligible to receive services through the National Disability Insurance Scheme (NDIS).

If you have been diagnosed with dementia below the age of 65, you will be eligible for support from the National Younger Onset Dementia Key Worker Program through Alzheimer’s Australia Vic. The program provides individualised information and support to improve quality of life for people with younger onset dementia.

The best way to access the Younger Onset Dementia Key Worker Program is to call the National Dementia Helpline on 1800 100 500.

In addition, Alzheimer’s Australia Vic has a Younger Onset Dementia Online Forum. It provides a place where people with younger onset dementia, their families, carers and friends can share information. This access to peer-to-peer support is available twenty-four hours a day, seven days a week. The forum can be accessed at talkdementia.org.au

For more information see our series of Help Sheets on Younger onset dementia. Available at fightdementia.org.au

**Things to consider**

- Are there any particular services you think might be able to offer you support?
- Have you considered meeting with other people living with dementia to share and learn from each of your personal experiences?
- Have you contacted Alzheimer’s Australia Vic for advice on accessing support services (including peer support programs)?
Support for carers

In this part

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Key points: Support for carers

Caring for someone with dementia can be stressful and at times upsetting, but can also be very rewarding.

Carers often go through a wide range of emotions, including loss, guilt and anger. They may also experience grief for the loss of the person their family member or friend previously was, their hopes and dreams for the future, and their prior relationship.

They may also have positive feelings, such as a sense of fulfilment from being able to support the person with dementia.

A lot of information and advice is available to support you in your caring role. Sources of support for carers include family and friends, health professionals, carer support groups, Alzheimer’s Australia Vic and organisations such as Carers Victoria.

As a carer, it is important to make sure you look after your own health and wellbeing. Try to eat a balanced diet, and to get enough sleep and exercise. Make sure you have some time to yourself.

There are practical tips that can make caring for someone with dementia a little easier. For example, encourage the person to keep doing what they can to retain their independence.

When communicating, make eye contact, listen carefully, be aware of your body language and tone of voice, and make sure you speak clearly.

As a carer, you may find changes in the person’s behaviour difficult to cope with. This might include aggression, repetitive behaviour or agitation. Keep in mind that they aren’t doing these things deliberately, and try not to take it personally. They may be confused, in pain or trying to tell you something, for example that they are bored or frustrated.

Talk to a professional about challenging behaviour, or behaviour that is causing either of you distress or worry. These behavioural changes are very common and there are many things that can be done to help.

A range of respite options is available, to give carers some valuable time to themselves and help them continue to provide care at home for as long as they are able to do so.
Looking after yourself

"My dementia hasn’t just affected me – it’s affected my friends and family, too."  
Gerry Anderson

If someone close to you has been diagnosed with dementia, do not underestimate the impact this may have on you. Whether you’re the husband, wife, partner, daughter, son, brother, sister or friend of the person, your relationship will change.

Many people find themselves gradually taking on the role of ‘carer’ without making any conscious decision to do so.

As a family member or friend of someone living with dementia, you may provide a wide range of care, including:

- supporting the person to continue their involvement with hobbies, activities and interests they enjoyed before their diagnosis, for as long as possible
- working with a range of health care professionals and support agencies to ensure the person’s physical, psychological and social needs are met
- helping the person with daily activities, such as household chores, shopping, preparing meals, managing finances, appointments and taking medications
- providing personal care, such as bathing, dressing and going to the toilet
- supporting the person when they experience changes to their behaviour or psychological symptoms associated with dementia such as withdrawal, agitation, anxiety and/or night-time disturbances
- helping the person with physical tasks, such as getting in and out of bed, or walking

Caring for and supporting someone with dementia can be stressful and at times upsetting. It can also be very rewarding. It is important that you look after your own health and wellbeing, and turn to others for support when you need it. That way, you will be able to continue to provide the best care for the person with dementia, for as long as you feel able to do so.

There is advice available to help you understand dementia and offer practical assistance to support the person you care for. To access this advice, contact the National Dementia Helpline on 1800 100 500.

Emotional support

When you’re caring for someone with dementia, you are likely to experience a wide range of emotions. These may range from positive feelings – a sense of fulfilment from supporting the person – to more negative feelings of loss, grief, guilt, embarrassment, frustration, anger and feeling overwhelmed. You may also feel sad or challenged by the changes in the roles within your relationship. Experiencing this range of feelings is normal when caring for someone living with dementia.

Talk about how you are feeling, either to a professional, a friend or family member, or someone at a carer support group.

The Alzheimer’s Australia Vic team is specifically trained to provide emotional support and counselling for carers. For more information call the National Dementia Helpline on 1800 100 500.

Carers Victoria is another valuable source of information, advice, education and counselling for carers across Victoria. For more information, call 1800 242 636.

For more information see Alzheimer’s Australia Vic services and support on page 141 and other useful organisations listed at various points throughout this guide.

Practical support

Caring for a person with dementia can gradually become more demanding, physically and emotionally. Getting support yourself can make it easier for you to provide support for the person you care for.

There are many sources of support, including:

Friends and family

While it can be difficult to accept help, try to involve family members and share responsibilities, as it will take some of the pressure off you.

Benefits and your employer

If you work, explore carer leave and other flexible working options with your employer. If you decide to stop working, find out about any government benefits you might be entitled to. See Benefits on page 85.
Alzheimer’s Australia Vic
The organisation has trained staff who specialise in dementia care and support services. Call 1800 100 500 or visit fightdementia.org.au/vic

Carers Victoria and regional carer respite centres
Qualified staff at these organisations can provide information, support and access to respite services. Call 1800 242 636 or visit carersvictoria.org.au

Online discussion forums
You can talk online with other people who are going through similar experiences, seek their advice and share practical suggestions. Examples include helpwithdementia.org.au and, for people with younger onset dementia, talkdementia.org.au

Support groups
Local carer support groups give you the chance to talk to others going through similar experiences. You can share practical tips and get emotional support. Ask Alzheimer’s Australia Vic about groups in your area.

National Dementia Helpline 1800 100 500
Trained advisers can support you, provide information and refer you to other sources of support.

Carer Gateway
This national online and phone service provides practical information and resources to support carers and connects you to local support services. Visit carergateway.gov.au or call 1800 422 737.

Victorian Support for Carers Program

Your health and wellbeing
As a carer, it can be easy to put the other person’s needs first and ignore your own. Looking after yourself is vital for your health and wellbeing. It will also help make sure you can do your best to care for the person with dementia.

Make sure that you eat a balanced diet and make time for regular exercise and physical activity.

See your doctor about your own health on a regular basis. If you have to help move or lift the person you are caring for, ask your doctor to refer you to an allied health clinician for advice so that you don’t risk injuring yourself. If you regularly feel sad or anxious, talk to your doctor or an Alzheimer’s Australia Vic counsellor as early as possible, as these could be signs of depression.

Make sure you have some regular time to relax or do something just for yourself. Try to get out regularly to meet friends, or if possible, consider an outing or short break.

Find out about planned activity groups or respite support for the person you care for so that you can take time out, comfortable in the knowledge that they are being well looked after.

Call the National Dementia Helpline on 1800 100 500 or Carer Gateway on 1800 422 737 for more information, or see our series of Help Sheets, Looking after families and carers available at fightdementia.org.au

Tips for supporting a person with dementia
"Caring often calls us to lean into love we didn’t know possible." Tia Walker, Author

Much of how you care for a person living with dementia will come naturally and will be based on instinct and your relationship with them.

Because dementia affects everybody differently, every carer will have a different experience. The care provided will be as unique as the individual you are caring for. Learn to be creative and flexible with your caring strategies. Identifying your strengths and the strengths of the person you care for will make it easier to identify the areas where you need extra support.

Always see the person and not just their dementia.
Everyday care
With time, dementia will affect the person’s ability to carry out the tasks in everyday life they would previously have found straightforward. Try to support and encourage them to do as much as they can for themselves. When you help out, try to do things with them, not for them. This can help the person retain their independence as well as improve their wellbeing, confidence and self-esteem.

- Focus on what they can do rather than on what they can’t. This will help to promote their independence and self-esteem.
- They may find it hard to remember or concentrate on things, so try to be flexible and patient.
- Put yourself in their shoes. Try to understand how they might be feeling and how they may want to be cared for.
- Be sensitive and offer encouragement.
- Make sure they have meaningful things to do, from everyday chores to leisure activities.
- Include the person in conversations and activities as much as possible.

For more information, see our series of Help Sheets, Caring for someone with dementia available at fightdementia.org.au and livingwellwithdementia.org.au.

Nutrition
For families and carers, maintaining good nutrition can present challenges. The person with dementia may experience a loss of appetite, forget how to chew or swallow, or fail to recognise the food or drink they are given. Some people may develop an insatiable appetite, a craving for sweets or suffer from dry mouth or mouth discomfort.

A few tips to aid good nutrition are as follows:
- Meals should be social occasions whenever possible.
- Stock up on healthy snacks that do not need preparation or cooking.
- Don’t use complicated table settings.
- Allow time for the memory to respond to food.
- Serve only one plate of food at a time.
- If there are swallowing issues an assessment by a speech therapist may provide appropriate strategies.

A dietician or doctor can provide extra advice about maintaining good nutrition in a person with dementia.

Communicating
“They may forget what you said – but they will never forget how you made them feel.” Carl W. Buehner

How dementia affects the way someone communicates will vary. In most types of dementia, people will sometimes struggle to find the right words or follow a conversation. This can be upsetting and frustrating for you and the person with dementia. However, there are lots of ways that can help you understand each other.

- Make eye contact. Try to listen as carefully as you can, even when you are busy.
- Make sure you have the full attention of the person and consider the impact of any distractions, such as noise.
- Notice your body language. Think about how you use gestures, facial expressions and touch. You can provide a lot of reassurance through physical contact, if it feels right.
- Speak clearly and think about the words you use. If you are not being understood, use simpler words or explain things differently.
- Stick to one topic and make sure questions are simple and easy to understand – having too many choices can make decisions difficult.
- Keep in mind that other things, not just the dementia, can affect communication e.g. hearing or eyesight problems, pain or side effects of medication.
- It can sometimes help to deal with misunderstandings and mistakes by using humour. Laughing together can ease tension, but you will need to judge how the person responds to this.
- Ensure you involve the person in group conversations and avoid talking across them.
In cases where English is a second language, some people living with dementia may revert to their first language. This can pose challenges, if the person with dementia reverts to a language unfamiliar to the carer. Looking out for visual cues, communication aids such as word and picture cards, and non-verbal communication such as body language and gestures will all become increasingly important.

For more information see Help Sheet, Caring for someone with dementia 1: Communication. Available at fightdementia.org.au

**Interests**

Help the person with dementia maintain their interests by getting involved with activities you both enjoy. You can do this by:

- tapping into past interests and hobbies
- building on the person’s strengths, and focusing on what they can still do
- listening to music, dancing, playing with animals and looking at old photos
- considering some gentle exercise or outdoor activities
- trying different things until you find what works for you

**Changes in behaviour**

At times, people with dementia behave differently from how they used to. While it can be difficult, it is best to deal with any potentially tense situations as calmly as you can. Take some deep breaths or leave the room for a while if you need to. And remember, even where the behaviour appears to be targeted at you personally, it may simply be because you are the one that happens to be there.

Some examples of potential changed behaviours are:

- aggression
- overreaction
- hoarding
- repetition e.g. asking the same question, or repeating an action
- restlessness e.g. pacing or fidgeting
- lack of inhibition, such as socially inappropriate behaviour in public
- night-time waking, sleeplessness and ‘sundowning’ (increased agitation or confusion in the late afternoon and early evening)
- following you around or calling out to check where you are
- putting things in unusual places, and then forgetting where they are
- suspicion e.g. the person thinking someone has taken something belonging to them when they cannot actually recall where they put it.

Try to think from the perspective of the person with dementia and offer reassurance. Working out what the problem is, if there is one, will be the first step to resolving it. Avoid correcting or directly contradicting the person with dementia. At times it might be appropriate to try distracting the person, for example by changing the conversation, having something to eat or going for a walk together.

Over time, as the dementia progresses, these behaviours may change even more and other unusual behaviours might emerge. Family members can often find this distressing, as can the person with dementia.

Try to understand why the person’s behaviour has changed. A sudden change is unlikely to be due to the progression of dementia, which is typically slow. A curable physical or medical issue is more likely to be the cause. For that reason, seeing your doctor for a medical assessment is important when behaviours change.

If there are no physical causes, it might be an indication that the person has a need that isn’t being met. For example, there may be aspects of the person’s care or home environment that they are finding frustrating, upsetting or confusing. It can help to keep a record of when the behaviours are happening to help you understand them or spot any triggers.

See if activities, particularly social ones, help. What are the activities that the person with dementia enjoyed prior to diagnosis? Continuing with these activities will help them remain engaged and feel valued.
You could also try aromatherapy, massage, or music or dance therapy. Contact with animals can also help some people. Other useful activities include talking therapies, reminiscing with the person or life story work. See Non-drug treatments on page 48 for more information.

If these issues persist or cause distress, seek advice and support from Alzheimer’s Australia Vic on 1800 100 500 or the Dementia Behaviour Management Advisory Service on 1800 699 799.

For more information about unusual changes in behaviour see our series of Help Sheets, Changed behaviours and dementia. Available at fightdementia.org.au

Person-centred care
You may have come across the term ‘person-centred care’. In the context of dementia, person-centred care means offering care that reflects the following principles:

• valuing the person with dementia – treating them with dignity and respect, and promoting their rights
• treating them as an individual – understanding their history, lifestyle, culture, likes and dislikes
• seeing things from their perspective
• providing a positive social environment in which they can live well, with opportunities for nurturing relationships in the wider community

When caring for a person living with dementia, these principles should always be followed. You and the person with dementia, where possible, should be involved in the development of care plans. As a partner, family member or friend, your knowledge and understanding of the person is invaluable.

Respite care
A range of different respite options is available to people in care relationships. Access to respite can help you continue to provide care at home for as long as you are able to do so.

These include flexible respite, in-home respite, day centres, overnight cottage respite and residential respite.

Contact Alzheimer’s Australia Vic or alternatively visit myagedcare.gov.au, carersvictoria.org.au or carergateway.gov.au to find out more about the services available.

"Never believe that a few caring people can’t change the world. For, indeed, that’s all who ever have." Margaret Mead, Anthropologist

Things to consider

• What do you do to take care of yourself?
• Have you booked regular check ups with your doctor to monitor your own health?
• Are there services available that you think may be able to assist you, on either a practical or emotional level?
• Have you contacted Alzheimer’s Australia Vic to discuss accessing these services?
• Do you know the ways to bring out the best in the person you are caring for?

Call the National Dementia Helpline on 1800 100 500

For more information visit fightdementia.org.au
Residential care
When living at home is no longer possible

In this part

Key points: Residential care
Identifying the right time
Where to begin
Assessment
Residential respite care
Choosing the right facility
Visiting somebody with dementia
Fees and costs
The process
Support
Key contacts
Things to consider
Key points: Residential care

Making the decision to explore residential care options for a person living with dementia can be difficult for the person with the condition and their family and friends. In this part, you will learn more about the process of finding and placing a loved one into suitable residential care, including services, government policies and costs. These considerations are equally important for younger people diagnosed with dementia.

Many decisions go into identifying when a person living with dementia should enter a residential care facility and finding the right place. The person living with dementia should be involved in the decision making process as much as possible.

Family carers should ask themselves whether the care needed by their family member or friend is beyond their ability to provide, whether the residential care facility provides everything the person might need and whether they will be able to remain in contact easily.

The Aged Care Assessment Service (ACAS) must assess a person before they can enter a government funded residential care facility. Privately owned and funded Supported Residential Services also exist, and do not require an assessment.

It is important to choose the right facility for the individual. Many considerations must be taken into account, including location and accessibility, the friendliness and competence of staff, access to medical care, cleanliness, space, ambiance, a dementia-friendly environment, good quality meals, and social and recreational activities.

When you are visiting prospective facilities, take a check list of what is important to the person with dementia and their family and friends.

While the Australian government funds care in residential facilities, most residents will be expected to make a contribution towards the costs. The amount of this contribution depends on the facility and the person’s individual financial circumstances. These fees and charges range according to the person’s income and assets.

Call the National Dementia Helpline on 1800 100 500
Identifying the right time

Making the decision to explore residential care options for a person living with dementia can be difficult for everybody involved. Include the person with dementia early in conversations about alternative living arrangements. If it is agreed that a residential care facility is the best option, it can be a challenge to identify the right time. On one hand, the person may be continuing to live independently in many ways. On the other hand, there may be instances where their dementia seriously jeopardises their wellbeing.

Every situation is unique. Safety situations need to be considered in each case. Memory loss, confusion and disorientation can cause problems, as well as limited mobility and coordination.

Has it become apparent that the person with dementia requires ongoing supervision? Do the personal needs of the individual outweigh the capabilities of the carer, family or support services to provide them? If so, it may be time to consider residential care options.

For more information see Help Sheet, Residential care and dementia 1: Deciding on residential care. Available at fightdementia.org.au

Where to begin

You can discuss the changing needs of the person with dementia, as well as the health and wellbeing of family members and carers with your doctor. You can also visit myagedcare.gov.au for additional information.

The process of considering residential care can bring up many conflicting feelings including stress, sadness, relief, loneliness and guilt. There may be some disagreement within the family and there may be concerns about the quality of care available.

Alzheimer’s Australia Vic offers advisory and counselling services that can help during this time. For more information, call the National Dementia Helpline on 1800 100 500.

Assessment

The Aged Care Assessment Service (ACAS) must assess a person before they can enter a government funded Home Care Package or residential care facility. The assessment is free of charge and is normally conducted in your home (or hospital) with family members, carers or close friends.

The assessment:
- determines the level of care required by the person with dementia
- recommends appropriate types of residential care
- provides details of suitable facilities
- provides a written statement of eligibility to show residential care facilities.

A doctor can refer the person with dementia for assessment, or you can request an assessment directly by calling My Aged Care on 1800 200 422 or visiting myagedcare.gov.au.

Privately owned and funded residential care services also exist, and do not require an assessment.

Residential respite care

Before deciding on full time residential care, a short stay or multiple short stays in a residential respite care facility could have numerous benefits. The carer is given a break, which may result in them being able to maintain care at home for longer, and it can also provide a stepping stone to longer term care.

Regular respite stays in the same facility can have the added benefit of familiarising the person living with dementia with that facility, which could make an eventual transition into full time care easier.

Choosing the right facility

Visit at least three facilities to get an overall impression of how well they can each meet the needs of the person with dementia in the short term, and as the condition progresses. Take a check list of what is important to the person with dementia and their family and friends.
First impressions are important. Let your instincts play a part in the decision making process.

Many considerations should be taken into account, including:
- location (i.e. close to family and friends)
- accessibility by public transport and car
- welcoming and informative staff
- positive staff interactions with residents and family
- 24-hour care under a registered nurse
- care staff with appropriate dementia training
- appropriate overnight staffing levels
- a clean and homely environment
- respect for privacy and personal space
- comfortable bedrooms with personal belongings
- pets being welcome to visit
- ambiance of communal areas and garden
- a dementia-friendly environment e.g. clear signs and paths to the toilets
- good quality, varied meals served in suitable dining facilities
- consultation on food preferences and dietary requirements
- families being welcome to stay for meals
- the person’s individual cultural and spiritual beliefs, social and emotional needs being respected and met
- family and friends being given the opportunity to continue playing a caring role
- social and recreational activities appropriate for people with dementia
- outings and special events
- provision of additional services such as hairdressing, podiatry, dental
- provision of appropriate medical care, and the option for the person with dementia to keep their own doctor
- flexible visiting hours
- a committee for residents and relatives
- vacancies and waiting lists

A useful resource to take with you when viewing potential residential care facilities is ‘Choosing a care home: the 7 signposts of person-centred care’, developed by BUPA Care Services in collaboration with the Alzheimer’s Australia Consumer Dementia Research Network.

Call BUPA on 1300 302 305 or download a copy by visiting bit.ly/BUPA_ResidentialCareGuide

A full list of residential care homes in Victoria is available through the DPS Guide to Aged Care. Call 1300 186 688 or visit agedcareguide.com.au

You can search for facilities in your area using My Aged Care, Aged Care Homes Finders at myagedcare.gov.au or call 1800 200 422.

To help with the transition into an aged care facility, the ‘Five Steps to Entry into an Aged Care Home’ booklet provides an overview of the considerations to make, from eligibility through to adjusting to life in full time care. You can order a free printed version by calling My Aged Care on 1800 200 422.

For more information see Help Sheet, Residential care and dementia 2: Deciding on residential care. Available at fightdementia.org.au

Involve the person with dementia

The person living with dementia should be involved in the decision making process wherever possible. If they are involved in selecting the facility, the prospect of leaving home may not seem as daunting when the time comes. Respite care or short stays might be helpful in making the decision by giving you an indication as to whether a facility meets everyone’s needs.

Ask questions

When visiting prospective facilities, feel free to ask as many questions as you need to. In particular, find out what proportion of residents have dementia. You are looking for assurance that staff are trained and experienced in caring for a person with the condition.
Visiting somebody with dementia

Visits can be difficult, particularly as the person with dementia’s cognitive abilities decline. But there are ways to make visits meaningful and in doing so, helping to improve or maintain the person’s emotional wellbeing.

- Develop a flexible attitude. We all have high and low energy days and your friend or family member may be tired the day you visit.
- If your visit does not go as you had planned, remember it is still important – for you and the person you are visiting.
- Be kind to yourself. Maintaining a carer’s good morale is important. Perhaps take a supportive friend with you or plan a treat for yourself on the way home.
- Engage the person you are visiting by taking a magazine or newspaper with you. Read out interesting articles or do a quiz together. Take old photos or postcards to aid stimulation and reminiscence.
- Establish a visiting ritual. Say and do the same things on arrival and departure each time to create structure for your relative or friend.
- Introduce yourself on arrival. This reduces your friend or family member’s anxiety as you remind them of your name and connection to them.
- Working together, write a letter to your mutual friends or family. This can nourish and maintain important links in their life.
- Get to know the care staff by name.
- Remember that talking isn’t everything. Hugs, neck massages and hand holding can replace or complement conversation.
- Request a private space during visits, to facilitate intimacy between the person with dementia and their partner, if they have one.
- Make a life book. This is a wonderful way of validating the life journey of your friend or family member and remembering accomplishments.
- If allowed by the facility, take an animal or your pet with you. A visit from a well-loved pet can improve the emotional health and wellbeing of your friend or relative.

Communication

As a person’s dementia progresses, it may become more difficult for family and friends to communicate with them.

Communication do’s:

- Introduce yourself.
- Maintain eye contact.
- Remain calm and speak in a matter of fact way.
- Keep sentences short and simple.
- Use positive language e.g. ‘let’s enjoy the moment.’
- Use humour.
- Focus on one topic at a time.
- Give time for responses.
- Focus on body language and non-verbal communication (e.g. tone of voice).
- Repeat yourself – don’t assume you have been understood.

Communication don’ts:

- Don’t give too many choices.
- Don’t argue or confront.
- Don’t talk down to the person.
- Don’t talk about the person as if they are not there.
- Don’t ask questions that require remembering too much.
- Don’t give information too far in advance.

"If you learn to listen for clues as to how I feel instead of what I say you will be able to understand me much better."

Mara Botonis
Keeping in touch

Encourage friends and family to stay in touch with the person living with dementia by sending cards and notes. In many cases, due to diminished memory, each time the person looks at a card they will experience a fresh sense of wellbeing.

Fees and costs

While the Australian Government funds residential facilities to assist with the cost involved, most residents will be expected to make a financial contribution.

The amount of this contribution depends on the person's individual financial circumstances and can vary between facilities. No one will be excluded from care if they cannot afford it.

Fees and charges may include:
- a basic daily fee
- a means-tested care fee
- an accommodation payment
- fees for extra or optional services

Fees are based on an assessment of income and assets by Centrelink or the Department of Veterans’ Affairs. Contact details for Centrelink can be found at humanservices.gov.au/customer/dhs/centrelink

My Aged Care is an Australian Government service providing information on organising residential care and can help estimate bonds and fees with its Residential Care Fee Estimator. Visit myagedcare.gov.au/fee-estimator/residential-care/form or call 1800 200 422.

As you look into residential care options, seek independent advice from a financial specialist in aged care, or from an accountant.

The process

Applications

Applications can be made to more than one residential care facility at a time. The facility must keep applications private. If there is a waiting list, ask to be placed on it. This can give you some extra time to consider if the time is right for the move. If you or your relative or friend need to move in urgently, let the facility know.

Stay in regular contact with the facility while you or your relative or friend is on the waiting list. This lets the facility know you are still interested.

Placement agencies can provide assistance to find an appropriate facility or even manage the whole process on your behalf, for a fee. You can view a list of such agencies by visiting bit.ly/ACG_PlacementAgencies

Being offered a place

When a place becomes available, the facility will make contact to ask if you are still interested and when you may be able to move in. Generally, you will be given seven days to complete the move into the facility.

Charges may apply from the date of acceptance of a place. The Australian government will offer financial assistance from the date of acceptance.

Moving into one care facility doesn’t mean that you or your relative or friend has to stay there forever. It is possible to move from one facility to another.

Agreements

Before moving in, the facility will offer a Resident Agreement covering services, fees, rights and responsibilities, including the circumstances under which a person might be asked to leave a facility. It is important to understand everything before an agreement is signed.
Assessment

Care facility staff will gather information about the person due to move in. The information gathered might include personal preferences, interests, life and family history, medical conditions, food likes and dislikes, as well as social and activity preferences.

A care plan will then be drafted. This is a good time to let staff know as much as you can about yourself or your relative or friend, as this will help them provide the best possible care.

Moving in

Some things to consider when preparing to move into a facility include:

- putting labels on all personal belongings
- considering what personal items and furniture will go into the room at the facility
- having a pharmacist or doctor review all medications and pass on these details to staff
- remembering that, once the person goes into residential care, Home Care Packages cease, as do the carer payment and carer allowance from Centrelink

Support

Support for the person with dementia, their family and friends should not cease when the person enters full time care. Transitioning into care can be an emotionally charged time, and can be challenging and confusing for all involved. It can take some time for the person with dementia to settle into their new environment and for families to deal with the transition on a practical and emotional level.

Alzheimer’s Australia Vic is available to support you through this process. To access information and support call the National Dementia Helpline on 1800 100 500.

Carers Victoria offers support and advice throughout the transition from home to residential care – either respite or permanent. The organisation offers free ‘Carers in Transition’ group counselling sessions to provide support before, during and after placement. Call 1800 242 636 for more information.

If you are concerned about the care or service you or your relative or friend is receiving in a facility, you should raise your concerns with the manager of the facility in the first instance.

You may also contact Elder Rights Advocacy on 1800 700 600 or the Aged Care Complaints Commissioner by calling 1800 550 552 or online at agedcarecomplaints.gov.au

For more information see our series of Help Sheets, Residential care and dementia. Available at fightdementia.org.au
Key contacts

Please note, all contact details listed in this guide are correct at the time of printing. For updates, please visit fightdementia.org.au/vic, helpwithdementia.org.au or call the National Dementia Helpline on 1800 100 500.

Alzheimer’s Australia Vic
1800 100 500
fightdementia.org.au/vic

My Aged Care
1800 200 422
myagedcare.gov.au

ACAS Aged Care Information Line
1800 200 422

Aged Care Complaints Commissioner
1800 550 552
agedcarecomplaints.gov.au

Carer Advisory and Counselling Service
1800 242 636
carersaustralia.com.au

Carers Victoria Advisory Line
1800 242 636
carersvictoria.org.au

Centrelink
132 300

National Disability Insurance Scheme
1800 800 110
ndis.gov.au

Elder Rights Advocacy
era.asn.au

Things to consider

- What are the considerations to make when looking at residential care options?
- Have you organised an Aged Care Assessment Team (ACAT) or Aged Care Assessment Service (ACAS) assessment?
- What are the things that are most important to you about a residential care facility?
- What are the costs involved with residential care?
- Do you know how to get the best out of the person living with dementia when visiting them in residential care?
9 End of life issues

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Key points: End of life issues

As a person with dementia approaches the end of their life, there are a number of considerations to be made. Whether the person with dementia is living at home, in hospital or in residential aged care, they will need quality care at the end of their life. Palliative care is specialised care and support that recognises the unique needs of a person with a terminal condition, as well as their family members and carers.

The goal of palliative care is to relieve the symptoms experienced by a person towards the end of their life, rather than on curing the condition or conditions causing their death. For family members and carers, palliative care concentrates on providing emotional and practical support at this time. Health care professionals can provide information about what support is available to assist with palliative care.

When a person with dementia has died, their family members and friends often experience a range of feelings. Sadness, shock, disbelief, guilt, anger, resentment, lack of purpose and even relief are all common.

It is important to remember that everyone reacts differently and there is no one right way to grieve. There is professional support available during this time, such as counselling. And there are lots of things you can do that might help, including accepting support from family and friends, sharing your experiences with others and re-establishing relationships with old friends.
Palliative care

Whether the person with dementia is living at home, in hospital or in residential aged care, they will need quality care at the end of their life.

Palliative care is specialised care and support that recognises the unique needs of the person with a terminal condition, as well as their family members and carers.

What is palliative care?

The goal of palliative care is to relieve the symptoms experienced by a person towards the end of their life, rather than on curing the condition or conditions that are causing their death. For family members and carers, palliative care concentrates on providing emotional and practical support up until the death of the person.

Personal comfort measures

Palliative care concentrates on providing comfort in an active way, including positioning to promote comfort, mouth care, assisting with difficulties in breathing, skin care, bowel management, mobilisation and pain management.

Symptom management

Managing symptoms will depend on the stage of the illness and any other conditions the person may be experiencing. Some symptoms that occur for people with dementia may also require difficult decisions to be made. The focus should be on the key palliative care questions:

• How useful is the treatment for the person with dementia?
• What choice would best promote the comfort of the person with dementia?
• What kind of care would the person with dementia want?

Pain

There is strong evidence that pain is often neither recognised nor appropriately managed in people with dementia. It is important that there is an ongoing and systematic approach to recording, assessing and managing pain.

Nutrition and hydration

A reduced desire to eat and difficulties with eating and swallowing are normal in the later stages of dementia and are often key indicators that the person is moving towards the end of their life. There is no evidence that artificial nutrition or hydration has any benefits towards prolonging life or providing a peaceful death for a person with dementia.

Antibiotics

Decisions about antibiotics need to be taken in context and on an individual basis.

Who provides palliative care?

Palliative care can be provided by a number of different health professionals including:

• general practitioners
• specialist doctors – oncologists, cardiology, neurologists, respiratory physicians
• nurses
• allied health clinicians – pharmacists, occupational therapists, physiotherapists
• social workers
• grief and bereavement counsellors
• pastoral care workers
Planning palliative care

Palliative care in dementia can be facilitated when the person with dementia and their family members and friends have explored issues related to treatment and management in advance. It is also helpful to have discussions with health care staff about what support is available at this time.

For information about palliative care and services in your area contact Palliative Care Australia on 02 6232 4433 or visit palliativecare.org.au

Grief and bereavement

When a person with dementia is dying or has died, their family members and friends often experience a range of feelings. They may grieve for the loss of that person, and for the relationship they once had, even if they did not wish for the person to go on living with dementia.

Some people find that they have grieved so much during the course of the illness that they have no strong feelings left when the person dies. However, these feelings may surface at a later time, sometimes unexpectedly.

Everyone reacts differently. Some reactions to the death of a person with dementia amongst their family and friends may include:

- sadness for what could have been, or for what has been lost
- shock and pain
- disbelief and an inability to accept the situation
- guilt
- relief, both for the person with dementia and for themselves
- anger and resentment
- lack of purpose in life now that the caring role has gone

What you feel and how long you feel it for will vary from person to person. The death of the same person produces different responses amongst different family members and friends. There are no rules for grieving – we all react in our own way and in our own time.

Professional help

If you would like to talk about your feelings or would like help coming to terms with your loss, it may be useful to talk to a professional.

Speak to your doctor, call the National Dementia Helpline on 1800 100 500 or Carers Victoria on 1800 242 636 for further information about grief counselling.

After death

You may feel shocked and vulnerable in the immediate period after the death.

- Try to avoid making any major decisions.
- Accept that, even though you may generally be coping, you may at times feel sad or upset.
- Events such as birthdays or anniversaries may be difficult.
- Talk to your doctor. You are more likely to become physically ill or depressed following a bereavement.

Remember, it will take time to adjust to your loss.

Getting back on your feet

Moving on with your life is not always easy. However, the time will come when you are ready to re-establish your own life and move forward. Consider these ideas for getting back on your feet:

- Take time
  The length of time needed to adjust varies from individual to individual. Be patient, and don’t try to rush the process.

- Accept assistance
  Letting other people help you can provide you with support and an opportunity to express your feelings, reflect and talk. Over time this will help you understand and adjust to your loss.
• **Share your experience**
Friends and family also benefit from the opportunity to share their feelings.

• **Remember the person**
Talk about the person you have lost, especially in earlier times before dementia affected them. Reminiscing about happy times can help.

• **Celebrate the person with family and friends**
Many people find this helpful on birthdays or anniversaries.

• **Re-establish your social networks**
Start to see old friends again, or start looking around for new friends.

• **Keep trying!**
You may not feel confident at first. You may find it difficult to make decisions, talk about ordinary things or cope with social gatherings. But don’t give up. Your confidence will gradually return.
10 Alzheimer’s Australia Vic services and support

Alzheimer’s Australia Vic provides a range of services and resources to support people living with dementia, their families and carers.

Our inclusive services have been specifically designed to meet the needs of the whole community, regardless of age, cultural background or health condition.

Services cater for individuals, couples, families and groups, the aged and community care sector and the broader community.

Our services can be accessed in a variety of ways including face-to-face, by telephone or online, depending on the needs and particular situation of each individual.

There are a number of ways people make initial contact with Alzheimer’s Australia Vic. Some call our National Dementia Helpline on 1800 100 500. Others are referred to us by health professionals or service providers.

Once contact has been made, we will identify the service required and make arrangements to connect the individual or group with that service.

Alzheimer’s Australia Vic partners with many external service providers within the community offering secondary consultation and advice. Whatever your needs, we will act as a gateway and connect you to the appropriate provider.

National Dementia Helpline 1800 100 500

The National Dementia Helpline is a telephone information, support and counselling service available across Australia. The Helpline is available for people with dementia, their carers, families and friends, as well as people concerned about memory loss. It is also used by health professionals, service providers, community organisations and students.
Trained and experienced professionals provide understanding and support for callers, practical information and advice, up-to-date written material about dementia, and details of the full range of services available.

The Helpline operates during business hours. If you need an interpreter call the Translating and Interpreting Service on 131 450. Users who are deaf or have a hearing or speech impairment can call the National Relay Service on 133 677.

Children’s website
Children and teens of all ages impacted by a diagnosis of dementia in their family can now find information and support at Alzheimer’s Australia Vic’s dementiainmyfamily.org.au website.

The website is full of colourful, interactive, age-appropriate content and provides dementia-related education through videos, games, quizzes and the shared experiences of other young people in similar circumstances.

Online dementia support service
Alzheimer’s Australia Vic’s online dementia support service – helpwithdementia.org.au – enhances existing services by enabling access to 24-hour information and resources; email or video conference counselling; a forum for participating in an online peer support community, and videos featuring experts and carers sharing their experiences.

Engage, Enable, Empower
Alzheimer’s Australia Vic’s resource ‘Engage, Enable, Empower’ comprises a website and booklet specifically developed by people living with dementia, for people living with dementia.

The resource aims to inspire anyone who is living with dementia to know that it is possible to live a good quality of life and to communicate important information about maintaining your mind, body and overall health.

The website can be found at livingwellwithdementia.org.au

The Younger Onset Dementia Online Forum can be accessed at talkdementia.org.au

Information
Alzheimer’s Australia Vic produces a wide range of information for people with dementia, carers, family, friends and health professionals. This includes the Dementia Help Sheets listed throughout this guide, which are available in 32 community languages. These can be accessed at fightdementia.org.au

To request printed copies of the Dementia Help Sheets, visit our website fightdementia.org.au, call the National Dementia Helpline on 1800 100 500 or drop into any of our offices.

A large range of in-depth dementia related information including books, journals and DVDs is available through the specialist library based at our Hawthorn site. Items loaned from the library can be dispatched via post, upon request.

Local services
Alzheimer’s Australia Vic has offices across Victoria. Aside from our metropolitan offices in Parkville and Hawthorn, additional offices are located in every region, enabling us to ensure we can meet the needs of people with dementia throughout the state.

For more information about any of our locations visit vic.fightdementia.org.au/vic/about-us/contact-us or call the National Dementia Helpline on 1800 100 500.

Dementia Consultants
Following a diagnosis of dementia, our trained and experienced Dementia Consultants provide personalised information and advice, as well as details on the most appropriate support available.

Often people wish to discuss emotional reactions, changed relationships, planning for the future, sourcing appropriate services, living arrangements, dealing with changes in behaviour, family and cultural reactions.
Dementia consultation sessions can be provided face-to-face at one of our offices, or in a family home. Alternatively, they can take place over the telephone, or by using internet-based video conferencing. If English is not your first language, interpreters can be arranged.

**Early intervention**

Alzheimer’s Australia Vic offers a range of information sessions that support people living with early stage dementia and their families. Participants have an opportunity to obtain information and have questions answered, meet with others in a similar situation, share experiences and express feelings in a safe environment.

**Counselling**

Our professional counsellors are trained to offer a range of services providing support and practical assistance to individuals, couples, families, children and friends. Alzheimer’s Australia Vic has over 25 years of experience providing dementia counselling.

- **Counselling for individuals**
  
  Our counsellors are available to provide support as you address the emotional impact of a dementia diagnosis. Often it is the family and carers that benefit from attending counselling sessions. However, sometimes people in the early stages of dementia or people with concerns about their memory will also benefit.

- **Counselling for families**
  
  The word ‘family’ means different things to different people. At Alzheimer’s Australia Vic, we class a family as any group of individuals who refer to themselves as such. Families often provide the main source of support for people living with dementia. Counselling can therefore be provided to the whole family, sections of the family or individuals within the family.

- **Counselling for couples**
  
  Couples impacted by dementia are a specific type of family group, many of whom receive counselling together. Our counsellors can support couples to work through the issues associated with changed relationships.

**Living With Dementia groups**

Often, people with a diagnosis of dementia can benefit from meeting and talking to people in similar circumstances. Our Living With Dementia programs fulfil this need while offering education and support. People in the early stages of dementia can attend alone, but are usually accompanied by a support person (e.g. a partner, relative or friend). Topics include symptoms and diagnosis, research and drug treatments, driving, planning for the future, living well with dementia, community services and legal issues.

**Memory Lane Cafés**

Our Memory Lane Cafés offer an opportunity for people living with dementia to have a social outing in a supportive and familiar environment. The person with the diagnosis can attend alone or with a partner or family member.

Each two-hour event is held in a community café setting, where guests are treated to morning or afternoon tea, entertainment and the opportunity to interact with people in similar circumstances. Our staff members are also available to support and discuss all aspects of dementia and our services. Memory Lane Cafés are held regularly at various locations throughout Victoria. There are also more specialised cafés catering to different cultural groups or people living with younger onset dementia.

**Younger Onset Dementia Key Worker Program**

People living with younger onset dementia, their families and carers, have particular needs arising from their age, stage of life and the type of dementia they have been diagnosed with. The term ‘younger onset dementia’ refers to anybody who is diagnosed with dementia below the age of 65.

People living with younger onset dementia will most probably have different interests to older people living with the condition. They may also still be in full-time employment, often at the peak of their career. They might have a mortgage and dependent children or elderly parents.
In order to meet these differing needs, we run the Younger Onset Dementia Key Worker Program. Participants have one point of contact (a Key Worker) to assist with information, support, education and counselling. The Key Worker provides individualised support and facilitates connections to other relevant services in the community, including where applicable, the NDIS.

Family information and support sessions
There will come a time when a person living with dementia will eventually need hands-on care and increased support from family and friends. Families and carers tend to manage better when they have a good understanding of dementia, have been educated on ways to manage the issues associated with the condition and have developed ways to deal with their own reactions and emotions.

Our Family Information and Support Sessions provide participants with an in-depth understanding of the issues associated with caring for a person living with dementia, while at the same time providing an environment where people in similar situations can share stories, concerns and reactions. Some are short, one-off sessions while others run over several weeks. All programs are offered in different locations across Victoria.

Services for people with mild cognitive impairment
Alzheimer’s Australia Vic also offers information sessions for people diagnosed with mild cognitive impairment and their families. The sessions look at the differences between normal aging, mild cognitive impairment and dementia, and ways to manage the impacts of the condition.

Additionally, the LaTCH program is designed to assist people with mild cognitive impairment to develop strategies that will improve their memories, and aids for managing their day-to-day lives.

To access any of the information or programs listed above, call the National Dementia Helpline on 1800 100 500 or contact us directly on 03 9815 7800.
11 Checklist

Below is a checklist of things you can do after reading this guide. These will help you to live well now and make plans for the future.

1. Understand more about your diagnosis, e.g. the type of dementia you have, and what your drugs are for (if prescribed).

2. Talk to others about how you are feeling and contact Alzheimer’s Australia Vic to find out what information or services might be appropriate for your needs.

3. Try some strategies to help you cope with changes to your memory or thinking.

4. Introduce exercise into your daily routine and review your diet to make sure it’s balanced.

5. Organise regular check-ups with your doctor, dentist, optician and podiatrist.

6. Register with My Aged Care.

7. Contact Centrelink to find out what payments might be available for you and your carer.

8. Write or update your Will and appoint your powers of attorney.

9. Tell your local road and traffic authority, and your car insurer about your diagnosis (if driving).

12 Keep in touch

Alzheimer’s Australia Vic is the charity representing people with all forms of dementia in Victoria. As the peak body, we provide specialised dementia information and are the leaders when it comes to education and providing support services.

All Victorians should know that we are here for them and their families when a diagnosis is received, or whenever they have concerns or questions.

Through our services, we take pride in assisting people to plan for their future, maintain the best possible quality of life and access the most appropriate care and support.

We campaign for a better quality of life for people with dementia and for greater understanding of the condition. We also fund an innovative program of medical and social research.

Receive all the latest news and developments from Alzheimer’s Australia Vic with our monthly eNews. Just email newsvic@alzheimers.org.au to sign up.

If you have any concerns about Alzheimer’s disease or any other form of dementia, visit fightdementia.org.au/vic or call the National Dementia Helpline on 1800 100 500

Join us – become a member

Alzheimer’s Australia Vic membership is open to anyone concerned about dementia and is currently available for individuals, concessions/students, families and organisations.

By becoming a member you have the opportunity to play an active part in the continued growth and future development of the organisation.

For more information on member benefits and how to sign up, visit vic.fightdementia.org.au/vic/support-us/become-a-member or call the National Dementia Helpline on 1800 100 500.
We hope you have found this publication helpful. If you have any comments or suggestions as to how it could be improved in the future, please get in touch.

Please write your comments below and send them to us at Alzheimer's Australia Vic, Locked Bag 3001, Hawthorn 3122 or fax: 03 9815 7801

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(Optional)

Name: ________________________________

Email: ______________________________

Address: ____________________________