



Section 11

Support and information for carers

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

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

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

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



“

Leanne, my wife, bought me a camera so I could take photos of places, things and people to remember them by. Well, it turns out according to people, I can take a pretty good photo ”

Kevyn, a Dementia Advocate who lives with dementia

Section 11

Support and information for carers

Section contents

Getting emotional support	158
Getting practical support	159
Looking after your health and wellbeing	162
Supporting a person with dementia	163
Changes in behaviour	171
Grief and bereavement	176

When someone in your family is diagnosed with dementia, they may approach living with dementia in different ways.

Some people seek to remain independent for as long as possible. Others will seek the support of another person to help them manage their symptoms and maintain a level of independence. Some people may not be aware of the support they need.

You may find yourself gradually taking on the role of 'carer'. It can often happen without making a conscious decision to do so.

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

- helping the person stay involved with the hobbies, activities and interests they enjoyed before their diagnosis
- working with healthcare professionals and support agencies to meet the person's physical, psychological and social needs

- 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
- helping the person with physical tasks, such as getting in and out of bed or walking.

If someone close to you is living with dementia, do not underestimate the impact this can have on you. Whether you are the partner, child, relative or friend, your relationship will change.

It is important to look after your health and wellbeing and turn to others for support when you need it. This will ensure you provide the best care for the person with dementia, for as long as you are able.

Getting emotional support

Caring for someone with dementia can be rewarding. It can also be challenging, life-changing and stressful. At times it may feel overwhelming.

You may have many different feelings over time as the person's needs change. As dementia gradually causes their abilities and personality to change, the nature of your relationship with them will change too.

There is no simple way to deal with these feelings, but it may help to know that the complex and varied emotions you feel are completely normal.

You may want to share how you feel with a professional, a friend or family member, or someone at a carer support group.

At Dementia Australia, we have trained counsellors, support groups and education programs for carers. Call the **National Dementia Helpline** on **1800 100 500**.

Getting practical support

Caring for a person with dementia can become more demanding over time. Getting help can make it easier for you to provide the best support.

There are many sources of support:

- **Friends and family:** Try to involve family members and share responsibilities. This will take some of the pressure off you.

- **Community support:** Connect with neighbours or groups you already have an association with. People may be happy to offer practical support such as shopping, cooking a meal or spending time with the person living with dementia.
- **Employer benefits:** If you work, ask about carer's leave or other flexible working options.
- **Government benefits:** Find out if you are eligible for any government benefits through Centrelink.
- **Carer support groups:** Talk to others going through similar experiences. You can share practical tips and get emotional support. Ask Dementia Australia about groups in your area.
- **National Dementia Helpline:** Get information and support from trained dementia support specialists. Call **1800 100 500**.
- **Carer Gateway:** Get practical information and resources specifically for carers. Visit [carergateway.gov.au](https://www.carergateway.gov.au) or call **1800 422 737**.

Person-centred care

Person-centred care for people living with dementia means offering care that:

- treats the person with dignity and respect
- promotes their rights
- understands their individual history, lifestyle, culture, likes and dislikes
- sees things from their perspective
- provides a positive social environment that nurtures their relationships in the community.

These principles help embrace the uniqueness of every person, regardless of their disease. It is important to see the person and not just their dementia.

You and the person with dementia should be part of developing their care plans. As a partner, family member or friend, your understanding of the person is invaluable.

Looking after 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.

- Make sure you eat a balanced diet, get adequate sleep, and make time for regular exercise and physical activity.
- See your doctor regularly about your health.
- If you have to move or lift the person you are caring for, seek advice from your doctor or an allied health professional to reduce your risk of injury.
- If you regularly feel sad or anxious, talk to your doctor as early as possible. These can be signs of depression.
- Make sure you have some regular time to relax or do something for yourself. Meet with friends, go on an outing or take a short break.

- Take time to connect with how you are feeling and think about what you might need. You might make a call to a friend or enjoy a cup of tea.
- Find out about social support groups or respite support for the person you care for. This will allow you to take time for yourself, knowing that they are being well looked after.

Supporting a person with dementia

Every carer experience is different. Much of how you care for a person living with dementia will come naturally. It will be based on instinct and the unique relationship you share with them.

Learn to be creative and flexible with your caring strategies. Identify your strengths and the strengths of the person you care for. This will help you see where you may need extra support.

Always try to see the person and not just their dementia.

Become a Dementia Friend

For people living with dementia, performing daily tasks and maintaining social networks can sometimes be challenging. This is why building communities in which people living with dementia feel understood, accepted, and included, is so important.

Businesses, organisations, groups, and individuals can all play a vital role in creating dementia-friendly communities.

By becoming a Dementia Friend, you can learn what it is like to live with dementia, and how you can help those living with this condition maintain connections with those around them. Find out more at dementiafriendly.org.au/register

Everyday care

With time, dementia will affect a person's ability to carry out everyday tasks. 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 helps the person keep their independence, confidence and self-esteem.

Tips to support ability

- Focus on what a person can do rather than what they cannot.
- Be flexible and patient if they find it hard to remember or concentrate on things.
- Put yourself in their shoes. Try to understand how they might be feeling and the care they may want.
- Be sensitive and offer encouragement.
- Give them meaningful things to do, from everyday chores to leisure activities.
- Include the person in conversations and activities as much as possible.

Nutrition

Maintaining good nutrition for the person you care for can present challenges. The person with dementia may:

- experience a loss of appetite
- forget how to chew or swallow
- fail to recognise food or drink
- develop an insatiable appetite
- develop a craving for sweets
- suffer from dry mouth or mouth discomfort.

Tips to support good nutrition

- Plan for meals to be social occasions, whenever possible.
- Stock up on healthy snacks that do not need preparation or cooking.
- Try not to use patterned table settings or busy tablecloths. Keep to plain colours.
- Allow time for the person to respond to food. Sometimes showing them what to do can help them get started.

- Serve only one plate of food at a time. Don't overload the plate.
- Sometimes leaving food out so the person can snack through the day instead of eating at set mealtimes can help with eating.
- If there are swallowing issues, visit a speech therapist for appropriate strategies.
- Visit a dietician or doctor for extra advice on maintaining good nutrition.

Communication

The way dementia affects a person's communication will vary. Many people struggle to find the right words or follow a conversation.

This can be upsetting and frustrating for you and the person with dementia. But there are things you can do to better understand each other.

Tips to support communication

- Make eye contact. Try to listen carefully, even when you are busy.
- Make sure you have the full attention of the person. Consider the impact of any distractions, such as noise. Try to eliminate noise if possible; turn off televisions or radios. Go to cafes and other venues at quieter times.
- Consider using gestures, facial expressions and touch.
- Speak clearly and think about the words you use. If you are not understood, use simpler words or explain things differently. Give one instruction at a time.
- Remain calm and use positive language.
- Stick to one topic and ask questions that are simple and easy to understand.
- Consider other factors that might affect communication. These include hearing or eyesight problems, pain, or side effects of medication.

- Give time for responses. Repeat yourself if needed.
- Deal with misunderstandings and mistakes by using humour. Laughing together can ease tension. Make sure it is appropriate by judging how the person responds.
- Involve the person in group conversations and avoid talking across them.

Try not to:

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

Interests

Interests and hobbies can help a person living with dementia enjoy the best quality of life. You can help maintain their interests by choosing activities you both enjoy.

Tips to maintain activity

- Tap into past interests and hobbies.
- Build on the person's strengths, focusing on what they can still do.
- Listen to music, dance, play with animals and look at old photos.
- Consider some gentle exercise or outdoor activities.
- Try different things until you find what works for you both.

Changes in behaviour

People living with dementia can sometimes behave differently from how they used to. Keep in mind this is not deliberate and try not to take it personally.

Some common changes in behaviour are:

- aggression
- overreaction
- hoarding
- repetition, such as asking the same question or repeating an action
- restlessness, such as pacing or fidgeting
- lack of inhibition, such as in appropriate 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, for example, thinking someone has taken their belongings when they cannot recall where they have put them
- apathy, poor motivation and ability to initiate activities.

Responding to changes in behaviour

- Try to think from the perspective of the person with dementia and offer reassurance.
- Work out if there is a problem so that you can try to resolve it.
- Avoid correcting or contradicting the person.
- Try distracting the person. You can change the conversation, have something to eat or go for a walk together.

- Engage in the activities they enjoyed before their diagnosis. This will help them remain engaged and feel valued.
- Try aromatherapy, massage, music or dance therapy, or contact with animals.
- Try talking therapies, reminiscing with the person or doing life story work.

Changes in behaviour can be stressful for family members as well as for the person living 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.

An underlying physical or medical issue is more likely to be the cause. When behaviour changes, it is important to see a doctor for a medical assessment.

If there are no physical causes, it could mean the person has an unmet need. Keep a record of when changes in behaviour occur to help you understand them or spot any triggers.

If these changes persist or cause distress, talk to a professional. Changes in behaviour are very common, and many things can help.

Dementia Behaviour Management Advisory Service

The Dementia Behaviour Management Advisory Service is a nationwide service funded by the Australian Government.

This service provides clinical support to carers of people living with dementia, where behavioural and psychological symptoms are impacting their care. This can be care provided at home or in a care home.

Clinicians conduct individual assessments and care planning to help carers in their roles. They also assist carers to identify triggers and develop strategies to prevent or minimise changes in behaviour. They can link carers with appropriate support networks.

For more information about the Dementia Behaviour Management Advisory Service, call **1800 699 799**.

Respite care

Access to respite can help you to have a break and look after yourself so that you can continue to provide care at home for as long as possible. Different respite options are available to people in care relationships. These include:

- flexible respite
- in-home respite
- day centres
- overnight cottage respite
- residential respite.

Grief and bereavement

When a person with dementia is dying or has died, family members and friends may experience a range of feelings.

Everyone has different reactions. You may experience:

- sadness
- a sense of loss
- shock and pain
- disbelief and an inability to accept the situation
- guilt
- relief, both for the person with dementia and for yourself
- anger
- resentment
- lack of purpose now that your caring role has gone.

Grieving is not always about experiencing negative emotions. You may also feel joy or happiness. What you feel and how long you feel it for will vary from person to person. There are no rules for grieving. We all react in our own way and in our own time.

Following a death, you may feel shocked and vulnerable:

- Try to avoid making any major decisions.
- Acknowledge your feelings.
- Arrange for support around emotional events, such as birthdays or anniversaries.
- Talk to your doctor if you feel overwhelmed, have feelings of depression or feel physically unwell.

It will take time to adjust. If you are finding it difficult, it may be useful to talk to a professional. Speak to your doctor or call the **National Dementia Helpline** on **1800 100 500**.

Getting back on your feet

It can be hard to move on with your life after your caring responsibilities change or the person you love has died. But the time will come when you are ready to re-establish your own life and move forward.

- Take your time. The length of time needed to adjust varies from person to person.
- Be patient. Do not try to rush the process.
- Accept help. Other people can support you and let you express your feelings, reflect and talk.

Share your experience

Sharing your feelings among family and friends can be beneficial for everyone.

- Remember the person. Talk about earlier times before dementia affected them.
- 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 look at making new friends.
- Keep trying. You may not feel confident at first. It can be difficult to make decisions, talk about ordinary things or cope with social gatherings. But do not give up. Your confidence will gradually return.