Call the National Dementia Helpline on 1800 100 500
7 Support for carers

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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, Dementia Australia 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 Dementia Australia 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 Dementia Australia services and support on page 139 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 83.

Dementia Australia

The organisation has trained staff who specialise in dementia care and support services. Call 1800 100 500 or visit dementia.org.au

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 Dementia Australia 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 a Dementia Australia 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 [dementia.org.au](http://dementia.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 [dementia.org.au](http://dementia.org.au) and [livingwellwithdementia.org.au](http://livingwellwithdementia.org.au).

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**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, for example, 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 dementia.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 46 for more information.

If these issues persist or cause distress, seek advice and support from Dementia Australia 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 [dementia.org.au](http://dementia.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 Dementia Australia 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 Dementia Australia to discuss accessing these services?
• Do you know the ways to bring out the best in the person you are caring for?