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## Dementia - taking care of carers

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### Summary

- If the carer is tired or stressed, it can become harder to care for a person with dementia.
  - It is important for carers to continue activities they enjoy.
  - For some men, taking responsibility for household jobs and being a carer may mean learning new skills.
  - Carers may experience feelings of guilt, grief, loss or anger.
  - Carers should take a break from caregiving to avoid becoming worn down.
  - Support and respite care are available for carers and can provide comfort and practical assistance.
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The physical and emotional demands of caring for someone with dementia can be high. As the amount of care that is needed increases, more time and energy is required from the carer. If you are caring for a person with dementia, you need to look after yourself or the demands may wear you down.

If you are worn down, caring will become even more difficult and it will not be easy to continue balancing your own needs as a carer with those of family and the person with dementia. You need support and assistance to care for someone with dementia.

### Carers of people with dementia are not alone

A large number of carer support groups exist throughout Australia. Many people find comfort and practical assistance by attending meetings with others who know what it is like to care for a person with dementia. Support groups bring together families, carers and friends of people with dementia under the guidance of a group facilitator. The facilitator is usually a health professional or someone with firsthand experience of caring for a person with dementia. Contact the National Dementia Helpline for more information.

### Managing stress as carers

Everyone has different ways to manage stress. Managing stress improves your wellbeing and may help in your caring role, so it can be useful to learn some better ways to manage it. Bookstores and libraries have a range of books and tapes on different ways to manage stress.

Some suggestions for managing stress include:

- A consistent schedule can make life easier when living with a person with dementia.
- It often helps to remember that the person with dementia is not being difficult on purpose, but that their behaviour and emotions are affected by dementia.
- Learn as much as possible about dementia, and encourage friends and relatives to do so as well.
- It is important to talk things over with family, friends and other people in a similar situation.
- Take care of yourself by looking after your diet, getting regular exercise and maintaining your social contacts and lifestyle.
- Be realistic about what you can expect of yourself and recognise that you will be a better carer if you take care of yourself.

### Getting out and about

It is very important to continue with activities that you enjoy. Some carers say that they feel guilty when they leave the house or enjoy an activity without the person they are caring for. Yet families and carers have the right to follow their own interests outside their caring role. In fact, it is essential that they do so. A carer who has regular time away will be a better carer.

If you have trouble coping with feelings of guilt about getting out and about, it may be a good idea to talk these feelings over with a supportive friend or relative, your doctor or a counsellor at Carers Victoria or [Dementia](#)

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## **Australia.**

### **Asking for help**

As a carer, you can take care of yourself by being open about what help you need now, and planning ahead for what help you may need in the future. Help often, but not always, comes from relatives, friends and neighbours. Seeking outside help is also important for many carers. Doctors, psychologists, social workers and counsellors all have experience helping people who are caring for others.

Some suggestions for reaching out to others include:

- Aim to share the care of the person with dementia.
- Don't hesitate to ask for help.
- Suggest specific ways that friends and relatives can help, such as bringing a meal, helping with the housework or shopping.
- Organise regular breaks – this is very important. Some friends and relatives may be able to care for the person with dementia on a regular basis. Local day centres can also offer suitable programs for people with dementia and respite for carers.
- Use the services of support organisations such as **Dementia Australia** and Carers Victoria.

### **Communicating with friends and relatives**

A carer's job can be made more difficult by a lack of understanding from other people. Helping friends and relatives understand what is happening may make your job easier.

Some suggestions to help with communication include:

- Provide information about dementia to friends and relatives. Useful material is available from **Dementia Australia** and much of it is written in community languages as well as English.
- Explain that although a person with dementia may look or appear fine, they have an illness that is devastating, but not contagious.
- Accept that some friends may drift away.
- Ask visitors to come for short visits.
- Do not have too many visitors at one time.
- Suggest that family and relatives who visit come prepared for activities, such as bringing a snack, going for a walk, bringing a simple project to do together or looking at a photo album.
- Prepare visitors for problems with communication and suggest ways that they might deal with these.

### **Men caring for a person with dementia**

Many men find themselves caring for a person with dementia. Most of these men are caring for their partners, although male carers may also include sons, brothers and friends.

In many homes, it is often the woman who takes the main responsibility for meal planning, cooking, cleaning and laundry, and for many of the other jobs that keep a household running. If the woman has dementia, she will gradually be unable to continue doing these tasks.

The man in the caring role may need to begin helping the person who has dementia, perhaps by asking the person to show them how to do things. For some men, taking responsibility for these jobs may mean learning new skills or ways of doing things.

Some of the issues that men can face include:

- helping with personal and intimate care – such as bathing, toileting, applying make-up, putting on pantyhose or arranging for hairdressing, all of which – for most men – are entirely new experiences
- helping with new everyday tasks – such as buying bras or helping a woman to try on new clothes in a women's change room
- losing the emotional support of a partner – men often rely on their partners for emotional support and to maintain friendships and family contacts, so men should make sure they have both social and emotional support.

### **Common feelings experienced by carers**

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**[betterhealth.vic.gov.au](http://betterhealth.vic.gov.au)**

As a carer, you are likely to experience a range of very different, and often quite extreme, feelings. This is particularly difficult because, as dementia gradually causes the person's abilities and personality to change, the nature of relationships will also change.

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

Some feelings commonly experienced by carers of people with dementia include distress, frustration, guilt, grief and loss, exhaustion, annoyance and anger.

### **Guilt experienced by carers**

It is quite common to feel guilty about things such as:

- the way the person with dementia was treated in the past
- feelings of embarrassment about the person's odd behaviour
- losing your temper
- not wanting the responsibility of caring.

If the person with dementia goes into hospital or residential care, carers may feel guilty that they have not kept them at home for longer, even though everything that could be done has been done. You may feel guilty about past promises that cannot be met, such as 'I'll always look after you'.

### **Grief and loss experienced by carers**

Grief is an emotional response to loss. The loss could be the loss of a relationship, moving house, loss of good health, divorce or death. If someone close to us develops dementia, we are faced with the loss of the person we used to know and the loss of a relationship.

People caring for partners are also likely to experience grief at the loss of the future they had planned together. Grief is a very individual feeling and people will feel grief differently at different times.

### **Anger experienced by carers**

It is natural to feel frustrated and angry. You may be angry at having to be the caregiver, angry with others who do not seem to be helping out, angry at the person with dementia for difficult behaviour and angry at support services.

Sometimes, you may feel like shaking, pushing or hitting the person with dementia. Feelings of distress, frustration, guilt, exhaustion and annoyance are quite normal. If you feel that you are losing control, it may help to discuss your feelings with your doctor or an [Alzheimer's Australia](#) counsellor.

### **Coping with feelings as a carer of someone with dementia**

If you are a carer, some helpful tips for dealing with feelings of guilt, loss and anger include:

- Feel the pain – allow yourself to really feel what you are feeling. Denying the feelings only intensifies and prolongs the pain.
- Cry – tears can be therapeutic.
- Talk – share the pain to help diminish grief. It can be helpful to talk to a person outside the family, such as a counsellor.
- Keep a journal – a private place where anything can be written, including unfulfilled wishes, guilt, anger or other thoughts and feelings.
- Let go. Try not to be engulfed by bitterness.
- Find comfort. Different people have different ways to find comfort, including using rituals like prayer, meditation or other activities.
- Hold off on decisions. Tread carefully before making decisions and thoroughly explore all options before you take any major steps.
- Be kind to yourself, be patient with your feelings, and find a balance between the happy and sad person, the angry and peaceful, the guilty and glad.
- Learn to laugh again and rediscover your sense of humour. Finding joy in life can be one way to honour the happy times that you used to share with the person you are caring for.

## **Take a break from caring for someone with dementia**

Try to make sure that you get adequate breaks from caregiving so that you do not become worn down. Ask other family members and friends for help. Day care centres, in-home respite and regular residential respite are available to provide a much-needed break. This can help you to continue in your role.

## **Resources for carers of someone with dementia**

A number of resources are available to help you care for someone who has dementia including:

- an Aged Care Assessment Team (ACAT) – helps older people and carers work out whether they need home-based support or residential care and can provide information on suitable care options and arrange access or referral to appropriate residential or community care
- the Aged Care Information Line – gives support and assistance with queries about access to home and community care, respite fees, and bonds and charges
- Commonwealth Respite and Carelink Centres around Australia – provide information about the range of community-care programs and services available to help people stay in their own homes
- the Carer Advisory and Counselling Service – provides carers with information and advice about relevant services and entitlements.

## **Where to get help**

- Your doctor
- Your local council
- Your local community health centre
- National Dementia Helpline – Dementia Australia Tel. 1800 100 500
- Aged Care Assessment Services Tel. 1300 135 090
- My aged care Tel. 1800 200 422
- Cognitive Dementia and Memory Service (CDAMS) clinics Tel. 1300 135 090
- Carers Victoria Tel. 1800 242 636
- Carer Respite Centres – Australian Government Tel. 1800 059 059
- Dementia Behaviour Management Advisory Service (DBMAS) Tel. 1800 699 799 – for 24-hour telephone advice for carers and care workers

## **Things to remember**

- If the carer is tired or stressed, it can become harder to care for a person with dementia.
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**This page has been produced in consultation with and approved by:**

Dementia Australia

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