

Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



Unit 3. Carer Support

Why is this unit important?

Carers play a central role in caring for, and supporting, people like the person you care for who are living with dementia in Australia. Your involvement as a carer for the person you care for enhances the person's ability to access and engage with a range of services and live as independently as possible.

How will this unit help me?

This learning unit will summarise how your role as a carer is important to provide support to the person. The learning unit will provide you with some advice for caring for yourself and accessing support when you need it.

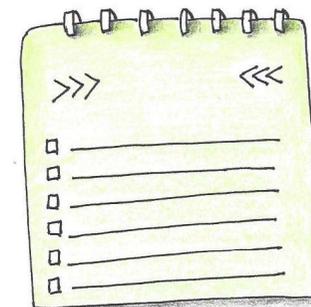
This learning unit provides:

- An overview of your legal rights and responsibilities
- Ways to ensure you look after yourself
- Services that are available to support you and the person you care for remain in charge
- Where to go for more information.

What is a carer?

A carer is anyone who looks after a friend or family member who can't cope alone due to illness or disability. You may not recognise yourself as a carer, but if you are helping someone you love to live a safe and healthy life at home then you are a carer. Being a carer is very rewarding, but it can also be demanding and sometimes it may be overwhelming.

To ensure you can provide the support and care that you want for the person you care for it is very important that you look after yourself including recognising that you may need some practical and emotional support. Please contact Dementia Australia (1800 100 500 or <https://www.dementia.org.au/> and/or Carers Australia (Phone: 1800 422 737 or www.carersaustralia.com) to find support that you want.



Legal considerations of being a carer

There are a number of legal and policy frameworks which recognise the important role of people in caring and supporting roles. The Australian Government has created an Act to increase recognition and awareness of carers. Most states and territories also have legislation that sets out your rights as a carer.

It's important to know your legal rights when you are an unpaid carer which include:

- being recognised by health providers as a contributor to the health of the person being cared for
- being heard and treated with respect
- using services to support the person you care for without discrimination
- being able to comment on services provided to the person being cared for
- acting in the best interests of the person being cared for.

Your involvement as a decision maker in aspects of the daily life of the person you care for will be dependent on [His/her] capacity to make decisions. You could be appointed as a nominee to discuss matters with Centrelink for example or be formally appointed as a Power of Attorney to manage the person you care for's financial affairs. Advance Care Directives can also ensure that the person with dementia has their wishes considered and you may be appointed by them as a Substitute Decision Maker when they no longer have a capacity to make decisions about medical and welfare matters concerning them. (www.carergateway.gov.au)

Let's look at an example

Antonio and Maria have been married for 40 years. Maria has always been happy to let Antonio manage their affairs. Antonio has recently been diagnosed as having the early signs and symptoms of dementia and they are now considering what they need to do to manage their affairs in the future.

What do you think is the best advice to give Antonio and Maria?

Check your understanding



What do you think are the right responses for Antonio and Maria?

- Maria must immediately start making all the decisions for Antonio in regards to his health care.
- Antonio and Maria should start managing their affairs together so that Antonio can show Maria what to do.
- Antonio should immediately stop managing their affairs and leave it to Maria.
- Antonio and Maria should seek advice about Advanced Care Directives and Enduring Powers of Attorney.

Check your understanding



- ✘ **Maria must immediately start making all the decisions for Antonio in regards to his health care.**
This is not a good response. Whilst Maria may have Antonio's best interests, Antonio is probably still able to make decisions for himself. Antonio and Maria should understand that as the disease progresses, Antonio's ability to make decisions will change. Maria will still need to offer options and give Antonio the chance to make decisions on his own, whether they are simple day to day decisions, or decisions about their future care and support. There may be a time when Maria will need to make decisions for Antonio, but with appropriate planning in the early stages of dementia Antonio should express his wishes for the future so the Maria knows how to best support him.
- ✔ **Antonio and Maria should start managing their affairs together so that Antonio can show Maria what to do.**
This is a good response as it provides both Maria and Antonio with the opportunity to ensure they can continue to successfully manage their affairs. It will provide assurance to Antonio that things will be looked after. It provides Maria with a chance to learn about managing their affairs while Antonio is still able to help her.
- ✘ **Antonio should immediately stop managing their affairs and leave it to Maria.**
This is not the best response. Living with dementia does not mean that you must immediately stop making decisions or managing affairs. However, it is wise that plans are discussed and made for the future when Antonio needs help to manage finances and legal matters.
- ✔ **Antonio and Maria should seek advice about Advanced Care Directives and Enduring Powers of Attorney.**
This is a good response as it will ensure arrangements are in place for when they may be needed. Advance Care Directives allow individuals to let others know what their wishes are if they are unable to make these decisions themselves and to know the wishes will be respected. Enduring Power of Attorney provides legal authorisation to act on behalf of someone in legal and financial matters after the person granting it loses capacity to manage their own affairs.

Supporting carers

Carers play an important role in dementia care. As a carer you may feel isolated or lonely because you are busy caring. Sharing your experiences with someone you trust - family, friends, neighbours, other carers or health workers - can help.

To help you in your role as a carer, you might consider:

- applying for Australian Government financial support, such as the Carer Payment and Carer Allowance
- respite care inside the home or outside
- asking other family members or friends of the person to help you on a regular or informal basis
- joining a local support group for carers.

There are also a wide range of services and organisations that can support you in your role as a carer for the person you care for. A great place to start for support and services is the Carer Gateway which is a national online and phone service that provides practical information and resources to support carers. You can contact them on free call: 1800 422 737 for support and advice Monday to Friday 8am to 6pm. (www.carergateway.gov.au)

Let's look at an example with Antonio and Maria.

It's now 5 years since Antonio was diagnosed with dementia. Maria is finding she needs to support Antonio with everyday activities more often than before. Maria feels like she has no time to herself and worries that Antonio may need more help than she can give him. Maria feels if she asks for help it may look like she is failing in her caring role.

Check your understanding



What do you think are the right responses for Maria?

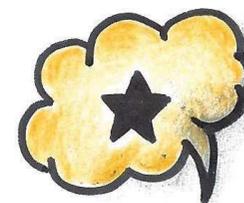
- Tell Maria to just get on with it and look after Antonio.
- Tell Maria to get her son to leave his job and come back from living overseas to help her and Antonio.
- Tell Maria to call My Aged Care to get information about her role as a carer.
- Tell Maria to get a hobby to distract her from her caring role.
- Give Maria the number to call the Carer Gateway for further information about her role as a carer and what support is available to her and Antonio.

Check your understanding



- ✗ **Tell Maria to just get on with it and look after Antonio.**
This is not a good answer as it does not provide help for Maria and may make her feel more isolated and worried.
- ✗ **Tell Maria to get her son to leave his job and come back from living overseas to help her and Antonio.**
This is not a good response. It is not a practical option. Maria should, however, share her concerns with her son and they might look at options together to help Maria.
- ✓ **Tell Maria to call My Aged Care to get information about her role as a carer.**
This is a good response. My Aged Care provides a central place to get information about services available to help. My Aged Care will give Maria some contacts to call for further assessment or assistance and suggest some services that may help her.

- ✗ **Tell Maria to get a hobby to distract her from her caring role.**
This may help a little but it will only be suitable if Maria feels she has time to get a new hobby. Maria may benefit more from talking to people who are in the same situation as she is. Maria can get advice and talk with people about things they have in common and maybe even get tips to make her caring role easier.
- ✓ **Give Maria the number to call the Carer Gateway for further information about her role as a carer and what support is available to her and Antonio.**
This is a good response. The Carer Gateway will be able to give Maria the contact details of services in her local area. Maria will be able to share and talk to other people to support her or advise her about services she can access.



Where to go for more information

It's never too early or too late to talk about the care the person needs or the support you need as a carer. Talking about getting some extra help doesn't mean you are not doing well in your role as a carer.

My Aged Care www.myagedcare.gov.au phone 1800 200 422 will help you work out the steps you need to take.

A few of these useful contacts and resources that My Aged Care recommend are listed below.

- **Carer Gateway** 1800 422 737
A national online and phone service that provides practical information and resources to support carers.
- **Commonwealth Respite and Carelink Centres** 1800 052 222
These centres can help link carers to a wide range of aged care services to help at home and in the community.
- **Carers Australia** 1800 242 636
The peak national body representing carers. Carers Australia provides information, support, education, training and counselling.
- **Carer support groups** 1800 200 422
Carer support groups are sometimes organised around specific conditions. Call for information about these groups in your area.



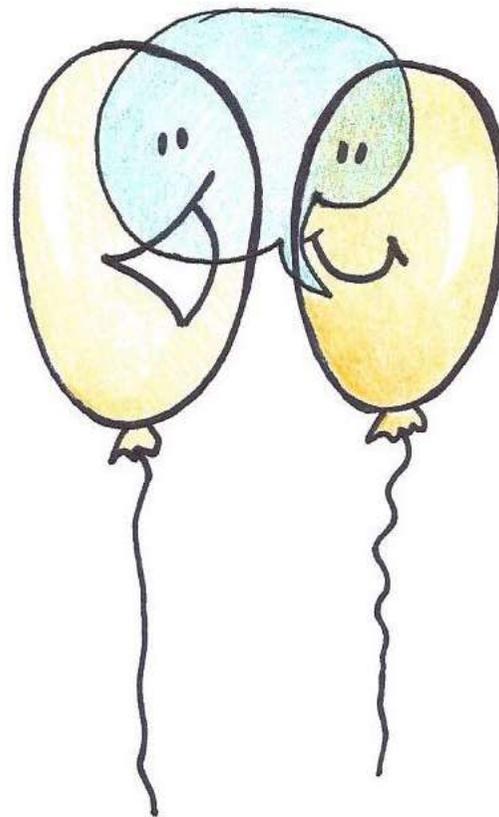
- **Independent Living Centres** 1300 885 886
Resource centres that display a range of products and equipment to assist with day-to-day living activities. You and the person you care for can try out products on display and talk to the centre's occupational therapists. Staff at these centres are trained to match products and services to your requirements and can help you locate suppliers of special-needs equipment.
- **Young Carers** 1800 242 636
An initiative of Carers Australia, Young Carers provides information and support groups targeted specifically to the needs of young carers.
- **Dementia Australia** 1800 100 500
- **Dementia Support Australia** 1800 699 799
- **Dementia Behaviour Management Advisory Service (DBMAS)** 1800 699 799

Let's review what you have learned

- Being a carer is rewarding but can also be stressful at times - having someone to talk to and get advice is very important.
- As a carer you have legal rights and responsibilities.
- It is important to plan ahead so you understand what the person you care for wishes are for future care.
- There are a range of services to support you in your caring role.
- Maintaining or developing social networks is important for you as a carer.

RELATED LEARNING UNITS

- Module 1 Unit 1 Introduction to dementia
- Module 2 Unit 4 Involving others
- Module 3 Unit 3 Thinking differently





You finished this unit, well done!