

Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



Unit 6. Activities and services to help carers relinquish their carer role

It is best for the carer if they start planning and putting things in place for themselves before giving up the caring role.

Why is this unit important?

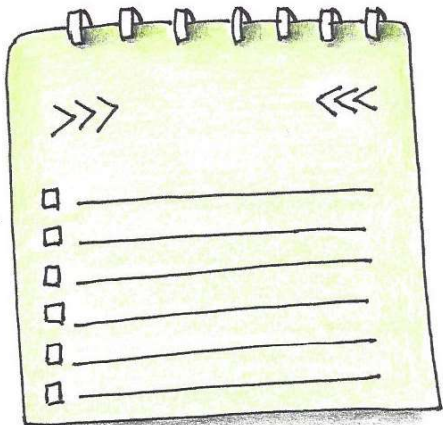
This Unit will summarise some of the emotions and feelings you may have if you can no longer provide some of the care that is needed for the person you care for. The Unit will outline activities and services that are available for carers to help when they have to give up or change their role as the carer.

How will this unit help me?

As a carer you have given a lot of time and emotion to care for the person. Your role as a carer may change as a result of circumstances and choices that have been made. This may be because the person you care for requires 24 hour care in a residential care facility, because of their death, or some of the care is provided by others. Whatever the reason for the change in your circumstances, it does not mean the end of the impact of caring. A sense of loss may be experienced, and it is normal that you will need to think about your own wellbeing and future.

This learning unit provides:

- What some of the feelings you may experience are
- Ways to ensure you look after yourself
- Services that are available to support you
- Where to go for more information.



Change in caring

Taking care of the person living with dementia has probably been your main focus for some time and now those responsibilities have changed or lessened, and you may be feeling a bit lost. Your daily routines have now changed, and you may feel a lack of purpose in your day. Now that you are not caring for the person it may be lonely. You may also feel relieved that the pressure has been taken away from you. This is very normal as caring for the person has been a big part of your life and you may have a lot of mixed feelings.

Support is available

It is helpful to talk about your feelings with someone. Family and friends are an obvious start, but for some people counselling and support services may better meet your individual needs.

If you feel so lost and like you are not managing, get help.

Lifeline

Lifeline is a national charity that can provide telephone counselling for people in a crisis situation. Any information you provide is confidential.

Lifeline can be contacted 24 hours a day, every day of the year on free call 13 11 14.

(lifeline.org.au)

Carers Australia

Carers Australia is the national peak body representing Australia's carers, and works with a network of state and territory Carers Associations.

Carers Australia can provide you with links to Carer Associations and supports in your area. Carers Australia offer counselling services provided by trained professionals.

For support services and advice call 1800 242 636 or visit website www.carersaustralia.com.au.

National Association for Loss and Grief Australia (NALAG)

The National Association for Loss and Grief Australia (NALAG) is a free service that can help you to work through issues such as loss, grief, bereavement and trauma. You can access NALAG's services by telephoning 02 6882 9222. Staff will register you over the phone and provide you with contact details of a centre or branch near you or access to the Grief Support Telephone Service.

Alternatively, you can access their website www.nalag.org.au.

Dementia Australia

Dementia Australia provide a range of resources to help carers understand their feelings and coping with loss. You can call Dementia Australia National Dementia Helpline 1800 100 500 or visit their website www.dementia.org.au.

Other sources

It may also be helpful for you to talk with your doctor or religious leader.

Everyone is different

Everyone responds to a change in or the end of their carer role differently.

Common reactions include feelings of:

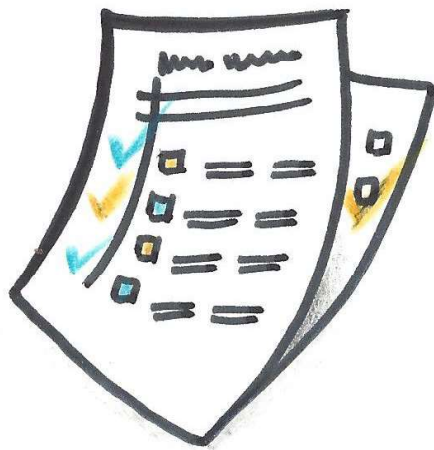
- sadness
- shock
- pain
- guilt
- relief
- resentment
- a loss of purpose.

Remember you have got to take care of yourself and get the support you need and deserve. If after a while you feel you're still not coping, you should talk to your doctor.

Let's look at an example.

With the support of the family and local doctor , Paul was admitted to an aged care facility. His wife, Maddie, had been caring for him at home but after a short illness Paul could no longer manage any of his own needs and Maddie was not strong enough to lift and help Paul move. The residential home is very nice, and Paul has settled really well, enjoying some of the different activities they are able to offer. Maddie tells their daughter she is physically and emotionally exhausted, but also feels lost now that she is no longer caring for Paul.

What advice would help Maddie?



Check your understanding



What advice would help Maddie?

You can choose more than one.

- ☐ Maddie must go on a holiday to get over her exhaustion.
- ☐ Maddie could talk to the staff at the residential aged care home to see how she can still contribute to Paul's care needs.
- ☐ Maddie should seek counselling to talk about her feelings.

Check your understanding



- ✗ **Maddie must go on a holiday to get over her exhaustion.**
This may not be the best response at this time as Maddie needs some time to adjust. Maddie's feelings are quite normal, and it is probably best that she be encouraged to talk about them and have access to any support she may need. A holiday may be a good idea once Maddie is feeling more relaxed and better able to deal with the change.
- ✓ **Maddie could talk to the staff at the residential aged care home to see how she can still contribute to Paul's care needs.**
This is a good response. If Maddie still wants to help care for Paul, there are many things she can do. It is important to discuss this with the staff so that Maddie's role in caring can be planned and supported. For example, Maddie may want to help Paul with his lunch time meal or take him for short walks in the garden in the afternoons. Maddie will still feel involved and it will also help Paul.

- ✓ **Maddie should seek counselling to talk about her feelings.**

This may be a good response if Maddie still feels emotionally and physically exhausted after a few weeks. It is best Maddie be encouraged to talk to her friends and family about her feelings which are perfectly normal. It is a good idea to get professional help when the feelings start to overwhelm a person and affect their wellbeing.



Let's review what you have learned

- It may take some time to adjust to not having a caring role.
- It is normal to feel emotional for a little while.
- Take some time for yourself just to do things you enjoy, such as reading, going for a walk or seeing family/friends.
- If you feel isolated after many years of caring, you may need to get some further support.



Where to go for more information

Professional support for carers during their caring role and when it has changed can be found at:

- **Lifeline**
For people in a crisis situation. Lifeline can be contacted 24 hours a day, every day of the year on free call 13 11 14.
- **Carers Australia**
Carers Australia can provide you with links to Carer Associations supports in your area. Carers Australia offer counselling services provided by trained professionals. Call 1800 242 636.
- **Dementia Australia**
Dementia Australia provide a range of resources to help carers understand their feelings and coping with loss. You can call the Dementia Australia Helpline on 1800 100 500.



You finished this unit, well done!