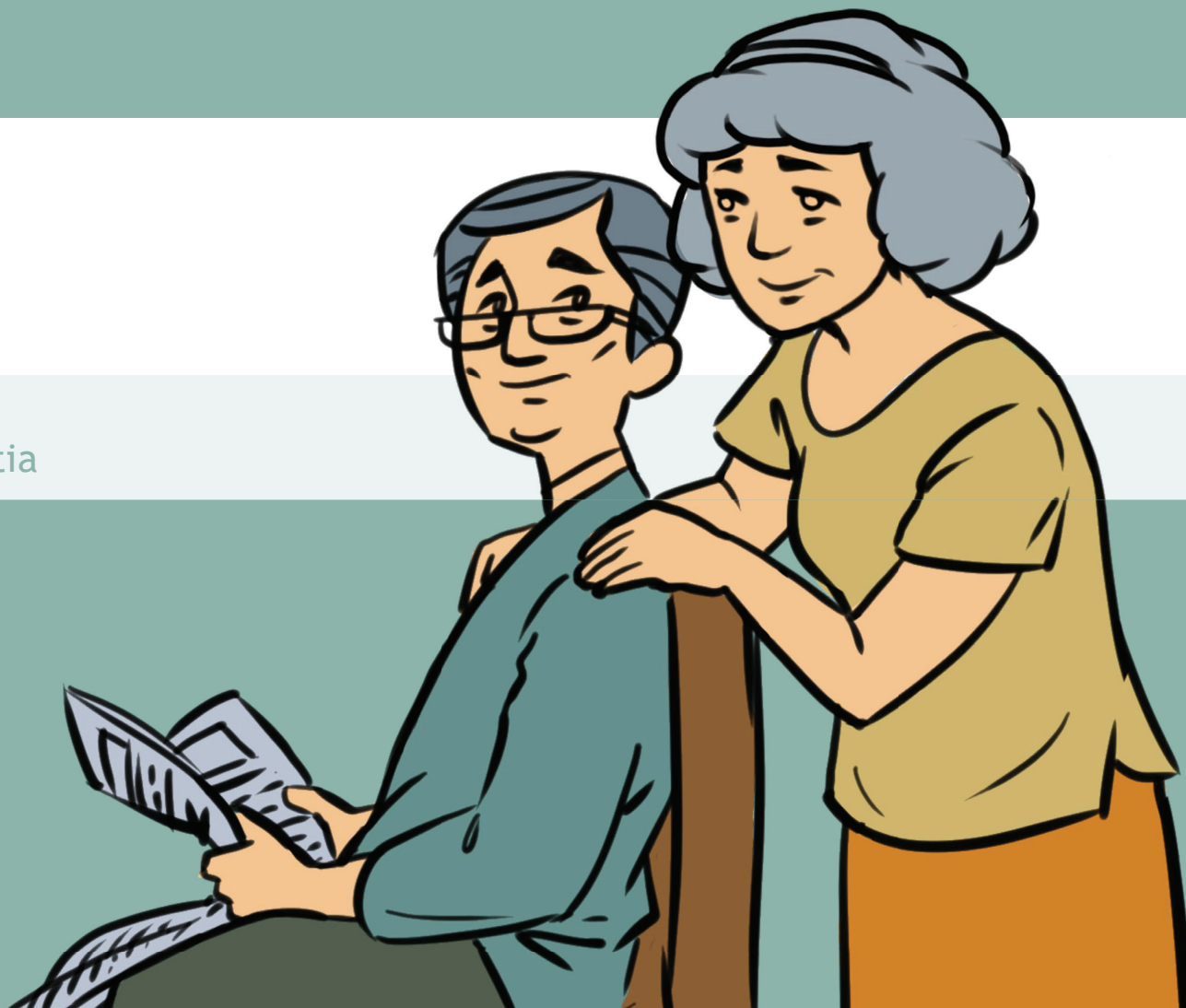


Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



Unit 1. The journey together

Why is this unit important?

Caring for someone can be challenging, both emotionally and physically. It can also be a rewarding experience.

Dealing with dementia is a journey you will take together because it changes the daily life of both the person with dementia and the carer.

How will this unit help me?

You might not think of yourself as a carer but more as a family member who looks after a person they love, but as their carer it is important to know about your caring role. This unit helps to learn skills for your journey together: to stay connected together, involve others, take care of yourself and plan for the future.

What will I learn?

- How to stay connected with the person living with dementia
- To plan pleasant activities and relaxation
- How to involve others
- To plan well for the future.

Pleasant Activities

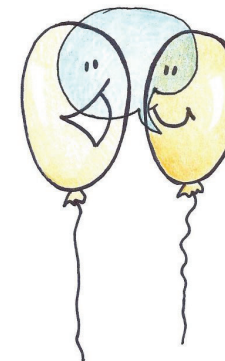
For a person with dementia, the need for a good quality of life is not diminished.

- Focus on the things you and the person you care for always enjoyed doing.
- The person may enjoy an outing even if they do not remember it afterward. What is important is that the moment is enjoyed, even though the experience may be soon forgotten.
- Give the time and space necessary to allow the person you care for to do as much as possible. Focus on one thing at a time and simple steps. Communicate one instruction at a time.

Assistance is available if you need it.
Dementia Australia can provide advice.

The National Dementia Helpline is open
nationally from 9.00am to 5.00pm Monday to
Friday excluding public holidays.

Tip



Changing roles

You may feel as if your role is changing.

In the early stages of dementia, you may still be able to enjoy many of the same activities together in the same way you always have.

As dementia progresses, the person will have more difficulty with everyday tasks. This will require a carer to do more to help with everyday life, such as giving medications and taking the person with dementia to appointments.

In the middle and later stages of dementia, a carer might need to do even more for the person with dementia. This may include personal care, such as bathing, going to the toilet and dressing.

Some tasks may be challenging for carers and cause stress.

Check your understanding

*Frustration about memory loss*

Olivia has dementia and lives with her husband Jacob. During the past few months, Olivia's memory loss seems to be more frequent. The last few times Olivia went shopping, she could not remember what to buy. She came home with the wrong things, which was frustrating.

How should Jacob approach Olivia about what happened?

- ☐ Leave Olivia alone and see what happens.
- ☐ Ask Olivia to 'work harder' to remember things.
- ☐ Do not let Olivia shop anymore.
- ☐ Ask Olivia how she feels about her memory loss.
- ☐ Do not blame Olivia but make a shopping list together with her each time prior to shopping.



ANSWERS - The journey together

Check your understanding



Frustration about memory loss

- ✗ **Leave Olivia alone and see what happens.**
This is not a helpful response because Olivia and Jacob both feel frustrated. To stay connected it is important to talk about their frustrations and worries about the future.
- ✗ **Ask Olivia to 'work harder' to remember things.**
This is not such a good response because memory loss is part of living with dementia, it is unlikely to change.
- ✗ **Do not let Olivia shop anymore.**
This is not a good response because doing the shopping is important for Olivia. Shopping may give her purpose in life and a feeling of dignity.



- ✓ **Ask Olivia how she feels about her memory loss.**
This is a good response because Jacob is addressing the issue by discussing its impact on Olivia and staying 'connected'. Jacob could share his own worries about her memory loss as well.
- ✓ **Do not blame Olivia, but make a shopping list together with her each time prior to shopping.**
This is a very good response because this will help Olivia to continue shopping and maintain her independence as long as possible.

Unit 1. The journey together

Tip: Keep talking together

It is important to keep talking together. The sooner you start talking about dementia and its effect on you and the person you care for, the better. Dementia will make doing this more difficult as time goes by. Talk about the changes happening now and what might happen in the future. Stay connected with each other and discuss the changes that may occur overtime.



Improving communication is important

Here are some small tips to help you communicate better with someone living with dementia:

- Reduce distractions in the environment. For example, lowering the volume of the TV or radio.
- Make sure that the person is wearing a working hearing aid and/or clean glasses if they have them.
- Use simple sentences.
- Use closed-ended questions which are focused and require a simple 'yes' or 'no' answer.
- Show respect and patience. Avoid using childish talk or any demeaning language. Don't talk about the person as if they are not there; try to include them in conversations with others.
- Try and stay in control of your feelings.
- Create time for yourself and for each other.

Other units

- For more tips on how to improve communication with the person with dementia, also for when communication becomes more difficult in the later stages of the disease, add the unit 'Communication' to My Plan.
- For more tips on how to relax, add the unit 'Relaxation' to My Plan.
- For more tips on how to stay in control of your feelings add the unit 'Thinking differently' to My Plan.
- For more tips on how to plan pleasant activities for yourself, add the unit 'Pleasant activities' to My Plan.

Taking care of yourself is important

Taking care of yourself: the importance of relaxation and pleasant activities

Being a carer and providing care may become increasingly time-consuming as the disease progresses.

Sometimes carers do not take enough time for themselves. It is really important to try and take care of yourself as best as you can.

Do not set aside your own health and well-being needs.

It is important to know that as a carer you may experience physical and emotional health fatigue and recognising this is the first thing to help yourself and the person you are caring for.

Part of the journey together should include planning pleasant activities and relaxation for you.

Other units

- For more tips on how to relax, add the unit 'Relaxation' to My Plan.
- For more tips on how to plan pleasant activities for yourself, add the unit 'Pleasant activities' to My Plan.



Taking care of yourself

Tip

Involving others is important

Caregiving can sometimes challenge friendships and relationships.

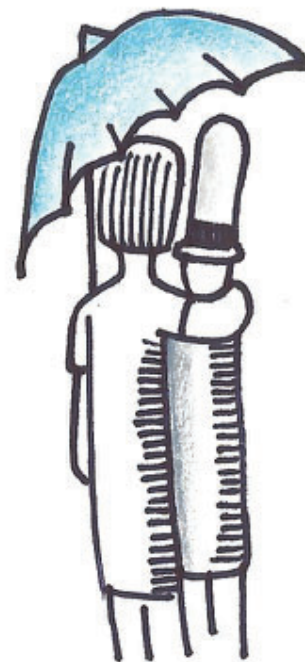
It is common for people providing care to feel that no one understands what they are going through.

Talking about your thoughts and feelings with others might help to make you feel better.

Caring for someone with dementia does not have to be a lonely experience.

Let friends and family members know when you need a break as they are often looking for ways to support you.

Caring for a loved one with dementia is sometimes too big a job for just one person.



Involving others

Tip

Check your understanding



*Feeling stressed due to conflicting duties.
Let's look at an example.*

Molly's mother-in-law, Jess, has dementia. Molly has a deadline to meet at work and needs to leave at 7:30am the next morning. The paid in-home helper is not able to arrive until 9am. This would mean Jess would be alone for over an hour. Molly wonders whether it would be okay to leave Jess alone and feels stressed because she is not sure what to do.

How could Molly deal with the situation?



- ☐ Leave Jess alone and see what happens.
- ☐ Ask a neighbour to come to visit Jess until the paid in-home helper arrives.
- ☐ Ask Jess to 'take care of herself'.
- ☐ Ask her husband to go into work late so he can be with Jess until the paid in-home helper arrives.
- ☐ Ask the paid-in home helper to come in early.

ANSWERS - The journey together

Check your understanding



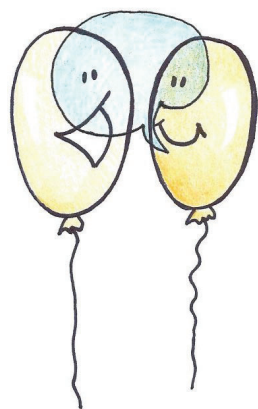
Feeling stressed due to conflicting duties

- ✗ **Leave Jess alone and see what happens.**
This is not a good response, because it potentially puts Jess in danger and Molly will not be able to perform well at work with the added stress of leaving Jess.
- ✓ **Ask a neighbour to come visit Jess until the paid in-home helper arrives.**
This is helpful because it ensures Jess' safety. Molly can do her work and also gets a short break from caregiving.
- ✗ **Ask Jess to 'take care of herself'.**
This is not a good response because her dependence on others is part of living with dementia and is unlikely to change.



- ✓ **Ask her husband to go into work late so he can be with Jess until the paid in-home helper arrives.**
This is a good response. It shows that Molly is trying to involve her family members for support and gives her the break she needs.
- ✓ **Ask the paid-in home helper to come in early.**
This is a good response but it may not happen because of the short notice.

Feeling stressed due to conflicting duties



Start2Talk is a program that has been developed by Dementia Australia to help people start the conversations involved in planning ahead. More information is available at www.dementia.org.au or call the National Dementia Helpline on 1800 100 500 (available 9am to 5pm weekdays) .

Other units

- For more tips on how to involve others in the care for the person you care for please check other units on involving others.

Preparing for the future

Preparing for the future is a topic that will need to be discussed.

You will need to make decisions with the person you care for about preferences for who might provide care, planning for the costs of future care needs, and preferences in case of more advanced care needs and end-of-life decisions.


Many people providing care, like you, worry about the future.

The earlier you plan for the future, the better and easier it will be for you, and the person you care for will be better able to say what their wishes are.

Where possible, discuss topics that concern you. Here are some common questions to assist carers :

- What are the person’s preferences when they are no longer able to bathe themselves? For example, would they prefer a male or female to help bathe them? How do they feel about having a close family member bathe them or would they prefer a qualified professional who is unrelated?
- If more assistance is needed at home, what kind of help would the person you care for prefer now and/or in the future?
- What are the person’s wishes at the end of life?
- Does the person living with dementia have an Advance (Health or Care) Directive (or other similar document)?

If you find it helpful, please write in the textbox what questions you might want to discuss:



Intimate relationships may change

As you progress through the journey together, partners may experience some changes in their intimate relationship.

At first, sexual relationships between partners may still be possible.

As the disease progresses, sexual relationships and physical intimacy may become more difficult.

Many people with dementia lose interest in a physical relationship and may become very withdrawn.

For many couples coping with dementia, physical intimacy continues to be a rich source of mutual comfort, support and pleasure for many years.

Where sexual difficulties do arise, it's important to remember that there is no single 'normal' way of dealing with this very personal issue.

While it may be a difficult subject to discuss, you might find it helpful to talk to someone you trust like your doctor.

Check your understanding

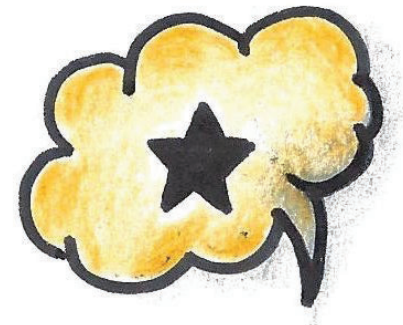


Let's visit the scenario with Olivia and Jacob again

Olivia is in the early stages of dementia and lives with her husband, Jacob. Olivia and Jacob have a healthy, mutually satisfying physical relationship, but Jacob is worried about the day when these relations may stop.

What are some ways Jacob and Olivia can maintain their intimacy as Olivia's dementia progresses?

Think about it before you go to the next page.



Ways to stay connected:

- Use touch, hold hands, or do a gentle massage to communicate warmth, connection, safety and love.
- Use music - it is truly a universal language. Play music the person you care for likes and that makes the person feel good.
- Try to maintain your sense of humour. This will help reduce frustration and tension.
- Talk with the person you care for about what their likes and needs - it's an important conversation to have more than once, as things change overtime.
- Talking about your feelings with someone trained in this area can help. Knowing that others have been through a similar experience may assist you to feel that you are not on your own.

Further information on Intimacy and sexual issues can be found on a Help Sheet produced by Dementia Australia.

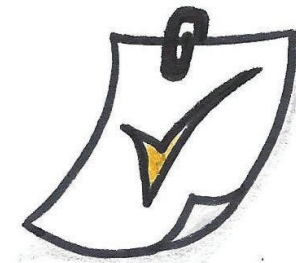
The National Dementia Helpline can be contacted on 1800 100 500 or Dementia Australia at dementia.org.au

Taking care of yourself

One of the most important things to remember as roles change is that you, as a person providing care for a person living with dementia, need to care for yourself too. Throughout this programme we will teach you ways to do this.

Remind yourself:

- Caring for someone with dementia can be frustrating and stressful at times, It is okay to take a break.
- It is okay to ask for help.
- It is okay to feel frustrated sometimes.
- It is okay to feel lonely sometimes if you feel the person you care for is no longer able to have meaningful communication with you.



Keep in Mind

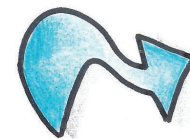


Let's review what you have learned

- As your role changes, it is important to stay connected during your journey together.
- Make sure you plan pleasant activities and relaxation, so your role does not become overwhelming.
- Ask for help because providing care to someone with dementia can be tiring.
- Make sure you plan well for the future.
- There are many different ways to maintain intimacy and stay connected.

You finished this learning unit, well done!

Would you like to try the following relaxation exercise?



Basic breathing

Focusing on your breathing is relaxing. By doing a breathing exercise you could reduce tension.

Caution: if you experience difficulty breathing, this exercise might not be the best option for you.



This is how you do it:

- When sitting down: Sit up straight in your chair with your back against the back of your chair.
- When standing: Stand up straight.
- Put both of your feet flat on the surface.
- Focus on your breathing.
- Keep breathing like you are used to. Try to feel how you breathe.
- Put your hand on your stomach to feel how you inhale and exhale.
- Exhale from your mouth and pull in your stomach as much as possible.
- Follow your breathing in this manner a couple of breathes and then stop with the exercise.

Additional help

Dementia Australia offers support, information, education and counselling. The National Dementia Helpline can be contacted on 1800 100 500 or visit Dementia Australia at dementia.org.au

Commonwealth Respite and Carelink Centres provide free and confidential information on local carer support, disability and community services. Centres are located throughout Australia, and you can contact your nearest Centre by phoning 1800 052 222 (Freecall except from mobile phones).

Information on aged care can be found on the **My Aged Care** website myagedcare.gov.au

The **Carer Advisory and Counselling Service** provides carers with information and advice about relevant services and entitlements. Contact your closest Carer Advisory and Counselling Service on 1800 242 636.

RELATED LEARNING UNITS

- Module 2 Unit 2 Improving communication
- Module 3 Unit 2 Making time for pleasant activities
- Module 4 Unit 3 Toileting and continence care





You finished this unit, well done!