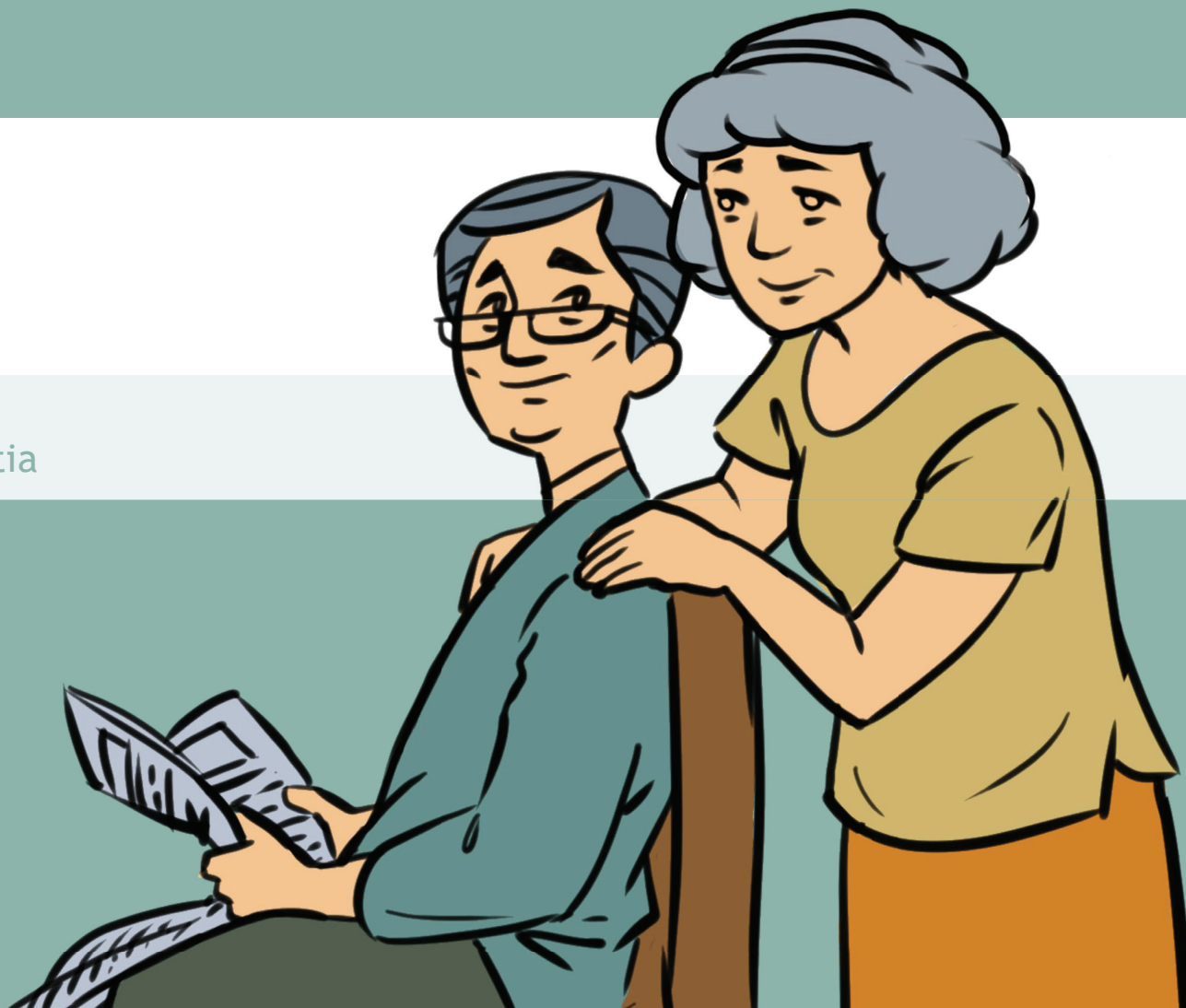


Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



iSupport For Dementia

Training and support manual
for carers of people with dementia

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iSupport for dementia. Training and support manual for carers of people with dementia

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The World Health Organization (WHO) developed iSupport for Dementia, a comprehensive online dementia education and skill training programme for informal carers of people living with dementia [1]. This programme has been adapted into the Australian social context [2]. Flinders University funded the research activities leading to the current version of Australian iSupport for Dementia. The research team members who contributed to the adaptation of the WHO iSupport for Dementia programme and to the new learning module in the programme entitled 'My engagement in consumer directed care' are:

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1. World Health Organization; (2019). iSupport for dementia. Training and support manual for carers of people with dementia. Geneva: World Health Organization. Licence: CC BY-NC-SA 3.0 IGO.
2. Xiao, L. D., McKechnie, S., Jeffers, L., De Bellis, A., Beattie, E., Low, L. F., per, B., Messent, P., & Pot, A. M. (2021). Stakeholders' perspectives on adapting the World Health Organization iSupport for Dementia in Australia. *Dementia* (London, England), 20(5), 1536-1552.

MODULE

2

BEING A CARER

- Unit 1. The journey together
- Unit 2. Improving communication
- Unit 3. Supported decision-making
- Unit 4. Involving others

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.

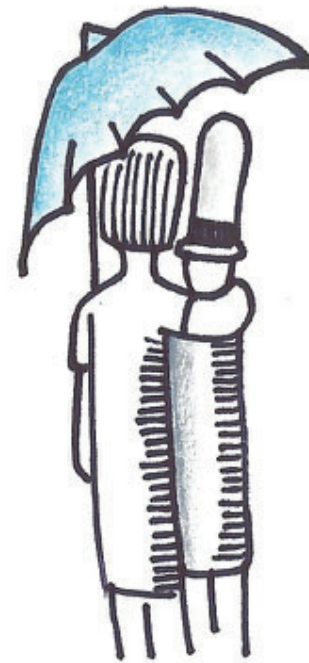
It is common for people providing care to feel that no one understands what they are going through.

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



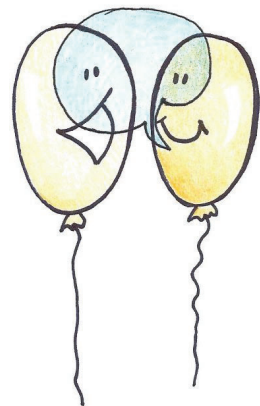
Feeling stressed due to conflicting duties

- ✗ **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

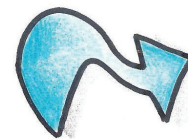


Let's review what you have learned

- 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

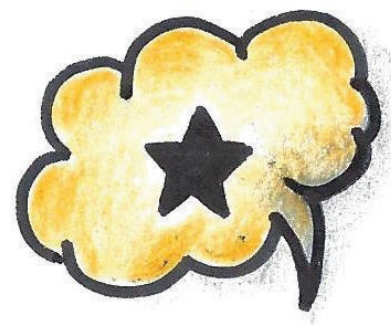
Commonwealth Respite and Carelink Centres provide free and confidential information on local carer support, disability and community services. Centres are located throughout Australia, and you can contact your nearest Centre by phoning 1800 052 222 (Freecall except from mobile phones).

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!

Unit 2. Improving communication

Improving communication**Why is this unit important?**

Dementia can often make communication difficult.

How will this unit help me?

This unit helps you to talk in a simple and direct way and show your compassion in everyday situations.

What will I learn?

- To check the ability to hear and see
- To get attention in a respectful way
- To keep it simple
- To take the person seriously
- To pay attention to reactions
- To give compliments
- To show compassion.

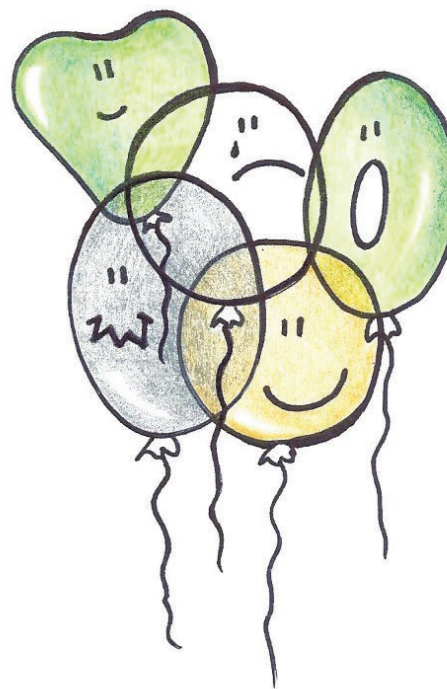
How to improve communication?

In this unit, you will receive tools and tips for good communication. Dementia can often make communication difficult.

This can have an impact on your relationship with the person you care for.

It can even make the person you care for or you frustrated, sad, or angry.

When you communicate with the person you care for, for example by talking or giving a hug, make sure the person you care for understands what you mean by your action and that you understand the person you care for too.



1. Show compassion

It is important that you show compassion, even if a person living with dementia is repeating the same questions over and over again, or understanding each other becomes increasingly difficult.

In this unit we help you to show your compassion. Some important basic skills for communication will be explained.

Check your understanding

?

Imagine for a moment that you are living with dementia. What would you like other people to do?

☐ Listen to how you feel

☐ Talk behind your back

☐ Give you a smile

☐ Say they do not care

☐ Tell you they love you

☐ Treat you like a child

☐ Approach you with respect and dignity.

Check your understanding

?

✓

Listen to how you feel

✗

Talk behind your back

✓

Give you a smile

✗

Say they do not care

✓

Tell you they love you

✗

Treat you like a child

✓

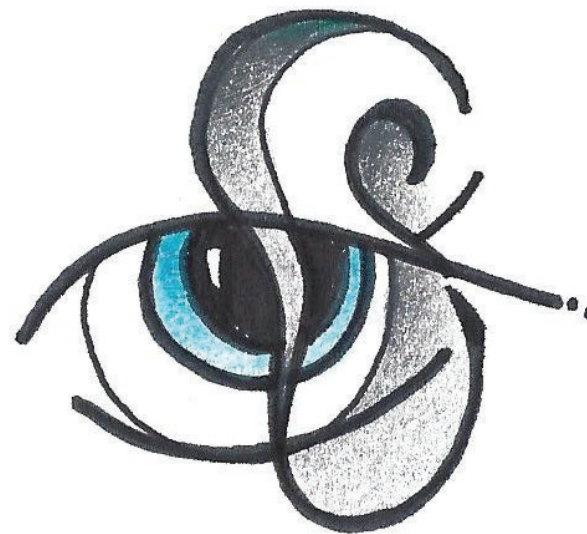
Approach you with respect and dignity.

2. Check ability to hear and see

For all communication - talking, touching, or gestures - the basics, like the ability to see and hear, are important.

Unfortunately, dementia may impair someone's ability to hear and see.

Therefore, it is important that you check if their hearing and sight could be improved by you making changes in their environment or arranging for any relevant medical check-ups.





1. Activity



To help improve sight

Check the following:

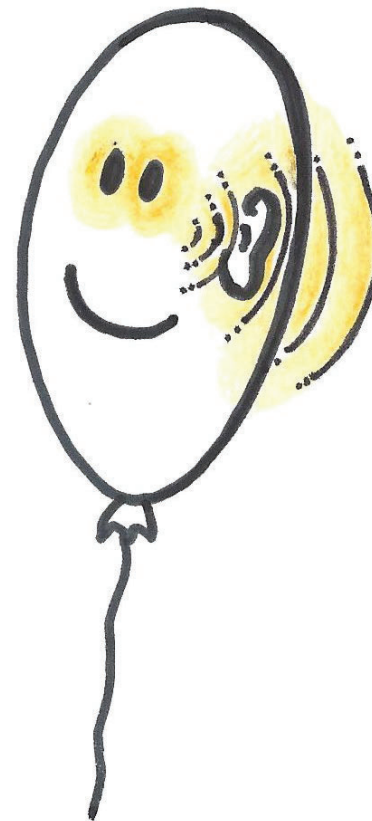
Is there enough light?	<i>In general, people living with dementia need more light to see clearly. Increase light levels and use natural daylight where possible. It will help the person with dementia to see better. You may also consider leaving some lights on at night so the person can find the bathroom/toilet.</i>
Is there enough contrast in colours?	<i>Dementia can make it hard to see contrasts. For example: if there is a white plate on a white table, people with dementia may have difficulty seeing the plate. A coloured plate or tablecloth may help.</i>
Is the person with dementia wearing his/her glasses?	<i>Make sure glasses are clean and in reach. Consider a glasses lanyard.</i>
Are the glasses still okay?	<i>If the person with dementia wears glasses, check whether they are clean and still comfortable to wear. Are the glasses comfortable around the ears and nose? Does the person with dementia lose the glasses often? Perhaps a neck cord would be helpful in that case.</i>
Do you need to consult a doctor?	<i>If the person with dementia does not have glasses, but cannot see well anymore, consult a doctor. If the person with dementia wears glasses, check to see if the prescription is still okay, or consult a doctor.</i>


3. To help improve hearing

Remember:

Hearing and seeing is important for communication.

There are different ways to help improve hearing and seeing.



1. Activity 	
To help improve hearing	
Check the following:	
Is there no background noise?	<i>Minimising background noise will help to improve hearing. Perhaps take the person with dementia to a quieter location with fewer distractions. Turn off the TV or radio when trying to communicate with them.</i>
If the person with dementia has a hearing aid, is he/she wearing it?	<i>Is the aid in reach and easily found when needed.</i>
Is the hearing aid still okay?	<i>If the person with dementia is wearing a hearing aid, check they are clean, fit snugly in the ear canal, are still comfortable to wear and the batteries are charged.</i>
Do you need to consult a doctor?	<i>If the person with dementia wears a hearing aid: Is the prescription still OK, or do you need to consult a doctor? If the person with dementia does not have a hearing aid, but cannot hear well anymore, you should also consult a doctor.</i>

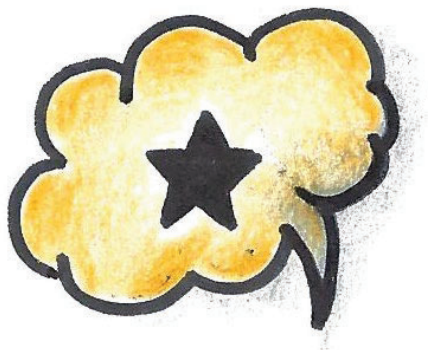
Many ways to improve communication

There are many ways to improve communication.

A first step is to optimise seeing and hearing.

To improve seeing, make sure that there is enough light and contrast in colours. Check glasses or consult a doctor if you are unsure.

To improve hearing, reduce background noise. Check hearing aids or consult a doctor if you are unsure.



Get attention in a respectful way

The person living with dementia is still a person with feelings, no matter how serious the disease is or communication problems are. Therefore, an important first step is to make contact with them by catching their attention.

Below are some suggested ways to get the attention of a person with dementia.

Please select which you think will help and drop them into the box:

Check your understanding



- ☐ Raise your voice or shout.
- ☐ Speak clearly, slowly, at a volume that is comfortable for the person, face to face and at eye level.
- ☐ Tap a hand, arm or front of the shoulder.
- ☐ Stop and hold the person to make their listen.
- ☐ Approach from the back and touch the person's shoulder.
- ☐ Call the person with dementia by a name that he or she recognises.

ANSWERS - Improving communication

Check your understanding



Get attention in a respectful way

- ✗ **Raise your voice or shout.**
Raising your voice is not a respectful way to gain attention. It may even make the person with dementia feel scared, sad, frustrated or angry.
- ✓ **Speak clearly, slowly, at a volume that is comfortable for the person, face to face and at eye level.**
This is an appropriate way to make contact. It shows that you are seeking contact in a respectful manner.
- ✓ **Tap a hand, arm or front of the shoulder.**
This is a good way to attract attention of a person with dementia.



- ✗ **Stop and hold the person to make their listen.**
This is not a respectful way to gain attention. It may even make the person with dementia distressed or angry.
- ✗ **Approach from the back and touch the person's shoulder.**
This may startle someone who is not expecting you or perhaps did not hear you coming.
- ✓ **Call the person with dementia by a name that he or she recognises.**
This is a good way to attract attention of a person with dementia. It might be the first name but also a nickname that was used in the past.

Be aware that:

- Gaining attention is a first important step for good communication.
- There are different ways to gain the attention of a person with dementia in a respectful manner.

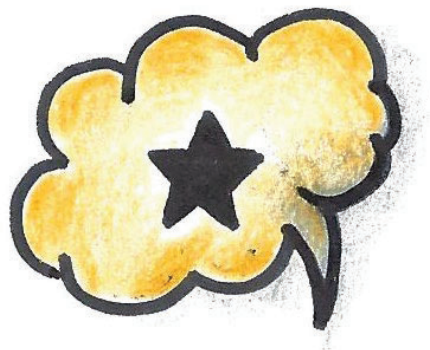


Keep it simple

Often the language we use to get a message across is too complicated. Keeping it simple will help the person living with dementia understand you better.

Let's look at an example:

Jonathan supports his father who has dementia.
Jonathan notices that his father does not understand him.



Can you tell why?

Select the objects in the list below and drop them in the box if you think they could impair communication between Jonathan and his father.

Check your understanding



- ☐ The radio is on.
- ☐ Jonathan is making a phone call.
- ☐ Jonathan asks multiple questions at the same time.

ANSWERS - Improving communication

Check your understanding



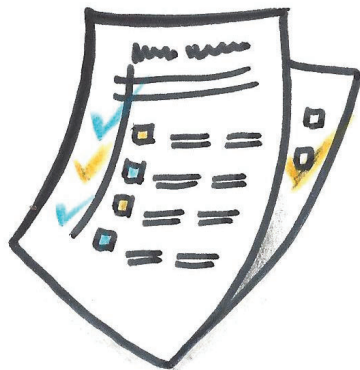
- ✓ **The radio is on.**
Very good! A radio can be very distracting. It makes it difficult to follow what someone else is saying, especially for people with dementia who can have difficulty concentrating.
- ✓ **Jonathan is making a phone call.**
Very good! Making a phone call does not show interest and will confuse his father. It's important for people with dementia to try and stay focused on one task. It will be difficult to get back on to the same subject after making a phone call.
- ✓ **Jonathan asks multiple questions at the same time.**
Well done! Jonathan is trying to ask too many questions at the same time. This makes it difficult for his father to understand.



Keep in Mind



- Ask or tell the person living with dementia one thing at a time.
- Use simple language and keep sentences short: avoid long and complicated sentences, focus on one subject at a time, and when needed change from open-ended questions to closed-ended questions that can be answered with YES or NO.
- Make sure there are no distracting background noises such as a TV or radio.



Take the person seriously

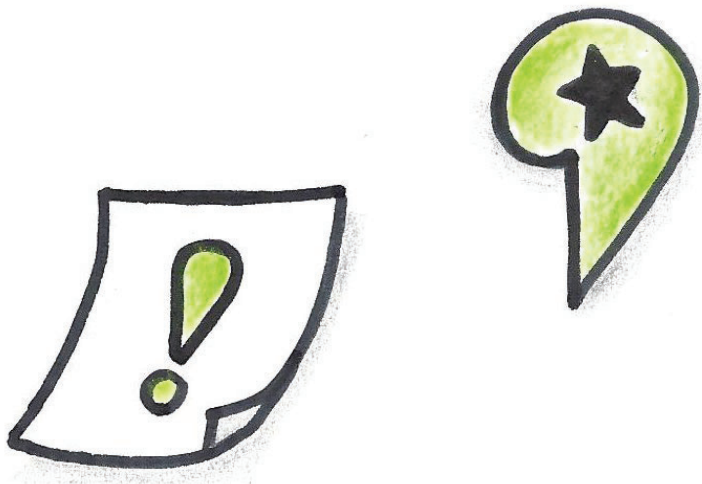
At some point, you may not understand what the person you care for means. The language the person uses may even seem strange or funny.

But be aware: it is important that you take the person seriously. the person you care for is trying to tell you something, however the person communication skills may be impaired due to the dementia.

Let's have a look at John

John and his wife are visiting John's father who has dementia. His father wants to describe his morning to John, but he cannot find the right words. John says to his wife in front of his father: 'I have no clue what he means!' His wife answers: 'Yes, I don't know either. He is just like a child!'

Which of the following statements do you think is correct?



Check your understanding



- ☐ John should not talk about his father when his father is in the same room. He could have said: 'It is difficult to understand what you mean.' In addition, he could have asked some questions that his father could have answered with a 'YES' or a 'NO'. For example: 'Have you gone outside this morning?'
- ☐ John and his wife could be more patient.
- ☐ John and his wife could ask John's father if it is okay when they try to guess what he wants to say.
- ☐ It is important that John and his wife talk about the difficulty to understand John's father in front of him.
- ☐ His wife is right: a person with dementia is just like a child.

ANSWERS - Improving communication

Check your understanding



- ✓ **John should not talk about his father when his father is in the same room. He could have said: 'It is difficult to understand what you mean.' In addition, he could have asked some questions that his father could have answered with a 'YES' or a 'NO'. For example: 'Have you gone outside this morning?'**

Correct! John takes his father seriously in trying to understand what he wants to say. Do not talk about the person, while the person is in the same room.

- ✓ **John and his wife could be more patient.**
Correct! It takes people with dementia longer to find the right words and they need time and patience to be understood.

- ✓ **John and his wife could ask John's father if it is okay when they try to guess what he wants to say.**
Correct! Some people with dementia appreciate help with finding the right words or fill in sentences.

- ✗ **It is important that John and his wife talk about the difficulty to understand John's father in front of him.**

This is not correct! Although it might be important to talk about ways to improve their understanding of their father, they should not do so in front of him.

- ✗ **His wife is right: a person with dementia is just like a child.**

This is not correct! It is important to take a person with dementia seriously, and treat them with respect and dignity.

Keep in Mind



- It is important to take the person seriously.
- It may help to ask closed-ended questions that can be answered with YES or NO to understand what the person living with dementia means.



Pay attention to reactions

You can tell a lot from the way someone speaks and looks. For example, if someone is smiling, you can assume that this person is in a good mood.

Keeping this in mind will help you communicate with the person living with dementia.

Check your understanding



Take a look at the cartoons.

Do you understand this feeling?

Select the right answer below and drop it into the box at the right.

☐
☐
☐
☐

Happy
Angry
Sad
Scared

☐
☐
☐
☐

Happy
Angry
Sad
Scared

☐
☐
☐
☐

Happy
Angry
Sad
Scared

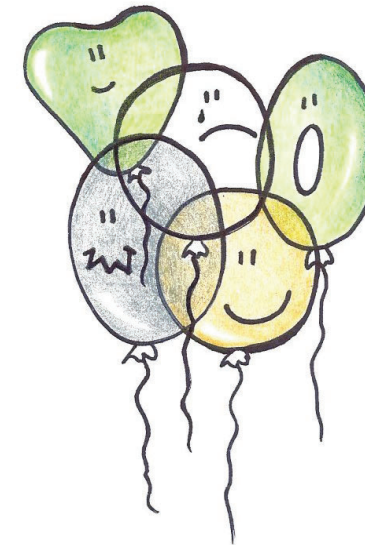
☐
☐
☐
☐

Happy
Angry
Sad
Scared

Keep in Mind



- Facial expressions and body language tell us how a person is feeling. Other examples of body language include fidgeting, having arms crossed or pacing. These can give us messages about how the person may be feeling, such as nervous, upset or anxious.
- Take notice the person's responses and body language.

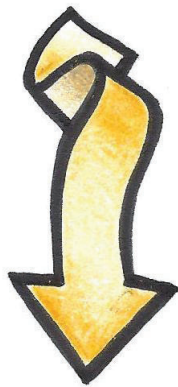


Give compliments

Complimenting the person is important.
In general, it is much more effective to say what someone is doing well, than to say what the person is doing wrong.

A compliment can range from commenting that someone has done something well to saying that they look nice.

You can give compliments in different ways and in different situations.



Below there is a list of statements.
These statements include several compliments. However, there are also some statements that are not compliments at all.
Click on the statements that are compliments and drop them in the box.

Check your understanding



- ☐ You look beautiful.
- ☐ You are good at...
- ☐ What are you doing?! Stop it!
- ☐ You are very helpful. Thank you.
- ☐ You are making a mess.
- ☐ You should be ashamed of forgetting everything.
- ☐ I love having you around.
- ☐ You are funny.
- ☐ You are driving me crazy.
- ☐ You have a great smile.

ANSWERS - Improving communication

Check your understanding



- ✓ You look beautiful.
- ✓ You are good at...
- ✗ What are you doing?! Stop it!
- ✓ You are very helpful. Thank you.
- ✗ You are making a mess.
- ✗ You should be ashamed of forgetting everything.
- ✓ I love having you around.
- ✓ You are funny.
- ✗ You are driving me crazy.
- ✓ You have a great smile.

Keep in Mind



- The person will feel good if you say something positive.
- Compliments can be given in many different ways.
- Saying something negative will make a person feel bad.



Think about all the things you like about the person.
Now try to write down something you would say to the person to
give the person a compliment.

Activity



Compliments:

Show compassion

It is important that you show compassion, even if a person with dementia is repeating the same questions over and over again, or when understanding each other becomes increasingly difficult.

You need to remember that dementia is a disease that can make communication difficult. For example, a person with dementia may have forgotten what the person has just said. You need to use extra effort and be patient with the person.

How to show compassion?

Let's look at an example.

Will often visits his sister, who is living with dementia. His sister lives with her brother-in-law. Her husband passed away six months ago. When Will is visiting, his sister often asks where her husband is. Will finds this difficult. He knows she is missing her husband and may have forgotten that he died. Will tries to distract her by asking questions about other things, such as: 'How was your day?' His sister persists in asking where her husband is.

Check your understanding

?

Did Will respond well?

☐

YES

☐

NO

Check your understanding

?

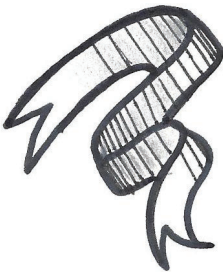
x

YES

✓

NO

That's right! Will wants to distract his sister's attention because he knows she is missing her husband and will be sad to be reminded that he died. Although Will has the best intentions, ignoring her questions is not a right way to respond especially because his sister persists in asking.



Today Will tries a different approach

He says: 'It must be difficult for you that he died.'
He gives her a hug.
He shows some pictures of her husband that he brought from home and starts to talk with her about her husband.

Will shows that he understands she is missing her husband and tries to support her.

Check your understanding		?
Did Will respond well?		
<input type="checkbox"/>	YES	
<input type="checkbox"/>	NO	

Check your understanding		?
<input checked="" type="checkbox"/>	YES	
<input type="checkbox"/>	NO	

Indeed! It is important to try different responses to identify the one which will cause the less distress. Initially Will tried to distract her with no success. Today by showing her pictures of her husband, they had a good conversation about her husband.

Further information

Talk to me is a help sheet for good communication for talking to people with dementia.
The document is available via:
https://www.dementia.org.au/sites/default/files/TalkToMe_Brochure_FoldedDL_HR.pdf

Keep in mind that people with dementia also have the right to grieve the loss of a loved one in a safe and supportive setting.

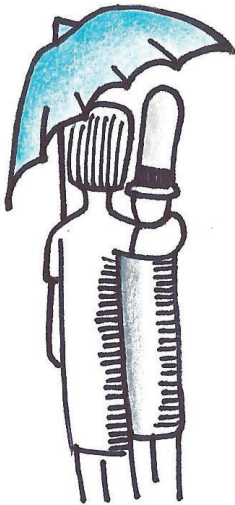
This example of Will and his sister shows:

You can show compassion in different ways.

It is important to take a person with dementia seriously and to pay attention to the questions he or she has.

Showing compassion helps to improve your relationship with the person you care for.

Tip



Congratulations!

This is your certificate for practising 7 communication skills:

- Check ability to hear and see
- Get attention in a respectful way
- Keep it simple
- Take the person seriously
- Pay attention to reactions
- Give compliments
- Show compassion.



RELATED LEARNING UNITS

- Module 4 Unit 1 Eating and drinking - More pleasant mealtimes
- Module 2 Unit 3 Supported decision making

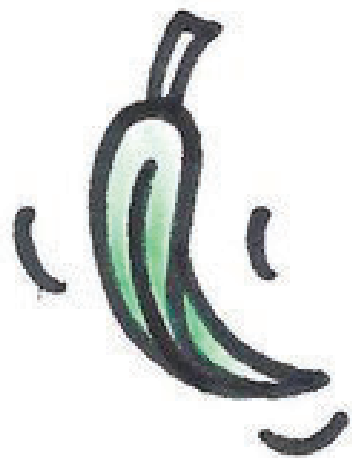
You finished this learning unit, well done!

Would you like to try the following relaxation exercise?



Neck movements

With this exercise you will feel less tension in your neck. It will also increase the blood flow to your brain.



This is how you do it:

- Make sure to move slowly and with attention.
- Bend your neck forward and backward.
- Inhale while you lift your head up and back. Exhale while you drop your chin to your chest.
- Rotate your chin from side to side.
- Inhale when your chin is in the centre. Exhale when you look to the side.
- Drop your ear towards your shoulder.
- Inhale when you are in the centre. Exhale when you drop your ear to your shoulder.
- Repeat 5 times.



You finished this unit, well done!

Unit 3. Supported decision-making

Supported decision-making

Why is this unit important?

Making decisions about our own lives is important for all of us.

For people with dementia the ability to make simple or complex decisions varies greatly and will depend on the extent of disease progression.

How will this unit help me?

People who provide care may not be aware of strategies that help make it easier for people with dementia to make many of their own decisions.

Practicing how to support a person with dementia to make their own decisions as long as possible will assist in making decisions in the person's best interest.

What will I learn?

- How to make decisions in someone's best interest
- How to support someone with dementia by making everyday decisions
- How to support someone with dementia by making complex decisions
- What support is available.

Why support for making decisions is needed

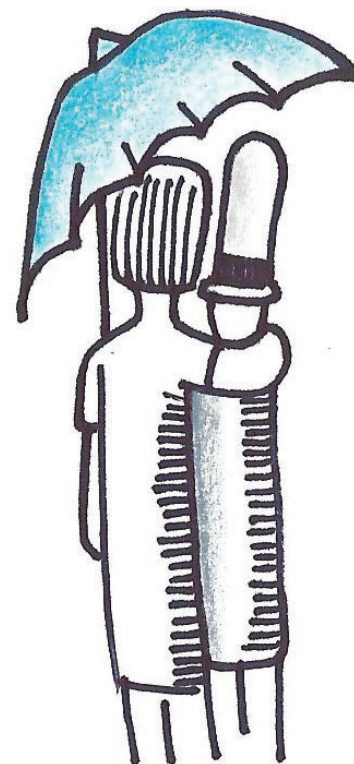
Support for someone with dementia to make their own decisions is very important.

The World Health Organization states that people living with dementia have the right to participate in all decisions which affect their lives and wellbeing.

However, making decisions may become difficult due to the progression of dementia.

Sometimes this results in relatives taking over decision-making, instead of supporting people with dementia to make their own decisions.

If you are making decisions on behalf of someone with dementia, it is important that you use the person's wishes as a guide.



How to support making decisions in someone's best interest

In this unit you will learn how you can support the person living with dementia when the person needs to make a decision.

Everybody needs to make decisions, whether they are big or small. Because the person has dementia, your support is needed to help the person make clear what the person wants.

Decisions in line with the interests, needs and wishes of the person living with dementia will make the person more independent and feel respected.



Why decision making can be difficult

Why do you think decision making can be difficult for a person with dementia?

Have a look at the reasons below to find out more.

Reasons:

- **Memory loss**

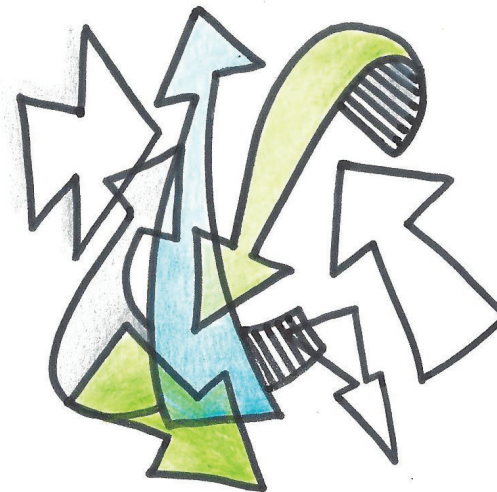
Having memory loss will cause the person to sometimes forget the information that is needed to make a decision.

- **Problems with thinking or difficulties identifying and describing what the person thinks**

When the person has problems with thinking, it will be difficult to provide support with making decisions.

- **Problems with making complex decisions**

Decisions which are complex, such as deciding whether or not to go outside alone, are more difficult to make and support is therefore important.



Think of your own situation


- Making decisions will become more difficult as the dementia progresses.
- Your support for the person living with dementia to make own decisions is needed.
- Letting the person living with dementia make own decisions might not be easy because of dementia.
- Recognise that the person living with dementia still has abilities that should be respected and encouraged.

Do you support the person living with dementia to **make decisions**?

You may want to write down
support in decision-making



which way you

Support for everyday decisions

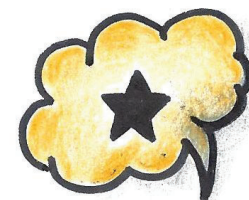
Let's look at an example.

Max has Alzheimer's disease and is married to Maria.

Max always used to lay out his clothes for the next day in the evening.

Now he has dementia, he forgets to do this and sometimes wears the same clothes every day.

What do you think is the best way to make sure that Max wears clean clothes, without taking over his decisions at the same time?



Check your understanding



- ☐ Before Maria and Max go to bed, Maria asks Max what he wants to wear the next day. She then asks Max to lay them out.
- ☐ Maria chooses clothes for Max, and she asks Max to lay them out.
- ☐ Maria chooses clothes for Max in the morning and gives them directly to Max to wear.

ANSWERS - Supported decision-making

Check your understanding



- ✓ **Before Maria and Max go to bed, Maria asks Max what he wants to wear the next day. She then asks Max to lay them out.**

Very good, this is the right choice! This way Max is encouraged to do the things he is still able to do.

- ✓ **Maria chooses clothes for Max, and she asks Max to lay them out.**

It is good that Max is encouraged to lay out his clothes himself, however, it would have been better if Maria supported Max in making his own decision about what to wear.

- ✗ **Maria chooses clothes for Max in the morning and gives them directly to Max to wear.**

This is not a good option. Maria is taking control from Max. It would be better if she could support Max in making his own decision and encourage him to do the things which he is still able to do, such as laying out the clothes.

Keep in Mind



- It is important to encourage people living with dementia to do whatever they still able to do.
- Supporting people living with dementia in making decisions will help them to be more independent.
- Supporting people in making decisions might add to their self-esteem.



Support for making everyday decisions as dementia progresses

After some time, Max feels stressed when choosing his clothes for the next day with Maria.

He starts to worry about everything else he needs to do the next day and becomes anxious.

This makes it difficult for Maria to support Max in making his decision.

What should Maria do?



Check your understanding



- ☐ Instead of supporting Max in choosing what he wants to wear in the evening for the next day, she asks him in the morning at the beginning of the day.
- ☐ Maria lays out Max's clothes in the evening.
- ☐ When Maria asks Max what he wants to wear in the evening she can give him only a few choices and, for example, ask him whether he wants to wear his blue or black trousers.

ANSWERS - Supported decision-making

Check your understanding



- ✓ **Instead of supporting Max in choosing what he wants to wear in the evening for the next day, she asks him in the morning at the beginning of the day.**

This is a good option: this way Maria still supports Max to decide what he wants to wear, but he will not start to worry the evening before.

- ✗ **Maria lays out Max's clothes in the evening.**

This is not a good option: Maria is deciding for Max, while he still might be able to make his own decisions.

- ✓ **When Maria asks Max what he wants to wear in the evening she can give him only a few choices and, for example, ask him whether he wants to wear his blue or black trousers.**

In some cases this might be a good option. Even though Maria decides which trousers Max should wear the next day, Max can still make the final decision himself. However, remember too if Max continues to worry about the next day it might not be the best thing to do because it might not solve the problem.

Keep in Mind



Be aware

- Supporting someone with dementia to make their own choices is possible, even as dementia progresses.
- It may help to simplify decisions by limiting the number of choices or discuss the situation at a better time when the person is in a better mood or less worried.

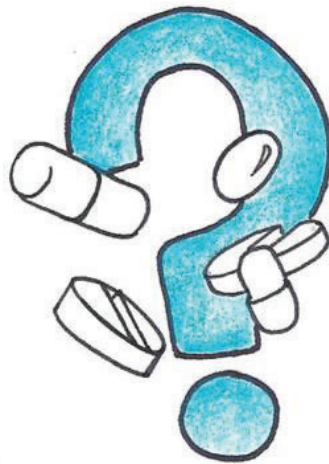


Support for making complex decisions

Mary has vascular dementia. The doctor advises Mary to start using medication for her blood pressure. Mary says that she does not want to take pills because she does not understand why she needs them. Chrissy, Mary's daughter, is concerned her mother will not do as the doctor suggested.

What should the doctor and Chrissy do?

What do you think is the correct answer?
Multiple answers are correct.



Check your understanding



- ☐ Mary says what she wants, so she does not need support in making the decision whether or not to start with the medication.
- ☐ The doctor says that she should take the medication because it is good for her health.
- ☐ The doctor explains that taking the medication is good for her health, because it will slow down further damage in her brain because of her dementia.
- ☐ Her daughter says: 'Mum, you know that you are forgetting things and that you have difficulties to find the right words when you want to say something. By taking the medication these problems may slow down a bit.'

ANSWERS - Supported decision-making

Check your understanding



✗ **Mary says what she wants, so she does not need support in making the decision whether or not to start with the medication.**

This is not correct. Because Mary has dementia, we are not sure whether or not she understands why she needs the medication and what the consequences might be of taking or not taking the medication.

✗ **The doctor says that she should take the medication because it is good for her health.**

Although it is true that the medication will be good for her health, the doctor is telling Mary what to do which is not so good.

✓ **The doctor explains that taking the medication is good for her health, because it will slow down further damage in her brain because of her dementia.**

This is right! The explanation of her doctor makes Mary understand the importance of taking the medication and will enable her to make an informed decision.

✓ **Her daughter says: 'Mum, you know that you are forgetting things and that you have difficulties to find the right words when you want to say something. By taking the medication these problems may slow down a bit.'**

Very good! Using different words to explain the possible reasons for taking the medication might help Mary to understand why taking the medication would be beneficial for her.

Keep in Mind



Recognise

- Someone with dementia can be involved in making complex decisions, such as medical decisions, with the right support.
- Support for the person living with dementia to make complex decisions should focus on providing correct information to help someone with dementia understand what the consequences of the decision are.

ANSWERS - Supported decision-making

Reasons for not being able to make an informed decision

Jack has vascular dementia. Jack is advised to start using medications for his blood pressure. Jack immediately refuses to take these medications. Jack's doctor explains his medical condition and why it is important to take the pills, however Jack does not understand and denies that he has medical issues. He becomes suspicious of his wife and the doctor.

What do you think are reasons that Jack can no longer make the decision himself?

Check your understanding

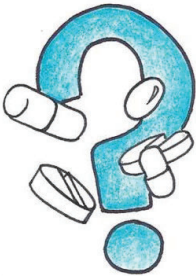


- ☐ Jack is unable to understand the information relevant for the decision.
- ☐ Jack does not agree with the doctor.
- ☐ Jack is unable to communicate his decision (by talking, using body language or any other means).
- ☐ Jack is unable to use or weigh the information as part of the process of making the decision.

Check your understanding



- ✓ Jack is unable to understand the information relevant for the decision.
- ✗ Jack does not agree with the doctor.
- ✗ Jack is unable to communicate his decision (by talking, using body language or any other means).
- ✓ Jack is unable to use or weigh the information as part of the process of making the decision.



Reasons for not being able to make an informed decision: Summary

There comes a time in the course of dementia when someone is not able to make complex decisions anymore, such as decisions concerning medical treatment.

Reasons for not being able to make an informed decision include:

- Inability to understand the information relevant for the decision.
- Inability to communicate the decision (whether by talking, using sign language or any other means).
- Inability to use all information as part of the process of making the decision.
- Inability to retain the information relevant for the decision.



Be aware that the capacity to make a decision

- **Depends on the type of decision being made.**
Someone with dementia might still be able to choose what kind of clothes to wear, but perhaps not whether to take medicines.
- **May change over time.**
Imagine that Jack had a severe infection that made him very confused. After this infection is cured, he might be able again to decide whether or not to take the medication.
- **Can be difficult to assess.**
Sometimes it isn't clear, in which case there is no other alternative than to work with this and to help to make a decision in the best interests of the person with dementia.

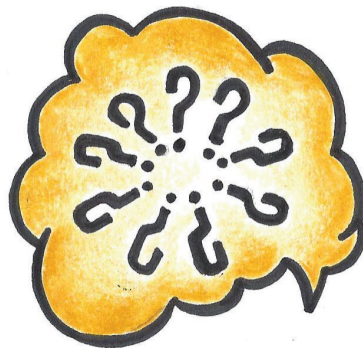
A decision in someone's best interest

Jack is living with dementia.

His wife, Ella, decides to make an appointment with the doctor without Jack to discuss his medical condition and to make a decision regarding his medication.

Ella discusses the issue with Jack's sister as well, who asks her what she thinks Jack would have decided before he was diagnosed with dementia.

Ella talks to the doctor and tries to imagine what Jack would have decided when given all the information.



How to make a decision in someone's best interest?

If you need to make a decision in the best interests of someone with dementia, what do you think is important to do and to take into account?

Check your understanding



- ☐ The views and wishes of family members.
- ☐ The person's past and present wishes and feelings (and in particular any relevant written statement of the person).
- ☐ Beliefs and values that may have influenced the person's decision.
- ☐ The views and wishes of yourself and what you would want in this situation.
- ☐ The views of anyone named by the person as someone to be consulted for making decisions in case he or she is no longer able to decide.

ANSWERS - Supported decision-making

Check your understanding



- ✗ **The views and wishes of family members.**
This is not correct. Because Mary has dementia, we are not sure whether or not she understands why she needs the medication and what the consequences might be of taking or not taking the medication.
- ✓ **The person's past and present wishes and feelings (and in particular any relevant written statement of the person).**
Although it is true that the medication will be good for her health, the doctor is telling Mary what to do which is not so good.
- ✓ **Beliefs and values that may have influenced the person's decision.**
This is a good answer. Although we may not agree with the person's beliefs and values, we should consider them in helping to make the right decision.

- ✗ **The views and wishes of yourself and what you would want in this situation.**
This is incorrect. Only the views of the person with dementia should be considered. Consider if you would want someone to make a decision for you according to his or her own views and wishes.
- ✓ **The views of anyone named by the person as someone to be consulted for making decisions in case he or she is no longer able to decide.**
This is a good answer as it implies that the person with dementia had a conversation with the named person and this person knows his or her wishes. It is best to have this person named in writing.

Keep in Mind

Like Ella, you can make decisions in the best interest of the people living with dementia you care for by taking the following into account:

- Their past and present wishes and feelings (and, in particular, any relevant statement written when the person you care for did not have dementia).
- Beliefs and values that may have influenced the person's decision when the person you care for did not have dementia.
- The views of anyone named by the person you care for as someone to be consulted to help with making decisions.

Keep in Mind

- Be aware that the best interest of the person living with dementia is not always the same as your own interest or that of other family members. In the end, it is the best interest of the person living with dementia that counts, since the decision concerns them.
- Take into account that someone's past wishes can be different from the present ones.



What may help to make important decisions in later stages of dementia?

Gina was recently diagnosed with dementia.

She is still in an early stage of dementia and is capable of making decisions about her daily life.

She is also still capable of making decisions on more complex issues like finances and health.

Gina finds it difficult to think about the future.

The doctor advised her to talk with someone she knows and trusts about choices that may have to be made in the future when Gina might not be able to make decisions herself anymore.

- Prepare instructions that accurately reflect the wishes of the person living with dementia, in accordance with advance directives.
- Inform each other and your doctor about your preferences and decisions concerning medical treatment.
- For more information: <https://www.myagedcare.gov.au/end-life-care/advance-care-planning>

Preparing for decisions

To prepare for decisions you might have to make for the person living with dementia, it is important to:

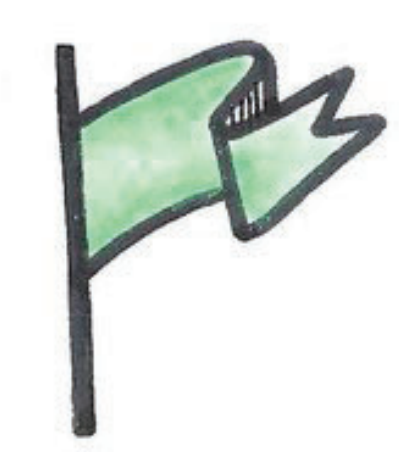
- Gather the information you need to make informed choices for the person living with dementia as early in the course of the disease as possible.
- Talk about decisions with your family, friends, doctor and any others close to you to help with decisions that are important to you and the person living with dementia.



Activity

Think of the following choices when you prepare instructions that accurately reflect the person's wishes:

- Where does the person prefer to live if it is no longer possible to stay at home?
- What does the person find important in care at home, in the community or a care facility?
- Who does the person want to take care of his or her finances when she is no longer capable of doing it?
- How does the person want to be treated at the end of her life?
- Are there medical treatments that the person wants to receive or refuse?
- What does the person want when eating is no longer possible? Would the person want to get a feeding tube?
- Does the person have any particular fears or concerns about medical treatments.



In Australia, each state and territory has different names for the legal documents you can use to create an advance care plan.

These can be obtained, along with general information on advance care planning, from Advanced Care Planning Australia (Respecting Patient Choices).

Tip

Further information

Advance Care Planning Australia

Advance Care Planning Australia (ACPA) is a national program funded by the Australian Government Department of Health, enabling Australians to make the best choices for their life and health care.

For further information call 1300 208 582 9am - 5pm Monday to Friday or go to the website <https://www.advancecareplanning.org.au>

Dementia and Your Legal Rights

Dementia and Your Legal Rights is a practical guide that sets out some of the legal issues a person with dementia, their families and carers may face, their legal rights and the actions they can take to protect their rights.

The guide offers specific information and important contacts for each state and territory about Advanced Care Directives, Power of Attorney, Enduring Guardianship, Superannuation and Wills.

The link can be found at <https://www.dementia.org.au/files/NATIONAL/documents/Dementia-and-your-legal-rights.pdf>

Start2Talk

Start2Talk has been developed by Dementia Australia to help all Australians start the conversations involved in planning ahead. <https://www.dementia.org.au/planning-ahead>

If you would prefer to talk to someone, call the **National Dementia Helpline** on 1800 100 500 (available 9am to 5pm weekdays).



RELATED LEARNING UNITS

- Module 2 Unit 4 Involving others
- Module 3 Unit 3 Thinking differently
- Module 1 Unit 3 Using memory aids in your care activities

You finished this learning unit, well done!

Would you like to try the following relaxation exercise?



Mindful breathing

This exercise will help you feel calm and reduces stress. You will breathe with your belly according to a rhythm.

This is how you do it:

- Sit straight on a chair and make sure your face and shoulders are relaxed.
- Bring your hands to your belly and breathe into your belly.
- Breathe in for 4 counts and breathe out for 8 counts at a comfortable pace.
- Your belly should expand with each inhale, and it contracts with each exhale.
- Return to your normal breathing and spend one minute just watching your breath and noticing how you feel.
- Practice listening without negative judgement.
- If your mind wanders, refocus on breathing and meditation.



You finished this unit, well done!

Unit 4. Involving others

Sharing tasks**Why is this unit important?**

Involving other people to share the responsibilities of providing care will help you to continue to care in the long term.

How will this unit help me?

By practising the skill 'Asking for help'.

What will I learn?

- What kind of help you might need
- How to ask others for help in an appropriate way

Involving family and friends

It might be difficult to involve others in the care of the person you care for.

You could think that others will not be able to provide care as good as you can or that they do not have time or might say 'no' when you ask for help.

As time progresses, the person you care for will need more and more help with daily activities and it is important to involve others so the tasks can be shared.

It can also be helpful to have someone to talk to who understands your situation and feelings.

Do not wait too long, since help early on will help you to continue the care for the person in the long term.



Who is helping? Let’s look at an example

Find out whether Lee, David and Mary are receiving help, and if so, what kind of help.

Lee

Lee takes care of her mother who has dementia.
She receives no help from others.
She spends a lot of time taking care of her mother and feels overwhelmed.
She would like to get some help from others.

David

David takes care of his wife who has dementia.
David has involved his two sisters in the care.
The sisters regularly take his wife out for shopping or help with cleaning the house.

Mary

Mary takes care of her husband who has dementia. Mary receives help from her family, friends and neighbours.
Some helpers assist with shopping or cleaning the home, others take her husband for a walk or just listen to the difficulties she has with his memory loss.

What types of help and support are provided?

The types of help and support that Mary receives are presented below.

Practical help

- Family: Once a month my sister helps with cleaning the house.
- Friends: Once a week my friend Joan comes over to help with shopping and cooking.

Emotional support

- Friends: Murray always has a listening ear when I need it.

Help with pleasant activities

- Family: Several family members take my husband out for a walk on a regular basis.

Providing information

- Acquaintances/neighbours:
- My neighbours help to find information on dementia.

Activity



Which help do you receive?

Tick the boxes for the types of help you receive. If the help you are receiving is not listed below, use the empty box at the end to fill in your answer. Do your family, friends, neighbours or others provide:

Practical help

Emotional help

Help with pleasant activities

Activity
Information
Other help



Tip

Keep in mind that sharing care tasks is common and may relieve you to do something pleasant for yourself, run an errand without having to bring the person you care for or just enjoy a well-deserved break.

Activity



Own support network

Take a look at your own network as stated in the previous pages, what do you see?

☐ **I receive help in 1 category.**

It is very good that you are already involving others. You might want to receive help in other ways too.

Think about people who might be able to help you.

My Aged Care

Help at Home, <https://www.myagedcare.gov.au/contact> or Phone 1800 200 422 Mon - Fri 8am - 8pm and Sat 10am to 2pm.

☐ **I receive help in more than 1 category.**

It is very good that you are already involving others in the care for the person you care for.

If needed, you can ask for help from other people as well. Perhaps the examples helped you identify people you had not considered before.

My Aged Care

Help at Home, <https://www.myagedcare.gov.au/contact> or Phone 1800 200 422 Mon - Fri 8am - 8pm and Sat 10am to 2pm.

☐ **I do not receive help.**

You have indicated that you do not receive help at the moment. Keep in mind that providing care can be difficult. Think about ways to involve others in sharing the tasks. Remember that you do not know whether people will want to help unless you ask. It can be difficult to find help if you don't have family nearby or live in a rural or isolated area, or if your family refuses to help. Think about alternatives such as your faith community, contacting your doctor to ask for advice, or the national carer support network, click <http://www.carersupportsa.org.au/>

My Aged Care

Help at Home, <https://www.myagedcare.gov.au/contact> or Phone 1800 200 422 Mon - Fri 8am - 8pm and Sat 10am to 2pm.

What are things you would like to get more help with?

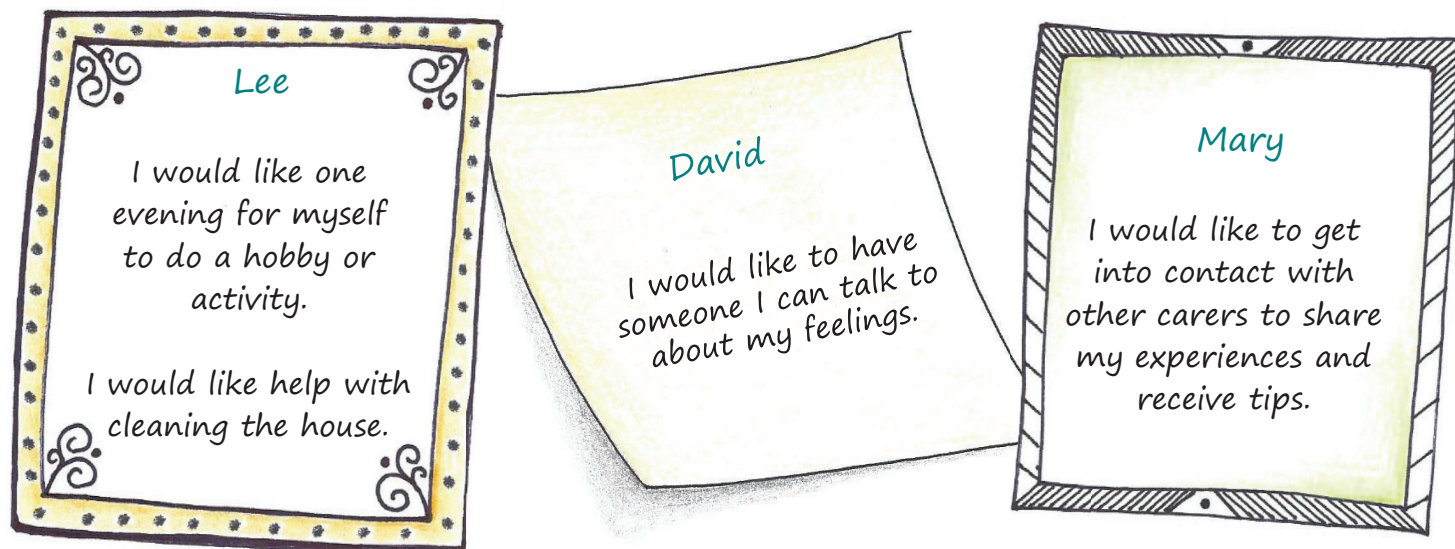
Before you ask someone to help, it is important to know what it is you would like to ask. It can help to make a wish list of your needs.

Let's first have a look at Lee, David and Mary. You can see their wish lists below.

What is your wish list?

Write your own wish list for the help or support you would like to receive. Wishes can be:

- I would like help with bathing the person
- I would like advice on how to deal with the person
- I would like adjustments to be made in my home to accommodate the person's care needs





What is your wish list?

List those wishes that you think are achievable.
If you know beforehand that you might not be able to achieve a certain wish, it might be better to list a different wish which is more attainable.
For instance, Lee would prefer to hire someone to clean the house everyday of the week.
However, Lee can not afford this and realises her wish is not realistic.
She could hire someone to clean the house once every two weeks or ask someone who she does not need to pay, such as a friend or relative.
She can ask the person to clean the whole house, or to help with specific tasks that are difficult for her, such as cleaning the floors.
She can also explore if her mother is eligible for government subsidised care support through

- (i) Commonwealth Home Support Programme or
- (ii) Home care packages by contact My Aged Care via 1800 200 422 or visit the website: <https://www.myagedcare.gov.au/contact>

Make a top 3 of wishes that seem achievable:

Activity	
Make a list of wishes that seem achievable	
Wish 1	
Wish 2	
Wish 3	

Who can I turn to?

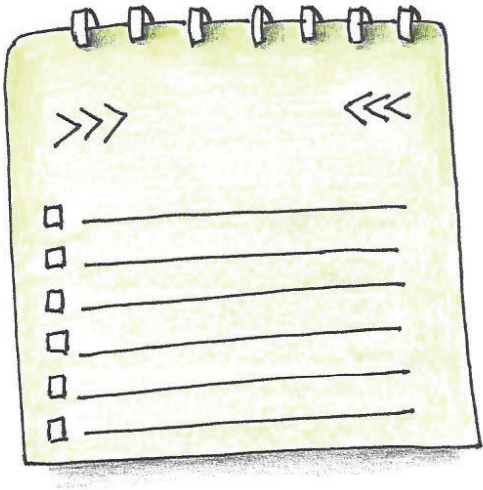
Now it is time to think about who could help.
Some people have no problem asking for help, other people are not used to it but do not mind giving it a try.
There are also people who find it very difficult to ask for help.
The next section will teach you skills to ask for help effectively.

How to ask others for help effectively?

If you would like to ask others for help it is important you do this in an effective way.
This means that you should be able to talk to others about your thoughts, feelings and experiences.
It also means that you stand up for yourself.

My top 3 wishes are:

Wish 1
Wish 2
Wish 3



Things that will help you to ask for help effectively

- Think about what you want or need and what your feelings are about the current situation.
- Describe your problem in one or two sentences.
- Describe your thoughts and feelings clearly, so that the other person can understand your point of view.
- Be honest and direct.
- Keep the feelings of the other person in mind.
- Give detailed information about what kind of help you need.
- Be flexible: maybe you won't get exactly what you asked for, but you will get something that will be helpful.
- Break it down into smaller parts - it's usually easier for people to say yes to a little request than to a big one.
- If you reach a point in which you do not know what to do any more: take a break - go back to the discussion at a future time. For example: agree to think about it and talk again tomorrow afternoon.
- If appropriate, offer to do the task first together.
- Don't give up. It may take many attempts before things change.
- Asking for help will not always lead to the result you want, but it is important that you feel you are able to ask for it.



How does Lee ask her sister for help effectively?

Let's have a look at Lee again.
She knows who to turn to for help and decides to ask her sister.
Lee would like to have an evening to herself once a week.
She tries to ask for help in three different ways.

Which of the following examples represents an effective way to ask for help?

Only one answer is correct.



Check your understanding



- ☐ 1. Lee tells her sister that she wants to take care of their mother, but that she just needs a short break from caregiving during the week. She says: 'I would like to discuss how you could help in a way that is possible for you.'
- ☐ 2. Lee decides to attend a weekly one-hour class in the evening to have a break from providing care. However, she does not discuss with her sister the importance of having a break during the week. When she asks her sister to take care of their mother for an hour, her sister said: 'Sorry, I have no time.' Lee cancels her class.
- ☐ 3. Lee approaches her sister by saying, 'I'm sick and tired of you not doing anything! You never have time to help me care for our mother!'

ANSWERS - Unit 4. Involving others

Check your understanding



- ✓ **Effective example1**
Correct! This is an effective way of asking for help. Lee stands up for herself, says what she is thinking and is honest about her need for a regular break. She keeps the interests of her sister in mind too.
- ✗ **Passive example2**
This is not an effective way of asking help. Her sister may not be aware that Lee is feeling overwhelmed. Lee is not being honest about her feelings and is trying to avoid a conflict with her sister. She does not stand up for herself. It is a passive way of asking for help.
- ✗ **Beliefs and values that may have influenced the person's decision.**
This is not an effective way of asking help. Lee becomes angry. However, her sister may not be aware that Lee is feeling overwhelmed, because she did not clearly mention this. She does not approach her sister in a respectful way. It is an aggressive way of asking for help.



Activity



Your own plan to involve others

Make your own plan to involve others in the care for the person.
Now think of your wishes and who you can turn to for help. Imagine yourself in a situation in which you will ask for help. Please answer the following questions.

Who would you like to ask for help?

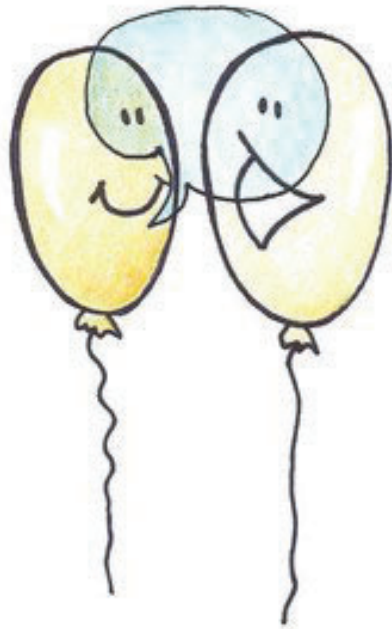
What would you do if the person does NOT want to help?

What would you like to say?

What would you do if the person does want to help?

Your own plan to involve others

How Lee answered these questions:



Activity Example



1. Who would you like to ask for help?

Answer Lee: My sister

2. What would you like to say?

Answer Lee: I want to care for our mother but sometimes it becomes too much.

I need to have time for myself once a week. I would like to ask whether you would be willing to help.

3. What would you do if the person does NOT want to help?

Answer Lee: First, I would explain how important it is that I can have a regular break to continue the care for our mother. Then, I would ask for the reason why she does not want to help. I would also ask if there is a better time that she would consider helping. But if she does not want to help maybe she knows someone else who will or can perhaps help cover the costs to pay for help.

4. What would you do if the person does want to help?

Answer Lee: I would say that I am very grateful that she is being supportive and thank her for her help.

Remember: to involve others and share care tasks early in caregiving

It will be good for your health and will enable you to continue the care for a longer period of time. Thus, the person you care for will benefit too from you having support.

Carers Australia

The peak national body representing carers of people with a disability, mental illness, chronic condition or those who are frail or aged. Carers Australia provides information, support, education, training and counselling.
<http://www.carersaustralia.com.au/> or to speak with someone phone Carer Supports and Services 1800 242 636

My aged care

<https://www.myagedcare.gov.au/caring-someone-particular-need/caring-someone-dementia>
or Phone 1800200422 Mon-Fri 8am-8pm and Sat 10am-2pm

Carer Gateway

Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services.
Free call:1800422737, Monday to Friday, 8am-6pm

Further Information

Australian Government Commonwealth Home Support Programme (CHSP)

The Commonwealth Home Support Programme (CHSP) is an entry-level home help program for older people who need some help with daily tasks to live independently at home.

The aim of the CHSP is to help older people live as independently as possible. Depending on needs and eligibility, support services may include:

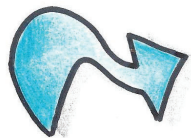
- domestic assistance - household jobs
 - personal care - help with bathing, showering or getting dressed
 - home maintenance - minor general repairs and care of your house
 - home modification - minor installation of safety aids such as alarms, ramps and support rails in your home
 - nursing care - a qualified nurse to dress a wound or provide continence advice in your home
 - social support - social activities in a community-based group setting
 - transport - help getting people out and about for shopping or appointments.
 - helping with shopping for food
 - help with making meals and storing food in your home
 - Allied health support services - such as physiotherapy
- To find out if you need an assessment and if you are eligible for help at home services, you should call My Aged Care on 1800 200 422.

RELATED LEARNING UNITS

- Module 3 Unit 1 Reducing stress in everyday life
- Module 4 Unit 4 Personal care
- Module 5 Unit 2 Aggression

You finished this learning unit, well done!

Would you like to try the following relaxation exercise?



Number counting

You can relax by focusing on your breathing and counting from 20 back to 1. This is how you do it:

- Sit or lie down comfortably in a quiet place.
- Breathe slowly.
- With each breath, take at least three seconds to breathe in and at least six seconds to breathe out.
- Focus on your breathing and your lower abdomen when you breathe until you feel calm and peaceful inside your heart and mind.
- Say the word 'relax' whenever you breathe out.
- Tell yourself that you will start counting down from 20 to 1.
- Tell yourself that you will double your level of relaxation for each and every count, and you will be totally relaxed when you reach 1.
- Start counting down from 20 to 1 slowly. Say the word 'relax' whenever you count. (That is, take a deep breath, say '20', breathe out slowly and say 'Relax', take a deep breath, count '19', breathe out slowly and say 'Relax', and so on.)

Now do this exercise again but close your eyes.



You finished this unit, well done!