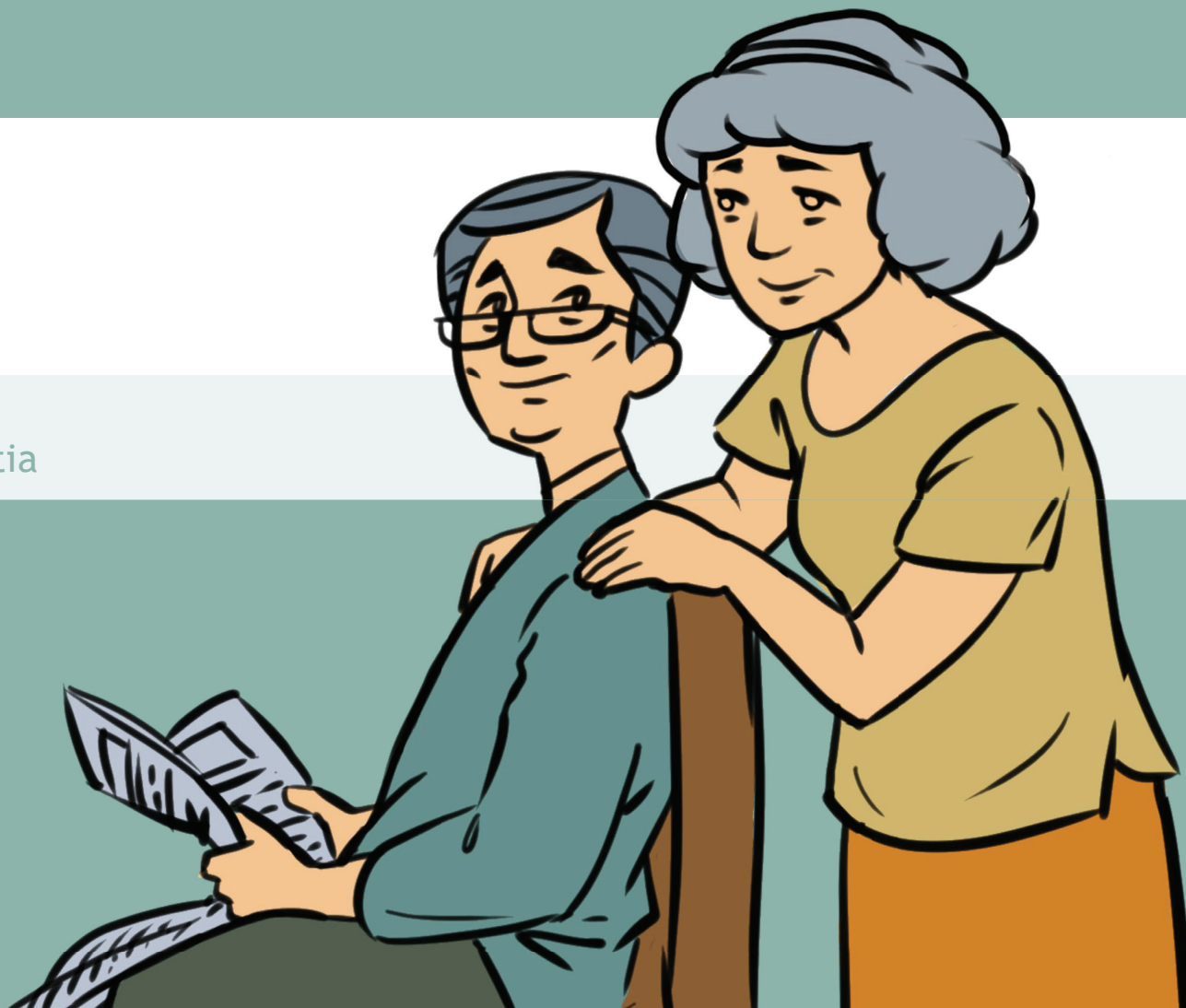


Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



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

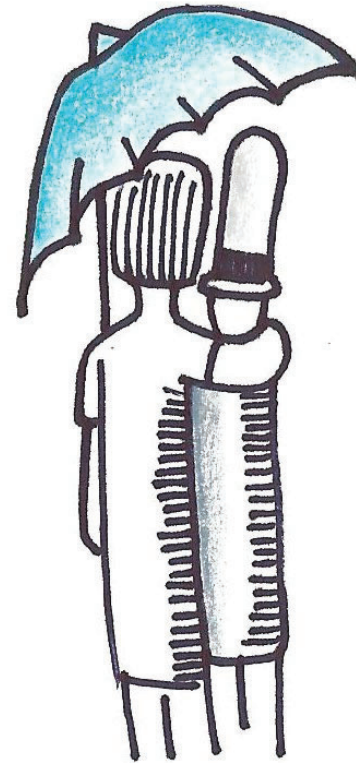
Support for someone with dementia to make their own decisions is very important.

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**

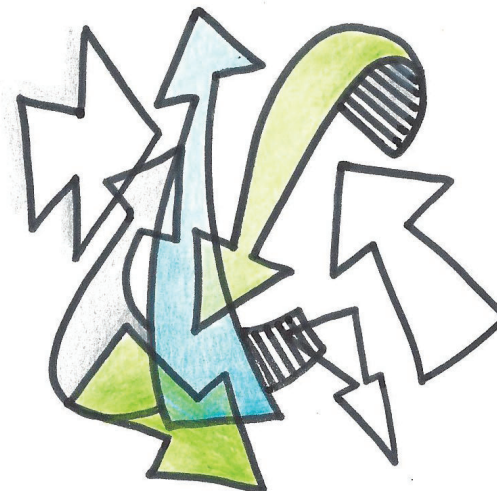
Having memory loss will cause the person to sometimes forget the information that is needed to make a decision.

- **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

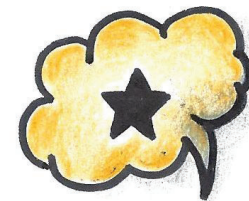
	

Support for everyday decisions

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.

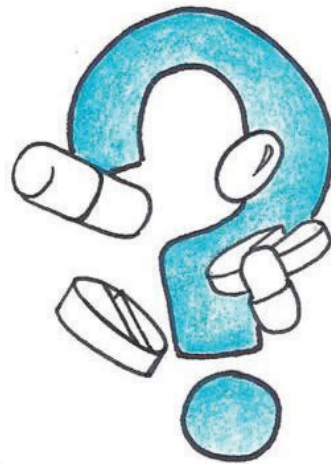


Support for making complex decisions

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.

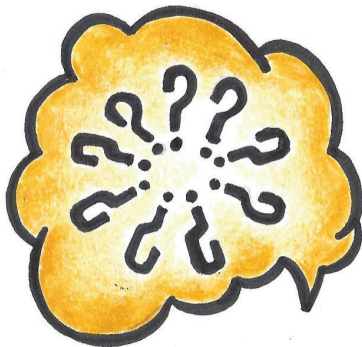


Be aware that the capacity to make a decision

- **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).

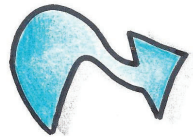


RELATED LEARNING UNITS

- 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!