

iSupport For Dementia Carers

Module 2 Being a carer



BEING A CARER

Session 1. The journey together

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Session 1. The journey together

Why is this session important?

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

How will this session help me?

This session teaches you skills for your journey together: to stay connected, involve others, take care of yourself, and plan for the future.

What will I learn?

1. How may your roles change over time?
2. How to stay connected with the person you care for?
3. How to plan pleasant activities and relaxation?
4. How to involve others?
5. How to plan well for the future?

1. How may your roles change over time?

You may feel as if your role is changing. In the early stages of dementia, you may still be able to enjoy many different activities together.

As dementia progresses, the person could experience more difficulty with everyday tasks. This could 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.

Let's look at an example

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

1. Check your understanding

Frustration about memory loss.

How should David approach Marian about what happened?

Check all the responses you feel are appropriate.

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

1. Check your understanding

Frustration about memory loss.

How should David approach Marian about what happened?

✓ **Ask Marian how she feels about her memory loss**

This is a good response because David is addressing the issue by discussing its impact on Marian and staying 'connected'. David could also share his own worries about her memory loss.

✓ **Do not blame Marian but make a shopping list together with her each time prior to shopping.**

This is a very good response, because this will help Marian to continue shopping and to maintain her independence for as long as possible.

✗ **Leave Marian alone and see what happens**

This is not a helpful response, because Marian and David both feel frustrated. To stay connected it is important to talk about their frustration and worries about the future.

✗ **Ask Marian to 'work harder' to remember things**

This is not a good response, because memory loss is part of living with dementia, it is unlikely to change.

✗ **Ask Marian to 'work harder' to remember things**

This is not a good response because doing the shopping is important to Marian. Shopping may give Marian purpose in life and a feeling of dignity.

2. How to stay connected with the person with dementia?

It is important to keep talking together. The sooner you start talking about dementia and its effects 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 over time.

Tips

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

- use simple sentences;
- try to stay in control of your feelings;
- create time for yourself and for each other.

3. How to plan pleasant activities and relaxation?

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, as some carers may break down from the stress. Part of the journey together should include planning pleasant activities and relaxation for yourself.

For more tips on how to relax, read **Session 1. Reducing stress in everyday life in Module 3.**

For more tips on how to stay in control of your feelings read **Session 3. Thinking differently in Module 3.**

For more tips on how to plan pleasant activities for yourself, read **Session 2. Making time for pleasant activities in Module 3.**

4. How to involve others?

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 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 could use a break. Caring for a loved one with dementia is sometimes too big a job for one person.

2. Check your understanding

Feeling stressed due to conflicting duties.

Sarah's mother-in-law, Joyce, has dementia. Sarah has a big deadline at work and needs to leave at 7:30 the next morning. The paid agency carer is not able to arrive until 9:00 in the morning. This leaves Joyce alone for over an hour. Sarah wonders whether it would be okay to leave Joyce alone and feels stressed because she is not sure what to do.

How could Sarah deal with the situation?

Check all of the responses that you feel are appropriate.

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

1. Check your understanding

Feeling stressed due to conflicting duties.

How could Sarah deal with the situation?

- ✓ Ask a neighbour to come visit Joyce until the agency carer arrives.

This is helpful because it ensures Joyce's safety. Sarah can do her work and also gets a short break from caregiving.

- ✓ Ask her husband to go into work late so that he can be with Joyce until the agency carer arrives.

This is a good response. It shows that Sarah is trying to involve her family members for support and gives her the break that she needs.

- ✓ Ask the agency carer to come in early.

This is a **good response** but it may not be possible because of the short notice.

- ✗ Leave Joyce alone and see what happens.

This is not a good response, because it potentially puts Joyce in danger and Sarah will not be able to perform well at work with the added stress of leaving Joyce.

- ✗ Ask Joyce to 'take care of herself'.

This is not a good response because Joyce's dependence on others is part of living with dementia and unlikely to change.

5. How to plan well 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. Planning early will also ensure that the person you care for will be better able to say what their wishes are. Where possible, discuss topics that concern you.

1. Activity

Here are some common questions that carers have. You may want to discuss these with the person you care for.

Write down the responses to the questions.

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?

What does the person you care for want to do themselves for as long as possible?

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 their wishes at the end of life?

If you find it helpful, please write down the questions that you might want to discuss in the space below.

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.

Let's revisit the scenario with Marian and David

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

2. Activity

What are some ways in which David and Marian can maintain their intimacy as Marian's dementia progresses?

Think about it before reading on.

Here are some tips for partners on how to maintain intimacy, even when sexual relations may no longer be possible with the person living with dementia.

Tips

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 that the person you care for likes and that makes them feel good.
- Try to maintain your sense of humour. This will help reduce frustration and tension.
- Talk with them about what they like and need – it's an important conversation to have more than once, as things change over time.

Taking care of yourself

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

Tips

- 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 that the person you care for is no longer able to meaningfully communicate with you.

Let's review what you have learned

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

Session 2. Improving communication

Why is this session important?

Dementia can often make communication difficult.

How will this session help me?

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

What will I learn?

1. How to improve communication?
2. How to check the person's ability to hear and see?
3. How to get attention in a respectful way?
4. How to keep it simple?
5. How to take the person seriously?
6. How to pay attention to reactions?
7. How to give compliments?
8. How to show compassion?

1. How to improve communication?

In this session you will learn about 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 them or you frustrated, sad or angry.

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

Show compassion by listening, take the person you care for seriously, treat them with respect and dignity, show interest, or give them a smile or a hug. This is very important for every human being, including people with dementia.

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

1. Check your understanding

Imagine that you are living with dementia.

Imagine for a moment that you are living with dementia.

What would you like other people to do?

Please select all that apply.

- Listen to how you feel.
- Talk behind your back.
- Give you a smile.
- Say that they do not care.
- Tell you that they love you.
- Treat you like a child.
- Approach you with respect and dignity.

1. Check your understanding

Imagine 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 that they do not care.
- ✓ Tell you that they love you.
- ✗ Treat you like a child.
- ✓ Approach you with respect and dignity.

2. How to check the person's 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 whether the person's hearing and sight could be improved by making changes in their environment or arranging for any relevant medical check-ups.

1. Activity

Exercise to improve sight

The ability to see is important for communication. *Check the items below to help improve sight.*

Tips

| | | |
|--|---|---|
| Is there enough light? | <input type="checkbox"/> Yes <input type="checkbox"/> No | In general, people with dementia need more light to see clearly. Increase light levels and use daylight where possible. It will help the person living with dementia to see well. You may also think of leaving lights on at night so the person can find the bathroom. |
| Is there enough contrast in colours? | <input type="checkbox"/> Yes <input type="checkbox"/> No | 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. |
| Is the person living with dementia wearing their glasses? | <input type="checkbox"/> Yes <input type="checkbox"/> No | Does the person living with dementia lose or misplace their glasses frequently? Encourage them to always put the glasses in the same spot to reduce frustration over having to look for them. Sometimes a neck cord is also helpful in that case. |
| Are the glasses still okay? | <input type="checkbox"/> Yes <input type="checkbox"/> No | If the person living with dementia wears glasses, check whether they are clean and still comfortable to wear. Are the glasses comfortable around the ears and nose? |
| Do you need to consult an optician? | <input type="checkbox"/> Yes <input type="checkbox"/> No | If the person living with dementia does not have glasses, but cannot see well anymore, consult an optician. If the person living with dementia wears glasses, check to see if the prescription is still accurate, or consult an optician. |

2. Activity

Exercise to improve hearing

The ability to hear is important for communication. *Check the items below to help improve hearing.*

Tips

| | | |
|--|---|---|
| Is there too much noise? | <input type="checkbox"/> Yes <input type="checkbox"/> No | Minimising background noise will help to improve hearing ability. Perhaps take the person living with dementia to a quieter location with fewer distractions. Turn off the television or radio when trying to communicate with them. |
| If the person living with dementia has a hearing aid, is he/she wearing it? | <input type="checkbox"/> Yes <input type="checkbox"/> No | The person living with dementia may forget to wear the hearing aid or require help or assistance with putting it in properly. |
| Is the hearing aid still okay? | <input type="checkbox"/> Yes <input type="checkbox"/> No | If the person living with dementia is wearing a hearing aid, check whether it is clean, fits snugly in the ear canal, is still comfortable to wear and the batteries are charged. |
| Do you need to consult an audiologist? | <input type="checkbox"/> Yes <input type="checkbox"/> No | If the person living with dementia wears a hearing aid, check if the prescription is still accurate, or whether you need to consult an audiologist. If the person living with dementia does not have a hearing aid, but cannot hear well anymore, you should also consult an audiologist. |

3. How to get attention in a respectful way?

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

Remember

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

2. Check your understanding

Get attention in a respectful way.

Below are some suggestions regarding how to capture the attention of a person living with dementia.

Please put a check mark in front of the answers that you think are correct.

- Raise your voice or shout.
- Speak clearly and 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 him or her listen.
- Approach the person from the back and touch their shoulder.
- Call the person living with dementia by a name that they recognise.

2. Check your understanding

Get attention in a respectful way.

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

What are the right and wrong answers?

✗ Raise your voice or shout. Raising your voice is **not a respectful way** to gain attention. It may even make the person living with dementia feel sad, frustrated, or angry.

✓ Speak clearly, slowly, at a volume which 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 the attention of a person living with dementia.

✗ Stop and hold the person to make them listen.

This is not a respectful way to get attention. It may even make the person living with dementia feel 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 living with dementia by a name that he or she recognises.

This is a good way to attract the attention of a person living with dementia. You might use their first name or a nickname that was used in the past.

4. How to keep it simple?

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

3. Check your understanding

Keep it simple

Jonathan takes care of his father who has dementia. Jonathan notices that his father does not understand him.

Can you tell why?

Check the items in the list below which you think could impair communication between Jonathan and his father.

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

3. Check your understanding

Keep it simple

Jonathan takes care of his father who has dementia. Jonathan notices that his father does not understand him.

Can you tell why?

✓ 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 the same subject after making a phone call.

✓ Jonathan asks multiple questions at the same time.

Correct! Asking too many questions at the same time 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 and focus on one subject at a time.
- When needed, change from open-ended to closed-ended questions that can be answered with either YES or NO.
- Make sure there are no distracting background noises such as a television or radio.

5. How to take the person seriously?

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

However, it is important that you take them seriously. The person you care for is trying to tell you something, even though their communication skills may be impaired due to the dementia.

Let's look at an example

John is visiting his father who has dementia. When his father wants to describe his morning to John, 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!"

4. Check your understanding

Pay attention to reactions.

Which of the following statements do you think is correct?

Check all the responses that you feel are appropriate.

- John should not talk about his father when he is in same the room. John 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 'YES' or 'NO'. For example: "Have you been 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.

4. Check your understanding

Pay attention to reactions.

Which of the following statements do you think is correct?

✓ John should not talk about his father when his father is in same the 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 'YES' or 'NO'. For example: "have you been outside this morning?"

Correct! John takes his father seriously when trying to understand what he wants to say. Do not talk about the person you care for while they are 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. This is a **correct** answer because some people with dementia appreciate help with finding the right words or to fill in sentences.

Remember

- It is important to take the person that you are care for seriously and treat them with respect and dignity.
- Do not talk about them in their presence.
- Be patient and give them time to find the right words.
- When the person you care for is difficult to understand, it may help to ask closed-ended questions which can be answered with YES or NO to understand what they mean.

6. How to 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 you care for.

5. Check your understanding

Pay attention to reactions.

Take a look at the cartoons below. Do you understand these feelings?

Select the right answer for each cartoon.



- Happy
- Angry
- Sad
- Scared



- Happy
- Angry
- Sad
- Scared



- Happy
- Angry
- Sad
- Scared



- Happy
- Angry
- Sad
- Scared

5. Check your understanding

Pay attention to reactions.

Take a look at the cartoons below. Do you understand these feelings?



- 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. For example, whether the person may be nervous, upset or anxious.
- Take notice of the responses and body language of the person you care for.

7. How to give compliments?

Complimenting the person you care for is important. In general, it is much more effective to say what someone is doing well, than to say what they are 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.

Keep in Mind

- The person you care for 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.

6. Check your understanding

Give compliments.

Here is a list of statements.

These statements include several compliments. However, there are also some statements that are not compliments.

Please put a check mark in front of the statements that are compliments.

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

6. Check your understanding

Give compliments.

Here is a list of statements.

These statements include several compliments. However, there are also some statements that are not compliments.

- ✓ 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 driving me crazy.
- ✓ You have a great smile.

3. Activity

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

8. How to 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 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 living with dementia may have forgotten what they just said. You need to use extra effort and be patient with the person you care for.

Let's look at an example

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

7. Check your understanding

How to show compassion (1).

Did William respond well?

Please select the correct answer below.

- Yes
- No

Today William tries a different approach

William says to Elena: "It must be difficult for you that he died". He gives Elena a hug. William shows Elena some pictures of her husband that he brought from home and talks to her about her husband.

William showed that he understands that Elena is missing her husband and tries to support her.

8. Check your understanding

How to show compassion (2).

Did William respond well?

Please select the correct answer below.

- Yes
- No

7. Check your understanding

How to show compassion (1).

Did William respond well?

Please select the correct answer below.

✗ No

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 the right way to respond especially because his sister persists in asking.

8. Check your understanding

How to show compassion (2).

Did William respond well?

Please select the correct answer below.

✓ Yes

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

Let's review what you have learned

You have practiced the following 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.

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.

The example of William and his sister, Elena, shows that:

- You can show compassion in different ways.
- It is important to take a person living with dementia seriously and to pay attention to the questions they have.
- Showing compassion helps to improve your relationship with the person you care for.

Session 3. Supported decision-making

Why is this session important?

Making decisions can become more difficult for a person living with dementia over time.

How will this session help me?

By practicing how to support a person living with dementia to make their own decisions for as long as possible or to assist in making decisions in the person's best interest.

What will I learn?

1. Why is support in decision-making needed?
2. How to make decisions in someone's best interest?
3. How to support someone with dementia to make everyday decisions?
4. How to support someone with dementia to make everyday decisions as the dementia progresses?
5. How to support someone with dementia in making complex decisions?

1. Why is support in decision-making needed?

Supporting someone with dementia to make their own decisions is very important. Like everyone else, people living with dementia have the right to participate in all decisions that 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.

In this session, you will learn how you can support the person you care for when they need to make a decision.

2. How to make decisions in someone's best interest?

Everybody needs to make decisions, whether they are big or small. Because the person you care for has dementia, your support is needed to help them to clarify what they want. Decisions in line with the interests, needs and wishes of the person you care for will make them more independent.

Decision-making can be difficult

Why do you think decision-making can be difficult for a person living with dementia? Have a look at the reasons below to find out more.

- **Memory loss**
Having memory loss will cause someone with dementia to sometimes forget the information that is needed to make a decision.
- **Problems with thinking or difficulties identifying and describing what someone with dementia thinks**
When a person living with dementia has problems thinking or describing what they are thinking, it might be more difficult for them to make a decision and share it with you.
- **Problems with making complex decisions**
Complex decisions, such as deciding whether or not to go outside alone, can be more challenging, therefore support is important.

1. Activity

Think about your own situation

- Making decisions will become more difficult as the dementia progresses.
- Your support for the person you care for to make their own decisions is needed.
- Enabling them to make their own decisions might not be easy because of their dementia.

Do you support the person you care for to make decisions? You may want to write down the ways that you support their decision-making:

3. How to support someone with dementia to make everyday decisions?

It is important to encourage the person you care for to do whatever they are still able to do. Supporting them in making decisions will help them to be more independent. Supporting them in making decisions might also improve their self-esteem.

Let's look at an example

John has Alzheimer's disease and is married to Sharon. John always used to lay out his clothes for the next day in the evening. Now he has dementia, he forgets to do so and sometimes wears the same clothes every day.

1. Check your understanding

Support for making everyday decisions.

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

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

Keep in Mind

- It is important to encourage the person that you care for to continue doing whatever they are still able to do.
- Supporting the person you care for in making decisions will help them be more independent.
- Support the person you care for in making decisions may add to their self-esteem.

1. Check your understanding

Support for making everyday decisions.

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

✓ Before Sharon and John go to bed, Sharon asks John what he wants to wear the next day. She then asks John to lay them out.

This is the right answer! This way John is encouraged to do the things he is still able to do.

✓ Sharon chooses clothes for John and she asks John to lay them out.

This answer is okay. It is good that John is encouraged to lay out his clothes himself; however, it would have been better if Sharon supported John in making his own decision about what to wear.

✗ Sharon chooses clothes for John in the morning and gives them directly to John to wear.

This is not a good option. Sharon is taking control away from John. It would be better if she supported him in making his own decision and encouraged him to do the things which he is still able to do, such as laying out the clothes.

4. How to support someone with dementia to make everyday decisions as the dementia progresses?

Let's look at an example

After some time, John feels stressed when choosing his clothes for the next day with Sharon. He starts to worry about everything else he needs to do the next day and becomes anxious. This makes it difficult for Sharon to support John in making his decision.

2. Check your understanding

Support for making decisions as the dementia progresses.

What should Sharon do?

Please check all the responses that you feel are appropriate.

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

Remember

- Supporting someone with dementia in making 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.

2. Check your understanding

Support for making decisions as the dementia progresses.

What should Sharon do?

✓ Instead of supporting John 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.

Correct! Sharon still supports John in deciding what he wants to wear, but he will not start to worry the evening before.

✗ Sharon lays out John's clothes in the evening.

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

✗ When Sharon asks John 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 Sharon decides which trousers John should wear the next day, John can still make the final decision himself.

However, in this case it might not be the best thing to do, because it might not solve the problem that John will worry about the next day.

5. How to support someone with dementia to make complex decisions?

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

Let's look at an example

Mary has vascular dementia and is taken care of by her daughter Teresa. 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.

3. Check your understanding

Support for making complex decisions (1).

What should the doctor and Teresa do?

Multiple answers are correct.

- 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."

3. Check your understanding

Support for making complex decisions (1).

What should the doctor and Teresa do?

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

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

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

Incorrect. 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 damage to her brain resulting from her dementia.

This is right! Her doctor's explanation allows Mary to 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."

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

Let's look at another example

Jack who has dementia lives with his wife, Eileen. Jack's condition deteriorates. Eileen decides to make an appointment with the doctor without Jack to discuss his medical condition and to make a decision regarding his medication. Eileen 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. Eileen talks to the doctor and tries to imagine what Jack would have decided if given all the information.

4. Check your understanding

Support for making complex decisions (2).

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

Please check all the responses that you feel are appropriate.

- Jack is unable to understand the information that is relevant to making 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 up the information as part of the decision-making process.

4. Check your understanding

Support for making complex decisions (2).

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

Multiple answers are correct.

- ✓ Jack is unable to understand the information that is relevant to making 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 up the information as part of the decision-making process.

The capacity to make a decision may be affected by the following considerations:

- **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.
- **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 is not clear, in which case there is no other alternative other than to help the person living with dementia make a decision which is in their best interest.

Remember

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

Preparing for decisions

To prepare for decisions that 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 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 which are important to you both.
- Prepare instructions that accurately reflect the wishes of the person living with dementia, in accordance with your country's law (advance directives or a 'living will') and inform each other and your doctor about your preferences and decisions concerning medical treatment.

Remember

You can make decisions in the best interest of a person living with dementia by taking the following aspects into account.

- Their past and present wishes and feelings (and, in particular, any relevant statement written by them when they did not have dementia).
- Beliefs and values that may have influenced the person's decision when he or she 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.
- Be aware that the best interest of the person you care for is not always the same as your own best interest or that of other family members. In the end, it is the best interest of the person you care for which counts, since the decision concerns them.
- Take into account that someone's past wishes can be different from their present ones.

2. Activity

Think of the following choices when you prepare instructions that accurately reflect the wishes of the person you care for.

Where does the person you care for prefer to live if it is no longer possible to stay at home?

What aspects of home/community/facility care are important to the person you care for?

Who does the person you care for want in charge of their finances when they are no longer capable of doing it?

How does the person you care for want to be treated at the end of their life?

Are there medical treatments that the person you care for wants to receive or refuse?

What does the person you care for want when eating is no longer possible? Would they want to get a feeding tube?

Does the person you care for have any particular fears or concerns about medical treatments?

Session 4. Involving others

Why is this session important?

Sharing caregiving responsibilities with other people will help you to continue providing care in the long term.

How will this session help me?

By practicing the skill 'asking for help'.

What will I learn?

1. The importance of involving family and friends.
2. Types of help and support that you might need.
3. Effectively asking for help from others.

1. The importance of involving family and friends

It might be difficult to involve others caring for the person living with dementia. You might think that others will not be able to provide care as well as you can, that they do not have time, or might say 'no' when asked for help.

As time progresses, the person you care for will need more and more help with daily activities. Therefore, it is important to involve others so that 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 allow you to continue providing care to your family member or acquaintance in the long term.

Tip

Keep in mind that sharing care tasks is common. It may allow 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.

2. Types of help and support that you might need

First let's look at an example to find out whether Lorraine, David and Fatima are receiving help, and if so, what kind of help.

- **Lorraine** 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** 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 clean the house.
- **Fatima** takes care of her husband who has dementia. Fatima 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. The types of help and support that Fatima receives are presented below.

| |
|---|
| Practical help |
| <ul style="list-style-type: none">• Family: once a month my sister helps with cleaning the house.• Friends: once a week my friend Hiba comes over to help with shopping and cooking. |
| Help with pleasant activities |
| <ul style="list-style-type: none">• Family: several family members take my husband out for a walk on a regular basis. |
| Emotional support |
| <ul style="list-style-type: none">• Friends: Mohammed is always there to listen when I need it. |
| Providing information |
| <ul style="list-style-type: none">• Acquaintances/neighbours: my neighbours help to find information on dementia. |

1. Activity

What kind of help do you receive?

Please write down the types of help that you receive in the spaces below. If the help you receive is not listed below, use the 'Other help' 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

Information

Other help

2. Activity

Your own support network

Take a look at your own network as stated in the previous pages, what do you see? *Please select the response that applies to the help that you receive.*

I receive help in one 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.

I receive help in more than one category.

It is very good that you are already involving others in caring for your family member or acquaintance. If needed, you can ask for help from other people as well. Perhaps the examples helped you identify people you had not considered before.

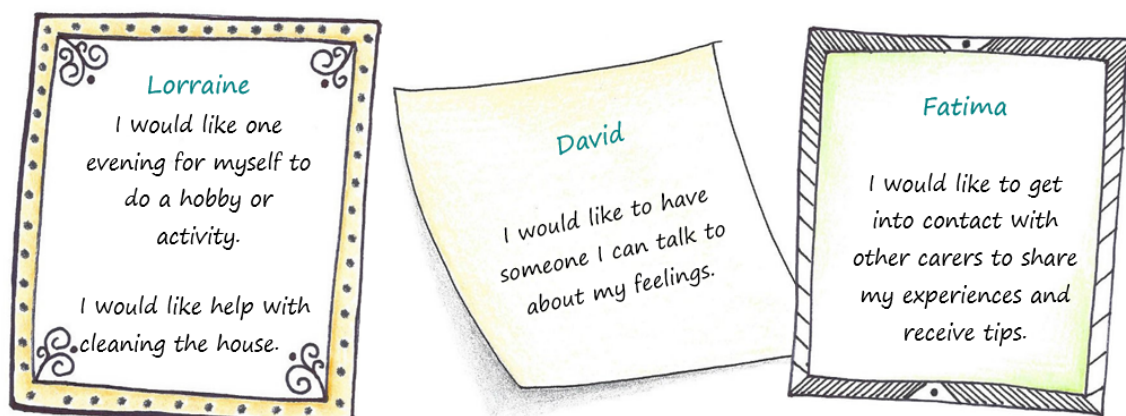
I do not receive help.

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 for advice, or your national / local Alzheimer's Society.

What would you like to get more help with?

Before you ask someone for 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 Lorraine, David and Fatima. You can see their wish lists below.



What is on your wish list?

Make your own wish list for the help or support that you would like to receive.

Wishes could be for example:

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

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 that is more attainable.

For instance, Lorraine would prefer to hire someone to clean the house every week. However, Lorraine cannot afford this and realises that 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.

3. Activity

Make a list of wishes that seem achievable.

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 session will teach you skills to ask for help effectively. Keep in mind your support wish list.

3. Effectively asking for help from others

If you would like to ask others for help it is important to do so 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.

Things that will help you to effectively ask for help:

- 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 where you do not know what to do anymore: 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 together first.
- 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 able to ask for it.

Let's have a look at Lorraine again

She knows who to turn to for help and decides to ask her sister. Lorraine would like to have an evening to herself once a week. She tries to ask for help in three different ways.

1. Check your understanding

Asking for help effectively.

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

Please check the one response that you think is correct.

- Lorraine 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."
- Lorraine 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." Lorraine cancels her class.
- Lorraine 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!"

1. Check your understanding

Asking for help effectively.

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

✓ Example 1

Effective. This is an effective way of asking for help. Lorraine stands up for herself, says what she is thinking and is honest about her need for a regular break. She also keeps the interests of her sister in mind.

✗ Example 2

Passive. This is not an effective way of asking for help. Her sister may not be aware that Lorraine is feeling overwhelmed. Lorraine 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.

✗ Example 3

Aggressive. This is not an effective way of asking for help. Lorraine becomes angry. However, her sister may not be aware that Lorraine 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.

4. Activity

Your own plan to involve others

Make your own plan to involve others in caring for your family member or acquaintance with dementia. 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 in the boxes below.

Who would you like to ask for help?

What would you like to say?

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

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

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