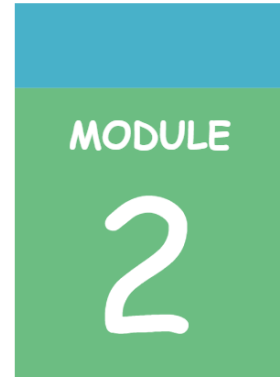


iSupport For Young People

Module 2 Being a carer



BEING A CARER

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



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Session 1. The journey together

Why is this session important?

Dealing with dementia is a journey you and your family will all take together, because it changes the daily life of both the person living with dementia and everyone that supports them.

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 your role may change over time.
2. How to stay connected with the person you help 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 your role may change over time



It is likely that your role and the things you do to help care for your family member with dementia will change over time. In the early stages of dementia, you may still be able to enjoy many different activities together.

As dementia progresses, the person will have more difficulty with everyday tasks. This will require more support with everyday life, such as giving medication 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 of these tasks could be challenging for carers and can cause them to feel stressed or worried.

Let's look at an example

Olivia has dementia and lives with her husband Jacob and their two teenage children. 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 for everyone.

1. Check your understanding

Frustration about memory loss

How could Jacob and his sons approach Olivia to deal with what happened?

Check all the responses you feel are appropriate.

- 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 before she goes shopping.

1. Check your understanding

Frustration about memory loss

How could Jacob and his sons approach Olivia to deal with what happened?

- ✓ **Ask Olivia how she feels about her memory loss.** This is likely to be a helpful response because Jacob is addressing the issue by discussing its impact on Olivia and staying 'connected'. Jacob could also share his own worries about her memory loss.
- ✓ **Do not blame Olivia, but make a shopping list together with her each time before she goes shopping.** This is likely to be a helpful response because this will help Olivia to continue shopping and maintain her independence as long as possible.
- ✗ **Leave Olivia alone and see what happens.** This is not a helpful response, because Olivia and her family feel frustrated. To stay connected it is important to talk about their frustration and worries about the future.
- ✗ **Ask Olivia to 'work harder' to remember things.** This is not a helpful response because memory loss is part of living with dementia, it is unlikely to change.
- ✗ **Ask Olivia to 'work harder' to remember things.** This is not a helpful response because doing the shopping is important to Olivia. Shopping may give Olivia purpose in life and a feeling of dignity.

2. How to stay connected with the person with dementia

It is important that you keep talking and spending time with your family member with dementia. You can also talk to them about dementia and how it is affecting you and them. This can be hard so maybe ask other people in your family to do it with you as well. You can think about nice things you can do together so you all stay connected. As time goes by this might be more difficult.

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.

For more tips on how to improve communication with the person living with dementia, including in the later stages of the disease, read [Session 2. Improving communication in this module.](#)

3. Making time to enjoy yourself



As dementia progresses, you might have to spend more time helping your family member with dementia. It is really important that you take time to have fun and enjoy yourself doing the things that make you feel good. You can talk to the other members of your family and make a plan so everyone gets to have some time to relax.

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

It is very normal for young people who help care for a family member 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.

Helping care for someone with dementia does not have to be a lonely experience. It is OK to tell your family members and friends how things are going and when you could do with a break.

2. Check your understanding

Feeling stressed

Molly's husband, Alan, has dementia. Molly has a big deadline at work and needs to leave at 7:30 the next morning. Carys, their daughter, needs to be at the bus stop by 8:15. The paid home helper is not able to arrive until 9:00 in the morning but this leaves Alan alone for almost an hour. Carys and her mum wonder whether it would be okay to leave Alan alone and feel stressed because they are not sure what to do.

How could Molly and Carys deal with the situation?

Check all of the responses that you feel are appropriate.

- Alan alone and see what happens.
- Ask a neighbour to come visit Alan until the paid home helper arrives.
- Ask Alan to 'take care of himself'.
- Carys can go into school late so she can be with her dad until help arrives.
- Ask the paid home helper to come in early.

2. Check your understanding

Feeling stressed

How could Molly and Carys deal with the situation?

- ✓ Ask a neighbour to come visit Alan until the paid home helper arrives. **This is likely to be a helpful response** because it is a way of making sure Alan is safe. Molly can do her work and Carys can get to school on time.
- ✓ Ask the paid home helper to come in early. **This is likely to be a helpful response** but it may not be possible because of the short notice.
- ✗ Ask Alan to 'take care of himself'. **This is not a helpful response because his dependence** on others is part of living with dementia and unlikely to change.
- ✗ Carys can go into school late so she can be with her dad until help arrives. **This is not a helpful response** because Carys will be missing out on her education and she could get behind on her school work.
- ✗ Leave Alan alone and see what happens. **This is not a helpful response** because it potentially puts Alan in danger and neither Molly or Carys will be able to concentrate at work/school with the added stress of leaving Alan.

How school can help

It is important that your mum or dad or family members let the school know about your situation. If your teachers know that you have caring responsibilities outside school, they will be able to support you better and put you in touch with services or people that can help if you want. They might also be able to help you if you are struggling with school work and deadlines.

5. How to plan well for the future

Many families in your situation worry about the future. Preparing for it is a topic that your parents or family members will need to discuss with the person living with dementia. They will need to talk about planning for future care and at some point also end of life choices. Your parents/grandparents or family members might or might not involve you in these conversations.

Planning early will also ensure that the person you help care for will be better able to say what their wishes are.

Planning for future care

Sometimes the person living with dementia moves to live in a care home. This can be a sad and difficult time for families.

Let's look at an example

Elliot is 15 years old. For ten years his grandma, Jean, who has dementia lived with him and his parents. During this time Elliot helped care for his grandma every day, often sitting with her and keeping her company.

Elliot's family hoped that Jean would be able to remain living with them. However, as Jean's care needs increased, things became very difficult. Recently, Jean moved to live in a care home near their home.

Elliot misses his grandma and feels guilty and sad. He talks to his parents about:

- His feelings of guilt and how he can reduce this by knowing that Jean is well looked after and happy in her new home and this was the best decision for her and their family.
- Putting together a sketchbook with photos and memories that they can take to the care home so they can look at it with grandma when they go visit.
- Organising a small family holiday now that Jean is well looked after in the care home. They haven't had one for many years!

Relationships may change



As time goes by and the dementia progresses, the relationships between you, your family members and the person living with dementia may change.

However, it is important that you know that although you might not all be able to do the same things you did before, you can still find new

ways to show love and stay connected.

Here are some tips for you on how to stay connected with your family member with dementia.

Ways to stay connected

- Use touch, hold hands to communicate warmth, connection, safety and love.
- Use music - it is truly a universal language. Play music that the person you help care for likes and that makes them feel good.
- Try to maintain your sense of humour.
- Talk with them about what they like and need. For example, look at photographs of you and them and talk about them.

Taking care of yourself

One of the most important things to remember as roles change is that you, as a young person that helps care for a person with dementia, need to care for yourself too. In the following sections we will give you ideas on ways to do this.

Tips

- It's OK to take a break
- It's OK to ask for help
- It's OK to feel frustrated sometimes
- It's OK to feel lonely or sad sometimes if you see that you can no longer talk or connect with your family member with dementia as you did before

Let's remember what we've talked about

- As your caring responsibilities change, it is important that you stay connected to your family and the person living with dementia.
- Make sure you save time to do things that you enjoy so that your role does not become overwhelming or too much.
- Ask for help because supporting someone with dementia can be tiring.

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 section, you will find out about tools and tips that will help you communicate better. As you know, dementia can often make communication a bit difficult and this can have an impact on your relationship with the person with dementia. It can even make them or you frustrated, sad or angry.

When you communicate with the person with dementia, 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 them seriously, and treat them with respect and dignity. Show interest or give them a smile or a hug. This is very important for every human being.

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.
- ✓ Smile at you.
- ✗ 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



Talking, touching and using body language is really important. Unfortunately, some people with dementia may struggle to hear and see. It is important that your family checks whether the person's hearing and sight could be improved by for example changing the house environment a bit or arranging any relevant medical check-ups. As a young person, you might or might not be involved in this.

1. Activity

Exercise to improve vision

The ability to see is important for communication. *Check the items below that can help people with dementia see better.*

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. 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 a doctor? | <input type="checkbox"/> Yes <input type="checkbox"/> No | If the person living with dementia does not have glasses, but cannot see well anymore, consult a doctor. If the person living with dementia wears glasses, check to see if the prescription is still accurate, or consult a doctor. |

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. 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, are they 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 a doctor? | <input type="checkbox"/> Yes <input type="checkbox"/> No | If the person living with dementia wears a hearing aid, your family would want to check if the prescription is still accurate, or whether they need to consult a doctor. If the person living with dementia does not have a hearing aid, but cannot hear well anymore, your family should consult a doctor (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 them 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 select all answers that you feel are appropriate.

- 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.

- ✗ 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 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 helpful 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 helpful 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 with dementia that you help care for 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 that you think could impair communication between Jonathan and his father.

- The radio is on.
- Jonathan is on his phone, staring down at his screen.
- 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!** Having the radio on 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 on his phone, staring down at his screen. **Very good!** Being on his phone does not show interest and will confuse his father. It is important for the person with dementia to see your face when you are talking to them. It makes it easier for them to understand.
- ✓ 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.
- Try to use simple language and short sentences.
- Sometimes it might be useful to use questions that can be answered simply with 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 with dementia means. The language they use may even seem strange or funny.

However, it is important that you take them seriously. The person you help care for is trying to tell you something, even though their communication skills may not be as good as they were because of the dementia.

Let's look at an example

John helps care for his grandmother, Louise, who has dementia. He asks his grandma to describe her morning but she is struggling to find the right words. John says to his dad in front of Louise: "I have no clue what she means!" His dad answers: "Yes, I don't know either. She is just like a child!"

4. Check your understanding

Pay attention to reactions.

Which of the following statements do you feel are helpful?

Check all the responses that you feel are appropriate.

- John should not talk about his grandma when she is in the same room. John could have said: "It is difficult to understand what you mean." In addition, he could have asked some questions that Louise could have answered with 'YES' or 'NO'. For example: "Have you gone outside this morning?"
- John and his dad could be more patient.
- John and his dad could ask Louise, if it is okay when they try to guess what she wants to say.

4. Check your understanding

Pay attention to reactions.

Which of the following statements do you feel are helpful?

- ✓ John should not talk about his grandma when she is in the same room. John could have said: "It is difficult to understand what you mean." In addition, he could have asked some questions that his grandma could have answered with 'YES' or 'NO'. For example: "Have you gone outside this morning?" **Very helpful!** John takes his grandma seriously when trying to understand what she wants to say. Do not talk about the person you help care for while they are in the same room.
- ✓ John and his dad could be more patient. **Very helpful!** It takes people with dementia longer to find the right words and they need time and patience to be understood
- ✓ John and his dad could ask Louise if it is okay when they try to guess what she wants to say. This is an **appropriate answer** because some people with dementia appreciate help with finding the right words or fill in sentences

Remember

- It is important to take the person with dementia 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 help care for is difficult to understand, it may help to ask questions that can be answered with YES or NO.

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 your family member living with dementia.

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

- Take notice of the body language and facial expressions of the person with dementia. It can help you understand how they are feeling. Examples of body language include fidgeting, having arms crossed or pacing. For example, whether the person may be nervous, upset, or anxious.

7. How to give compliments



Complimenting the person you help 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.

For example, you can let the person know if they have done something well or that they look nice.

Keep in Mind

- The person you help care for will feel good if you say something positive.
- Compliments can be given in many different ways. For example you can say 'you look really pretty today' or you can give the person a hug to congratulate them for doing something well.
- 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!
- 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.

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 your family member with dementia that you help care for. Now try to write down something you would say to give them a compliment. You can either write this on a notepad or in the text box below.

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 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 make an effort and be patient with them.

Let's look at an example

Will helps care for his grandma, Elena, who lives with dementia. Will's grandad (Elena's husband) passed away six months ago. Elena often asks Will where her husband is. Will finds this difficult. He knows Elena 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?" Elena persists in asking where Will's grandad is.

7. Check your understanding

How to show compassion (1).

Did Will respond in a helpful way?

- Yes
- No

Today Will tries a different approach

Will says to his grandma: "It must be difficult for you that grandad died". He gives Elena a hug. Will shows Elena some pictures of grandad and talks to her about him. Will showed that he understands that his grandma is missing her husband and tries to support her.

8. Check your understanding

How to show compassion (2).

Did Will respond well?

Yes

No

7. Check your understanding

How to show compassion (1).

Did Will respond in a helpful way?

✗ **No.** Will wants to distract his grandma'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 helpful way to respond, especially because his grandma persists in asking.

8. Check your understanding

How to show compassion (2).

Did Will respond well?

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

Let's remember what we've talked about

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 Will and his grandma, 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 with dementia.

Session 3. Supported decision-making

Why is this session important?

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

What are we going to talk about in this session?

We are going to look at examples of how your family can support the person living with dementia to make their own decisions for as long as possible.

What will I learn?

We will look at why support in decision-making is needed and we will discuss how your family can support your loved one with dementia:

1. Making decisions in their best interest.
2. Making everyday decisions as the dementia progresses.
3. Making complex decisions.

1. Why does the person you help care for need support when making decisions?



Supporting someone with dementia to make their own decisions is very important. Like everyone else, people living with dementia have the right to be involved in all decisions that affect their lives and wellbeing. However, making decisions may become difficult due to the progression of dementia. Sometimes what happens is that family members take over decision making, instead of supporting their loved one with dementia

to make their own decisions.

In this session, we will talk about how you and your family can support the person living with dementia when they need to make a decision.

2. Making decisions that are in the best interest of the person with dementia

Everybody needs to make decisions, whether they are big or small. Because the person you help care for has dementia, sometimes you will need to help them explain what they want and what their wishes are.

This can be difficult for you and your family because of a number of reasons:

- **Memory loss**

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

- **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.

- **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.

1. Activity

Think about your own situation.

Do you support your family member with dementia to make decisions? Can you think of any examples? You can either write this on a notepad or in the text box below.

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

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

Let's look at an example

George has Alzheimer's disease and is married to Maria. George 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 everyday.

1. Check your understanding

Support for making everyday decisions.

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

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

Keep in Mind

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

1. Check your understanding

Support for making everyday decisions.

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

✓ Before Maria and George go to bed, Maria asks George what he wants to wear the next day. She then asks George to lay them out. **This is a very helpful answer!** This way George is encouraged to do the things he is still able to do.

✓ Maria chooses clothes for George and she asks George to lay them out. **This answer is okay.** It is good that George is encouraged to lay out his clothes himself; however, it would have been better if Maria supported George in making his own decision about what to wear.

✗ Maria chooses clothes for George in the morning and gives them directly to George to wear. **This is not a helpful option.** Maria is taking control away from George. 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, George 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 George in making his decision.

2. Check your understanding

Support for making decisions as the dementia progresses.

What should Maria do?

Please check all the responses that you feel are appropriate.

- Instead of supporting George to choose his clothes the evening before, she asks him in the morning, at the beginning of the day.
- Maria lays out George's clothes in the evening.
- When Maria asks George 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 be useful to simplify decisions by limiting the number of choices or discussing 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 Maria do?

- ✓ Instead of supporting George 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 very helpful option!** Maria still supports George in deciding what he wants to wear, but he will not start to worry the evening before.
- ✗ Maria lays out George's clothes in the evening. **This is not a helpful option.** Maria is deciding for George, while he still might be able to make his own decisions.
- ✗ When Maria asks George 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 helpful option.** Even though Maria decides which trousers George should wear the next day, George 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 George 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 dementia and lives with her daughter Chrissy, her son in law and her granddaughter. 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 can Chrissy and her family do?

- Mary should do what she wants, so she does not need support in making the decision whether or not to start with the medication.
- Chrissy says: "Mum, you know that you have problems with your blood pressure and that can be risky. By taking the medication these problems may slow down a bit."

3. Check your understanding

Support for making complex decisions (1).

What can Chrissy and her family do?

✗ **Mary should do what she wants, so she does not need support in making the decision whether or not to start with the medication. This is not helpful.** Since Mary has dementia, we are not sure whether or not she understands why she needs the medication and what the consequences of not taking it are.

✓ **Chrissy says: "Mum, you know that you have problems with your blood pressure and that can be risky. By taking the medication these problems may slow down a bit."** This is likely to be a very helpful response! Using different words to explain the possible reasons for taking the medication might help Mary understand why taking it would be beneficial for her.

Let's look at another example

Jack who has dementia lives with his wife, Ella. Jack's condition deteriorates. Ella decides to make an appointment with the doctor without Jack 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 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 the information as part of the decision-making process.

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 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 their medicine.

- **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 for the family other than to help the person living with dementia make a decision that is in their best interest.

Remember

- As a young person you might not be involved in helping your family member make complex decisions, however it is important for you to know that with the **right support, someone with dementia can be involved in making complex decisions, such as treatment choices.**
- Support for making complex decisions should focus on providing correct information to help the person your family cares for understand what the consequences of the decisions are.

As a young person you might not be involved in asking these questions to your family member living with dementia. Each family's situation is different. These are some questions that your parents or adults in your family might want to consider and discuss with the person with dementia so that they can be sure they are following their wishes:

- Where do they prefer to live if it is no longer possible to stay at home?
- Who do they want in charge of important decisions when they are no longer capable of making decisions themselves?
- How do they want to be treated at the end of their life?
- Are there medical treatments that they want to receive or refuse?
- Do they have any particular fears or concerns about medical treatments?

Session 4. Involving others

Why is this session important?

It is important that you share caregiving responsibilities with other people.

What are we talking about in this session?

1. The importance of involving family and friends.
2. Types of help and support that you might need.
3. Being able to ask for help from others.

You can find more information about different types of support available by going to the website of the Alzheimer's Association in your country:

<https://www.alzint.org/our-members/member-associations/>

1. The importance of involving family and friends



It might be difficult for you and your family to involve others in the care of the person living with dementia. This might be because you could think that others will not be able to provide care as well as you and your family can or that they don't have time

or might say 'no' when asked for help.

As time progresses, your family member with dementia will need more help. Because of this, 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.

2. Types of help and support that you might need

First let's look at a few examples that relate to you or maybe someone in your family:

- **Leah** is 14. She cares for her dad, who has dementia, every day after school and during weekends when her mum needs to go to work. She receives no help 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 teenage sons in the care. The brothers regularly take their mum out for walks or help clean the house and prepare meals.
- **Fatima** is 17 and helps her mum care for her dad who has dementia. Fatima receives help from her school if for example she is struggling to submit her homework on time. She also feels supported by her friends and some of her teachers who listen to her when she is feeling a little bit sad and is struggling with her dad's memory loss.

The types of help and support that Fatima receives are listed below.

| |
|---|
| Practical help |
| <ul style="list-style-type: none">• Family: every Saturday morning my aunt takes dad out for the day to do something nice.• Friends: once a week my friend Hiba comes over to help me catch up with schoolwork |
| Help with pleasant activities |
| <ul style="list-style-type: none">• Family: my uncle takes me to netball training every week. |
| Emotional support |
| <ul style="list-style-type: none">• Friends: Jacob is always there to listen when I need it.• Teachers: Mrs Hart, my form teacher, understands my situation and I often chat with her about how things are going at home.• Local Young Carers Support Group: Fatima joined the group when she started helping to care for her dad. She enjoys the group because everyone in it understands what her and her family are going through. |
| 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?

You can either write this on a notepad or in the text box below. Do your family, friends, teachers, neighbours, or others provide:

Practical help?

Emotional help?

Help with pleasant activities?

Information?

Other help?

Remember

- Keep in mind that feeling like you don't have a lot of help is very normal. Sharing care tasks is very common and it is perfectly fine to ask for help. In this module, we will help you think about who you can ask for help. Asking for help may allow you to spend more time with your friends or do something you enjoy doing. It will allow you to enjoy a well-deserved break!

2. Activity

Let's think a bit more about the help you are receiving.

Take a look at the previous activity where you thought about the type of help you receive. Now have a look at the boxes below and see how many you can tick.

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 helping you deal with your caring responsibilities. If needed, you can ask for more help from other people or other organisations (e.g., charities that support young carers and families affected by dementia, school) as well. Perhaps the examples helped you identify people you had not thought of before.

I do not receive help.

Keep in mind that helping care for somebody 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 for you and your family to find help if you don't have many family members nearby or live in a rural or isolated area. Think about alternatives, for example contacting the pastoral care team in your school, or your local dementia or young carers association.

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. Making a 'wish list' might help.

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



What is on your wish list?

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

Wishes could be for example:

- I would like to speak to my teachers about my caring responsibilities.
- I would like to talk to other young people in a similar situation to mine.
- I would like to be able to invite a friend for a sleepover.

In the next activity, please list 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 likely to happen.

For instance:

Leah would like to be able to have her own bedroom but she knows that her wish is not realistic because her dad needs his own bedroom and she needs to share with her sister. However, she might be able to agree with her sister to sleep in the lounge for her to be able to have a friend for a sleep over once in a while.

3. Activity

Think about wishes that seem achievable. You can write them down in the space below or if you prefer you can use your own notepad.

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.

Tips on how to ask for help:

- **Think about who would be the best person to talk to** (e.g., your parents? your teacher?) - Think about what you want or need.
- **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.**
- **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.
- **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 Leah again

She knows who to turn to for help and decides to ask her sister. Leah 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 select the response that you think is likely to be helpful.

- Leah tells her mum that she enjoys helping to care for her dad, but she just needs a bit of time after school some days to spend with her friends. She says: "I know that it is difficult for you but what would you think if we asked uncle Rob whether he could come and stay with dad one afternoon a week?"
- Leah decides to make plans with her friends one afternoon after school. However, she doesn't discuss with her mum how important this would be for her. When she asks her mum she replies: "Sorry, I can't be late for work" Leah feels guilty and cancels her plans after school.
- Leah approaches her mum by saying, "I'm sick and tired! I never have time to spend time with my friends!"

1. Check your understanding

Asking for help effectively.

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

✓ Example 1 **Effective**. This is an effective way of asking for help. Leah stands up for herself, says what she is thinking and is honest about her need for an afternoon off to see her friends. She also shows that she is trying to support her mum.

✗ Example 2 **Passive**. This is not an effective way of asking for help. Her mum may not be aware that Leah is feeling overwhelmed. Leah hasn't shared her feelings with her mum and is trying to avoid conflict.

✗ Example 3 **Aggressive**. This is not an effective way of asking for help. Leah becomes angry. However, her mum may not be aware that Leah is feeling overwhelmed, because when she asks Leah always replies, 'I'm OK'. She does not approach her mum in a respectful way. It is an aggressive way of asking for help.

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