

iSupport for Rare Dementias

Part 2 Being a carer



BEING A CARER

Session 1. The journey together

Session 2. Improving communication

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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. Doing something for yourself
4. How to involve others
5. How to plan well for the future

1. How your role may 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 will have more difficulty with everyday tasks. This will require a carer to do more to help with everyday life, such as helping with medications and accompanying 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

Olivia has frontotemporal dementia and lives with her husband Jacob. During the past few months, Olivia has developed a sweet tooth and become more impulsive. The last few times Olivia went shopping she came home with lots of biscuits and sweets, which was frustrating.

1. What could you do?

Frustration about impulsive buying.

Below are some suggestions that Jacob could try:

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

This is a good response, because this may help Olivia to continue shopping and maintain her autonomy as long as possible.

✓ **Arrange a click and collect order for Olivia to pick up.**

This is another good response, it doesn't take away Olivia's autonomy but may help to control her spending and limit the sugary foods that are bought.

2. How to stay connected with the person with dementia

It is important to keep talking together. Rare dementias often progress a lot faster than more common types. 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. Attempt to stay connected with each other and discuss the changes that may occur over time. It is important to remember that some people with dementia will lack awareness about their symptoms (known as anosognosia) which will make it difficult to have conversations with them about the changes that they are experiencing.

Tips

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

- use simple sentences;
- try to note how you are feeling and how that might influence how you respond;
- take a deep breath and try to stay patient, it's probably frustrating for you both;
- try different ways of communicating if the person struggles with verbal and written communication (e.g., images, photos and hand signs);
- create some 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.**

3. Doing something for yourself



Providing care may become increasingly time consuming as the condition progresses. It can be really difficult to look after yourself when you are looking after someone with dementia and juggling work, care for children, and have other family commitments. It is really important to try and take care of yourself as best as you can by making some time for yourself. If you can, plan some activities that might bring some relaxation and enjoyment. For example, staying under the shower a bit longer and having a coffee with a friend.

For more tips on how to relax, read **session 3. Reducing stress in everyday life in Part 3.**

For more tips on how to stay in control of your feelings read **session 2. Thinking differently in Part 3.**

For more tips on how to plan pleasant activities for yourself, read **session 1. Making time for enjoyable activities in Part 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 how you are feeling and if you are struggling and perhaps when you could use a break. Caring for a person with dementia is sometimes too big a job for one person.

2. What could you do?

Feeling stressed due to conflicting duties.

Molly lives with her sister, Jess, who has Lewy body dementia. Molly has a big deadline at work and needs to leave at 7:30 the next morning. The paid in-home helper is not due to arrive until 9:00 in the morning. This leaves Jess alone for over an hour. Molly wonders whether it would be okay to leave Jess alone and feels stressed because she is not sure what to do.

Below are some suggestions for Molly:

✓ Ask if a neighbour can come and visit Jess until the paid in home helper arrives.

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

✓ Ask her husband to go into work late so he can be with Jess until the paid in-home helper arrives.

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

✓ Ask the paid in-home helper to come in early.

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

Important

Informing others about a diagnosis of dementia can be a legal requirement in some circumstances. The person with dementia is legally obliged to inform the DVLA of their diagnosis and depending on their job role, you may have to inform their employer too. If they are not prepared to inform others, you might have to do this on their behalf.

Employment



Rare dementias can affect younger people who may still be working at the time of their diagnosis. Dementia is classed as a disability, which means that legally the person with dementia cannot be fired for having dementia. Informing an employer of a dementia diagnosis may be a legal requirement, if the person with dementia is operating machinery or is responsible for the health and safety of others. However, under the

Equality Act, employers should make reasonable adjustments to support people with dementia in the workplace.

For more information on this and tips on how to make a workplace dementia friendly, please visit: <https://www.dementiauk.org/get-support/living-with-dementia/employment-and-young-onset-dementia/#adjustments-workplace>

For more information please see:

- Employment - Rare Dementia Support - <https://www.raredementiasupport.org/general-advice/employment/>
- Employment.pdf (alzheimers.org.uk) - <https://www.alzheimers.org.uk/get-support/publications-and-factsheets/living-dementia-employment>

Financial support



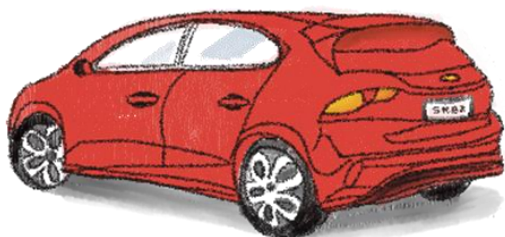
If you or the person you care for are unable to work, you may need some financial support. In the UK, you or the person with dementia may be eligible for:

- Personal Independence Payment (PIP);
- Attendance allowance;
- Carers allowance;
- Council tax discounts.

For more information on financial support please visit:

<https://www.raredementiasupport.org/general-advice/financial-support/>

Driving



Legally, you have to inform the DVLA and your insurance company when someone receives a diagnosis of dementia. This does not mean someone with dementia will have to stop driving straight away but the DVLA will speak to a nominated doctor

who will advise the DVLA as to whether they are safe to drive or not. You might be able to apply for public transport discounts to help the person with dementia to stay independent for as long as possible.

For more information please see:

- [Transport and travel - Rare Dementia Support](#)
- [Driving - Living with dementia series](#)

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.

As well as discussing the future, it is important to make legal arrangements. The person with dementia will at some point lose the ability to make decisions. The person can appoint someone to help or take over making their decisions. This is called **Lasting Power of Attorney**. There are two types of Lasting Power of Attorneys: 1) Property and Financial Affairs Lasting Power of Attorney and 2) Health and Welfare Lasting Power of Attorney.

The person with dementia can also write an advance decision (also known as a living will). A living will is a legal document that describes the type of medical treatments that a person would not want. For example, the person might want to refuse blood transfusions in certain circumstances.

Having these documents completed early on can reassure both you and the person you care for that their wishes are known and will be respected. For more information on planning ahead please visit:

<https://www.alzheimers.org.uk/get-support/legal-financial/lasting-power-attorney>

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 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?

What are the person's preferences when they are no longer able to bathe themselves?

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 physically and emotionally. As the dementia progresses, it will be important to ensure any sexual activity is consensual. As the disease progresses, sexual relationships and physical intimacy may become more challenging and difficult.

For younger couples, birth control is important to think about. The person with dementia may not remember to take a contraceptive pill, so you might need to think about other contraceptives, such as an implant or injection. For further guidance on this, speak to your GP.

Let's revisit the scenario with Olivia and Jacob

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

2. Activity

What are some ways that Jacob and Olivia can maintain their intimacy as Olivia'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 enjoyable 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. Positive communication
8. Compassionate care

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.

Certain types of rare dementias will make communication harder than others. For example, primary progressive aphasia affects the part of the brain responsible for language processing, which means that a person with primary progressive aphasia may experience difficulties with their speech as well as their ability to fully understand you. The advice in this section can help to improve communication for some but it might not work for everyone. For primary progressive aphasia specific advice, please visit:

<https://www.raredementiasupport.org/primary-progressive-aphasia/living-with-primary-progressive-aphasia/>

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. What could you do?

Imagine that you are living with dementia.

Imagine for a moment that you are living with dementia.

You would like people to:

- ✓ Listen to how you feel
- ✓ Smile at you
- ✓ Tell you that they love you
- ✓ 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.

For posterior cortical atrophy specific advice please visit:

<https://www.raredementiasupport.org/posterior-cortical-atrophy/living-with-posterior-cortical-atrophy/>

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. To help the person see clearly, try increasing light levels, using daylight where possible, and avoiding stark shadows which can be confusing. You can also try leaving the 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. This may not be relevant to someone who already has a diagnosis of posterior cortical atrophy, where vision is affected.

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, 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 a doctor?	<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 a doctor. If the person living with dementia does not have a hearing aid, but cannot hear well anymore, you should also consult a doctor.

3. How to get attention in a respectful way

Attentional difficulties can be a symptom of dementia which can be frustrating but, 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. What could you do?

Get attention in a respectful way.

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

✓ Speak clearly, slowly, at a volume that is comfortable for the person, face to face and at eye level.

This is an appropriate way to make contact. It shows that you are seeking contact in a respectful manner.

✓ Tap a hand, arm or front of the shoulder.

This is a good way to attract the attention of a person living with dementia.

✓ 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 understand you better.

3. What could you do?

Keep it simple.

Fu takes care of his father who has posterior cortical atrophy. Fu notices that his father doesn't always understand him.

Below is a list of things that could impair communication between Fu and his father.

- ✗ The radio is on.
- ✗ Fu is making a phonecall.
- ✗ Fu asks multiple questions at the same time.

Keep in Mind

- Ask or tell the person living with dementia one thing at a time.
- Use simple language and keep sentences short. Avoid long and complicated sentences, focus on one subject at a time.
- Try changing from open-ended to closed-ended questions that can be answered with YES or NO, but, this won't work for everyone, some people may get YES and NO mixed up.
- Make sure there are no distracting background noises such as a television or radio.
- A speech and language therapist will be able to give personalised advice on communication strategies to try.

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 a scenario

John is visiting his son who has primary progressive aphasia. When his son wants to describe his morning to John, he cannot find the right words. John says to his wife in front of his son: "I have no clue what he means!" His wife answers: "Yes, I don't know either. He is just like a child!".

4. What could you do?

Take the person seriously

John is visiting his son who has primary progressive aphasia.

Below are some different responses that could be appropriate.

- ✓ John should not talk about his son 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 son could have answered with 'YES' or 'NO'. For example: "Have you gone outside this morning?"
- ✓ John and his wife could wait for his son to find the words
- ✓ John and his wife could ask John's son if it is okay when they try to guess what he wants to say.

Remember

- It is important to take the person that you are caring 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 that 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. What could you do?

Pay attention to reactions.

Try to notice different facial expressions, it's a good way to understand how someone is feeling. Match the emotion to the correct facial expression – **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.
- People with dementia may be able to interpret your body language and facial expressions to understand your mood even if they don't understand your words.

7. Positive communication

Positive communication with 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.

Positive communication can range from commenting that someone has done something well to saying that they look nice. You can communicate positively 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. What could you do?

Communicate positively

Here is a list of several positive statements:

- ✓ You look beautiful.
- ✓ You are good at ...
- ✓ You are very helpful. Thank you.
- ✓ I love having you around.
- ✓ 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. Compassionate care



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 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 Lewy Body 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.

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. What could you do?

Compassionate care

Did William respond well?

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. Trying to distract the person from the topic may work for some people, but for William this strategy was not successful.

Today, by showing his sister pictures of her husband, they had a good conversation about him. This won't be appropriate for everyone, reminding Elena that her husband has passed away might cause her to become distressed every time like it's the first time she's heard the news.

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 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 support in decision-making is 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 support in decision-making is needed



Supporting someone with dementia to make their own decisions is very important. People living with dementia have the right to participate in all decisions that affect their lives and wellbeing. However, difficulty making decisions may be an early symptom of dementia and will become increasingly difficult as the dementia progresses.

It can become very tempting to take over the decision making, however trying to support people with dementia to make their own decisions on a day-to-day basis is important to maintain their self-worth. For more major decisions that need to be made, you might be able to get ask a professional to help advice you on how best to do this.

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

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 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 communicating**

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 tell you what it is.

- **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

Manuel has frontotemporal dementia and is married to Maria. Manuel always used to lay out his clothes for the next day in the evening. Now he has dementia, he lacks the motivation to do this and sometimes wears the same clothes everyday.

1. What could you do?

Support for making everyday decisions.

To help Manuel make his own decisions but still wear clean clothes, Maria could:

- ✓ Ask him before bed, what he wants to wear the next day, then ask Manuel to lay them out. This way Manuel is encouraged to do the things he is still able to do.
- ✓ Maria could choose clothes for Manuel and ask Manuel to lay them out. It is good that Manuel is encouraged to lay out his clothes himself; however, it would be better if Maria supported Manuel in making his own decision about what to wear.
- ✓ Maria could choose clothes for Manuel in the morning and give them directly to Manuel to wear. This is taking the decision out of Manuel's hands which may be necessary as the disease progresses but it is important to try and encourage people with dementia to do things for themselves for as long as possible.

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.

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

Let's look at an example

After some time, Manuel 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 Manuel in making his decision.

2. What could you do?

Support for making decisions as the dementia progresses.

Maria could:

- ✓ Rather than asking Manuel in the evening to choose his clothes, she asks him in the morning, at the beginning of the day. Maria is still supporting Manuel in deciding what he wants to wear, but he will not start to worry the evening before.
- ✓ When Maria asks Manuel what he wants to wear she can give him a few choices and, for example, ask him whether he wants to wear his blue or black trousers. In some cases, this might be a good option. Even though Maria decides which trousers Manuel should wear the next day, Manuel can still make the final decision himself.

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.

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. When a person loses the ability to understand the impact of a specific decision, they could be considered as lacking "mental capacity". Whether or not they lack capacity is decided by a mental capacity assessment carried out by a person with expertise in the area where the decision needs to be made. This usually relates to important decisions, rather than

everyday ones.

For more information on this please visit: <https://www.alzheimers.org.uk/get-support/legal-financial/dementia-mental-capacity-act#content-start>.

Let's look at an example

Mary has vascular dementia and is taken care of by her daughter Chrissy. 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. What could you do?

Support for making complex decisions (1).

Chrissy could:

- ✓ Have the doctor explain that taking the medication is good for her health, because it will slow down further damage in her brain because of her dementia. Her doctor's explanation allows Mary to understand the importance of taking the medication and will enable her to make an informed decision. It might help if the doctor wrote this down.
- ✓ Say: "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." 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 advanced primary progressive aphasia lives with his wife, Ella. Jack's condition deteriorates and his doctor has said that he lacks the mental capacity to make decisions for himself. Ella decides to make an appointment with the doctor without Jack to discuss his medical condition and to make a decision regarding his medication.

Ella discusses the issue with Jack's sister as well, who asks her what she thinks Jack would have decided. Ella talks to the doctor and tries to imagine what Jack would have decided if given all the information.

4. What could you do?

Support for making complex decisions (2).

Here are some reasons that jack can no longer make the decision himself.

- ✓ Jack is unable to understand the information that is relevant to making the decision.
- ✓ 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 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 that 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 correct information to help the person you care for 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 that 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), 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 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 that 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.

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?

Deprivation of Liberty



A Deprivation of Liberty Safeguards (DoLS) may be necessary in certain circumstances for keeping people with dementia safe. This is when people who lack mental capacity, already in a care home or hospital, can have certain decisions made for them. For example, being unable to leave the care home or hospital or having decisions about medications made for them. Under the Mental Health Act, a person can be kept in hospital against their will if there is a risk of them harming themselves or someone else. This is regardless of whether they have "mental capacity" and is known as "sectioning".

For more information on UK laws, including the Mental Health Act or the Mental Capacity Act, please visit: <https://www.alzheimers.org.uk/get-support/legal-and-financial/mental-health-act-1983#content-start>

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 could 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.

2. Types of help and support that you might need

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

- **Li** takes care of her mother who has Lewy body 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 frontotemporal 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 posterior cortical atrophy. 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 vision.

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.

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.

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

Help with pleasant activities

Emotional support

Providing information

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.

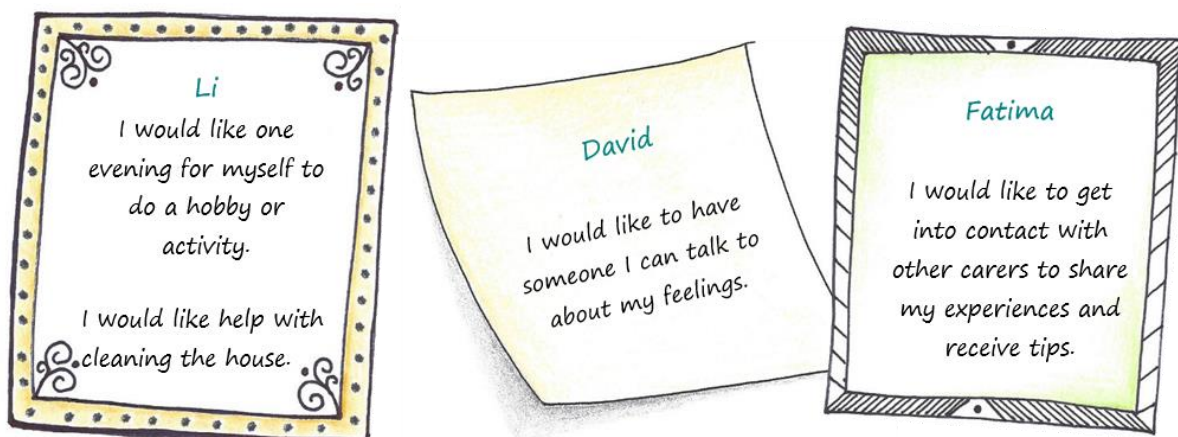
It is very good that you are already involving others in caring for your family member or acquaintance. If needed, you can ask for help from other people as well. Perhaps the examples helped you identify people you had not considered before.

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 dementia 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. It can help to make a wish list of your needs. Let's first have a look at Li, 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, Li would prefer to hire someone to clean the house every week. However, Li 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

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. There are several organisations that provide support for people with dementia and those caring for them including befriending services, day care or support groups. You might also want to ask friends or family for their support. Some people have no problem asking for help,

other people are not used to it but do not mind giving it a try. There are also people who find it very difficult to ask for help. The next section will offer you suggestions on how you could ask for help. 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. Using leaflets and websites to help explain the type of dementia and associated symptoms may be useful. For useful information please visit:
 - <https://www.dementiauk.org/>
 - <https://www.raredementiasupport.org/>
 - <https://www.alzheimers.org.uk/>
 - <https://www.lewybody.org/>
- 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 Li again

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

1. What could you do?

Asking for help effectively.

To effectively ask for help from her sister, Li could:

- ✓ Tell 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 could say: "I would like to discuss how you could help in a way that is possible for you." This is an effective way of asking for help. Li says what she is thinking and feeling and is honest about her need for a regular break. She also keeps the interests of her sister in mind.

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.*

Available support services

As well as involving friends and family, you might want to access professional support too, below is a list of three organisations and the services they offer.

- Dementia cafes, befriending services and other types of support are available from the Alzheimer's society at
 - <https://www.alzheimers.org.uk/find-support-near-you>
- Age UK run memory cafes, dance for dementia and other services
 - <https://www.ageuk.org.uk/services/in-your-area/dementia-support/>
- Rare dementia specific services are less common, however, Rare Dementia Support offer support groups online and in person for people living with dementia and their carers
 - <https://www.raredementiasupport.org/meetings/>
- Lorenzo's House offers support for families affected by young onset dementia including online support groups for children and young adults
 - <https://lorenzohouse.org/>

Carers assessment



Any carers over the age of 18 in the UK are entitled to a carers assessment. This will be completed by your local council and will tell you if you're eligible for any support. This can include respite care, financial support and equipment to help you

care for the person with dementia (such as hand rails).

For more information on carers assessments, please visit:

https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment?gclid=CjwKCAjwu5yYBhAjEiwAKXk_eBZsf_Fygmy6P8A2tValpxCQZAI5bWpSIIGFE2DFaliVqCUVzJwZYRoCcccQAvD_BwE

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