

iSupport for Rare Dementias

Part 5 Dealing with symptoms and behaviour changes

DEALING WITH SYMPTOMS AND BEHAVIOUR CHANGES

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PART

5

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Session 1. Symptoms and behaviour changes

Why is this session important?

Dementia changes the way that people behave, think or act. This can be distressing or upsetting not only for the person with dementia, but also for their families, friends and carers.

How will this session help me?

This session helps to improve your skills to prevent and cope with behaviour changes.

What will I learn?

1. Behaviour changes that may be particularly stressful.
2. Understanding the cycle of behaviour change.
3. Different approaches to respond to behaviour changes.

1. Behaviour changes that may be particularly stressful

Dementia changes the way people behave, think or act. This not only affects the person living with dementia, but can also be distressing and upsetting for carers.

“Any behaviour that gets you or the person you care for upset is stressful.”

In this introduction you will learn:

- How you can identify behaviours that are potentially upsetting, stressful or difficult for you and the person you care for.
- How you might handle behaviour changes.
- How you might change circumstances to reduce or prevent behaviour changes.

1. Activity

Does the person you help care for ever experience any of the following behaviour changes? Please select any that apply.

| Behaviour changes | Examples |
|--|--|
| <input type="checkbox"/> Depression and anxiety | Feeling sad, worried, that life is not worth living, frightened, frustrated or angry, being unusually emotional, crying, agitated or restless, withdrawn, unhappy, apathetic or reacting slowly. |
| <input type="checkbox"/> Apathy | Appearing withdrawn, uninterested, lacking in empathy or motivation. |
| <input type="checkbox"/> Anger, verbal or physical | Talking or acting in a threatening way, swearing, shouting or doing things that make you feel frightened, such as hitting others, kicking or destroying objects. |
| <input type="checkbox"/> Changes in judgement | Saying the wrong thing at the wrong time, acting inappropriately or misjudging a situation, not understanding own limitations. |
| <input type="checkbox"/> Repetitive and obsessive behaviour: doing things over and over | Repeating a question or an action over and over. |
| <input type="checkbox"/> Difficulty sleeping | Restless at night or experiencing vivid dreams, waking you or other family members up or getting up and dressed too early. |
| <input type="checkbox"/> Delusions and hallucinations: seeing or hearing things that are not there | Misinterpreting the world, having fixed ideas and beliefs that are not accurate, things a person sees or hears that are not there, or becomes suspicious of those around them. |
| <input type="checkbox"/> Visual changes | Misjudging distances, difficulty distinguishing between moving and still objects or trouble seeing contrast between objects and their backgrounds. |
| <input type="checkbox"/> Walking and movement problems | Leaving the house and getting lost or having difficulty walking possibly due to balance issues. |

| | |
|---|---|
| <input type="checkbox"/> Memory loss | Forgetting or losing things, not being able to recall recent events or remember dates and days of the week. |
| <input type="checkbox"/> Not at this time | None of these symptoms are present at this point in time. |

Remember

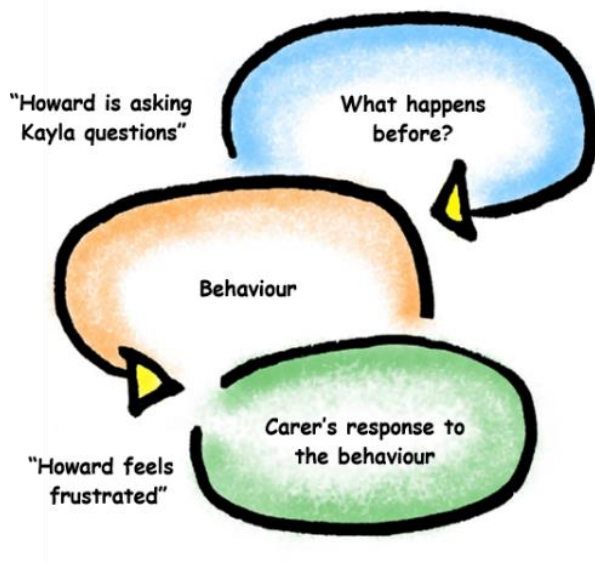
Many things can cause behaviour changes that are upsetting to you or the person you care for. Some behaviours are a form of communication, if the person with dementia can't express their needs, they might become angry or upset.

In this session you will learn some tips that might help to reduce some of these situations.

2. Understanding the cycle of behaviour change

Understanding behaviour changes can be helpful if you can work out what happens before and after the behaviour is very important. Sometimes you can reduce the behaviour. If you pay attention and understand what happens before or “triggers” the behaviour, this can sometimes help you to reduce the behaviour.

The diagram below shows what's happening.



Let's look at the following example

Kayla has primary progressive aphasia, her husband Howard is taking care of her.

Howard often asks Kayla if she can remember who came to visit last week or what she had for dinner yesterday. Kayla struggles to find the words to answer and gets agitated. As a result, Howard feels frustrated.

What happens before the behaviour?

What do you think happens before Kayla gets agitated that you might be able to change? Below are some examples.

1. Howard asks questions that Kayla cannot answer.
2. The tone of voice that Howard uses to ask these questions makes Kayla feel nervous.

1. What could you do?

Identifying what happens before the behaviours

What event came before Kayla got agitated? Please write down any ideas in the box below.

Remember

Some behaviours can be managed by reducing or avoiding certain triggers BUT this won't work for all behaviours such as hallucinations or apathy.

Now let's look at Howard's response

So, what are we trying to do? We are trying to separate what comes **before** the behaviour and what the carer's response is **after** the behaviour.

How does Howard respond in this example?

Howard gets frustrated because his wife Kayla forgot who came to visit and what she had for dinner.

Howard can choose to change his response.

1. What could you do?

Different ways of responding to behaviour change.

What are some of the ways that Howard could respond?

- ✓ Take a deep breath.
- ✓ Remind himself that his wife has dementia and cannot help that she struggles to speak. She is not doing it on purpose.
- ✓ Next time, he could remind Kayla about the events so they can have a more enjoyable conversation about their shared experiences.
- ✓ Howard could try asking her fewer questions as this causes frustration for him and for his wife.
- ✓ He could try simpler, yes or no questions to try and help Kayla respond to his questions.

3. Different approaches work at different times

Different approaches work at different times, so Howard could try several approaches until he finds one that works. Here are some examples of what Howard could do:

- He can ask other people's advice, for example his doctor.
- He can also ask someone at the Alzheimer's society (<https://www.alzheimers.org.uk/>) or rare dementia support (<https://www.raredementiasupport.org/>)
- He can search for information on the internet.

2. Activity

Now think about your own situation.

It is important to apply what you have just learned to your own situation with the person you care for. *Use the space below, like a diary.*

Let's review what we've talked about

- People with dementia may experience behaviour changes that are distressing or upsetting to them or those around them.
- It is helpful to identify what happens before the stressful behaviour to understand what might cause it or make it worse.
- It is also helpful to identify how you usually respond, what you feel or what you do.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for.
- Try different responses and approaches, as the first one does not always work.
- Seek professional help if you cannot manage a situation.

Session 2. Depression and anxiety

Why is this session important?

Dementia may affect a person's mood and interest in daily activities, people and events.

How will this session help me?

This session helps you to understand the possible causes of depression and anxiety, while improving your skills to prevent or reduce mood problems.

What will I learn?

1. What are depression and anxiety?
2. How to respond when a person living with dementia is feeling depressed or anxious.

1. What are depression and anxiety?



Depression and anxiety are common feelings/emotions experienced by people with dementia.

Dementia may affect a person's mood and interest in daily activities, people and events. This may be due to changes in the brain, but also to the emotional reaction of what is happening to them.

People with dementia may feel sad, worried, frightened, frustrated or angry, may cry and be unusually emotional, agitated or restless. They may also be withdrawn, unhappy and react slowly. These are all symptoms of depression, which has some overlap with apathy. For more information on apathy please see **Session 3. Apathy**.

Anxiety can lead to behaviours similar to depression. People with dementia can be worried about being left alone, who is handling their money, or where lost items have gone to and become anxious.

2. How to respond when a person living with dementia is feeling depressed or anxious?

Let's look at an example

Juan has posterior cortical atrophy and lives with his husband, Marco. On several occasions Marco has found Juan sitting in his favourite chair looking very sad, hunched over, and sometimes crying. Marco tries to cheer him up. Unfortunately, nothing that he tries seems to work.

1. What could you do?

Responding to a person with dementia who is feeling depressed.

Below are some things that Marco could do or say.

- ✓ Walk over to Juan and say in a calm, reassuring tone, "I'm sorry that you're not feeling good, do you want to talk about how you're feeling?"
- ✓ Go over and touch Juan on the arm or shoulder. "I know that you feel bad, I do too. What we're going through is really hard."
- ✓ Sit with Juan and suggest that they do a pleasant activity together.
- ✓ Talk to Juan about making an appointment with the GP.

Important

It's normal to feel sad or anxious sometimes, but if the person you're caring for is showing signs of depression or anxiety then please visit your GP. Medication or talking therapies might be helpful.

Here is another example

Emma has primary progressive aphasia and lives with her family. Benjamin is her grandson, who is still in school. Because Benjamin's parents work and he is in school, he is the main carer in the afternoons. Benjamin is watching a TV show while his grandmother is sewing. The TV show has loud music and vulgar language. Suddenly, his grandmother jumps up and paces up and down the room, wringing her hands. She is muttering to herself "I need to go home", "I need to go home".

2. What could you do?

Responding to a person with dementia who is feeling anxious.

Below are some things that Benjamin may do or say.

- ✓ Think "Grandmother cannot help the way that she behaves."
- ✓ Give his grandmother a smile and reassure her that she is safe.
- ✓ Ask his grandmother to help him with something.
- ✓ Look for his headphones and encourage his grandmother to go back to her sewing so that she is busy.

2. Activity

Now think about your own situation.

It is important to apply what you have just learned to your own situation with the person you care for. *Use the space below, like a diary.*

Let's review what you have learned

- Signs of depression and anxiety are common in people with dementia.
- Changes in mood can be very upsetting to the person living with dementia and the carer.
- People with mood problems need extra love and support.
- It is important to identify ways to stop or reduce mood changes, by comforting and getting the person interested in things that they like to do.
- If one approach doesn't work, try another one.
- In case of mood changes, remind yourself that they may be part of the disease or a reaction to the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for in case they have mood problems or experience a loss of interest.

Remember

It is important to recognise when things get serious. If the person you care for has serious and constant mood changes or you think that they are in danger of harming themselves, it is important to seek medical advice right away.

Session 3. Apathy

Why is this session important?

Apathy can be very challenging to deal with for carers.

How will this session help me?

This session will help you to understand apathy and suggest some strategies on how to respond to apathy.

What will I learn?

1. What is apathy?
2. How to manage a lack of motivation?
3. How to manage a lack of emotion?

1. What is apathy?

Apathy is a lack of interest, motivation or emotion. It can present as someone not wanting to do things or seeming to not care about other people's feelings. This is particularly common in those with frontotemporal dementia but can occur in all dementias.

Keep in Mind

Apathy can be a symptom of dementia but it might be a symptom of depression, which can be treated with medication or talking therapies. If you're worried about which it is, please see a GP.

2. How to manage lack of motivation?

Apathy is a lack of interest, motivation or emotion. It can present as someone not wanting to do things or seeming to not care about other people's feelings. This is particularly common in those with frontotemporal dementia but can occur in all dementias.

Here's an example

Jeremy has frontotemporal dementia and lives with his wife, Brenda and two children, Dylan and Carys. Dylan is six and plays football as a part of the local children's team. Jeremy usually goes to watch Dylan playing but has recently wanted to stay at home and watch TV, which is confusing for Dylan.

1. What could you do?

Responding to a person with a lack of motivation.

Below are some suggestions for Brenda to try and help in this situation.

- ✓ Try to explain to the children that Jeremy has dementia and that he can't always help his behaviour. Please follow these links for advice on how to explain dementia to children <https://www.alzheimers.org.uk/get-support/daily-living/explain-dementia-children-young-people> and <https://www.theaftd.org/living-with-ftd/kids-and-teens/>
- ✓ Try recording the game for Dylan and Jeremy to watch on the TV together.
- ✓ Try breaking down the task into smaller parts for Jeremy so it seems less overwhelming. For example, ask him to get his coat and scarf on, go and sit in the car, walk to the football field, have a sit down etc.
- ✓ Go to the game for a shorted time so that Jeremy doesn't lose interest.

3. How to manage lack of emotion?

Apathy can also present as someone showing a lack of emotion. This can be difficult for carers to adjust to if the person with dementia was previously very caring.

Let's look at an example

Tina is married to Eric who is living with Lewy body dementia. Tina received a phone call to tell her that a close friend had passed away. She was very upset and went to talk to Eric, who did not show any empathy or try to comfort her. Tina is worried that this response is because Eric isn't happy in their relationship.

2. What could you do?

Responding to a person with a lack of emotion.

Below are some suggestions for Tina to try in this situation.

- ✓ She could try explaining in more detail how she's feeling, if he's struggling to understand how she's feeling this might help him.
- ✓ Try talking to other people, support groups, family or a counsellor might be able to offer the support that she needs.

Tip

You might not be able to change apathy but you can use the time where they want to watch TV to do pleasant activities for yourself, housework or relaxation exercises from Part 3.

1. Activity

Let's look at your own situation

Has the person you care for become apathetic? How do you respond to this behaviour? Could you use it to get tasks done for yourself? *The space below is for you, like a diary.*

Let's review what you have learned

- Apathy is common for people with dementia and is unlikely to be a reflection of the quality of your relationship with the person.
- Apathy can be a part of dementia or a symptom of depression (which can be treated).
- It can be difficult to deal with, especially for children.
- Try to find activities that will interest them.
- Breaking down activities into smaller parts might make them seem less overwhelming.
- Remember that sometimes tips will work but sometimes they won't.
- Talking to friends, family or support groups will help you deal with things that you can't change.
- If the person you care for doesn't want to do anything, use that time for yourself to try relaxation exercises from **Part 3** or other activities.

Session 4. Anger, verbal or physical

Why is this session important?

From time to time, people with dementia may become angry, aggressive or violent. This is often one of the most difficult things to cope with for carers.

How will this session help me?

This session helps to understand possible causes of aggression and improve your skills to prevent or deal with aggression.

What will I learn?

1. Why does aggression happen?
2. How to respond to aggressive behaviour.
3. How to deal with ongoing aggression.

1. Why does aggression happen?



From time to time, people with dementia may become angry, either verbally or physically. This is particularly relevant for those with frontotemporal dementia who might have trouble with impulse control.

Aggression can happen for a variety of reasons. It can be due to unmet needs, illness such as a urinary tract infection, medication combinations or side effects, or something that is happening around the person with dementia.

In addition, people with dementia may have difficulty understanding others, judging social situations, controlling their feelings or expressing themselves like they did before. They may also have personality or mental health changes that contribute to aggressive behaviours.

At times, aggression is displayed towards people known to the person living with dementia. At other times it can be with strangers. Aggression is often one of the most difficult things to cope with for carers.

1. Activity

Let's look at your situation. Check your answer, yes or no.

Does the person you care for ever **talk** to you or other people in an aggressive way?

- Yes
 No

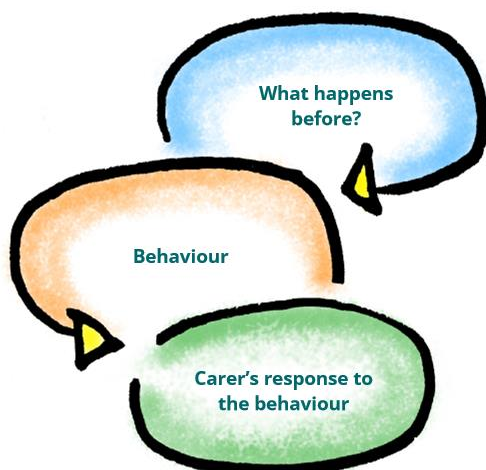
Does the person you care for ever **act** aggressively towards you or other people?

- Yes
 No

Warning!

If the person is suddenly behaving aggressively, there may be an underlying cause (for example a urinary infection) that should be investigated by a doctor.

Applying the cycle of behaviour change



The cycle of behaviour change that was introduced in Session 1. Introduction to symptoms and behaviour changes, can be useful to break down the cycle of stressful responses into three parts in order to help you deal with the situation.

WARNING!

Rarer dementias often affect younger people, who can be physically strong. However difficult it is, it's important that if you feel that you, the person you care for or anyone else is in danger, please ring 999 for help.

Applying the cycle to a different example.

Neil wants to assist his son-in-law, Amit, who has primary progressive aphasia, in taking a bath because Amit needs to see a doctor. Neil says: "it is time for your bath". Amit refuses. Neil has little time and tugs on his son-in-law's arm. He says: "you need to bathe because you're going to see the doctor."

Amit pulls his arm back and resists. He is much stronger than Neil. Neil tugs it again and says angrily: "you must take a bath because you are going to the doctor and need to be clean". Amit gets very angry, shouts and even tries to shove Neil, who becomes upset.

1. What could you do?

Understanding aggressive behaviour

Can you break down the cycle of behaviour change in this example into its three parts? *Please fill in the boxes below.*

| What comes before the behaviour? | What is the stressful behaviour? | What is Neil's response? |
|----------------------------------|----------------------------------|--------------------------|
| | | |

2. How to respond to aggressive behaviour

2. What could you do?

Responding to angry behaviour.

Neil could:

- ✓ Maintain the dignity and privacy of his son-in-law. Neil could keep him in a robe or towel until he actually takes a bath.
- ✓ Play soothing music that Amit likes or walk away and come back later.
- ✓ Put himself in Amit's shoes and try to understand why Amit might not want to take a bath.
- ✓ Make sure that there is enough time so that it is not so stressful. Rather than trying to bathe Amit right before the doctor's appointment, when things are rushed, Neil might try to assist with bathing the day before.
- ✓ Identify the best time of day for Amit to take a bath and find out whether he prefers a bath or a shower.
- ✓ When bathing Amit, keep a towel over his shoulders to help him maintain dignity and to keep him warm.
- ✓ Ask for someone else to help with Amit's bath time.
- ✓ Help Amit with a bed bath by using warm, wet towels with soap without taking Amit to the bath.

3. How to deal with ongoing aggression

Sometimes your first approach may not work. Don't get discouraged, different responses may work at different times.

3. What could you do?

Ongoing aggressive behaviour.

Below are some suggestions to help Neil if his approach does not work the first time.

- ✓ Neil could try several approaches until he finds one that works.
- ✓ Neil could get suggestions from others such as from support groups that may be dealing with similar situations.

Remember

Take a deep breath and think about the most positive ways to respond that will be the least distressing to you and the person you care for.

Remind yourself that aggression can be a part of the dementia, or a reaction to the disease.

2. Activity

Let's look at your own situation

It is important to apply what you have just learned to your own situation. Has the person that you care for ever been aggressive towards you? *If so, describe the last time that this happened in the space below.*

Let's review what you have learned

- Aggression like shouting, shoving or pushing can happen to carers of people with dementia.
- Aggression can be very upsetting for the person living with dementia as well as the carer.
- Try to change the environment to make it more calming.
- Try to maintain the dignity of the person living with dementia; do not force them to engage in activities that they do not wish to do.
- If one approach does not work, try another one.
- Realise that there may be worse, but also better moments.
- Remind yourself that aggression can be a part of the dementia, or a reaction to the disease.
- If the person is suddenly behaving aggressively, there may be an underlying cause (for example a urinary infection) that should be investigated by a doctor.
- Take a deep breath and think about the most positive ways to respond that will be the least distressing to you and the person you care for. If the person you care for continues to show verbal or physical anger, there are many resources available on the internet. For example, the Alzheimer's society <https://www.alzheimers.org.uk/>.

Session 5. Changes in judgement and disinhibited behaviour

Why is this session important?

Changes in judgement can be upsetting to the person living with dementia and the carer.

How will this session help me?

This session will help you understand the reasons causing changes in judgement and teach you skills to manage this.

What will I learn?

1. What are changes in judgement?
2. How you can manage changes in judgement.
3. What to do if the changes in judgement are more serious.

1. What are changes in judgement and disinhibited behaviour?

Changes in judgement and disinhibited behaviours may include not understanding one's own limitations, engaging in risky or impulsive behaviours, saying the wrong thing at the wrong time or acting inappropriately. These behaviours can occur in any dementia but are particularly common in frontotemporal dementia. Usually these actions are not harmful, but they can be stressful or embarrassing for the person living with dementia or the carer. People with dementia are often looking for guidance or reassurance.

1. Activity

Did you ever notice that the person you care for sometimes has a change in their judgement? If so, what did you observe? *Please describe this in the space below.*

Tips

Changes in judgement will increase as dementia progresses. In this session you can practice several ways of responding to changes in judgement and find out what may help.

2. How can you manage changes in judgement?

Let's go through an example

Ivan is in town visiting his sister Isabel who has frontotemporal dementia. They are on their way to a restaurant for dinner. In order to get there, Ivan decides to hail a taxi. All of a sudden, the car pulls up alongside Isabel and startles her. Isabel, who is normally a very gentle woman, starts scolding the taxi driver.

1. What could you do?

Managing changes in judgement.

Below are some suggestions for Ivan to try.

- ✓ Stay calm and reassure Isabel everything is alright.
- ✓ Accept the behaviour. If the taxi driver doesn't seem to notice, let it be. Find ways to adapt.
- ✓ Ivan could carry a business card that explains, 'My companion has dementia, please be patient with us.' and give this card to the taxi driver (available from the Alzheimer's society website: <https://www.alzheimers.org.uk/get-support/publications-factsheets/helpcards>)

3. What to do if changes in judgement are more serious?

The last example was a brief and one-time experience for Ivan. However, what happens if the changes in judgement experienced by a person living with dementia are more serious? Here are three examples to help you learn how to react.

Mishandling finances

Sophie has Lewy body dementia and lives alone. Her cousin Julia has come to visit her. Despite the fact that Sophie has always been organised, Julia arrives to find that there is a large pile of unopened mail on the kitchen table. Julia wonders if Sophie has had some trouble paying her bills. She asks Sophie about her finances. Sophie cannot remember whether she has paid her bills or not, does not know when they are due, and cannot recall how much money she has in her bank account. Julia becomes quite concerned.

2. What could you do?

Managing more serious changes in judgement (1).

Below are some suggestions for Julia to try.

- ✓ Stay calm and call Sophie's daughter.
- ✓ Julia shares her worries with Sophie's closest relative, her daughter, who might know more and can arrange help if needed.
- ✓ Ask Sophie if she would like some help in opening her mail. Sophie may be able to pay her bills if given the right prompts, such as opening the bills in front of her and cueing her to pay one at a time.
- ✓ Try to find out whether Sophie has someone who handles her finances, like a family member or a professional.
- ✓ Sophie may be at the point in her illness where she is no longer able to handle the finances on her own. If it seems that she is not getting any help with handling her finances, Julia may want to call her daughter to share her worries.

Insisting on driving

Hugo is living with posterior cortical atrophy. His neighbour, Pablo, notices that his car is parked very strangely one day, obstructing some of the other cars on the street.

Pablo walks out of his apartment, sees Hugo and attempts to start a conversation.

Instead of stopping, Hugo jumps in his car, speeds off and takes an illegal left turn at the junction. Hugo returns quickly and nothing bad seems to have happened.

Tip

It is better if the decision not to drive comes from the person living with dementia. Giving up driving is typically a difficult time in the person's life where they are losing independence.

Alternatives such as offering regular rides, teaching the person how to use public transportation or arranging taxis will help the person stay active and involved in their community activities.

It is important that the person does not become isolated or lonely once they give up driving. More effort will be needed to keep them connected to the world outside their home.

3. What could you do?

Managing more serious changes in judgement (2).

Below are some suggestions for Pablo to try.

- ✓ Stay calm and ask whether Hugo has any other places to go that day, and if so, offer him a ride.
- ✓ This might prevent Hugo from driving unsafely and provides safe transportation, so Hugo can run his errands.
- ✓ Ask Hugo if he would like some help figuring out transportation.
- ✓ Hugo may be able to safely ride a bus or walk, preventing any unsafe behaviour.
- ✓ Tell Hugo that he is concerned about his driving and suggest visiting his doctor to discuss it.
- ✓ This way Pablo respects Hugo by being honest and raising a concern.
- ✓ Report the incident to Hugo's carer, friend or family member.
- ✓ Pablo may not know if Hugo has dementia and could be concerned about the risk of harm to Hugo and others.

Inappropriate sexual advances

Mateo is in his late 50s, has frontotemporal dementia and lives alone. Two days a week, a paid carer, Camila, who is 22 years old, comes to help him take a bath and administer his medication. This arrangement has been working well for several months.

One day, while preparing for his bath, Mateo makes some sexual remarks and tries to pull Camila close to him. Camila is shocked and surprised. She runs out of the room and telephones Mateo's family to say that she can no longer work there.

Tip

If the inappropriate advances continue, the family might want to consider hiring a male in-home aide instead of a female one which could prevent this behaviour. They also might seek help from a professional.

4. What could you do?

Managing more serious changes in judgement (3).

Below are some suggestions for Pablo to try.

- ✓ Stay calm and tell Mateo that this behaviour is unacceptable. Explain who Camila is.
- ✓ Change the bathing situation. Perhaps Camila can set up a sponge bath and Mateo can do more himself.
- ✓ Change the environment. Put a towel or robe over Mateo's shoulders while he is being bathed to keep him covered for privacy.

2. Activity

Let's look at your own situation

It is important to apply what you have learned to your own situation. Earlier, we asked whether the person you care for sometimes shows changes in judgement. After going through these examples, think again about your own situation. *The spaces below are for you, like a diary.*

Remember

Changes in judgement may hamper decision-making. If you want to know more, review **Session 3. Supported decision-making in Part 2.**

Let's review what you have learned

- Changes in judgement usually increase as dementia progresses.
- Changes in judgement can be very upsetting for the person living with dementia and the carer.
- It is important to reduce or prevent changes in judgement, whenever possible.
- Realise that there may be good and bad days.
- Remind yourself that this is a part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for.
- Plan for increasing levels of changes in judgement.

Session 6. Repetitive and obsessive behaviour

Why is this session important?

If a person living with dementia repeats things over and over it can be stressful for themselves and the carer. We will refer to this as a 'repetitive behaviour'.

How will this session help me?

This session will help you understand why repetitive behaviours occur, and how to respond to, and reduce, them.

What will I learn?

1. What is repetitive behaviour?
2. How to comfort a person living with dementia in case of repetitive behaviours

1. What is repetitive behaviour?



People with dementia, particularly frontotemporal dementia, may engage in repetitive or obsessive behaviours such as repeating questions or obsessing over foods/ clothes.

Usually doing things over and over is not harmful to the person living with dementia, if the carer knows how to deal with it. If not, the person living with dementia can become anxious, angry or depressed. The carer can become stressed and may respond in a less helpful way, for example by screaming, which can aggravate the situation and could make the person with dementia feel guilty and upset.

1. Activity

Let's look at your own situation

Does the person you care for ever do or say things over and over again? What behaviour(s) do they repeat? *You can describe them in the space below, like a diary.*

2. How to comfort a person living with dementia in case of repetitive behaviours

Let's look at this example

Cath is living with frontotemporal dementia. She lives with her husband Eddie and their daughter, Emily who is 8 years old. Cath has recently become obsessive about the time, she worries that Emily will be late for school or her sports lessons. The other day, while having dinner at 8pm, Cath looked at her watch and became anxious because Emily wasn't ready to leave for school. This was upsetting for everyone.

1. What could you do?

Obsessions with time

Below are some suggestions for Eddie to try and help Cath with her timekeeping.

- ✓ Stay calm and reassure Cath that it's the evening and Emily made it to school on time that morning.
- ✓ Eddie could buy clocks or watches that say am or pm next to the time to help Cath recognise whether Emily does need to get ready for school.
- ✓ Accept the obsession with timekeeping but find ways to help Cath tell the time accurately. People in support groups may have practical tips to share of similar situations.

2. Activity

Let's look at your own situation

It is important to apply what you have learned to your own situation. *The space below is for you, like a diary.*

Let's review what you have learned

- Doing or saying things over and over again (repetitive behaviour) is common in people with dementia.
- Repetition can be very stressful to deal with.
- In case of repetition, try to focus on comforting the person you care for.
- Try to identify what comes before the repetitive behaviour and what may increase it. Then try to change it. Try to identify how you respond and change that also.
- Realise there may be worse, but also better moments.
- Remind yourself that repetitive behaviours are part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person living with dementia if they do or say things over and over again.

Session 7. Difficulty sleeping

Why is this session important?

People with dementia may have difficulty sleeping which can impact the carer's sleep as well.

How will this session help me?

This session will provide examples and practice to promote good sleep.

What will I learn?

1. How to deal with sleeping problems in a person with dementia.
2. How to deal with a person with dementia who wakes up in the middle of the night.

1. How to deal with sleeping problems in a person with dementia?



Difficulty sleeping can be a problem for people with dementia and their families. People with dementia can have difficulty falling asleep, may wake up in the middle of the night or too early in the morning. REM

sleep behaviour disorder is also very common in people with Lewy body dementia, this is when people experience vivid dreams that they will act out in their sleep. This can appear as shouting or jerky arm or leg movements in their sleep. Carers may have their sleep disrupted as a result, which can make it harder to provide care.

In this session, you will practice how to promote good sleep for the person living with dementia.

1. Activity

What are the main sleeping problems of the person that you help care for? *Please select all that apply.*

- Difficulty falling asleep
- Waking up in the middle of the night
- Vivid dreams
- Combination of the above
- Other (please specify): _____
- No problems at this point

Difficulty falling asleep

Rosie has posterior cortical atrophy and she lives with her family. She has her bedroom near her granddaughter, Grace. Usually, the family has dinner around 6pm. The family is used to doing some activities together afterwards. Rosie does not always like these activities so the family often encourage her to go to bed as early as 8pm. Rosie has trouble falling asleep that early. Rosie continues to open and shut her dresser drawers noisily during the evening. When Grace goes to bed, the noise Rosie is making keeps Grace awake.

1. What could you do?

Understanding sleeping difficulties

Can you break down the cycle of behaviour change in this example into its three parts?

| What comes before the behaviour? | What is the stressful behaviour? | What is Neil's response? |
|----------------------------------|----------------------------------|--------------------------|
| | | |

2. What could you do?

Responding to sleeping difficulties.

Here are some examples of what Rosie's family could do.

- ✓ Go for a walk with Rosie and add more physical activity during the day.
- ✓ Try and ensure that Rosie does not drink coffee or too much fluid a few hours before going to bed.
- ✓ Make lunch the bigger meal of the day.
- ✓ Limit daytime naps to 15 to 30 minutes.
- ✓ Play soothing music before bedtime to help Rosie sleep.
- ✓ Create a bedtime routine, like lowering the lights, washing face and teeth, and changing into pyjamas.
- ✓ Keep in mind that some people may require less sleep. Generally, 6 to 8 hours sleep from 20:00 means night waking between 2:00 to 4:00 in the morning.
- ✓ Encourage Rosie to do something else she likes to do by herself.

2. How to deal with a person with dementia who wakes up in the middle of the night?

Let's look at another example

It is 3:00 in the morning, Vani, who has Lewy body dementia, wakes up and starts walking around the house. Her mother, Geeta, is sleeping. Vani paces throughout the house and then goes to Geeta and wakes her up. Vani asks: "Where are we? I want to go home". Geeta is upset, because she has a long day at work tomorrow. Geeta says: "you need to go back to bed, it is 3:00 in the morning." Vani says: "I am not sleepy." Geeta yells: "I can't take this anymore."

3. What could you do?

Dealing with waking in the middle of the night (1).

Below are some suggestions for Geeta to try.

- ✓ Try to understand what will help Vani sleep. Some people prefer to keep the room dark with no television or as little noise as possible while others prefer a night light, soft music or a television playing.
- ✓ Schedule an appointment with the doctor to find out if there is a medical reason for her trouble sleeping (e.g. urinary tract infection, pain, medication causing hallucinations).
- ✓ Develop an activity schedule to keep Vani awake and busy during the day.
- ✓ Encourage physical exercise during the day (e.g. walking, stretching).
- ✓ Ask if she has to go to the bathroom or is hungry or thirsty. If she says "yes", then just assist her to meet these needs.
- ✓ Ask for help from a family member, friend or a paid professional.

Let's look at another example

Tina has Lewy body dementia and lives with her husband Emile. Recently Tina has been having vivid dreams at night which she has been acting out in her sleep. Last night, her arm jerked and hit Emile in the face. Tina is upset that she hurt Emile and scared that it will happen again.

4. What could you do?

Dealing with waking in the middle of the night (2).

Below are some suggestions for Tina and Emile to try and resolve the issue.

- ✓ Tina could take pain relief before bed, if she is in pain or discomfort.
- ✓ They could try reducing their caffeine intake, alcohol and heavy meals prior to bedtime.
- ✓ Tina could try maintaining a regular routine, including some exercise and/or activity during the day.
- ✓ They could move into twin beds so they're still together in the same room but Tina can't accidentally hit Emile again but put an additional mattress on the floor next to Tina's bed in case she falls out of a single bed.
- ✓ If nothing else works try asking the GP for medications for specific conditions that disturb sleep, such as 'restless leg syndrome'

Keep in Mind

Good sleep hygiene techniques can help reduce sleep problems. For more information please visit <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/healthy-sleep-tips#content-start>.

Sleeping problems may also be related to depression. If the person you care for has difficulty sleeping, you might want to read **Session 2 Depression and anxiety**. Please also seek advice from a doctor.

In the previous exercise, you identified several ways of dealing with waking in the middle of the night. Now let's look at your own situation and some additional responses.

2. Activity

Let's look at your own situation

In an earlier activity in this session, you identified the main sleeping problem of the person you care for. It is important to apply what you have learned to your own situation. What could you do to help tackle the sleeping problems? What could you do to improve your reaction to sleeping problems?

The space below is for you, like a diary.

Let's review what you have learned

- Difficulty sleeping is common in people with dementia.
- Sleeping problems can be very stressful to deal with.
- If the person you care for is having difficulty sleeping, try to make them more comfortable.
- Try to identify circumstances that may increase difficulty sleeping and change or address them.
- When one approach doesn't work, try another one.
- Realise that there will be good and bad days.
- Remind yourself that difficulty sleeping is part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing for you and the person you care for in case of sleeping problems.
- Ask for help. It is hard to provide good care on limited sleep.

Session 8. Delusions and hallucinations

Why is this session important?

Unreal thoughts and seeing things that aren't there (delusions and hallucinations) can be very upsetting to the person living with dementia and the carer.

How will this session help me?

This session will help you identify ways to stop or reduce delusions and hallucinations and how you might change the way that you respond to them.

What will I learn?

1. Why do people with dementia have unreal thoughts and see or hear things that aren't there?
2. How to stop or reduce delusions and hallucinations.

1. Why do some people with dementia have unreal thoughts and see or hear things that aren't there?

People with dementia may not understand the world around them because of changes in their brain. These misunderstandings are called delusions (unreal thoughts) and hallucinations (seeing or hearing things that are not there).

A delusion is a fixed false belief. For example, the person may hold the false belief of being under threat or harm from the carer. To the person living with dementia the error in thinking is very real, causes fear and may result in distressing self-protective behaviours.

If the person is experiencing a hallucination, they might see or hear things that are not there, for example, people talking in the room. In some cases, this can be comforting or funny to the person with dementia but other times hallucinations can be distressing. If hallucinations are upsetting for the person with dementia, it's important to seek professional advice, however, hallucinations can be more distressing for the carer than the person with dementia. In this circumstance, reaching out to others can be helpful, please see part 2 for advice on involving others.

Hallucinations are particularly relevant for those with Lewy Body dementia.

Hallucinations can be experienced by a person with dementia. Ensuring that these are not misinterpretations caused by an eye problem will be important. For example cataracts etc. Please speak to your GP if you are worried about this.

1. Activity

Has the person you care for ever had any unreal thoughts or seen or heard things that were not there? You can describe them in the space below, like in a diary.

Tip

If someone is hallucinating or delusional, it's important to remember that whatever they're seeing/ hearing/ feeling, is very real to them and telling them that they're wrong may be upsetting or trigger angry behaviour. You might feel guilty about "lying" to them but it can be an option that sometimes causes them the least amount of distress.

2. How to stop or reduce delusions and hallucinations

Let's look at the following example

Martin's wife Betty is living with Lewy body dementia. They have a very active social life and enjoy eating out regularly. One day, Martin and Betty are out for a dinner but when Betty's food is brought out, she says that the chef is trying to poison her and refuses to eat anything. Martin tries to show her that the food is fine by eating some, but she gets upset and knocks the plate onto the floor to stop him eating the poisoned food.

1. What could you do?

Responding to delusions.

Below are some suggestions for Martin to try.

- ✓ Soothe her in a calm voice but do not argue. It is better to acknowledge that Betty may be frightened by the delusions than to challenge them.
- ✓ Attempt to distract Betty if possible, by talking about their day or future plans, she might forget about her worries and eat the food without thinking. *NOTE* This won't work for everyone but is worth a try.
- ✓ Check the food for something that Betty could think is poison, e.g. flakes of dried herbs sprinkled on top.
- ✓ Leave the restaurant and carry on as normal but try and make some food with Betty later on, hopefully if she's involved in making the food, she'll be more likely to eat it.
- ✓ Speak to a doctor about the delusions, they may be caused by side effects of medications or another underlying problem such as a urinary tract infection (UTI).
- ✓ If the delusions are upsetting and can't be managed another way, then anti-psychotic medication may be a necessary last resort.

Now let's look at another example

Mercedes' brother Larry is living with frontotemporal dementia. One day, Larry is a bit restless. Suddenly, he starts to look very frightened while staring at a corner in the room. He calls out to his sister and says, "Do you see them talking?" He screams, "What are you doing there?" Mercedes is so overwhelmed that she feels like running away. She thinks to herself "Larry's illness is much worse than I thought it was."

Tip

Check with the doctor regarding medication side effects that the person living with dementia is using. These may contribute to the problem.

2. What could you do?

Seeing people that are not there.

Below are some suggestions for Mercedes to try.

- ✓ Soothe her brother, by saying in a calm voice "You are safe, I am with you" and patting his hand.
- ✓ Check if there is anything in the environment that could be causing Larry's hallucination, such as shadows in the room from the sunlight. Make changes as necessary.
- ✓ Lead him away from the room.

IMPORTANT

If the person you care for develops these symptoms suddenly or over a day, they may be experiencing delirium. This is a sign that the person may be unwell and you should contact the GP immediately. The exception for this is Lewy Body dementia, because the symptoms of this dementia can fluctuate from hour to hour.

2. Activity

Let's look at your own situation

It is important to apply what you have learned to your own situation. Unreal or unusual thoughts do not happen all the time. What would you do if the person you care for experiences them?

Remember - Sometimes people with dementia have pleasant hallucinations, like seeing beautiful colours or children who are not there. If these visions are not causing the person distress then try to enjoy them together.

Let's review what you have learned

- Unreal thoughts or seeing/hearing things that are not there (delusions and hallucinations) are common in people with dementia.
- They can be very upsetting to the person living with dementia and the carer.
- Often, people with these visions and unreal thoughts need a lot of reassurance.
- It is important to identify ways to reduce them, not by arguing with the person you care for, but by comforting and distracting them.
- Check the environment to see if there is a cause for the delusion or hallucination.
- If one approach doesn't work, try another one.
- Remind yourself that unreal thoughts or visions are part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for if they are experiencing unreal thoughts or visions.

Session 9. Visual changes

Why is this session important?

People with dementia can experience changes to the way they perceive things. There is nothing wrong with their eyesight, but their brain is not processing the information correctly. This can be challenging emotionally and make everyday tasks difficult.

How will this session help me?

This session will help you think about the visual changes that the person living with dementia could experience and how to manage them.

What will I learn?

1. What are visual changes?
2. Adapting the house to make it safe for someone with visual difficulties.
3. How to support the person you care for to continue daily activities with visual difficulties.

1. What are visual changes?

People with dementia can experience changes to their vision that are different to hallucinations. For example:

- Stationary objects can appear to be moving e.g. words on a page can swirl around.
- Depth perception can be affected - people might knock things over because they can't tell how close they are.
- Difficulty recognising faces - this is not always due to memory loss, it can be visual.
- 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.

These changes can occur in any dementia but perceptual changes are a main symptom for those with posterior cortical atrophy.

Important

Visual changes can be caused by dementia but it's important to rule out any other problems. If the person you care for is experiencing visual changes please see an optician.

Let's look at an example

Ellie is visiting her mother, Vicky, who is living alone with a diagnosis of posterior cortical atrophy. During dinner, Vicky keeps knocking her glass over and spilling her drink while reaching for it. This is upsetting for Vicky and worrying for Ellie.

1. What could you do?

Visual changes.

Below are some suggestions for Ellie to try in this situation.

- ✓ Buy some adaptive drinking aids with lids to avoid spills.
- ✓ Ensure adequate lighting to help Vicky see where her drink is.
- ✓ Try a coloured glass rather than a clear one to create contrast from the background/table.

2. Adapting the house to make it safe for someone with visual difficulties.

There are several things that you can do around the house to make everyday tasks easier for someone experiencing visual changes.

- Try to use contrasting colours where possible e.g. dark toilet seats on white toilets, dark placemats with light plates etc.
- Ensure that there is enough lighting but try to avoid shadows which can look like something else.
- Avoid busy patterns on carpets, plates etc. as these can look like they're moving.
- Remove trip hazards, tape down edges of rugs or remove completely.

For more tips please visit: <https://www.raredementiasupport.org/posterior-cortical-atrophy/living-with-pca/> or <https://www.nib.org.uk/professionals/health-social-care-education-professionals/social-care-professionals/dementia-and-sight-loss/>.

3. How to support the person you care for to continue daily activities with visual difficulties.

Niamh lives with posterior cortical atrophy. She is cared for by her husband James, and her brother Liam visits every weekend so that James can meet up with friends.

Last weekend, it was dark and Niamh did not recognise Liam when he came to the door so she wouldn't let him in the house.

2. What could you do?

Dealing with visual difficulties.

Below are some suggestions for Liam and James to try.

- ✓ Install an outside light so that Niamh can see better when she answers the door.
- ✓ James could try to answer the door before Niamh and announce that Liam has arrived so that Niamh can hear.
- ✓ Liam could identify himself when Niamh comes to the door. If she's struggling with her vision, she might recognise his voice.

1. Activity

Let's look at your own situation

Has the person you care for experienced visual changes? Are there any adaptations around the house that you could try?

Let's review what you have learned

- Visual changes can occur in any dementia but are a main symptom in posterior cortical atrophy.
- Visual changes can be stressful and require lots of adaptations.
- Depth perception, facial recognition and identifying stationary objects can be impaired.
- Using contrasting colours can be useful.
- Busy patterns can appear to move, so avoid these where possible.
- Try to ensure good lighting, especially on staircases and bathrooms.

Session 10. Walking and movement problems

Why is this session important?

Concerns about walking and getting lost can cause distress. Carers may worry whether the person will get lost.

How will this session help me?

This session will help you understand the reasons for walking and what to do to reduce the chances of the person living with dementia getting lost.

What will I learn?

1. Why is walking a concern?
2. Why a person with dementia might want to walk around.
3. How to manage habits and reduce the chances that the person you care for gets lost.
4. Movement problems.

1. Why is walking a concern?

People with dementia may have the habit of walking around the home or leaving the house and wanting to walk around the neighbourhood, this was previously known as wandering. This is very common. However, there are several symptoms that may make this dangerous, including:

- They may get lost.
- Have mobility issues or be at risk of falling.
- Have difficulty judging how close cars are when crossing roads.
- Show disinhibited behaviours and talk to strangers.

Not everyone with a dementia diagnosis is unsafe to walk alone and trying to keep someone safe by stopping them walking might cause more challenges and behaviours that might be difficult to manage.

This session will teach you why people with dementia may have a desire to walk. You will also learn about the steps that you can take to help make this safer.

It is important to find ways to help prevent people with dementia from getting lost or ending up in an unsafe situation.

1. Activity

Does the person you care for sometimes walk around or walk away? *You can describe what happens in the space below, like in a diary.*

2. Why a person with dementia might want to walk around

A person with dementia who walks a lot may be:

- Wanting to exercise.
- Continuing a lifelong habit of walking regularly.
- Relieving boredom due to not being sufficiently stimulated.
- Using up energy from sitting all day.
- Relieving pain and discomfort from joint pain or stiffness.
- Responding to stress or anxiety.
- Feeling lost or uncertain about their surroundings.
- Going out and forgetting where they were going.
- Searching for someone or something in the past or present.
- Seeking fulfilment and purpose such as the desire to go to work.
- Getting confused about the time.

3. How can I manage habits and reduce the chances that the person I care for gets lost

There are certain things that may help manage a person's walking habits and prevent them from getting lost.

For example, try to:

- Keep to the routines and activities of the person you care for. Identify the most likely times of the day that their walking may occur and plan activities such as a walk in the park together at that time.
- Reassure the person you care for if they feel lost, abandoned or disoriented, or want to leave to "go home" or "go to work". For example, try saying: "we are staying here tonight. We are safe and I'll be with you. We can go home in the morning after a good night's rest." Try to refrain from correcting the person living with dementia.
- Ensure that all basic needs are met. Has the person gone to the bathroom? Are they thirsty or hungry?
- Avoid busy places that are confusing and can cause disorientation, such as shopping malls, markets, grocery stores or other crowded places.
- Make sure that the person carries some form of identification.
- Make sure that your home is secure, that the person is safe in your home and cannot leave without you knowing. For example, using a bell that makes noise when someone uses the door.

- GPS trackers can be useful to support people to walk safely by themselves.
- Keep an up-to-date photograph in case the person you care for gets lost and you must ask for help from others.
- After the person you care for is found, speak calmly, with acceptance and love, try to avoid blaming and showing anger.

Let's look at an example

Omar has primary progressive aphasia and is supported by his wife, Tumi. Tumi is cooking dinner when she hears Omar heading for the door. She knows that he likes to go for afternoon walks, but now is not a good time since she is cooking.

1. What could you do?

Dealing with walking away.

Below are some suggestions for Tumi to try.

- ✓ Turn the cooker off and follow Omar.
- ✓ Go to where Omar is standing by the door and calmly say: "let's eat dinner first and we'll go for a walk later."
- ✓ Let Omar leave and call a neighbour to keep an eye out for him.
- ✓ Ask another family member to go for a walk with him.
- ✓ Ask Omar to help with a task in the kitchen.
- ✓ Schedule more afternoon walks before dinner.

2. Activity

Let's look at your own situation. What are the possible reasons why the person you help care for may have the desire to walk? *Please select all answers that apply.*

- Wanting to exercise
- Continuing a lifelong habit of walking regularly
- Relieving boredom due to not being sufficiently stimulated
- Using up energy from sitting all day
- Relieving discomfort from joint pain or stiffness
- Responding to stress or anxiety
- Feeling lost or uncertain about their surroundings
- Going out and forgetting where they were going
- Searching for someone or something in the past or present
- Seeking fulfilment and purpose such as the desire to go to work
- Getting confused about the time
- Other (please state): _____

4. Movement problems

People with Lewy body dementia may experience problems with movement making walking or other daily tasks difficult. These symptoms can include:

- Shuffling while walking.
- Stiffness in limbs.
- Stooped posture.
- Balance problems.

People experiencing these symptoms are at a higher risk for falls.

Let's look at an example

Sioned has Lewy body dementia and lives with her husband Henry. Sioned's walking has become slower, she has trouble initiating movements and her balance is a little off but they still try to stay active by walking to the park everyday. Henry has recently noticed that when she walks into the house, she steps over the black doormat rather than wiping her feet as normal, which is causing her to wobble due to her balance issues.

2. What could you do?

Movement problems.

Below are some suggestions for Henry to try.

- ✓ Talk to Sioned to see why she's stepping over the doormat, she might be seeing the black mat as a hole that she needs to avoid.
- ✓ Try removing the mat or buying a different coloured one but try to avoid patterns.
- ✓ Give Sioned verbal instructions on which foot to move might help her initiate her movements.
- ✓ Speak to the GP about seeing a physiotherapist, occupational therapist or the falls prevention team.

3. Activity

Based on the reasons that you selected, how might you react or respond the next time the person you care for wants to go outside or walk?

Let's review what you have learned

- Walking around or walking away is common.
- Walking can be healthy exercise, reduce boredom, and be a common habit or routine of the person.
- Walking away or walking alone might be a safety risk.
- Concerns about walking and getting lost can be very upsetting to the person living with dementia and the carer.
- It is important to identify possible reasons for walking around or walking away.
- How you respond to the desire to walk should be based on the possible reasons for it.
- If one approach doesn't work, try another one.
- Realise that there may be worse, but also better moments.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person living with dementia.
- People with dementia may have movement difficulties.
- If you're worried about the person with dementia falling, please speak to your GP who can refer you to the falls prevention team.

Important

Different types of floor can impact a person with dementia's walking. For example:

- Patterned carpets may look like there is something that needs picking up.
- Shiny floors may look wet or slippery.
- Edges on rugs or carpet dividers may appear at different depths, so need stepping over.

For advice on making your home dementia friendly please visit:

https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/making_your_home_dementia_friendly.pdf

Session 11. Memory loss

Why is this session important?

Memory loss can be frustrating for the person living with dementia and the carer.

How will this session help me?

In this session you will practice several ways to respond to memory loss, and find out what may help you deal with the person's increasing forgetfulness.

What will I learn?

1. What is memory loss?
2. How to respond to memory loss?

1. What is memory loss?



People with dementia will increasingly lose their memory over time. People with certain types of dementia such as Alzheimer's disease, will experience memory loss as a symptom in the early stages of dementia. In rarer dementias, this is often not the case but it can affect people in the later stages.

1. Activity

Does the person you care for sometimes forget things?

If so, what kinds of things do they forget? Please write them down.

2. How to respond to memory loss?

This session will give you several examples of ways that you could respond to memory loss. It's important to remember that every situation is different so some of these suggestions won't work for you and the person you care for but it's worth trying them to find one that does work.

Let's have a look at an example

Anne is living with dementia. She has a daughter named Maya. They live very close to each other. When Maya goes to visit Anne's house, she notices that the fridge or cupboard is empty. Anne often forgets what she usually buys from the market.

1. What could you do?

Forgetting to buy groceries.

Below are some suggestions for Maya to help her mother.

- ✓ Ask a neighbour to go with Anne once a week to the market to buy groceries.
- ✓ Create a memory aid together with Anne, e.g. a list of groceries that Anne needs to buy, and put the list in a place where it can be seen, so that it is easy to access.
- ✓ Sit down with Anne and make a list of groceries. Go shopping together.

Let's have a look at a further example

Maya and Anne are talking on the phone. Maya notices that Anne often forgets what she normally does during the day. Maya is impatient with Anne, and tells her mother, "this is getting worse".

2. What could you do?

Forgetting daily activities.

Below are some more suggestions for Maya to help support her mother.

- ✓ Ask her mother what she usually does on that given day. For example, Monday is wash day; Thursday is going to the market day.
- ✓ Plan to visit Anne every weekend and write out to-do lists for every day of the week, or consider using images or photos instead of writing lists.
- ✓ Ask her mother while on the phone to get a pencil and paper. Talk through the plan for the day together.

Sometimes memory loss can be more serious, like in the next example.

Let's have a look at an example

Maya comes to visit and discovers that Anne is having trouble remembering which medications to take and at what time.

3. What could you do?

Forgetting medications.

Below are some more suggestions to help Maya support her mother.

- ✓ Maya puts notes near the clock when her mother needs to take a pill.
- ✓ Maya goes over the medications with her mom. She purchases a pill box, and puts the pills in the box at the right day and time and calls her mom every day to instruct her to take her medications. Try adding an alarm on her mum's phone that says "take your blue tablet now".

2. Activity

Let's look at your own situation

It is important to apply what you have learned to your own situation. How could you respond to help the person you care for deal with their memory loss, if they experience it? Write down some ideas.

Let's review what you have learned

- Memory loss is less common for people with rarer dementia but can still occur in the later stages.
- Memory loss can be stressful to deal with.
- In case of memory loss, try a memory aid like a note, pill-box, reminder/alarm, etc.
- If possible, involve the person you care for to find the best way to support them in case of memory problems.
- It is important to remember that the person living with dementia is not to blame, because he/she can't help that they forget.
- When one approach doesn't work, try another one.
- Realise there may be good and bad days.
- Remind yourself that memory loss is part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for in the case of memory loss.

Session 12. Putting it all together

Why is this session important?

Certain changes in behaviour can be particularly stressful for the person living with dementia and the carer.

How will this session help me?

This session will summarise ways to prevent, reduce or manage behaviour changes.

What will I learn?

1. The most important things to keep in mind when dealing with challenging behaviours.
2. Practical tips on not blaming yourself, sharing your feelings with others and making time for yourself.

1. The most important things to keep in mind when dealing with behaviour changes

- Behaviour changes can be stressful for the person you care for and yourself. This is understandable as often this change can feel like a loss, since the person you know and care for is behaving differently.
- Try to make the person you care for feel comfortable.
- Look for ways to prevent or reduce behaviour changes that are stressful, by working out what happened before the behaviour occurred.
- Try to distract the person you care for if possible, don't argue.
- When one approach does not work, try another one. Every person and situation is different, what works one day might not work the next.
- Realise that there may be good and bad days.
- Understand that dementia is an ever-changing condition and you may want to revisit iSupport at different times.
- Consult a medical doctor to identify any causes related to medication or physical illness.
- Identify whether the environment or your approach could be the trigger of a particular behaviour.

- Remind yourself that behaviour changes are part of the disease but other possible causes should be identified before accepting the disease as a cause.

2. Practical tips on not blaming yourself, sharing your feelings with others and making time for yourself

Here are some tips from related sessions. If you did not take these sessions yet, you can complete them after finishing this one.

- Try not to blame yourself or the person living with dementia for the problems that you encounter. If you want to work on ways to manage your feelings, take a look at the last page of **Session 3. Thinking differently in Part 3.**
- Share your feelings about your experiences as a carer with others. If you keep them to yourself it may be more difficult for you to look after your family member or friend. If you want to learn more about involving others, take a look at **Session 4. Involving others in Part 2.**
- It is really important that you make time for yourself. This will allow you to do the things that you value in life, such as spending time with others or enjoying your favourite hobbies. If you want to learn more about doing enjoyable activities, take a look at **Session 2. Making time for enjoyable activities in Part 3.**

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