

iSupport For Dementia Carers

Module 5 Dealing with behaviour changes

DEALING WITH BEHAVIOUR CHANGES

- Session 1. Introduction to behaviour changes
- Session 2. Memory loss
- Session 3. Challenging behaviour
- Session 4. Depression, anxiety or apathy
- Session 5. Difficulty sleeping
- Session 6. Delusions and hallucinations
- Session 7. Repetitive behaviour
- Session 8. Walking and getting lost
- Session 9. Changes in judgement
- Session 10. Putting it all together

MODULE

5

Contents

| | |
|--|----|
| Session 1. Introduction to behaviour changes | 3 |
| Session 2. Memory loss..... | 12 |
| Session 3. Challenging behaviour | 22 |
| Session 4. Depression, anxiety or apathy | 33 |
| Session 5. Difficulty sleeping | 42 |
| Session 6. Delusions and hallucinations | 54 |
| Session 7. Repetitive behaviour | 63 |
| Session 8. Walking and getting lost | 69 |
| Session 9. Changes in judgement | 77 |
| Session 10. Putting it all together | 89 |

Session 1. Introduction to 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 and carers, like you.

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, like you.

“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 care for ever experience any of the following behaviour changes? Please select any that apply.

| Behaviour changes | Examples |
|--|---|
| <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"/> Challenging behaviour | Talking or acting in a threatening way or doing things that make you feel frightened. |
| <input type="checkbox"/> Depression, anxiety or apathy | Feeling sad, worried, frightened, frustrated or angry, being unusually emotional, crying, agitated or restless, withdrawn, unhappy, apathetic or reacting slowly. |
| <input type="checkbox"/> Difficulty sleeping | Restless at night, waking you or other family members up. |
| <input type="checkbox"/> Delusions and hallucinations: seeing or hearing things that are not there | Misinterpreting the world, having fixed false beliefs, things a person sees or hears that are not there, or becomes suspicious of those around them. |
| <input type="checkbox"/> Repetitive behaviour: doing things over and over | Repeating a question or an action over and over. |
| <input type="checkbox"/> Wandering: walking around a lot | Continuously walking around, leaving the house and getting lost. |
| <input type="checkbox"/> Changes in judgement | Saying the wrong thing at the wrong time, acting inappropriately in a situation, not understanding own limitations. |
| <input type="checkbox"/> Not at this time | None of these symptoms are present at this point in time. |

Remember

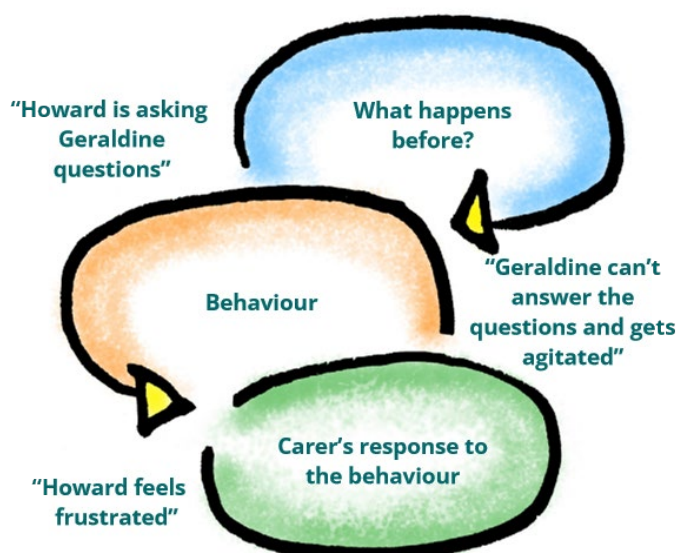
Many things can cause behaviour changes that are upsetting to you or the person you care for. This can have a bad effect on your relationship with the person you care for. It can even make you feel sad, angry, confused, or anxious.

In some instances, you might even feel as though you can't cope with the situation. In this session you will learn what you can do to reduce or prevent these situations.

2. Understanding the cycle of behaviour change

Understanding any behaviour change and what happens before and after the behaviour is very important. Sometimes you can reduce or even prevent certain behaviours. If you pay attention and understand what happens before or "triggers" the behaviour, this can help you to reduce or prevent the behaviour.

Let's look at the following example



Geraldine has dementia like the person you care for. Her husband Howard is taking care of her, like you are caring for your family member or friend.

Howard often asks Geraldine if she can remember who came to visit last week or what she had for dinner yesterday. Geraldine cannot remember these things and gets agitated. As a result, Howard feels frustrated.

What happens before the behaviour?

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

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

1. Check your understanding

Identifying what happens before the behaviour.

Now you try the next one. Please fill in your ideas on what comes before Geraldine gets agitated in the box below. When you are done, check the answer at the end of this session for more ideas.

1. Check your understanding

Identifying what happens before the behaviour.

- Geraldine has dementia. Remembering who came to visit last week is difficult for her.
- Geraldine has dementia and cannot remember what she had for dinner.

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 Geraldine forgot who came to visit and what she had for dinner.

Howard can choose to change his response.

2. Check your understanding

Different ways of responding to behaviour change.

Here are some responses, some are good, others are not. Please check what you think could be good responses.

Howard could:

- Show that he is frustrated.
- Take a deep breath.
- Show his irritation by saying: "I already answered that, please stop bothering me".
- Remind himself that his wife has dementia and cannot help that she forgets things. She is not forgetting on purpose.
- Next time, remember that asking her such questions will only cause frustration, not only for him, but also for his wife.
- Work with Geraldine to record significant family and social events in a family diary.

2. Check your understanding

Different ways of responding to behaviour change.

What are some of the ways that Howard could respond?

✗ Show that he is frustrated.

This is not the best response. Showing that he is frustrated is an inappropriate way to deal with the stressful behaviour, it may even make the person living with dementia irritable.

✓ Take a deep breath.

This is a good response. It shows that Howard is trying to control his frustration.

✗ Show his irritation by saying: "I already answered that, please stop bothering me".

This reaction is not so good, because Howard's irritability may upset Geraldine even more.

✓ Remind himself that his wife has dementia and cannot help that she forgets things. She is not forgetting on purpose.

This is a good response, because Howard recognises that Geraldine is living with dementia.

✓ Next time, remember that asking her such questions will only cause frustration, not only for him, but also for his wife.

This is a good response, because it may prevent this frustrating situation.

✓ Work with Geraldine to record significant family and social events in a family diary.

This is a good response, because they can revisit the events from time to time if Geraldine is missing family members and friends.

3. Different approaches work at different times

What if Howard's approach doesn't work the first time? Different approaches work at different times, so Howard should not give up! 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 health care provider.
- He can also ask someone at the Alzheimer's Association (a community based organisation that provides support for people with dementia and their carers) in his country: <https://www.alzint.org/our-members/member-associations/>.
- 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 spaces below, like a diary.*

What is the behaviour that was the most distressing or upsetting to you in the past month?

What could you do to change what happened before the behaviour in order to reduce or prevent it?

How could you respond in that situation?

Let's review what you have learned

- 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. 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?



are often preserved for a longer period of time.

People with dementia will increasingly lose their memory over time. In the beginning, they may forget recent events, where they put their keys, their wallet or a particular piece of paper. They find it harder to remember phone numbers, important dates and appointments. However, past memories, such as childhood memories,

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?

In this session you can practice several ways to respond to memory loss and find out what may help you deal with it.

Let's look at an example

Anne is living with dementia. She has a daughter named Patricia. They live very close to each other. When Patricia 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.

The person you care for might also forget other things.

1. Check your understanding

Forgetting to buy groceries.

How would you advise Patricia to deal with her mother's memory loss?

Please check all the responses that you feel are appropriate from the list below.

- 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.
- Go out and buy groceries immediately.
- Ask: "Mum, what's wrong with you, there is no food in the house".
- Sit down with Anne and make a list of groceries. Go shopping together.

1. Check your understanding

Forgetting to buy groceries.

What would you advise Patricia?

✓ Ask a neighbour to go with Anne once a week to the market to buy groceries.

This might be helpful. Anne will have groceries and a nice visit with the neighbour.

✓ Create a memory aid together with Anne, e.g. a list of groceries that Anne needs to buy, and put it in a prominent place, so that the list is easy to access.

This is a good response. It addresses Anne's memory loss and may become a weekly shared pleasant activity.

✗ Go out and buy groceries immediately. This answer is **not so good** because it is a panic reaction and a one-time solution. It does not solve the problem at hand.

✗ Ask: "Mum, what's wrong with you, there is no food in the house". This answer is **not so good** because Anne cannot help that she forgets to buy food and may feel embarrassed that she has done something wrong. It does not improve the situation.

✓ Sit down with Anne and make a list of groceries. Go shopping together. This answer may be **a good one** because Patricia is addressing her mother's needs. However, she might first want to try another approach. For example, with a list of groceries that her mother may still be able to go shopping without help.

Let's look at an example

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

2. Check your understanding

Forgetting daily activities.

What do you think Patricia's response should be?

Please check all the responses that you feel are appropriate from the list below.

- Tell her mother what to do over the phone.
- Ask her mother what she usually does on that given day. For example, Monday is wash day; Thursday is going to the supermarket day.
- Move in with her mother.
- Go straight over and take charge of the situation, by ordering her mother around.
- Plan to visit Anne every weekend and write out to-do lists for every day of the week.
- Hire someone to stay with her mother all the time.
- Ask her mother while on the phone to get a pencil and paper. Talk through the plan for the day together.

2. Check your understanding

Forgetting daily activities.

What do you think Patricia's response should be?

- ✗ Tell her mother what to do over the phone. This response is **not so good** because her mother may not understand or be able to follow a phone conversation.
- ✓ Ask her mother what she usually does on that given day. For example, Monday is wash day; Thursday is going to the supermarket day. This response **may be a good one** because Patricia can use this information to remind her mother.
- ✗ Move in with her mother. This is **not the right response**. There are several other less drastic approaches that Patricia has not yet tried.
- ✗ Go straight over and take charge of the situation, by ordering her mother around. This response **is not so good** because it is a one-time solution and does not solve the problem at hand.
- ✓ Plan to visit Anne every weekend and write out to-do lists for every day of the week.

This is **a good response** because it may help her mother to remember.

- ✗ Hire someone to stay with mother all the time.

This is **not the right response**. There are several less drastic approaches that Patricia has not tried yet.

- ✓ Ask her mother while on the phone to get a pencil and paper. Talk through the plan for the day together.

This is a good response because it may help her mother to remember. Patricia could call her mother every morning at a certain time, and ask her to get a pencil and paper and to plan her day together.

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

Let's look at an example

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

3. Check your understanding

Forgetting medication.

How do you think Patricia should respond to this situation?

Please check all the responses that you feel are appropriate from the list below.

- Patricia puts notes near the clock when her mother needs to take a pill.
- Patricia says, "Mum, how could you forget your medications?", and "you know you really need them to stay healthy!"
- Patricia goes through the medicine cabinet, sits down and cries about her mother's memory loss.
- Patricia goes over the medications with her mum. She purchases a pill box and puts the pills in the box at the right day and time and calls her mum every day to instruct her to take her medications.

3. Check your understanding

Forgetting medication.

How should Patricia respond?

- ✓ Patricia puts notes near the clock when her mother needs to take a pill. This may be **good to do** because a memory aid could help Anne remember to take her pills.
- ✗ Patricia says, “Mum, how could you forget your medications?”, and “You know you really need them to stay healthy!” This response is **not helpful** because Anne cannot help that she forgets to take her medications. Memory loss is part of her disease.
- ✗ Patricia goes through the medicine cabinet, sits down and cries about her mother’s memory loss. This is **not the way to deal** with her mother’s memory loss. Getting upset will not solve her mother’s problem of forgetting to take medications.
- ✓ Patricia goes over the medications with her mum. She purchases a pill box and puts the pills in the box at the right day and time and calls her mum every day to instruct her to take her medications. This is a **good response** because this memory aid might help Anne to take medications at the right day and time. Some pill reminder boxes come with alarms that are pre-set to remind the person to independently take their medications.

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? *Write down some ideas.*

Let's review what you have learned

- Memory loss is very common for people with dementia.
- 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 3. Challenging behaviour

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 challenging behaviour and improve your skills to prevent or deal with this behaviour.

What will I learn?

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

1. Why does challenging behaviour happen?

From time to time, people with dementia may become angry, aggressive or violent.

Challenging behaviour 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 challenging behaviours.

At times, challenging behaviour is displayed towards people known to the person living with dementia. At other times it can be with strangers. Challenging behaviour 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 a challenging way?

Yes

No

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

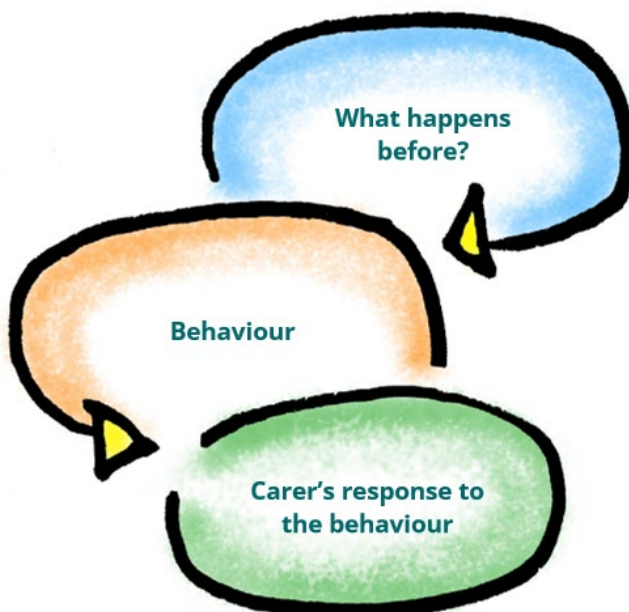
Yes

No

Warning!

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

Do you remember the cycle of behaviour change?



Just like we mentioned in Session 1. Introduction to behaviour changes, it is important to break down the cycle of stressful responses into three parts in order to help you deal with them

Let's see how the cycle works with a different example.

Kevin wants to assist his father-in-law, Colin, in taking a bath because Colin needs to see a doctor. Kevin says: "it is time for your bath". Colin refuses. Kevin has little time and tugs on his father-in-law's arm. He says: "you need to bathe because you're going to see the doctor." Colin pulls his arm back and resists. He is much stronger than Kevin. Kevin tugs it again and says angrily: "you must take a bath because you are going to the doctor and need to be clean". Colin gets very angry, shouts and even tries to shove Kevin, who becomes upset.

1. Check your understanding

Understanding challenging behaviour.

Colin angrily refuses to take a bath

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 Kevin's response? |
|----------------------------------|----------------------------------|---------------------------|
| | | |

1. Check your understanding

Understanding challenging behaviour.

Colin angrily refuses to take a bath

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 Kevin's response? |
|---|---|---------------------------|
| Kevin tugs Colin's arm and says angrily: "you must take a bath because you are going to the doctor and need to be clean". | Colin gets very upset and shouts and even tries to shove Kevin. | Kevin becomes upset. |

2. How to respond to challenging behaviour?

There are many ways to respond to challenging behaviour. Some are good, others are not. In the exercise below you can learn more.

2. Check your understanding

Understanding challenging behaviour.

Please indicate what you think are good responses.

Kevin could:

- Force his father-in-law to start bathing anyway.
- Maintain the dignity and privacy of his father-in-law. He could keep him in a robe or towel until he actually takes a bath.
- Play soothing music that Colin likes.
- Walk away and come back later.
- Explain logically why he should bathe.
- Put himself in Colin's shoes and try to understand why Colin 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 Colin right before the doctor's appointment, when things are rushed, Kevin might try to assist with bathing the day before.
- Before the next bath time, identify the best time of day for Colin to take a bath and find out whether he prefers a bath or a shower.
- When bathing Colin, keep a towel over his shoulders to help him maintain dignity and to keep him warm.
- Ask for someone else to help with Colin's bath time.
- Help Colin with a bed bath by using warm, wet towels with soap without taking Colin to the bath.
- Say in an irritated voice: "I have already answered that, please stop bothering me." "You must take a bath!"

2. Check your understanding

Understanding challenging behaviour.

How could Kevin react differently?

Kevin could:

- ✗ Force his father-in-law to start bathing anyway.

This is not helpful, because it does not change the situation and may only make it worse.

- ✓ Maintain the dignity and privacy of his father-in-law. He could keep him in a robe or towel until he actually takes a bath.

Correct. Maintaining dignity and privacy is always a good idea when caring for someone with dementia. By doing this Kevin makes sure that the person living with dementia is comfortable.

- ✓ Play soothing music that Colin likes.

Yes. Though it may take extra time to arrange the music, this option may help soothe both Kevin and Colin. This may create relaxation and less negative responses from both of them.

- ✓ Walk away and come back later.

This is a good response. It gives Kevin time to calm down, take a deep breath and come up with a new strategy. It also gives Colin time to forget about the negative encounter and he may be in a better mood if approached differently later.

- ✗ Explain logically why he should bathe.

This answer is not so good. It does not take into account that Colin may not be able to understand because of his dementia.

- ✓ Make sure that there is enough time so that it is not so stressful. Rather than trying to bathe Colin right before the doctor's appointment, when things are rushed, Kevin might try to assist with bathing the day before. Though taking more time may not always be feasible, **this option is good.** It may reduce tension for Kevin and Colin.

- ✓ Before the next bath time, identify the best time of day for Colin to take a bath and find out whether he prefers a bath or shower.

This answer is good. Keeping people with dementia to their regular routines shows attention to their preferences.

✓ When bathing Colin, keep a towel over his shoulders to help him maintain dignity and to help keep him warm.

This answer is good. Colin could be embarrassed to be naked in front of his son-in-law or the temperature of the water or the room could be too cold. It's important to look for ways to make the situation more pleasant.

✓ Kevin could ask for someone else to help with Colin's bath time.

This answer is good. Sometimes the person living with dementia is more comfortable with one family member helping them bathe than another. Sometimes even a stranger might find it easier as the person living with dementia might be less embarrassed than with a family member.

✓ Kevin could help Colin with a bed bath by using warm, wet towels with soap without taking Colin to the bath.

This answer is good. If the person living with dementia is afraid of the bath, or running water, this option will help relieve their distress and can sometimes be used instead of baths. There are also products such as dry shampoo and cleaning products used for young children that might help.

✗ Say in an irritated voice: "I have already answered that, please stop bothering me." "You must take a bath!"

This is not helpful, because it does not change the situation.

3. How to deal with ongoing challenging behaviour?

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

3. Check your understanding

Ongoing challenging behaviour.

What could Kevin do if his approach does not work the first time? *Check all that apply.*

- Kevin could try several approaches until he finds one that works.
- Kevin could get suggestions from others.

3. Check your understanding

Ongoing challenging behaviour.

What could Kevin do if his approach does not work the first time?

- ✓ Kevin could try several approaches until he finds one that works.
- ✓ Kevin could get suggestions from others.

There may be other approaches that you could try. This can be information from people that you know or that is available on the Internet. See for example: <https://www.alzint.org/>.

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 challenging behaviour 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. What happened before the person you care for showed challenging behaviour? *If so, describe the last time that this happened in the spaces below.*

What happened before the person you care for became aggressive?

What could you do to change your response to this behaviour?

What could change in the environment to make it more calming?

Let's review what you have learned

- Challenging behaviour like shouting, shoving or pushing can happen to carers of people with dementia.
- The behaviour 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 challenging behaviour can be a part of the dementia, or a reaction to the disease.
- If the person is suddenly behaving in a challenging way, 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 challenging behaviour, there are many resources available on the internet. For example, look at the website of the Alzheimer Association in your country (<https://www.alzint.org/our-members/member-associations/>).

Session 4. Depression, anxiety or apathy

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, anxiety and apathy?
2. How to respond when a person living with dementia is feeling depressed or anxious?
3. How to respond when a person living with dementia loses interest in daily activities?

1. What are depression, anxiety and apathy?

Depression, anxiety and apathy are common among 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 behaviours of depression and 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

James has dementia and lives with his sister, Linda. On several occasions Linda has found James sitting in his favourite chair looking very sad, hunched over, and sometimes crying. Linda tries to cheer him up. Unfortunately, everything that she tries does not seem to work.

1. Check your understanding

Responding to a person with dementia who is feeling depressed.

How should Linda handle this situation?

Below are some things that Linda may do or say.

Please select all responses that you think might work.

- Walk over to James and say in a calm, reassuring tone, "I have some ideas about how you can feel better, let's talk."
- Say: "James, what's the matter with you? I'm tired of seeing you like this. Just get up and do something."
- Say: "men don't cry and get sad, we used to have so much fun together."
- Go over and touch James on the arm or shoulder. "I know that you feel bad, I do too. What we're going through is really hard."
- Sit with James and suggest that they do a pleasant activity together.
- Sigh and walk away, thinking that there is nothing that she can do.

Here is another example

Emma has dementia and lives with her family. Benjamin is her grandson. 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. Check your understanding

Responding to a person with dementia who is feeling anxious.

How do you think that Benjamin should respond to this situation?

Below are some things that Benjamin may do or say. *Please select all the correct responses.*

- Think "Grandmother cannot help the way that she behaves."
- Say "Grandmother! Sit down, you're making it impossible for me to watch my show."
- Give his grandmother a smile and reassure her that she is safe.
- Turn up the volume to drown out the muttering and turn away from her.
- Look for his headphones and encourage his grandmother to go back to her sewing so that she is busy.
- Ask his grandmother to help him with something.

1. Check your understanding

Responding to a person with dementia who is feeling depressed.

Below are some things that Linda may do or say.

✓ Walk over to James and say in a calm, reassuring tone, "I have some ideas for how you can feel better, let's talk."

This is a good response because James needs more support due to the changes in his mood.

✗ Say: "James, what's the matter with you? I'm tired of seeing you like this. Just get up and do something."

This response is **not helpful** because James cannot help that he is feeling sad.

✗ Say: "men don't cry and get sad, we used to have so much fun together."

This response is **not good** because it might embarrass James and may make him feel even more sad.

✓ Go over and touch James on the arm or shoulder. "I know that you feel bad, I do too. What we're going through is really hard."

This is a good response because people who are feeling sad need extra love, support and understanding.

✓ Sit with James and suggest that they do a pleasant activity together.

This is **a good response** because it may distract James and make him feel better.

✗ Sigh and walk away, thinking that there is nothing that she can do.

This is **not helpful** because Linda is further isolating James.

2. Check your understanding

Responding to a person with dementia who is feeling anxious.

Below are some things that Benjamin may do or say.

Please select all the correct responses.

- ✓ Think "Grandmother cannot help the way that she behaves."

This is a good response because it recognises that Emma's reaction might be due to changes in her brain.

- ✗ Say "Grandmother! Sit down, you're making it impossible for me to watch my show."

This response is not good because a direct order like this may make Emma feel even more anxious.

- ✓ Give his grandmother a smile and reassure her that she is safe.

This is a good response because people who are feeling anxious need extra love and support.

- ✗ Turn up the volume to drown out the muttering and turn away from her.

This is not a good response. It will only increase his grandmother's anxiety.

- ✓ Look for his headphones and encourage his grandmother to go back to her sewing so that she is busy.

This is a good response. Benjamin can still watch TV with headphones so it is not too loud for Emma, and Emma might be able to engage in her sewing again.

- ✓ Ask his grandmother to help him with something.

This might help because it might distract Emma and change her reaction.

3. How to respond when a person living with dementia loses interest in daily activities?

Let's look at an example

George has dementia and lives with his wife Carole. George used to be a shopkeeper and was very active in the community.

Recently, George has been sitting in a chair near a large window and staring blankly outside, this type of behaviour can also be known as apathy where the person with dementia has trouble becoming interested in doing something. Carole has become very concerned, because this is not like him. He seems removed and distant from her. One day, she walks in and says "George, shall we go out for a walk?" He does not respond.

3. Check your understanding

Responding to a person with dementia who loses interest in daily activities.

How do you think Carole should react? Please check all the responses that you think are appropriate.

- Carole walks over to George and says "I'm sick and tired of this laziness, get up and let's go".
- Carole goes over to George and strokes his hair. She says that she loves him and that she would like to do something together. George turns to her and smiles weakly.
- Carole says: "you never do anything I want anymore, it is impossible to keep on living with you. I don't know what I'm going to do."
- Carole says: "let's go for a walk together, I know how much you would enjoy getting out of the house for a little while."
- Carole closes the door and doesn't try to engage with George anymore.
- Carole thinks back to what George used to really like doing and thinks how she could help, or for example by reading the newspaper to him, cooking his favourite dish.

3. Check your understanding

Responding to a person with dementia who loses interest in daily activities.

How do you think Carole should react?

✗ Carole walks over to George and says "I'm sick and tired of this laziness, get up and let's go".

This response is not good because a direct order may make George more withdrawn. It doesn't show any understanding of his dementia.

✓ Carole goes over to George and strokes his hair. She says that she loves him and that she would like to do something together. George turns to her and smiles weakly.

This is a good response because it recognises that the problem is related to his dementia. She is not taking it personally and is expressing extra love and support.

✓ Carole says: "you never do anything I want anymore; it is impossible to keep on living with you. I don't know what I'm going to do."

This is not a good response because it shows that she is giving up on George. He may become even more withdrawn from her.

✓ Carole says: "let's go for a walk together, I know how much you would enjoy getting out of the house for a little while."

This is a good response because it is reassuring and may comfort George.

✗ Carole closes the door and doesn't try to engage with George anymore.

This is not the right response because it may worsen George's loss of interest.

✓ Carole thinks back to what George used to really like doing and thinks how she could help, for example by reading the newspaper to him, cooking his favourite dish or visiting a shop to let him straighten the shelves with the shopkeeper's permission.

This is a good response because it shows Carole cares about George and wants to help him engage in an activity that he would enjoy.

1. Activity

Let's look at your own situation

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

Does the person living with dementia ever show changes in mood or interest, or any signs of depression or anxiety? If so, what do these changes look like?

What could you do to prevent this?

How could you respond in a different way?

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 5. 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 wake up too early in the morning. 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 care for? *Please select all that apply.*

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

Difficulty falling asleep

Rosie is an older woman with dementia. She lives with her family. She sleeps 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 wants her to go to bed as early as 8pm. Granddaughter Grace notices that Rosie has trouble falling asleep. 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. Check your understanding

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 Grace's response? |
|----------------------------------|----------------------------------|---------------------------|
| | | |

1. Check your understanding

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 Grace's response? |
|---|---|---------------------------|
| Rosie is sent to bed as early as 20:00, so that the family can do activities together that Rosie does not like. | Rosie has trouble falling asleep and continues to open and shut her dresser drawers noisily during the evening. | This keeps Grace awake. |

So far, we have covered some basic steps to help the person with dementia fall asleep. What if the problems are a bit more complex?

2. Check your understanding

Responding to sleeping difficulties.

Here are some examples of what Grace could do.

Please select all that you think may be appropriate to help Rosie fall asleep:

- Go for a walk with Rosie and add more physical activity during the day.
- Give her a pill to sleep.
- 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.

2. Check your understanding

Responding to sleeping difficulties.

Rosie has trouble falling asleep

- ✓ Go for a walk with Rosie and add more physical activity during the day.

This is a good idea! Physical exercise during the day may help sleep at night.

- ✗ Give her a pill to sleep.

This is not a good idea. It can make someone with dementia even more confused or agitated and sleeping pills may become addictive.

- ✓ Try to ensure that Rosie does not drink coffee or too much fluid a few hours before going to bed.

This is a good response. Coffee, tea, or too much liquid can keep people awake, and cause frequent urination.

- ✓ Make lunch the bigger meal of the day.

This is helpful. A light dinner makes it easier to sleep.

- ✓ Limit daytime naps to 15 to 30 minutes.

This might be a good idea. It addresses the need for sleep during the day, but it does not prevent Rosie from falling asleep later on.

- ✓ Play soothing music before bedtime to help Rosie sleep.

Good idea. Find relaxing activities before bed such as music or reading to Rosie. Too much activity before bed can cause a person to be stimulated and stay awake.

- ✓ Create a bedtime routine, like lowering the lights, washing face and teeth, and changing into pyjamas.

This is a good response because a routine will relax the person living with dementia.

- ✓ 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.

This is a good response. Select a normal sleeping time as much as possible.

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 wakes up and starts walking around the house. Her daughter-in-law, 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: "mother, 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. Check your understanding

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

What can Geeta do to keep Vani from wandering at 3:00 in the morning?

Please select all responses that you feel are appropriate.

- 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.
- Give Vani a favourite object to relax (e.g. blanket or stuffed animal).
- 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).
- Tell Vani that you won't take care of her anymore if you are continuously woken up at night.
- 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.
- Physically take hold of her and put her back in bed.
- Ask for help from a family member, friend or a paid professional.

3. Check your understanding

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

What can Geeta do to keep Vani from wandering at 3:00 in the morning?

✓ 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.

This answer is a good one. Each person is different and you may need to try several possible solutions before finding one that works.

✓ Give Vani a favourite object to relax (e.g. blanket or stuffed animal).

This response is a good one. It may help Vani feel relaxed and secure.

✓ 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). While it is not necessary to seek medical attention every time that a person living with dementia can't sleep, **seek advice if it worries or upsets you or the person living with dementia.**

✓ Develop an activity schedule to keep Vani awake and busy during the day.

This is a good idea. It may improve sleep at night.

✓ Encourage physical exercise during the day (e.g. walking, stretching).

This may be helpful to improve sleep at night.

✗ Tell Vani that you won't take care of her anymore if you are continuously woken up at night.

This is not a good response. Keep in mind that dementia is a disease and someone with dementia will be dependent on the care that others provide.

✓ Ask if Vani has to go to the bathroom or is hungry or thirsty. If she says "yes", then just assist her to meet these needs.

This is helpful. Such a break might help the person go back to sleep.

✗ Physically take hold of Vani and put her back in bed.

Never do this. Although it may be very difficult to deal with sleeping

problems, respect the dignity of someone with dementia. Moreover, they may become agitated or angry. It definitely will not solve the sleeping problems.

✓ Ask for help from a family member, friend or a paid professional.

This might be helpful. Eventually, the lack of sleep can affect any family's ability to provide care. Someone else can assist by giving the family member a night or a weekend off.

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.

Tip

Sleeping problems may be related to depression. If the person you care for has difficulty sleeping, you might want to read **Session 4 Depression, anxiety or apathy**. Please also seek advice from a doctor.

4. Check your understanding

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

Which of the responses below would you choose if the person you care for experiences sleeping problems?

Please select all responses that you feel are appropriate.

- Remind yourself to stay calm and focus on getting the person living with dementia to sleep. This way, you will use your energy to solve the sleeping problem, rather than reacting emotionally.
- Gently remind the person that it is dark outside, and it is time to sleep. If needed try to relax the person, for example by playing soothing music.
- Read aloud to the person you care for. Choose something that you know has a calming effect, perhaps a poem or story. Sing a song or chant together. Another option is to pray or meditate for 15 minutes together.
- Comfort the person living with dementia. Give them a stuffed animal and hug or hold them until they fall asleep.

4. Check your understanding

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

Which of the responses below would you choose if the person you care for experiences sleeping problems?

✓ Remind yourself to stay calm and focus on getting the person living with dementia to sleep. This way, you will use your energy to solve the sleeping problem, rather than reacting emotionally.

Correct!

✓ Gently remind the person that it is dark outside and it is time to sleep. If needed try to relax the person, for example by playing soothing music.

Great idea!

✓ Read aloud to the person you care for. Choose something that you know has a calming effect, perhaps a poem or story. Sing a song or chant together. Another option is to pray or meditate for 15 minutes together.

Good response!

✓ Comfort the person living with dementia. Give them a stuffed animal and hug or hold them until they fall asleep.

Great idea!

2. Activity

Let's look at your own situation

Earlier, 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. *The space below is for you, like a diary.*

What could you do to help tackle the sleeping problems?

What could you do to improve your reaction to sleeping problems?

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 6. 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 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.

People with dementia with these ideas need a lot of understanding and support from the person taking care of them.

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

Unreal thoughts or seeing/hearing things that are not there are common problems for some people with dementia. In this session, you will learn how to deal with them.

2. How to stop or reduce delusions and hallucinations?

Let's look at the following example

Martin's wife Betty is living with dementia. One day, Martin and Betty are out for a walk. They see a woman in the distance. Betty starts calling loudly "Susan, Susan, I'm over here". Then she starts running towards a woman unknown to Martin; a young lady who is probably about 20 years old. Betty mistakenly believes that the young woman in the park is her sister who died in a car accident over 30 years ago. The young woman ignores her. Betty becomes very upset.

1. Check your understanding

Mistaking a person for someone else.

What would you recommend Martin do?

Please check all correct answers.

- Soothe her in a calm voice.
- Lead her away from the woman in the park.
- Directly tell the truth, harshly, to set the record straight.
- Argue with Betty that the young woman is not her sister.
- Say that the young woman in the park is someone who looks like her, but it is not her.
- Involve the woman in the park in any way.
- Try to 'convince' Betty of the truth.
- Say "Yes you are right, it is Susan".
- Say "When we get home, you can look at pictures of Susan and remember her".

1. Check your understanding

Mistaking a person for someone else.

✓ Soothe her in a calm voice.

This is a good response because people with delusions and hallucinations may feel frightened and insecure.

✓ Lead her away from the woman in the park.

This is a good response because it will distract her from the young woman in the park.

✗ Directly tell the truth, harshly, to set the record straight.

This is not a good response as it may make Betty even more upset.

✗ Argue with Betty that the young woman is not her sister.

This is not a good response as it may make Betty even more upset.

✓ Say that the young woman in the park is someone who looks like her, but it is not her.

This is a good response because it maintains a positive social environment.

✗ Involve the woman in the park in any way.

This is not helpful because it may make the situation more complicated.

✗ Try to 'convince' Betty of the truth.

This is not a good response as Betty may not understand.

✗ Say "Yes you are right, it is Susan".

This is not correct because it is not the truth.

✓ Say "When we get home, you can look at pictures of Susan and remember her".

This is a good response because Martin addresses the importance of her sister, without arguing that the young woman Betty saw in the park was not her sister.

Now let's look at another example

Anne's father Christopher is living with dementia. One day, Christopher is a bit restless. Suddenly, he starts to look very frightened while staring at a corner in the room. He calls out to his daughter and says, "Do you see them talking?" He screams, "What are you doing there?" Anne is so overwhelmed that she feels like running away. She thinks to herself "Dad'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. Check your understanding

Seeing people that are not there.

What would you recommend Martin do?

Please check all correct answers.

- Soothe her father, by saying in a calm voice "You are safe, I am with you".
- Soothe her father, by taking his hand and patting it.
- Check if there is anything in the environment that could be causing Christopher's hallucination, such as shadows in the room from the sunlight. Make changes as necessary.
- Lead him away from the room.
- Say that it is simply not true, that there are no other people in the room.

2. Check your understanding

Seeing people that are not there.

- ✓ Soothe him, by saying in a calm voice "You are safe, I am with you".

This is a good response because people with delusions and hallucinations may feel frightened and insecure.

- ✓ Check if there is anything in the environment that could be causing his hallucinations, such as shadows in the room from the sunlight. Make changes as necessary.

This is a good response because although a person's brain may be misinterpreting the environment there could still be a reasonable cause for confusion.

- ✓ Lead him away from the room.

This is a good response because changing the environment may distract her father and end the hallucination.

- ✗ Say that it is simply not true, that there are no other people in the room.

This is not a good response because arguing about what one sees or hears will not help a person experiencing delusions or hallucinations to calm down.

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? Try to describe different appropriate responses.

Which one would you try first?

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 7. Repetitive 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?

A person living with dementia may forget what they have said, heard or did from one moment to the next, leading to repeated questions and actions.

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, aggressive or depressed and the carer can become stressed. As a result, carers may respond inappropriately, for example by screaming, which often makes the person with dementia feel guilty.

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

John is taking care of his father Joe, because his mother, the main carer, is out of the house for a few hours. All seems fine, although John notices that his father is rather tense because John's mother is not there.

John and Joe eat lunch together. Sometime after finishing lunch, Joe asks "When is lunch?" and, "What are we having for lunch?" John does not think much of it at first. Then, again, a few minutes later, Joe asks "When is lunch?", "What are we having for lunch?", and "Where is your mother?" Joe repeats these questions again and again.

John is confused about why Joe is doing this and gets more and more worried about his father. John continues to answer the questions, but gets a bit upset and raises his voice. John responds, loudly and is annoyed, "I have already answered these questions, why do you keep asking?"

1. Check your understanding

Repeating questions.

What would you recommend to John?

Please select all correct responses.

- Say "What's wrong with you? Can't you remember? We just had lunch!"
- Stay calm and reassure his father that his wife will be home soon.
- Engage his father in an activity.
- Write down the answers to his questions, for example where his wife is and when she is expected to return.
- Walk away.
- Accept the repetitive questions. If it isn't harmful, let it be. Find ways to adapt.
- Accept the repetitive questions. If it isn't harmful, let it be. Find ways to adapt.

1. Check your understanding

Repeating questions.

✗ Say "What's wrong with you? Can't you remember? We just had lunch!"

This is not a good response because John is blaming his father for something that he can't help.

✓ Stay calm and reassure his father that his wife will be home soon.

This is a good response as repetition might worsen due to Joe's feelings of insecurity. He seems to feel insecure because his wife went out. By reassuring Joe that his wife will come back soon, the repetition may lessen or stop.

✓ Engage his father in an activity.

This can be a good response because it may distract his father and offer something else to see, hear or do.

✓ Write down the answers to his questions, for example where his wife is and when she is expected to return.

This might work well, may reassure Joe and stop him from asking again.

✗ Walk away.

This response is not so good because it will only upset his father more.

✓ Accept the repetitive questions. If it isn't harmful, let it be. Find ways to adapt.

This can be a good response. Perhaps if it is just repetitive questioning, by remaining calm the behaviour may decrease.

✓ Offer his father a snack or a drink.

This might be a good response. Perhaps Joe is still hungry or thirsty. It may help to calm him and meet his need.

2. Activity

Let's look at your own situation

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

Now look back at the examples that you identified in the previous activity. Choose the repetitive behaviour that is the most stressful to the person that you care for, or to yourself, and list it here.

What could you do to help reduce this behaviour?

How could you change your response to this behaviour?

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.

Session 8. Walking and getting lost

Why is this session important?

Concerns about walking and getting lost can cause distress. Carers like you 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 can I manage habits and reduce the chances that the person I care for gets lost?

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 is also called wandering. This is very common. However, they may get lost. So, safety is a primary concern when people with dementia are out alone.

It is important to prevent wandering.

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 wanders or walks away 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 centres, supermarkets, 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, camouflaging doors and door knobs may help, or using a bell or curtain that makes noise when someone uses the door.

- 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

Colin has dementia and is supported by his wife, Samantha. Samantha is cooking dinner when she hears Colin 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. Check your understanding

Dealing with walking away.

What would you recommend to Samantha?

Please select all correct responses

- Yell to Colin from the kitchen, "please stop! I can't come with you now."
- Turn the cooker off and follow Colin.
- Forbid Colin to leave and pull him back into the house.
- Go to where Colin is standing by the door and calmly say: "let's eat dinner first and we'll go for a walk later."
- Lock the door so that Colin cannot leave
- Let Colin leave and call a neighbour to keep an eye out for him.
- Ask another family member to go for a walk with him.
- Ask Colin to help with a task in the kitchen.
- Schedule more afternoon walks before dinner.

1. Check your understanding

Delio â cherdded i ffwrdd.

✘ Yell to Colin from the kitchen, "please stop! I can't come with you now."

This is not a good response because yelling at Colin from the kitchen may confuse and agitate him. It may also not stop him from going out on his own.

✓ Turn the cooker off and follow Colin.

This is a good response if there are no other alternatives.

✘ Forbid Colin to leave and pull him back into the house.

This is not a good response because Colin may get agitated and resist being pulled which could result in Colin or Samantha being harmed.

✓ Go to where Colin is standing by the door and calmly say: "Let's eat dinner first and we'll go for a walk later."

This is a good response because Samantha stays calm, does not yell, and honours Colin's wishes by telling him that they will go together after dinner.

✓ Lock the door so that Colin cannot leave.

This is a good response if no other options exist and Samantha is in the house with Colin. For fire safety reasons, a person living with dementia who requires supervision should never be locked inside a house without another person there.

✓ Let Colin leave and call a neighbour to keep an eye out for him.

This is a good option if Samantha has prearranged with the neighbours to keep an eye out for him. If Colin is in the very early stages of dementia, he may be okay while going out on his own to places that are familiar to him.

✓ Ask another family member to go for a walk with him.

This is a good option. Samantha can finish cooking dinner and Colin can enjoy a nice walk before dinner.

✓ Ask Colin to help with a task in the kitchen.

This is a good response because it involves distracting Colin from going for a walk alone and gives him purpose and keeps him occupied.

✓ Schedule more afternoon walks before dinner.

This is a good response because planning ahead will prevent Samantha from being interrupted when cooking dinner to assist Colin. It may also help Colin to release some energy and come home to relax before dinner.

2. Activity

Let's look at your own situation

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

What are the possible reasons why the person you 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 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
- Other (please state): _____

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?

What could you do to help the person enjoy walking in a safe way?

Take a moment to summarize the points that you have learned in this lesson, which will help you going forward:

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.

Session 9. Changes in judgement

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

1. What are changes in judgement?

Changes in judgement may include saying the wrong thing at the wrong time, acting inappropriately in a situation, or not understanding one's own limitations.

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? How did it affect you as the carer? *Please describe this in the space below.*

Tip

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

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

1. Check your understanding

Managing changes in judgement.

What would you recommend to Andrew to help him deal with this situation? *Please select all correct responses.*

- Put his hand on Linda's mouth in order to stop her scolding the driver.
- Walk Linda back to her apartment and leave because what happened is embarrassing.
- Stay calm and reassure Linda everything is alright.
- Accept the behaviour. If the taxi driver doesn't seem to notice, let it be. Find ways to adapt.
- Andrew could carry a business card that explains, 'My companion has dementia, please be patient with us.' and give this card to the taxi driver.

1. Check your understanding

Managing changes in judgement.

What would you recommend to Andrew?

✗ Put his hand on Linda's mouth in order to stop her scolding the driver.

This response is not good because it may even worsen the situation and cause Linda further agitation.

✗ Walk Linda back to her apartment and leave because what happened is embarrassing.

This response is not good because Linda may feel bad and isolated.

✓ Stay calm and reassure Linda everything is alright.

This is a good response because it shows Andrew cares about Linda. It may stop her from scolding the taxi driver and make her feel more relaxed.

✓ Accept the behaviour. If the taxi driver doesn't seem to notice, let it be. Find ways to adapt.

This can be an appropriate response if the behaviour is not harming anyone.

✓ Andrew could carry a business card that explains, 'My companion has dementia, please be patient with us.' and give this card to the taxi driver.

This is a good response because it relieves Andrew from explaining the situation to the taxi driver which may embarrass Linda.

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

The last example was a brief and one-time experience for Andrew. 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 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. Check your understanding

Managing more serious changes in judgement (1).

What would you recommend to Julia?

Please select all correct responses.

- Stay calm and call Sophie's daughter.
- Go to the bank and ask for control of Sophie's finances.
- Leave because she feels uneasy.
- Ask Sophie if she would like some help in opening her mail.
- Try to find out whether Sophie has someone who handles her finances, like a family member or a professional.

2. Check your understanding

Managing more serious changes in judgement (1).

What would you recommend to Julia?

✓ Stay calm and call Sophie's daughter.

This response is good because Julia shares her worries with Sophie's closest relative, her daughter, who might know more and can arrange help if needed.

✗ Go to the bank and ask for control of Sophie's finances.

This is not appropriate because it is Sophie's decision to appoint a person that she is comfortable with to help manage her finances.

✗ Leave because she feels uneasy.

This response is not appropriate. If Sophie has problems dealing with her finances, letting the situation continue could make things worse.

✓ Ask Sophie if she would like some help with opening her mail.

This response is good because 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.

This is a good response because 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

Richard is living with dementia. His neighbour, Anthony, notices that his car is parked very strangely one day, obstructing some of the other cars on the street.

Anthony walks out of his apartment, sees Richard and attempts to start a conversation.

Instead of stopping, Richard jumps in his car, speeds off and takes an illegal left turn out of the compound. Richard 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. Check your understanding

Managing more serious changes in judgement (2).

What would you recommend to Anthony? *Please select all correct responses.*

- Immediately seize Richard's car keys when he returns. This will prevent it from happening again.
- Stay calm and ask whether Richard has any other places to go that day, and if so, offer him a ride.
- Ignore the situation because it is embarrassing.
- Ask Richard if he would like some help figuring out transportation.
- Tell Richard that he is concerned about his driving and suggest visiting his doctor to discuss it.
- Report the incident to Richard's carer, friend or family member.

3. Check your understanding

Managing more serious changes in judgement (2).

What would you recommend to Anthony?

✗ Immediately seize Richard's car keys when he returns because this will prevent it from happening again.

This is not a good response because Anthony cannot decide whether his neighbour should drive anymore, and Richard may become angry.

✓ Stay calm and ask whether Richard has any other places to go that day, and if so, offer him a ride.

This is a good response because it prevents Richard from driving unsafely and provides safe transportation, so Richard can run his errands.

✗ Ignore the situation because it is embarrassing.

This response is not good because Richard's driving may cause harm to himself and others.

✓ Ask Richard if he would like some help figuring out transportation.

This response is appropriate because Richard may be able to safely ride a bus or walk, preventing any unsafe behaviour.

✓ Tell Richard that he is concerned about his driving and suggest visiting his doctor to discuss it.

This is a good response as Anthony respects Richard by being honest and raising a concern.

✓ Report the incident to Anthony's carer, friend or family member.

This is a possible response. Anthony may not know if Richard has dementia and could be concerned about the risk of harm to Richard and others.

Inappropriate sexual advances

Ian is in his late 70s, has dementia and lives with his family. Two days a week, an in-home aide, Katie, 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, Ian makes some sexual remarks and tries to pull Katie close to him. Katie is shocked and surprised. She runs out of the room and tells the family 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. Check your understanding

Managing more serious changes in judgement (3).

What would you recommend to Ian's family?

Please select all correct responses

- Stay calm and tell Ian that this behaviour is unacceptable. Explain who Katie is.
- Change the bathing situation. Perhaps Katie can set up a sponge bath and Ian can do more himself.
- Change the environment. Put a towel or robe over Ian's shoulders while he is being bathed to keep him covered for privacy.
- Shout at Ian, shaming him for his conduct.
- Ignore the situation.

4. Check your understanding

Managing more serious changes in judgement (3).

What would you recommend to Ian's family?

✓ Stay calm and tell Ian that this behaviour is unacceptable. Explain who Katie is.

This option is a good one. Ian's family does not overreact because they remember it is the disease taking effect. They redefine the appropriate boundaries for Katie's safety.

✓ Change the bathing situation. Perhaps Katie can set up a sponge bath and Ian can do more himself.

This is a good option. Letting Ian do more himself will distract him. In this way, both Katie and Ian's dignity are maintained.

✓ Change the environment. Put a towel or robe over Ian's shoulders while he is being bathed to keep him covered for privacy.

This is a good response. Perhaps because Ian is naked, he misunderstands the situation.

✗ Shout at Ian, shaming him for his conduct.

This response is not good because as part of his dementia Ian may not know that these advances are inappropriate. Therefore, try not to overreact.

✗ Ignore the situation.

This response is not good because Ian may continue to make inappropriate sexual advances and cause distress to Katie.

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.*

Did you ever notice that the person you care for sometimes has a change in their judgement? If so, what did you observe?

How did it affect you as the carer?

What could you do to help the person enjoy walking in a safe way?

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 10. 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 quite common.
- Try to make the person you care for feel more comfortable.
- Look for ways to prevent or reduce behaviour changes that are stressful, for example by using memory aids.
- Try to distract the person you care for, don't argue.
- When one approach does not work, try another one.
- Realise that there may be good and bad days.
- Consult a medical doctor to identify any causes related to medication or illness.
- Identify whether the environment or your approach could be causing the particular symptom.
- 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.

- Don't 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 Module 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 Module 2.**
- It is essential 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 pleasant activities, take a look at **Session 2. Making time for pleasant activities in Module 3.**

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