

iSupport For Young People

Module 5 Dealing with behaviour changes

DEALING WITH BEHAVIOUR CHANGES

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MODULE

5

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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 those that help care for them.

How will this session help me?

This session will help you understand behaviour changes better and will show you different ways in which you and your family can respond to them.

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 young people, like you.

“Any behaviour that gets you or the person you help care for upset can be very stressful”

In this section we will talk about how you and your family:

- Can identify behaviours that are potentially upsetting, stressful or difficult for you and the person you help care for.
- Might handle behaviour changes.
- 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"/> Memory loss	Forgetting or losing things, not being able to recall recent events or remember dates and days of the week.
<input type="checkbox"/> Aggression	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apathy	Feeling sad, worried, frightened, frustrated or angry, being unusually emotional, crying, agitated or restless, withdrawn, unhappy, apathetic or reacting slowly.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"/> Repetitive behaviour: doing things over and over	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.

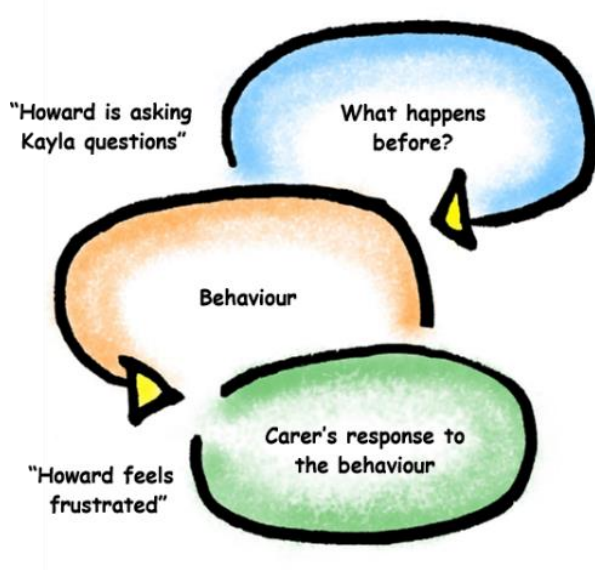
Remember

Many things can cause behaviour changes that are upsetting to you or the person you help care for. This can have an impact on you and your family's relationship with the person with dementia. This can make you feel sad, angry, confused, or anxious. As a young person remember that adults in your family and also professionals can help and support you. Reach out and talk to them if you feel you are not coping, and things are getting too difficult.

2. Understanding the cycle of behaviour change

Understanding any behaviour change and what happens before and after the behaviour is very important. Sometimes you or other members of your family might be able to reduce or even prevent certain behaviours by paying attention and understanding what "triggers" the behaviour.

The diagram below shows what's happening.



Let's look at the following example

Kayla has dementia. Her husband Howard is taking care of her. Their son Paul also helps with caring for her. Howard often asks Kayla if she can remember who came to visit last week or what she had for dinner yesterday. Kayla cannot remember these things and gets angry and agitated. As a result, Howard feels frustrated.

What happens before the behaviour?

Why do you think Kayla gets agitated? 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.
3. Kayla has dementia. Remembering who came to visit last week or what she had for dinner is difficult for her.

Now let's look at Howard's response

- 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. Check your understanding

Different ways of responding to behaviour change.

Here are some responses, please check the ones that you think are likely to be helpful.

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 Kayla to record significant family and social events in a family diary.

1. 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 most helpful 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 likely to be a helpful 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 helpful,** because Howard's irritability may upset Kayla even more.
- ✓ Remind himself that his wife has dementia and cannot help that she forgets things. She is not forgetting on purpose. **This is likely to be a helpful response,** because Howard recognises that Kayla 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 likely to be a helpful response,** because it may prevent this frustrating situation.
- ✓ Work with Kayla to record significant family and social events in a family diary. **This is likely to be a helpful response,** because they can revisit the events from time to time if Kayla 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! He 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 Association (a community-based organisation that provides support for people with dementia and their carers) in his country: <https://www.alz.co.uk/associations>.
- He can search for information on the internet and for example join a Facebook group for carers of people living with dementia. He can then ask others in that group for advice.

2. Activity

Now think about your own situation.

Now think about your own situation as a young person who helps care for a family member with dementia. *Using what we have just talked about in Howard's example try to answer the questions below, like if it was 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 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 and other members of your family usually respond, and what you all feel and 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 help care for.
- Talk to members of your family about different responses and approaches, as the first ones might not always work.
- If you are struggling to manage the situation talk to an adult and ask for help.

Session 2. Memory loss

Why is this session important?

Memory loss can be frustrating for the person living with dementia and also for those with caring responsibilities.

How will this session help me?

In this session we will talk about what memory loss is and also how to best deal with the person's increasing forgetfulness.

1. What is memory loss?



Many 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 their phone. They find it harder to remember phone numbers, important dates and appointments.

However, past memories, such as childhood memories, are often preserved for a longer period of time.

1. Activity

Does the person you help care for sometimes forget things?

If so, what kind of things do they forget? *Please write them down in the text box below or in your own notepad.*

2. How to respond to memory loss?

We are now going to practice several ways to respond to memory loss and find out what may help you and your family deal with it.

Let's have a look at an example

Anne is living with dementia. She lives with her husband Lee and 14 year old daughter Maya. Up until now Anne has been able to continue doing the shopping but lately Maya and her dad start noticing that the fridge is not as full as it used to be. Anne is struggling to keep up with the shopping and often forgets what she usually buys from the supermarket.

1. Check your understanding

Forgetting to buy groceries.

How would you advise Lee and Maya to deal with Anne's memory loss?

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

- Create a memory aid together with Anne (e.g. a list of groceries) 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: "What's wrong with you, there is no food in the house".
- Lee and Maya can sit down with Anne and make a list of groceries. They can go shopping together once a week.

1. Check your understanding

Forgetting to buy groceries

How would you advise Lee and Maya to deal with Anne's memory loss?

- ✓ Create a memory aid together with Anne (e.g. a list of groceries) and put the list in a place where it can be seen, so that it is easy to access. **This is likely to be a helpful 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 helpful** because it is a panic reaction and a one-time solution. It does not solve the problem at hand.
- ✗ Ask: "What's wrong with you, there is no food in the house". This answer is **not so helpful** because Anne cannot help that she forgets to buy food and may feel embarrassed and sad that she has done something wrong. It does not improve the situation.
- ✓ Lee and Maya can sit down with Anne and make a list of groceries. They can go shopping together once a week. This answer may be **a helpful one** because Lee is addressing his wife's needs. However, Lee might first want to try another approach. For example, with a list of groceries see if Anne may still be able to go shopping without help.

Sometimes memory loss can be more serious. The person you help care for is likely to take medication. Their main carer will be helping them to remember what they need to take and when.

Let's have a look at an example

Saul is 16 years old. His mum Paula is living with dementia. Recently Saul and his dad, Tom have noticed that Paula is having trouble remembering which medications to take and at what time.

2. Check your understanding

Forgetting medication.

How do you think Saul and his dad Tom could respond to this situation?
Please check all the responses that you feel are appropriate from the list below.

- Saul can help his dad put notes near the clock when it is time for Paula to take a pill.
- Tom says, "Paula, how could you forget your medication?" and "you know you really need them to stay healthy!"
- Tom goes over the medications with Paula. He purchases a pill box, and puts the pills in the box at the right day and time and calls Paula from work every day to remind her to take her medication.

Remember

As a young person make sure you are only doing as much as you are comfortable with. You should have the support from an adult or a professional if you are dealing with medications. Make sure that you ask for help if you are finding things too difficult or you are struggling to cope.

2. Check your understanding

Forgetting medication.

How do you think Saul and his dad Tom could respond to this situation?

✓ Saul can help his dad put notes near the clock when it is time for Paula to take a pill. This may be a **helpful thing to do** because a memory aid could help Paula remember to take her pills.

✗ Tom says, "Paula, how could you forget your medication?" and "you know you really need them to stay healthy!" This response is **not helpful** because Paula cannot help that she forgets to take her medication. Memory loss is part of her disease.

✓ Tom goes over the medications with Paula. He purchases a pill box, and puts the pills in the box at the right day and time and calls Paula from work every day to remind her to take her medication. This is a **helpful response** because this memory aid might help Paula to take medication 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 medication.

Let's review what we have talked about

- Memory loss is very common for people with dementia.
- Memory loss can be stressful to deal with for you and your family.
- In case of memory loss, your family can try a memory aid like a note, reminder/alarm, etc.
- If possible, involve the person you help care for to find the best way to support them.
- It is important to remember that the person living with dementia is not to blame, because they can't help that they forget.
- When one approach doesn't work, try another one.
- Realise there may be good and bad days.

Session 3. Aggression

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 family members and carers.

How will this session help me?

In this session we will help you understand possible causes of aggression and we will talk about how you and your family can respond or deal with it.

Remember

As a young person you shouldn't be dealing with this on your own. If you feel like things are becoming too difficult or you are not coping please ask for help from a family member or an adult close to you.

1. Why does aggression happen?

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

Aggression can happen for a variety of reasons:



- Illness such as an urinary tract infection, medication combinations or side effects
- 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, people living with dementia can be aggressive towards people they know. Other times it can be with strangers.

1. Activity	
Let's look at your situation. <i>Check your answer, yes or no.</i>	
Does the person you help care for ever talk to you or other people in an aggressive way?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Does the person you help care for ever act aggressively towards you or other people?	<input type="checkbox"/> Yes <input type="checkbox"/> No

Remember

If your family member is suddenly behaving aggressively, you shouldn't have to deal with it on your own, please ask for help and support from an adult.

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

Lisa has dementia and lives with her husband and 13 year old daughter Amy.

Amy is helping her dad assist Lisa in taking a bath because she has a doctor's appointment. Neil says: "it is time for your bath". Lisa refuses. Neil has little time and tugs on his wife's arm. He says: "you need to bathe because you're going to see the doctor." Lisa pulls his arm back and resists. Neil tries again and says angrily: "you must take a bath because you are going to the doctor and need to be clean". Lisa gets very angry, shouts at both of them and even tries to shove Neil.

Both Amy and Neil become upset.

2. How to respond to aggressive behaviour?

There are many ways to respond to aggressive behaviour. Some are good and might even help prevent similar behaviour in the future, others are not. We can learn a little bit more about this in the following exercise.

1. Check your understanding

Understanding aggressive behaviour.

How could Amy's dad Neil react differently? Please select the responses that are likely to be most helpful.

- Force Amy's mum Lisa to start bathing anyway.
- Maintain the dignity and privacy of his wife.
- Amy can help by playing her mum's favourite music.
- Amy and her dad Neil could walk away and come back later when everyone has calmed down.
- Neil could take the time to explain logically why Lisa should bathe.
- When bathing Lisa, Neil can keep a towel over her shoulders to help her maintain her dignity and to keep her warm.
- Make sure that there is enough time so that it is not so stressful. Rather than trying to bathe Lisa right before the doctor's appointment, when things are rushed. Neil might try to assist with bathing the day before.
- Before the next bath time, identify the best time of day for Lisa to take a bath and find out whether she prefers a bath or a shower.
- Ask for someone else to help with Lisa's bath.
- Help Lisa with a bed bath by using warm, wet towels with soap without taking her to the bath.
- Say in an irritated voice: "Please stop being difficult, you must take a bath!"

1. Check your understanding

Responding to aggressive behaviour.

How could Amy's dad Neil react differently?

- ✗ Force Amy's mum Lisa 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 wife. Maintaining dignity and privacy is always a **helpful idea** when caring for someone with dementia. By doing this Neil makes sure that Lisa is comfortable.
- ✓ Amy can help by playing her mum's favourite music. **This response is likely to be helpful**. Though it may take extra time to arrange the music, this option may help soothe both Neil and Lisa. This may create relaxation and less negative responses from all of them.
- ✓ Amy and her dad Neil could walk away and come back later when everyone has calmed down. **This is likely to be a helpful response**. This is a good response. It gives Neil and Lisa time to calm down, take a deep breath and come up with a new strategy. It also gives Lisa time to forget about the negative encounter and she may be in a better mood if approached differently later.
- ✗ Neil could take the time to explain logically why Lisa should bathe. **This answer is not so helpful**. It does not take into account that Lisa may not be able to understand because of her dementia.
- ✓ When bathing Lisa, Neil can keep a towel over her shoulders to help her maintain her dignity and to keep her warm. **This answer is likely to be helpful**. Lisa could be embarrassed to be naked in front of her husband and daughter 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.
- ✓ Make sure that there is enough time so that it is not so stressful. Rather than trying to bathe Lisa right before the doctor's appointment, when things are rushed. Neil might try to assist with bathing the day before. Though taking more time may not always be feasible, **this option is helpful**. It may reduce tension for Neil and Lisa.
- ✓ Before the next bath time, identify the best time of day for Lisa to take a bath and find out whether she prefers a bath or a shower. **This answer is**

likely to be helpful. Keeping people with dementia to their regular routines shows attention to their preferences.

✓ Ask for someone else to help with Lisa's bath time. **This answer is likely to be helpful.** 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.

✓ Help Lisa with a bed bath by using warm, wet towels with soap without taking her to the bath. **This answer is likely to be helpful.** 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: "Please stop being difficult, you must take a bath!" **This is not helpful,** because it does not change the situation.

3. How to deal with ongoing aggression?

Sometimes the first approach that you and your family use may not work. Don't worry, different responses may work at different times.

Remember: Take a deep breath and think about the most positive ways to respond that will be the least distressing to you and your family and the person living with dementia.

Aggression can be a part of the dementia, or a reaction to the disease.

As a young person you shouldn't have to deal with this on your own, ask for help from your family members or an adult close to you.

Remember

As a young person remember that adults in your family and also professionals can help and support you. Reach out and talk to them if you feel you are not coping and things are getting too difficult.

2. Activity

Let's look at your own situation

Has the person that you help care for ever been aggressive towards you or a family member? *If so, describe the last time that this happened in the spaces below.*

What happened before the person you help care for became aggressive?

What could you or your family have done to change your response to this behaviour?

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

Let's review what we have talked about

- Aggression like shouting, shoving or pushing can happen to family members of people with dementia.
- Aggression can be very upsetting for the person living with dementia as well as their family members.
- You and your family can try to change the environment to make it more calming. And try to maintain the dignity of the person living with dementia, not forcing them to do things they do not wish to do.
- If one approach does not work, try another one.
- Remind yourself that aggression can be a part of the dementia, or a reaction to the disease.
- 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 help care for.
- If the person continues to show aggression, there are many resources available on the internet. For example, look at the website of the [Alzheimer Association](#) in your country.
- As a young person you shouldn't have to deal with this on your own, ask for help from a family member or an adult close to you.
- If you are worried, it is ok to leave a situation, making it as safe as possible for the person with dementia. Your safety should be the top priority.

Session 4. Depression, anxiety and 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?

In this session we will help you to understand the possible causes of depression and anxiety. We will also discuss how you and your family can respond when the person you help care for is feeling depressed or anxious or loses interest in things.

Remember

As a young person you shouldn't be dealing with this on your own. If you feel like things are becoming too difficult or you are not coping please ask for help from a family member or an adult close to you.

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.

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 dementia and lives with his wife, Isabel and two teenage sons, Lucas and Pablo. On several occasions Lucas and Pablo have found their dad sitting in his favourite chair looking very sad, hunched over, and sometimes crying. They try to cheer him up. Unfortunately, everything that Lucas and Pablo try doesn't seem to work.

1. Check your understanding

Responding to a person with dementia who is feeling depressed.

How could Lucas and Pablo handle this situation? *Please select all responses that you think might work.*

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

Here is another example

Emma has dementia and lives with her family. Benjamin is her grandson. Because Benjamin's parents work, he is the main carer in the afternoons, when he comes back from school. Benjamin is watching a TV show while his grandmother is sewing. The TV show has loud music. 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 could respond to this situation? Below are some things that he may do or say. *Please select the ones that you think are more likely to be helpful.*

- Think "Grandma cannot help the way that she behaves."
- Say "Grandma! 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.

How could Lucas and Pablo handle this situation?

✓ Walk over to their dad and say in a calm, reassuring tone, "I have some ideas about how you can feel better, do you want to talk?" **This is likely to be a helpful response** because Lucas and Pablo's dad needs more support due to the changes in his mood.

✗ Say: "Dad, 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 their dad cannot help that he is feeling sad.

✗ Say: "Dad, men don't cry and get sad, we used to have so much fun together." This response is **not likely to be helpful** because it might embarrass their dad and may make him feel even more sad.

✓ Go over and touch their dad on the arm or shoulder. "I know that you feel bad, I do too. What we're going through is really hard." **This is likely to be a helpful response** because people who are feeling sad need extra love, support and understanding.

✓ Sit with their dad and suggest that they do a pleasant activity together. **This is likely to be a helpful response** because it may distract their dad and make him feel better.

✗ Sigh and walk away, thinking that there is nothing that they can do. This is **not helpful** because that will make their dad feel very isolated and lonely.

2. Check your understanding

Responding to a person with dementia who is feeling anxious.

Below are some things that Benjamin may do or say.

- ✓ Think "Grandma cannot help the way that she behaves." **This is likely to be a helpful response** because it recognises that Emma's reaction might be due to changes in her brain.
- ✗ Say "Grandma! Sit down, you're making it impossible for me to watch my show." **This response is not helpful** 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 likely to be a helpful 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 response is not helpful.** 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 likely to be a helpful 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 Sofia and 13 year old daughter, Megan. George used to be a keen runner and footballer, he was very active. 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.

Sofia and Megan have become very worried, because this is not like him. He seems removed and distant from everybody. One day, Megan walks in and says "Dad, 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 Megan could react? Please check all the responses that you think are appropriate.

- Megan walks over to her dad and says "I'm sick and tired of this laziness, get up and let's go".
- Megan goes over to her dad and holds his hand. She says that she loves him and that she would like to do something together. George turns to her and smiles weakly.
- Megan says: "you never do anything with me anymore, I am not going to ask you again because you always say no"
- Megan says: "let's go for a walk together, I know how much you would enjoy getting out of the house for a little while."
- Megan closes the door and doesn't try to engage with her dad anymore.
- Megan thinks back to what her dad used to really like doing and thinks how she could help, for example by reading the newspaper to him, or watching a match on TV of his favourite football team.

3. Check your understanding

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

How do you think Megan could react?

✗ Megan walks over to her dad and says "I'm sick and tired of you being so lazy, get up and let's go". **This response is not helpful** because a direct order may make George more withdrawn. It doesn't show any understanding of his dementia.

✓ Megan goes over to her dad and holds his hand. She says that she loves him and that she would like to do something together. George turns to her and smiles weakly. **This is likely to be a helpful 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.

✗ Megan says: "you never do anything with me anymore, I am not going to ask you again because you always say no". **This response is not helpful** because it shows that she is giving up on George. He may become even more withdrawn from her.

✓ Megan 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 likely to be a helpful response** because it is reassuring and may comfort George.

✗ Megan closes the door and doesn't try to engage with her dad anymore. **This response is not helpful** because it may worsen George's loss of interest and make him feel very lonely.

✓ Megan thinks back to what her dad used to really like doing and thinks how she could help, for example by reading the newspaper to him, or watching a match on TV of his favourite football team. **This is likely to be a helpful response** because it shows Megan cares about her dad and wants to help him engage in an activity that he would enjoy.

1. Activity

Let's look at your own situation

You might find it useful to apply what we have discussed to your own family's 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 we have talked about

- 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 their family.
- People with mood problems need extra love and support.
- Your family could decide to visit the doctor to ask advice and explore different options that might help with depression and anxiety symptoms such as for example psychological support or art therapy.
- It is important to identify ways to stop or reduce mood changes, by for example, 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 due to having dementia or a reaction to it.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you help care for.

Remember

It is important that you recognise when things are getting too difficult for you or when you are struggling to cope. It is important that you ask for help from a family member or an adult you are close to.

Session 5. Difficulty sleeping

Why is this session important?

People with dementia may have difficulty sleeping which can impact the sleep of the people that help care for them as well.

How will this session help me?

We will talk about how you and your family can help and also 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. Family members may have their sleep disrupted as a result, which can make it harder to provide care.

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
- Combination of the above
- Other (please specify): _____
- No problems at this point

Difficulty falling asleep

Jacob is 16. His grandmother Rosie, who has dementia, lives with him and his parents. She is using the room next door to Jacob's.

The family is used to doing activities together in the evenings. Rosie does not always like these activities so the family often want her to go to bed as early as 8pm. Jacob notices that his grandma has trouble falling asleep.

1. Check your understanding

Responding to sleeping difficulties.

Here are some examples of what Jacob and his family could do. Please select all the responses that are likely 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. If, for example, 6 to 8 hours is enough for them and they go to sleep at 8pm they are likely to wake up between 2 and 4 in the morning.

1. Check your understanding

Responding to sleeping difficulties.

Here are some examples of what Jacob and his family could do.

- ✓ 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 need to go to the toilet.
- ✓ 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. If, for example, 6 to 8 hours is enough for them and they go to sleep at 8pm they are likely to wake up between 2 and 4 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. Everyone else in the house is sleeping. Vani paces throughout the house and then goes to her daughter 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". Vani's two grandchildren that are sleeping in the room next door are woken up by the yelling and struggle to go back to sleep.

2. Check your understanding

Dealing with waking in the middle of the night.

Which of the responses below would you and your family choose if the person living with dementia experiences sleeping problems?

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

2. Check your understanding

Dealing with waking in the middle of the night.

Which of the responses below would you and your family choose if the person living with dementia experiences sleeping problems?

- ✓ Remind yourselves to stay calm and focus on getting the person living with dementia to sleep. This way, you will all use your energy to solve the sleeping problem, rather than getting upset or angry about it. **This is likely to be a very helpful idea!**
- ✓ Gently remind the person that it is dark outside, and it is time to sleep. If needed you and your family can try to relax the person, for example by playing soothing music. **Great idea!**
- ✓ Read aloud to the person you help care for. Choose something that you and your family know has a calming effect, perhaps a poem or story. Sing a song or chant 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!**

Let's review what we have talked about

- Difficulty sleeping is common in people with dementia.
- Sleeping problems can be very stressful to deal with.
- If the person you help care for is having difficulty sleeping, you and your family can try to make them more comfortable. Also, your family can try to identify what are the circumstances that may increase difficulty sleeping and try to address them.
- When one approach doesn't work, don't give up, you can try another one.
- Realise that there will be good and bad days.
- Remind yourself that difficulty sleeping is part of the disease.
- Ask for help. It is hard for your family to provide good care if the people with caring responsibilities are not getting enough sleep.

Session 6. Delusions and hallucinations

Why is this session important?

Having strong beliefs that are not shared by others (delusions) or seeing things that aren't there (hallucinations) can be very upsetting for the person living with dementia and their family members that help care for them.

How will this session help me?

We will talk about why people with dementia sometimes believe things that are not real (unreal beliefs) and see or hear things that aren't there. We will also discuss how you might change the way that you and your family respond to them.

1. Why do some people with dementia have unreal beliefs 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 beliefs) 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 their family member that cares for them. To the person living with

dementia the error in thinking is very real and can cause fear and distress.

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 family members that help care for them.

1. Activity

Has the person you and your family care for ever had any unreal beliefs or seen or heard things that were not there? *You can describe them in the space below or in your own notepad, like in a diary.*

2. How to stop or reduce delusions and hallucinations?

Let's look at the following example

Martin is 15 years old and Liam is 13 years old. Their mum, Caroline is living with dementia. One day, the boys and Caroline are out shopping. They see a woman in the distance. Caroline starts calling loudly "Susan, Susan, I'm over here". Then she starts running towards a woman that Martin and Liam have never seen before; a young lady who is probably about 20 years old. Caroline mistakenly believes that the young woman in the shop is her sister who died in a car accident over 30 years ago. The young woman ignores her. Caroline becomes very upset.

1. Check your understanding

Mistaking a person for someone else.

What would you recommend Martin and Liam do? *Please check all the answers that are likely to be helpful.*

- Soothe her in a calm voice.
- Lead their mum away from the woman in the shop.
- Directly tell the truth, harshly, to set the record straight.
- Argue with their mum 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 shop in any way.
- Try to 'convince' their mum 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.

What would you recommend Martin and Liam do?

- ✓ Soothe her in a calm voice. **This is likely to be a helpful response** because people with delusions and hallucinations may feel frightened and insecure.
- ✓ Lead their mum away from the woman in the shop. **This is likely to be a helpful response** because it will distract her from the young woman in the shop.
- ✗ Directly tell the truth, harshly, to set the record straight. **This response is not helpful** as it may make their mum even more upset.
- ✗ Argue with their mum that the young woman is not her sister. **This response is not helpful** as it may make their mum even more upset.
- ✓ Say that the young woman in the shop is someone who looks like her, but it is not her. **This is likely to be a helpful response** because it maintains a positive social environment.
- ✗ Involve the woman in the shop in any way. **This is not helpful** because it may make the situation more complicated.
- ✗ Try to 'convince' their mum of the truth. **This response is not helpful** as Caroline may not understand.
- ✗ Say "Yes you are right, it is Susan". **This response is not helpful** because it is not the truth.
- ✓ Say "When we get home, you can look at pictures of Susan and remember her". **This is likely to be a helpful response** because Martin and Liam address the importance of her sister, without arguing that the young woman their mum saw in the shop was not her sister.

Now let's look at another example

Mercedes' grandfather Larry is living with 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 granddaughter 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 "Grandad's illness is much worse than I thought it was."

Tip

Sometimes the medication that the person living with dementia is using can have side effects such as hallucinations or delusions.

2. Check your understanding

Seeing people that are not there.

What would you recommend Mercedes do? *Please select the answers that you feel are likely to be helpful.*

- Soothe her granddad, by saying in a calm voice "You are safe, I am with you".
- Soothe her grandfather, by taking his hand and patting it.
- Check if there is anything in the room that could be causing Larry's hallucination, such as shadows 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.

What would you recommend Mercedes do?

- ✓ Soothe her granddad, by saying in a calm voice "You are safe, I am with you" or taking his hand and patting it. **This is likely to be a helpful response** because people with delusions and hallucinations may feel frightened and insecure.
- ✓ Check if there is anything in the room that could be causing Larry's hallucination, such as shadows from the sunlight. Make changes as necessary. **This is likely to be a helpful 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 likely to be a helpful response** because changing the environment may distract her grandfather and end the hallucination.
- ✗ Say that it is simply not true, that there are no other people in the room. **This is not a helpful option** because arguing about what one sees or hears will not help a person experiencing delusions or hallucinations to calm down.

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 we have talked about

- 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 people that care for them.
- 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 help care for, but by comforting and distracting them.
- Check the environment to see if there is a cause for the delusion or hallucination.
- 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 help care for.

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 people that help care for them. We call this 'repetitive behaviour'.

How will this session help me?

We will help you understand what repetitive behaviour is and how you and your family can 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 and family members know how to deal with it. If not, the person living with dementia can become anxious, aggressive or depressed and everyone that helps care can become stressed and 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 help 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 or in your own notepad, 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 one day after school, 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 the answers that you feel are likely to be helpful.*

- Say "What's wrong with you? Can't you remember? We just had lunch!"
- Stay calm and reassure his father that John's mother will be home soon.
- Engage his father in an activity.
- Write down the answers to his questions, for example where John's mother 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.
- Offer his father a snack or a drink.

1. Check your understanding

Repeating questions.

What would you recommend to John?

✗ Say "What's wrong with you? Can't you remember? We just had lunch!" **This response is not so helpful** 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 likely to be a helpful 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 could be a helpful 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 helpful** 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 is likely to be a helpful response**. Perhaps if it is just repetitive questioning, by remaining calm the behaviour may decrease.

✓ Offer his father a snack or a drink. **This is likely to be a helpful response**. Perhaps Joe is still hungry or thirsty. It may help to calm him and meet his need.

1. Activity

Let's look at your own situation

It is important to apply what you have learned to your own family 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 help care for, or to yourself.

What could you do to help reduce this behaviour?

How could you change your response to this behaviour?

Let's review what we talked about

- 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 help care for.
- Try to identify what comes before the repetitive behaviour (what causes it) and what may make it worse. Then try to change it. Try to identify how you respond and change that also.
- Remind yourself that repetitive behaviours are part of the disease.

Session 8. Walking and getting lost

Why is this session important?

Concerns about walking and getting lost can cause distress. Your family and you may worry whether the person living with dementia will get lost.

How will this session help me?

We will discuss why a person with dementia might want to walk around and we will talk about things you and your family can do to reduce the chances of the person living with dementia getting lost.

1. Why is walking a concern?



person living with dementia safe.

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 so we will talk about steps you and your family can take to help make the

1. Activity

Does the person you help care for sometimes walk around or walk away? You can describe what happens in the space below like in a diary. Or if you prefer you can use your own notepad.

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 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?

Your family and you can try to:

- Keep to the routines and activities of the person. 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 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 them.
- Ensure that all basic needs are met. Has the person gone to the bathroom? Are they thirsty or hungry? This is important because the person might be walking because they are hungry or because they need to go to the bathroom.
- 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, 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 gets lost and you must ask for help from others.
- After the person is found, speak calmly, with acceptance and love, try to avoid blaming and showing anger.

Let's look at an example

Amit has dementia and is supported by his wife, Samia and his 15 year old son, Josh.

Samia is at work so Josh is cooking dinner and keeping an eye on his dad. Josh hears his dad heading for the door. He knows that he likes to go for afternoon walks, but now is not a good time since he is cooking, and his mum is at work.

1. Check your understanding

Dealing with walking away.

What could you recommend to Josh? *Please select the answers that you feel are likely to be helpful.*

- Yell to Amit from the kitchen, "please stop! I can't come with you now."
- Turn the cooker off and follow Amit.
- Forbid Amit to leave and pull him back into the house.
- Go to where Amit 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 Amit cannot leave.
- Let Amit leave and call a neighbour to keep an eye out for him.
- Ask another family member to go for a walk with him.
- Ask Amit to help with a task in the kitchen.
- Tell his mum that maybe they need to schedule more afternoon walks before dinner.

1. Check your understanding

Dealing with walking away.

What could you recommend to Josh?

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

This is not a helpful response because yelling at Amit 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 Amit. **This is likely to be a helpful response** if there are no other alternatives.

✗ Forbid Amit to leave and pull him back into the house. **This is not a helpful response** because Amit may get agitated and resist being pulled which could result in Josh or his dad being harmed.

✓ Go to where Amit is standing by the door and calmly say: "Let's eat dinner first and we'll go for a walk later." **This is likely to be a helpful response** because Josh stays calm, does not yell, and acknowledges his dad's wishes by telling him that they will go for a walk together after dinner when Josh's mum is back home from work.

✓ Lock the door so that Amit cannot leave. **This is likely to be a helpful response** if no other options exist and Josh is in the house with Amit. For fire safety reasons, a person living with dementia who requires supervision should never be locked inside a house without another person there.

✓ Let Amit leave and call a neighbour to keep an eye out for him. **This is likely to be a helpful option** if Josh's mum has prearranged with the neighbours to keep an eye out for him. If Amit 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 likely to be a helpful option.** Josh can finish cooking dinner and Amit can enjoy a nice walk before dinner.

✓ Ask Amit to help with a task in the kitchen. **This is likely to be a helpful response** because it involves distracting Amit from going for a walk alone and gives him purpose and keeps him occupied.

✓ Tell his mum that maybe they need to schedule more afternoon walks before dinner. **This is likely to be a helpful response** because planning ahead will prevent Josh and his mum from being interrupted when cooking dinner to assist Amit. It may also help Amit to release some energy and come home to relax 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

3. Activity

Based on the reasons that you selected, think about the following questions. How might you react or respond the next time the person you help care for wants to go outside? / What could you do to help the person enjoy walking in a safe way?

Let's review what we have talked about

- Walking around or walking away is common.
- Walking can be a healthy exercise, reduce boredom, and be a common habit or routine of the person you help care for.
- Walking away or walking alone might be unsafe.
- Concerns about walking and getting lost can be very upsetting to the person living with dementia and the family members that share caring responsibilities.
- It is important to identify possible reasons for walking around or walking away.
- If one approach doesn't work, try another one.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you, your family and the person living with dementia.

Session 9. Saying the wrong thing at the wrong time

Why is this session important?

Changes in judgement can, for example, make the person living with dementia say the wrong thing at the wrong time. This can be upsetting for them and also for their family members.

How will this session help me?

This session will help you understand the reasons causing changes in judgement and it will also discuss skills that can help you and your family manage this.

1. What are changes in judgement?

Changes in judgement may include things like 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 for you and your family members who help care for them.

2. How can you manage changes in judgement?

Let's go through an example

Ivan is 15. His grandma Isabel has dementia and lives with him and his parents since his grandfather passed away.

Ivan is in the local shop with Isabel getting a few things for dinner. A little kid is running around the aisles and bumps into Isabel and startles her. Isabel, who is normally a very gentle woman, starts scolding the child and his mum.

1. Check your understanding

Managing changes in judgement.

What could you recommend to Ivan to help him deal with this situation?

Please select the answers that you feel are likely to be helpful.

- Put his hand on Isabel's mouth in order to stop her scolding the child.
- Walk Isabel back home and leave the shop as soon as possible because what happened is embarrassing.
- Stay calm and reassure Isabel everything is alright.
- Accept the behaviour. Find ways to adapt.
- Ivan could carry a business card that explains, 'My grandma has dementia, please be patient with us.' and give this card to the mum.

1. Check your understanding

Managing changes in judgement.

What could you recommend to Ivan to help him deal with this situation?

- ✗ Put his hand on Isabel's mouth in order to stop her scolding the child. **This response is not so helpful** because it may even worsen the situation and make Isabel become more agitated.
- ✗ Walk Isabel back home and leave the shop as soon as possible because what happened is embarrassing. **This response is not so helpful** because Isabel may feel bad and isolated.
- ✓ Stay calm and reassure Isabel everything is alright. **This is likely to be a helpful response** because it shows Ivan cares about Isabel. It may stop her from scolding the child and his mum and make her feel more relaxed.
- ✓ Accept the behaviour. If the child or the mum don't seem to care, let it be. Find ways to adapt. **This can be an appropriate response** if the behaviour is not harming anyone.
- ✓ Ivan could carry a business card that explains, 'My grandma has dementia, please be patient with us.' and give this card to the mum. **This is likely to be a helpful response** because it relieves Ivan from explaining the situation to the child's mum which may embarrass Isabel.

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

The last example was a brief and one-time experience for Ivan. However, as the dementia progresses the changes in judgement experienced by the person living with dementia that you help care for can become more serious. For example, your family may need to make decisions about whether the person is safe to continue to drive.

Remember

As a young person you shouldn't have to deal with changes on your own. Adults in your family and also professionals can help and support you. Reach out and talk to them if you feel you are not coping and things are getting too difficult.

Let's review what we have talked about

- Changes in judgement usually increase as dementia progresses.
- Changes in judgement can be very upsetting for the person living with dementia and their family members.
- It is important to reduce or prevent changes in judgement, whenever possible.
- Remember that there may be good and bad days.
- Remind yourself that this is a part of the disease, that it is not the person's fault.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and your family and the person you help care for.
- Your family may want to plan for increasing levels of changes in judgement as the disease progresses. As a young person shouldn't have to deal with changes on your own. Reach out and ask for help if you feel you are not coping and things are getting too difficult.

Session 10. Putting it all together

The most important things to keep in mind



- Behaviour changes can be stressful for the person you help care for and yourself. This is quite common.
- Try to make the person you help care for feel more comfortable.
- With the help of your family look for ways to prevent or reduce behaviour changes that are stressful,

for example by using memory aids.

- Try to distract the person you help care for, don't argue.
- When one approach does not work, try another one.
- Realise that there may be good and bad days.
- Your family members may want to consult a medical doctor to identify any causes related to medication or illness.
- Identify whether the environment or the way your family approaches the situation could be causing the particular symptom.
- Remind yourself that behaviour changes are part of the disease but other possible reasons should be identified before accepting the disease as a cause.

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

Here are some general tips that we have discussed in this and other sessions:



- Don't blame yourself or your family 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 with others. If you keep them

to yourself it may be more difficult for you to help look after your family member with dementia. 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 and that you enjoy doing, such as spending time with friends 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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