

Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



Unit 3. Changes in mood or interest

Why is this unit important?

Dementia may affect people's mood and interest in daily activities.

How will this unit help me?

This learning unit helps understand possible causes of feeling frightened, sad, agitated and becoming withdrawn. It will also improve your skills to prevent or reduce mood problems.

What will I learn?

- Possible causes of feeling frightened, sad and agitated.
- How to respond when a person with dementia shows these changed behaviours.
- How to respond when a person with dementia loses interest in daily activities.

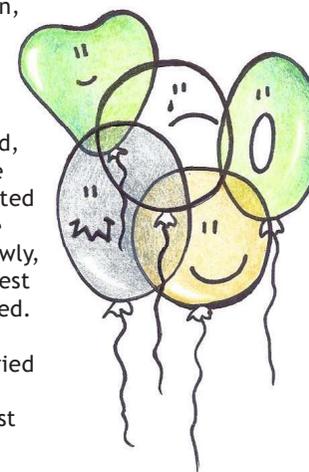
Feel frightened and sad

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

People with dementia may feel sad, worried or frightened, and may be unusually emotional, crying, agitated or restless. They may also become withdrawn, unhappy and react slowly, lose their appetite, and lose interest in activities they previously enjoyed.

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.

These changed behaviours are also described as depressive symptoms by health professionals. Your GP (family doctor) is your first contact person to assess these symptoms. It is important to get a timely diagnosis and treatment for these symptoms.



This first example is about feeling sad

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

How should Isabel handle this situation?



Person-centred care

Imagine being in the shoes of the person living with dementia and how would you like to be treated.

Check your understanding



Response of Isabel. How should Isabel handle this situation using person-centred care?

Here are some things Isabel may do or say. Click on any of the responses you think might work.

- Walk over to John and say in a calm, reassuring tone, 'I have some ideas for how you can feel better, let's talk.'
- Say: 'John, 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 John on the arm or shoulder. 'I know you feel bad, I do too. What we're going through is really hard.'
- Sigh and walk away, thinking to herself there is nothing she can do.
- Sit with him and suggest that they do a pleasant activity together.
- Make an appointment for John to see his local doctor to discuss the matter.

Check your understanding

*How should Isabel handle this situation using person-centred care?*

- ✓ **Walk over to John 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 John needs more support due to the changes in his mood.
- ✗ **Say: 'John, what's the matter with you? I'm tired of seeing you like this. Just get up and do something.'**
This response is less desirable because John 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 John and may make him feel even sadder.
- ✓ **Go over and touch John on the arm or shoulder. 'I know 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 to feel understood.
- ✗ **Sigh and walk away, thinking to herself there is nothing she can do.**
This is a less desirable response because Isabel is further isolating John.
- ✓ **Sit with him and suggest that they do a pleasant activity together.**
This is a good response because it may distract John and make him feel better.
- ✓ **Make an appointment for John to see his local doctor to discuss the matter.**
This is a good response because the doctor may be able to help John with the changes in his mood.

Here is an example about feeling agitated

Emma has dementia and lives with her family. Benjamin is her grandson, and as his 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.'

Benjamin is upset.

How do you think Benjamin should handle this situation?

A: What comes before the changed behaviour?
Benjamin is watching a TV show with loud music and vulgar language.



B: Changed behaviour
Emma starts pacing and wringing her hands



C: Consequences
Benjamin is upset.

Response of Benjamin. How do you think Benjamin could handle this situation?

Here are some options, click on all of the responses you think might work for Benjamin:

- Think 'Grandma cannot help the way 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.
- Ask his grandmother to help him with something.
- 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 she is busy.

Check your understanding

*How do you think Benjamin could handle this situation?*

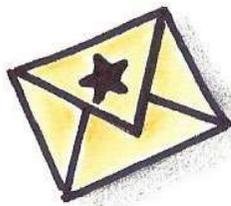
- ✓ **Think 'Grandma cannot help the way she behaves.'**
This is a good response because it recognises that Emma's behaviour might be due to changes in the brain, and she cannot tolerate an intrusive TV show. She is overstimulated.
- ✗ **Say 'Grandma! Sit down, you're making it impossible for me to watch my show.'**
This response is not good because a direct order like this one may make Emma even more agitated.
- ✓ **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.
- ✓ **Ask his grandmother to help him with something.**
This is a good response because it may distract Emma and may help lessen her agitation.
- ✗ **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 agitation.
- ✓ **Look for his headphones and encourage his grandmother to go back to her sewing so 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.

If a person with dementia loses interest in daily activities

Now let's examine what to do if a person with dementia loses interest in daily activities.

George has dementia and lives with his wife, Sofia. George used to be a shop keeper and was very active in the community. Recently, George has been sitting in a chair near a large window and staring blankly outside. Sofia has become very concerned because this is not like him. He seems removed and distant from her. One day, she walks in and she says 'George, shall we go out for a walk?'

He says he is not interested in any activities.



Person-centred care
Imagine being in the shoes of the person living with dementia and how would you like to be treated.

Check your understanding



Response of Sofia

Indicate how you think Sofia could act appropriately based on person-centred care.

Select the answers you think are appropriate and drop them in the box.

- Sofia walks over to George and says, 'I'm sick and tired of this laziness, get up and let's go.'
- Sofia 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.
- Sofia 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.'
- Sofia closes the door and doesn't try to engage with George anymore.
- Sofia 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 asking him to help her arrange some shelves as he would have when he was a shopkeeper.
- Make an appointment for George to see his local doctor to discuss the matter.

Check your understanding



Indicate how you think Sofia could act appropriately based on person-centred care.

Select the answers you think are appropriate and drop them in the box.

- ✗ Sofia 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 about his dementia.
- ✓ Sofia 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. George may respond to this positively.
- ✗ Sofia 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.
- ✗ Sofia closes the door and doesn't try to engage with George anymore.

This is not the right response because it may make George's loss of interest worse.
- ✓ Sofia 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 asking him to help her arrange some shelves as he would have when he was a shopkeeper.

This is a good response because it shows Sofia cares about George and wants to help him engage in an activity he would enjoy.
- ✓ Make an appointment for George to see his local doctor to discuss the matter.

This is a good response because the doctor may be able to help George with the changes in his mood.

What is apathy?

Some people living with dementia can sometimes appear to be unresponsive and apathetic. This is more common as the disease progresses. Apathy can be seen as being unmotivated, not wanting to join conversations, lack interest in things they used to enjoy.

Apathy can be distressing for you, family and friends. Understanding the causes of apathy and how to respond to it can be helpful.

Why does someone living with dementia become apathetic?

People living with dementia become apathetic for many reasons. Some of the more common reasons include:

- Damage to the part of the brain responsible for planning, judgment and insight as the disease progresses.
- Boredom because they can no longer do the things they once did and are unable to engage in other activities without help or encouragement.
- Illness or medication that can sometimes affect energy or concentration levels.

Here is a common example

Linda is 78 and has been living with dementia for 3 years. Recently her husband, Kevin, has been concerned that Linda is not interested in going to her regular morning social group at the local church and Kevin struggles to get her out of bed in the morning.

Check your understanding



How would you advise Kevin?

- Kevin should accept that there is nothing he can do.
- Kevin should tell Linda he is frustrated and that she is not doing enough to help herself.
- Kevin should make an appointment for Linda to see her family doctor (or GP) to discuss the matter.
- Kevin should attend a carer support group where he could talk with others facing similar situations.
- Kevin should consider structuring Linda's daily activities, using simple steps and allow time so that Linda is not rushed.

Check your understanding***How would you advise Kevin?***

- × **Kevin should accept that there is nothing he can do.**
This is not a desirable response as it will isolate Linda and doesn't address Kevin's concern and frustrations.
- × **Kevin should tell Linda he is frustrated and that she is not doing enough to help herself.**
This is not a good response. Linda cannot help the way she is acting and Kevin's emotions may distress Linda and stop her engagement in the task. Whilst it is difficult, Kevin needs to maintain a positive tone and should try to reframe apathy as brain-based rather than the result of stubbornness.
- ✓ **Kevin should make an appointment for Linda to see her family doctor (or GP) to discuss the matter.**
This is a good response because the doctor may be able to help Linda with the changed behaviour.
- ✓ **Kevin should attend a carer support group where he could talk with others facing similar situations.**
This is a good response as it provides support and encouragement for Kevin to help cope with his emotions and the stress he is feeling. This will help him continue to manage Linda's care while acknowledging his own need for support and assistance.
- ✓ **Kevin should consider structuring Linda's daily activities, using simple steps and allow time so that Linda is not rushed.**
This is an excellent response. By developing individualised activities based on needs and interests that motivate and direct the person, it can encourage them to be more involved. Kevin should follow the schedule consistently and adapt the level of activities to meet Linda's abilities.

Activity

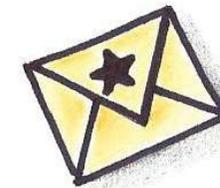


Let's look at your own situation

It is important to relate what you have learned to your own situation. These boxes are for you, like a diary:

Does the person with dementia you care for ever have changes in mood or interest?

What could you do to prevent this or to respond in a different way?



Let's review what you have learned

- Changes in mood or interest are common in people with dementia.
- Changes in mood can be very upsetting for the person 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 distracting the person.
- 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 for you and the person you care for in case the person you care for has mood problems or a loss of interest.

REMEMBER, it is important to recognise when things get serious. If the person you care for has serious and persistent mood changes or you think the person you care for is in danger of harming the person you care for, it is important to seek medical advice right away. For further information go to Dementia Australia www.dementia.org.au to learn more about mood changes.

Further Information

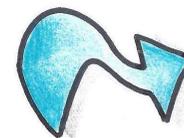
- **Dementia Australia** www.dementia.org.au
The National Dementia Helpline is a free confidential phone and email information and support service. The Helpline number is 1800 100 500 and operates from 9.00 am to 5.00 pm Monday to Friday excluding public holidays. A message service is available so if you call outside operating hours, you will get a call to you back the next working day.

RELATED LEARNING UNITS

- Module 2 Unit 3 Supported decision-making
- Module 4 Unit 1 Eating and drinking - more pleasant mealtimes
- Module 5 Unit 4 Difficulty sleeping

You finished this learning unit, well done!

Would you like to try the following relaxation exercise?





Meditation

This exercise will help you feel calm and reduces stress. You will breathe with your stomach according to a rhythm.

This is how you do it:

- Sit straight on a chair and make sure your face and shoulders are relaxed.
- Bring your hands to your stomach and breathe into your belly.
- Breathe in for 4 counts and breathe out for 8 counts at a comfortable pace.
- Your stomach should expand with each inhale, and it contracts with each exhale.
- Return to your normal breathing and spend one minute just watching your breath and noticing how you feel.
- Practice listening without negative judgement.
- If your mind wanders, refocus on breathing and meditation.



You finished this unit, well done!