Australian version



Training and support manual for carers of people with dementia



iSupport For Dementia

Training and support manual for carers of people with dementia

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iSupport for dementia. Training and support manual for carers of people with dementia

Online ISBN: 978-1-925562-75-0 Print ISBN: 978-1-923178-16-8

DOI: https://doi.org/10.25957/99qa-zy38

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The World Health Organization (WHO) developed iSupport for Dementia, a comprehensive online dementia education and skill training programme for informal carers of people living with dementia [1]. This programme has been adapted into the Australian social context [2]. Flinders University funded the research activities leading to the current version of Australian iSupport for Dementia. The research team members who contributed to the adaptation of the WHO iSupport for Dementia programme and to the new learning module in the programme entitled 'My engagement in consumer directed care' are:

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Suggested citation: Australian iSupport for dementia. Training and support manual for carers of people with dementia. Adelaide: Flinders University; 2022. ISBN: 9781925562750.

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- 1. World Health Organization: (2019), iSupport for dementia, Training and support manual for carers of people with dementia, Geneva: World Health Organization, Licence: CC BY-NC-SA 3.0 IGO.
- 2.Xiao, L. D., McKechnie, S., Jeffers, L., De Bellis, A., Beattie, E., Low, L. F., per, B., Messent, P., & Pot, A. M. (2021). Stakeholders' perspectives on adapting the World Health Organization iSupport for Dementia in Australia. Dementia (London, England), 20(5), 1536-1552.

MODULE 5

DEALING WITH CHANGED BEHAVIOUR

- Unit 1. Introduction to person-centred care approach
- Unit 2. Aggression
- Unit 3. Changes in mood or interest
- Unit 4. Difficulty sleeping
- Unit 5. Delusions and hallucinations
- Unit 6. Walking and getting lost
- Unit 7. Changes in judgement

Unit 1. Introduction to person-centred care approach to changed behaviour

Why is this unit important?

People with dementia can have changed behaviour. These behaviours affect them, but can also be difficult for carers, like you.

How will this unit help me?

This learning unit helps you as a carer improve knowledge and skills to understand, prevent and manage changed behaviours.

What will I learn?

- The commonly identified changed behaviours among people with dementia
- Using the ABC approach to analyse, prevent and manage changed behaviour
- Using the person-centred approach to prevent and manage changed behaviours.

What is a changed behaviour?

Dementia will affect what a person thinks, how a person feels and what that person does. Behaviours, such as aggression, suspicion or wandering, are caused by damage to the brain, misunderstanding of their environment or inability to communicate their needs. They are not something your relative can control or prevent.

People with dementia, like the person, often have changes in their behaviours. Health professionals may use the term 'Behavioural and psychological symptoms of dementia or BPSD' to describe changed behaviours.

The changed behaviour can be a source of distress both to the person with dementia, the carer, family members, friends and service providers.



Activity



Pick any changed behaviour

Does the person ever have one of the following behaviours? Please click on any changed behaviour that you think the person may have.

Behaviour changes	Examples		
Aggression	Doing or saying something that makes you scared or frightened.		
Changes in mood or interest	Feeling sad, worried, frightened, frustrated or angry; being unusually emotional, crying, agitated or restless, withdrawn, unhappy, reacting slowly.		
Difficulty sleeping	Restless at night, waking you or other family members up.		
Delusions and hallucinations	Misinterpreting the world; having fixed false beliefs; things a person sees or hears that are not there.		
Walking and getting lost	Continually walking around; leaving the house and getting lost.		
Changes in judgement	Saying the wrong thing at the wrong time, acting inappropriately in a situation; not understanding own limitations; sexual and other socially inappropriate behaviours.		

Changed behaviour

Many things can cause changes in behaviours. This may have a negative impact on your relationship with the person. It can even make you feel sad, angry, confused, or anxious. In some instances, you might even feel you 'can't handle' the behaviours.

Changed behaviours can have an impact on how you feel.

How to use the "ABC approach" (as shows in the boxes) to analyse changed behaviours

The three boxes on the right show the 'ABC approach'.

You will need to recognise:

- 1. Antecedent (A): what comes before the behaviour;
- 2. Changed behaviour (B): changed behaviour the person with dementia demonstrates; and
- 3. Consequences (C): the impact of the changed behaviour on the carer.

A: What comes before the changed behaviour?



B: Changed behaviour



C: Consequences

Let us analyse an example

The three boxes on the right show what's happening. Emma has a diagnosis of dementia and is cared for by her husband, John. Emma appears to do very little and is staying in her pyjamas all day.

- 1. Antecedent (A): John tries to help Emma get dressed.
- 2. Changed behaviour (B): Emma becomes very angry and yells.
- Consequences (C): John becomes frustrated and yells back at Emma.



A: John tries to help her get dressed



B: Emma becomes very angry and yells



C: John becomes frustrated and yells back at Emma



What are some of the things John could do differently?

Here are some responses, some are good, others are not. Please indicate what you think could be good responses. John could:

- Take a deep breath.
- Say to Emma that wearing pyjamas all day is not acceptable and insist Emma to get dressed.
- Remind himself that his wife has dementia, and the disease damages her judgement about what to wear appropriately during the day.
- Show two of Emma's favourite dresses and ask her to choose what she would like to wear.
- Accept Emma's choice to wearing pyjamas if she likes to do.

Check your understanding



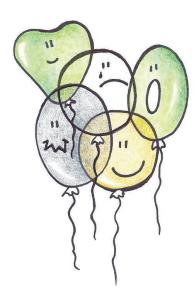
- Take a deep breath.
 - It shows that John is trying to calm down, if he calms down Emma might too.
- Say to Emma that wearing pyjamas all day is not acceptable and insist Emma to get dressed. Forcing a person living with dementia to do something that they do not want will make the situation worse.
- Remind himself that his wife has dementia and the disease damages her judgement about what to wear appropriately during the day.

 John recognises that Emma is living with dementia.
- Show two of Emma's favourite dresses and ask her to choose what she would like to wear.
 - This is a good response, because it shows that John includes Emma in decision making and respects Emma's choice.
- Accept Emma's choice to wearing pyjamas if she likes to do.
 - This is a good response, because wearing pyjamas all day has no harm to Emma.

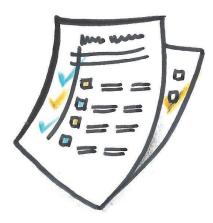
How to use person-centred care approach to prevent and manage changed behaviours?

The best way to understand person-centred care is to imagine being in the shoes of the person living with dementia; how would you like to be treated and how would you feel in the same situation. This care approach considers the needs and wishes of the person living with dementia when providing everyday care.

A changed behaviour is viewed as a way for the persons with dementia to express their unmet needs. Using person-centred care approach helps you meet the care needs of the person you care for and prevent changed behaviours.



Person-centred care helps you meet the care needs of the person you care for and prevents changed behaviours.



Let us analyse an example

Deborah lives with dementia and is cared for by her daughter, Linda. She likes cooking and always helps Linda to prepare meals for the family.

However, Deborah's condition has deteriorated recently. She misplaces things and breaks plates. Therefore, Linda decides not to have her mother around her in the kitchen. She tells Deborah to stay in the living room to watch TV while she is cooking.

Deborah becomes restless in the living room, walks to the kitchen many times and tries to help Linda with cooking. Linda becomes impatient and raises her voice and says 'Can you please stop doing this'!

Deborah becomes upset and yells back to Linda.



What are some of the ways Linda could do differently?

Here are some responses, some are good, others are not. Please indicate what you think could be good responses. Linda could:

- Help Deborah stay in living room by closing the door so that she won't disturb Linda.
- Take a deep breath.
- Provide opportunities for Deborah to prepare meals that is safe for her to do, for example, setting a table in the dining room, that will provide Deborah with a sense of accomplishment.
- Set the environment up to simulate cooking experience for Deborah which helps to make her life meaningful and could potentially reduce the unmet needs.

Check your understanding



- Help Deborah stay in living room by closing the door so that she won't disturb Linda.
 - This practice does not reflect person-centred care and is seen as a restraint.
- √ Take a deep breath.
 - It shows that Linda is trying to calm down, if she calms down Deborah might too.
- Provide opportunities for Deborah to prepare meals that is safe for her to do, for example, setting a table in the dining room, that will provide Deborah with a sense of accomplishment.
 - This is good practice as it shows that Linda demonstrates an understanding of her mother's life experience.
- Set the environment up to simulate cooking experience for Deborah which helps to make her life meaningful and could potentially reduce the unmet needs
 - This practice is good as it shows that Linda understands person-centred care.

Keep in Mind



When dealing with changed behaviour, keep the following in mind:

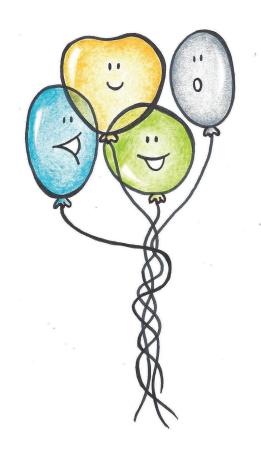
- Changed behaviours are common.
- Changed behaviours can be stressful for the person you care for and you.
- Try to make the person more comfortable.
- Look for ways to prevent or reduce changed behaviour, for example by using memory aids.
- Try to distract the person from the behaviour.
- Do not argue with the person.
- When one response or approach does not work, try another one.
- Realise there may be good and bad days.
- Consult your local doctor to identify any causes related to medications or illness.
- Identify whether the environment or your approach could be causing the changed behaviour.
- Try to identify what leads to the behaviour happening so that changes can be made.
- Remind yourself that changed behaviour can be part of the disease, but other possible causes should be identified before accepting the disease as a cause.





Here are some tips for related learning units:

- Don't blame yourself or the person you care for for the problems you encounter.
- 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 the person.
- It is essential that you make time for yourself. This will allow you to do the things you value in life, such as spending time with others or enjoying your favourite hobbies.
- Learn as much as you can to understand the behaviours and how to respond to them.

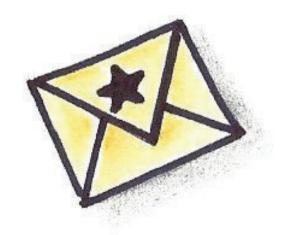


Useful resources

- Dementia Australia, https://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 9.00am to 5.00pm 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.
- Dementia Support Australia https://www.dementia.com.au/ The Dementia Behaviour Management Advisory Service (DBMAS) offers people with dementia and their carers support in managing behavioural and psychological symptoms of dementia, such as walking and getting lost and aggression. Contact them on 1800 699 799 (24 hours a day).
- My Aged Care https://www.myagedcare.gov.au Carer support groups can sometimes be organised around specific caring roles and the situation of the person you care for. For information about these groups in your area visit the website or call My Aged Care on 1800 200 422.
- Beyondblue www.beyondblue.org.au/getsupport Learn more about anxiety and depression or to talk to someone call 1300 22 4636 (available 24 a day, 7 days a week)
- Lifeline Crisis Support 24 hour crisis support call 13 11 14. Your local council may have resources to support you.

RELATED LEARNING UNITS

- Module 1 Unit 1 Introduction to dementia
- Module 2 Unit 4 Involving others
- Module 4 Unit 5 An enjoyable day
- Module 3 Unit 3 Thinking differently
- Module 3 Unit 2 Making time for pleasant activities





You finished this unit, well done!

Unit 2. Aggression

Why is this unit important?

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

How will this unit help me?

This learning unit helps you understand possible causes of aggression and improves your skills to recognise and to prevent or deal with aggression.

What will I learn?

- Possible causes of aggression
- Ways to change the environment to make it more calming
- How to prevent or deal with aggression.

Why does this happen?

Aggression can happen for a variety of reasons. It can be due to:

- unmet needs such as hunger, pain, tiredness,
- Illness, such as a urinary tract infection, medication combinations or side effects,
- or something happening in the environment such as someone trying to get them to do something they do not understand or do not want to do.

In addition, people with dementia may experience difficulties in understanding others, judging social situations, controlling their feelings or expressing themselves in the way they did before. They may also have personality or mental health changes that contribute to aggressive behaviour.

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



Talking aggressively Does the person you care for ever talk aggressively to you or other people including speaking too loudly, shouting, yelling or swearing? Yes No Rather not say Acting Aggressively And does the person you care for ever act physically aggressively towards you or other people including pushing, shoving, pinching or punching? Yes No Rather not say



Activity



Do you remember the "ABC approach" to analyse changed behaviours?

Just as we mentioned in the Introduction Unit of 'Personcentred care approach to changed behaviour', it is important to break down behaviours into three parts in order to help you deal with them.

Do you remember	what they are?
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Here they are

Let's see how it works with a different example.

Have a look at Don, who angrily refuses to take a bath.

Here is a common example:

Neil wants to assist his father, Don, in taking a bath. Neil says: 'It is time for your bath.' Don refuses. Neil is in a hurry and tugs on his father's arm. He says: 'You need to have a bath because you're going to see the doctor.' Don pulls his arm back and resists. He is much stronger than Neil. Neil tugs it again and says angrily: 'You must take a bath because you are going to the doctor and need to be clean.' Don gets agitated and shouts and even tries to shove Neil, who feels stressed and anxious.

Can you break down the behaviour of this example into the three parts?



Let's look at the ABC approach to analyse the changed behaviour.

A: What comes before the changed behaviour? Neil insists that his father should take a bath.



B: Changed behaviour

Don refuses. Then he shouts and tries to shove

Neil.



C: Consequences
Neil is very upset.



What are some ways Neil could react differently?

Here are possible options, some are good responses, and others are not. Please indicate what you think are good responses. Drag the good responses and drop them in the box.

Neil could:

- Physically force his father to start bathing.
- Maintain the dignity and privacy of his father. He could keep him in a robe or towel until he actually takes a bath.
- Play soothing music that Don likes.
- Decide that Don does not need a bath before his visit to the doctor.
- Explain calmly and logically why Don should bathe.
- Next time, make sure there is enough time so that it is not a stressful situation. Rather than do the bath right before the doctor's appointment, Neil might try to assist with bathing the day before.

- Neil could put himself in Don's shoes and try to understand why Don might not want to bathe.
- Identify the best time of day for Don to take a bath and find out whether he prefers a bath or shower.
- When bathing Don, Neil could keep a towel over his shoulders to help him maintain dignity and to help keep him warm.
- Neil could ask for someone else to help with Don's bath time.
- Neil could help Don with a wash by using warm, wet towels with soap without taking Don to the bath.
- Say in an irritated voice: 'I have already answered that, please stop bothering me'; 'You must take a bath!'.





What are some ways Neil could react differently?

- Physically force his father to start bathing.
 - This might result in further physical aggression and may make the situation worse.
- Maintain the dignity and privacy of his father. He could keep him in a robe or towel until he actually takes a bath.

 Maintaining dignity and privacy is always a good idea when caring for someone with dementia. It makes sure that the person with dementia is comfortable.
- √ Play soothing music that Don likes.
 - Though it may take extra time to arrange the music, this option may help soothe Neil and Don. This may create relaxation and less negative responses from both of them.
- Decide that Don does not need a bath before his visit to the doctor.
 - Neil may relax his standards if Don is not dirty and does not need to bathe.
- Explain calmly and logically why Don should bathe.
 - This treats Don with respect and as a reasonable person.
- Next time, make sure there is enough time so that it is not a stressful situation. Rather than do the bath right before the doctor's appointment, Neil might try to assist with bathing the day before.
 - Allowing more time may reduce tension for Neil and Don. Rushing into anything may not give Don enough time to get used to the idea.

Check your understanding (Countinued)



What are some ways Neil could react differently?

- Neil could put himself in Don's shoes and try to understand why Don might not want to bathe.

 People with dementia can be embarrassed to have someone else help them bathe, or Don might not want his son to help him bathe.
- Identify the best time of day for Don to take a bath and find out whether he prefers a bath or shower.

 Respecting the routines and preference of the people with dementia will make them more likely to agree to activities.
- When bathing Don, Neil could keep a towel over his shoulders to help him maintain dignity and to help keep him warm. This answer is good. Don could be embarrassed to be naked in front of his son 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.
- Neil could ask for someone else to help with Don's bath time.

 Sometimes the person with dementia is more comfortable with one family member than another family member. Sometimes even a stranger might find it easier than a family member as the person with dementia might be less embarrassed than with a family member.
- Neil could help Don with a wash by using warm, wet towels with soap without taking Don to the bath.

 If the person with dementia is afraid of the bath, or running water, this option will help relieve their distress and can sometimes be used in place of baths. There are also products such as dry shampoo and cleaning products used for young children which might help.
- Say in an irritated voice: 'I have already answered that, please stop bothering me'; 'You must take a bath!'.

 This is unhelpful and might make the situation worse.

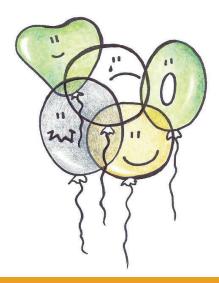


What could Neil do?

What could Neil do if his approach does not work the first time? Check as many as apply.

- Neil could try several approaches until he finds one that works.
- Neil could get suggestions from others, such as family members, or ideas from care support groups and Dementia Australia.

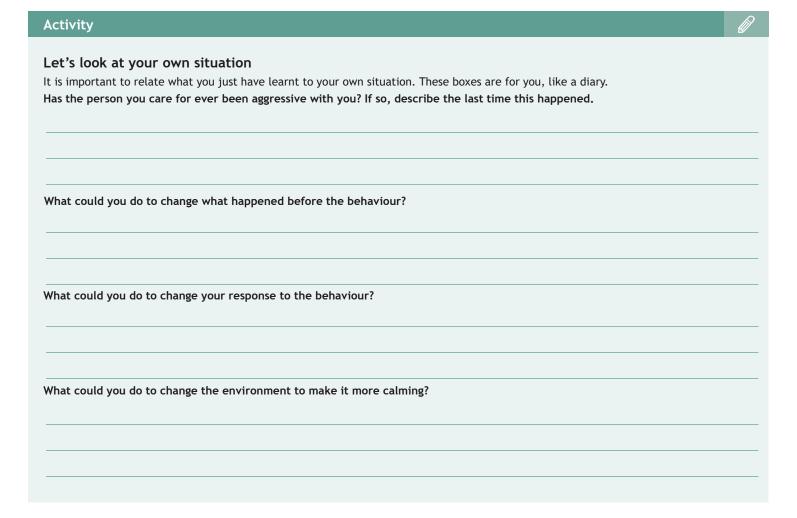




Check your understanding



- Neil could try several approaches until he finds one that works.
 - Different approaches may work at different times so Neil should not give up!
- Neil could get suggestions from others, such as family members, or ideas from care support groups and Dementia Australia.
 - Getting ideas from others can sometimes help find an approach that works.



Let's review what you have learned

- Aggression like shouting, shoving or pushing can happen to carers of people with dementia.
- Aggression can be very upsetting for the person with dementia as well as the carer and others.
- Try to change the environment to make it more calming, do not rush things.
- Try to maintain the dignity of the person you care for, do not force the person you care for.
- If one approach does not work, try another one.
- Realise there may be good and bad moments.
- Try different responses and approaches, as the first one does not always work.
- Remind yourself that aggression can be a part of the dementia, or a reaction to the disease.
- If the person is suddenly behaving aggressively, there may be an underlying cause (for example, a urinary infection) that should be investigated by a doctor.

- Take a deep breath and think about the most positive ways to respond that will be least distressing for you and the person you care for.
- Don't force the situation consider if leaving it for now is an option.
- If the person you care for continues to show aggression, there are a lot of resources available on the internet. Look for examples on the Dementia Australia website: https://www.dementia.org.au/

RELATED LEARNING UNITS

- Module 2 Unit 2 Improving communication
- Module 4 Unit 4 Personal care

Additional resources

• Home Support Programme

Dementia Australia: https://www.dementia.org.au/
 The National Dementia Helpline 1800 100 500 is open nationally from 9.00am to 5.00pm Monday to Friday excluding public holidays. A message service is available if you call outside operating hours.

Dementia Support Australia https://www.dementia.com.au/
 The Dementia Behaviour Management Advisory Service
 (DBMAS) offers people with dementia and their carers
 support in managing behavioural and psychological
 symptoms of dementia, such as walking and getting lost and aggression. Contact them on 1800 699 799 (24 hours a day).

My Aged Care https://www.myagedcare.gov.au
 Carer support groups can sometimes be organised around specific caring roles and the situation of the person you care for. For information about these groups in your area visit the website or call My Aged Care on 1800 200 422.

https://www.myagedcare.gov.au/getting-started

The My Aged Care is an Australian Government website and phone line to help you find out what aged care services may be available to help you. call My Aged Care on 1800 200 422.

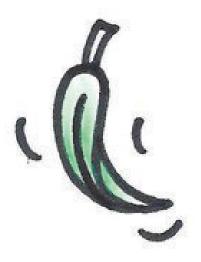
You finished this learning unit, well done!

Would you like to try the following relaxation exercise?



Neck movements

With this exercise you will feel less tension in your neck. It will also increase the blood flow to your brain.



This is how you do it:

- Make sure to move slowly and with attention.
- Bend your neck forward and backward.
- Inhale while you lift your head up and back. Exhale while you drop your chin to your chest.
- · Rotate your chin from side to side.
- Inhale when your chin is in the centre. Exhale when you look to the side.
- Drop your ear towards your shoulder.
- Inhale when you are in the centre. Exhale when you drop your ear to your shoulder.
- Repeat 5 times.



You finished this unit, well done!

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?

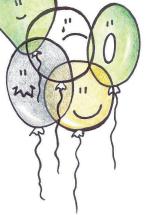
- Possible causes of feeling frightened, sad and agitated.
- How to respond when a person with dementia shows these changed behaviours.
- How to respond when a person with dementia loses interest in daily activities.

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.



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.



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.



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.

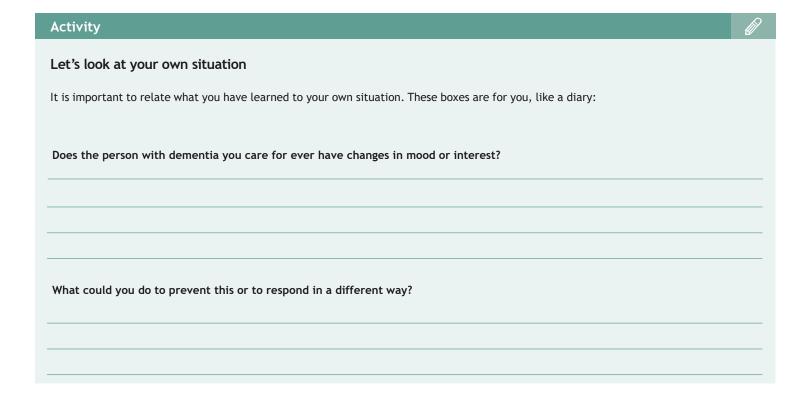


How would you advise Kevin?

- 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.





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.

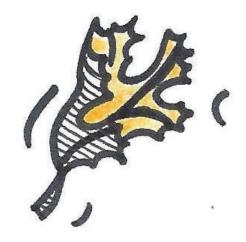
RELATED LEARNING UNITS

- · 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!

Unit 4. Difficulty sleeping

Why is this unit important?

People with dementia may be confused between night and day, making sleeping during the night difficult. People with dementia may have affected sleep habits due to other medical conditions. Disturbed sleep habits can impact the carer's sleep as well.

How will this unit help me?

This learning unit will provide examples and practices to promote good sleep.

What will I learn?

- How to help someone with dementia who has difficulties falling asleep.
- How to help someone with dementia who wakes up in the middle of the night.
- What may cause sleeping difficulties and how to change this.

Difficulty with sleeping: What happens?

Difficulty with sleeping can be a problem for people with dementia and their families. People with dementia can have difficulty falling asleep, wake up in the middle of the night, or wake up too early in the morning. People who provide care can have their sleep disrupted as a result which can make it harder to provide care.

If the person you care for wakes up at night, the person may start to wander.

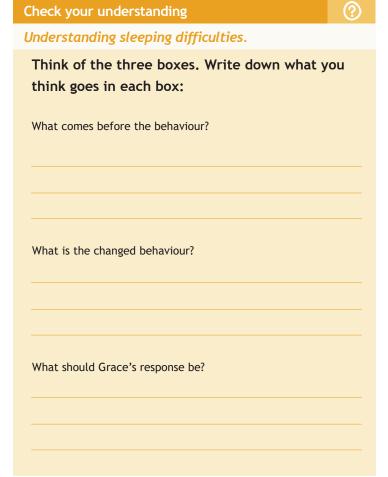
You can now practice how to help promote good sleep for the person.



What is the main problem? What is the main problem that the person you care for has with regard to sleeping? Click all that apply. Difficulty falling asleep Waking up in the middle of the night or early morning Combination of the above Sleeps through the day Other (please specify):

Difficulty falling asleep

Rosie has dementia. She lives with her family and 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 want her to go to bed by 8pm. Grace notices that Rosie has trouble falling asleep. Rosie continues to open and shut her dresser drawers noisily during the evening. When her granddaughter goes to bed, the noise keeps her awake.





Grace's response

Here are some responses,

click all that you think may be appropriate to help Rosie falling asleep:

- Give her a pill to sleep.
- Go for a walk with Rosie and add more physical activity during the day.
- Try to ensure Rosie does not drink coffee or too much fluid a few hours before going to bed.
- Make lunch the bigger meal of the day.
- Make sure the bedroom is a comfortable temperature and provide security objects, such as nightlights, if needed.
- 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 8pm means night waking between 2 to 4 am.
- Take the dresser away.

?

Grace's response

- × 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.
- 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.
- Try to ensure 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.
- Make sure the bedroom is a comfortable temperature and provide security objects, such as nightlights, if needed.
 - This is helpful as ensures the environment meets Rosie's needs to make 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 not so long that it will prevent Rosie from falling asleep later on.
- Play soothing music before bedtime to help Rosie sleep.
 - This is a good idea. Too much activity before bed can cause a person to be stimulated and stay awake. Find relaxing activities before bed such as music or reading to Rosie.
- Create a bedtime routine, like lowering the lights, washing face and teeth, and changing into pajamas.
 - This is a good response because a routine will relax the person with dementia.
- Keep in mind that some people may require less sleep. Generally, 6 to 8 hours sleep from 8pm means night waking between 2 to 4 am.
 - Stick to normal sleeping time as much as possible.
- Take the dresser away.
 - This is not a good response as it does not address Rosie's need or the cause of the behaviour.

Waking up in the middle of the night

It is 3 am in the morning and Annie wakes up and begins to walk around the house. Her daughter, Grace, is sleeping.

Annie paces throughout the house and then goes to Grace and wakes her up. Annie asks: 'Where are we? I want to go home.'

Grace is upset because she has a long day at work tomorrow. Grace says: 'Mum, you need to go back to bed, it is 3 am.' Annie says: 'I am not sleepy.' Grace yells: 'I can't take this anymore.'

How do you think Grace should handle this situation with her mother?

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

Person-centred care

Check your understanding



Grace's response. If Grace wants to keep Annie from walking at 3 am, what can she do?

Which of the following responses do you think are appropriate? Select all that apply and drop them in the box.

- Tell Annie how foolish it is to be awake at 3 am.
- Try to understand what will help Annie sleep. Some people prefer to keep the room dark with no TV or as little noise as possible and some people prefer a night light, soft music or a television playing.
- Give Annie a favourite object to relax (blanket or stuffed animal, etc.).
- Schedule an appointment with the doctor to find out if there is a medical reason for her trouble sleeping (urinary tract infection, pain, medications).
- Develop an activity schedule to keep Annie awake and busy during the day.
- Encourage physical exercise during the day (e.g., walking, stretching).
- Tell Annie 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 the answer is '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.



Grace's response

- Tell Annie how foolish it is to be awake at 3 am.
 - This answer is not good. Annie cannot help her confusion and this will not help Annie to fall asleep again. It may cause her to feel embarrassed or agitated preventing sleep.
- Try to understand what will help Annie sleep. Some people prefer to keep the room dark with no TV or as little noise as possible and some people 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 Annie a favourite object to relax (blanket or stuffed animal, etc.).
 - This response is a good one. It may help Annie feel relaxed and secure.
- Schedule an appointment with the doctor to find out if there is a medical reason for her trouble sleeping (urinary tract infection, pain, medications).
 - While it is not necessary to seek medical attention every time a person with dementia can't sleep, seeking advice if it happens all the time or upsets the person with dementia or you.

Check your understanding (Continued)



Grace's response

- Develop an activity schedule to keep Annie 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 Annie 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 others provide.
- Ask if she has to go to the bathroom or is hungry or thirsty. If the answer is 'yes', then just assist her to meet these needs.

 This is helpful. Such a break might help the person to get to sleep again.
- Physically take hold of her 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, Annie may get agitated or angry. It definitely will not solve 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 care. Someone else can assist by giving the family member a night or a weekend off.



Your response

You've identified several ways to improve sleep.

Which of the previous responses would you choose in case of sleeping problems of the person you care for? More responses may apply:

- Remind yourself to stay calm and focus on getting the person 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 provide some relaxation, such as soothing music.
- Read aloud to the person you care for. Choose something that you know has a calming effect, perhaps a calming poem or story. Sing a song or chant together. Another option is to meditate for 15 minutes together.



- Provide the person with dementia comfort. Give a stuffed animal and hug or hold the person until he/she falls asleep.
- Consider using a sleep diary to see if you notice any trends or habits that could be affecting sleep patterns. For example, is the person drinking too much coffee at night?
- Try to maintain the person's lifelong sleeping pattern. For example, if the person used to get up early in the morning, see if maintaining this habit helps.



Your response

Remind yourself to stay calm and focus on getting the person 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 provide some relaxation, such as soothing music.

Great idea!

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

Good response!

Provide the person with dementia comfort. Give a stuffed animal and hug or hold the person until he/she falls asleep.

Great idea!

Consider using a sleep diary to see if you notice any trends or habits that could be affecting sleep patterns. For example, is the person drinking too much coffee at night?.

Good response!

Try to maintain the person's lifelong sleeping pattern.
For example, if the person used to get up early in the morning, see if maintaining this habit helps.

Great idea!

Activity Let's look at your own situation It is important to relate what you have learnt to your own situation. This box is for you, like a diary. What could you do to help tackle sleeping problems or improve your reaction to sleeping problems?









Let's review what you have learned

- Difficult sleep patterns are common in people with dementia.
- Sleeping problems can be very stressful to deal with.
- In case of difficulty sleeping, try to increase the comfort of the person you care for.
- Try to identify circumstances that may increase sleeping difficulties and change or address them.
- When one approach doesn't work, try another one.
- Realise there will be good and bad days.
- Remind yourself that sleeping difficulties are part of the disease.
- Take a deep breath and think about the best ways to respond that will be 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.

Difficulty sleeping may be related to depression.

If the person you care for has difficulty sleeping, you might want to continue with the part on depression and anxiety.

Tip

Useful Resources

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 9.00am to 5.00pm 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.

Dementia Support Australia www.dementia.com.au/
Dementia Support Australia (DSA) is an industry partnership led by HammondCare. Sleep Health 24 Hour Helpline is available on 1800 699 799.

RELATED LEARNING UNITS

- Module 3 Unit 2 Making time for pleasant activities
- Module 4 Unit 4 Personal care
- Module 5 Unit 5 Delusions and hallucinations

You finished this learning unit, well done!

Would you like to try the following relaxation exercise?

Breathing

Focusing on your breathing is relaxing. By doing a breathing exercise you could reduce tension.

Caution: if you experience difficulty breathing, this exercise might not be the best option for you.

This is how you do it:

- When sitting down: Sit up straight in your chair with your back against the back of your chair.
- When standing: Stand up straight.
- Put both of your feet flat on the surface.
- · Focus on your breathing.
- Keep breathing like you are used to. Try to feel how you breathe.
- Put your hand on your stomach to feel how you inhale and exhale.
- Exhale from your mouth and pull in your stomach as much as possible.
- Follow your breathing in this manner a couple of breaths and then stop with the exercise.





You finished this unit, well done!

Unit 5. Delusions and hallucinations

Unreal thoughts and seeing things that aren't there

Why is this unit important?

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

How will this unit help me?

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

What will I learn?

- What hallucinations and delusions are?
- Delusions and hallucinations are not uncommon among people with dementia.
- Different ways to stop or reduce delusions and hallucinations.
- To check the environment to see if there is a cause for the delusion or hallucination and to change this.

What are hallucinations and delusions?

Hallucinations and delusions can be symptoms of dementia. With hallucinations or delusions, people do not experience things as they really are.

Delusions are false beliefs. Even if you give evidence about something to the person with dementia, they will not change the belief.

Hallucinations are incorrect perceptions of objects or events involving the senses. They seem real to the person experiencing them but cannot be verified by anyone else.



Why do people with dementia have unreal thoughts and see things that aren't there?

People with dementia may not understand the world around them because of changes in the brain. These misunderstandings are called delusions (unreal thoughts) and hallucinations (seeing things that aren't 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 with dementia the thinking is very real and causes fear and may result in distressing self-protective behaviours. If the person is experiencing a hallucination, he or she might see or hear things that are not there, for example, people talking in the room when there is no one there.

People with dementia experiencing delusions or hallucinations need a lot of understanding and support from the people taking care of them.

Activity



Has the person you care for ever had any unreal thoughts or seen things that were not there?

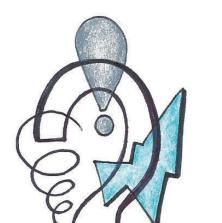
If you want, you can describe it in the box:

Note



Please note that misinterpretations can be common for people with dementia.

Now we will show you some ways to deal with them.





Mistaking someone for someone else

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.

What would you recommend Martin to do?



Check your understanding



Mistaking someone for someone else

What would you recommend Martin to do?

- Soothe her in a calm voice.
- Try to distract her and 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.'



Mistaking someone 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. It is important to respond to the feelings.
- Try to distract her and lead her away from the woman in the park.

This is a good response because it will distract her thinking.

- 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 the delusion is real to Betty and it may make her 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.

Seeing people that are not there

Now let's look at another example.

Mercedes' father, 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 daughter 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: 'Dad's illness is much worse than I thought it was.'



Check your understanding

What would you recommend?

Which of the following responses would you recommend to Mercedes? Select those responses you recommend and drop them in the basket.

- Soothe him, by saying in a calm voice: 'You are safe, I am with you.'
- Soothe him, by taking his hand and staying close.
- Check if there is anything in the environment that could be causing his 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.

?

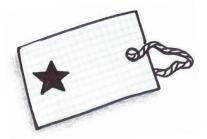
What would you recommend?

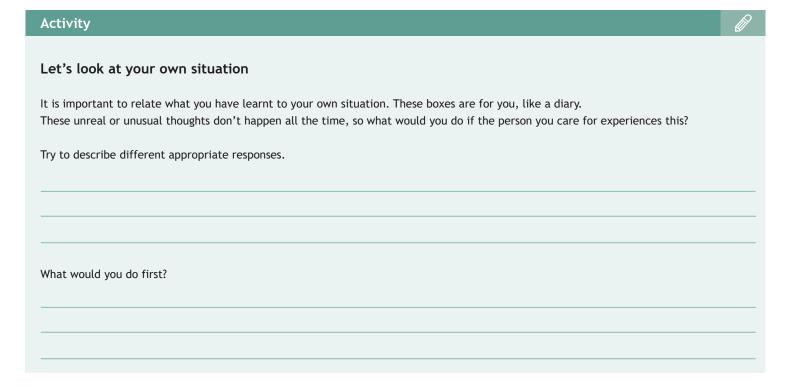
- Soothe him, by saying in a calm voice: 'You are safe, I am with you.'
 - This is a good response, because people with hallucinations are often feeling frightened and insecure.
- Soothe him, by taking his hand and staying close.
 This is a good response because this may be comforting.
- Check if there is anything in the environment that could be causing his hallucination, 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 the 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 with delusions or hallucinations to calm down.

Tip

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





Let's review what you have learned

- Unreal thoughts or seeing things that are not there (delusions and hallucinations) are common in people with dementia.
- They can be very upsetting to the person with dementia and to 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, but by comforting and distracting.
- 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 they are part of the disease.
- Take a deep breath and think about the best ways to respond that will be least distressing for you and the person you care for in case the person has unreal thoughts or visions.

Tip

Check with the doctor about the side effects of medications that the person you care for is using. These may add to the problem.

Useful Resources

- Dementia Australia, https://www.dementia.org.au/
- The National Dementia Helpline 1800 100 500 is open nationally from 9.00am to 5.00pm Monday to Friday excluding public holidays. A message service is available if you call outside operating hours.
- Dementia Support Australia https://www.dementia.com.au/
 The Dementia Behaviour Management Advisory Service
 (DBMAS) offers people with dementia and their carers support in managing behavioural and psychological symptoms of dementia, such as walking and getting lost and
- My Aged Care https://www.myagedcare.gov.au

Carer support groups can sometimes be organised around specific caring roles and the situation of the person you care for. For information about these groups in your area visit the website or call My Aged Care on 1800 200 422.

aggression. Contact them on 1800 699 799 (24 hours a day).

RELATED LEARNING UNITS

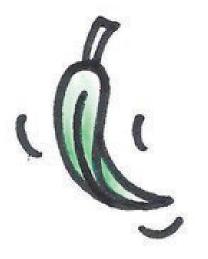
- Module 2 Unit 4 Involving others
- Module 3 Unit 3 Thinking differently
- · Module 1 Unit 4 How to respond to repetitive behaviour

You finished this learning unit, well done!

Would you like to try the following relaxation exercise?

Neck movements

With this exercise you will feel less tension in your neck. It will also increase the blood flow to your brain.



This is how you do it:

- Make sure to move slowly and with attention.
- Bend your neck forward and backward.
- Inhale while you lift your head up and back. Exhale while you drop your chin to your chest.
- Rotate your chin from side to side.
- Inhale when your chin is in the centre. Exhale when you look to the side.
- Drop your ear towards your shoulder.
- Inhale when you are in the centre. Exhale when you drop your ear to your shoulder.
- Repeat 5 times.



You finished this unit, well done!

Unit 6. Walking and getting lost

Why is this unit important?

Concerns about walking and getting lost can cause distress. Walking may lead the person with dementia outdoors, which can expose them to dangers such as traffic or dangerous weather conditions. Walking may occur on foot, by car or public transportation.

How will this unit help me?

This learning unit will help you to understand the reasons for getting lost and what to do to reduce the chances of the person becoming lost.

What will I learn?

- Walking around or wandering away is common in people with dementia.
- Possible reasons why someone with dementia may wander.
- Practical tips to reduce the chances that someone gets lost and to manage wandering habits.

Why is wandering a concern?

People with dementia may have the habit of wandering around the home or leave the house and want to walk around the neighbourhood. They may get lost, so safety is a primary concern when people with dementia are out alone.

It is important to prevent wandering

This learning unit will help you understand the possible reasons people desire to wander and steps you can take to help make it safer.

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

Activity



Does the person you care for sometimes walk around or wander away?

Can you describe what happens?



Possible reasons for wandering

- Wanting to exercise
- Continuing a lifelong habit of walking regularly
- Relieving boredom due to lack of stimulation
- Using up energy from sitting all day
- Relieving pain and discomfort from joint pain or stiffness or in need of the toilet
- Responding to stress, anxiety, delusions or hallucinations
- 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
- Agitation from over-stimulation
- Confusion relating to a new environment.

Let's look at an example

Aron has dementia and is supported by his wife, Sandra. Sandra is cooking dinner when she hears Aron heading for the door. She knows he likes to go for afternoon walks, but now is not a good time since she is cooking.

Check your understanding



What should Sandra do?

Choose from the following options:

- Yell to Aron from the kitchen: 'Please stop! I can't come with you now.'
- Turn the oven off and follow Aron.
- Go to where Aron is standing by the door and calmly say: 'Let's eat dinner first and we'll go for a walk later.'
- Forbid Aron from leaving and pull him back into the house.
- Lock the door so Aron cannot leave.
- Let Aron leave and call a neighbour to keep an eye out for him.
- Ask another family member to go for a walk with him.
- Schedule more afternoon walks before dinner.
- Ask Aron to help with a job in the kitchen.
- Keep a log or record when Aron wants to go for a walk.

?

What should Sandra do?

- Yell to Aron from the kitchen: 'Please stop! I can't come with you now.'
 - This is not a good response because yelling at Aron from the kitchen may confuse and agitate him. It may also not stop him from going out on his own.
- Turn the oven off and follow Aron.
 - This is a good response only if there are no other alternatives.
- Go to where Aron 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 Sandra stays calm, does not yell and respects Aron's wishes by telling him they will go together after dinner.
- Forbid Aron from leaving and pull him back into the house.
 - This is not a good response because Aron may get agitated and resist being pulled which could result in Aron or Sandra being harmed.

- ✓ Lock the door so Aron cannot leave.
 - Consider this response only if no other options exist and someone is in the house with Aron. For fire and other safety reasons, a person with dementia who requires supervision should never be locked inside a house without another person there.
- Let Aron leave and call a neighbour to keep an eye out for him.
 - This may be an option only if Sandra has prearranged with the neighbours to keep an eye out for him. If Aron 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. Sandra can finish cooking dinner and Aron can enjoy a nice walk before dinner.

Check your understanding (Continued)



What should Sandra do?

- Schedule more afternoon walks before dinner.

 This is a good response because planning ahead will prevent Sandra from having to interrupt cooking dinner to assist Aron. Exercise can help the person use up extra energy and may improve the person's sleep patterns.
- Ask Aron to help with a job in the kitchen.

 This is a good response because it involves distracting Aron from going for a walk alone and gives him purpose and activity.
- Keep a log or record when Aron wants to go for a walk.

This is a good response as it can help provide insight into reasons for the person's wandering behaviour. Understanding the person's wandering patterns and triggers can help you put strategies in place.



Things that may help

Here is a list of things that may help to manage a person's wandering habits and prevent the person from getting lost:

- Keep to the routines and activities of the person you care for.
 Identify the most likely times of the day that the person you care for wandering may occur and plan activities such as a walk together at that time.
- Reassure the person you care for if the person feels lost, abandoned or disoriented, or wants to leave to 'go home' or 'go to work'. For example: 'We are staying here tonight. We are safe and I'll be with you. We can walk in the morning after a good night's rest.' Try to refrain from correcting the person with dementia.
- Ensure all basic needs have been met. Has the person gone to the toilet? Is he or she thirsty or hungry?
- Avoid going out to busy places that are confusing and can cause disorientation, such as shopping malls, markets, or other places when they are busy.

- Make sure the person carries some form of identification.
 Consider the use of a medical alert bracelet.
- Make sure your home is secure and 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.
- When the person is found, speak calmly with acceptance and love, try to avoid blaming and showing anger. Reassure the person about where they are.
- Remember that neither you nor the person is to blame.
- It is helpful to keep an up-to-date photograph in case the person gets lost and you must ask for help from others.

Activity



Let's look at your own situation

It is important to relate what you have learnt in this learning unit to your own situation. These boxes are for you, like a diary.

- 1. What are the possible reasons listed in this learning unit that the person you care for may have the desire to walk?
- Wanting to exercise
- Continuing a lifelong habit of walking regularly
- Relieving boredom due to lack of stimulation
- Using up energy from sitting all day
- Relieving pain and discomfort from joint pain or stiffness
- Responding to stress, anxiety, delusions or hallucinations
- 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.

2. These boxes are for you like a diary:

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

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

Take a moment to summarise what you have learnt in this learning unit that will help you.

Let's review what you have learned

- Walking around or wandering 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 may be a safety risk.
- Concerns about wandering and getting lost can be very upsetting for the person with dementia and the carer.
- It is important to identify possible reasons for wandering.
- How you respond to the wandering should be based on the possible reasons.
- If one approach doesn't work, try another one.
- Realise there will be good and bad days.
- Remember that neither you nor the person is to blame.
- 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.

Additional Resources

- Dementia Australia, https://www.dementia.org.au/
 The National Dementia Helpline 1800 100 500 is open nationally from 9.00am to 5.00pm Monday to Friday excluding public holidays. A message service is available if you call outside operating hours.
- Dementia Support Australia https://www.dementia.com.au/
 The Dementia Behaviour Management Advisory Service
 (DBMAS) offers people with dementia and their carers
 support in managing behavioural and psychological
 symptoms of dementia, such as wandering and aggression.
 Contact them on 1800 699 799 (24 hours a day).
- My Aged Care https://www.myagedcare.gov.au

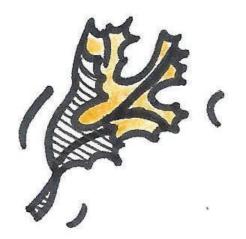
Carer support groups can sometimes be organised around specific caring roles and the situation of the person you care for. For information about these groups in your area visit the website or call My Aged Care on 1800 200 422.

RELATED LEARNING UNITS

- Module 2 Unit 2 Improving communication
- Module 4 Unit 3 Toileting and continence care
- Module 5 Unit 7 Changes in judgment

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!

Unit 7. Changes in judgement

Why is this unit important?

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

How will this unit help me?

This learning unit will help you understand the reasons for changes in judgement and teach you skills to manage.

What will I learn?

- Changes in judgement increases as dementia progresses
- How to reduce or prevent changes in judgement
- How to plan for increasing levels of changes in judgement in the future.



What is 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 with dementia and/or the carer. People with dementia are often looking for guidance or reassurance.

Activity



Did you ever notice that the person you care for sometimes has changes in judgement?
What did the person you care for do?

Describe it here:

How did it affect you as the person providing care?

Note



Please note that changes in judgement can increase as dementia progresses. In this learning unit, you can practice several ways to respond to changes in judgement and find out what may help.

Saying the wrong thing in public Let's go through an example.

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

Ivan feels embarrassed.

A: What comes before the changed behaviour? Ivan hails a taxi.



B: Changed behaviour Isabel starts to scold the taxi driver.



C: Consequences Ivan feels embarrassed.

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

Click on any responses you think might be appropriate.

- Put his hand on Isabel's mouth in order to stop her yelling at the driver.
- Walk Isabel back to her home and leave because what happened is embarrassing.
- Stay calm and reassure Isabel everything is alright.
- Accept the behaviour. If the taxi driver doesn't seem to notice, let it be. Find ways to adapt.
- Ivan could simply apologise to the taxi driver without making too much fuss.





What would you recommend?

- Put his hand on Isabel's mouth in order to stop her yelling at the driver.
 - This response is not good because it may make the situation worse and cause Isabel further agitation.
- Walk Isabel back to her home and leave because what happened is embarrassing,
 - This response is not good because Isabel may feel bad and isolated.
- Stay calm and reassure Isabel everything is alright.
 This is a good response because it shows Ivan cares about and respects Isabel. It may stop her from yelling at 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.
 If the behaviour is not harming anyone, ignoring it can be an appropriate response.
- Ivan could simply apologise to the taxi driver without making too much fuss.This is a good response because it respects all the

people involved and keeps the situation in proportion.

What happens if changes in judgement is more serious?

The last example was a brief and one-time experience for Ivan. What happens if changes in judgement by someone living with dementia is more serious? Here are two examples about finances and driving.

Example: 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.

What should Julia do?



Person-centred care

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



What would you recommend to Julia?

Click on all responses you think are appropriate.

- 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.

Check your understanding



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.

Check your understanding

her finances.



- 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 she is comfortable with to help manage
- × 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 in 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

Hugo is living with dementia. His neighbour, Pablo, notices that his car is parked very strangely one day, obstructing some of the other cars in the street. Pablo walks out of his home, sees Hugo and attempts to start a conversation. Instead of stopping, Hugo jumps in his car, speeds off and takes an illegal right turn at the end of the street. Hugo returns home very soon and nothing bad seems to have happened.

What should Pablo do?

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

What responses would you recommend to Pablo? Click on all responses you think are appropriate.

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



What responses would you recommend to Pablo?

- Immediately seize Hugo's car keys when he returns because this will prevent it from happening again. This is not a good response because Pablo cannot decide for his neighbour if he should not drive anymore and Hugo may become angry.
- Stay calm and ask whether Hugo has any other places to go that day, and if so, offer him a ride.
 This is a good response because it prevents Hugo from driving unsafely and provides safe transportation so Hugo can attend to his errands.
- Ignore the situation because it is embarrassing.
 This response is not good because Hugo's driving may cause harm to himself and others.
- Ask Hugo if he would like some help figuring out transportation.

This response is appropriate because Hugo may safely ride a bus or walk, preventing any unsafe behaviour.

Tell Hugo that he is concerned about his driving and suggest to visit his family doctor (or GP) to discuss it. This response is appropriate because Hugo may safely ride a bus or walk, preventing any unsafe behaviour.

It is better if the decision not to drive comes from the person with dementia. Giving up driving is typically a difficult time in the person's life where they are losing independence and their ability to go where they want to go. Alternatives, such as offering regular rides, teaching the person to use public transport or arranging taxis, will help the person to stay active and involved in their community activities. It is important that the person not becomes isolated or lonely once he or she gives up driving. More effort will be needed to keep this person connected to the world outside their home.

People in Australia with permanent disabilities that limit their ability to drive or use public transport may apply for subsidised taxi fares or use community bus schemes.

Further information can be gained from:

My Aged Care https://www.myagedcare.gov.au or local councils

Inappropriate sexual advances

Matt is in his late 70s, has dementia and lives with his family. Two days a week, an in-home carer, Camila who is 22 years old, comes to help him take a bath and administer his medications. This arrangement has been working well for several months. One day, while preparing for his bath, Matt makes some sexual remarks and tries to pull Camila close to him. Camila is shocked and surprised. She runs out of the room and tells the family she can no longer work there.

What should Camila and Matt's family do?

A: What comes before the changed behaviour? Camila comes to help Matt with bathing



B: Changed behaviour
Matt shows inappropriate
sexual advances pulling
Camila



C: Consequences

Camila is shocked and runs out.



Check your understanding

?

What responses would you recommend to Matt's family? Click on all responses you think are appropriate.

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





What responses would you recommend to Matt's family?

- Stay calm and tell Matt that this behaviour is unacceptable. Explain who Camila is.
 This option is a good one. Matt's family does not overreact because they remember it is the disease taking effect. They redefine the appropriate boundaries for Camila's safety.
- Change the bathing situation. Perhaps Camila can set up a sponge bath and Matt can do more himself.
 This is a good option. Let Matt do more himself will distract him. In this way, both Camila and Matt's dignity are maintained.
- Change the environment. Put a towel or robe over Matt's shoulders while he is being bathed to keep him covered for privacy.

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

- Shout at Matt, shaming him for his conduct.
 - This is an inappropriate response, because Matt may not recognise that these advances may be a part of his dementia. Therefore, try not to overreact.
- x Ignore the situation.

This response is not good, because Matt may continue to make inappropriate sexual advances and cause distress to Camila or others.



If the inappropriate advances continue, talk with the person's doctor, they may be able to work out what's causing the behaviour and how to treat it. The family might want to consider employing a male in-home carer for bathing which could prevent this behaviour.

Activity



Let's look at your own situation

It is important to relate what you have learnt to your own situation.

After going through these examples, think again about your own situation. These boxes are for you, like a diary:

Does the person with dementia sometimes show changes in judgement?

Take a moment to summarise what you have learnt in this learning unit to deal with changes in judgement and in what ways you could respond.













Let's review what you have learned

- Changes in can increase as dementia progresses.
- Changes in judgement can be very upsetting for the person with dementia and the carer.
- It is important to reduce or prevent changes in judgement, whenever possible.
- Realise there may be good days 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 for you and the person you care for.
- Plan for increasing levels of changes in judgement in the future.

RELATED LEARNING UNITS

- Module 3 Unit 3 Thinking differently
- Module 4 Unit 2 Eating, drinking and preventing health problems

Additional Resources

- Dementia Australia, https://www.dementia.org.au/
 - The National Dementia Helpline 1800 100 500 is open nationally from 9.00am to 5.00pm Monday to Friday excluding public holidays. A message service is available if you call outside operating hours.
- Dementia Support Australia https://www.dementia.com.au/

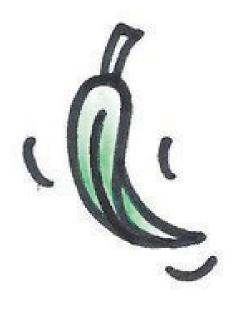
The Dementia Behaviour Management Advisory Service (DBMAS) offers people with dementia and their carers support in managing behavioural and psychological symptoms of dementia, such as walking and getting lost and aggression. Contact them on 1800 699 799 (24 hours a day).

You finished this learning unit, well done!

Would you like to try the following relaxation exercise?

Neck movements

With this exercise you will feel less tension in your neck. It will also increase the blood flow to your brain.



This is how you do it:

- Make sure to move slowly and with attention.
- Bend your neck forward and backward.
- Inhale while you lift your head up and back. Exhale while you drop your chin to your chest.
- Rotate your chin from side to side.
- Inhale when your chin is in the centre. Exhale when you look to the side.
- Drop your ear towards your shoulder.
- Inhale when you are in the centre. Exhale when you drop your ear to your shoulder.
- Repeat 5 times.



You finished this unit, well done!