

Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



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for carers of people with dementia

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

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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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References

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

4

PROVIDING EVERYDAY CARE

- Unit 1.** Eating and drinking - more pleasant mealtimes
- Unit 2.** Eating, drinking and preventing health problems
- Unit 3.** Toileting and continence care
- Unit 4.** Personal care
- Unit 5.** An enjoyable day

Unit 1. Eating and drinking - more pleasant mealtimes

Creating pleasant mealtimes

Why is this unit important?

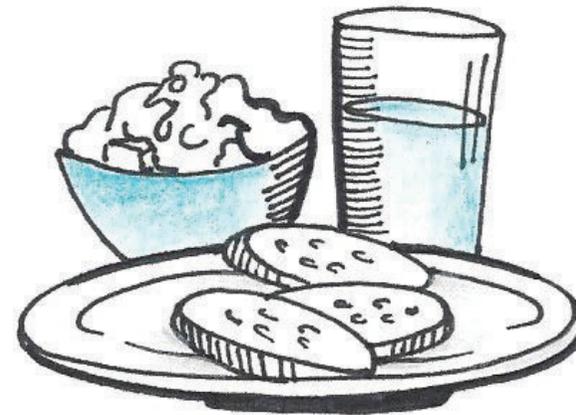
Dementia can affect the ability to eat and drink in various ways. This may be dependent on the stage of dementia and/or other health conditions.

How will this unit help me?

By learning how to help create pleasant mealtimes and to support good hydration and nutrition.

What will I learn?

- How to encourage the person to eat and drink
- How to create a pleasant mealtime for the person
- How to facilitate eating and drinking for the person
- Some health conditions that affect eating and drinking
- How to prevent poor nutrition and dehydration.



Making mealtimes pleasant

Engaging people with dementia in simple tasks around mealtime helps to make the most of people's skills, promotes a feeling of self-worth and provides meaning to mealtimes.

Let's look at an example.

Margaret is a housewife and has cooked every day for her family for many years. Recently, she lost her husband and now lives with one of her sons. Susan, her daughter-in-law, provides all the cooking in the new household. Margaret has been very sad in her new home and says she's not hungry when she is offered food. She does not join the family for dinner.



Check your understanding



Making mealtimes more pleasant.

How would you advise Margaret's family to deal with this situation?

Pick all the responses you think are appropriate.

- Bring Margaret's dinner to her room.
- Demand that Margaret joins the family for dinner.
- Margaret's family should let her help with the preparation of meals and cleaning activities.

ANSWERS - Unit 1. Eating and drinking - more pleasant mealtimes

Check your understanding

*Making mealtimes more pleasant.*

- ✗ **Bring Margaret's dinner to her room.**
This is not helpful because it might further isolate Margaret from her family. Margaret may not feel welcome in the new home. She has lost her husband, her own home and now her role as cook and housekeeper.
- ✗ **Demand that Margaret joins the family for dinner.**
This is not such a good response because it may make Margaret angry or withdraw further.
- ✓ **Margaret's family should let her help with the preparation of meals and cleaning activities.**
This is a good response because her family knows Margaret still enjoys cooking and should therefore support her to continue engaging in the thing she likes and is still able to do.



Examples of mealtime activities

Try to think about the person's involvement in mealtimes.

Please click on any activities that you think the person still can engage in and would enjoy.

Activity 	
Mealtime activities	Example
Shopping together	<input type="checkbox"/> Let the person with dementia choose what food and drink he/she likes for breakfast, lunch and dinner.
Meal preparation	<input type="checkbox"/> Let the person with dementia help chopping, stirring or cooking.
Preparation of the table	<input type="checkbox"/> Let the person with dementia lay the table for breakfast, lunch and dinner. Don't use complicated table settings and avoid lots of different cutlery, crockery and glasses together.
Eating together	<input type="checkbox"/> It can help to eat together so that the person with dementia can copy you. Make sure that the food is accessible. Put it on a flat plate with no pattern so that the food can be seen clearly. Make sure the plate is in comfortable reaching distance.
Cleaning the table	<input type="checkbox"/> Let the person with dementia remove everything from the dining table and wipe the table.
Washing or drying dishes	<input type="checkbox"/> Let the person with dementia put dishes in the sink or wash and dry the dishes.

If you think that the person you care for can still engage in and would enjoy any of the listed activities, perhaps you could ask or assist them in trying these activities the next time you have a meal.

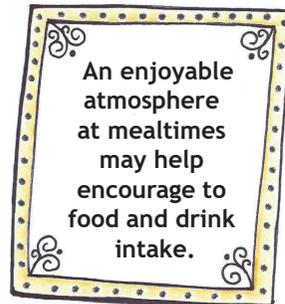
Promoting a pleasant mealtime atmosphere

Mealtimes are a good opportunity for carers to show their care and support for the person living with dementia. An enjoyable atmosphere at mealtimes may help encourage them to eat and drink.

Spilling food

Ray has Alzheimer's disease and lives with his oldest son since his wife passed away a year ago. The family now has three generations living in the home and they eat together at the table. Ray has always enjoyed mealtimes and looks forward to sharing with his family. Recently, Ray's hands have started to tremble, and he often spills drinks or drops food on the table and the floor.

How would you advise Ray's son to deal with this situation?



Check your understanding



How would you advise Ray's son to deal with this situation?

- Buy special eating and drinking aids for Ray, you may need to find an independent living centre to see the best range.
- Set up a separate table for his father to eat in his own bedroom, because spilling and dropping food may make the family irritated.
- Tell Ray to be more careful as he is making a mess.
- Organise a family meeting to ask all family members to think of some positive and constructive ways to respond to the situation at mealtimes.



ANSWERS - Unit 1. Eating and drinking - more pleasant mealtimes

Check your understanding

*How would you advise Ray's son to deal with this situation?*

- ✓ **Buy special eating and drinking aids for Ray, you may need to find an independent living centre to see the best range.**
This is a good response because Ray's son recognises that his father is having difficulty using everyday eating and drinking utensils. By providing other utensils he is trying to solve this problem and respect Ray's need for independence.
- ✗ **Set up a separate table for his father to eat in his own bedroom, because spilling and dropping food may make the family irritated.**
This is not helpful because separation will make Ray feel sad or angry, which might prevent him from eating and drinking properly.
- ✗ **Tell Ray to be more careful as he is making a mess.**
This is not helpful, because Ray cannot help his unsteadiness and telling him "to be more careful" may make Ray feel sad or lose confidence and independence, which might prevent him from eating and drinking properly.
- ✓ **Organise a family meeting to ask all family members to think of some positive and constructive ways to respond to the situation at mealtimes.**
This is a good response because Ray's son is trying to provide a positive mealtime atmosphere for everyone.



Here are some examples of how carers can contribute to a caring, respectful and pleasant atmosphere at mealtimes for people with dementia.

- Help the person to sit down and also to leave the table.
- Make the food and drinks look and smell appealing. Include food and drinks he is familiar with and likes.
- Explain what the food and drinks are.
- Limit the number of items on the plate.
- Enhance lighting and reduce unnecessary noise that might be distracting.
- Use specially designed eating and drinking aids such as different coloured plates with no-spill cups and utensils with easy-grip handles.
- Cut food into bite-size pieces or make finger foods that can be easily gripped.
- Provide a straw to drink liquids, make sure liquids are not too hot or too cold.
- Encourage to eat and drink enough for good nutrition.
- Do not rush mealtime.

Health conditions that affect eating and drinking

Many health conditions can affect eating and drinking. Identifying and treating these conditions will help the person with dementia maintain a healthy diet and enjoy mealtimes.

Artificial dentures

Jack has Alzheimer's disease and is often unable to communicate with family members, but he can still manage to eat without assistance from others. Recently, his wife, Rosie, has noticed that Jack throws his artificial dentures on the floor, is not eating or drinking and is restless.

How would you advise Rosie to deal with this situation?

Check your understanding



How would you advise Rosie to deal with this situation?

Pick all the responses you think are appropriate.

- Tell Jack that throwing his artificial dentures on the floor is not good, and ask him to wear them so that he can eat.
- Take Jack to his general practitioner or dentist.

Check your understanding



- ✗ **Tell Jack that throwing his artificial dentures on the floor is not good, and ask him to wear them so that he can eat.**

This answer is not good. The reason that Jack throws his artificial dentures away may be because they do not fit anymore and are uncomfortable, or because of another issue. Rosie needs to find out what the problem is by asking Jack or taking him to the general practitioner or dentist.

- ✓ **Take Jack to his general practitioner or dentist.**

This is a good response, as Rosie is identifying the reason why Jack is barely eating and drinking. The general practitioner or dentist may identify loose dentures, ulcers or infections in Jack's mouth, which may be caused by the dentures.



Health conditions

These are some examples of common health conditions that can affect eating and drinking and what can be done to improve these conditions.

Does the person ever experience any of the following?

Please click on any health condition the person has or conditions you want to learn more about.

Activity 		
Health conditions	Changes you may observe	Recommended actions you may need to take
Poor appetite	<ul style="list-style-type: none"> <input type="checkbox"/> Does not want to eat the meal <input type="checkbox"/> Eats only small amounts of food <input type="checkbox"/> Takes a long time to eat a small amount of food 	<ul style="list-style-type: none"> ● Make food familiar, appealing: use different textures, flavours, smells, tastes and colours that the person enjoys ● Eat with the family, rather than alone ● Make the mealtime a pleasant time ● Play soft music they like during mealtime ● Increase physical activities during daytime to promote appetite ● Serve only one plate of food at a time
Toothache	<ul style="list-style-type: none"> <input type="checkbox"/> Refuses to eat and drink <input type="checkbox"/> Is restless <input type="checkbox"/> Has a facial expression or holds side of face indicating pain 	<ul style="list-style-type: none"> ● Ask whether they have pain ● Ask to point out the area of pain ● Check whether there are loose teeth, mouth ulcers, etc. ● Seek help from a doctor or dentist

Activity 		
Health condition	Changes you may observe	Recommended actions you may need to take
Poorly fitting artificial dentures	<ul style="list-style-type: none"> <input type="checkbox"/> Refuses to eat and drink <input type="checkbox"/> Is restless <input type="checkbox"/> Has a facial expression indicating pain <input type="checkbox"/> Refuses to wear dentures <input type="checkbox"/> Removes dentures 	<ul style="list-style-type: none"> ● Check dentures are inserted correctly ● Ask whether he/she is in pain ● Ask to point out the area of pain ● Check whether there are reddened areas , mouth ulcers etc. ● Seek help from a doctor or dentist
Body pain	<ul style="list-style-type: none"> <input type="checkbox"/> Refuses to eat and drink <input type="checkbox"/> Is restless <input type="checkbox"/> Unusual body postures <input type="checkbox"/> Facial expressions of pain (grimacing) <input type="checkbox"/> Guarding a particular body part or reluctance to move <input type="checkbox"/> Moaning with movement <input type="checkbox"/> Limited range of motion or slow movement <input type="checkbox"/> Crying or distress <input type="checkbox"/> Increased or decreased vocalisations <input type="checkbox"/> Withdrawn social behaviour 	<ul style="list-style-type: none"> ● Ask whether he/she is in pain ● Ask to point out the area of pain ● Seek help from doctor

Activity 		
Health conditions	Changes you may observe	Recommended actions you may need to take
Slow or no bowel movement for more than three days	<ul style="list-style-type: none"> <input type="checkbox"/> Hard and dry stools <input type="checkbox"/> Difficulty passing stools/straining <input type="checkbox"/> Having a feeling of incomplete bowel movements <input type="checkbox"/> Becomes anxious/agitated <input type="checkbox"/> Develops diarrhoea <input type="checkbox"/> Hard stomach <input type="checkbox"/> Nausea and vomiting 	<ul style="list-style-type: none"> ● Seek help from GP/medical assistance <p>On the resolution of the problem:</p> <ul style="list-style-type: none"> ● Increase fibre in diet ● Increase drinking of fluids ● Increase physical activity
Diarrhoea	<ul style="list-style-type: none"> <input type="checkbox"/> Liquid faeces <input type="checkbox"/> Increased number of bowel motions <input type="checkbox"/> Difficult to control bowel and incontinent of faeces 	<ul style="list-style-type: none"> ● Seek urgent help from GP/medical assistance
Side effects from medications	<ul style="list-style-type: none"> <input type="checkbox"/> Nausea, vomiting, liquid faeces or has difficulty in passing faeces <input type="checkbox"/> Does not want to have a meal <input type="checkbox"/> Eats only small amounts of food 	<ul style="list-style-type: none"> ● Check you are giving medications as instructions indicate ● Seek help from GP/medical assistance

2. Activity 		
Health condition	Changes that you may have observed	Recommended actions you may try
Memory loss; forgets to eat or drink	<ul style="list-style-type: none"> <input type="checkbox"/> Asks when the next meal is even if it already happened <input type="checkbox"/> Says he or she is hungry even if they already ate 	<ul style="list-style-type: none"> ● Remind the person to eat and drink regularly ● Model eating and drinking by eating and drinking with the person ● Have low calorie snacks available, such as apples and carrots
Sadness/Depression	<ul style="list-style-type: none"> <input type="checkbox"/> Refuses to eat or says he or she is not hungry <input type="checkbox"/> Eats only small amounts of food <input type="checkbox"/> Has no interest in food 	<ul style="list-style-type: none"> ● Seek help from GP/medical assistance
Weight loss	<ul style="list-style-type: none"> <input type="checkbox"/> Forgets to eat <input type="checkbox"/> Eats smaller amounts of food <input type="checkbox"/> Eats regular amounts of food but still loses weight 	<ul style="list-style-type: none"> ● Increase the amount of food ● Provide foods that he or she will like ● Increase foods with greater flavour as the taste might be impaired ● Offer nutritious drinks like milkshakes ● Ask General Practitioner for recommendations for supplements
Weight gain	<ul style="list-style-type: none"> <input type="checkbox"/> Eats everything served <input type="checkbox"/> Eats more snacks than before because he or she forgets if eaten <input type="checkbox"/> Is obsessed with food 	<ul style="list-style-type: none"> ● Model eating and drinking by eating and drinking with the person ● Serve smaller portions ● Remove plate when someone indicates it has been enough ● Provide low calorie snacks

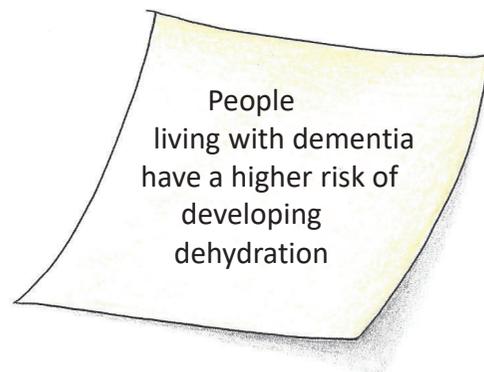
Preventing dehydration

People living with dementia can have a high risk of developing dehydration.

There can be several reasons for this:

- Inability to explain their needs
- Decreased thirst sensation
- Not offered enough to drink
- Swallowing problems in the late stage of dementia.

The person needs to be encouraged to drink 8-10 glasses (1500-2000 ML) of fluid (water, iced lollies, soup and juice, not including tea or coffee) every day.



Severe dehydration

Ben has Alzheimer's disease, but he is able to eat and drink without assistance from his wife, Mary. Ben likes to walk a lot. One hot afternoon, Mary notices that Ben seems very tired, walks very slowly and then collapses on the floor. Ben is sent to the Emergency Department of the local hospital and is diagnosed with dehydration. After treatment in the hospital, Ben has recovered and is able to go home again.

How would you advise Mary to deal with this situation after Ben is discharged home?

Check your understanding



How would you advise Mary to deal with this situation after Ben is discharged home?

Pick the suggestion you think is appropriate.

- Mary needs to let Ben make the decision about when to drink.
- Mary needs to ensure Ben drinks 8-10 glasses of water during the daytime.
- Mary records the time and the amount of fluid Ben actually consumes.

Check your understanding



How would you advise Mary to deal with this situation after Ben is discharged home?

- ✗ **Mary needs to let Ben make the decision about when to drink.**

This answer is not good even though she is respecting Ben's autonomy. Since people with dementia have decreased thirst sensations, it could be dangerous to leave them to decide to drink or not without reminding them. If not, the incident of dehydration and collapsing may happen again.

- ✓ **Mary needs to ensure Ben drinks 8-10 glasses of water during the daytime.**

This is a good response. Mary notices that Ben may forget to drink, so she is trying to help her husband drink enough water everyday.

- ✓ **Mary records the time and the amount of fluid Ben actually consumes.**

This is a good response. It can be helpful to establish a routine and record the number of glasses Ben drinks from breakfast time to dinner time. Drinking after dinner time may potentially increase night time visits to the toilet.



Activity



Timetable for eating and drinking

The timetable below is for you to remind the person to eat and drink. Give them the opportunity to choose what to drink.

Time of day	Type of fluid: water (Example)	The amount of fluid: 3 glasses (Example)
Morning - Noon		
Afternoon till 5 pm		
Dinnertime - Bedtime		

WARNING!



If the person is on restricted fluids due to a cardiac condition, you need to follow the doctor's order regarding how much to drink.

Let's review what you have learned

- The person needs to be encouraged and supported to eat and drink.
- You can engage the person in a variety of mealtime activities to create a pleasant mealtime for the person that helps to improve self-worth and a feeling of achievement.
- Eating and drinking can be better facilitated by modifying food, utensils and the environment.
- You can maintain good eating and drinking for the person by improving the person health condition. Seeking assistance from health professionals might be necessary.
- To help prevent dehydration, it is important to prompt the person to drink and to record and monitor the amount of fluid the person has actually taken.

RELATED LEARNING UNITS

- Module 3 Unit 2 Making time for pleasant activities
- Module 4 Unit 2 Eating, drinking and preventing health problems
- Module 5 Unit 5 Delusions and hallucinations

A dietician or doctor can advise you about good nutrition. Your local hospital, community health service or your doctor can put you in touch with a dietician.

For more information contact:

National Dementia Helpline on 1800 100 500.

<https://www.dementia.org.au/support-and-services/families-and-friends/personal-care/eating>

Other Resources:

<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/dementia-eating>

Further Assistance



You finished this unit, well done!

Unit 2. Eating, drinking and preventing health problems

Why is this unit important?

Dementia can affect eating and drinking in various ways depending on the individual, the stage of dementia and other health conditions which in turn can lead to poor nutrition. Poor nutrition can lead to other health problems.

How will this unit help me?

By learning how to encourage good nutrition, prevent weight loss, promote drinking and eating safely can prevent health problems caused by poor nutrition.

What will I learn?

- How to modify food, drinks and eating patterns for the person to improve nutrition and prevent weight loss.
- How to help the person to eat safely and prevent choking.

Improving nutrition and preventing weight loss

In the late stages of dementia, a person with dementia may experience chewing and swallowing problems. In addition, reduced abilities to smell, taste and see can all cause the person with dementia to have problems eating and drinking and can have a negative impact on health. Depression and changes of sleep patterns may also impair appetite.

Dot is not awake during normal mealtimes

Dot has been living with dementia for 9 years and is cared for by her daughter, Anne. Recently, Anne notices that her mother sleeps during the day and is very difficult to wake and assist with her meals during the normal mealtimes. Anne believes that her mother is not hungry and does not want to disturb her sleeping. A recent check-up showed that Dot had lost 2.5 kg since the last check-up 5 weeks ago (5% of her body weight).



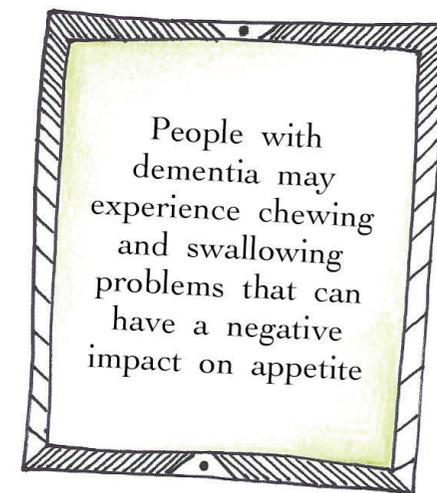
Check your understanding *Your advice for Anne***What would you advise Anne to do to improve Dot's eating?**

Pick all the answers you think are appropriate.

- Be flexible to have meals when her mother is awake.
- In a diary, keep a record of what and how often her mother eats.
- Ensure Dot has access to foods she enjoys eating.
- Have nutritious finger foods and drinks available for Dot to snack on when she is awake.
- Discuss with your doctor the need for food supplements between meals to add calories.

Check your understanding 

All answers are right.



If the person is unable to chew normal food due to the loss of teeth, chop vegetables into small pieces, use minced meat to make dishes for them or provide soft food such as noodles, pasta, mashed potatoes, rice cakes etc. Use nutritious drinks such as milkshakes.

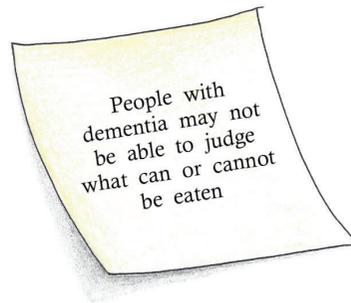
Staying hydrated is very important. Encourage fluids by offering small cups of water or other liquids throughout the day or foods with high water content, such as fruit, soups, milkshakes and smoothies.

Tips

Ensuring safe eating and drinking

People with dementia may experience the following problems:

- 1) People with dementia may not be able to judge what can or cannot be eaten. People may eat inedible materials in front of them when they feel hungry. You need to keep inedible materials and chemicals in safe places.
- 2) If the person is in the late stages of dementia, they may experience swallowing difficulties that can cause choking and may lead to aspiration pneumonia. Aspiration pneumonia is caused when food or liquid is breathed in and goes down the windpipe rather than the food pipe. Although generally rare, aspiration pneumonia is, unfortunately, more common in people with dementia. Eating, drinking and feeding methods may need to be modified to prevent this life-threatening problem. The pages that follow will provide examples of each type of problem.



Inedible materials

Oliver has been living with dementia for 10 years and is cared for by his wife, Ella. Recently, Ella notices that the soaps she put in the kitchen and bathroom have disappeared. She also notices that her husband is eating the flowers she puts on the dining table. She has seen Oliver go to the kitchen and mistakenly pick up a soy sauce bottle and a bottle of dishwashing detergent to drink.

Check your understanding



Inedible materials

What do you think Ella should do?

- Recognise that she needs to lock household chemicals, such as dishwashing detergent, in a cabinet.
- Remove all non-edible items from the dinner table.
- Leave some inedible household materials in the places Oliver is able to reach, because she thinks Oliver should be taught that those cannot be eaten.

Check your understanding

*Inedible materials*

- ✓ **Recognise that she needs to lock household chemicals, such as dishwashing detergent, in a cabinet.**
This is a good response. People with dementia may get confused about what to eat. Remembering that this is not their choice and making some simple changes to the eating environment can help. Keeping dangerous things away will help protect the person with dementia.
- ✓ **Remove all non-edible items from the dinner table.**
Correct! This is a good response. This focuses attention on the food provided, rather than other non-food items. Having too many things on the table can be confusing for the person with dementia and takes the focus off of food. Try to get the person with dementia to focus attention on the food provided, rather than other non-food items.
- ✗ **Leave some inedible household materials in the places Oliver is able to reach, because she thinks Oliver should be taught that those cannot be eaten.**
This could be dangerous for the person with dementia. Remembering that this is not their choice and making some simple changes to the environment can help. Keeping dangerous things away will help protect the person with dementia.

Helping a person to eat safely

Di has been living with dementia for 10 years and is bedridden. Her husband, Joe, and his two adult daughters help her to eat safely. Recently, they found Di has difficulty swallowing the soft food that they have made for her. They also notice that Di coughs when she drinks something. She seems to have a high temperature and after the family seek medical help Di is admitted to the hospital.

Di is diagnosed with aspiration pneumonia and after treatment in the hospital, Di has recovered enough to go home. The doctor orders a healthy, soft diet and thickened drinks for Di to consume at home to prevent future aspiration pneumonia.

Check your understanding

*Helping a person to eat safely***How can Joe and his two daughters help Di?**

- Learn how to make healthy, soft food and thickened drinks for Di.
- Let Di eat and drink while she is lying in bed.

Check your understanding

*Helping a person to eat safely*

- ✓ **Learn how to make healthy, soft food and thickened drinks for Di.**
Providing a healthy diet of soft food and thickened drinks will make it easier for people in the late stage of dementia to continue to eat and drink and maintain a healthy weight.
- ✗ **Let Di eat and drink while she is lying in bed.**
They should sit Di in an upright position which will help her eat and drink better and prevent food from going down her windpipe which could lead to aspiration pneumonia.

A healthy soft diet can be made by finely chopping and mashing food or using an electric blender. Thickened fluids can be made by adding a paste of cornflour and water to liquid while heating and stirring until it thickens. Note: Commercial stir-in thickeners are available in many supermarkets in Australia.

If you need assistance with the level of fluid and food texture modification required, contact a Speech Pathologist available through your local doctor or hospital.

Tips

Let's review what you have learned

- You can modify eating patterns for the person to improve nutrition.
- You can modify food to improve eating for the person.
- You can help the person to eat and drink safely by keeping inedible materials and household chemicals in a safe place.
- You can help to prevent choking and aspiration pneumonia by modifying food and drinks and by positioning the person in an upright position when helping the person to eat.



Additional Information

Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services. Free call 1800 422 737 Monday to Friday, 8am to 6pm.

National Dementia Helpline www.dementia.org.au/search/node/eating

You can call the National Dementia Helpline on 1800 100 500 for information. They can also tell you about National Dementia Awareness Month held in September each year or about conferences and seminars on the subject of dementia. The National Dementia Helpline can also put you in touch with support groups around the country for carers of people with dementia. The groups let you share experiences, learn from others and discuss issues and emotions in a safe environment.

Carer support groups can offer you a safe place to talk about your role as a carer. They can put you in touch with other carers who may be experiencing similar things to you so you can share advice and suggestions to support each other.

My Aged care website - www.myagedcare.gov.au/caring-someone-particular-need/caring-someone-dementia

Phone 1800 200 422 Mon - Fri 8am - 8pm Sat 10am - 2 pm.

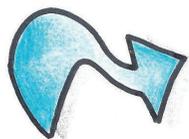


RELATED LEARNING UNITS

- Module 1 Unit 4 How to respond to repetitive behaviour
- Module 4 Unit 1 Eating and drinking - more pleasant mealtimes

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 3. Toileting and continence care

Why is this unit important?

Poor toileting and incontinence may lead to infections and other health problems, low self-esteem and withdrawal from social activities for a person with dementia.

How will this unit help me?

This Unit will help you think about the health concerns and assist the person you care for with toileting and continence.

What will I learn?

- What incontinence means
- Possible solutions for problems like urinating on the floor or losing control of the bladder
- How to use incontinence aids and equipment
- How to prevent urinary tract infections
- How to support regular toileting.

What is incontinence?

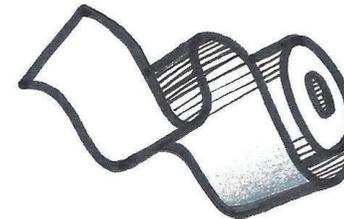
Incontinence is a term that describes any accidental or involuntary loss of urine from the bladder (urinary incontinence) or bowel motion, faeces or wind from the bowel (faecal or bowel incontinence).

In the early stages of dementia, most people can remain continent, particularly if they are in a familiar environment. Studies have shown that one of the most important factors to help people with dementia to maintain bladder and bowel control is to ensure the toilet is visible and accessible.

However, as a person's dementia progresses, they usually need increasing levels of assistance.

They may need assistance to locate the toilet.

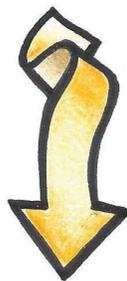
They might also need increasing levels of help to recall the tasks associated with using the toilet, such as adjusting their clothing, lifting the toilet seat (for men), sitting on the toilet, using toilet paper, readjusting their clothing, flushing the toilet and washing their hands.



Some common Issues: Urinating on the floor

Dementia affects the person's ability to find their way to go to the toilet and to identify the toilet and/or the toilet seat. They may not be able to recognise the need to pass urine or get their clothes off to use the toilet.

You should not blame the person for this behaviour or punish them as this type of response will cause stress to them and yourself. Modifications in your house may help to enable the person to use the toilet.



Joe urinates on the floor

Mary is taking care of her husband, Joe, since he developed vascular dementia several years ago.

Joe is able to go to toilet himself without assistance, but recently, Mary finds Joe urinates on the floor outside the toilet.

Check your understanding



Joe urinates on the floor

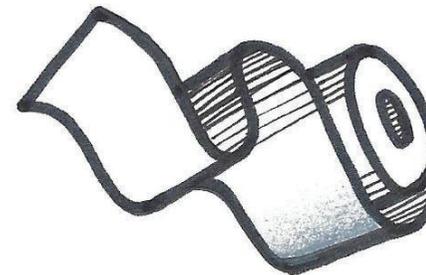
What would you think is the right response for Mary?

- Make some simple changes to the environment and clothing, such as putting an image of a toilet on the toilet door, using a contrasting colour for the toilet seat and keeping the toilet free of clutter. Changing Joe's trousers to a pair of pants that don't need a belt or buttoning.
- Tell her husband he is making trouble and punish him by not taking him for his daily walk in their neighbourhood.
- Remind Joe to use the toilet at regular intervals - at the times when he usually needs to go, or before he is likely to be wet.

Check your understanding

*Joe urinates on the floor*

- ✓ **Make some simple changes to the environment and clothing, such as putting an image of a toilet on the toilet door, using a contrasting colour for the toilet seat and keeping the toilet free of clutter. Changing Joe's trousers to a pair of pants that don't need a belt or buttoning.**
People with dementia may have difficulties finding and using the toilet, so these changes could help Joe.
- ✗ **Tell her husband he is making trouble and punish him by not taking him for his daily walk in their neighbourhood.**
You should never threaten people with dementia in this way. Joe will feel ashamed and embarrassed, and this response could cause him to become upset.
- ✓ **Remind Joe to use the toilet at regular intervals - at the times when he usually needs to go, or before he is likely to be wet.**
People with dementia should be taken to the toilet at regular intervals as they may no longer recognise the need to go themselves. This may be every 2 to 3 hours, depending on how much they drink. It may be necessary to stay with them to help them and remind them why they are there.

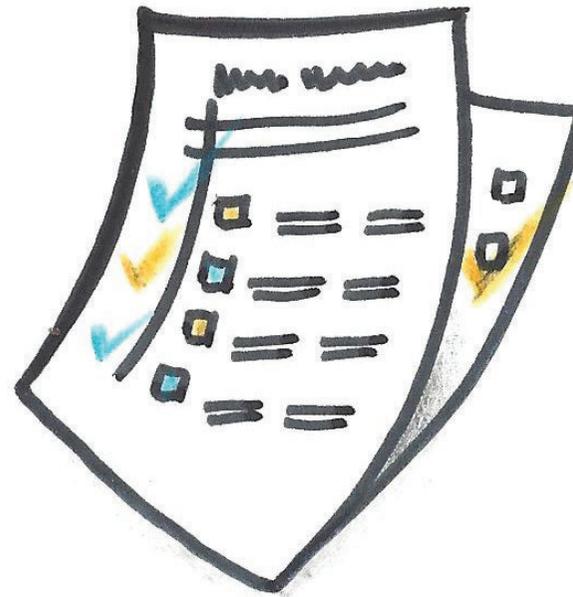


Tips



Here are some tips in case the person you care for has difficulties with toileting:

- Put an image of a toilet on the toilet door to assist finding the toilet.
- Provide directions to the toilet if the person living with dementia seems to not remember where it is.
- Provide adequate nightlights to help find the toilet.
- Use a toilet seat with a contrasting colour to the toilet bowl as it helps define the seat.
- Change to clothes that do not need belts or have buttons or zips as they are easier for the person you care for to manage.
- Instruct step-by-step if the person living with dementia forgets the process the person living with dementia needs to take while toileting.



Would you like to see what else may contribute to incontinence?

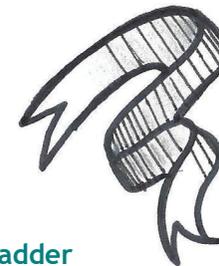
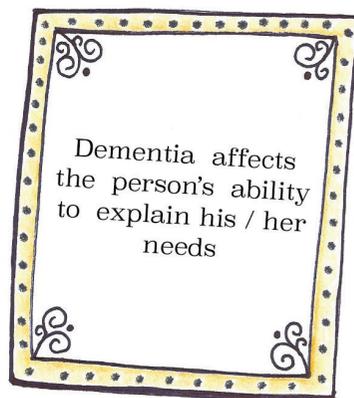
Factors contributing to urinating or losing control of the bladder	Recommended solutions
A long distance to go to the toilet in the house	<ul style="list-style-type: none"> ● Direct the person you care for to the toilet ● Provide a bedside commode at night or for men try a non-spill urinal available for most chemists ● Use nightlights to safely guide the way to the toilet at night
Not being able to find the toilet	<ul style="list-style-type: none"> ● Put a picture of a toilet on the door ● Remind the person to use the bathroom just before his or her usual time
Missing the toilet bowl when urinating	<ul style="list-style-type: none"> ● May be due to poor colour contrast of the toilet seat to the bowl. Replace the toilet seat with a different colour toilet seat
Poor lighting at night to find the way to the toilet	<ul style="list-style-type: none"> ● Provide adequate night lighting in the house
Poor lighting in the toilet	<ul style="list-style-type: none"> ● Leave the toilet light on to avoid risk of falls and to help locate the toilet
Narrow toilet doors that do not allow the walker or wheelchair to pass	<ul style="list-style-type: none"> ● Modify the door opening to allow a walker or wheelchair to pass

Factors contributing to urinating or losing control of the bladder	Recommended solutions
Person with dementia has visual impairment	<ul style="list-style-type: none"> ● Direct them to the toilet during the day ● Provide a bedside commode at night
Unable to undo pants that have belts, buttons and /or zips	<ul style="list-style-type: none"> ● Change trousers into ones that are easily undone and removed (e.g., track or pull-on pants) ● Assist them to pull on and do up trousers
Forgetting what to do in the toilet	<ul style="list-style-type: none"> ● Remind them of activities they needs to do ● Provide step-by-step instructions to complete toileting tasks ● Identify when accidents occur, then plan for them. If they happen every two hours, get the person to the toilet before that time
Continues to be incontinent despite actions taken	<ul style="list-style-type: none"> ● Consider using incontinence products, such as waterproof mattress covers, incontinence pads on the person's bed, padded undergarments or adult briefs
Remains incontinent of faeces	<ul style="list-style-type: none"> ● Ensure they are not constipated ● Try setting a regular schedule for toilet use ● Give the person plenty of time in the bathroom to empty bladder and bowels

Urinating in public places

Dementia affects the person's ability to explain their needs, for example needing to go to the toilet. Additionally, dementia can also affect the person's judgement of what is normal and what is not normal in public.

You could help prevent these accidents (incontinence) by maintaining a regular toileting schedule for the person during the day. If you think that might be helpful, try to identify how often the person used the toilet before the person had dementia or the times that the person is incontinent. You can also identify whether the person needs to go to the toilet through behavioural changes, i.e., if the person becomes agitated, stressed, anxious or restless.



Esther is losing control of her bladder

Joshua is taking care of his mother, Esther, who was diagnosed with dementia 5 years ago. Joshua usually takes his mother to the local shops as she enjoys meeting people.

Recently, Joshua notices that his mother has lost control of her bladder during the day.

Check your understanding



Esther is losing control of her bladder

What do you think is the right response for Joshua?

- Since this is an embarrassing situation for Joshua, he should stop taking his mother to the shops.
- Joshua should make sure his mother uses the toilet before leaving to go to the shops.

Check your understanding

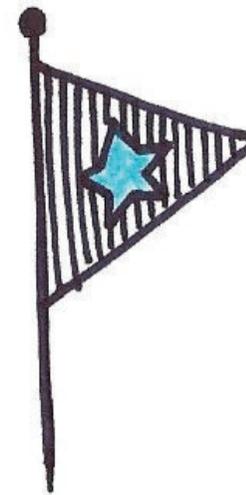
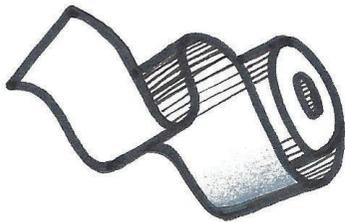
*Esther is losing control of her bladder*

- ✗ **Since this is an embarrassing situation for Joshua, he should stop taking his mother to the shops.**
This is poor advice, because his mother will miss out on a very important regular pleasant activity.
- ✓ **Joshua should make sure his mother uses the toilet before leaving to go to the shops.**
It is a good way to help prevent Esther from losing control of her bladder.

Tip



- To improve the control of bladder or bowels, it may help to fill out a toilet diary.



Toileting diary			Date:
Time	Trips to the toilet	Lost control of bladder or bowels	What possible causes did you observe?
06:00-07:00 am			
07:00-08:00 am			
08:00-09:00 am			
09:00-10:00 am			
10:00-11:00 am			
11:00-12:00 noon			
12:00-1:00 pm			
01:00-02:00 pm			
02:00-03:00 pm			

Toileting diary			Date:
Time	Trips to the toilet	Lost control of bladder or bowels	What possible causes did you observe?
03:00-04:00 pm			
04:00-05:00 pm			
05:00-06:00 pm			
06:00-07:00 pm			
07:00-08:00 pm			
08:00-09:00 pm			
09:00-10:00 pm			
10:00-11:00 pm			
11:00-12:00 midnight			

Toileting diary			Date:
Time	Trips to the toilet	Lost control of bladder or bowels	What possible causes did you observe?
12:00-01:00 am			
01:00-02:00 am			
02:00-03:00 am			
03:00-04:00 am			
04:00-05:00 am			
05:00-06:00 am			

Being unable to control urine and bowels (urinary and faecal incontinence)

In the late stages of dementia, the person with dementia may not be able to control their bladder and bowel movements. Before using any incontinence aids and/or equipment, you should ask health professionals to help identify the causes of incontinence, as some causes may be treatable.

Tips



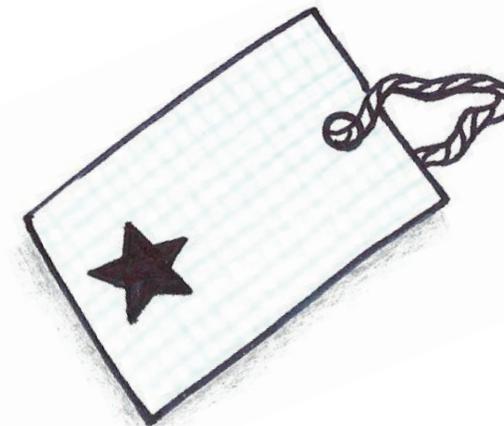
- There are numerous disposable and/or washable incontinence aids, pads and equipment. When selecting products, you should consider their cost, effectiveness, comfort and convenience.
- For bedridden males, using urinals to collect urine may help. Some of these urinals are designed to prevent the backward leaking of urine.

Types of bowel control problems

Diarrhoea - frequently passing loose bowel motions. Causes include infection, food poisoning or bowel conditions such as Crohn's disease and ulcerative colitis.

Constipation - passing hard, dry bowel motions (with difficulty or straining). Causes include not drinking enough fluid, eating a diet low in fibre and lack of exercise.

Faecal incontinence - an uncontrolled loss of a bowel motion. Causes include diarrhoea and constipation. It can also result from a problem in the lower bowel or anus, making it difficult to hold onto a bowel motion. Causes include childbirth and nerve problems such as diabetes.



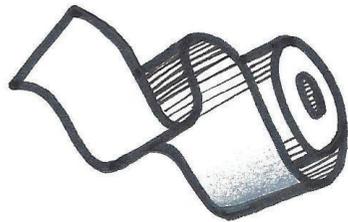
Incontinence pads for Gloria

Gloria is in a late stage of Alzheimer's disease and is living with her son's family.

Her daughter-in-law, Marina, is taking care of her. Since Gloria cannot control her bladder or bowels, the General Practitioner suggests that Marina tries incontinence pads for Gloria.

In the beginning, Marina encounters a number of problems:

- Gloria constantly takes the pad off and throws it on the floor.
- Gloria still has wet pants even when using incontinence pads.
- Gloria has skin problems in her genital area.



Check your understanding



Incontinence pads for Gloria

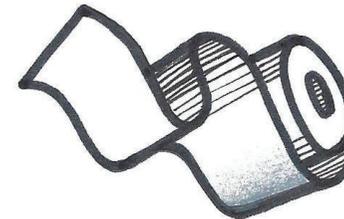
What would you think is the right response for Gloria and Marina?

- Marina should force Gloria to have the pad on.
- Marina should remind her mother-in-law to use the toilet at scheduled times if she is not going to the toilet herself.
- Marina should seek some assistance from a trained continence consultant to ensure she is using the correct products for Gloria.

Check your understanding

*Incontinence pads for Gloria*

- ✗ **Marina should force Gloria to have the pad on.**
This is not the right answer! It's very important to check why a person with dementia may feel uncomfortable with the pad. Is the size incorrect? Is the pad wet and needs to be changed?
- ✓ **Marina should remind her mother-in-law to use the toilet at scheduled times if she is not going to the toilet herself.**
Scheduled toileting visits may help to minimise incontinence and the need for pads.
- ✓ **Marina should seek some assistance from a trained continence consultant to ensure she is using the correct products for Gloria.**
The type and size of pads are adjustable to individuals needs and should not be uncomfortable for the person using them.



Tips for incontinence care



Problems you may encounter

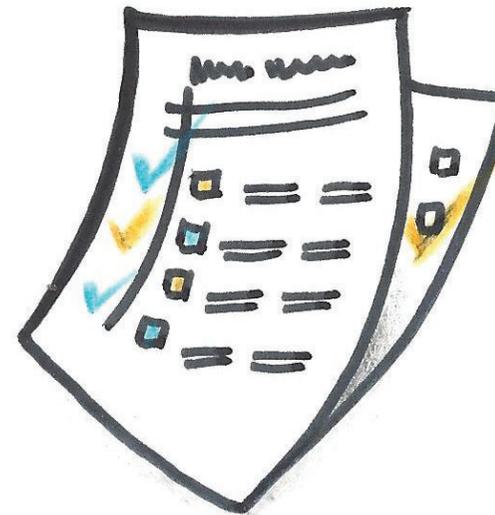
Problems	Possible causes	Recommended solutions
Constantly taking the pad off and throwing it on the floor	<ul style="list-style-type: none"> ● Feeling uncomfortable with the pad ● The pad size is incorrect ● The pad is wet and needs to be changed 	<ul style="list-style-type: none"> ● Check whether the pad size is correct ● Change the wet pad on time ● Consult a Continence Practitioner regarding the behaviour and the type of aides you are using
Still having wet pants even while using the incontinence pads	<ul style="list-style-type: none"> ● The pad size is incorrect ● The toileting schedule has not been maintained 	<ul style="list-style-type: none"> ● Use the right size and type of pads. Note pads have volume ratings and come in different sizes that need to be considered as part of use ● Use scheduled toileting visits to minimise the use of pad
Having sore or irritated skin in the genital area	<ul style="list-style-type: none"> ● Incontinence pads that do not have adequate volume will not draw moisture away from the skin and can cause skin breakdown ● Unsuitable size and failure to change soiled pads in a timely manner can cause skin irritation and/or infection 	<ul style="list-style-type: none"> ● Select suitable size, volume and type of pads ● Change the soiled pads on time and maintain hygiene around genital area ● Apply protective creams or lotions that maintain healthy skin
Having fever, being in pain, strong smelling urine	<ul style="list-style-type: none"> ● Urinary tract infections are triggered by a number of things, including poor incontinence and genital care 	<ul style="list-style-type: none"> ● See the General Practitioner ● Maintain 6-8 glasses of water or juice per day if someone is not under fluid restriction ● Maintain good genital care

Let's review what you have learned

- Do not blame the person after any accidents, such as urinating on the floor, this will only make the situation worse.

Modify the environment to reduce the chance of bladder and bowel accidents (for example put a picture of a toilet on the door of the toilet).

- Take the person with dementia to the toilet regularly to reduce accidents.
 - The frequency of toilet visits will need to be established based on the toilet pattern that the person with dementia had before the onset of their dementia.
 - If these changes do not help, incontinence aids and equipment may help.
 - Be aware that incontinence aids can irritate the skin if used incorrectly.
- Maintain good genital care to reduce the risk of skin infections and urinary tract infections.
 - If the person with dementia is not under fluid restriction, encourage them to drink 6-8 glasses of water or juice a day to help prevent urinary tract infections.
 - Ensure the person with dementia does not become constipated and this may lead to incontinence.



Further Information

National Continence Helpline

- The National Continence Helpline is staffed by qualified continence nurse advisers who can give you prompt, confidential and expert advice. Anyone from health professionals to members of the public can call them. Helpline staff can give you information about continence products, national and state government continence subsidy schemes and arrange for continence information resources to be sent to you. Phone the National Continence Helpline on 1800 33 00 66 between 8.00am to 8.00pm EST, Monday to Friday. It is closed on national public holidays. Outside of these hours, please contact the After Hours GP Helpline on 1800 022 222.

Bladder and Bowel website

- The Australian Government's Bladder Bowel website promotes bladder and bowel health. It also provides information to people affected by incontinence, their families and carers, as well as to health professionals, service providers and researchers on the prevention, management and treatment of bladder and bowel problems.

Resources

My Aged Care <https://www.myagedcare.gov.au/getting-started/health-conditions/incontinence> Phone 1800 200 422 Mon-Fri 8am - 8pm Sat 10am - 2pm

Continence Foundation of Australia
<https://www.continence.org.au/pages/dementia.html> National Continence Helpline 1800 330 066

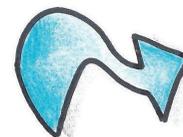
Dementia Australia <https://dementia.org.au> National Dementia Helpline 1800 100 500

RELATED LEARNING UNITS

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

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 4. Personal hygiene and care

Why is this unit important?

Poor personal hygiene and care may lead to skin complaints, infections and other health problems, low self-esteem, discomfort and withdrawal from social activities for people with dementia.

How will this unit help me?

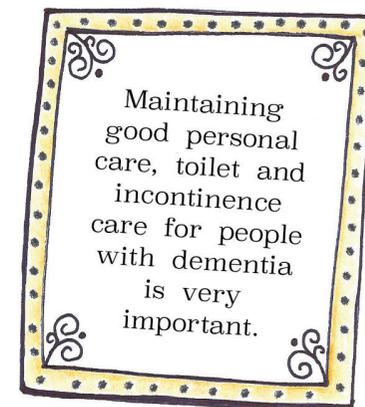
This unit will help you think about the health concerns for the person you care for and assist with their personal hygiene and care needs.

What will I learn?

- How to modify the environment to make personal hygiene and care easier
- Tips for dressing, grooming, oral care and assisting in bathing/showering
- To coach/encourage with personal hygiene and care.

Dementia affects people's ability to maintain personal hygiene and care, for example brushing teeth, showering/bathing and grooming.

To ensure their comfort, safety and health assistance with maintaining good personal care is very important.



Locating items needed for personal care

There are different reasons for not being able to perform personal hygiene and care. One reason is that people with dementia may not be able to find the things they need for personal care.

For example, when they cannot find their own toothbrush and toothpaste due to memory loss, it will be difficult for them to brush their teeth.

However, you can modify the environment to make it easier to find things that are needed for personal hygiene and care.

Marion forgets to wash herself before breakfast

Marion has Alzheimer's disease, but she is able to care for herself without assistance from others in the family.

Recently, her husband David has noticed that she sits at the table for breakfast in a nightgown without having washed her face, brushed her hair and without doing her make-up as she usually did.

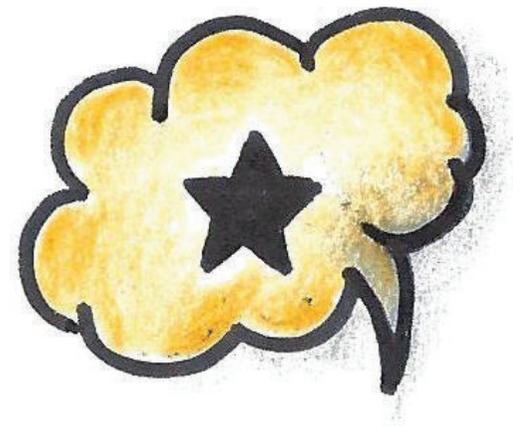
Check your understanding



Marion forgets to wash herself before breakfast

What would you think is the right response for David?

- Put personal hygiene and care products in the same place and in order of use with large print labels for Marion to read.
- Ask their daughter-in-law to take Marion from the table to the bathroom and assist her with washing and changing clothes.



Check your understanding

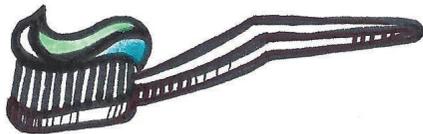


- ✓ **Put personal hygiene and care products in the same place and in order of use with large print labels for Marion to read.**

People with dementia may lose the ability to find the things that are not obvious. Creating an 'easy to find' environment for them is very important.

- ✗ **Ask their daughter-in-law to take Marion from the table to the bathroom and assist her with washing and changing clothes.**

David needs to first find out what the reasons may be for Marion not doing all her personal care before breakfast anymore. Also, David needs to ask Marion if she wants to be helped by their daughter-in-law. Not asking may upset her.



Tips



Here are some tips that may help people with dementia to find what they need to attend to personal care activities themselves.

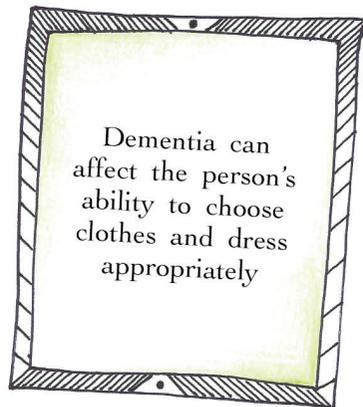
- To find the bathroom or toilet: Put a picture and/or words on the bathroom or toilet door or direct people with dementia to the bathroom or toilet.
- To find personal care materials: Make things easy to see in the bathroom, label things with their name, use pictures or words on the bathroom wall to point out items, use contrasting colours.
- To help turn on and off the tap: Use colour indicators to label the direction for turning on and off the tap, instruct them to turn on and turn off the tap, assist if needed.
- Stay with them and prompt activities but do not take over as this can be very frustrating for the person with dementia

If the person with dementia is unable to choose their clothes and dress themselves

Dementia can affect the person's ability to choose clothes and dress appropriately.

You can assist the person to choose clothes and to dress, in a way which makes the most use of the person remaining skills. You should not take over these tasks when the person can still perform them.

The person may need advice on the best clothes to wear for the weather or guidance on where they can find different items of clothing.



Buttons not done, belt not fastened, laces not tied

Ted has Alzheimer's disease and is cared for by his wife, Jane. Ted used to lay out his clothes for the next day in the evening.

Recently, Jane has found that Ted forgets to do this and is inclined to wear the same clothes day in and day out. Jane also observes that Ted leaves some buttons of his shirt undone, his belt unfastened and forgets to lace up his shoes.

Check your understanding



Buttons not done, belt not fastened, laces not tied

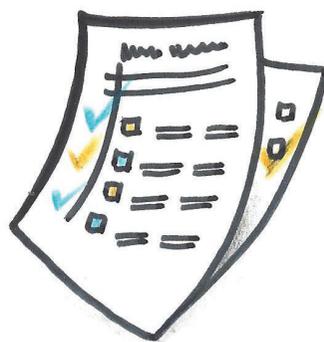
What would you think is the right response for Jane?

- Tell Ted that he needs to be less messy, choose clothes for Ted and dress him.
- Remind Ted to lay out his clothes in the evening and encourage him to wear pants that do not need a belt and shoes that do not need laces.

Check your understanding



- ✘ **Tell Ted that he needs to be less messy, choose clothes for Ted and dress him.**
It is not Ted's fault that he is finding this task challenging. With some extra help, Ted may still be able to dress himself.
- ✔ **Remind Ted to lay out his clothes in the evening and encourage him to wear pants that do not need a belt and shoes that do not need laces.**
It will enable Ted to dress himself, which may also help to improve his sense of self-worth.



Tips



Here are some tips to help someone with dementia with daily dressing:

- To help find clothes from the wardrobe: Put a picture and/or words on the wardrobe door to show that there are clothes behind the door, direct them to take clothes from the wardrobe, get clothes from the wardrobe for **them** if needed.
- To help choose clothes to wear: Enable **them** to select clothes by giving them two different pieces of clothing to choose from and give a compliment for the choice made.
- To help put clothes on: Remind the person of the correct order of putting clothes on and to do up all buttons, and assist if needed.
- To help wear pants with belt: Remind the person to fasten the belt and assist if needed. Consider changing to pants that do not need a belt.
- To help wearing shoes with laces: Remind the person to tie the laces on the shoes and assist if needed. Consider changing to shoes that do not need laces.

Tips



Here are some tips to help someone with dementia to brush their teeth

- Dementia affects organisation, coordination and concentration, all of which are required to perform mouth care. Poor mouth care is associated with poor appetite, bad breath, infections of the teeth or gums and other health problems. The goal of assisting with mouth care is to help the person make the most use of his or her remaining skills.

Ted's difficulty with mouth care

Ted has Alzheimer's disease but is able to brush his teeth without assistance from other family members. Recently, Ted's wife, Jane, notices that her husband makes a mess in the bathroom with water and toothpaste over the vanity and the floor. She also observes that her husband is unable to brush his teeth in the order that he usually does and is unable to insert his artificial dentures himself.

Check your understanding



What would you think is the right response for Jane?

- Put Ted's dentures into his mouth without asking.
- Instruct her husband to brush his teeth step-by-step and encourage him when he is doing well.

Check your understanding



- ✗ **Put Ted's dentures into his mouth without asking.**
Jane is completely taking over care tasks, and even worse, without asking his permission. This response may upset Ted and does not support him to maintain his abilities.
- ✓ **Instruct her husband to brush his teeth step-by-step and encourage him when he is doing well.**
Ted maintains a level of independence in this way, which may also help to improve his sense of self-worth.

Mouth care

Select below any mouth care steps the person needs help with.

Activity	
<i>Main activities in performing mouth care:</i>	
<input type="checkbox"/>	Put toothpaste on the toothbrush
<input type="checkbox"/>	Brush teeth in an order that will clean teeth and gums
<input type="checkbox"/>	Rinse and clean mouth
<input type="checkbox"/>	Use floss or toothpick to clean between teeth daily
<input type="checkbox"/>	Apply balm to moisturise lips when needed
<input type="checkbox"/>	Check for signs of mouth infections or toothache when needed
<input type="checkbox"/>	Remove, wash, clean, and store artificial dentures if needed.

Mouth care steps

These are the mouth care steps the person needs help with and breaking the task down into small steps will help them remain independent as long as possible.

If the person with dementia is unable to perform general personal care

Dementia affects the person's ability to organise, coordinate and concentrate on personal care, such as mouth care, and may affect their ability to wash their hair or take a shower or bath. A person living with dementia may view assistance with personal care as a threat to his or her privacy, safety and security, and may refuse or resist any help.

When assisting with personal care, ask the person's preferences whenever possible and respect their choices. Reassure that the person living with dementia is safe and comfortable.

Tips



- If providing someone's personal care needs is difficult for you consider eligibility for government-supported home care. Support services can include assistance with bathing, showering and dressing. If assessment shows the person with dementia is eligible for services, you can work with the assessor to decide which service provider(s) you want to receive services from. Contact My Aged Care on 1800 200 422 or website www.myagedcare.gov.au.

Joe does not want help with bathing

Joe has Alzheimer's disease and is cared for by his wife, Sue. Due to her age, Sue is not strong enough to help bathe Joe anymore, so the family decides that the three sons-in-law could take turns to help with Joe's weekly bath.

The oldest son-in-law is very kind to Joe and reassures Joe that he will make him comfortable during the bath. He takes Joe to the bathroom and starts to undress him. Joe suddenly pushes him away, shouts at him and tells him to go away.

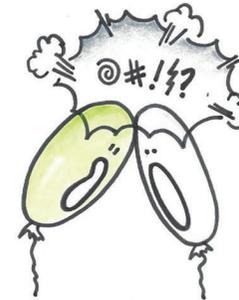
Check your understanding



Joe does not want help with bathing

What would you think is the right response for Joe's family?

- Since the family notices that Joe thought his son in law was a stranger, Sue decides to be with Joe while their son-in-law bathes him.
- Give Joe time to adjust but do not force him to do this - consider trying again later in the day.
- They should say to Joe that he should be grateful for the help he receives and if he continues to behave in this way, he will be sent to a long-term care facility.



Check your understanding



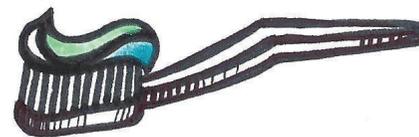
- ✓ **Since the family notices that Joe thought his son in law was a stranger, Sue decides to be with Joe while their son-in-law bathes him.**
Good advice! A person with dementia may no longer recognise people they used to know, so giving them plenty of transition time to get familiar with people is very important.
- ✓ **Give Joe time to adjust but do not force him to do this - consider trying again later in the day.**
Good advice! A person with dementia may just need some time to get used to the idea.
- ✗ **They should say to Joe that he should be grateful for the help he receives and if he continues to behave in this way, he will be sent to a long-term care facility.**
This is bad advice! Never threaten people with dementia in this way. Saying things like this will not help the situation and will make Joe feel very distressed.

Tips



Here are some tips for assisting in bathing:

- Identify the times of day that the person prefers a bath/shower.
- Switch from a shower/bath to a sponge bath. (Note: Bathtubs are particularly difficult as they may lead to falls, and it may be hard for the caregiver to lift the person with dementia out of.)
- Adaptive seating or equipment like safety bars and shower chairs may help.
- For people with dementia who are afraid of water, try to slow down the water flow.
- A slippery bathtub and bathroom floor will cause falls. Use a non-slip bath or shower mat to help prevent this.



Activity-Care steps

Select below any personal care steps the person needs help with and use the list to coach the person through each step.

Main activities in performing personal care:

- Select daytime clothing
- Put non-slip mats on the floor
- Take pyjamas off
- Wash and dry hands
- Wash and dry face
- Wash and dry feet
- Wash and dry genital areas
- Dry body after washing
- Change night attire into daytime attire

Preparing for a shower/bath:

- Turn the tap on, adjust the water temperature and prepare for bathing

- Undress before shower/bath
- Wash hair/body during shower/bath
- Shave - consider using an electric shaver as it is much safer than a razor blade shaver
- Use towel to dry hair/body
- Apply body lotion to moisturise skin
- Check for signs of skin problems
- Dress after shower/bath
- Comb hair
- Using electrical hairdryer
- Putting on make-up
- Cutting fingernails and toenails when needed

Let's review what you have learned

- Encourage the person to attend to their personal hygiene and mouth care as long as possible using remaining skills.
- Modify the environment, for example by providing guidance, encouraging them to select clothes that are easier to manage without buttons and belts or enable seating while performing personal care.
- Engage the person in daily decision making, for example, what clothes the person would like to wear.
- Keep in mind that inadequate assistance and encouragement with personal care may cause agitation or aggression. Put yourself in the person's shoes and try to understand why he or she resists being assisted with personal care.
- Ultimately, personal hygiene is a vital part of dementia care because it is integral to the sense of identity of someone with dementia, as well as being a key part in ensuring their comfort. Taking steps to maintain it is important for ensuring a good quality of life for them.



More Information

- If you're living at home and need some extra help, there are a range of aged care services that can be delivered through an Australian Government-subsidised Home Care Package. These services may include help with day-to-day personal care activities such as dressing or grooming.
- Some home care service providers may also receive an additional Dementia Supplement to help you access the services you need to stay in your own home. Find out more about eligibility to access a Home Care Package by accessing the My Aged Care Website or phone them on 1800 200 422 open 8am to 8pm Monday to Friday and 10am to 2pm on Saturday.

More Information(Continued)

National Dementia Helpline

- You can call the National Dementia Helpline on 1800 100 500 for information. They can also tell you about National Dementia Awareness Month held in September each year or about conferences and seminars on the subject of dementia. The National Dementia Helpline can also put you in touch with support groups around the country for carers of people with dementia. The groups let you share experiences, learn from others and discuss issues and emotions in a safe environment.

Carer support groups

- **Carer support groups** can offer you a safe place to talk about your role as a carer. They can put you in touch with other carers who may be experiencing similar things to you so you can share advice and suggestions to support each other. 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, read about caring for someone with a particular need_or call My Aged Care on 1800 200 422.

RELATED LEARNING UNITS

- Module 2 Unit 4 Involving others
- Module 4 Unit 5 an enjoyable day
- Module 5 Unit 7 Changes in judgement





You finished this unit, well done!

Unit 5. Creating an enjoyable day

Why is this unit important?

It is important to maintain routines and activities that are familiar to a person with dementia to help create a sense of safety, routine and an enjoyable day. Activities help to sharpen focus and can ease agitation.

How will this unit help me?

By learning how to adapt routines and activities as the abilities of the person with dementia change. A good routine, with meaningful activities will slow decline and create the best lifestyle possible.

What will I learn?

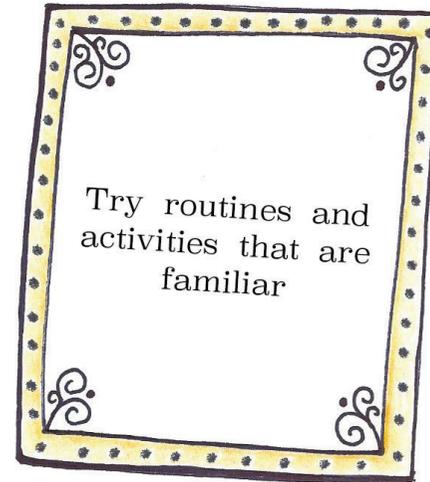
- To establish routines for the person living with dementia for morning time, during the day and bedtime.
- To keep routines similar to the ones the person living with dementia had before developing dementia.
- To adapt routines to the changing abilities of the person living with dementia.

Maintaining routines and activities is important

When someone is living with dementia, it is important to create an environment that supports them to do the things they like to do and helps to maintain their abilities.

This is also true for you and the person living with dementia.

It is important to try and maintain routines and activities that are familiar to the person living with dementia, and to adapt them as their abilities change.



What is a routine?

A routine is something the person living with dementia does every day or almost every day.

It is important to try and continue the person living with dementia's routine for as long as possible. This is reassuring and can promote less stress at home. It is important to be aware of **[his, her]** usual routine. If there has not been a routine, for example for the evening, then it is helpful to develop one and to follow it regularly - such as drinking a cup of tea, listening to restful music, usual time for bed. Maintain a sense of structure and familiarity by having consistent times for activities such as waking up, mealtimes, bathing, dressing, receiving visitors and bedtime.

Doing chores and preparing for activities on your own might be easier, but try to involve the person living with dementia in daily activities as much as able. Use your best judgment as to what is safe and what they can handle.



Morning time - starting the day

It's helpful to have a set time for waking up and then several things to do in sequence to get the day started. Think of bathing, brushing teeth, getting dressed and then sitting down to breakfast. As dementia progresses, the person living with dementia will need help with each of these things, but one way to lower stress is to keep the basic routines as similar as possible.

During the day, it's also important to try and make time for activities the person living with dementia enjoys, such as visiting a friend or another family member, going for a walk, reading, playing games, or listening to the radio. These activities will depend on prior interests and current abilities.

In the early stages of dementia, the person may be able to do things the person likes to do with minimal guidance. However, as the disease progresses, activities will need to be changed or modified so that the person can still do them with enjoyment and pleasure. Explain activities beforehand and consider if they will be able to do an activity to avoid frustration. If the health of the person permits, an increase in daily physical activity may be beneficial. It's important to be flexible and creative in figuring out the routines and then adapting them as needed over time.

Back to routines

Let's look at an example

Martha has dementia and is used to drinking a cup of tea immediately after getting ready and having her breakfast. Her daughter, Penny, really wants to encourage her mother to walk every day, as recommended by her doctor. Penny is not aware of the regular 'order' her mother is used to, so when she tries to get Martha to go for a walk right after breakfast, Martha refuses.

Check your understanding



Back to routines

What suggestions do you have for Penny?

Mark all that apply.

- If Penny suggests keeping to the routine by having a cup of tea first, it is likely that Martha will go for a walk afterwards.
- Penny should ask Martha what activities she is used to and what order she would like to do them in.
- Penny should force Martha to go for a walk, because it was advised by the doctor.

Check your understanding



- ✓ **If Penny suggests keeping to the routine by taking tea first, it is likely that Martha will go for a walk afterwards.**
Right! It will help keep to Martha's routine.
- ✓ **Penny should ask Martha what activities she is used to and what order she would like to do them in.**
Indeed! Penny can learn Martha's routines. However, this may only work if Martha is in the early or middle stages of dementia. Later on Martha might not be able to remember her routines.
- ✗ **Penny should force Martha to go for a walk, because it was advised by the doctor.**
This response is not good because it may make Martha feel agitated and upset as it changes her usual routine.



Tips



Keep in mind that:

- It is important to try and keep the routines (something the person does every day or almost every day) for as long as possible. This may help to avoid confusion, agitation, restlessness and boredom. It also helps to maintain the person's dignity. Think for a moment how you might feel if your routines were changed or planned by another person.

Adaptations of routines during the disease process

It is important to adapt routines as the abilities of the person with dementia change.

Here are some common routines to establish during the day for a person with dementia. How have you adapted the person's routine at home?



IN THE MORNING

- Wake up at the same time every day

Adaptation: Help might be needed to wake up the person because the person may not be able to set the alarm correctly.

- Have breakfast at a fixed time. In the earlier stages of dementia, the person might be able to make the person own breakfast. Remember to let the person help as much as able.

Adaptation: the person may need someone to put out ingredients. Later on the person may need more help with preparing and eating breakfast.

- Doing grooming activities, such as brushing teeth, bathing/showering, and getting dressed. In the early stages, the person may be able to do all of these things with a little prompting and without help.

Adaptation: Tools, such as toothbrush, paste, etc., can be laid out in the bathroom in plain view to prompt the activity of bathing or brushing teeth. In the later stages it may be necessary for someone to do these things for or with the person.

Keep in mind

- It is important to develop routines for morning activities and maintain them as long as possible.
- Make adjustments as needed when the abilities of the person with dementia change.

During the day

It is helpful to plan activities that the person enjoys doing, based on the person prior interests and current abilities.

How to continue prior activities and interests?

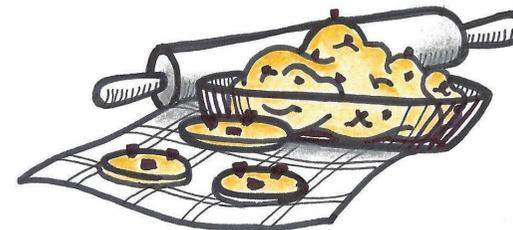
An example:

Martha loves baking and used to prepare special cakes and biscuits for family gatherings. Now that she has dementia, she sometimes forgets the ingredients and which order to put them in. At first, Martha used a cookbook to help her to continue baking, but she found this increasingly difficult. The cakes and biscuits did not taste very good and had to be thrown away. Penny wants to help her mother keep up this activity.

Check your understanding**What suggestions do you have for Penny?**

Mark all that apply.

- Penny should put away the baking and cooking pans and tell her mother that it's just not possible to do this anymore.
- Penny should go shopping with her mother and buy easy to prepare cakes and biscuits, 'out of the box', with limited added work to enable Martha to continue to do some cooking and baking.
- As Martha's abilities change, Penny could plan some time during the afternoon with her mother to do baking and cooking together.



Check your understanding



- ✘ Penny should put away the baking and cooking pans and tell her mother that it's just not possible to do this anymore.
This is not very helpful. Penny has not tried to come up with an alternative to help her mother, and it may make Martha feel upset.
- ✔ Penny should go shopping with her mother and buy easy to prepare cakes and biscuits, 'out of the box', with limited added work to enable Martha to continue to do some cooking and baking.
This is a good suggestion. It respects Martha's routine but adapts the activity to her current abilities.
- ✔ As Martha's abilities change, Penny could plan some time during the afternoon with her mother to do baking and cooking together.
This is an excellent plan for the future. It allows Martha to continue her routine with support as needed.



Sundowning

Sometimes people with dementia become more agitated, aggressive or confused in the late afternoon or early evening. This is often referred to as 'sundowning'. It can be particularly distressing for caregivers. The exact causes of sundowning are not yet clear, but a loss of routine might be one of the reasons. Try to have something meaningful to do at this time of day. Also try to discourage too much daytime napping and inactivity as this can lead to unsettled behaviour in the evening.

Let's look at another example from Penny and Martha

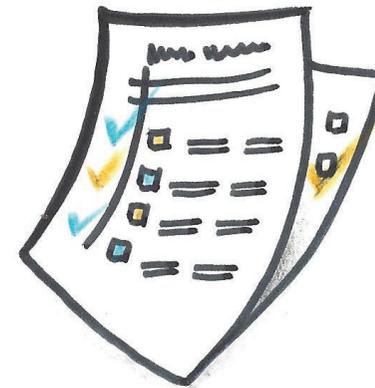
Martha likes to go to a community centre every day from 12 noon until 3 pm. There she has lunch and meets with friends to do some activities together. At first, she walks there by herself, but as her memory loss becomes more frequent, she cannot find her way to the centre anymore. Penny asks another family member to take Martha to the centre and bring her back home again. This works well for a while but eventually the family member is unable to take Martha. Penny does not know what to do since she cannot be with Martha every afternoon.

Check your understanding



What suggestions do you have for Penny?

- Penny could ask another family member to help Martha.
- Penny could ask other people outside the family to walk with Martha to the seniors centre such as a neighbour.
- Penny could tell her mother to do a quiet activity in the afternoons like watching TV or listening to the radio.



Check your understanding



- ✓ **Penny could ask another family member to help Martha.**
This is a good idea. If others can come on a regular basis, this is the best solution for Martha as it maintains the routine and adapts to Martha's changing abilities.
- ✓ Penny could ask other people outside the family to walk with Martha to the senior centre such as a neighbour.
This is a concrete task you could ask for help with.
- ✗ Penny could tell her mother to do a quiet activity in the afternoons like watching TV or listening to the radio.
This is not likely to be a good solution at this time – it isolates Martha from other people and doesn't allow her to engage in the activities she enjoys. It might be a better solution in the later stages when Martha's abilities change, but not for now.

Keep in Mind



- It is important to respect the current daily routines of the person and continue them as long as possible.
- When this is no longer possible, adapt the routine the best you can so that the key activities important to the person are maintained for as long as possible.



At bedtime

At night, Martha is used to reading quietly for about 30 minutes before she goes to sleep. As her dementia progresses, she finds she is no longer able to read. Sometimes she is just staring at her book. She increasingly finds reading confusing.

Penny wants to adapt this routine to fit Martha's current abilities.

Check your understanding



What suggestions do you have for Penny?

Mark all that apply.

- Penny could read to Martha for 15 minutes before she goes to sleep.
- Penny should take the books out of Martha's room.
- Penny should get some books that have more pictures than words or books on tape (sometimes called audiobooks) for Martha.

Check your understanding



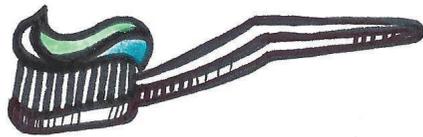
- ✓ **Penny could read to Martha for 15 minutes before she goes to sleep.**
This is a good idea. It helps Martha to continue enjoying reading but adapts the activity to her abilities.
- ✗ **Penny should take the books out of Martha's room.**
This is not a good response because it does not recognise the importance of reading to Martha. Penny should recognise that she and her mother can share this routine still, it just needs to be adapted.
- ✓ **Penny should get some books that have more pictures than words or books on tape (sometimes called audiobooks) for Martha.**
This is a helpful adaptation for people in the later stages of dementia who liked to read but find they aren't able to read books with lots of words anymore.



Keep in Mind



- For the morning, afternoon and bedtime, establish and maintain routines for as long as possible, but be prepared to adapt and change them as the abilities of the person with dementia change over time.
- Printing out a list of the daily routines can help. Do one for each day and stick it up in a prominent place.
- Asking someone with dementia what they want to do each day can be asking too much. If you limit choice, such as asking if they would like to read or go on a walk, that would be less confusing. Yes/No questions are also good, for example asking if they would like to go for a walk, will help decision making easier.



Activity



Any ideas about routines for the person?

Please write down any ideas about the routines for the person with dementia and how they can be adapted:

Let's review what you have learned

- Establishing routines is important for people living with dementia. That also holds for the person.
- Try to keep routines similar to the ones the person had before developing dementia.
- Limit choice so the person with dementia does not become overwhelmed. Yes/No questions are also good, for example asking if they would you like to go for a walk will help decision making to be easier.
- Be prepared to adapt routines as necessary as the abilities of the person living with dementia change.

RELATED LEARNING UNITS

- Module 1 Unit 1 Introduction to dementia
- Module 4 Unit 1 Eating and drinking - more pleasant mealtimes
- Module 5 Unit 1 Introduction to person-centred approach

Further Information

- **Carer support groups**

Carer support groups can offer you a safe place to talk about your role as a carer. They can put you in touch with other carers who may be experiencing similar things to you so you can share advice and suggestions to support each other.

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, read about caring for someone with a particular need or call My Aged Care on 1800 200 422. **The National Dementia Helpline** can also put you in touch with support groups. The groups let you share experiences, learn from others and discuss issues and emotions in a safe environment.

- **Dementia Australia**

The Dementia Australia website produces a series of help-sheets for carers of people with dementia, including a useful safety checklist.

- **Dementia Behaviour Management Advisory Service**

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 sundowners, wandering and aggression. Visit the DBMAS website or contact them on 1800 699 799 (24 hours a day) to find out more.



You finished this unit, well done!