

iSupport For Dementia Carers

Module 4 Providing everyday care



**PROVIDING
EVERYDAY CARE**

Session 1. Eating and drinking - more pleasant mealtimes

Session 2. Eating and drinking - preventing health problems

Session 3. Toileting and continence care

Session 4. Personal care

Session 5. An enjoyable day



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Session 1. Eating and drinking – more pleasant mealtimes

Why is this session important?

Dementia can affect eating and drinking in various ways depending on the stage of dementia and other health conditions.

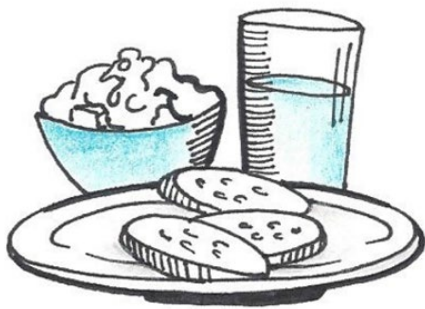
How will this session help me?

By learning how to help create more pleasant mealtimes and prevent dehydration.

What will I learn?

1. Making mealtimes more pleasant.
2. Promoting a good mealtime atmosphere.
3. Health conditions that affect eating and drinking.
4. Preventing dehydration.

1. Making mealtimes more pleasant



Engaging people with dementia in simple tasks around mealtime helps to make the most of people's skills, promote feelings of self-worth, and enjoy the mealtime.

Let's look at an example

Maureen was a housewife and cooked every day for her family for many years. Recently, she lost her husband and now lives with one of her sons. Sheila, her daughter-in-law, provides all the cooking in the new household. Maureen 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.

1. Check your understanding

Making mealtimes more pleasant.

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

Please select the answer that you think is correct from the list.

- Bring Maureen's dinner to her room.
- Demand that Maureen joins them for dinner.
- Let Maureen help with meal preparation and cleaning activities.

1. Check your understanding

Making mealtimes more pleasant.

How could Maureen's family deal with the situation?

✗ Bring Maureen dinner in her room.

This is not helpful because it might further isolate Maureen from her family. Maureen may not feel welcome in the new home. She has lost her husband, her own home and now also her previous roles as cook and housekeeper.

✗ Demand that Maureen joins them for dinner.

This is not such a good response because it may make Maureen angry or cause her to further withdraw.

✓ Maureen's family should let her help with the meal preparation and cleaning activities.

This is a good response because her family knows Maureen still enjoys cooking and should therefore support her to continue engaging in the activities that she likes and is still able to do.

Now, try to think about involving the person that you care for around mealtimes.

1. Activity	
<p>Mealtime activities</p> <p><i>Please select all activities from the list below that you think the person you care for can still engage in and would enjoy.</i></p>	
Mealtime activities	Example
<input type="checkbox"/> Shopping together	Let the person living with dementia choose what food and drinks they like to buy for breakfast, lunch and dinner.
<input type="checkbox"/> Meal preparation	Let the person living with dementia help chopping, stirring, or cooking.
<input type="checkbox"/> Preparation of the table	Let the person living with dementia lay the table for breakfast, lunch and dinner.
<input type="checkbox"/> Cleaning the table	Let the person living with dementia remove everything from the dining table and wipe the table.
<input type="checkbox"/> Washing or drying dishes	Let the person living 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.

2. Promoting a good mealtime atmosphere

Mealtime is a good opportunity for carers to show their care and support for the person living with dementia. An enjoyable mealtime atmosphere may help encourage them to eat and drink. Let's look at an example again.

Spilling food

Phillip has Alzheimer's disease and lives with his oldest son since his wife passed away a year ago. The family now has four generations who eat together at the table. Phillip sees the mealtime as the best time of the day. Recently, Phillip's hands have started to tremble, and he often spills or drops food on the table and the floor.

2. Check your understanding

Promoting a good mealtime atmosphere.

How would you advise Phillip's son to deal with this situation? *Please check the responses that you feel are appropriate.*

- Buy adaptive eating and drinking aids from the shop for Phillip.
- Set up a separate table for his father to eat in his own bedroom, because spilling and dropping food may make the family irritated.
- Organise a family meeting to ask all family members to think of more positive and constructive ways to respond to the situation at mealtimes.

2. Check your understanding

Promoting a good mealtime atmosphere.

How could Phillip's son deal with the situation?

✓ Buy adaptive eating and drinking aids from the shop for Phillip.

This is a good response because Phillip's son recognises that his father is no longer able to manage eating and drinking using the usual utensils. By providing other utensils he is trying to solve this problem.

✗ 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 Phillip feel sad or angry, which might prevent him from eating and drinking properly.

✓ Organise a family meeting to ask all family members to think of more positive and constructive ways to respond to the situation at mealtimes.

This is a good response because Phillip's son is trying to provide a positive mealtime atmosphere for everyone.

Health conditions

Common health conditions can affect eating and drinking. The activity below teaches you how to improve these conditions if they are present.

2. Activity		
Health condition	Changes that you may have observed	Recommended actions you may try
Poor appetite	<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 appealing: use different textures, flavours, smells, tastes, sounds and colours that the person enjoys • Eat with the family, rather than alone • Play soft music that they like during mealtime • Increase physical activities that they can do during the day
Toothache	<input type="checkbox"/> Refuses to eat and drink <input type="checkbox"/> Is restless <input type="checkbox"/> Has a facial expression indicating pain	<ul style="list-style-type: none"> • Ask whether the person is in pain • Ask them to point out the area of pain • Check whether there are loose teeth, mouth ulcers, etc. • Seek help from a doctor or dentist
Poorly fitting artificial dentures	<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"/> Refusing to wear dentures <input type="checkbox"/> Throws dentures on the floor	<ul style="list-style-type: none"> • See above for toothache • Check that the dentures are in good condition and fit properly

Body pain	<input type="checkbox"/> Refuses to eat and drink <input type="checkbox"/> Is restless <input type="checkbox"/> Unusual body postures <input type="checkbox"/> Has a facial expression of pain	<ul style="list-style-type: none"> • Ask whether the person is in pain • Ask them to point out the area of pain • Seek help from a doctor
Does not have bowel movement for more than 7 days	<input type="checkbox"/> Hard and dry faeces <input type="checkbox"/> Difficulty passing faeces/straining <input type="checkbox"/> Having a feeling of incomplete bowel movements <input type="checkbox"/> Hard stomach <input type="checkbox"/> Nausea and vomiting <input type="checkbox"/> Becomes anxious or agitated	<ul style="list-style-type: none"> • Seek help from a doctor • Upon resolution of the problem: <ul style="list-style-type: none"> • Increase fibre in diet • Increase drinking of fluids • Increase physical activity
Diarrhoea	<input type="checkbox"/> Liquid faeces <input type="checkbox"/> Increased number of bowel movements <input type="checkbox"/> Incontinency and difficulty controlling bowel movements	<ul style="list-style-type: none"> • Seek help from a doctor
Side effects from medications	<input type="checkbox"/> Nausea, vomiting, liquid faeces or constipation <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"> • Seek help from a doctor

Memory loss; forgets to eat or drink	<input type="checkbox"/> Asks when the next meal is even if it already happened <input type="checkbox"/> The person says that they are hungry even if they already ate	<ul style="list-style-type: none"> • Remind the person to eat and drink regularly • Model eating and drinking (i.e. eat and drink with the person) • Provide snacks between meal times
Depression	<input type="checkbox"/> Refuses to eat or says they are not hungry <input type="checkbox"/> Eats small amounts of food <input type="checkbox"/> Has no interest in food	<ul style="list-style-type: none"> • Seek help from a doctor
Weight loss	<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 they will like • Increase flavourful foods as the person's taste might be impaired • Seek advice from a doctor
Weight gain	<input type="checkbox"/> Eats all the food that is served <input type="checkbox"/> Eats more snacks than before because they forget that they already ate <input type="checkbox"/> Is obsessed with food	<ul style="list-style-type: none"> • Model eating and drinking (i.e. eat and drink with the person) • Serve smaller portions • Remove the plate when the person indicates that they are full • Provide low calorie snacks

3. Preventing dehydration

People living with dementia have a higher risk of being dehydrated.

There can be several reasons for this:

- inability to explain their needs;
- decreased thirst sensation;
- not offered enough to drink; and,
- swallowing problems in the late stage of dementia.

The person you care for needs to be encouraged to drink 8-10 glasses (1500-2000 millilitres) 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 also notices that Ben seems very tired, walks very slowly and then collapses on the floor. Ben is sent to the local hospital's Emergency Department and is diagnosed with dehydration. After treatment in the hospital, Ben has recovered and is able to go home again.

3. Check your understanding

Severe dehydration.

How would you advise Mary to deal with the situation after Ben is discharged home? *Please select all the responses that you feel are appropriate.*

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

3. Check your understanding

Severe dehydration.

How could Mary 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 so good even though she is respecting Ben's autonomy. Since people with dementia have decreased thirst sensation, it could be dangerous to leave it up to them whether to drink or not without reminding them. If not reminded, Ben may get dehydrated again and collapse.

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

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

- ✓ 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 bathroom.

3. Activity

Timetable for drinking

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

Time of day	Type of fluid (e.g. water)	Amount of fluid (e.g. 3 glasses)
Morning - Noon		
Noon - Dinnertime		
Dinnertime - Bedtime*		

*Note that drinking after dinnertime may potentially increase night time visits to the toilet.

WARNING! If the person you care for is not allowed fluids due to a heart condition, you need to follow the doctor's order regarding how much to drink.

Let's review what you have learned

- The person you care for needs to be encouraged and supported to eat and drink.
- You can engage the person you care for in a variety of mealtime activities to create a pleasant mealtime for them, which helps to improve self-worth and a feeling of achievement.
- Eating and drinking can be facilitated by modifying food, utensils and the environment.
- You can maintain good eating and drinking for the person you care for by improving their health condition. Seeking assistance from health professionals might be necessary.
- To help prevent dehydration, it is important to prompt the person living with dementia to drink.
- Record and monitor the amount of fluid they consume.

Session 2. Eating, drinking – preventing health problems

Why is this session important?

Dementia can affect eating and drinking in various ways depending on the stage of dementia and other health conditions.

How will this session help me?

By learning how to improve eating and drinking, prevent weight loss and promote drinking and eating safely.

What will I learn?

1. Improve eating and prevent weight loss.
2. Help the person you care for to eat safely and prevent aspiration pneumonia.

1. Improve eating and prevent weight loss

In the late stages of dementia, a person living with dementia may experience difficulty chewing and swallowing. Reduced abilities to smell, taste and see may also happen due to ageing and dementia. These can have a negative impact on the person's health. Depression and changes in eating patterns may also impair eating and digestion.

Let's look at an example

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

1. Check your understanding

How to improve eating and prevent weight loss.

What would you advise Ling to do to improve Chiu's eating? *Please select all the responses that you feel 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 that Chiu has access to foods she enjoys eating.

1. Check your understanding

How to improve eating and prevent weight loss.

What would you advise Ling to do to improve Chiu's eating?

✓ Be flexible to have meals when her mother is awake.

This is a good response. People in late stages of dementia need rest, so flexibility in planning meals will be very helpful when they are sleeping during normal mealtimes.

✓ Keep a record of what and how often her mother eats in a diary.

This is a good response. Recording what people with dementia eat is important. This way, carers will better understand when and what kind of food is needed for sufficient food intake.

✓ Ensure Chiu has access to foods that she enjoys eating.

This is a good response. What foods did she enjoy eating before her diagnosis of dementia? What foods does she seem to enjoy now?

2. Help the person you care for to eat safely and prevent aspiration pneumonia

People with dementia may experience the problems listed below.

- People with dementia may not be able to judge what can or cannot be eaten. They may eat inedible materials that are within reach when feeling hungry. Make sure to keep inedible materials and chemicals in safe places.
- If the person is in the late stages of dementia, they may experience swallowing difficulties that can cause a lung infection called aspiration pneumonia. Aspiration pneumonia occurs when food is swallowed in the wrong way and goes into the person's lungs instead of their stomach. This can then cause an infection. Eating, drinking and feeding methods may need to be modified to prevent this life-threatening problem.

Inedible materials

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

2. Check your understanding

Inedible materials.

What do you think Eileen should do? *Please select all the responses that you feel are appropriate.*

- Recognise that she needs to lock household chemicals, such as dishwashing soap, in a cabinet.
- 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.

2. Check your understanding

Inedible materials.

What do you think Eileen should do?

✓ Recognise that she needs to lock household chemicals, such as dishwashing soap, in a cabinet.

This is a good response. Keeping these dangerous things away will help protect the person living with dementia.

✗ Leave some inedible household materials in the places Oliver is able to reach because she thinks that Oliver should be taught that those cannot be eaten.

This is not a good response. People in late stages of dementia can have a changed judgement of what they can or cannot eat. Keeping these dangerous things away from them is very important.

Helping a person to eat safely

Barbara has been living with dementia for 10 years and is bedridden. Her husband, James, helps her to eat safely. Recently, he found Barbara has difficulty swallowing soft foods that he makes for her. He also notices that she coughs when she drinks something. She seems to have a high temperature and is admitted to the hospital.

Barbara is diagnosed with aspiration pneumonia. After a month of treatment in the hospital, Barbara has recovered and is discharged home. The doctor orders a healthy, soft diet and thickened drinks for Barbara to consume at home to prevent future aspiration pneumonia.

3. Check your understanding

Helping a person to eat safely.

What do you think James should do? *Please select all the responses that you feel are appropriate.*

- Learn how to make healthy, soft foods and thickened drinks for Barbara.
- Not pay attention to how Barbara is sitting when he helps her eat.

Tip

A healthy soft diet can be made by hand without using an electric blender. Thickened fluids can be made by adding corn flour to water or other fluids while heating and stirring it, until it thickens.

Note: commercial stir-in thickeners are available in the supermarket in many countries.

3. Check your understanding

Helping a person to eat safely.

How can James help Barbara?

✓ Learn how to make healthy, soft food and thickened drinks for Barbara.

This is a good response. Providing healthy, soft food and thickened drinks will make it easier for people in the late stage of dementia to continue to eat and drink on their own and maintain a healthy weight.

✗ Not pay attention to how Barbara is sitting when they are helping her eat.

This is not a good response. They should sit Barbara in an upright position which will help her eat and drink better and prevent aspiration pneumonia.

Let's review what you have learned

- You can modify eating patterns for the person you care for to improve nutrition.
- You can help the person living with dementia to eat and drink safely by keeping inedible materials and household chemicals in a safe place.
- You can help prevent aspiration pneumonia by modifying the foods and drinks that they eat and positioning the person you care for in an upright position when helping them eat.

Session 3. Toileting and continence care

Why is this session important?

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

How will this session help me?

This session will help you think about the health concerns, and assist the person you care for with using the toilet and continence.

What will I learn?

1. Possible solutions for problems such as urinating on the floor or losing bladder control.
2. Using incontinence aids and equipment.

1. Possible solutions for problems such as urinating on the floor or losing bladder control

Urinating on the floor

Dementia can affect a person's ability to find their way to the bathroom and identify the toilet and/or toilet seat.

You should not blame the person living with dementia for this behaviour, nor punish them as this type of response will cause them and yourself stress. Modifying your house may help them use the bathroom.

Let's look at an example

Sandra is taking care of her husband, Brian, since he developed vascular dementia several years ago. Brian is able to go to the toilet himself without assistance, but recently, Sandra finds Brian urinating on the floor outside the toilet.

1. Check your understanding

Prevent urinating on the floor.

What do you think is the right response for Sandra?

Please select the correct answer.

- Make some simple changes to the environment and clothing, such as putting an image of a toilet on the bathroom door, using a contrasting colour for the toilet seat or changing Brian's trousers to a pair of trousers that does not need a belt.
- Tell her husband, Brian, that he is making trouble and punish him by not taking him for his daily walk in their neighbourhood.

Tips

Below are some tips in case the person you care for experiences difficulties using the toilet.

- Put an image of a toilet on the toilet door to help them find it.
- Provide directions to the toilet if they are unable to find it.
- Provide adequate nightlights in the hallway between the bedroom and the toilet.
- Use contrasting colours for the toilet seat.
- Change the person's trousers to some that are easier to remove.
- Provide step-by-step instructions to the person if they forget how to use the toilet.

1. Check your understanding

Prevent urinating on the floor.

What do you think is the right response for Sandra?

✓ Make some simple changes to the environment and clothing, such as putting an image of a toilet on the bathroom door, using a contrasting colour for the toilet seat or changing Brian's trousers to a pair of trousers that doesn't need a belt.

This is the best answer. People with dementia may have difficulties finding and using the toilet, so these changes could help Brian

✗ Tell her husband that he is making trouble and punish him by not taking him for his daily walk in their neighbourhood.

This is not a good answer. You should never threaten people with dementia in this way. Brian will feel ashamed and embarrassed and this response could cause him to become upset.

What other factors may contribute to urinating on the floor or losing bladder control?

Contributing factors	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
Public toilet that is at a distance from the house	<ul style="list-style-type: none"> • Direct the person you care for to the toilet • Provide a bedside commode at night
Not being able to find the toilet	<ul style="list-style-type: none"> • Put a picture of a toilet on the toilet door
Not enough colour contrast of the toilet seat	<ul style="list-style-type: none"> • Replace the toilet seat with a different colour to increase the contrast
Not enough lighting in the hallway	<ul style="list-style-type: none"> • Provide adequate lighting in the hallway
Not enough lighting in the toilet	<ul style="list-style-type: none"> • Provide adequate lighting in 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
Visual impairment	<ul style="list-style-type: none"> • Direct the person you care for to the toilet during the day • Provide a bedside commode at night

Unable to undo trousers	<ul style="list-style-type: none"> • Change trousers to ones that are easily undone and removed • Assist the person you care for to pull on and do up trousers
Forgetting what to do in the toilet	<ul style="list-style-type: none"> • Remind the person you care for of the activities they need to do • Provide step-by-step instructions for them to use the toilet

Urinating in public places

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

You could help prevent these accidents (incontinence) by maintaining a regular, daily schedule to assist the person you care for to go to the toilet. Identifying how often they used the toilet before they had dementia might be helpful. You can also identify whether the person you care for needs to go to the bathroom by the way they behave, e.g. if they become agitated, stressed, anxious or restless.

Let's look at an example

Joshua is taking care of his mother Penelope, who received a diagnosis of dementia 5 years ago. Joshua usually takes his mother shopping in the neighbourhood as she enjoys meeting people.

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

2. Check your understanding

Dealing with losing bladder control.

What do you think is the right response for Joshua? *Please select the correct answer.*

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

2. Check your understanding

Dealing with losing bladder control.

What do you think is the right response for Joshua?

✗ Since this is an embarrassing situation for Joshua, he should stop taking his mother shopping.

This is not the best response because his mother will miss out on a very important pleasant activity.

✓ Joshua should try to make sure that his mother uses the toilet before leaving to go shopping.

This is a good response. It is a good way to help prevent Penelope from losing bladder control.

To improve bladder or bowel control, it may help to fill out a toilet diary.

Toilet use diary		Date:	
Time	Number of trips to the toilet	Number of times lost control of bladder or bowl	What possible causes did you observe?
06:00-09:00			
09:00-12:00			
12:00-15:00			
15:00-18:00			
18:00-21:00			
21:00-00:00			
00:00-03:00			
03:00-06:00			

2. Using incontinence aids and equipment

In the late stages of dementia, the person living with dementia may not be able to control their bladder and bowel movements. Before using any incontinence aids and equipment, you should ask a health professional to help identify the cause(s) of incontinence, as these may be treatable and therefore reversible.

Tip

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.

Let's look at an example

Dawn is in a late stage of Alzheimer's disease and is living with her son's family. Her daughter-in-law, Gillian, is taking care of her. Since Dawn cannot control her bladder or bowel movement, the doctor suggests that Gillian try incontinence pads for Dawn.

In the beginning, Gillian encounters a number of problems:

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

3. Check your understanding

Use of personal hygiene products.

What do you think is the right response for Gillian?

Please select the correct answer.

- Gillian should force Dawn to wear the pad.
- Gillian should remind her mother-in-law to use the bathroom at scheduled times if she is not doing so herself.

3. Check your understanding

Use of personal hygiene products.

What do you think is the right response for Gillian?

✗ Gillian should force Dawn to have the pad on.

This is not the right answer! It's very important to check why a person living with dementia may feel uncomfortable with the pad. Is the size wrong? Is the pad wet and does it need to be changed?

✓ Gillian should remind her mother-in-law to use the toilet at scheduled times if she is not doing so herself.

This is the best answer. Scheduled toilet visits may help minimise incontinence and the need for pads.

Below are some tips for incontinence care.

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 wrong • 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 the doctor regarding the person's behaviour
Still having wet trousers even while using the incontinence pads	<ul style="list-style-type: none"> • The pad size is incorrect • The schedule for using the toilet has not been maintained 	<ul style="list-style-type: none"> • Use the right size and type of pad • Maintain scheduled trips to the toilet to minimise the use of pads
Having sore or irritated skin in the genital area	<ul style="list-style-type: none"> • Incontinence pads can cause skin breakdown • Unsuitable pad size and delaying changes of soiled pads in a timely manner can cause skin infection 	<ul style="list-style-type: none"> • Select suitable pad size and type • Change the soiled pad 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 factors, including incontinence and poor genital care 	<ul style="list-style-type: none"> • See the doctor • Maintain an intake of 6-8 glasses of water or juice per day except if the person is under fluid or dietary 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.
- Modify the environment to reduce the chance of bladder and bowel accidents (for example, put a picture of a toilet on the bathroom door).
- Take the person living 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 living with dementia had before the onset of dementia.
- If these changes do not help, incontinence aids and equipment may help.
- Be aware that the use of incontinence aids can irritate the skin if used incorrectly.
- Maintain good genital care to reduce the risk of a urinary tract infection.
- If the person living with dementia is not under fluid restriction, encourage them to drink 6-8 glasses of water or juice per day to help prevent urinary tract infections.

Session 4. Personal care

Why is this session important?

Dementia affects people's ability to maintain personal care, for example brushing teeth, showering/bathing and grooming. Therefore, assistance with maintaining good personal care is very important. Poor personal care may lead to infections and other health problems, low self-esteem and withdrawal from social activities for people with dementia.

How will this session help me?

This session will help you think about the health concerns of the person you care for and assist them with personal care.

What will I learn?

1. Modifying the environment to make personal care easier.
2. Tips for daily dressing, oral care and assisting in bathing.

1. Modifying the environment to make personal care easier

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

For example, when you cannot find your toothbrush and toothpaste due to memory loss, it will be difficult to brush your teeth.

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

Let's look at an example

Mariam has Alzheimer's disease, but she is able to care for herself without assistance from family members.

Recently, her husband, Mohammed, notices that she sits at the table for breakfast in a nightgown without having washed her face, brushed her hair, or doing her make-up as she usually does.

There may be several reasons why Mariam may not undertake personal care before breakfast anymore. One of them is that she may be depressed. For more information on depression please see **Session 4. Depression, anxiety or apathy in Module 5.**

1. Check your understanding

Promoting personal hygiene.

What would you think is the right response for Mohammed? *Please select the correct answer.*

- Put personal care items in the order of use and label them with large print words and different colours for Mariam to read.
- Ask their daughter-in-law to take Mariam from the table to the bathing room and assist her with washing and changing clothes.

Tips

Below are some tips that may help people with dementia find items or places, and to do personal care activities independently.

- To find the bathroom or toilet: put a picture or words on the bathroom door or direct the person to the bathroom.
- To find personal care materials: make items easy to see in the bathroom, label items with their name, use pictures or words on the bathroom wall to point out items, use contrasting colours.
- To help turn the tap on and off: use colour indicators to label the direction for turning the tap on and off, instruct the person to turn the tap on and turn off, assist if needed.

1. Check your understanding

Promoting personal hygiene.

What would you think is the right response for Mohammed?

✓ Put personal care items in the order of use and label them with large print words and different colours for Mariam to read.

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

✗ Ask their daughter-in-law to take Mariam from the table to the bathing room and assist her with washing and changing clothes.

This is not the right answer. Mohammed needs to first find out what the reason is for her not doing the personal care before breakfast anymore. Also, instead of assuming, Mohammed needs to ask his wife first if she wants help from their daughter-in-law. Not asking may upset her.

2. Tips for daily dressing, oral care and assisting in bathing

Difficulties choosing the right clothes or dressing appropriately

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

You can assist the person you care for to choose clothes and to dress in a way that makes the most use of their remaining skills. You should not take over these tasks when the person living with dementia can still perform them.

Let's look at an example

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

2. Check your understanding

Getting dressed.

What would you think is the right response for Jane? *Please select the correct answer.*

- 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 trousers that do not need a belt and shoes that do not need laces.

2. Check your understanding

Getting dressed.

What do you think is the right response for Jane?

✗ Tell Ted that he needs to be less messy, choose clothes for Ted and dress him.

This answer is not helpful. 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 trousers that do not need a belt and shoes that do not need laces.

You are right! It will enable Ted to dress himself, which may also help improve his sense of self-worth.

Difficulties brushing one's teeth

Dementia not only affects memory but also organisation, coordination and concentration, 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 their remaining skills.

Let's look at an example

Keith has Alzheimer's disease but is able to brush his teeth without assistance. Recently, Keith's wife, Nancy notices that her husband makes a big mess in the bathroom with water and toothpaste on the countertop and the floor. She also observes that her husband is unable to brush his teeth in the order that he usually does and can't insert his artificial dentures himself.

3. Check your understanding

Promoting mouth care.

What would you think is the right response for Nancy? *Please select the correct answer.*

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

3. Check your understanding

Promoting mouth care.

What do you think is the right response for Nancy?

✗ Put Keith's dentures in his mouth without asking.

This is not the right answer. Nancy is completely taking over care tasks and not even asking his permission. This response may upset Keith.

✓ Instruct Keith how to brush his teeth in a step-by-step manner and praise him when he is doing well.

This is the best answer. Keith maintains a level of independence in this way, which may also help to improve his sense of self-worth.

1. Activity

Please select any mouth care steps that the person you care for needs help with from the list below.

- Putting toothpaste on the toothbrush
- Brushing teeth in an order that will clean teeth and gums
- Rinsing and cleaning mouth
- Using floss or toothpick to clean between teeth daily
- Applying balm to moisturise lips when needed
- Checking for signs of mouth infections or toothache when needed
- Removing, washing, cleaning, and storing artificial dentures if needed

Difficulties performing personal care and bathing

Dementia may also affect the person's ability to wash their hair and take a shower or a 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.

Let's look at an example

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

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

4. Check your understanding

Resisting help with bathing.

What would you think is the right response for Graham's family? *Please select the correct answer.*

- Since the family notices that Graham thought his son-in-law was a stranger, Judith decides to be with Graham while her son-in-law bathes him.
- They should say to Graham that he should be grateful for the help he receives and if he continues to behave this way, he will be sent to a long-term care facility.

4. Check your understanding

Resisting help with bathing.

What do you think is the right response for Graham's family?

✓ Since the family notices that Graham thinks that his son-in-law is a stranger, Judith decides to be with Graham while her son-in-law bathes him.

Good advice! A person living 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.

✗ They should say to Graham that he should be grateful for the help that 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 Graham feel very distressed.

When assisting with personal care, ask the person living with dementia for their preferences whenever possible and respect their choice. Reassure them that they are safe and comfortable.

People with dementia may show resistance during personal care, or even become challenging like Graham in this example. To read more about how to prevent or deal with challenging behaviour, please refer to **Session 3. Challenging behaviour in Module 5.**

Tips

Below are some tips for assisting with bathing.

- Identify the times of day that the person you care for prefers to have a bath/shower.
- Switch from a shower/bath to a sponge bath. (Note: bath tubs are particularly difficult as they may lead to falls and it may be hard for the carer to lift the person living with dementia out of the tub.)
- If using the shower or bathtub, use a non-slip bath or shower mat to help prevent falls.
- Adaptive seating or equipment, such as grab bars and shower chairs, may help.
- For people with dementia who are afraid of water, try to reduce the water flow.

1. Activity

Select any personal care activities that the person living with dementia needs help with. Coach them through the individual steps involved in each activity.

<input type="checkbox"/> Selecting daytime clothing	<input type="checkbox"/> Undressing before shower/bath
<input type="checkbox"/> Putting non-slip mats on the floor	<input type="checkbox"/> Washing hair/body during shower/bath
<input type="checkbox"/> Taking pyjamas off/on	<input type="checkbox"/> Shaving
<input type="checkbox"/> Washing and drying hands	<input type="checkbox"/> Using towel to dry hair/body
<input type="checkbox"/> Washing and drying face	<input type="checkbox"/> Applying body lotion to moisturise skin
<input type="checkbox"/> Washing and drying feet	<input type="checkbox"/> Checking for signs of skin problems
<input type="checkbox"/> Washing and drying genital areas	<input type="checkbox"/> Dressing after shower/bath
<input type="checkbox"/> Drying body after washing	<input type="checkbox"/> Combing hair
<input type="checkbox"/> Changing night clothing into daytime clothing	<input type="checkbox"/> Using electrical hairdryer
<input type="checkbox"/> Preparing for a shower/bath	<input type="checkbox"/> Putting on make-up
<input type="checkbox"/> Turning the tap on, adjusting the water temperature needed and preparing for bathing	<input type="checkbox"/> Cutting fingernails and toenails when needed

Let's review what you have learned

- Engage the person living with dementia in personal and mouth care as long as possible, using remaining skills.
- Modify the environment, for example by providing guidance, encouraging them to select different types of clothes or providing seating while performing personal care.
- Engage the person you care for in daily decision making, for example what clothes they would like to wear.
- Keep in mind that not having enough assistance with personal care may cause agitation or challenging behaviour.
- Be compassionate and try to understand why they resist being assisted with personal care.
- Keep in mind that not having enough assistance with personal care may cause agitation or challenging behaviour.

Session 5. An enjoyable day

Why is this session important?

It is important to maintain routines and activities that are familiar to a person living with dementia to help create an enjoyable day.

How will this session help me?

By learning how to adapt routines and activities as the abilities of the person living with dementia change.

What will I learn?

1. Establishing routines for the person with dementia during the day.
2. Adapting routines to the changing abilities of the person you care for.

1. Establishing routines for the person with dementia during the day

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

This is also true for you.

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 that a person does every day or almost every day.

It is important to try and continue the routine of the person living with dementia for as long as possible. This is reassuring and can reduce stress at home. Be aware of the person's usual routine. If there has not been a routine, for example in the evening, then it is helpful to develop one and follow it regularly. This might include drinking a cup of tea, listening to soothing music, or saying prayers.

It is helpful to have routines for other times of the day as well, such as immediately after getting up from bed in the morning, when having the midday meal or planning what to do in the afternoon.

The simpler and easier these routines are to follow, the more likely they will reassure the person living with dementia and reduce stress at home.

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 one's teeth, getting dressed and then sitting down for breakfast. As dementia progresses, the person you care for will need help with each of these activities 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 that 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 the person's prior interests and current abilities.

In the early stages of dementia, your family member or friend may be able to do things that they like to do with minimal guidance. However, as the disease progresses, activities will need to be changed or modified so that they can still enjoy them. It's important to be flexible and creative in figuring out the routines and then adapting them as needed over time.

Let's look at an example

Angela has dementia and is used to drinking tea immediately after getting ready in the morning. Her daughter Valerie really wants to encourage her mother to walk every day, as recommended by her doctor. Valerie is not aware of her mother's usual routine, so when she tries to get Angela to go for a walk right after breakfast, Angela refuses.

1. Check your understanding

Morning routines.

What suggestions do you have for Valerie?

Please select the correct answer from the responses below.

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

1. Check your understanding

Morning routines.

What suggestions do you have for Valerie?

✓ If Valerie suggests keeping to the routine by drinking tea first, it is likely that Angela will go for a walk afterwards.

Right! It will help Angela keep her routine.

✓ Valerie should ask Angela what activities she is used to and in what order she would like to do them.

Indeed! Valerie can learn Angela's routines. However, this may only work if Angela is in the early or middle stages of dementia. Later on, Angela might not be able to remember her routines.

✗ Valerie should force Angela to go for a walk because it was advised by the doctor.

This response is not so good because it may make Angela feel agitated and upset.

Keep in Mind

It is important to keep routines (something the person living with dementia 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 honour the person's dignity. Think for a moment about how you might feel if your routines were changed or planned by another person.

2. Adapting routines to the changing abilities of the person you care for

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

Here are some common routines to establish during the day for a person living with dementia.

In the morning

Wake up at the same time every day

- **Adaptation:** help might be needed to wake up because the person with dementia may not be able to set the alarm correctly.

Have breakfast at a fixed time. In the earlier stages of dementia, your family member or friend might be able to make their own breakfast.

- **Adaptation:** the person with dementia may need someone to lay out ingredients. Later on, they may need more help with preparing and eating breakfast.

Performing grooming activities, such as brushing teeth, bathing / cleaning, getting dressed. In the early stages, the person you care for may be able to do all of these activities without help.

- **Adaptation:** items such as the toothbrush, toothpaste, etc. can be laid out in the bathroom in plain view to prompt the activity. In the later stages of dementia, it may be necessary for someone to do these activities for, or with, the person living with dementia.

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 living with dementia change.

During the day

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

Let's look at an example

Angela loves baking and used to prepare special cakes and cookies for family gatherings. Now that she has dementia, she sometimes forgets the ingredients and the order in which to put them in.

At first, Angela uses a cookbook to help her continue baking but she finds this increasingly difficult. The cakes and cookies do not taste very good and have to be thrown away. Valerie wants to help her mother keep up this activity.

2. Check your understanding

Maintaining prior activities and interests during the day.

What suggestions do you have for Valerie?

Please select the correct answer from the responses below.

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

2. Check your understanding

Maintaining prior activities and interests during the day.

What suggestions do you have for Valerie?

✗ Valerie 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. Valerie has not tried to come up with an alternative to help her mother and it may make Angela feel upset.

✓ Valerie should go shopping with her mother and buy easy to prepare cakes and cookies, "out of the box", with limited added work to enable Angela to continue to do some cooking and baking.

This is a good suggestion. It respects Angela's routine but adapts the activity to her current abilities.

✓ As Angela's abilities change, Valerie could plan some time during the afternoon to bake and cook with her mother.

This is an excellent plan for the future! It allows Angela to continue her routine with support as needed.

What is 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 carers. The exact cause of sundowning is not yet clear but a loss of routine might be one of the reasons. Try to give the person something meaningful to do at this time of day.

Let's look at an example

Angela likes to go to a community centre every day from 12:00 until 15:00. She has lunch there and meets friends to do activities together. At first Angela walks there by herself but as her memory loss becomes more severe, she cannot find her way to the centre anymore. Valerie asks another family member to take Angela to the centre and bring her back home. This works well for a while but eventually the family member is unable to take Angela. Valerie does not know what to do since she cannot be with Angela every afternoon.

3. Check your understanding

Maintaining activities and interests outside the house.

What suggestions do you have for Valerie?

Please select the correct answer from the responses below.

- Valerie could ask another family member to help Angela.
- Valerie could ask other people outside the family to walk with Angela to the community centre, such as a neighbour.
- Valerie could tell her mother to do a quiet activity in the afternoons such as watching television or listening to the radio.

3. Check your understanding

Maintaining activities and interests outside the house.

What suggestions do you have for Valerie?

- ✓ Valerie could ask another family member to help Angela.

This is a good idea. If others can come on a regular basis, this is the best solution for Angela as it maintains her routine and adapts to Angela's changing abilities.

- ✓ Valerie could ask other people outside the family to walk with Angela to the community centre such as a neighbour.

This is a good response. Family is not always available and sometimes other people don't know how they can help. This is a concrete way that Valerie could ask for help.

- ✗ Valerie could tell her mother to do a quiet activity in the afternoons like watching television or listening to the radio.

This is not likely to be a good solution at this time. It isolates Angela from other people and doesn't allow her to engage in the activities that she enjoys. It might be a better solution in the later stages of dementia, when Angela's abilities change.

Keep in Mind

It is important to respect the daily routines of the person you care for and maintain them for as long as possible.

When this is no longer possible, adapt the routine to the best of your ability so that the key activities that are important to the person with dementia are maintained for as long as possible.

At bedtime

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

Valerie wants to adapt this routine to fit Angela's current abilities.

4. Check your understanding

Adapting routines.

What suggestions do you have for Valerie?

Please select the correct answer from the responses below.

- Valerie could read to Angela for 15 minutes before she goes to sleep.
- Valerie should take the books out of Angela's room.
- Valerie should get some books that have more pictures than words or audiotapes for Angela.

4. Check your understanding

Adapting routines.

What suggestions do you have for Valerie?

✓ Valerie could read to Angela for 15 minutes before she goes to sleep.

This is a good idea. It helps Angela to continue enjoying reading but adapts the activity to her abilities.

✗ Valerie should take the books out of Angela's room.

This is not a good response because it does not recognise how important reading is to Angela. Valerie should recognise that her mother and her can still share this routine; it just needs to be adapted.

✓ Valerie should get some books that have more pictures than words or audiotapes for Angela.

This is a **helpful adaption** for people in the later stages of dementia who liked to read but find that they are not able to read books with a lot of words.

Tips

- For the morning, afternoon and bedtime, establish and maintain routines for as long as possible, but be prepared to adapt these as the abilities of the person living with dementia change over time.
- Printing out a list of daily routines can help. Do one for each day and put it up in a prominent place.

1. Activity

Do you know any of the routines of the person with dementia that you care for?

Please write down any ideas that you have about routines for the person you care for and how they can be adapted.

Let's review what you have learned

- Establishing routines is important for people living with dementia.
- Try to keep routines similar to the ones your family member or friend had before developing dementia.
- Be prepared to adapt routines as necessary as the abilities of the person living with dementia change over time.

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