

# iSupport For Young People

## Module 4 Providing everyday care



### PROVIDING EVERYDAY CARE

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



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## Session 1. Eating and 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?**

You might or might not be involved in the caring responsibilities that have to do with eating and drinking. However, you might find it useful to learn a little bit about how to improve the eating and drinking of the person with dementia that you help care for. And also how to help them eat and drink safely.

### **1. Improve eating and prevent weight loss**



In the late stages of dementia, a person living with dementia may experience difficulty chewing and swallowing. They might also have difficulty smelling, tasting or seeing the food. These can have a negative impact on the person's health. Depression and changes in eating patterns may also impact on how much they eat and how well they digest the food.

### **Let's look at an example**

Paula has been living with dementia for 9 years and is cared for by her daughter, Mia, son in law and grandson. Recently, Mia notices that her mother sleeps during the day and is very difficult to wake her up for normal mealtimes. Mia believes that her mother is not hungry and does not want to disturb her sleep. A recent check-up showed that Paula 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 Mia and her family to do to improve Paula's eating?** *Please select all the responses that you feel are appropriate.*

- Be flexible and have meals when Paula is awake.
- In a diary, keep a record of what and how often Paula eats.
- Ensure Paula has access to foods she enjoys eating.

## 1. Check your understanding

How to improve eating and prevent weight loss.

**What would you advise Mia and her family to do to improve Paula's eating?**

- ✓ Be flexible and have meals when Paula is awake. **This is likely to be a helpful 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.
- ✓ In a diary, keep a record of what and how often Paula eats. **This is likely to be a helpful response.** Recording what people with dementia eat is important. This way, Paula's family will better understand when and what kind of food she needs.
- ✓ Ensure Paula has access to foods that she enjoys eating. **This is likely to be a helpful response.** What foods did she enjoy eating before her diagnosis of dementia? What foods does she seem to enjoy now?

## 2. Preventing dehydration

When a person doesn't have the normal amount of water in their body they can become dehydrated and feel ill or weak. People living with dementia have a higher risk of being dehydrated. There can be several reasons for this:

- They can find it difficult to explain their needs
- They have a decreased thirst sensation so their body doesn't feel thirsty.
- They might not be offered enough to drink
- They might develop swallowing problems in the late stage of dementia

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

### Severe dehydration

Leah is 16. Her dad, Ben, has Alzheimer's disease, but he is able to eat and drink without assistance from Leah or her mum, Mary. Ben likes to walk a lot. One hot afternoon Leah notices that her dad seems very tired, walks very slowly and then faints.

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.

### 2. Check your understanding

#### Severe dehydration.

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

- Mary and Leah need to let Ben make the decision about when to drink.
- Leah can help Mary during the day to ensure that Ben drinks 8-10 glasses of water during the day.
- Leah helps her mum record the time and the amount of fluid her dad actually consumes.

## 2. Check your understanding

### Severe dehydration.

**How would you advise Leah and her mum Mary to deal with the situation after Ben is discharged home?**

- ✗ Mary and Leah need to let Ben make the decision about when to drink. **This answer is not so helpful** even though they are respecting Ben's right to make his own decision. Since people with dementia often don't feel thirsty (even if they are), 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 faint.
- ✓ Leah can help Mary during the day to ensure that Ben drinks 8-10 glasses of water during the day. **This is likely to be a helpful response.** Mary and Leah notice that Ben may forget to drink, so they are trying to help him drink enough water every day.
- ✓ Leah helps her mum record the time and the amount of fluid her dad actually consumes. **This is likely to be a helpful 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.

## 1. Activity

### Timetable for drinking

You and your family may want to use the timetable below 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 your family member with dementia is not allowed fluids due to a heart condition, you need to follow the doctor's order regarding how much to drink.

### 3. Help the person you care for to eat safely



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 things that are not meant to be eaten (inedible) if they are within reach when feeling hungry. Families who live with a person with dementia should make sure to keep inedible materials and chemicals in safe places.

- If the person is in the late stages of dementia, they may have difficulty swallowing and this 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. Families will need to modify the way they help the person with dementia eat and drink to prevent this life-threatening problem.

### **Inedible materials**

Oliver has been living with dementia for 10 years and is cared for by his wife, Ella and his teenage children Lua and Josh. Ella starts to observe her husband closely during the day. Recently, the family notice that the soaps Ella puts in the kitchen and bathroom have disappeared. They also notice that Oliver is eating the flowers that are on the dining table. One day Lua and Josh see Oliver go to the kitchen and mistakenly pick up a bottle of dishwashing detergent to drink.

### **3. Check your understanding**

#### **Inedible materials**

**What do you think Ella, Lua and Josh could do?** *Please select all the responses that you feel are appropriate.*

- Recognise that they need 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 Ella thinks Oliver should be taught that those cannot be eaten.

### 3. Check your understanding

#### Inedible materials

**What do you think Ella, Lua and Josh could do?**

✓ Recognise that they need to lock household chemicals, such as dishwashing soap, in a cabinet. **This is likely to be a helpful 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 Ella thinks that Oliver should be taught that those cannot be eaten. **This is not a helpful 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.

***Remember** - As a young person make sure that you are only doing as much as you are comfortable with and that you speak to your parents or an adult if you feel you are not coping or things are getting too difficult.*

### Let's look at an example

Ana has been living with dementia for 10 years and is bedridden. Her son, Liam and his wife help her to eat safely. Sometimes her 16 year old grandson Callum helps as well.

Recently, the family found that Ana has difficulty swallowing soft foods that Callum's mum makes for her. They also notice that she coughs when she drinks something. She seems to have a high temperature and is admitted to the hospital.

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

#### 4. Check your understanding

Helping a person to eat safely.

**What do you think Callum and his family could do?** *Please select all the responses that you feel are appropriate.*

- Learn how to make healthy, soft foods and thickened drinks for Ana.
- Not pay attention to how Ana is sitting when they help 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.

#### 4. Check your understanding

##### Helping a person to eat safely.

##### What do you think Callum and his family could do?

✓ Learn how to make healthy, soft food and thickened drinks for Ana. **This is likely to be a helpful 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 Ana is sitting when they are helping her eat. **This is not a helpful response.** They should sit Ana in an upright position which will help her eat and drink better and prevent aspiration pneumonia.

##### Let's review what we have talked about

- Your family and you can modify eating patterns for the person you help care for to improve nutrition.
- Your family and you can help the person living with dementia to eat and drink safely by keeping inedible materials and household chemicals in a safe place.
- Aspiration pneumonia can be prevented by modifying the foods and drinks that the person with dementia eats and also by positioning him/her in an upright position when helping them eat.
- To help prevent dehydration, it is important to prompt the person living with dementia to drink.
- It is a good idea to record and monitor the amount of fluid they consume

## Session 2. 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.

### What will we talk about?

1. Making mealtimes more pleasant.
2. What you and your family can do to promote a good mealtime atmosphere.
3. Health conditions that affect eating and drinking.

### 1. Making mealtimes more pleasant



Engaging people with dementia in simple tasks around meal preparation helps to make the most of their skills, promotes feelings of self-worth, and helps them enjoy mealtimes.

### Let's look at an example

Siya is living with dementia. Until recently she enjoyed and was able to cook every day for her husband Rashid and teenage son Noa. Recently, she is no longer able to cook safely on her own. Not being able to cook has made Siya very sad and lately she says she is not hungry and does not join the family for dinner.

## 1. Check your understanding

Making mealtimes more pleasant.

**How can Rashid and Noa deal with this situation?**

*Please select the answer that you feel is likely to be helpful.*

- Bring Siya's dinner to her room.
- Demand that Siya joins them for dinner.
- Let Siya help with meal preparation as much as possible.

## 1. Check your understanding

### Making mealtimes more pleasant.

#### How can Rashid and Noa deal with this situation?

- ✗ Bring Siya dinner in her room. **This is not helpful** because it might further isolate Siya from Rashid and Noa. She has lost her role as the cook and is feeling sad about it.
- ✗ Demand that Siya joins them for dinner. **This is not such a helpful response** because it may make Siya angry or cause her to feel sad.
- ✓ Rashid and Noa should let Siya help with the meal preparation as much as possible. **This is a helpful response** because Rashid and Noa know Siya still enjoys cooking and should therefore support her to continue engaging in the activities that she likes and is still able to do.

1. Activity	
<b>Mealtime activities</b>	
<i>Please select all activities from the list below that you think the person you help care for can still engage in and would enjoy.</i>	
Mealtime activities	Example
<input type="checkbox"/> Shopping together	If you and your family go shopping with the person living with dementia you can let them choose what food and drinks they like to buy for a meal.
<input type="checkbox"/> Meal preparation	Let the person living with dementia help you with chopping, stirring, or cooking.
<input type="checkbox"/> Preparation of the table	Let the person living with dementia lay the table for meals.
<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 the dishes	Let the person living with dementia put dishes in the dishwasher or the sink. They can also wash and dry the dishes.

## 2. Promoting a good mealtime atmosphere

Mealtimes are a good opportunity for you and your family to show your 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.

### Spilling food

Pete has Alzheimer's disease and lives with his son, daughter in law and granddaughter Anwen, who is 13. The family now has three generations who eat together at the table. Pete sees the mealtime as the best time of the day. Recently, his 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 Anwen and her family to deal with this situation?**

*Please check the responses that you feel are appropriate.*

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

## 2. Check your understanding

### Promoting a good mealtime atmosphere.

**How would you advise Anwen and her family to deal with this situation?**

- ✓ Buy adaptive eating and drinking aids from the shop for Pete. **This is likely to be a helpful response** because Pete's family recognises that grandad is no longer able to manage eating and drinking using the usual utensils. By providing other utensils the family is trying to solve this problem.
- ✗ Set up a separate table for granddad to eat in his own bedroom, because spilling and dropping food may make the family irritated. **This is not helpful** because separation will make Pete feel sad or angry, which might prevent him from eating and drinking properly.
- ✓ Organise a family meeting so they can all think of more positive and constructive ways to respond to the situation at mealtimes. **This is likely to be a helpful response** because Pete's family is trying to provide a positive mealtime atmosphere for everyone.

## Health conditions

Common health conditions can affect eating and drinking. The activity below shows ideas on how to improve these conditions. You might want to discuss this activity with your family member who is the main carer for the person living with dementia.

2. Activity		
Health condition	Changes that you and your family may have observed	Suggestions that your family may try
Poor appetite	<input checked="" 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"> <li>• Make food appealing: use different textures, flavours, smells, tastes, sounds and colours that the person enjoys</li> <li>• Eat with the family, rather than alone</li> <li>• Play soft music that they like during mealtime</li> <li>• Increase physical activities that they can do during the day</li> </ul>
Toothache	<input checked="" 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"> <li>• Ask whether the person is in pain</li> <li>• Ask them to point out the area of pain</li> <li>• Check whether there are loose teeth, mouth ulcers, etc.</li> <li>• Seek help from a doctor or dentist</li> </ul>

<p>Poorly fitting artificial dentures</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Refuses to eat and drink</li> <li><input type="checkbox"/> Is restless</li> <li><input type="checkbox"/> Has facial expression indicating pain</li> <li><input type="checkbox"/> Refusing to wear dentures</li> <li><input type="checkbox"/> Throws dentures on the floor</li> </ul>	<ul style="list-style-type: none"> <li>• See above for toothache</li> <li>• Check that the dentures are in good condition and fit properly</li> </ul>
<p>Body pain</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Refuses to eat and drink</li> <li><input type="checkbox"/> Is restless</li> <li><input type="checkbox"/> Unusual body postures</li> <li><input type="checkbox"/> Has facial expression indicating pain</li> </ul>	<ul style="list-style-type: none"> <li>• Ask whether the person is in pain</li> <li>• Ask them to point out the area of pain (where it hurts)</li> <li>• Seek help from a doctor</li> </ul>
<p>Does not have bowel movement for more than 7 days</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Hard and dry faeces</li> <li><input type="checkbox"/> Difficulty passing faeces/straining</li> <li><input type="checkbox"/> Having a feeling of incomplete bowel movements</li> <li><input type="checkbox"/> Hard stomach</li> <li><input type="checkbox"/> Nausea and vomiting</li> <li><input type="checkbox"/> Becomes anxious or agitated</li> </ul>	<ul style="list-style-type: none"> <li>• Seek help from a doctor</li> <li>• Upon resolution of the problem: <ul style="list-style-type: none"> <li>○ Increase fibre in diet</li> <li>○ Increase drinking of fluids</li> <li>○ Increase physical activity</li> </ul> </li> </ul>
<p>Diarrhoea</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Liquid faeces</li> <li><input type="checkbox"/> Increased number of bowel movements</li> <li><input type="checkbox"/> Incontinency and difficulty controlling bowel movements</li> </ul>	<ul style="list-style-type: none"> <li>• Seek help from a doctor</li> </ul>

<p>Side effects from medications</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Nausea, vomiting, liquid faeces or constipation</li> <li><input type="checkbox"/> Does not want to have a meal</li> <li><input type="checkbox"/> Eats only small amounts of food</li> </ul>	<ul style="list-style-type: none"> <li>• Seek help from a doctor</li> </ul>
<p>Memory loss; forgets to eat or drink</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Asks when the next meal is even if it already happened</li> <li><input type="checkbox"/> The person says that they are hungry even if they already ate</li> </ul>	<ul style="list-style-type: none"> <li>• Remind the person to eat and drink regularly</li> <li>• Model eating and drinking (i.e. eat and drink with the person)</li> <li>• Provide snacks between meal times</li> </ul>
<p>Depression</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Refuses to eat or says they are not hungry</li> <li><input type="checkbox"/> Eats small amounts of food</li> <li><input type="checkbox"/> Has no interest in food</li> </ul>	<ul style="list-style-type: none"> <li>• Seek help from a doctor</li> </ul>
<p>Weight loss</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Forgets to eat</li> <li><input type="checkbox"/> Eats smaller amounts of food</li> <li><input type="checkbox"/> Eats regular amounts of food but still loses weight</li> </ul>	<ul style="list-style-type: none"> <li>• Increase the amount of food</li> <li>• Provide foods that they will like</li> <li>• Increase flavourful foods as the person's taste might be impaired</li> <li>• Seek advice from a doctor</li> </ul>

<p>Weight gain</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Eats all the food that is served</li> <li><input type="checkbox"/> Eats more snacks than before because they forget that they already ate</li> <li><input type="checkbox"/> Is obsessed with food</li> </ul>	<ul style="list-style-type: none"> <li>• Model eating and drinking (i.e. eat and drink with the person)</li> <li>• Serve smaller portions</li> <li>• Remove the plate when the person indicates that they are full</li> <li>• Provide low calorie snacks</li> </ul>
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**Let's review what we have talked about**

- The person you help care for needs to be encouraged and supported to eat and drink.
- You and your family can engage the person you help care for in a variety of mealtime activities to create a pleasant mealtime for them, which helps to improve self-worth and feelings of achievement.
- Modifying food, utensils and the home environment can help the person living with dementia eat and drink better.
- Your family can maintain good eating and drinking for the person you help care for by improving their health condition. Seeking assistance from health professionals might be necessary.

## Session 3. Toileting and continence care

### **Why is this session important?**

Poor toileting and incontinence (not being able to get to the toilet in time) 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 how you and your family can help the person living with dementia with using the toilet and continence.

### **What will I learn?**

We will show you some possible solutions for problems such as urinating on the floor and we will also talk about 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.

### **Remember**

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

## Let's look at an example

Ethan is 17. He helps his mum care for his dad, Will, since he developed early onset dementia three years ago. Will is able to go to the toilet himself without assistance, but recently, Ethan finds Will urinating on the floor outside the toilet.

### 1. Check your understanding

Prevent urinating on the floor.

**What do you think would be a helpful response for Ethan and his mum?**

*Please select the answer that you feel is more helpful.*

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

## Tips

Below are some tips for you and your family in case the person you help 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 night lights in the hallway between the bedroom and the toilet.
- Use contrasting colours for the toilet seat.
- Change the person's trousers/skirt 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 would be a helpful response for Ethan and his mum?**

✓ Make some simple changes to the house and clothing, such as putting an image of a toilet on the bathroom door, using a contrasting colour for the toilet seat or changing Will's trousers to a pair of trousers that doesn't need a belt. **This is likely to be the most helpful answer.** People with dementia may have difficulties finding and using the toilet, so these changes could help Will.

✗ Tell Will that he is making trouble and punish him by not taking him for his daily walk in their neighbourhood. **This is not a helpful answer.** You should never threaten people with dementia in this way. Will can feel ashamed and embarrassed and this response could cause him to become upset.

## 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.

Your family could help prevent these accidents (incontinence) by maintaining a regular, daily schedule to assist the person you help care for to go to the toilet. Identifying how often they used the toilet before they had dementia might also be helpful. You and your family can also identify whether the person 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

Amy helps care for her mother Esther, who received a diagnosis of dementia 5 years ago when Amy was 13 years old. She usually takes her mother shopping in the neighbourhood as she enjoys meeting people. Recently, Amy notices that her mother has lost bladder control during the day.

### 2. Check your understanding

#### Dealing with losing bladder control.

**What do you think is the most helpful response for Amy and her family?**  
*Please select from the options below.*

- Since this is an embarrassing situation for Amy, she should stop taking her mother shopping.
- Amy and her family should try to make sure that Esther uses the toilet before leaving to go shopping.

## 2. Check your understanding

### Dealing with losing bladder control.

**What do you think is the most helpful response for Amy and her family?**

- ✗ Since this is an embarrassing situation for Amy, she should stop taking her mother shopping. **This is not a very helpful response** because her mother will miss out on a very important pleasant activity.
  
- ✓ Amy and her family should try to make sure that Esther uses the toilet before leaving to go shopping. **This is likely to be a helpful response.** It is a good way to help prevent Esther from losing bladder control.

## 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, your family should ask a health professional to help identify the cause(s) of incontinence, as these may be treatable and therefore reversible.

There are numerous disposable and/or washable incontinence aids, pads and equipment. When selecting products, your family will consider their cost, effectiveness, comfort, and convenience.

### Let's look at an example

Gloria is in a late stage of Alzheimer's disease and is living with her daughter Marina, her husband and their daughter Lucia, who is 15. Gloria is cared for by Marina but Lucia often helps her mum. Since Gloria cannot control her bladder or bowel movements, the doctor suggests that the family try incontinence pads for Gloria. In the beginning, Marina and Lucia encounter 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.

## 3. Check your understanding

### Use of personal hygiene products.

**What do you think Marina and Lucia could do?** Please select from the options below.

- Marina and Lucia should force Gloria to wear the pad.
- Marina and Lucia should remind Gloria 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 Marina and Lucia could do?**

✗ Marina and Lucia should force Gloria to wear the pad. **This is not a helpful 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?

✓ Marina and Lucia should remind Gloria to use the bathroom at scheduled times if she is not doing so herself. **This is likely to be the most helpful answer.** Scheduled toilet visits may help minimise incontinence and the need to use pads.

#### Let's review what we have talked about

- Do not blame the person after any accidents, such as urinating on the floor.
- Your family may want to try modifying 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.
- If these changes do not help, your family can think about using incontinence aids and equipment which may help.
- Be aware that the use of incontinence aids can irritate the skin if used incorrectly.

## 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, support 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?

We will talk about how you and your family can assist the person with dementia with their personal care. We will also give you some tips for daily dressing, oral care and bathing.

### Remember

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

### 1. 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 and your family can make small changes in your house 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 and her daughter Noor, who is 14, notice that she sits at the table for breakfast in a nightgown without having washed her face, brushed her hair, or done 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. We will talk about depression in the next module.

### 1. Check your understanding

#### Promoting personal hygiene.

**What do you think is the most helpful response for Mohammed and Noor?**  
*Please select from the options below.*

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

### Tips

Here are some tips that your family might want to try to help the person with dementia so they can continue to do their own personal care independently for as long as possible.

- 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 and label them with their name, use pictures or words on the bathroom wall to point out items and 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. Explain how to turn the tap on and turn off and assist them if needed.

### 1. Check your understanding

### Promoting personal hygiene.

**What do you think is the most helpful response for Mohammed and Noor?**

✓ 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 likely to be a helpful 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.

✗ Take Mariam from the table to the bathing room and assist her with washing and changing clothes. **This is not a helpful answer.** Mohammed and Noor need 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. 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 and your family can support the person you help care for to choose clothes and to dress in a way that makes the most use of their remaining skills. It is best to allow the person to be as independent as possible, not taking over

these tasks when they can still do them on their own.

### Let's look at an example

Ted has dementia and is cared for by his wife Jane. His 15 year old son James and his 13 year old daughter Ellie also help as much as they can. 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. James and Ellie also observe 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 do you think is the most helpful response for Jane, James and Ellie?** Please select from the options below.

- 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 most helpful response for Jane, James and Ellie?**

✗ 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. **This is likely to be a very helpful response!** 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 brush one's teeth. If someone's mouth is not well cared for, they are likely to have poor appetite, bad breath, infections of the teeth or gums and other health problems.

You and your family might need to help the person with dementia to brush their teeth but letting them do as much as they can on their own.

### Let's look at an example

Sian's granddad, Arwyn, has dementia and lives with her and her parents. Arwyn is able to brush his teeth without assistance. Recently, Sian and her family notice that granddad makes a big mess in the bathroom with water and toothpaste. They also observe that Arwyn is unable to brush his teeth in the right order and can't insert his artificial dentures himself.

### 3. Check your understanding

#### Promoting mouth care.

**What do you think is the most helpful response for Sian and her family?**  
*Please select from the options below.*

- Put Arwyn's dentures into his mouth without asking.
- Take the time to explain to Arwyn 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 most helpful response for Sian and her family?**

- ✗ Put Arwyn's dentures into his mouth without asking. **This is likely to be the most helpful answer.** This means completely taking over care tasks and not even asking his permission. This response may upset Arwyn.
- ✓ Take the time to explain to Arwyn how to brush his teeth step-by-step and praise him when he is doing well. **This is not a helpful answer.** Arwyn maintains a level of independence in this way, which may also help him feel better about himself.

## 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. As a young person you might or might not be involved in supporting your family member to take a shower or bath. You may find it difficult. It is important that you discuss this with your family members.

### Let's look at an example

Carlos has Alzheimer's disease and is cared for by his wife Sofia. Sofia is not strong enough to help bathe Carlos anymore, so the family decides that their 16 year old son Luis can help with Carlos' weekly bath.

Luis is very kind to Carlos and reassures him that everything is ok. He takes Carlos to the bathroom and start to undress him. Carlos suddenly pushes Luis away, shouts at him and tells him to go away. This makes Luis feel sad and worried.

#### 4. Check your understanding

##### Resisting help with bathing.

**What would you think is the most helpful response for Carlos and his family? Please select from the options below.**

- Since Luis and his mum notice that Carlos was upset about Luis supporting him, Sofia decides to be with them while Luis helps with bathing.
- They should say to Carlos 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 would you think is the most helpful response for Carlos and his family?**

✓ Since Luis and his mum notice that Carlos was upset about Luis supporting him, Sofia decides to be with them while Luis helps with bathing. **Helpful advice!** A person living with dementia may no longer recognise people they used to know and might struggle with changes to routine, so giving them plenty of transition time to get familiar with a new situation is very important. 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.

✗ They should say to Carlos 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. **This is not very helpful advice.** Never threaten people with dementia in this way. Saying things like this will not help the situation and will make Carlos feel very upset.

#### Tips

Here are some tips that might be useful if you help your family with bathing the person living with dementia.

- Identify the times of day that the person you help 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.
- Some people with dementia are afraid of water. In these cases try to reduce the water flow.

## 1. Activity

Select any personal care activities that your family member living with dementia needs help with. Coach them through the individual steps involved in each activity. You might want to do this with an adult who is the main carer of the person with dementia.

<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 and preparing for bathing	<input type="checkbox"/> Cutting fingernails and toenails when needed

**Let's review what you have learned. This can help you and your family:**

- Try to get the person living with dementia to do as much personal and mouth care as possible for as long as possible. This will get them to use their remaining skills.
- Try to 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 help care for in daily decision making, for example what clothes they would like to wear.
- Be compassionate and try to understand why the person with dementia might resist being assisted with personal care.

## 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?**

We will give you tips that you can use to adapt routines and activities as the abilities of the person living with dementia change.

### **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 and your family.

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 that you help care for as long as possible.

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 as it 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.

## Let's look at an example

Evie's grandmother, Martha, has dementia and has recently moved in to live with her family. On Sunday mornings Evie likes encouraging her grandma to go for a walk with her around the park near their house. Martha is used to having a cup of tea just after getting ready in the morning. Evie is not aware of this so when she tries to get her grandma to leave the house, once she is dressed and ready, Martha refuses.

### 1. Check your understanding

#### Morning routines.

**What suggestions do you have for Evie and her family?** *Please select the answer that you feel is likely to be helpful.*

- If Evie keeps to the routine by giving her grandma enough time to drink her tea, it is likely that Martha will join her to go for a morning walk.
- Evie and her family could ask Martha what activities she is used to doing and in what order she would like to do them.
- Evie should force her grandma to go for a walk because the exercise is good for her.

## 1. Check your understanding

### Morning routines.

**What suggestions do you have for Evie and her family?**

- ✓ If Evie keeps to the routine by giving her grandma enough time to drink her tea, it is likely that Martha will join her to go for a morning walk. **This is likely to be a very helpful response!** It will help Martha keep her routine.
- ✓ Evie and her family could ask Martha what activities she is used to doing and in what order she would like to do them. **This is likely to be a very helpful response!** Evie and her family 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.
- ✗ Evie should force her grandma to go for a walk because the exercise is good for her. **This response is not so helpful** because it may make Martha feel agitated and upset.

## 2. Adapting routines to the changing abilities of the person with dementia

It is important to adapt routines as the abilities of the person living with dementia change. It is also very helpful to plan activities that the person enjoys doing, based on their prior interests and current abilities.

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 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.

### During the day

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

## Let's look at an example

Martha loves baking and used to prepare special cakes and cookies for family gatherings. Since moving in with her daughter Penny, she struggles to find her way around the new kitchen and forgets the ingredients and the order in which to put them in. She is finding it increasingly difficult. The cakes and cookies do not taste very good and have to be thrown away. Penny and her 15-year-old granddaughter Evie want to help her keep up this activity.

### 2. Check your understanding

*Maintaining prior activities and interests during the day.*

**What suggestions do you have for Penny and Evie?** *Please select the answers that you feel are likely to be helpful.*

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

## 2. Check your understanding

Maintaining prior activities and interests during the day.

What suggestions do you have for Penny and Evie?

- ✗ 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 and Evie could go shopping with Martha and buy easy to prepare cakes and cookies, "out of the box", with limited added work to enable her to continue to do some cooking and baking. **This is a helpful suggestion.** It respects Martha's routine but adapts the activity to her current abilities.
- ✓ As Martha's abilities change, Evie could plan some time after school or the weekends to bake and cook with her grandma. **This is an excellent plan for the future!** It allows Martha 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. Sometimes it can help if you and your family try to give the person something meaningful to do at this time of day.

## Let's look at an example

Evie's grandma, Martha, likes to go to the community centre every Saturday from 14:00 until 16:00. She meets friends there and they do activities together. Evie helps out by walking with Martha to the centre and then bringing her back home. This works well for a while, but Evie's netball training is moved to Saturdays, so she is no longer able to take Martha. Evie's mum, Penny is at work and cannot take Martha either.

### 3. Check your understanding

#### Maintaining activities and interests outside the house

**What suggestions do you have for Evie and her family?** *Please select the answers that you feel are likely to be helpful.*

- Evie's mum, Penny, could ask another family member to help Martha.
- Evie's mum, Penny, could ask other people outside the family, for example a neighbour, to walk with Martha to the community centre.
- Penny and Evie could talk to Martha and encourage her 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 Evie and her family?

- ✓ Evie's mum, Penny, could ask another family member to help Martha. **This is a helpful idea.** If others can come on a regular basis, this is the best solution for Martha as it maintains her routine and adapts to Martha's changing abilities.
- ✓ Evie's mum, Penny, could ask other people outside the family to walk with Martha to the community centre, for example a neighbour. **This is a helpful response.** Family is not always available and sometimes other people don't know how they can help. This is a concrete way that Penny could ask for help.
- ✗ Penny and Evie could talk to Martha and encourage her to do a quiet activity in the afternoons such as watching television or listening to the radio. **This is not likely to be a helpful solution at this time.** It isolates Martha 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 Martha's abilities change.

## At bedtime

At night, Evie's grandma, Martha, likes reading quietly for about 30 minutes before she goes to sleep. As her dementia progresses Evie notices that Martha is no longer able to read and sometimes, she finds her just staring at her book.

Evie and her mum Penny want to adapt this activity to fit Martha's current abilities.

### 4. Check your understanding

#### Adapting routines.

**What suggestions do you have for Evie and her mum? Please select the answers that you feel are likely to be helpful from the responses below.**

- Evie or her mum could read to Martha for 15 minutes before she goes to sleep.
- Evie and her mum should take the books out of Martha's room.
- Evie and her mum could look for books that have more pictures than words or audiotapes for Martha.

#### 4. Check your understanding

##### Adapting routines.

**What suggestions do you have for Evie and her mum?**

- ✓ Evie or her mum could read to Martha for 15 minutes before she goes to sleep. **This is likely to be a helpful idea.** It helps Martha to continue enjoying reading but adapts the activity to her abilities.
- ✗ Evie and her mum should take the books out of Martha's room. **This is not a helpful response** because it does not recognise how important reading is to Martha. Martha can still enjoy this activity; it just needs to be adapted.
- ✓ Evie and her mum could look for books that have more pictures than words or audiotapes for Martha. **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.

## 1. Activity

**Do you know any of the routines of the person with dementia that you help care for? Please write down the routines and how they might need to be adapted. You can either write this on a notepad or in the text box below.**

## Let's review what we have talked about

- Establishing routines is important for people living with dementia.
- It might help you and your family to try to keep routines that are similar to the ones your family member had before developing dementia.
- Your family will need to be prepared to adapt routines as necessary as the abilities of the person living with dementia change over time.

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