iSupport for Rare Dementias

Part 4 Providing everyday healthcare

PART

4

PROVIDING
EVERYDAY CARE

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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, type 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

Siya was a housewife and cooked every day for her family for many years. She recently moved in with one of her sons. Adi, her daughter-in-law, provides all the cooking in the new household. Siya says she's not hungry when she is offered food and does not join the family for dinner.

1. What could you do?

Making mealtimes more pleasant.

Below are some suggestions for Siya's family, on how to help in this situation.

✓ Bring Siya’s dinner to her room. If Siya is feeling overwhelmed by the noises of a large family dinner, it might be worth trying. But an alternative would be to try and have quieter mealtimes so that Siya is not isolated from the family.

✓ Ask Siya to help with meal preparation and cleaning activities. Her family knows Siya still enjoys cooking and they could support her to continue engaging in the activities that she likes and is still able to do.

✓ Check for physical causes. Siya might not want to eat because e.g., she has toothache or trouble swallowing.

✓ If possible, speak to Siya about why she isn't eating. It could be that her tastes have changed and she doesn't like the food that she used to or the way her daughter-in-law cooks.

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

1. Activity

Mealtime activities

Please select all activities from the list below that you think the person you care for can still engage in and would enjoy.

Mealtime activities	Example
☐ Shopping together	Support the person living with dementia in choosing what food and drinks they like to buy for breakfast, lunch and dinner (this may not be suitable advice for people frontotemporal dementia who may have difficulty with impulse control).
☐ Meal preparation	Encourage the person living with dementia to help chopping, stirring, or cooking.
☐ Preparation of the table	Involve the person living with dementia in laying the table for breakfast, lunch and dinner.
☐ Cleaning the table	Encourage the person living with dementia to remove everything from the dining table and wipe the table.
☐ Washing or drying the dishes	Support the person living with dementia in putting dishes in the sink or washing and drying the dishes.

Keep in Mind

Be mindful of having alcoholic drinks at mealtimes, consider alcohol free alternatives or other. Alcohol can be a depressant, and might aggravate certain behaviours. It might be harder to manage intake for people with impulse control issues.

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

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

Spilling food

Shang has Lewy Body dementia and lives with his sister since his wife passed away a year ago. His sister has a large family with five children. Shang sees the mealtime as the best time of the day. Recently, Shang's hands have started to tremble and he often spills or drops food on the table and the floor.

2. What could you do?

Promoting a good mealtime atmosphere.

Below are some suggestions to help Shang's sister deal with the situation.

✓ Buy adaptive eating and drinking aids from the shop for Shang. Shang's sister recognises that he is no longer able to manage eating and drinking using the usual utensils. By providing other utensils she is trying to solve this problem.

✓ 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 Shang's sister is trying to provide a positive mealtime atmosphere for everyone.

✓Consider meal options that involve food you can eat with your fingers (e.g., sandwiches). If the whole family can have the same food, this might give Shang a sense of normality and avoid a mess on the floor.

Tip

People with dementia may feel self-conscious about needing eating and drinking aids. It might help for other people to use them too, or things like travel mugs are a way of reducing spills without being obvious as an adaptive drinking aid.

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 and your family may have observed**	**Suggestions that your family may try**
Poor appetite	☐ Does not want to eat the meal ☐ Eats only small amounts of food ☐ Takes a long time to eat a small amount of food ☐ Refuses to eat and drink	• 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	☐ Is restless ☐ Has a facial expression indicating pain	• 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

Body pain	☐ Refuses to eat and drink ☐ Is restless ☐ Unusual body postures ☐ Has facial expression indicating pain	• Ask whether the person is in pain • Ask them to point out the area of pain (where it hurts) • Seek help from a doctor
Does not have bowel movement for more than 7 days	☐ Hard and dry faeces ☐ Difficulty passing faeces/straining ☐ Having a feeling of incomplete bowel movements ☐ Hard stomach ☐ Nausea and vomiting ☐ Becomes anxious or agitated	• Seek help from a doctor • Upon resolution of the problem: ○ Increase fibre in diet ○ Increase drinking of fluids ○ Increase physical activity
Diarrhoea	☐ Liquid faeces ☐ Increased number of bowel movements ☐ Incontinency and difficulty controlling bowel movements	• Seek help from a doctor
Side effects from medications	☐ Nausea, vomiting, liquid faeces or constipation ☐ Does not want to have a meal ☐ Eats only small amounts of food	• Seek help from a doctor

Memory loss; forgets to eat or drink	☐ Asks when the next meal is even if it already happened ☐ The person says that they are hungry even if they already ate	- 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	☐ Refuses to eat or says they are not hungry ☐ Eats small amounts of food ☐ Has no interest in food	- Seek help from a doctor
Weight loss	☐ Forgets to eat ☐ Eats smaller amounts of food ☐ Eats regular amounts of food but still loses weight	- 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	☐ Eats all the food that is served ☐ Eats more snacks than before because they forget that they already ate ☐ Is obsessed with food	- Try more frequent but smaller plates of food so the person isn't overwhelmed by the portion size - 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

Visual problems or co-ordination	☐ Misses the plate with their fork, knocks over drinks	• Use plates of a high contrasting colour but without patterns. • Avoid patterned tablecloths. • Try plate guards. • Use verbal cues, tell the person their glass is on their left and try to be consistent every mealtime.
Disinhibited eating	☐ Crams everything in their mouth without swallowing, tries to eat inedible objects, craves sweet or carbohydrate foods.	• Remind them to slow down and swallow their food • Remove inedible objects from eating areas and lock away household chemicals • Try fruits to satisfy sweet cravings

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;
- unable to find their cup or remember to finish their drink;
- worry about needing the toilet or incontinence;
- decreased thirst sensation;
- not offered enough to drink; and,
- swallowing problems.

The person you care for needs to be encouraged to drink 8-10 glasses (1500-2000 millilitres) of fluid (water, iced lollies and juice).

Tip

Fluid filled meals such as soups can be useful in preventing dehydration but for personalised advice, contact your GP, a speech and language therapist or a dietitian.

Severe dehydration

Ben has primary progressive aphasia, 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. What could you do?

Severe dehydration.

Below are some suggestions to help Mary deal with the situation.

✓ 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. 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 we have talked about

- 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.
- By maintaining good eating and drinking for the person you care for you can improve their health condition. Seeking assistance from health professionals might be necessary.
- To help prevent dehydration, it may be necessary to prompt the person living with dementia to drink.
- Record and monitor the amount of fluid they consume.
- Those with primary progressive aphasia or swallowing difficulties will need advice from a specialist and a swallowing assessment.

Session 2. Eating and drinking – preventing health problems

Why is this session important?
Dementia can affect eating and drinking in various ways depending on the stage or type 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 primary progressive aphasia or the later stages of other types of dementia, a person living with dementia may experience difficulty chewing and swallowing. Dementia may also reduce a person's abilities to smell, taste and see. These can have a negative impact on the person’s eating habits. Depression and changes in eating patterns may also impair eating and digestion.

Let’s look at an example

Chiu is in the late stages of Lewy body dementia 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. What could you do?

How to improve eating and prevent weight loss.

Below are several suggestions to help Ling to improve Chiu's eating.

✓ Be flexible to have meals when her mother is awake. 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 her mother eats. Recording what people with dementia eat can be useful. This way, carers and healthcare professionals will be able to see how much food is being eaten.

✓ Ensure Chiu has access to foods and snacks that she enjoys eating. She is more likely to eat foods that she likes.

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. Whether due to poor impulse control or visual problems, 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 or has primary progressive aphasia, 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.

Tip

A Speech and Language Therapist will be able to assess the person with dementia and offer tailored advice around how to manage swallowing difficulties. If you are worried about the person you are caring for and their swallowing, speak to your GP about being referred to a Speech and Language Therapist.

Inedible materials

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

2. What could you do?

Inedible materials

Below are some suggestions that Oliver could do to keep Ella from eating inedible objects

✓ Lock household chemicals, such as dishwashing soap, in a cabinet.

✓ Remove non-food items from the dinner table such as napkins, flowers or spices.

✓ It may be helpful to have some food that is easily accessible throughout the day but, be aware that this may encourage over-eating for some people.

Helping a person to eat safely

Lu is in the later stages of posterior cortical atrophy and is cared for in bed. Her husband, Wei, helps her to eat safely. Recently, he found Lu 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.

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

3. What could you do?

Helping a person to eat safely.

What do you think Wei should do?

✓ Learn how to make healthy, soft foods and thickened drinks for Lu.

✓ Pay attention to how Lu is sitting when he helps her eat. Sitting in an upright position makes swallowing easier, it might be useful to use cushions to help Lu stay upright while eating.

Tip

A healthy soft diet can be made by hand without using an electric blender. Thickened fluids can be made using stir-in thickeners which are often available from the NHS on prescription. If the person that you care for has problems swallowing, please speak to your GP about seeing a Speech and Language Therapist.

Let's review what we have talked about

- 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.
- It's important to get professional advice before changing someone's diet. Please speak to a GP, dietitian, Speech or Language Therapist.

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 toileting habits. Sometimes incontinence is unavoidable, in the later stages, but sometimes people with dementia struggle to find their way to the bathroom and identify the toilet and/or toilet seat.

The dementia is affecting them and they are not doing these things deliberately. Modifying your house may help them use the bathroom, by adding a sign on the door, leaving the bathroom door open so the toilet is in sight or changing the colour of the toilet seat. A regular reminder to see if they need to go to the bathroom can work for some. You can also ask your GP for a continence assessment to help work out whether the cause can be treated and addressed (urinary tract infection , can't find the toilet) or not (loss of bladder control, unable to identify the sensation of needing the toilet).

Let’s look at an example

Tom is taking care of his wife, Rebecca, since she developed posterior cortical atrophy several years ago. Rebecca is able to go to the toilet by herself, but recently, Tom finds Rebecca urinating on the floor outside the toilet.

1. What could you do?

Prevent urinating on the floor.

Below are some suggestions for Tom on how to deal with this situation.

✓ Make some simple changes to the environment, such as putting an image of a toilet on the bathroom door, using a contrasting colour for the toilet seat or adding lights to direct Rebecca to the toilet.

✓ Make some changes to Rebecca's clothing, such as changing her trousers to a pair of leggings or other elasticated trousers that do not require opening belts, zips and buttons.

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.

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	• 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	• Use nightlights in the bedroom and the house • Provide a commode for them to use in the house
Not being able to find the toilet	• Put a picture of a toilet on the toilet door
Not enough colour contrast of the toilet seat	• Replace the toilet seat with a different colour to increase the contrast
Not enough lighting in the hallway	• Provide adequate lighting in the hallway
Not enough lighting in the toilet	• Provide adequate lighting in the toilet
Narrow toilet doors that do not allow the walker or wheelchair to pass	• Modify the door opening to allow a walker or wheelchair to pass
Visual impairment	• Direct the person you care for to the toilet during the day • Provide a bedside commode at night
Unable to undo trousers	• 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	• Remind the person you care for of the activities they need to do • Provide step-by-step instructions for them to use the toilet

Behavioural disinhibition	• Ask the person you care for if they need to use the toilet and direct them to it • Carry helpcards from the Alzheimer's society to explain the person's diagnosis. You can find these here: https://www.alzheimers.org.uk/get-support/publications-factsheets/helpcards
Lacking motivation	• The person you care for might find tasks less overwhelming if broken down into smaller parts • Gently prompt the person with dementia to use the toilet and create a routine: before lunch/dinner, you go to the toilet
Not recognising the sensation of needing the toilet	• Remind the person to use the toilet • Use incontinence pads

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 may be able to reduce these accidents (incontinence) by maintaining a regular, daily schedule to assist the person you care for to go to the toilet. Recalling how often they used the toilet before they had dementia might be helpful. You might also be able to recognise 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 Esther, who received a diagnosis of primary progressive aphasia 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. What could you do?

Dealing with losing bladder control.

Below are some suggestions for Joshua to deal with the situation.

✓ Joshua could encourage his mother to use the toilet before leaving to go shopping. Consider wearing some incontinence materials/ underwear.

✓ Joshua should contact the GP to make sure Esther doesn't have a urinary tract infection or other underlying physical cause for her loss of bladder control.

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

Toilet diary		Date:	
Time	Numbers of trips To the toilet	Numbers of times lost control of bladder or bowel	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 speak to a GP to help identify the cause(s) of incontinence, as these may be treatable and therefore reversible. They may refer the person with dementia for a continence assessment to receive incontinence products from the NHS.

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. Some are available from the NHS but you may have to wait for an assessment to be eligible for these. There are many options available from supermarkets in the UK or online.

For more information on the types of incontinence products available, please visit:

- https://www.alzheimers.org.uk/get-support/daily-living/toilet-problems-continence#content-start
- https://www.nhs.uk/conditions/urinary-incontinence/incontinence-products/
- https://www.incontinence.co.uk/choosing-a-product-for-someone-with-dementia-and-incontinence

Let’s look at an example

Gloria is in a late stage of primary progressive aphasia and is living with her brother’s family. Her sister-in-law, Marina, is helping to take care of her. Since Gloria cannot control her bladder or bowel movement, the doctor suggests trying incontinence pads for Gloria.

In the beginning, Marina encounters a number of problems:

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

3. What could you do?

Use of personal hygiene products.

Below are some suggestions for Marina to help her deal with the situation.

✓ Marina could remind her mother-in-law to use the bathroom at scheduled times if she is not doing so herself.

✓ They could experiment with different types of incontinence pads to see if a pull-up pad would irritate Gloria less than a slip pad.

Below are some tips for incontinence care.

Problems	**Possible causes**	**Recommended solutions**
Constantly taking the pad off and throwing it on the floor	• Feeling uncomfortable with the pad • The pad size is wrong • The pad is wet and needs to be changed	• Check whether the pad size is correct • Change the wet pad on time • Consult the doctor regarding the person's behaviour
Still having wet pants even while using the incontinence pads	• The pad size is incorrect • The schedule for using the toilet has not been maintained	• 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	• Incontinence pads can cause skin breakdown • Unsuitable pad size and delaying changes of soiled pads in a timely manner can cause skin infection	• 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	• Urinary tract infections are triggered by a number of factors, including incontinence and poor genital care	• 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 we have talked about

- Modify the environment to reduce the chance of bladder and bowel accidents (for example, put a picture of a toilet on the bathroom door).
- Accompany the person living with dementia to the toilet regularly to reduce accidents.
- The frequency of toilet visits could be based on the toilet pattern that the person living with dementia had before the onset of dementia. Do note that toilet patterns can change over time, with the dementia or other factors, like eating or anxiety.
- 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 be able to find the things that they need for personal care.

For example, if they can't find their toothbrush or toothpaste, they may not brush their 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 frontotemporal dementia, 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.

1. What could you do?

Promoting personal hygiene.

Below are suggestions to help Mohammed deal with this situation.

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

✓ Ask Mariam if she needs help washing or changing her clothes. She may be lacking motivation to wash so a gentle nudge might help. Consider what the minimum self care is that does not put her hygiene at risk. Perhaps make-up is no longer essential. Select clean clothing with Mariam if possible and remove the other garments. Place them in the order in which Mariam will put them on.

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 2. Depression, anxiety or apathy in Part 5.**

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 go with the person to the bathroom if they are unable to read/ see the signs.
- To find personal care materials: make items easy to see in the bathroom, put out in the correct order, label items, use pictures or

words on the bathroom wall to point out items, use contrasting colours or hand them products as they need them.

- 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.

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 dress appropriately for many reasons including:

- visual/ co-ordination problems
- lack of motivation
- obsessions with specific clothing
- decision making difficulties.

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 and respects their personal style. Try not to take over these tasks when the person living with dementia can still perform them.

Keep in Mind

You might want to help the person with dementia in certain tasks if they're becoming slower or making a mess. However, if a person with dementia isn't using certain skills, they will often lose that skill altogether, so it's important to support people with dementia to do things for themselves as long as possible. This might well take longer and can be frustrating.

Let's look at an example

Imka has posterior cortical atrophy and is cared for by her wife Jane. Imka used to lay out her clothes for the next day in the evening.

Recently, Jane found that Imka has stopped doing this and is inclined to wear the same clothes every day. Jane also observes that Imka leaves some buttons of her shirt undone, her belt unbuckled and does not lace up her shoes.

2. What could you do?

Getting dressed.

Below are some suggestions for Jane to help Imka.

✓ Encourage her to wear trousers that do not need a belt and shoes that do not need laces.

✓ Hanging whole outfits on one hanger in the wardrobe will help Imka to feel confident that her clothes match even if she can't see herself.

✓ Large print labels or verbal directions from Jane may help her find other clothes to wear.

Difficulties brushing one's teeth

Dementia can affect 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 existing skills.

Let's look at an example

Gus has Lewy body dementia but is able to brush his teeth without assistance. Recently, Gus's wife, Rozalina notices that her husband makes a 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.

3. What could you do?

Promoting mouth care.

Below are some suggestions to help Rozalina with the situation.

✓ Instruct her husband how to brush his teeth step-by-step and praise him when he is doing well.

✓ Rozalina could brush her teeth at the same time so Gus can mirror her movements. People with dementia can have difficulty remembering the order of tasks (sequencing) so being able to copy Rozalina, might be helpful.

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

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

Feng has frontotemporal dementia and is cared for by his mother Yuan. Due to her age, Yuan is not strong enough to help bathe Feng anymore, so the family decides that the three brothers-in-law could take turns to help with Feng's bathing.

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

4. What could you do?

Resisting help with bathing.

Below are some suggestions for Feng's family to try in this situation.

✓ Since the family notices that Feng thought his brother-in-law was a stranger, Yuan decides to be with Feng while her son-in-law bathes him.

✓ If affordable, the family could look at hiring a professional carer to come in once a week to help bathe Feng.

✓ Spot-washing Feng might be more manageable for Yuan and reduce the number of full baths he needs.

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 aggressive like Feng in this example. To read more about how to prevent or deal with aggression, please refer to **Session 4. Aggression in Part 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.
- Try using wet-wipes, non-rinse shampoos, shampoo shower caps etc to do a bit at a time. This might seem less overwhelming than a full shower or bath for the person with dementia.

Menstruation

Rare dementias are often diagnosed in people in their 40s or 50s but in very rare cases, people can be in their 30s when they start showing symptoms. This means that women might still be menstruating and need help managing this. For male carers, this can be something that you've never had to think about and might seem overwhelming. For advice on caring for someone who has periods please visit: https://www.mobiliseonline.co.uk/carers-guide-to-menstruation

Menopause

Due to hormone changes, menstruation usually stops around the age of 50, however, this can vary person to person. The symptoms of the menopause can be very similar to those of rare dementias including:

- Mood changes (anxiety or low mood)
- Memory or concentration problems
- Difficulty sleeping

For more information on the menopause please see:
https://www.nhs.uk/conditions/menopause/

If you think the person that you care for is showing symptoms of the menopause, you should speak to your GP for advice on potential treatments. While a woman is menstruating, there is a possibility to become pregnant. Consider and discuss contraceptive options with your GP.

2. Activity	
Select any personal care activities that the person living with dementia needs help with.	
☐ Selecting daytime clothing	☐ Undressing before shower/bath
☐ Putting non-slip mats on the floor	☐ Washing hair/body during shower/bath
☐ Taking pyjamas off/on	☐ Shaving
☐ Washing and drying hands	☐ Using towel to dry hair/body
☐ Washing and drying face	☐ Applying body lotion to moisturise skin
☐ Washing and drying feet	☐ Checking for signs of skin problems
☐ Washing and drying genital areas	☐ Dressing after shower/bath
☐ Drying body after washing	☐ Combing hair
☐ Changing night clothing into daytime clothing	☐ Using electrical hairdryer
☐ Preparing for a shower/bath	☐ Putting on make-up
☐ Turning the tap on and preparing for bathing	☐ Cutting fingernails and toenails when needed

Keep in Mind

Some people with dementia dislike physical contact which will make personal care more difficult. It's important to try and be patient, even if you can only cut one fingernail at a time, it's better than nothing.

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

- 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 aggression.
- 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 aggression.
- Younger people with dementia may need support dealing with menstruation or the menopause.

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.

Keep in Mind

Sticking to a routine won't always be possible, caring for someone with dementia often means you have to adapt to changing circumstances.

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

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

1. What could you do?

Morning routines.

Below are some suggestions to help Penny handle the situation.

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

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

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 with dementia

It is important to adapt routines as the abilities, motivation and mood of the person living with dementia changes.
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 activities and maintain them as long as possible.
- Make adjustments as needed when the abilities, motivation or mood of the person living with dementia changes.

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

Martha loves baking and used to prepare special cakes and cookies for family gatherings. Now that she has frontotemporal dementia, she finds it difficult to read the recipes and sometimes gets the quantities of the ingredients wrong.

At first, Martha uses cooking videos to help her continue baking but she finds measuring the ingredients increasingly difficult. The cakes and cookies do not taste very good and have to be thrown away. Penny wants to help her mother keep up this activity.

2. What could you do?

Maintaining prior activities and interests during the day.

Below are some suggestions that Penny could try to help Martha continue baking.

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

✓ As Martha’s abilities change, Penny could plan some time during the afternoon to bake and cook with her mother.

Sundowning and tiredness

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 the symptoms of dementia can appear worse when the person is tired or experiencing sleep disturbances. Try to schedule activities at the time of day when the person with dementia is feeling more awake.

Let’s look at an example

Martha 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 Martha walks there by herself but as her spatial awareness becomes more impaired, she cannot safely find her way to the centre anymore. Penny asks another family member to take Martha to the centre and bring her back home. This works well for a while but eventually the family member is unable to take Martha. Penny does not know what to do since she cannot be with Martha every afternoon.

3. What could you do?

Maintaining activities and interests outside the house

Below are some suggestions for Penny to try.

✓ Penny could ask another family member to help Martha.

✓ Penny could ask other people outside the family to walk with Martha to the community centre, such as a neighbour, or someone from the community centre can come and collect Martha.

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, Martha is used to reading quietly for about 30 minutes before she goes to sleep. As her dementia progresses, she begins experiencing visual symptoms and she finds that she is no longer able to read. Sometimes she is just staring at her book.

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

4. What could you do?

Adapting routines.

What suggestions do you have for Penny?

✓ Penny could read to Martha for 15 minutes before she goes to sleep.

✓ Penny should get some books that have more pictures than words or audiobooks for Martha.

✓ Perhaps Martha finds it relaxing to hold the book and doesn't need any adaptations.

Tip

- 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. (This might not be appropriate for those with obsessions, schedules might cause more stress).

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 we have talked about

- 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.