

ADVANCED/END-STAGE DEMENTIA

Draft for Comment

Aim

To support friends, family, and carers of people with advanced and end-stage dementia to provide nutrition and hydration to help maintain quality of life, optimise well-being and food enjoyment.

Learning Outcomes

The target group (friend/family/carer) will:

- have improved understanding and confidence on how to provide nutrition care for people with advanced dementia.
- be aware of signs and symptoms that may affect the person's nutritional status and be able to apply practical strategies.
- be aware that appetite changes may be related to physical health.
- know the importance of social interaction and environment at mealtimes.
- understand how the focus of care changes as the person moves towards end-of-life e.g. comfort over nutrition.
- that tube feeding does not benefit a person with advanced dementia and may cause more distress (when swallowing difficulties are a result of dementia progression).
- know how to identify if further support is needed and where to go for this.

Request for comments

Please send comments to jenni.henderson@ndr-uk.org by Thursday 30th May on:

- Clarity of key messages
- Suitability for purpose
- Length and amount of detail given
- Resource title

Eating and Drinking in Advanced Dementia

Contents

Introduction	3
Signs and Symptoms	4
Mealtime support	5
Preparing to eat and drink	5
Positioning	7
Support when eating	9
Making every mouthful count	11
Nourishing drinks	12
Fluid	14
Addressing concerns	16
Eating and drinking at the end of life	16

Introduction

When someone's dementia enters the advanced stages, it is normal for them to experience further changes in their eating and drinking. This is because the amount someone feels able to eat and drink may change, they may require more assistance with meals, they may refuse to eat or take drinks, or require to be offered a different texture of food and fluids.

As their body starts to slow down, their nutritional needs also reduce. At this point, the focus of care should move to providing food and fluids which are enjoyed and can be managed. This helps to promote the person's quality of life and enjoyment from the food and drinks they can take, while limiting any distress.

This booklet provides practical advice on the nutritional care of people in advanced stages of their dementia and towards the end of life. Everyone's experience will be different, therefore some of the information discussed may not be relevant to you. However, it is hoped you will find some of guidance helpful.

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Signs and symptoms

Dementia is an umbrella term for a number of diseases/conditions that cause a gradual decrease in brain functioning. This means it can be difficult to accurately determine which stage of dementia a person is living with. A person may experience a stage of dementia for a long time. However, some signs and symptoms are more common in the advanced stages of dementia. These include:

- Difficulty with movements (lifting a cup to their mouth, holding a fork to eat).
- Pain when moving (difficulty walking).
- Problems communicating.
- Difficulty eating and swallowing.
- Signs of distress or agitation.
- Increased sleeping/drowsiness (not linked to medications) or altered sleep pattern (awake at night and sleeping during the day).
- Incontinence.
- Increased risk of infections (chest infections, urinary tract infections) and pressure ulcers.
- Unplanned weight loss.

If the person you are caring for is experiencing any of these signs and symptoms, it is important to rule out any physical health causes for these first e.g. an infection, change in medication, poorly controlled diabetes or delirium. If there is not a physical health cause for these symptoms, it is likely that the person is entering the more advanced/end stage of their dementia.

Many of these signs and symptoms can impact a person's appetite and their ability to eat and drink. It may become more difficult to meet their food and fluid requirements. During the very advanced stages and end stage dementia, it becomes more important to provide food and fluid to help maintain comfort and dignity rather than to meet nutritional requirements. This may mean that the person loses weight. Like lots of terminal conditions, people living with dementia experience a loss of appetite towards the end of their life. This is often related to the dying process and so trying to provide too much food or fluid can lead to distress or discomfort.

Mealtime support

Dementia affects each person individually and this is no different when it comes to eating and drinking. Some people will require more support at mealtimes than others. Some people may sit at a table for meals, while others may find it easier to eat and drink in bed.

People may need mealtime support if they:

- find it difficult seeing the food on their plate
- are not able to hold utensils or get the utensil to their mouth
- find chewing difficult or take a long time to chew and swallow
- are not able to maintain a good position when eating
- have lost their appetite
- have a short concentration span.

Preparing to eat and drink

When supporting a person with dementia at mealtimes, it is important to consider the eating environment – think about lighting, noise levels, distractions and smells. Small changes can help to make mealtimes more enjoyable and less stressful.

- Cooking smells can be off-putting especially if the person feels sick. However, the person may also find the smell of some foods pleasant and enjoyable. The focus on all eating experiences should be comfort and pleasure.
- Encourage fresh air before offering food. Opening a nearby window or door may help.
- Ask if the person needs to go to the toilet before meals and provide help if needed – this can help them feel more comfortable before they eat.
- If the person has glasses or a hearing aid, find out if they wish to use these when being offered food. Being able to see the food may help them have a more enjoyable eating experience.
- If they have dentures, it is often more comfortable for the person to remove them. Try to find out if they wish to wear them while eating. Check they are clean and offer to help insert them if needed, making sure they fit as comfortably as possible.
- Clean and clear the eating area around their chair or bed. It is a good idea to cover any medical equipment such as catheter bags.
- Ensure the person is in a good position when they are being helped with eating and drinking (guidance on page X).
- Keep the times that you offer the food or drink short, but do this frequently throughout the day if they show interest. This may mean moving away from traditional mealtimes and taking a flexible approach. Offer meals and drinks when the person appears most alert and settled.
- Keep calm and try not to rush the person when they are eating or drinking.
- Try eating together. This can be a good chance to reminisce about times where you have enjoyed the food before. For example, eating chips and ice cream by the sea.

- What a person with dementia wants to eat and drink may vary day to day. It is normal to feel anxious if they refuse to eat and drink. However, it is important not to force them as this can make them feel uncomfortable. Instead, keep them company, offer to read to them, watch a film together or simply sit with them and hold their hand.

Setting the table

Keeping things simple can help when eating a meal at the table.

- Place food within easy reach and where it can be seen by the person.
- Only set the table with the cutlery the person uses and what is suitable for the food they are eating.
 - A person with dementia may not remember what cutlery they need to use and when faced with a variety of options, may get confused and make the wrong choice. For example, they may try to eat soup with a fork instead of a spoon.
- Serving soup in a mug often works well.
- Only serve one course at a time.
- Avoid unnecessary clutter on the table.
- Using a high contrast plate may help improve intake.

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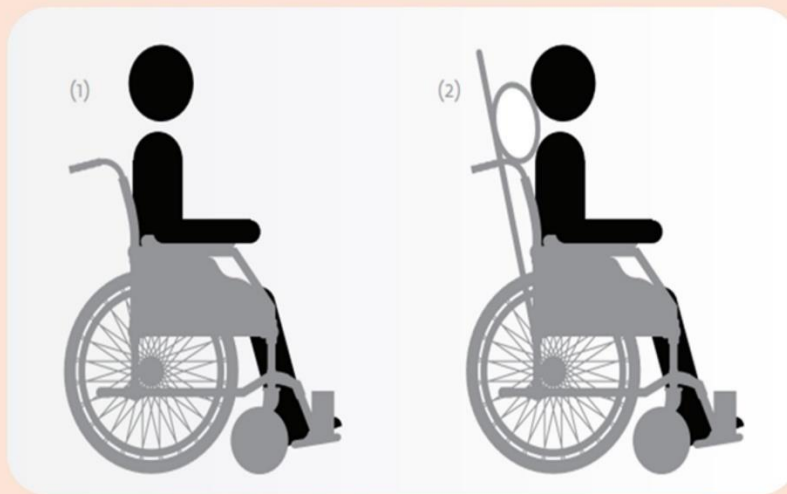
Positioning

Poor positioning at mealtimes may contribute to a poor intake and difficulties swallowing. Below are some ways to help you support a person at mealtimes.

Sitting at a table for meals

A comfortable chair that supports the person's back in an upright position is ideal. Help them to sit as comfortably as possible. The following will help:

- Hips and knees should be at a 90-degree angle with their arms, legs and body supported.
- Head should be in a neutral position or flexed very slightly forward.
- If they lean to one side, try using a pillow or cushion to support them to sit up straight.

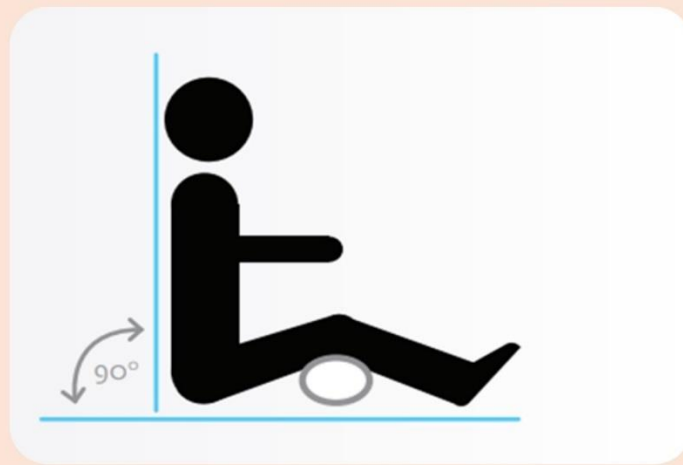


Some people may be unable to sit at a table due to fatigue, feeling unwell, general frailty or may just prefer to be in bed. Helping them to sit comfortably in bed when eating or drinking is also important.

Eating and drinking in bed

Help the person to sit as upright as possible to help achieve a good and safe position to eat.

- Use bed adjustments and pillows (behind their upper back) to get the right position.
- If unable to sit at a 90-degree angle, try to position them as upright as possible, using pillows, foamed wedges or rolled up blankets to support their head.
- Slightly bent knees supported with a pillow or rolled up blanket can help prevent them from slipping back down the bed.



Once the person is properly positioned, seat yourself beside and slightly in front of them. This will allow them to see you and the food they are eating and makes for a better mealtime experience.

After a meal, help the person to remain comfortably upright for at least half an hour after eating.

Support when eating

Verbal encouragement and direction is often enough to help someone at a mealtime.

- Identify food by its name or taste.
- Help the person by telling them where the food is on the plate or which utensil to use.
- Prompt the person to eat, take another mouthful or swallow if needed.
- Positive encouragement may help.
- Only serve one course at a time.
- Ensure any adaptive crockery or cutlery is in place.

Physical support

In some cases, verbal encouragement may not be enough and physical support is required. This can be done in different ways. It is important to support the abilities of the person needing help so that they can do as much as they can for themselves.

- If the person can get their hand to their mouth, but is unable to load their fork or spoon, you can try placing food on a spoon or fork and then handing this to the person. The same can work for drinks.
- Some people just need help getting started, so try to initiate the eating process and then allow them to take over.

If the person is unable to get their hand to their mouth on their own, one of the following techniques may work.

Hand-Over-Hand Technique

This can be helpful when the person you are supporting has the required finger skill and range of motion but needs extra help in getting food from their plate to their mouth.

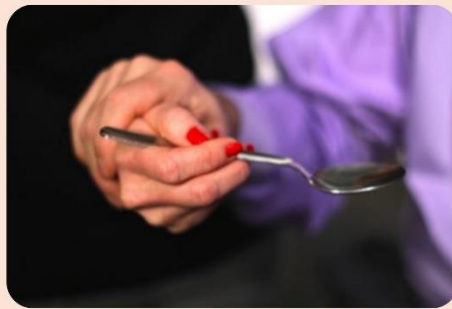
- Place yourself on the dominant side of the person. The hand you will **not** use for feeding assistance is placed on the person's shoulder.
- Place your hand (hand with red fingernails in the image below) over the person's hand which is holding the eating utensil. Guide their hand with the utensil towards their mouth.
- Be sure you have your hand and the person's hand coming toward the person's mouth from the centre of their body so that the person can see the food they are about to eat.



Hand-Under-Hand Technique

This technique is useful when the person no longer understands language and has lost the ability to hold cutlery themselves.

- Place yourself on the dominant side of the person. The hand you will **not** use for feeding assistance is placed on the person's shoulder.
- Perform the under-handshake with the person. This position provides support to the person while freeing up your skill fingers (hand with red fingernails in the image below). You can use this position to guide the person through the movements of eating.
- The under-hand technique provides the person with a physical cue. You can use verbal and visual cues as well.



Some people may need full mealtime support. This means placing the food in their mouth for them to eat. The following tips can make this easier.







- Use a teaspoon – this can reduce the risk of choking by making sure too much food is not given at once.
- Talk to the person and make use of verbal prompts to open their mouth, chew or swallow. Tell the person what you are giving them to eat or drink.
- Take your time – rushing the process can make the person anxious. This can result in them eating less and increases the risk of choking.
- Allow time for two swallows between mouthfuls – watch for the movement of their Adam's apple.
- If the person you are supporting is no longer able to communicate verbally, recognise requests for more and signs that they have had enough.
 - For example, this could be when they complete a swallow, nod, give a verbal request, or open their mouth.
 - If they are tiring, stop until they are alert enough and ready to continue.
- If the person does not want to open their mouth to eat, verbal prompting or gently rubbing the spoon over the lower lip may encourage them to open their mouth.
- Alternating the taste, texture and temperature of food may help to increase awareness of food in their mouth and improve intake at mealtimes.
- If the person has been advised to follow a pureed diet by their health professional, avoid blending/mixing the foods together as this may make the meal less enjoyable.

Making every mouthful count




If the person with dementia has a small appetite and managing meals is difficult, try reducing their portion sizes so that meals are not visibly off putting. To boost their nutrient intake, try fortifying meals by adding extra energy and protein.

Try adding the foods at the top of the tables to the foods along the side. You don't need to use all the suggestions for each food at one time, but be generous with whatever you do use.

Savoury foods

	 Cream, fortified milk or skimmed milk powder*	 Butter/spread or oil (olive/rapeseed)	 Cheese (grated or soft)	 Pesto, tahini or hummus	 Dressings, mayonnaisse or salad cream	 Pâté or paste (meat, egg, fish)
Mashed potato	✓	✓	✓			
Cooked vegetables		✓	✓	✓	✓	
Pasta or rice		✓	✓	✓		
Soups	✓	✓	✓			
Sauces	✓	✓	✓	✓		
Baked beans		✓	✓			
Eggs	✓	✓	✓	✓	✓	
Bread, scones, crackers		✓	✓	✓	✓	✓
Sandwiches		✓	✓	✓	✓	✓

Sweet foods

	 Skimmed milk powder* or fortified milk	 Cream	 Sugar, syrup, honey or flavoured sauces	 Nut butter or chocolate spread	 Nuts or seeds (ground or chopped)
Porridge/cereal	✓	✓	✓	✓	✓
Puddings	✓	✓	✓	✓	✓
Yoghurt	✓	✓	✓	✓	✓
Milky drinks (hot or cold)	✓	✓	✓	✓	
Stewed/canned fruit	✓	✓	✓	✓	✓

*Add 1 tablespoon of skimmed milk powder to foods when cooking (mix the powder with a small amount of milk to make a smooth paste first, then add to food).

Snacks

Offer small, nutrient-dense snacks frequently throughout the day. Choose foods that don't require a lot of chewing as they may be easier to manage. Here are some ideas.

- Soft pieces of bread with cream cheese, pâté or tuna/egg mayonnaise.
- Buttered brioche, soft pastries and sponge cakes topped with custard, chocolate spread, peanut butter, lemon curd or jam and dash of cream.
- Add some cream to readymade milk puddings such as crème caramel, rice pudding, mousse, thick yoghurts or custard pots.

If the person with dementia has been diagnosed with a swallowing problem, follow their speech and language therapist's advice on choosing appropriate texture foods.

Nourishing drinks

Use whole milk (blue top) to make high energy and protein drinks.

Fortified Milk

- 4 tablespoons skimmed milk powder
- 1 pint whole milk

Mix the powder with a small amount of milk to make a paste. Gradually add the remaining milk, stirring continuously.

Store in the fridge, ready to use throughout the day. Use to make hot chocolate, milky coffee, or malted drinks e.g. Ovaltine, Horlicks.

Thick Milkshake

- 200ml fortified milk
- 1 scoop of ice cream
- 3 tablespoons vitamin fortified milkshake powder e.g. Nesquik, Ovaltine or supermarket's own brand

Add all the ingredients together and whisk.

Creamy Smoothie

- 200ml fortified milk
- 150g whole milk or soya yoghurt
- 1 banana (or other soft fruit)
- 2 teaspoons honey

Mix all the ingredients together until blended – use a food blender, or mash with a potato masher.

Fortified Soup

- 1 instant soup sachet
- 200ml fortified milk
- 1 tablespoon cream (optional)

Warm the milk. Gradually add the soup sachet and cream (if desired). Stir well.

Dairy-free Pineapple and Coconut Nourishing Drink (no blender required)

- 100ml coconut milk
- 100ml pineapple juice
- 3 tablespoons icing sugar
- 1 tablespoon honey or golden syrup
- 2 x 5g sachets egg white powder*

Mix all the ingredients together.

Non milky drinks options include:

- Fizzy drinks or fruit squash (try to avoid sugar free, diet and no-added-sugar varieties).
- Fruit juice.
- Use dairy-free milk alternatives (e.g. soya, oat) or fruit juice instead of water as the base ingredients for drinks.

Milk powder can usually be found in the same aisle as long-life milk, and egg white powder can be found in the home baking section of most supermarkets. Bulk packs are often better value and can be purchased online.

Fluid

It is important that people with dementia have enough fluid to prevent dehydration. This can be difficult in the more advanced stages of dementia as people can experience swallowing problems, taste changes, they may not feel thirsty, and/or be nursed in bed. A trial-and-error approach to see what helps each day is usually the best way to support a person's fluid intake.

All fluid helps to hydrate including tea, coffee and fluid rich foods. Small cups, glasses or adapted light weight plastic cups with lids and spout may be easier to manage.

The ideas below have helped many people living with advanced dementia.

- Know the person with dementia's personal preferences. For example, what do they like to drink and at what time of day, how do they take their tea/coffee, do they prefer water with medication, do they like a hot milky drink before bed?
- Provide fluids in their preferred drinking vessel e.g. their favourite cup, mug or glass.
- Provide small amounts of fluid regularly throughout the day. Offer a drink before any interaction with the person.
- Provide and assist with small sips of fluids at mealtimes. This can help the person swallow food and maintain good oral health by ensuring food has been cleared from their mouth.
- Offer a variety of hot and cold drinks throughout the day e.g. tea, coffee, squash, milky drinks. Different temperatures or fizzy drinks can help to stimulate the person's swallow reflex.
- Provide drinks that are the correct consistency (thickness). Only provide thickened fluids if the person has been assessed by a speech and language therapist and advised to have them. Many people do not like thickened fluids, and this can lead to drinking less.
- Provide strong flavoured drinks as taste changes are common. Some people may prefer sweeter flavours.
- If the person is being nursed in bed, ensure they are sat upright, well supported and fully alert when providing a drink.
- Encourage and prompt with fluids – do not just leave them next to the person as they may not realise the drink is there. They may also need assistance to have a drink.
- Have a drink together and engage in conversation. This can help the person know how to drink and take the focus away from drinking so that they enjoy the time together.
- Provide fluid rich foods such as soups, stews, casseroles, milky puddings, puddings with plenty of cream or custard, milky porridge, breakfast cereal with plenty of milk, ice-cream, fluid rich fruits.

- Offer ice lollies – these are fluid rich and the cold may help with the person’s swallow reflex. It may be possible for them to have these independently when drinking from a cup has become more difficult.
- Provide plenty of fluid when the person is taking their medication.

If you have concerns about the person’s fluid intake, you can monitor how much they have in the day by filling a measuring jug with water and using this for all their fluid intake including tea, coffee and squash.

When a person with dementia is approaching the end of their life, they may have a reduced fluid intake. This is to be expected, but it can be upsetting and worrying. However, it is unlikely that the person will be feeling thirsty at this stage and so focus on providing small sips or small amounts of fluid rich foods to help prevent any feelings of discomfort.

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Addressing concerns

As dementia progresses, it is okay to focus on food enjoyment rather than nutrition.

Many therapeutic diets can be relaxed. For example, a person who has not been allowed salt, may be allowed to increase the amount of salty foods they eat, or someone with diabetes may be able to include more sugary foods like cakes and sweets. Caution is needed when the person follows a specific diet for an allergy, intolerance, or condition such as Coeliac Disease, as relaxing their diet can impact their quality of life. For example, if they have an allergic reaction to nuts, they should continue to avoid them at all stages of their dementia.

It is important to take an individual approach – discuss what is realistic and good for the person with dementia with their healthcare professional.

Eating and drinking at the end of life

When someone is approaching the end of their life, we often see a natural decline in eating and drinking. Very often this goes together with a decrease in general alertness, and more time sleeping. It is important to understand that this is a natural part of the dying process and most people who are dying do not experience thirst or hunger. The body is slowing down and all the organs, including the digestive system, work less effectively. This means the need for food and drink decreases.

At this stage, the focus for nutrition and hydration is no longer on meeting nutritional needs, eating a balanced diet, or preventing weight loss. The focus is comfort and quality of life. Food and drink, preferably the person's favourite food and drink, should be offered as and when that person wants to eat and drink.

The introduction of tube feeding or the provision of oral nutritional supplements is not recommended at this time and will not improve quality of life or prolong life and can be distressing for the person who is dying. However, if the person with dementia is already taking oral nutritional supplements or receiving tube feeding, then this can continue.

For most people who may only have days or hours to live, thirst and hunger will no longer be an issue. It is nature's way of preparing the person for a peaceful death. Frequent mouth and lip care can help provide comfort at this time.

It is helpful to remember that the person you care for is not dying because they are not eating or drinking, they are not eating or drinking because they are dying.