

Eating and drinking

Information for family and friends as dementia progresses towards the end of life



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Who is this booklet for?

This booklet has been designed for family or friends providing support for someone living with dementia who is experiencing difficulties with eating and drinking in the later stages.

This booklet may help you to make decisions, provide care, plan for future care, and it may also help to guide discussions with health professionals. You may not want to read all of this information at this time but might wish to come back to this booklet at a later time.

Eating and drinking difficulties in dementia

Dementia is a progressive terminal condition; so it is not possible to stop or reverse the overall decline. Everyone will experience this decline differently, as the speed and way this progression happens varies from person to person.

As someone's dementia advances, symptoms will worsen. Some people will have difficulties with swallowing, eating and drinking (described on page 15). However, some people living with dementia may experience these difficulties earlier. This does not necessarily mean they are approaching the end of life.

Causes of eating and drinking difficulties

There are a number of things which can cause eating and drinking difficulties in dementia, including:

- Physical health issues, like pain, constipation, infections,

cancer, oral or teeth health.

- Psychological issues, like anxiety or depression.
- The progressive effects of dementia on the brain. As a result, appetite can be affected. Likewise, swallowing difficulties can also appear.

Progression of eating and drinking difficulties

The following three scenarios describe the potential progression of eating and drinking difficulties experienced by Saleem, a person living with dementia at the later stages. With each scenario, think about the questions below. There is no one correct way for managing dementia, as everyone is different. Your values, culture or the help you have in supporting someone with dementia might influence what you would do in each scenario.

While reading think about:

- What would you do in each situation?
- How would you like to be treated if you were Saleem?
- Who would you ask if you had questions or needed support?
- Would home be the best place to live in each scenario?
- Who would you speak to if you were not sure?

Use the space below each scenario to write your thoughts

What do we mean by end of life?

End of life is particularly difficult to recognise in dementia and can last for months or even years.

People can die from dementia itself, however, many people with dementia will die from another illness (eg cancer, heart disease) and some may not reach the advanced stages of dementia. For some people, their health may quickly deteriorate (for example if they experience a stroke), but others may experience a slower deterioration.

For many, the end of life is not defined by a specific time period but rather a series of events, for example declining physical health (people may be at increased risk of infections, falls or hospital stays).

Towards the end of life in dementia there is often:

- Greater dependency on others for basic care, including help with eating and drinking.
- Inability to communicate.
- Double incontinence (loss of bladder and bowel control).
- Increasing frailty and problems walking, including becoming bedbound.
- Increased risk of pressure (bed) sores.
- Increased risk of infections.
- Eating and drinking less.
- Swallowing difficulties.
- Weight loss.

Find out more about end of life care at:

mariecurie.org.uk

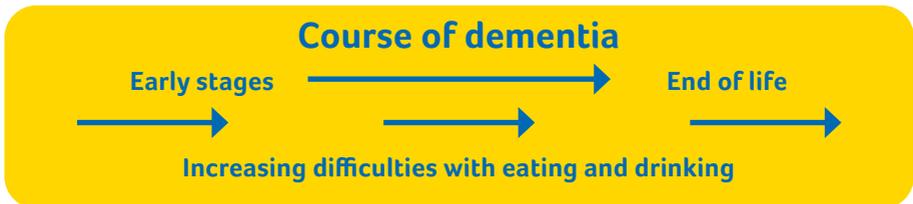
alzheimers.org.uk

hospiceuk.org

dyingmatters.org

Eating and drinking needs as dementia progresses and towards the end of life

Some difficulties may have already appeared at earlier stages of dementia (eg needing prompts around mealtimes, support with food preparation or adapting cutlery). However, it is often towards the end of life when more difficulties around eating and drinking might develop and it can become more time-consuming to support someone with eating.



Does the person I'm caring for need the same amount of food and drink towards the end of life?

Palliative care professionals describe the end of life as a process where the body is closing down; so the needs of the body are reduced, including its need for food and drink:

“As we reach the final stages of life we would expect the swallow to change, although it can happen at any time in someone’s dementia. We can minimise the risk of aspiration pneumonia (lung infection caused by saliva, food and drink going the wrong way), which causes discomfort by coughing, by giving food in a gravy or sauce so that it has a softer consistency, making sure the person is upright, keeping their mouth clean and ensuring no food is left in their mouth before moving to another task or leaving the room.”

Palliative care nurse

“Three factors are common in anybody and any diagnosis of the end stage and last year: weight loss, eat less and sleep more. You can’t eat when you’re asleep and if you’re not eating you’re going to lose weight.”

End of life facilitator

“We expect swallow to change as a person approaches those final few weeks in life, this is part of the body closing down. People often don’t feel as hungry or thirsty as we expect. They’re not doing as much as they once did, so they don’t need as many calories.”

Palliative care nurse

When should I flag up eating and drinking difficulties to professionals?

You should flag up eating and drinking difficulties to professionals when the person living with dementia:

- Is coughing or spluttering when eating or drinking, or shortly afterwards.
- Has stopped eating or drinking or is eating or drinking less.
- Is losing weight unintentionally – eg clothes may look looser or may need a smaller size.
- Is experiencing pain when swallowing.
- Has had more than one chest infection in the previous few months.
- Experiences any sudden change in their health or wellbeing.
- Is behaving differently to normal – eg appearing distressed or anxious with eating and drinking.
- Eyes water when eating and drinking, or shortly afterwards.
- Is more confused, drowsy or agitated than normal for them.

Some of these changes may also be indicators that the person with dementia is approaching the end of life. However, it is important to discuss these changes with your GP or healthcare team.

Who can help me?

You do not have to wait for a big problem to come - if you have any questions, professionals are there to help you; ask for a referral from your GP.

Speech and Language Therapist (SLT)

Provides a specialist assessment of swallowing and advises on the safest thickness of food and drink. They can also advise on strategies that can make swallowing safer, and on methods of delivery of food and drink for the person living with dementia. Some local SLT teams accept direct referrals from patients and their families.

Dietitian

Assesses the nutritional needs of the person living with dementia and provides advice on how to keep a healthy diet and lifestyle. They can also advise on nutritional supplements.

GP

Can advise on ways to encourage eating and drinking, can prescribe nutritional drinks or supplements, can advise on medications, refer on to other specialists (eg dietitian, SLT), and can provide medical assessments and treatments.

Admiral Nurse

Offers practical solutions to potential difficulties encountered in different places (eg community, care homes, etc.), which include eating and drinking difficulties.

If you have any questions about dementia you can contact the Admiral Nurse Dementia Helpline: 0800 888 6678.

Community or District Nurse

Assists with coordination of patient care in the community, such as supporting individuals recently discharged from hospital, as well as providing a range of services, such as administration of medications or help with dressings.

Occupational Therapist (OT)

Provides advice on how to overcome difficulties related to the environment of the person when eating and drinking (eg cutlery adaptations). Can also perform positioning and seating assessments.

Palliative Care Team

Offers advice on how best to support someone with eating and drinking difficulties at the later stages. Their focus is on quality of life. Their involvement is not restricted to the end of life, but to terminal illnesses.

Pharmacist

Can provide advice on different available forms of medications (eg liquid) if appropriate and on the best ways of providing medicines. The chosen form needs to then be prescribed, usually by the GP.

Swallowing difficulties

Somebody with swallowing difficulties struggles moving food, liquid or other substances (eg saliva or medicine) safely and efficiently from the mouth to the stomach. In this situation the associated risk can be acknowledged, in some cases artificial nutrition and hydration may be used, or preferably, different strategies can be used to encourage eating and drinking by mouth.

Acknowledging risk of eating and drinking

Sometimes, even if strategies and different textured food and drink have been tried, it's not possible to prevent food and drink going down the wrong way or for full nutrition to be met. Eating and drinking with acknowledged risk (sometimes known as risk or comfort feeding) means acknowledging and accepting the risks that someone with swallowing difficulties has when eating and drinking by mouth. The main risk is for food or drink to go the wrong way down towards the lungs. This can cause coughing, choking and chest infections. By accepting this risk, the individual continues to be provided food and drink for comfort. This often involves careful hand feeding.

The principles of eating and drinking with acknowledged risk



Artificial nutrition and hydration (ANH)

Artificial nutrition (or tube feeding) and hydration is a medical treatment used when the person cannot take food and drink by mouth.

While it may help families and care staff to feel they are doing something to increase nutrition for the person living with dementia at the end of life, it is also associated with:

- Discomfort and does not improve quality of life.
- Risk of aspiration (ie saliva going the wrong way into the windpipe and possibly causing pneumonia).
- Creating distress due to the person living with dementia not understanding the purpose of the tube and attempting to pull it.
- Risks of surgery and associated complications eg infections.

The use of artificial nutrition towards the end of life of the person living with dementia is **generally not recommended** as evidence shows that it does not extend life or prevent the risk of aspiration.

At the end of life, a palliative care approach is used instead to provide maximum comfort to the person living with dementia. This might involve the provision of small amounts of food and drink if the person wants them or mouth care. Mouth care contributes to comfort and reduces risks of pneumonia.

If you have any questions, discuss this with their GP or other healthcare professional.

Under some circumstances, medical professionals may consider tube feeding and/or artificial hydration appropriate or necessary to use when there is an acute and reversible condition. Artificial hydration might be in the form of an intravenous (needle into the vein) or subcutaneous (needle under the skin) for a few days. In terms of tube feeding, sometimes a nasogastric tube (from the nose to the stomach) is suggested for a few days or weeks. A gastrostomy (tube directly to the stomach) is rarely recommended for people with dementia.



What are the challenges people living with dementia have with eating and drinking?

Challenges	Difficulties with memory, communication and recognition <ul style="list-style-type: none"> - Forgetting to swallow and eat - Unable to recognise food and pureed food - Not hungry or thirsty - Cannot say what he or she wants 	Swallowing difficulties <ul style="list-style-type: none"> - Holding food in mouth - Choking - Coughing - Difficulty swallowing medication 	Physical health <ul style="list-style-type: none"> - Infections/severe illnesses - Mouth care and dentures - Drowsiness and sleepiness - Position when eating and drinking - Weight loss 	Changes in behaviour <ul style="list-style-type: none"> - Overeating - Eating too quickly or slowly - Particular behaviours (eg repeatedly cutting food in small pieces) - Changes in preferences or diet - Reluctance to eat/drink 	Mood <ul style="list-style-type: none"> - Feeling sad - Apathy (lack of feeling, emotion, interest or concern about something)
Key tips	<ul style="list-style-type: none"> - Use regular verbal encouragement. - Monitor meals and provide support if required. - Present food in a visually attractive and colourful way. Do not mix pureed food. - Provide foods you know the person likes or culturally appropriate foods. 	<ul style="list-style-type: none"> - Request SLT assessment (via GP or directly from local SLT services if available in your area). - Provide softer foods in smaller amounts. - Monitor meals. - Make sure the person has swallowed before offering the next mouthful or leaving the room. 	<ul style="list-style-type: none"> - Report any sudden changes and concerns to their GP. - Make sure the person is fully awake and upright before eating. - Regularly encourage food and drink. - Enrich food (eg with full cream or nutritional supplements). 	<ul style="list-style-type: none"> - Accept changes in eating behaviours are common and not an affront. - Offer food and drink regularly in smaller portions. - Have finger foods or snacks available around the house. - Explore different flavours and textures. - Do not force-feed. Stop and try later. 	<ul style="list-style-type: none"> - Report any concerns to their GP. - Keep notes of their food and fluid intake. - Explore foods and drinks with different textures, colours, flavours and temperatures. - Social interaction may be important for some people and help them recognise mealtimes.

Monitor any changes, improvements or decline – if you are concerned talk to your GP or healthcare team

Strategies to support eating and drinking

Over the next few pages we provide some strategies to support challenges you may face. However please bear in mind:

- Not every strategy will work with everyone. If a strategy does not work, try another one.
- Flexibility is key. Changes are common, including changes in personal preferences around food. Dementia can alter taste, so food that was previously enjoyed may no longer be a favourite. A strategy can work today or now and not later - this is normal.
- When implementing these strategies bear in mind the cultural, spiritual and personal preferences and emotional needs of the person with dementia.
- If you are concerned, talk to your GP or healthcare team.

Strategies for difficulties with memory, communication and recognition

- Show food/drink or pictures of a few choices.
- Use moulds to make puree look more like food or piping bags to make it more attractive.
- Show the food on the plate before blending it.
- Have snack foods and drinks easily accessible around the home.
- Encourage food and drink the person likes (eg sweet tooth).
- Maintaining food related roles might be important for some people (eg helping with food preparation).
- Continuing to have cultural celebrations might be important for some people.
- Offer foods that may link to earlier positive memories, eg favourite childhood meals.
- Monitor what the person eats, drinks and whether there is any change in weight.
- Look for non-verbal signs of distress, tiredness, or not wanting any more.
- Look for cutlery and cups that are easy to hold and colourful, and special plates that avoid spills.
- Guide their hand to their mouth, if required.
- If the person forgets that they have already eaten, provide meals in separate and smaller plates.

Strategies for swallowing difficulties

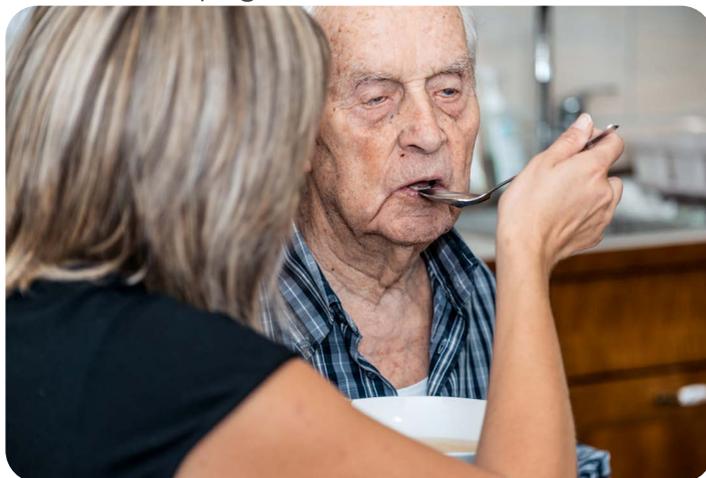
- Professionals might advise on thickeners for drinks, consistencies of food, or food supplements.
- Prompt the person with a small spoon to encourage swallowing.
- Make sure there is no food left in the person's mouth before leaving the person.
- If still not swallowing, remove the food from their mouth and try later.
- Keep offering food and drink that is adapted to their needs (eg correct texture/consistency and size).
- Make sure the person is upright and comfortable (as upright and as comfortable as possible). If you are supporting them, check your posture too.
- Reduce the feeding speed avoid using large spoons or overfilling them.
- Avoid mixing different textures.

If the person living with dementia is struggling to take medication: first check with their GP – some might need to be changed or adapted (eg to liquid/soluble forms) or stopped.

Do not crush medications without first speaking to the person living with dementia's GP or pharmacist, because this might cause some medicines to work incorrectly.

Strategies for physical health challenges

- Get advice from their GP/Healthcare team if there is an infection, illness or sensory impairment.
- Observe the person's daily routines and sleep/awake patterns and provide food/drink when they are awake for longer.
- Consult professionals regarding medication if the person is unwell.
- Where possible, the person might need to be transferred to an armchair with pillows during meals.
- Consider providing enriched food (eg with butter, full cream, whole milk) in smaller portions and the use of nutritional supplements.
- Physically support the person as they eat and drink by putting your hand over their hand on the cutlery and providing guidance in moving the food from the plate to the person's mouth. This might include helping them to sit upright.



Strategies for oral health challenges

- Visit the dentist regularly or request a home visit.
- Check if it is easier to eat without dentures.
- Make sure dentures are clean and well fitted, if do not fit consult a dentist.
- Clean the person's teeth and gums carefully check roof and sides of mouth.
- Search for special brushes if required.
- Check for infections and oral thrush (eg sore mouth and white coating on tongue) and see GP if noticed.

Mouth care is important to reduce the risk of pneumonia, in case something (eg food, drink or saliva) goes down the wrong way. It also reduces the risk of pain when eating and drinking.



Strategies for changes in behaviour

- If the person is eating too quickly use smaller cutlery, and introduce additional servings or courses gradually.
- If the person with dementia is becoming agitated, stop and try later.
- Accept the person may not want more food/drink, or three main meals a day.
- Consider adding choice, using a little and often approach and having finger foods or snacks that are safe available around the house.
- Consider the environment: reduce noise, ensure comfort, temperature, use calming music.
- People living with dementia might respond differently to distractions (eg TV) and having others around (eg eating together). For some, this might help them to eat, but for others this might not.
- If you are worried, check with the person living with dementia's GP.
- Ice lollies, jellies and fruit with high water content can promote hydration.

Strategies for mood challenges

- Speak to their GP or psychiatrist.
- Keep offering food and drink regularly.
- Provide the person with the opportunity to smell food, this might stimulate their interest/appetite.
- Try to talk about food and its smell before and during meals to raise interest.
- Consider foods that might encourage them to think of previous memories (eg certain cultural foods/during cultural festivals).
- Offer appealing food/drink that stands out from the table and gets the person's attention.
- Experiment with colours in cutlery/food and flavours.
- Some people develop a sweet tooth.

Top tips when offering food/drink

- Use a little and often approach.
- Enrich food (eg with cheese, full cream, whole milk).
- Use nutritional supplements or build up drinks advised by professionals.
- Avoid confrontation around food and drink, and never force-feed – stop and try later.
- If taste or preferences change, use trial and error to find suitable alternatives.
- Talk to others in your family or in your community (eg local family carers support group) for advice.

Top tips about eating and drinking at the end of life

- Focus on keeping the person comfortable.
- Make eating and drinking an enjoyable experience. Offer food only if the person wants it and when they want it. Offer foods they like and are culturally appropriate (although be aware that preferences can change).
- If the person with dementia does not want to eat or drink when the end of life is approaching they should not be forced to.
- Spend quality time with the person, avoid fights around food and drink. Quality time is more important than quantity of food.
- Don't worry about ensuring the person has a balanced diet or certain amounts of specific food groups. Be led by them. If you have any concerns about this (eg if the person living with dementia has diabetes or any other condition) discuss with healthcare professionals.
- Changes in preferences are common. What the person living dementia may want or accept to eat when offered one day (an old favourite or new food) may not work the next day. New food preferences may clash with the person's traditional or cultural views. You should discuss this with your family and consider the person's wishes and preferences.
- When the body is closing down, mouth care might be enough instead of food to provide comfort and you can help with this.
- Eating and drinking might not be the most comfortable option at the end of life.

Things to discuss with professionals

Tick what you would like to discuss in future appointments:

- I am concerned about the person living with dementia's health and wellbeing (eg changes in eating patterns, weight, mood).
- I would like to discuss the cultural beliefs/personal preferences related to eating and drinking of the person with dementia.
- I have noticed recent changes or unusual behaviours.
- I have observed eating or drinking difficulties in the person living with dementia.
- I would like to talk to a Speech and Language Therapist (SLT).
- I would like to talk to a Dietitian.
- I would like to talk to an Occupational Therapist.
- I would like to know what professional support is available in my community.
- I would like to have the palliative care team involved if the person living with dementia is approaching the end of life.
- I would like to find out what is an advance care plan and/or Lasting Power of Attorney.
- I would like to work on an advance care plan with the person living with dementia and professionals.
- I would like to discuss with the person living with dementia and professionals the possibility of adding a statement about artificial nutrition and hydration as part of the advance care plan.
- I would like to discuss with the person living with dementia and professionals having a Lasting Power of Attorney for health and welfare in place.

Support for family carers

Decisions about nutrition and hydration often place family carers under stress, so it is very important that you look after yourself:

Marie Curie has a support line for people towards the end of life and those providing support on **0800 090 2309** and also online chat **mariecurie.org.uk/support**

The **GP** or any healthcare professional visiting the person living with dementia can be a source of support and information. They might also be aware of support available for carers living in your area.

Memory clinics might run carers' groups and information sessions for those caring for a person living with dementia at different stages.

Alzheimer's Society runs carers' groups around the UK, you can find out if there is any group close to you or get some support on **0333 150 3456**. There may also be local groups offering specific support for people from diverse backgrounds.

Carers UK have online forums for carers **carersuk.org** and provide advice over the phone to carers on **0808 808 7777**.

Dementia UK has information on how to look after yourself **dementiauk.org** and an **Admiral Nurse Dementia Helpline** on **0800 888 6678**.

Other resources with further information

Eating and drinking difficulties at different stages of dementia and practical advice including recipes

[Alzheimers Society, Eating and drinking factsheet pdf](#)

[Carers UK, dementia and nutrition](#)

[Bournemouth University, The Eating and Drinking Well with Dementia Toolkit](#)

[Royal College of Physicians, guide to supporting people who have difficulty eating and drinking](#)

Eating and drinking difficulties in advanced dementia and practical advice

[Eating Well with Dementia, A carers' guide pdf](#)

[NHS Lanarkshire, Eating and drinking pdf](#)

Advance care planning

[Planning your care in advance](#)

Who has developed this booklet?

This booklet has been developed by a leading team of researchers and health and social care professionals including GPs, psychiatrists, geriatricians, speech and language therapists and experts in social care. We have had input from professionals across a range of specialities, including palliative care, speech and language therapists, and psychologists.

We have used the latest evidence from research and clinical practice, together with the views and experiences of people with dementia, family carers, and health and social care professionals to develop the content and design.

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