Eating and drinking in dementia towards the end of life

Information for carers, family and friends

Marie Curie

IN PARTNERSHIP WITH

UCL

* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

Introduction

This booklet is for carers, family or friends supporting someone with dementia who is having difficulties with eating and drinking towards the end of life. It may help you to make decisions, provide care now, and plan for future care. It may also help to guide discussions with healthcare professionals.

We've divided this booklet into short chapters so you can read through it at your own pace. You could also look at it with someone else, like a nurse, friend or family member, so you have their support.

iStock

Contents

Eating and drinking problems in people with dementia

Dementia is a progressive terminal condition. This means it is not possible to stop the illness from getting worse over time. The speed and way the dementia gets worse over time is different from person to person.

As the dementia gets worse and someone nears the end of life, the symptoms will also get worse. Some people will have problems with swallowing, eating and drinking.

Having problems with swallowing, eating or drinking does not always mean someone with dementia is near the end of life. Some people with dementia may experience these problems earlier.

Causes of eating and drinking problems in people with dementia

Different things can cause eating and drinking difficulties in dementia, including:

- physical health issues, like pain, constipation, infections, cancer, and oral or teeth health
- psychological issues, like anxiety or depression
- the progressive effects of dementia on the brain, which mean the person's appetite may be affected and they may have problems swallowing.

Read tips for supporting people with dementia with eating or drinking problems on page 26.

What is end of life?

End of life is usually used to describe people who are thought to be in the last year of life. This stage is particularly difficult to recognise in dementia. It can last for months or even years.

People can die from dementia itself, but many people with dementia will die from another illness such as cancer or heart disease. Some people may not reach the advanced stages of dementia.

For some people with dementia, their health may get worse quickly – for example, if they have a stroke. But others may experience their health getting worse more slowly.

For many people with dementia, end of life is not a specific time, but a series of events. These events could be linked to physical health getting worse, including being at increased risk of infections, falling, or having hospital stays.

iStock

Signs of end of life in people with dementia

You may hear healthcare professionals describe the end of life as a process where the body is closing down. This means the needs of the body are reduced, including the need for food and drink. The following may all be signs of the end of life:

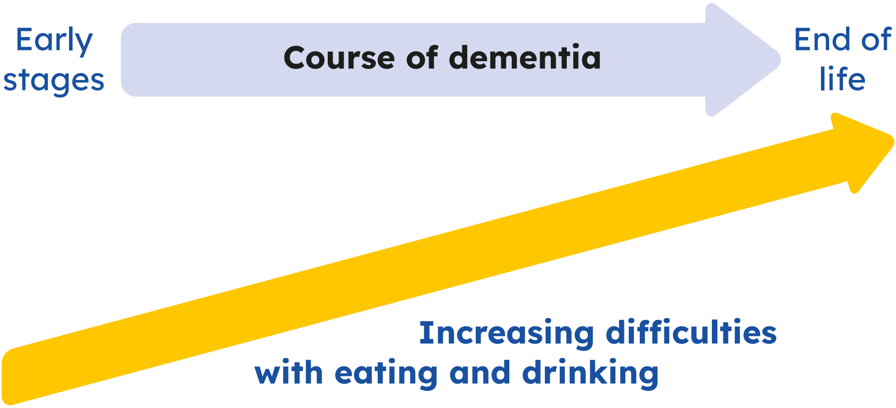
- Depending more on other people for basic care, including help with eating and drinking.
- Not being able to communicate.
- Loss of bladder and bowel control (double incontinence).
- Increasing frailty and problems walking, including becoming bedbound.
- Increased risk of pressure damage (pressure sores).
- Increased risk of infections.
- Eating and drinking less.
- Swallowing difficulties.
- Weight loss.

Read more about end of life at **mariecurie.org.uk/what-to-expect**, or order Marie Curie's free booklet **What to expect at the end of someone's life** by visiting **mariecurie.org.uk/publications** or calling **0800 090 2309***.

Eating and drinking problems towards the end of life

Some eating and drinking problems may have started in the earlier stages of dementia. For example, needing prompts around mealtimes, support with food preparation, or adapting cutlery. But it's often towards the end of life when more problems with eating and drinking might develop. This means it can take more time to support someone with eating or drinking.

Eating and drinking needs as dementia progresses



> **"Three factors are common in anybody with any diagnosis of the end stage or last year of life – weight loss, eating less and sleeping 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

Problems with eating and drinking – scenarios to think about

The following three scenarios describe how eating and drinking problems may progress. It uses Saleem, a person living with dementia in the later stages, as an example.

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 each scenario, think about these questions:

- 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.

You might like to use these scenarios as a way to ask questions to the healthcare professionals supporting the person with dementia.

Scenario A – Eating less

Saleem is 86 years old and has dementia. He lives at home with his daughter and her family.

Saleem has recently started to eat less, and no longer seems to find pleasure in foods he once really enjoyed. He often leaves food at the end of his meal and finds it more difficult to feed himself. At times Saleem refuses to eat. His daughter does not know what the right thing to do is and whether she should encourage her dad to eat or not.

Return to contents page

Scenario B – Difficulty swallowing

Saleem has experienced swallowing difficulties for some time. Lots of thought has been given to providing suitable foods for his meals, which has prevented choking episodes.

His daughter is having problems giving him medicines. His healthcare team have substituted many of his tablets with liquid medicine and some have been stopped, but one of his medicines remains a problem.

Although a medicine which can be dissolved in water has been prescribed, it still leaves a gritty residue in the water. Saleem is refusing to take it, as it has caused him to choke a couple of times recently. His GP is very reluctant to stop this medication.

Scenario C – End of life

Saleem has continued to have difficulties with eating. All his foods are now pureed, and his daughter often uses sweet foods which she knows her dad enjoys. His daughter has been spending time with her dad providing careful hand feeding. Liquid is thickened to ensure he does not choke. However, even careful hand feeding, or carefully bringing food to her father's mouth, no longer works. Saleem cannot swallow food and holds the food in his mouth. His daughter is afraid he is not getting enough nutrition. Saleem's health is becoming worse, and the clinical team have said he is approaching the end of life.

> **“We expect swallowing to change as a person approaches those final few weeks of life, because 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

iStock

Telling health and social care professionals

You should tell professionals if someone with dementia is having problems with eating and drinking. You should also let them know if there are changes to their eating or drinking. This could include the person living with dementia:

- coughing or spluttering when eating or drinking, or shortly afterwards
- stopping eating or drinking
- eating or drinking less
- losing weight without meaning to – for example, clothes may look looser or they may need a smaller size
- experiencing pain when swallowing
- having more than one chest infection within a few months
- having any sudden change in their health or wellbeing
- behaving differently – for example, appearing distressed or anxious about eating and drinking
- having watering eyes when eating and drinking, or shortly afterwards
- being more confused, drowsy or agitated than normal for them.

Some of these changes may mean that the person with dementia is nearing the end of life. It is important to discuss these changes with the person’s GP or healthcare team.

Return to contents page

Who can help?

There may be several health and social care professionals involved in caring for someone with dementia. But there might be one person who co-ordinates that care – you may hear them being called a **key worker** or **named person**.

The person's condition and health and care needs will help decide who their key worker is. For example, they could be a GP, district nurse, clinical nurse specialist, or social worker.

As the person's needs change throughout their illness, so will their key worker. If you do not know who their key worker is, the best person to contact is their GP.

In this section, we list some of the professionals who can offer specific support around eating and drinking.

GP

A GP can:

- advise on ways to encourage eating and drinking
- prescribe nutritional drinks or supplements
- advise on and prescribe medicines
- refer the person with dementia to other specialists, such as a speech and language therapist or dietitian
- provide medical assessments and treatments.

Speech and language therapist

A speech and language therapist (SLT) can provide treatment, support and care for people who find it difficult to communicate, eat, drink or swallow. They can:

- do a specialist assessment of swallowing
- advise on the safest thickness of food and drink.
- suggest strategies to make swallowing safer
- advise on the best methods for the person with dementia to have food or drink – for example, a liquid meal replacement.

Some local SLT teams accept direct referrals from people needing support and their families. You can also ask the person’s GP or district nurse to refer them.

Dietitian

A dietitian can:

- assess the nutritional needs of the person living with dementia
- give advice on how to keep a healthy diet and lifestyle
- advise on nutritional supplements.

Admiral Nurse

Admiral Nurses are specialist dementia nurses.

They can offer practical solutions to potential difficulties, including eating and drinking difficulties. They can help in different places, such as at home or in care homes.

You can find out if there are Admiral Nurses in your area by calling the Admiral Nurse Dementia Helpline on **0800 888 6678** or emailing **helpline@dementiauk.org**

Return to contents page

District or community nurse

A district or community nurse may be involved with:

- organising care at home
- giving medical care, such as managing symptoms or changing dressings
- ordering equipment, such as a commode or adjustable bed
- arranging for other services to help with your care, such as an occupational therapist.

District and community nurses co-ordinate lots of services, but the availability of these may vary from area to area. These can include healthcare assistants, care workers, or other care agencies.

Occupational therapist (OT)

Occupational therapists support people in hospices, hospitals, and at home. They can help if someone has difficulty with tasks like eating and drinking by sharing new ways of doing things. They may also recommend adaptations and equipment, such as cutlery adaptations.

You could get occupational therapy for free by:

- contacting the person's GP for a referral
- asking the local council if the person lives in England, Scotland and Wales, or the Health and Social Care Trust if the person lives in Northern Ireland.

You can also get occupational therapy privately. You can search for qualified therapists in your area on The Royal College of Occupational Therapists' website at rcot.co.uk

Specialist palliative care team

Palliative care offers physical, emotional and practical support to people with a terminal illness, including dementia. It also focuses on managing symptoms, such as eating or drinking difficulties, and supporting them to have a good quality of life. This kind of care could be offered in the person's home, in hospital, in a hospice or in a care home.

A specialist palliative care team will involve healthcare professionals who specialise in palliative care. This might include doctors, nurses, occupational therapists and physiotherapists.

iStock

Return to contents page

Pharmacist

Pharmacists are based in the community. They can support you by:

- giving advice on different medicines that are available, such as liquid medicines
- giving out (dispensing) medicines that have been prescribed by a GP or other healthcare professional
- working with the rest of your palliative care team to help you get the right support.

Some pharmacies have palliative care pharmacists. These pharmacists are trained in palliative care and can offer more specialised support, such as advising on the management of any symptoms and suggesting local palliative care services. You could ask your GP about palliative care pharmacists in your area.

Read more about who can help at **mariecurie.org.uk/support**, or order Marie Curie's free booklet **Getting care and support** by visiting **mariecurie.org.uk/publications** or calling **0800 090 2309***.

Methods of eating and drinking

Eating and drinking with acknowledged risk

Eating and drinking with acknowledged risk means acknowledging and accepting the risks that someone with problems swallowing has when they eat and drink by mouth. It is sometimes known as risk feeding or comfort feeding.

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 person can continue to be given food and drink for comfort. This often involves careful hand feeding.

Sometimes it's not possible:

- to prevent food and drink going down the wrong way
- for full nutritional need to be met.

This can be the case even if strategies, including different textured food and drink, have been tried.

Return to contents page

The principles of eating and drinking with acknowledged risk

Eating and drinking with acknowledged risk

Acknowledges the risk of providing food/drink by mouth

Focuses on the **enjoyment and comfort** of the individual

Is the **preferred approach** when the end of life is approaching

Allows the individual to stay at home, or their **preferred place of care/death**

Only **preferred food/drink** is offered in the safest way possible

Food/drink is only provided **if the individual accepts it**

Artificial nutrition and hydration

Artificial nutrition and hydration (ANH) may be used when someone cannot take food and drink by mouth.

How is artificial nutrition and hydration given?

Artificial nutrition is sometimes called tube feeding. It may use:

- a tube that goes from the nose to the stomach (nasogastric tube) **or**
- a tube that goes directly to the stomach (gastrostomy tube).

Sometimes artificial nutrition using a nasogastric tube is suggested for a few days or weeks. A gastrostomy tube is not usually recommended for people with dementia.

Artificial hydration might be given using:

- an intravenous needle, that goes directly into the vein **or**
- a subcutaneous needle, that goes under the skin for a few days.

Making a decision about artificial nutrition and hydration

Artificial nutrition and hydration may be a difficult subject, especially if the person with dementia is not able to make decisions for themselves (does not have capacity) and you are unsure of their wishes.

There are benefits and risks to artificial nutrition and hydration. It may help those caring for the person with dementia to feel they are doing something to increase nutrition, especially towards the end of life. But it is also associated with:

- discomfort
- risk of accidentally breathing fluid or an object into the lungs (aspiration) – for example, saliva or food going the wrong way into the airway, which can block it and possibly cause pneumonia
- causing distress if the person with dementia does not understand the purpose of the tube and attempts to pull it out
- risks of surgery and associated complications, such as infections.

It has also not been proven to improve the person's quality of life.

Artificial nutrition and hydration towards the end of life

In someone with dementia, artificial nutrition towards the end of life is **usually not recommended**. This is because evidence shows that:

- it does not extend life
- it does not prevent the risk of aspiration.

Instead, healthcare professionals will give palliative care to make sure the person with dementia is as comfortable as possible. This might involve giving small amounts of food and drink if the person wants them, or providing mouth care. Mouth care contributes to comfort and reduces risks of pneumonia.

For some people with dementia, healthcare professionals may say artificial nutrition, artificial hydration, or both, are appropriate or necessary to use towards the end of life. This is usually if the person has another condition that may get better because of the treatment.

If you have any questions about artificial nutrition and hydration, it’s best to ask the person’s GP or other healthcare professional.

Eating and drinking tips to support someone with dementia

Challenges	Key tips
Memory, communication and recognition difficulties	
• Forgetting to swallow and eat. • Unable to recognise food or pureed food. • Not hungry or thirsty. • Cannot say what they want.	• Tell them that they're doing well and encourage them while eating or drinking. • Monitor meals and help them during mealtimes, if needed. • Try to present food in an attractive and colourful way. Do not mix pureed food. • Try to give them foods they like or that follow any culture requirements, such as halal foods.
Swallowing difficulties	
• Holding food in their mouth. • Choking. • Coughing. • Difficulty swallowing medicines.	• Ask for a speech and language therapist assessment. You can ask for a referral from your GP or directly from local services, if they are available in your area (see page 14). • Give softer foods in smaller amounts. • Monitor meals. This includes how often they are eating and what they are eating. • Make sure they have swallowed before offering the next mouthful or leaving the room.

Challenges	Key tips
Changes to physical health	
• Infections or severe illnesses. • Keeping the mouth and dentures clean. • Feeling tired or drowsy. • Position when eating and drinking. • Losing weight.	• Tell the person’s GP about any sudden changes and concerns you have. • Make sure the person is fully awake and upright before eating. • Encourage them to eat and drink regularly. • Add nutrients to food – for example, with full cream or nutritional supplements.
Changes in behaviour	
• Eating too much (overeating). • Eating too quickly or slowly. • New behaviour specific to the person, such as repeatedly cutting food into small pieces. • Changes in food or drink preferences or diet. • Being reluctant to eat or drink.	• Accept that changes in eating behaviours are common and not an attack on you or the things you’re trying to help with. • Offer them food and drink regularly in smaller portions. • Have finger foods or snacks available. • Explore food and drink with different textures, colours, flavours and temperatures. • Do not force-feed them. Instead, stop and try later.

Challenges	Key tips
Mood	
• Feeling sad. • A lack of feeling, emotion, interest or concern about things (apathy).	• Tell the person's GP about any concerns you have. • Keep notes of their food and drink intake. • Explore food and drinks with different textures, colours, flavours and temperatures. • Try to have someone, or a group of people, be with them at mealtimes. This 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 the person's GP or healthcare team.

Tips to support eating and drinking

In this section, we share some tips that may help someone with dementia with eating and drinking. It is important to speak with the person's healthcare team before trying these. They can give advice about the person's individual situation.

While reading these tips, remember that:

- not every tip will work with everyone, or it may only work some of the time – if a tip does not work, try a different one
- being as flexible as possible will help – dementia can alter taste, so changes in food and drink preferences may happen
- it's important to bear in mind the cultural, spiritual and personal preferences, as well as the emotional needs, of the person with dementia while using these tips
- it's best to talk to the person's GP or healthcare team if you have any concerns or questions.

Return to contents page

Top tips when offering food and drink

- Use a little and often approach.
- Enrich food, for example with cheese, full cream, or 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, for example a local support group, for advice.

iStock

Tips for memory, communication and recognition difficulties

- Before a meal, show the person the actual food or drink and try to give them a few different options. If you cannot show the actual food or drink, try to get pictures.
- 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 wherever the person is staying – for example, at home or in their room at a care home.
- Use your knowledge of the food and drink the person usually likes to encourage them to eat or drink. For example, they might have a sweet tooth.
- Think about whether the person might want to be involved in preparing or serving the food or drink. Try to accommodate this where it’s safe and possible.
- Think about whether any cultural or religious celebrations, especially if they involve food or drink, are important to the person.
- Try to offer foods that may link to earlier positive memories, such as 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.
- Use cutlery and cups that are easy to hold and colourful, and specifically designed 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.

Return to contents page

Tips for swallowing difficulties

Somebody with swallowing difficulties struggles to move substances safely from the mouth to the stomach. This could include:

- food
- liquid
- saliva
- medicines.

If someone has difficulty swallowing, the associated risk can be acknowledged (see page 18) or, in some cases, artificial nutrition and hydration may be used (see page 22).

> **“As we reach the final stages of life, we would expect swallowing to change, although it can happen at any time in someone’s dementia. We can minimise the risk of aspiration pneumonia – a 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

Different strategies can be used to encourage eating and drinking by mouth:

- Healthcare 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. For example, food that is the correct texture, consistency and size.
- Make sure the person is as upright and comfortable as possible. If you're 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 medicines, tell their GP. Some medicines might need to be changed, adapted, or stopped. For example, the medicines may be available in liquid or soluble forms. Do not crush medicines without speaking to their GP or pharmacist, because this might cause some medicines to work incorrectly.

Return to contents page

Tips for physical health challenges

- Get advice from their GP or healthcare team if they have an infection, illness or sensory impairment.
- Observe their daily routines, including when they are asleep and when they are awake. Give food and drink when they are awake for longer.
- Ask their healthcare professionals about medicines if they are ill.
- Where possible, encourage the person to sit upright during meals – for example, in an armchair with pillows.
- Consider providing enriched food in smaller portions, such as food with butter, full cream, or whole milk. You could also use nutritional supplements.
- Support their eating and drinking by putting your hand over their hand on the cutlery. You can then help to guide them to move the food from the plate to their mouth. This might include helping them to sit upright.

iStock

Tips for good oral health and mouth care

Mouth care is important to reduce the risk of pneumonia if something, such as food, drink or saliva, goes down the wrong way. It also reduces the risk of pain when eating and drinking.

- Arrange for them to visit the dentist regularly or request a home visit.
- Check if it is easier for them to eat without dentures.
- Make sure dentures are clean and well fitted. If they do not fit, ask their dentist about it.
- Clean their teeth and gums carefully. Make sure you check the roof and sides of mouth.
- Search for special brushes if required.
- Check for infections and oral thrush – look out for a sore mouth and white coating on tongue. If you notice anything, see their GP.

For more information about supporting someone with mouth care, visit **mariecurie.org.uk/mouthcare**

Tips for changes in behaviour

- If they are eating too quickly, you could try using smaller cutlery. You could also introduce additional servings or courses gradually.
- If they are becoming agitated, stop giving the food or drink and try later.
- Accept they may not want more food or drink, or three main meals a day.
- Consider adding a choice of food, using a little and often approach, and having finger foods or snacks that are safe available around the house.
- Make the environment as comfortable as possible. You could try reducing any noise, making the temperature comfortable, and using calming music.
- People living with dementia might respond differently to distractions, such as having the TV on, or eating with others around them. For some, these distractions might help them to eat, but for others they might not.
- If you are worried, check with the person living with dementia’s GP.
- Ice lollies, jellies and fruit with high water content, such as strawberries or watermelon, can help them to stay hydrated.

Tips for mood challenges

- Speak to their GP or psychiatrist if you notice any changes to their mood.
- Keep offering them food and drink regularly.
- Give them the opportunity to smell food. This might stimulate their interest and appetite.
- Try to talk about food and its smell before and during meals to raise interest.
- Consider giving foods that might encourage them to think of previous memories. For example, certain foods that may have been eaten during cultural festivals.
- Offer appealing food and drink that stands out from the table, and gets their attention.
- Experiment with colours in cutlery and food, as well as different flavours.
- Some people develop a sweet tooth, and it is OK to offer foods that cater to this.

Tips to support eating and drinking towards the end of life

As well as using the tips we shared above, you may want to focus more on certain things towards the end of someone's life:

- Focus on keeping them as comfortable as possible.
- Try to make eating and drinking an enjoyable experience. Only offer food if they want it and when they want it. Offer foods they like and that are culturally appropriate – although be aware that preferences can change.
- If the person with dementia does not want to eat or drink towards the end of life, they should not be forced to.
- Spend quality time with them and try to avoid fights around food and drink. Quality time is more important than quantity of food.
- Do not worry about making sure that they have a balanced diet or certain amounts of specific food groups. Instead, be led by them. If you have any concerns about this, for example if they have diabetes or any other condition, you can discuss it with their healthcare professionals.
- It's common for food and drink preferences to change. What they may want or accept to eat one day may not work the next day. New food preferences may clash with their traditional or cultural views. You should discuss this with your family or those important to them, and consider their wishes and preferences.
- When the body is closing down, mouth care might be enough to provide comfort instead of offering food. You can help give mouth care (see page 32).
- Remember that eating and drinking might not be the most comfortable option at the end of life.

Questions and concerns to discuss with professionals

Use this list to tick what you would like to discuss in future appointments. Where we've left a blank underlined space (____________), you can fill in the person with dementia's name.

- ☐ I am concerned about ____________'s health and wellbeing (for example, changes in eating patterns, weight, mood).
- ☐ I would like to discuss ____________'s cultural beliefs or personal preferences related to eating and drinking.
- ☐ I have noticed recent changes or unusual behaviours.
- ☐ I have observed eating or drinking difficulties in ____________.
- ☐ 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 ____________ is approaching the end of life.

Return to contents page

☐ I would like to find out about an advance care plan or a Power of Attorney (see resources on page 42).

☐ I would like to work on an advance care plan with ____________ and professionals.

☐ I would like to discuss adding a statement about artificial nutrition and hydration to the advance care plan with ____________ and professionals.

☐ I would like to discuss having a lasting or welfare Power of Attorney for health and welfare in place with ____________ and professionals (England, Scotland and Wales).

iStock

Support for carers, family and friends

Seeing changes in someone's eating or drinking, and helping to make decisions about eating and drinking, can be hard. It's important that you look after yourself, as well as the person with dementia that you're supporting.

Health and social care professionals

You can get support and information from your GP, the person living with dementia's GP, or any healthcare professional visiting them. They might also be aware of support available for carers living in your area.

Support groups

Some memory clinics run support groups for carers, as well as information sessions for those caring for someone living with dementia at different stages.

Alzheimer's Society runs carers groups around the UK. You can find out if there is a group close to you, or get other support, by calling **0333 150 3456**.

There may also be local groups offering specific support for people from diverse backgrounds. Your GP should be able to help you find local groups.

Return to contents page

Phone or online support

Marie Curie has a free Support Line for anyone affected by terminal illness, including dementia, that can offer emotional support and information. You can call **0800 090 2309*** and or chat online at **mariecurie.org.uk/support**

Carers UK has an online forum for carers at **carersuk.org** It can also provide guidance over the phone to carers on **0808 808 7777**.

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

See pages 40–42 for more useful organisations and resources.

iStock

Useful organisations and resources

Dementia organisations

Alzheimer Scotland

Offers information, support and community-based services for people affected by dementia in Scotland.
Dementia Helpline: **0808 808 3000**
alzscot.org

Alzheimer's Society

Provides guidance on diagnosis, symptoms and care for people living with Alzheimer's, as well as information about local services and support groups.
Dementia Support Line: **0333 150 3456**
alzheimers.org.uk

Dementia Carers Count

Offers free services for family carers to help them understand more about dementia and give them the chance to connect with others in a similar situation.
Support line: **0800 652 1102**
dementiacarers.org.uk

Dementia UK

Provides information about dementia, including practical and emotional matters, as well as phone and face-to-face support from Admiral Nurses.
Dementia Helpline: **0800 888 6678**
dementiauk.org

Return to contents page

Palliative care and end of life care organisations

Hospice UK

Provides information and support about hospice care in the UK, as well as a search function to find where your nearest hospice is.
hospiceuk.org

Marie Curie

Offers information and support to anyone affected by terminal illness, including carers, family and friends. Has a free Support Line, web chat, printed and online information, and ongoing support services, such as the Companion over the phone service and the Telephone Bereavement Support Service.
Support Line: **0800 090 2309**
mariecurie.org.uk

Booklets, PDFs and other resources about dementia

Eating and drinking

Factsheet by Alzheimer's Society
PDF: alzheimers.org.uk/sites/default/files/pdf/factsheet_eating_and_drinking.pdf
Read more online: alzheimers.org.uk/eating

The Eating and Drinking Well with Dementia Toolkit

Toolkit by the Aging and Dementia Research Centre at Bournemouth University
Download toolkit: bournemouth.ac.uk/eating-drinking-well-dementia-toolkit

Planning your care in advance

Webpage by Marie Curie
Webpage: mariecurie.org.uk/planningahead
Read more in a booklet: mariecurie.org.uk/help/support/publications/planning-ahead

Supporting people who have difficulty eating and drinking: A guide to practical care and clinical assistance, particularly towards the end of life

Guide by the Royal College of Physicians
Download PDF: rcplondon.ac.uk/projects/outputs/supporting-people-who-have-eating-and-drinking-difficulties

Talking about eating and drinking for people with severe dementia during hospital stays

Factsheet by University College London
Download PDF: ucl.ac.uk/psychiatry/sites/psychiatry/files/eating_drinking_hospital_dementia.pdf

Did you find this information useful?

If you have feedback about this booklet, please email us at review@mariecurie.org.uk or call the free Marie Curie Support Line on **0800 090 2309***.

Thanks and acknowledgements

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.

Health and social care professionals

Esther Wiskerke, Dementia Service Manager

Ruth Crossley, End of Life Care Facilitator (Registered Nurse)

Hanna Sampson, Occupational Therapist

Joanna Wild, Regional Quality Manager for Care Homes (Registered Nurse)

Sophie Whitehead, Highly Specialist Speech and Language Therapist, Care of the Elderly

Dr Barber Qadir, GP

Dr Jennifer Pigott, Specialty Registrar in Geriatric and General Internal Medicine

Dr Howell T. Jones, Academic Clinical Fellow and Specialist Registrar in Geriatric Medicine

Dr Danielle Nimmons, Academic Clinical Fellow in General Practice

Research team

Dr Nathan Davies, Associate Professor, and Director, Centre for Ageing Population Studies

Dr Yolanda Barrado-Martín, Research Fellow

Dr Pushpa Nair, GP

Dr Kanthee Anantapong, Psychiatrist

Dr Kirsten J. Moore, Senior Research Fellow

Dr Christina H. Smith, Associate Professor, and Speech and Language Therapist

Professor Greta Rait, GP

Professor Elizabeth L. Sampson, Psychiatrist

Professor Jill Manthorpe, Professor of Social Work

Notice

The information in this publication is provided for the benefit and personal use of people with a terminal illness, their families and carers.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

Your notes

Your notes

Your notes

Marie Curie

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.

0800 090 2309*

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them.

Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Visit **mariecurie.org.uk/support**

We also have an Online Community where you can share thoughts, feelings and experiences at **community.mariecurie.org.uk**

We can't do it without you

Our free information and support services are entirely funded by your generous donations. Thanks to you, we can continue to offer people what they need, when they need it.
To donate, visit **mariecurie.org.uk/donate**

Trusted Information Creator
Patient Information Forum

---

* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

Published January 2024. Edition 1. Next review January 2027.
Registered charity in England and Wales (207994) and Scotland (SC038731). M365