

Eating, drinking and swallowing

A guide for carers of people living with a dementia



Eating, drinking and swallowing difficulties (dysphagia) may be experienced by people living with a dementia. These difficulties may become more common as their dementia progresses.

Eating, drinking and swallowing are complex processes and poor coordination of the swallow can result in food or drink entering the lungs instead of the stomach, potentially leading to chest infections or pneumonia.

If the person is unable to eat or drink adequately this can lead to malnutrition, weight loss and/or dehydration, which can worsen the symptoms of dementia. The person's ability to communicate that they are hungry or thirsty may be reduced. Food and fluid intake needs to be monitored on a daily basis to ensure it is adequate.



If you notice the person's eating and drinking habits changing over a period of time, it may be due to:

- apathy (lack of interest in food or drink)
- progression of dementia
- swallowing difficulties
- depression or anxiety
- loss of appetite
- social isolation/loneliness
- loss of independence
- lack of physical activity.

If there is a sudden change in the person's eating and drinking, it may be due to:

- an oral or dental infection
- a urinary/kidney infection or chest infection
- medication
- pain
- tiredness
- loss of dignity and independence
- constipation
- new or fluctuating symptoms of dementia.

Caring for someone with a dementia can be challenging. This booklet aims to provide you with information on how the eating, drinking and swallowing of a person with a dementia may be affected. It includes sections on:

Memory and concentration

Coordination

Swallowing food and drinks

Behaviours displayed at mealtimes

Oral care advice

Not everyone with a dementia will experience all of these difficulties.

Helpful hints

Things to think about before eating and drinking:

- encourage the person to get involved in meal preparation and choice (or provide assistance as appropriate)
- offer as much choice and variety as possible, taking into account the person's likes and dislikes
- the environment where the person eats and drinks is as calm and relaxing as possible, reduce noise and distractions
- offer a large napkin or tea towel over the person's knees if there are concerns about food or drinks spilling and prompt the person to use it
- dentures, glasses and hearing aids are worn as needed
- the table is free from any unnecessary items
- the person is sitting as upright as possible to encourage them to be alert
- use colour contrast to help the person see their food - for example put white foods like potatoes on a coloured plate (red and blue are commonly used), and coloured foods like tomato soup in a white bowl
- the person's plate isn't overloaded, too much food can be off putting
- avoid using patterned plates or tablecloths
- serve one course at a time
- use a warm plate so food stays warmer for longer.

If Recommendations for Eating, Drinking and Swallowing (REDS) are in place, they should be followed at all times.

Memory and concentration

A person with a dementia often has difficulties concentrating and sitting at a table for the duration of a meal. It could wrongly be assumed that the person is finished or not hungry.

Helpful hints

- Try to find out if the person prefers to eat alone or in company as this can encourage eating. Eating with the person may help so they can copy you and makes eating more sociable.
- Encourage the person to go to the table only when the meal is ready so they do not have to wait.
- Direct the person's attention to the food and cutlery and ensure the food is in the person's line of vision.
- Serve food close to the middle of the plate.
- Put the cutlery or cup in their hand (if needed) or guide them to take the first mouthful (and further mouthfuls if needed), using gentle physical prompts while sitting opposite the person.
- If necessary, offer the first mouthful and then try to encourage them to feed themselves.
- Give reminders to swallow each mouthful as needed.
- If the person leaves the table gently guide them back and prompt them to continue.
- If they forget that they have already eaten or are concerned about where the next meal is coming from, reassure the person and provide them with a snack if appropriate.
- Avoid unnecessary interruptions during meal and snack times.



Coordination

A person with a dementia often has difficulty feeding themselves. It is however important to encourage independence as this helps the swallow process.

Helpful hints

- Use weighted cutlery or cutlery aids as recommended.
- Cut food up before presenting it.
- Only give the person the cutlery required.
- Put the cutlery or cup directly into the person's hand.
- Consider use of finger foods like sandwiches, slices of fruit or vegetables and cheese.
- Use gentle physical prompts, for example place your hand over the person's hand to guide their food or drink to their mouth.
- Only as a last resort consider assisting them to finish part or all of the meal.
- Many people will still be able to hold a cup after the ability to use a fork or spoon has been lost, and this should be encouraged.
- Make sure the person's seating is appropriate to the height of the table being used and that they are well supported with their feet on the ground.
- Encourage all attempts the person makes to feed themselves to promote independence even if it is messy.



Swallowing food and drinks

A person with dementia may have difficulty swallowing some types of food and drinks, and may spit out lumps or hold food in the mouth.

How you can help

- Give a soft, moist diet. Avoid hard, dry or fibrous foods that need a lot of chewing like steak, bacon, wheaten bread and pineapple.
- Use gravy or sauces to moisten food.
- Encourage small sips of drinks.



If the person keeps coughing or choking when eating or drinking, please contact a healthcare professional for advice as a speech and language therapy assessment may be required.

Advice on medications

People with dysphagia may also have difficulties swallowing prescribed medications. If you notice this at any time you should seek immediate advice from your doctor or pharmacist.

Also consider the effects of medication on the person's level of alertness. Offer food and drinks when the person is most alert.

Helpful hints if the person is spitting out lumps

- Try not to draw attention and think about personal preferences for food and taste - you might use the food diary to keep a record of this and establish which foods the person likes best.
- Offer another part of the meal or offer an alternate food if possible.
- Consider avoiding bitty food or mixed textures, for example biscuits, soup with bits, skins or lumps. Or perhaps consider softening by adding extra moisture/sauce or cutting up.

Helpful hints if the person forgets to swallow

- Alternate temperature and taste within a meal, for example sweet and savoury food or hot and very cold foods or fluids.
- Offer sips of ice cold drink prior to a meal or in between mouthfuls.
- Give verbal prompts to swallow.
- Try placing an empty spoon in the mouth between mouthfuls to help stimulate a swallow.

Helpful hints if food remains in the mouth at the end of a meal

- Check mouth after each meal and encourage or provide regular teeth brushing or denture cleaning, as food left in the mouth can cause mouth infections and bad breath.
- The person should remain upright for 20 to 30 minutes to avoid reflux.
- If food remains in the mouth despite these attempts to encourage a swallow, you should safely attempt to remove it.

Drinks

It is important to stay hydrated throughout the day. Ensure the person is alert and awake when drinking to avoid fluids 'going down the wrong way' into the lungs.

Offer a range of drinks including strong or sweet flavours, fizzy drinks, fruit juices, milk, water, tea and coffee.



- Have a drink first thing in the morning before breakfast.
- Drink fluids with oral medications.
- Drink regularly throughout the day. Try to establish a routine or set an alarm to remind yourself. A visual schedule may help to remind the person to eat and drink or may prompt them that they may have already had food or drink.

- Try keeping track of how much the person drinks each day. You could fill a jug to pour drinks from to help monitor fluid intake.
- Include foods with high fluid content, like soups, sauces, custard, yoghurt, fruit and vegetables. This must always be in line with your recommended IDDSI level.
- If you are caring for someone with dysphagia, be aware of their preferences for drinks and how they are presented, for instance use their favourite glass or cup.
- Take time to enjoy drinks together.

Tips when thickening drinks:

- Ensure you measure correctly.
- Let hot drinks cool slightly before thickening.
- Do not add ice.
- Milk can take longer to thicken (10-15 mins).
- Stir fizzy drinks with a metal spoon before thickening to prevent them from separating.
- Do not add thickening powder to nutritional supplement drinks - speak to your Dietitian.

Please note: thickening powder should only be used if prescribed.

If you need support or advice about using thickening powder contact your SLT or doctor for more information.

Thickening powder must always be stored safely as it is a serious choking risk if eaten in dry, powdered form.

Behaviours displayed at mealtimes

A person with a dementia often displays changes in behaviours at meal times.

Helpful hints if the person refuses food or drink

- Find out what the person likes and dislikes.
- Do not force foods and drinks.
- Encourage the person to try the first mouthful to get a taste.
- Use prompts, for example naming the food or drink: "Here's some..."
- If the person opens their mouth to a cup more readily than to a spoon, try a few mouthfuls of fluid first, then move on to the spoon.
- If the person doesn't open their mouth for the cup either, try placing a very small amount of a moist food on their lips with a teaspoon or gloved fingertip for foods such as smooth jam, fruit yoghurt or chocolate mousse.
- Experiment with different tastes and textures for both hot and cold foods. People with dementia often have a preference for sweet foods, which can be included for both main courses and desserts. Sweeten meals by adding sugar, maple syrup or ketchup.
- Make food look, smell and taste appealing using colour and flavour, including stronger flavours and seasoning.
- If food is puréed, each element such as meat, veg and potatoes, should be puréed and served separately on the plate.
- Offer regular small meals or snacks and encourage the person to eat when they are at their best and in good form.
- Do not overfill the plate.
- Ensure all Recommendations for Eating, Drinking and Swallowing (REDS) are followed for all meals and snacks.



Helpful hints if the person's food preferences change

A person with a dementia may develop a preference for sweeter foods. It is important to offer a person with a dementia a choice of foods if practical.

- If the person has a preference for sweet foods, try sprinkling sugar on foods before or after cooking. Honey, jam, syrup and fresh fruit can be used in savoury dishes to add a sweet flavour.
- Sweet toppings can be used in certain savoury dishes, for example sweet pastry on vegetables, meat or fish pies and crumbles.
- Try savoury dishes already containing a sweet flavour, like sweet and sour sauces, pork and apple in cider sauce, barbecue sauces, honey glazed ham, gammon and pineapple and sweeter curries.
- Try adding strong tasting sauces such as ketchup or sweet chilli sauce to food. These should be tested out in small quantities in order to identify likes and dislikes.
- Herbs and spices can be used to enhance flavours.
- Try using strong flavoured dips like garlic mayo, barbeque sauce, tomato sauce or brown sauce if the person does not like gravy.

Helpful hints if the person is over filling their mouth with food

- Cut all food into small pieces before presenting it.
- Encourage the person to take small mouthfuls and eat at a slower rate.
- Use smaller items of cutlery, like a teaspoon or dessert fork.
- Encourage the person to put their cutlery down and chew or swallow.
- A gentle hand on the arm with a verbal prompt may help, such as "take your time."
- Offer a soft, moist diet.
- Offer smaller servings at one time.
- Ensure the person swallows between mouthfuls.



Cramming food into the mouth can place a person at risk of choking. If coughing or choking occurs, discuss with healthcare professional. If the person coughing or choking persistently, contact your GP as a speech and language therapy assessment may be required.



A person with a dementia may misinterpret household items , such as tissues, buttons or liquid tabs, as food and attempt to eat or drink these items. This would place the person at high risk of choking or other harm.



Helpful hints if the person eats non-food items

- Ensure everyone involved in the person's care is aware of this, including visitors.
- Lock away all harmful substances like cleaning products.
- Be vigilant and remove small items that may be easily placed in mouth.
- The person may be hungry. Offer food as an alternative to the item.
- All HSC Trusts should ensure that there are effective systems for the secure storage of thickening agent.

How to help with oral hygiene:

- Encourage the person to brush their own teeth twice daily for two minutes.
- Use a smear of low-foaming toothpaste like Pronamel or Oranurse on a dry toothbrush.
- Clean the whole mouth (tongue/teeth/gums).
- If you are assisting, stand behind the person tilting their head slightly forward to reduce their risk of swallowing residue or toothpaste.
- Spit out toothpaste, do not rinse.
- For those at increased risk of choking, please seek further advice from a dentist.

Dentures should be:

- removed at night
- cleaned twice daily
- labelled with person's name
- stored in a named denture box.



Further information

If you have any other concerns, please discuss these with your GP who can refer you to a relevant professional, which may include:

- Dietitian
- Physiotherapist
- Occupational therapist
- Speech and language therapist

Useful contacts

Alzheimer's Society

30 Skegoneill Street
Belfast
BT15 3JL
Tel: 0333 150 3456
www.alzheimers.org.uk

Age NI

3 Lower Crescent
Belfast
BT7 1NR
Tel: 028 9024 5729
freephone 0808 8087575
www.ageuk.org.uk/northern-ireland

Dementia Services Development Centre

University of Stirling
www.dementia.stir.ac.uk
Tel: 01786 467740

Carers Northern Ireland

58 Howard Street
Belfast
BT1 6PJ
Tel: 028 9043 9843

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Franklin Street
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Dementia NI

NICVA Building
61 Duncairn Gardens
Belfast
BT15 2GB
Tel: 028 9693 1555
Email: info@dementiani.org
www.dementiani.org

Eating and drinking with dementia - the lived experience

The weighted cutlery the occupational therapist gave me really helps with my coordination when eating and drinking

Ask me what I would like to eat and drink.

Mum used to enjoy drinking tea, but she now prefers milkshakes and this keeps her hydrated.

My Dad loves ice cream but we need to be careful with the sweet stuff because he is diabetic.

I use my wife's favourite glass for her drinks. I find that she drinks more this way.

I make small snack like meals for my husband as I think she finds large meals overwhelming

Every day is different, some days I am hungrier than others.

I like company when I am eating.

Quotes from people living with dementia and their carers.

For Public Health Agency regional resources on dysphagia, follow the QR codes or links below.



Dysphagia information and resources

Do you have eating, drinking or swallowing difficulties? booklet



Universal swallow awareness training

<https://cec.hscni.net/learningcontent/universal-swallow-awareness>



**Public Health
Agency**



**Health and
Social Care**



Public Health Agency

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