

Do you have eating, drinking or swallowing difficulties?

Advice for people living with swallowing difficulties (dysphagia) and their carers



Hello...

This booklet aims to raise awareness of swallowing difficulties and provide support to help you or your family member with a swallowing difficulty.

This regional booklet is based on a resource originally developed by Mid and East Antrim Agewell Partnership (MEAAP) through an innovative collaboration project (called 'Hard to swallow') with the Northern Health and Social Care Trust Speech and Language and Dietetics teams. The resource was co-produced in partnership with people with lived experience and local health charities aimed at

supporting communities and raising awareness of dysphagia. The Public Health Agency gratefully acknowledges MEAAP and their funders for permission to adapt their resource for use throughout Northern Ireland.



Contents

What is dysphagia?	4
Why does it happen?	5
What are the signs of dysphagia?	6
What problems can dysphagia lead to?	7
Who should I talk to?	8
Making the most of mealtimes	9 - 13
What else can I do?	14 - 15
Other tips	16
Eating out	17
What can I do if I have difficulty swallowing medication?	18
How can I keep my mouth clean if I have swallowing difficulties?	19
What should I do if someone is choking?	20
Where can I find more information?	22
Useful contact information	23

What is dysphagia?

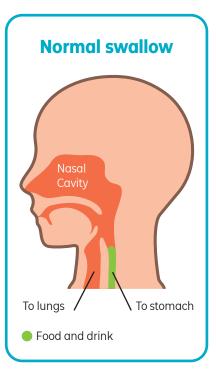
Dysphagia (pronounced dys – fay – juh) is the medical term used when a person has difficulty eating, drinking or swallowing.

Difficulties with eating, drinking or swallowing can affect people at any stage in life.

Some people with dysphagia have problems swallowing certain foods or liquids, while others cannot swallow at all.

Dysphagia can improve, remain the same or get worse over time, depending on the cause.

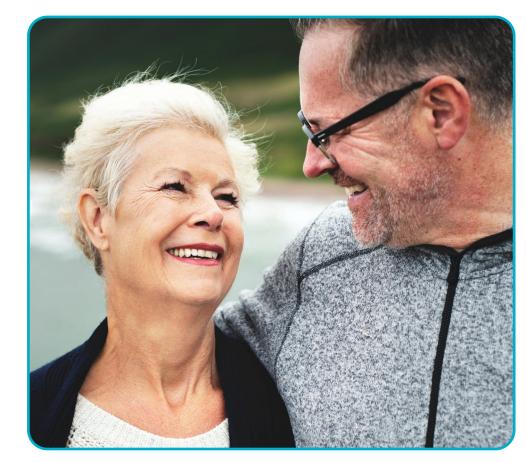
Research has shown that 16–23% of the general population have difficulties eating, drinking or swallowing, rising to 27% of those over 76 years of age.



Why does it happen?

Some medical conditions can cause dysphagia, for example conditions that affect the nervous system such as dementia, stroke, head injury, Parkinson's, multiple sclerosis, motor neurone disease and frailty.

People with other conditions such as head and neck cancer, cerebral palsy, learning disabilities and some mental health conditions may also experience dysphagia. Dysphagia may present as a short-term or long-term condition.



⁶ What are the signs of dysphagia?

You may notice one or more of the following signs:

- coughing or choking during or after food or drinks
- frequent chest infections not accompanied by symptoms of the cold
- change in voice quality during or after eating and drinking, for example 'gurgly' or wet sounding voice
- change in breathing when eating and drinking, for example wheezy, shortness of breath or gasping for air
- change of colour in the face when eating or drinking
- pieces of food found inside the mouth after eating
- · difficulty controlling food or liquid in the mouth
- pain when swallowing or increased swallowing difficulties.

You may also observe:

- high risk behaviours when eating and drinking, for example cramming or holding food in the mouth, not chewing food, eating or drinking very quickly;
- · difficulty managing own saliva.



What problems can dysphagia lead to?

The physical health risks and complications of dysphagia include:

- increased risk of choking
- aspiration (when food, fluid or other material go into the lungs, which can lead to chest infections or aspiration pneumonia)
- dehydration from drinking less
- increased risk of other infections such as urinary tract infections
- poor nutrition from eating less, which may lead to weight loss
- loss of dignity, independence and potential for social isolation
- admission to hospital or increased time in hospital.

Dysphagia can also affect your quality of life because it may prevent you from enjoying meals and social occasions.

Who should I talk to?

It is **essential** to speak to your GP or another professional if you, or someone you care for, is having difficulty swallowing or notice any signs of dysphagia. They may refer you to:

A Speech and Language Therapist (SLT)

A Speech and Language Therapist assesses eating, drinking and swallowing difficulties and may suggest ways to make food and drinks easier and safer to swallow. This may include advice about:

- · changing the texture/thickness of food or drinks
- · certain high risk foods to avoid
- swallowing exercises.

You can also contact your local Speech and Language Department directly to ask for advice and discuss whether you might need an assessment (see "Useful contact information" on page 23).

A dietitian

A dietitian can assess diet, nutritional and fluid intake and weight. They can provide you with advice on how to cook and prepare your meals to best meet your needs.

A specialist

Your GP may also refer you to a specialist doctor/consultant, for example Gastroenterology, ENT (Ear, Nose and Throat) – if further tests are needed.

How can I make the most out of mealtimes?

The following sections contain some general advice for individuals, and their families, who are experiencing eating, drinking and swallowing difficulties. This will help ensure you are eating and drinking enough to make mealtimes more enjoyable.

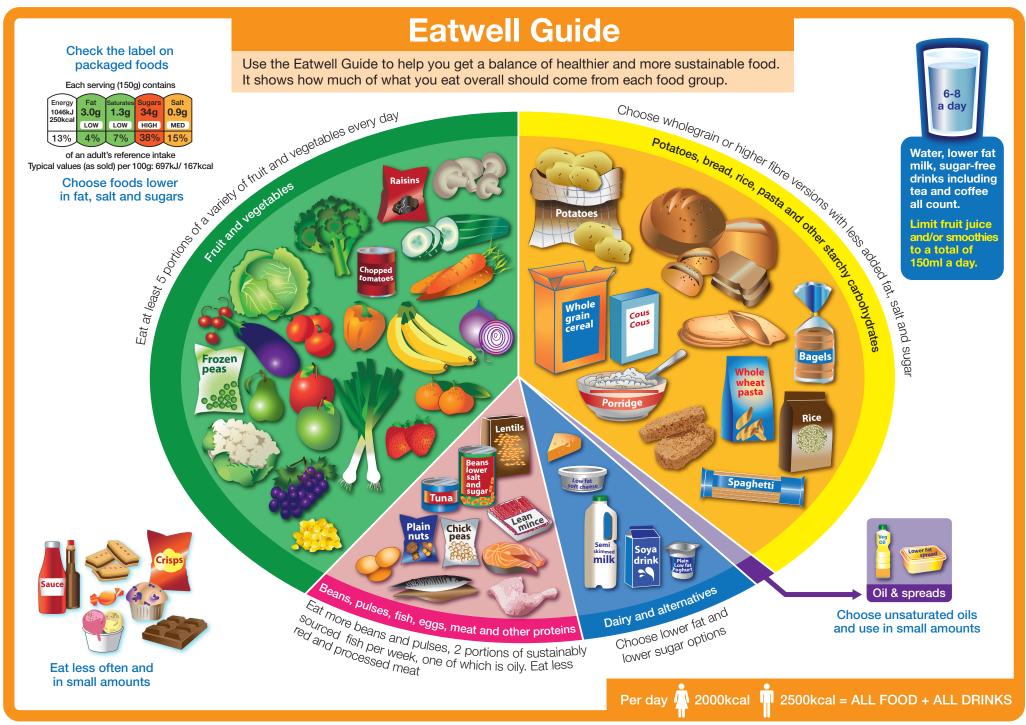
Ensuring a balanced diet

Some people find they eat less because they are anxious about choking; or meals can take much longer to eat and can be less enjoyable. There may also be certain foods you feel you are unable to eat so you may have less variety in your diet.

In order to get all the nutrition you need, ensure you eat foods from each of the food groups in the 'Eatwell Guide'. The guide shows how much of what we eat should come from each food group to achieve a healthy, balanced diet. The advice in the guide applies to most healthy adults.

Some foods may not be suitable for you personally or you may need to change how they are prepared or cooked before you eat them. A dietitian can give you personalised advice.

Older adults should note that weight loss is not a normal part of aging. If you or someone you are caring for is losing weight unintentionally, contact your GP.



Source: Public Health England in association with the Welsh Government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

11

12 If you are unintentionally losing weight or you have any special dietary requirements, or medical needs, you may need to speak to a registered dietitian to get advice on how to adapt the *Eatwell Guide* to meet your individual needs. You can request a referral via your GP.

If you have been advised to follow a therapeutic diet for a medical condition, consult your dietitian for individualised advice.

What are modified texture foods and drinks?

People with dysphagia who have been assessed by a Speech and Language Therapist may be advised to change the texture of their food and/or drinks to make them easier and safer to swallow.

For some people, this could mean their food should be puréed, soft and/or cut into bite-sized pieces*. For others this could mean adding a thickening powder to their drinks. *Your healthcare professional can advise on sizing.

The advice you receive may help you to feel that you can enjoy eating and drinking again.



Making sure you drink enough

Not drinking enough can cause dehydration, which can result in poor health.

Dehydration may lead to:

- being thirsty
- feeling tired or lightheaded
- reduced memory and concentration
- low blood pressure
- having a dry mouth, lips or eyes
- dark yellow and strong-smelling urine, passing very little urine, and increased risk of urinary tract infections
- constipation
- increased risk of falls.

How much do I need to drink each day?

You should aim to drink 6-8 large glasses or mugs (around 2 litres) per day, but more if the weather is hot or you have been more active. Water, squash/diluting juice, minerals, fruit juice, milk, tea and coffee all count towards your fluid intake.

Tips to improve your fluid intake

- Have a drink beside you take small sips.
- Choose foods that have a high-water content, for example thick soups, sauces or milky puddings such as custard or yoghurt.
- Try drinks that are naturally thicker (smoothies or milkshakes).
- Try keeping track of how much you drink some reusable drinks bottles have amounts marked.
- Set an alarm to remind yourself to have a drink.

What else can I do?

The first thing to do is to seek advice from a healthcare professional.

If you have done this, and you are waiting for an appointment, or for the results of any tests, the following may help to make eating and drinking safer and mealtimes more enjoyable:

Position

- Make sure you sit fully upright ideally try to remain sitting upright for 30 minutes after you have finished eating and drinking.
- Don't lean to one side and avoid tilting your head backwards.
- Try lowering your chin before swallowing (this may not work for everyone).

During meals

- · Take small mouthfuls of foods and drinks.
- Eat slowly. Chew your food extremely well and allow extra time to eat and drink.
- Only take a drink when you have swallowed your food and mouth is clear.
- Make sure each mouthful is swallowed properly before taking the next. You may need to swallow at least twice after every mouthful to make sure everything has gone.
- Don't try to talk while eating or drinking.
- Small, frequent meals may be easier to manage.

General tips

- Ensure you are fully alert when eating and drinking.
- Avoid distractions at mealtimes, for example TV, music (you may be more likely to choke if you are focusing on something else).
- Be mindful using spouted beakers or straws as the flow of liquid is more difficult to control.
- Fizzy drinks and very cold drinks can stimulate more sensation leading to a stronger swallow.

If you are still struggling to drink enough each day, please speak to your healthcare professional.

High risk foods

While you are awaiting assessment with a Speech and Language Therapist, you may wish to avoid some foods that are more difficult to chew or swallow, such as:

- tough meat
- boiled or chewy sweets
- soup with bits and chunks
- breakfast cereals that are not smooth/one consistency
- fruit and vegetables with skins or stringy bits
- crumbly foods, for example pastry, biscuits
- hard or dry foods, for example nuts, raw vegetables.

Other tips

- Remove skin, bones, gristle or hard bits when preparing meat, fish and poultry.
- Vegetables that can be cooked until they are soft may be easier to swallow.
- Floury potatoes, like Maris Piper, make smoother mash.
- Hard pulses, like beans and peas, can be puréed. Use a sieve to remove the husk after pureeing.
- Brown rice, risotto and short grain rice are easier to mash or puree with liquid.
- · Soft and overcooked pasta will be easier to mash or purée.
- Slow cooking cuts of meat such as poultry thighs and legs or beef/pork shanks or cheeks, will result in softer, tender meat.
- Poach fish instead of frying.
- Moist food can often be easier to swallow so use a variety of sauces in or on your food.
- Items such as a potato ricer, sieve and hand blender can be useful to help remove lumps from foods.
- Avoid using jars of baby food the quantity, nutritional content and taste is not appropriate for adults.

Making food tasty and appealing

- Foods with stronger flavours can make swallowing easier.
- Herbs, spices and condiments improve how food tastes.
- Adding butter, sugar or cream to foods or drinks can improve the taste and increase calorie intake.
- When food turns cold it can be less appetising. Try serving food on a warm plate or in thermal bowls and mugs.
- Attractively presented food will stimulate the appetite.
- If a puréed diet has been recommended by a healthcare professional it is more appetising to puree and present each element of the meal separately.

Eating out

Just because someone has a swallowing difficulty, doesn't mean they can't still enjoy eating out or going to family gatherings.

It may make the experience easier if you plan ahead.

You could:

- request a table in a more private part of the restaurant
- let staff know that you may take a little longer to finish your meal
- ask for a copy of the menu, or access it online, to allow you more time to choose your meal
- let the restaurant or your host know of your requirements in advance
- if you use any particular crockery or cutlery bring these with you
- ask for extra sauce or gravy or for dishes to be served without certain ingredients if you know these are tricky for you to swallow.



What can I do if I have difficulty swallowing medication?

Most types of pills are designed to be swallowed whole.

Chewing, breaking, or crushing them can change how the medication is digested and absorbed into the body. This change can affect the way a medication works and increase the chance of side effects.

Those with trouble swallowing medications should speak to their doctor and/or pharmacist for advice.

NEVER cut or crush tablets, open capsules or thicken medicines without advice from your pharmacist or GP.



How can I keep my mouth clean if I have swallowing difficulties?

Mouth care (oral care) is very important for everyone, even if you wear dentures or are fed via a tube. Mouth care is especially important if you have swallowing difficulties.

Poor mouth care can lead to pain, gum disease and tooth loss. For people with swallowing difficulties, poor mouth care can increase the risk of chest infections and aspiration pneumonia.

Keep your mouth clean and healthy by:

- brushing your teeth (or dentures) twice a day for two minutes
- using a smear of low foaming toothpaste, for example Pronamel / oraNurse[®] on a dry toothbrush
- brushing the whole mouth tongue, including teeth, tongue and gums
- spit out toothpaste, do not rinse.

If you are helping, stand behind the person tilting their head slightly forward to reduce the risk of swallowing residue or toothpaste.

If you are at increased risk of choking, seek further advice from a dentist.

Daily oral care is important for everyone. Brush your teeth, gums and tongue twice daily.

空 What should I do if someone is choking?



If you think someone is choking, ask them 'Are you choking?' If they can breathe, speak or cough then they might be able to clear their own throat. If they cannot breathe, cough, or make any noise, then they need your help straight away.



Cough it out. Encourage them to cough and remove any obvious obstruction from their mouth.

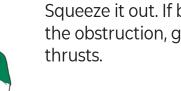


Hit it out. If coughing fails to work, you need to give five sharp back blows.

To do this, help them to lean forwards, supporting their upper body with one hand.

With the heel of your other hand give them five sharp back blows between their shoulder blades.

After each back blow, check to see if there's anything in their mouth.



Squeeze it out. If back blows fail to clear the obstruction, give five abdominal

To do this, stand behind them and put your arms around their waist.

Place one hand in a clenched fist between their belly button and the bottom of their chest.

With your other hand, grasp your fist and pull sharply inwards and upwards up to five times. Check their mouth again, each time.



If the blockage has not cleared, call 999 or 112 for emergency help straight away. Repeat five back blows and five abdominal thrusts until help arrives, re-checking their mouth each time.

• If they become unresponsive at any point, prepare to start adult CPR.

For guidance on what to do if a baby or child is choking, see www.sja.org.uk/get-advice/first-aid-advice/choking/childchoking/

The above information and graphics have been reproduced with permission from St John Ambulance.



Where can I find more information?

Public Health Agency

www.publichealth.hscni.net/directorates/nursingand-allied-health-professions/allied-healthprofessions/allied-health

NHS

www.nhs.uk/conditions/swallowing-problemsdysphagia/treatment/



The Eatwell Guide

More detailed information about healthy eating and the *Eatwell Guide* can be found online at www.nhs.uk/live-well/eat-well/the-eatwell-guide/

Rockwood frailty scale

This frailty assessment tool is available from www.england.nhs.uk/south/wp-content/uploads/ sites/6/2022/02/rockwood-frailty-scale_.pdf

Modified texture diets

The International Dysphagia Diet Standardisation Initiative (IDDSI) is used to describe the texture of foods and thickness of drinks. For more information and to download a free app, see **www.iddsi.org**

Useful contact information ²³

South Eastern Health and Social Care Trust

Email: CommunitySLTAdult@setrust.hscni.net Tel: 028 9055 0433

Western Health and Social Care Trust

Tel: 028 7161 1428 (Altnagelvin Area Hospital)
Tel: 028 6638 2547 (South West Acute Hospital and Adult Learning Disability, Omagh/Fermanagh)
Tel: 028 7724 6996 (Adult Learning Disability, Derry, Strabane, Limavady)

Northern Health and Social Care Trust

Speech and Language Therapy Services Tel: 028 9034 1571

Southern Health and Social Care Trust

Adult Community SLT Department Email: DysphagiaSupport.Team@southerntrust.hscni.net Tel: 028 3756 3833/028 3756 0428

Belfast Health and Social Care Trust

Tel: 028 9504 0330 (North and West Belfast) Tel: 028 9504 2324 (South and East Belfast)





Public Health Agency

12-22 Linenhall Street, Belfast BT2 8BS. Tel: 0300 555 0114 (local rate). www.publichealth.hscni.net



