

Dealing with swallowing problems

Stroke Helpline: 0303 3033 100
or email: helpline@stroke.org.uk

Swallowing problems are very common after a stroke. Around half of people who have a stroke will have some difficulties in the first few weeks.

In this guide we talk about what happens if swallowing problems last longer than a few weeks. It's aimed at people who have had a stroke, but there is information for family and friends as well.

We have information on all aspects of stroke. If you have a question that is not answered in this guide, visit **stroke.org.uk** or call our Stroke Helpline on 0303 3033 100.



If you want more information on this topic, take a look at our Complete guide to swallowing problems after stroke. Go to **stroke.org.uk/publications** to find it.

Softer Foods from

WILTSHIRE

EST. FARM 1991

FOODS

www.specialistnutrition.com

We would like to thank Wiltshire Farm Foods for funding the cost of producing this guide. The Stroke Association keeps full independent control over all content.

What's in this guide?

| | |
|--|----|
| Why can't I swallow? | 4 |
| What kinds of problems can this cause? | 5 |
| Will it get better? | 6 |
| What can I do about swallowing problems? | 7 |
| Where to get help and information | 18 |
| Tips for family and friends | 20 |
| Some terms you may have heard | 22 |
| About our information | 23 |

Why can't I swallow?



Swallowing is a complicated task that needs your brain to coordinate many different muscles.

If your stroke damages the parts of your brain that do this, then this will affect your ability to swallow.

Other effects of stroke can cause problems too. If your muscles are weak, or you can't control them very well, you may not be able to use a spoon or a cup properly. This can affect the way you swallow. If your face or lip muscles are affected, this can make you dribble.

If your balance has been affected, then you may not be able to sit up straight, which can make swallowing more difficult. If you're drowsy or not able to concentrate very well, then you may not swallow your food in the right way.

What kinds of problems can this cause?



If you can't swallow safely, you are more likely to cough or choke if your food 'goes down the wrong way'. You may also breathe in small amounts of food and drink, which can get into your airway and lungs. This can lead to infections and pneumonia, which can be very serious.

However, aspiration isn't always noticeable. Some people can seem to swallow well, but food and drink may still be getting into their lungs. This is called silent aspiration. So you'll need an assessment with a trained professional to confirm whether or not you are swallowing safely.



Everyone who has a stroke should have their swallowing checked within the first few hours of being in hospital.

Will it get better?



Swallowing problems can get better and most people are able to swallow safely again within the first few weeks after a stroke. Only a small number of people have problems that last longer than this.

Even if you are left with long-term swallowing problems, they don't have to stop you from doing what you want to do. Most people find that they're still able to live full lives despite them. But it may take some time to get used to the changes that you need to make.

What can I do about swallowing problems?

1

Listen to your therapist

If you have swallowing problems, you'll be referred to a speech and language therapist. They will explain to you and your family exactly what foods are safe for you to eat and suggest any other changes that they think you should make.

The most important thing for you to do is to follow the advice that your speech and language therapist gives you. Even though you may think that you're able to swallow safely, food may still be getting into your airway without you realising. So don't try to eat or drink anything new without checking with your speech and language therapist first.

It can be hard if you're not able to eat and drink the things you want to. If you're finding it difficult, talk to your speech and language therapist. There may be a way for you to have



Changing your diet

To help you swallow safely your speech and language therapist may suggest that you:

- **Thicken your drinks**

There are powders you can add to water or liquids to make them thicker and easier to swallow. Your speech and language therapist can prescribe these for you.

- **Eat soft or pureed food**

You may need to stick to soft or mashed food (like mashed potato), which doesn't need much chewing, or have pureed food, which is very smooth and doesn't need to be chewed at all.

- **Change the temperature**

You may need to stick to cold foods and drinks or let hot foods cool down before you eat them. This can give you more time to swallow safely.

- **Change how and when you eat**

You may find that eating small amounts throughout the day or eating in the morning, when you have more energy, may be better.

What kinds of problems can this cause?

2

Learn how to swallow safely

Although your speech and language therapist will show you, our swallowing dos and don'ts can remind you what you need to do to swallow safely.

Do

- ✓ Give yourself the time and space to concentrate on what you're doing. So turn off the TV or draw the curtain around your hospital bed.
- ✓ Sit up with a straight back, your arms and hands forwards. If you are in a chair, keep your feet flat on the floor.
- ✓ Take small amounts. Cut food up into small pieces and just take small sips when you drink.
- ✓ Swallow twice after each mouthful, to make sure nothing is left in your mouth.
- ✓ Take your time.

Don't

- ✖ Try to eat lying down.
- ✖ Talk while you're trying to swallow.
- ✖ Use straws or cups with spouts unless your speech and language therapist has told you that it's safe.
- ✖ Eat foods with a variety of textures, such as soup that has large chunks in it, or cornflakes and milk.

3

Ask questions

It's important that you understand the instructions and advice you're given. So ask your speech and language therapist to explain things again if you need them to. They would much rather you ask questions than do something that may put yourself at risk. If you think your swallowing has improved, ask for another assessment.

4

Get the information you need before you go home

If your overall recovery is good, then your stroke team may suggest that you go home, even if you're still having some problems with swallowing.

It's up to your stroke team to make sure that you and your family have all the information, support and equipment you need.

You're likely to have lots of questions, and the earlier you get the answers, the more confident you'll feel about going home. So ask your speech and language therapist to go through it all with you as soon as they can.

Make sure you know:

- what products you'll need to use at home
- how you can get more when you need them
- who to contact if you have a question.

5

Tube feeding

If your stroke team are worried that you're not getting enough food because of your swallowing problems, then they may talk to you about tube feeding. This means putting liquid food directly into your digestive system through a tube.

Some people don't like the idea of tube feeding. So it's important that you discuss it properly with your doctor, dietitian and speech and language therapist. Food can go through a tube in your nose, or one that goes straight into your stomach. You'll need to talk about both options to decide which one is best for you.



Tube feeding at home

You can still be discharged from hospital if you're being fed by tube.

This can worry some people, especially family members, as they think it will be a lot to cope with. However, most people cope very well with tube feeding at home, even those who live on their own.

The important thing is to get the right information before you leave hospital. To help you, we've suggested some things to ask below.

- How do I use the feeding machine?
- How do I know if the tube is in place?
- What do I do if the tube becomes blocked?
- Do I have to clean the machine?
- How do I clean it?
- Are there written instructions I can follow?
- How do I get more food?
- Who do I contact if I have a question?
- Who do I contact in an emergency?

6

Look after your mouth and teeth

If you don't clean your teeth and mouth, then bacteria will build up. This can make your mouth sore and lead to infections. Here are our tips to help you keep your mouth clean and healthy:

- Ideally you should clean your teeth or dentures after every meal, but this may not be possible. Try to aim for at least twice a day if you can.
- If you have swallowing problems, ask your nurse or speech and language therapist to show you the safest way to clean your teeth, tongue and mouth. You can get non-foaming toothpaste, which doesn't create as much foam in your mouth when you brush. Or you may need to use a special gel to clean your teeth.
- Make sure your toothbrush is dry before you start to use it. When you've finished brushing spit out the toothpaste, but don't rinse your mouth. That way, more fluoride from the toothpaste stays in your mouth and protects your teeth.

- If you wear dentures, it's still important to clean your mouth and tongue. You can do this with a soft brush or using some gauze wrapped around your finger.
- It's important to keep your mouth moist. Even if you can't drink, you may be able to use a saliva spray to stop your mouth from getting dry. Ask your speech and language therapist.
- Use lip balm to stop your lips getting dry or cracked.
- Make sure you know what you need to do before you go home and that you have any special equipment or products you need before you leave hospital.
- See your dentist regularly. They can make sure that your teeth and mouth are healthy and give you any other advice you need. You may also need new dentures, or have them adapted to make them easier for you to put in.

7

Find support

Swallowing problems can be especially difficult to cope with at home. A large part of our family and social lives is about eating and drinking, so it can have a big impact when you're not able to enjoy these things any more.

Many people feel left out when they're not able to take part in family mealtimes like they used to. Or they feel embarrassed to eat in front of other people. These feelings can take their toll, so it can help to talk to someone about it.

Many people find support groups helpful, because you can talk about your problems with people who are going through the same thing. Stroke clubs and groups are a good way to meet other stroke survivors and get advice and support.

But they're not for everyone, so talk to a friend or family member instead if you find it easier, whoever you feel comfortable confiding in when you're finding it tough.

Although swallowing problems can have a big impact, they don't have to stop you from doing the things that you want to do. There are lots of places where you can get advice and support.

- **Speak to your dietitian**

Your dietitian will be able to suggest different foods or recipes to try if you're feeling bored with your diet. They can also give you any advice you need about eating out or going on holiday.

- **Contact a support group**

There are support groups especially for people with swallowing problems, who may also be able to give you advice. We've listed some later in this guide.

- **Talk to your pharmacist**

If you're finding it hard to swallow your tablets, speak to your pharmacist. Your medication may come in a different form, such as a liquid or a patch, which could be easier for you to take. Always check with your pharmacist first before crushing tablets, as this can change the way some medications work and can even be dangerous.

Where to get help and information



Talk to us

Our Stroke Helpline is for anyone affected by a stroke, including family, friends and carers. The Helpline can give you information and support on any aspect of stroke. Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100** or email **helpline@stroke.org.uk**.



My Stroke Guide

My Stroke Guide is the stroke support tool and online community from the Stroke Association. Log on at **mystrokeguide.com**.



Talk to others affected by stroke

There may be a stroke group in your local area where you can meet other stroke survivors. You can meet people on our My Stroke Guide online chat forum at **mystrokeguide.com**, and our Facebook page **Facebook.com/TheStrokeAssociation**.

Other sources of help and information

The following organisations can provide information, advice and support. If you'd like to know about others in your area, contact our Stroke Helpline.

The Association for the Rehabilitation of Communication and Oral Skills (ARCOS)

Website: arcos.org.uk

Tel: 01684 576 795

Email: admin@arcos.org.uk

A charity that supports people who have problems with eating, drinking and swallowing, as well as communication.

Patients on Intravenous and Naso-gastric Nutrition Treatment (PINNT)

Website: pinnt.com

Tel: 020 3004 6193

Email: comms@pinnt.com

A charity that provides support for people who are being fed by tube. By becoming a member, you can receive information and invitations to local meetings.

Tips for family and friends

It can be difficult to know how to help someone when they have swallowing problems. So here are some suggestions.



Always check

It can be hard to know what helps and what doesn't when it comes to swallowing. A straw, for example, may seem pretty harmless. However, most people with swallowing problems shouldn't use them. You should be able to get advice about making foods and drinks before someone leaves hospital. If you want to make a meal or buy food and are unsure about what to do, just double check that it's safe with the speech and language therapist.



Don't ignore advice

The best way to support your friend or family member is to help them to stick to the advice they are given. You may be worried that they're going hungry or that not being able to eat is getting them down. Talking to their speech and language therapist about it should help to put your mind at ease. Together you may be able to think of something you can do to help your friend or family member feel better.

Do

- ✓ Make sure they sit up straight. A pillow may help support their trunk if they are leaning to one side.
- ✓ Allow plenty of time for eating.
- ✓ Show or describe to them what they're about to eat. Eating is just as much about how the food looks and smells, as well as how it tastes.
- ✓ Think about how food is presented. Keeping food separate on the plate is much more appetising than mashing it all together. Food moulds can also help to present food nicely.

Don't

- ✗ Try feeding someone if they are drowsy.
- ✗ Rush them or offer them too much at once.
- ✗ Move from one food to another without saying.
- ✗ Forget that you're feeding an adult, not a child.

Some terms you may have heard



Here's a guide to some of the technical words you may hear people in your stroke team use:

Aspiration is when food and drink gets into your airway and lungs.

Dysphagia is a medical term that is used to describe problems with swallowing.

Enteral feeding is when food is put directly into your digestive system. This is done using a tube.

A percutaneous endoscopic gastrostomy (or PEG) tube is a type of feeding tube. It is inserted directly into your stomach, through your skin.

A nasogastric (or NG) tube is another type of feeding tube. It's very thin and goes up your nose, down the back of your throat and into your stomach.

Nil by mouth is when you're told not to eat or drink anything. It's likely that you will be 'nil by mouth' until you've had an assessment to check your swallowing.

About our information

We want to provide the best information for people affected by stroke. That's why we ask stroke survivors and their families, as well as medical experts, to help us put our publications together.



How did we do?

To tell us what you think of this guide, or to request a list of the sources we used to create it, email us at feedback@stroke.org.uk.



Accessible formats

Visit our website if you need this information in audio, large print or braille.



Always get individual advice

This guide contains general information about stroke. But if you have a problem, you should get individual advice from a professional such as a GP or pharmacist. Our Helpline can also help you find support. We work very hard to give you the latest facts, but some things change. We don't control the information provided by other organisations or websites.

When stroke strikes, part of your brain shuts down.

And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at **stroke.org.uk**

Contact us

We're here for you. Contact us for expert information and support by phone, email and online.

Stroke Helpline: **0303 3033 100**

From a textphone: **18001 0303 3033 100**

Email: **helpline@stroke.org.uk**

Website: **stroke.org.uk**

Rebuilding lives after stroke



© Stroke Association 2020

Version 3.2. Published December 2020

To be reviewed: April 2021

Item code: **A01F05**