Life after stroke

# Dealing with swallowing problems

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

In this booklet 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 booklet, visit **stroke.org.uk** or call our Stroke Helpline on **0303 3033 100**.

If you’re looking for more information on this topic you may want to take a look at our *Complete guide to swallowing problems after stroke*. Go to [**stroke.org.uk/publications**](http://www.stroke.org.uk/publications) to find it.

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## Why can’t I swallow?

Swallowing is a complicated task, which needs your brain to coordinate lots of different muscles.

If your **stroke damages the part of your brain** that does 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 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 then food and drink may get into your airway and lungs. This is called aspiration. If this happens it 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**. 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. It may just take a bit of time to get used to the changes that you need to make.

## What can I do about swallowing problems?

### 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 them 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 some of your favourite meals or to enjoy something similar – it’s always worth asking.

**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.

**Eat soft or pureed food**

You may need to stick to soft 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 allow hot foods to cool down before you eat them.

**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.

### 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**.

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 you **discuss it properly with your doctors** and speech and language therapist. There are two types of tube that you are likely to have after a stroke. You’ll need to talk through both options to decide which one is best for you.

### 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 and your arms by your side. Have your hands in your lap, not on the table.
* Take small amounts. So 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 that are not the same consistency, such as soup that has large chunks in it, or vegetables with tough skins on them.

### 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 brush your teeth or clean your dentures after every mealtime, 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.

### 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.

**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?

### 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 because of their swallowing problems. 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 on page 16.

* **Talk to your pharmacist**

If you’re struggling 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. Sometimes it’s possible to crush tablets and put them in your food or water, but not all medication can be taken like this, so check with your pharmacist first.

## Where can I get help and support?

If you’re worried about your swallowing, then speak to your **doctor** or **speech and language therapist**.

### How we can help

Our **Stroke Helpline** can give you information and support on any issue you or your family may be facing after stroke. Whatever the problem, we’re here to help.

We have **coordinators** in some areas of the UK, who can give you information, practical advice and emotional support. We also run **stroke groups** across the UK. Even if we don’t run one in your area, we can tell you about others that do.

Or you can talk to other people affected by stroke on our online forum TalkStroke or on our Facebook page. Visit **stroke.org.uk/talkstroke** or **facebook.com/TheStrokeAssociation**

To find out how we can help, just get in touch:

* call our Stroke Helpline on **0303 3033 100**
* email **info@stroke.org.uk**
* visit **stroke.org.uk**

### Other organisations that can help

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)** is a charity that supports people who have problems with eating, drinking and swallowing, as well as communication.

**Website:** www.arcos.org.uk

**Tel:** 01684 576 795

**Email:** admin@arcos.org.uk

**Patients on Intravenous and Naso-gastric Nutrition Treatment (PINNT)** is a support group for people who are being fed by tube. By becoming a member, you can receive information and invitations to local meetings.

**Website:** www.pinnt.com

**Address:** PO Box 3126, Christchurch, Dorset BH23 2XS

## 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 percantaneous endoscopic gastromy (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 hadTips for family and friends

## 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. It should be OK to bring in food or drinks from home, but just **double check that it’s safe** with someone in the stroke team first.

**Don’t ignore advice**

The best way to help your friend or family member is to **make sure they 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 them feel better.

When you’re helping someone to eat or drink try to remember these simple dos and don’ts.

**Do**

* 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**

* Rush them.
* Move from one food to another without telling them.
* Forget that you’re feeding an adult, not a child.

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**



**We are the Stroke Association.**

We believe in life after stroke. That’s why we support stroke survivors to make the best recovery they can. It’s why we campaign for better stroke care. And it’s why we fund research to develop new treatments and ways of preventing stroke.

**We’re here for you. If you’d like to know more please get in touch.**

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

Email: info@stroke.org.uk

From a textphone: 18001 0303 3033 100

Text **STROKE 5** to 70300 to donate **£5**. It only takes a couple of seconds to make a BIG difference. For more information visit **stroke.org.uk/savelives**

Texts cost your donation amount plus one message at your standard network charity rate. The Stroke Association will receive 100% of your gift. Always ask the bill payer's permission. For questions about donating by text call 0330 6600 425.

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