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Stroke
association

A complete guide to

Swallowing problems after stroke



Swallowing problems are very common after a stroke. If your swallowing has been affected, this guide can help you understand what you need to do.

It explains why swallowing problems happen after a stroke and what you can do to improve them.

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**.



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Why can't I swallow?

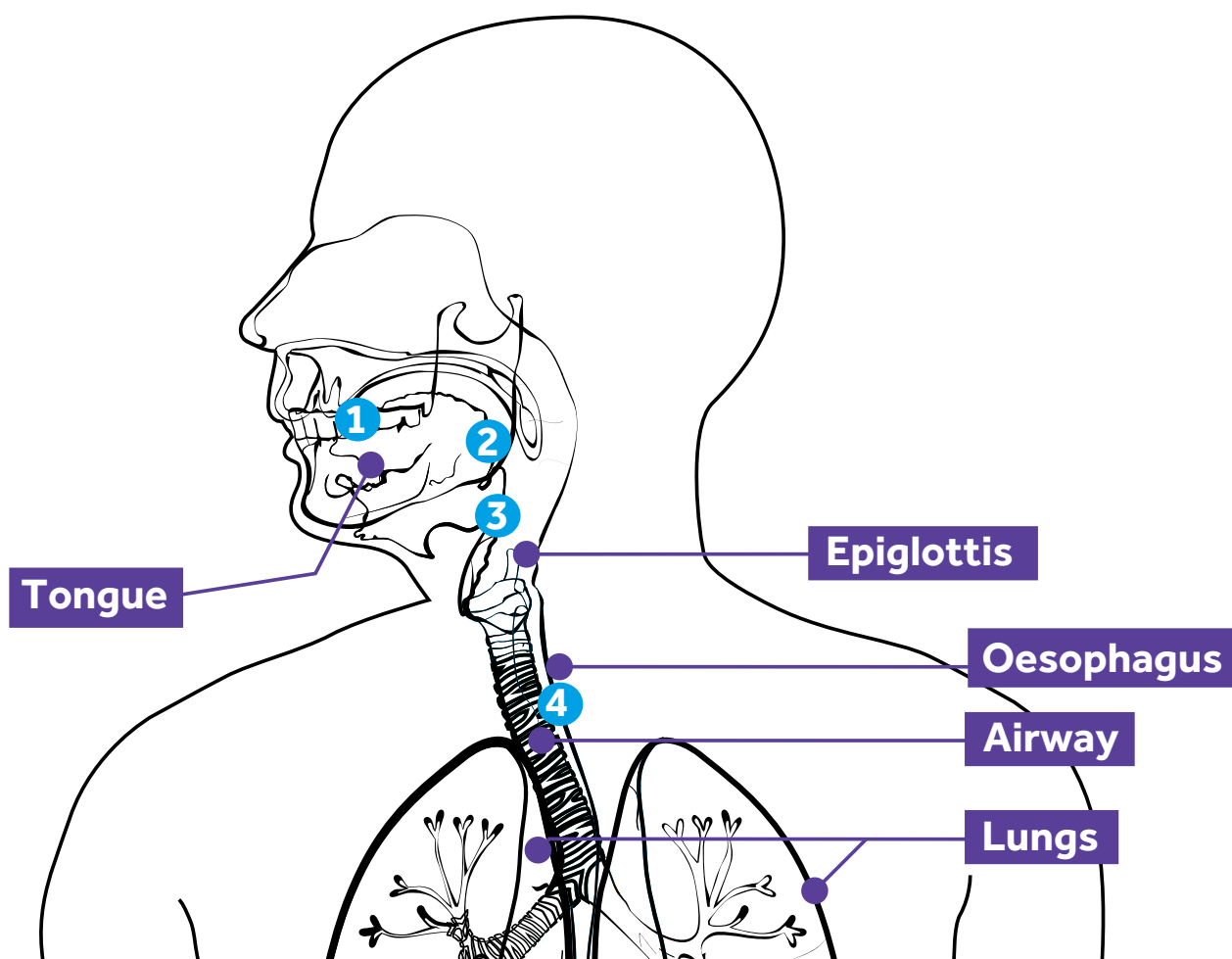
Swallowing is a complicated task, which needs your brain to coordinate lots of different muscles. If your **stroke damages the part of your brain that does this**, then this will affect your ability to swallow.

Doctors use the term **dysphagia** to describe problems with swallowing.

Other effects of stroke can make swallowing difficult too. If your arm or hand has been affected by your stroke, 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, 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.

There are four stages to swallowing. A stroke can affect any one of these stages.





The four stages of swallowing

1. You prepare your food by chewing and moving it around your mouth.
2. Your **tongue** moves the food to the back of your mouth.
3. The food moves through your throat to your **oesophagus** – this is your foodpipe, which carries food to your stomach. At the point of swallowing, a flap in your throat (called the **epiglottis**) moves to close over and protect your **airway**. This stops any food from going into your **lungs**.
4. The muscles in your oesophagus contract, which moves the food down into your stomach.

What kinds of problems can this cause?

If you can't swallow correctly then food and drink may be getting into your airway and lungs. This is called aspiration. If this happens it can **lead to infections and pneumonia**, which can be very serious. So it's extremely important that any change to your swallowing is spotted early, to avoid this happening.

Aspiration isn't always noticeable. Some people seem to swallow well, but food or 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 you are swallowing safely.

Signs of swallowing problems

Everyone who has a stroke should be checked to see if they can swallow safely. This should happen within the first few hours of being in hospital. However, problems aren't always obvious, so it's good to know what to look out for.

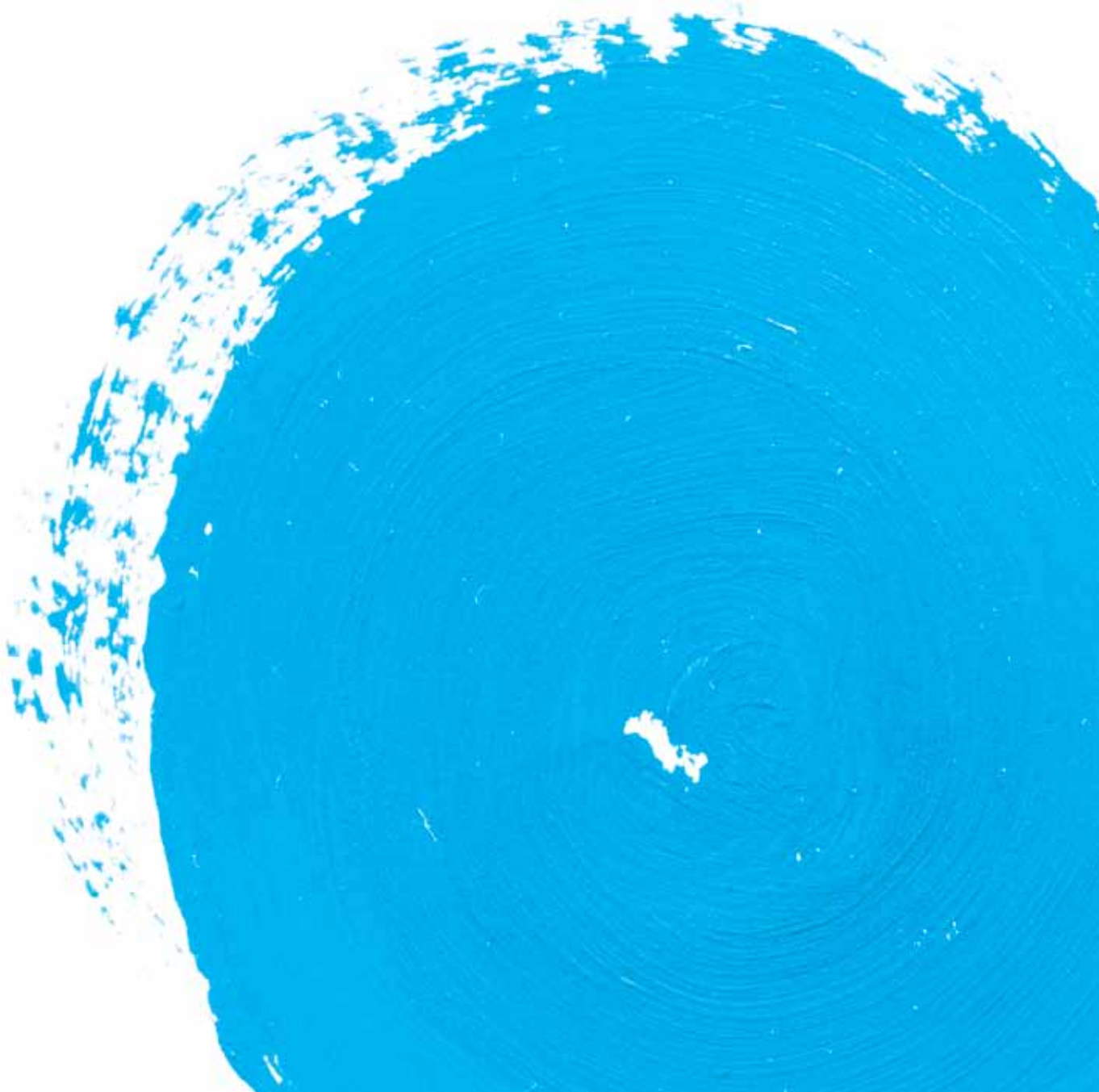
These are some signs of swallowing problems:

- coughing or choking when you're eating or drinking
- bringing food back up, sometimes through your nose
- food or drink going down the wrong way
- feeling that food is stuck in your throat
- not being able to keep food or drink in your mouth
- still having food or drink left in your mouth after you've swallowed
- not being able to chew food properly
- a croaky or 'wet' sounding voice
- dribbling
- taking a long time to swallow or finish a meal
- having to swallow a lot to clear your throat
- being short of breath when you're swallowing.

Will my swallowing get better?

Swallowing problems can get better and most people are able to swallow safely again within the **first few weeks**. A small number of people have problems that last longer than this. Only a very small number of people are left with lasting difficulties.

Even if you are left with permanent difficulties, 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 getting used to.



Are there treatments that can help?

If you have problems with swallowing you will be referred to a **speech and language therapist**, who will work with you to try to improve it.

Your speech and language therapist will complete an assessment with you, to work out exactly what's going on. Once they know this, they'll be able to talk to you and your family about the best ways to treat it.

It's important that you don't eat or drink anything until your swallowing has been checked. Your doctor or nurses may refer to you being 'Nil by mouth' until you've had an assessment – this is when you're told not to eat or drink anything.

To begin with, the most important thing will be making sure that you can swallow safely. If you're not swallowing safely, it could cause infections or mean that you're not getting enough food or fluids into your body. Your speech and language therapist will explain the different things you can do.

This could include:

- changing your diet
- learning techniques that can help you to swallow
- using aids that can help you to eat or drink more easily.

As well as these, your speech and language therapist may also get you to practise exercises. Strengthening the muscles in your face, lips and mouth, will help you to swallow better.

Changing your diet

If you can't swallow safely, then you'll probably need to make changes to your diet until you can. You may need to:

- **Thicken your drinks**
Water and other thin liquids are the hardest things to swallow because they're difficult to control. However, there are powders you can add to make them thicker and easier to swallow. There are lots of different powders, which can thicken drinks to different consistencies, depending on what you need.
- **Eat soft or pureed food**
Solid food needs to be chewed to make it easier to swallow. So if you're having problems, you may need to stick to soft food (like mashed potato), which doesn't need much chewing. Or you may need to have pureed food to begin with, which is very smooth and doesn't need to be chewed at all.
- **Change the temperature**
Hot foods and drinks can be difficult to swallow because you can't hold them in your mouth as long. So your therapist may suggest that you stick to cold foods, or allow hot food to cool down quite a bit before you try to eat it.
- **Change how and when you eat**
Eating small amounts throughout the day, rather than three big meals, for example, may be better for you if you're finding it hard to concentrate or you get tired very quickly. You may also find small portions are easier to manage, or that eating earlier in the day when you have more energy, works better.

Your speech and language therapist will explain to you and your family exactly what foods are safe for you to eat. They'll also make sure that the rest of your stroke team are clear about what you can and can't eat, and how you should be eating.

You may only have to change your diet for a short time. As you start to recover you'll probably move on to more solid foods and thinner drinks. Hopefully, you'll be able to introduce other foods bit by bit, until you're back to eating a normal diet again.

It's likely that your stroke team will have a **dietitian** who can help you with any changes to your diet.

Dietitians work with people to make sure that they're getting the nutrition and fluids that they need. They'll monitor your weight and how much you're eating and drinking, to make sure that you stay healthy. If they're worried that you're not getting everything you need, they may suggest that you take supplements or try special foods that can give you extra nutrients and calories.

Swallowing assessments

You'll probably have a number of swallowing assessments while you're in hospital, to monitor how well you're improving. These assessments will be carried out by your speech and language therapist and can involve different tests. You may have to do all of them or just one or two.

- Your therapist will usually begin by asking you to **swallow food and drinks of different consistencies**, to see whether you are able to swallow them safely. They may also do a physical examination.
- A **videofluoroscopy** involves taking a video x-ray of your mouth and throat while you swallow. This allows your speech and language therapist to see the food or fluid you are swallowing. You'll be sat beside an x-ray machine and given different foods and drink to swallow. These will be mixed with a special liquid called barium that will show up on the x-rays. Barium is safe to eat and won't cause you any harm, although it may make you feel slightly sick and can sometimes make you constipated. It can also make your poo white for a few days, while it passes through your body.
- A **fibreoptic endoscopic evaluation of swallowing (FEES)** uses an endoscope to find out what's happening when you swallow. An endoscope is a long, thin, flexible tube that has a light and a tiny camera at the end of it. It's inserted into one of your nostrils and up into your throat, so that your therapist can see how well your muscles are working and where the problems may be occurring.

Although your therapist will probably do regular assessments with you, don't be afraid to ask for another if you think you've improved. Your therapist may not be able to see you every day, so they may not realise how well you're progressing.

Although swallowing problems often get better within the first few weeks, it can take longer for them to improve. If you're not able to swallow, you'll be given fluids through a drip to make sure that you don't become dehydrated. It's also important that you get the right nutrition, so your stroke team may also talk to you about being fed by a tube.

Tube feeding

Tube feeding means putting liquid food directly into your digestive system through a tube. Doctors and dietitians often call this **enteral feeding**.

There are different types of feeding tubes. The two that are used most often after a stroke are **nasogastric (NG) tubes** and **percutaneous endoscopic gastrostomy (PEG) tubes**. There are advantages and disadvantages to both. You'll need to talk through both options with your stroke team and family to decide which one is best for you.

NG tubes tend to be temporary and are normally used if you'll need to be fed for less than four weeks. Whereas PEG tubes tend to be used for longer periods.

Your team may suggest that you try an NG tube to begin with, as you can always move to a PEG tube later. But if you don't think you're going to be able to cope with an NG tube, you can try a PEG tube straight away.

NG tube

A very thin tube, not much wider than a piece of spaghetti. It goes up your nose, down the back of your throat and into your stomach.

Advantages

- Easy to insert.
- Safer to insert than a PEG tube, as it's less invasive.
- Easy to remove.

Disadvantages

- Can be uncomfortable when it's in place.
- Can fall out easily, so it may need to be replaced regularly.
- Can be difficult to ensure you're getting enough food.

PEG tube

A tube that is inserted directly into your stomach, through your skin.

Advantages

- Rarely falls out.
- More comfortable.
- Can be hidden under your clothes.

Disadvantages

- More difficult to replace if it does fall out.
- You may need to be sedated when it's inserted, which has risks.
- The area around the tube can become infected.

Tube feeding at home

If your overall recovery is good, then your stroke team may suggest that you go home, even if you're still being fed by tube. This can worry some people as they think it can be a lot to cope with.

However, most people cope very well with tube feeding at home, even people who live on their own. Once you've given it a go, you'll probably find it's not as difficult as you thought.

Five reasons to consider tube feeding at home

1. Feeding machines are usually very easy to use.
2. There's not much that can go wrong and nothing that can put you in danger.
3. You and your family will be shown exactly what to do before you go home.
4. You'll have support from community nurses once you are home.
5. You can always consider other options later, if you do find it too much.

It's up to your stroke team to make sure that you and your family have all the information, support and equipment you need before you go home. 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 or dietitian to go through it all with you as soon as they can. We've suggested some things to ask them below.

Questions to ask before you go home

- 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 do it?
- Are there written instructions I can have?
- How do I get more food?
- Who do I contact if I have a question?
- Who do I contact in an emergency?

Unfortunately, some people don't completely recover and if you're left with lasting problems, you may have to continue being fed by tube or stay on soft food permanently.

Although this can take some getting used to, it doesn't have to stop you from doing anything that you want to do. Over time you'll adjust to the changes you need to make and, with a little extra planning, still be able to enjoy things like going out and going on holiday.

Your dietitian or speech and language therapist will be able to give you any advice you need. Or you can get in touch with one of the support groups we've listed on page 15.



What can I do about swallowing problems?

1

Listen to your therapist

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, you can't know for sure.

Not being able to eat the things you enjoy is difficult, especially when you're stuck in hospital or feeling down. However, avoiding difficult foods, however much you miss them, will help you recover.

2

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. Don't worry if you feel that you're always asking questions. Your stroke team would much rather you ask than do something that puts yourself at risk. So if you want to eat something but you're not 100% sure it's OK, double check. Or if you think your swallowing has improved, **ask for another assessment**, so that you can be sure.

3

Learn how to swallow safely

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

Do

- ✓ Create time and space for you to concentrate on what you're doing. So turn off the TV or draw the curtain round 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 your time.
- ✓ 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.

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 it's safe.
- ✗ Eat foods that are not the same consistency, such as soups that have large chunks in it or vegetables with tough skins.

4

Look after your mouth and teeth

If you don't clean your teeth and mouth, then bacteria will build up around them. This can make your mouth sore and lead to infections.

It's even more important if you have swallowing problems, because tiny traces of food and drink are more likely to stay stuck to your teeth and gums and in your cheeks. This encourages bacteria and plaque to grow. Plus, we all feel better when we have a clean mouth and fresh breath. Here are some tips to help:

1. Looking after your teeth may be the last thing on your mind, especially in the early stages after your stroke. 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.
2. If you have swallowing problems, **ask your nurse or your 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.
3. Make sure you use a toothpaste with a high fluoride count and that 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.
4. If you wear **dentures**, it's important to clean your mouth and tongue as well as your teeth. You can do this with a soft brush or using some gauze around your finger. Someone in your stroke team will be able to show you the safest way to do this.
5. **Avoid sugary drinks and snacks**, as these will damage your teeth. Food supplements can also increase your chance of developing tooth decay so clean your teeth or rinse your mouth with water after taking them.
6. It's important to **keep your mouth moist**. Even if you can't drink, you may be able to use a saliva spray or special gel to stop your mouth from getting dry. Ask your speech and language therapist.
7. Use **lip balm** to stop your lips getting dry or cracked.
8. Make sure you **know what you need to do** before you go home. If you're still having some problems with swallowing, make sure you have any special equipment or products you need to keep your teeth and mouth clean.
9. **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 your current ones adapted to help you put them in and take them out. If you can't get to your dentist's surgery yourself ask whether they can visit you at home.

5

Talk to someone about it

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 stroke survivors feel left out when they're not able to take part in family mealtimes like they used to. Or you may not look forward to meals out, because you're embarrassed to eat in front of other people or feel awkward if you're not eating with everyone else.

These feelings can take their toll. So make sure you talk to someone about them. **Support groups** can be helpful, because you can talk about your problems with people who are going through the same thing. But they're not for everyone, so talk to a friend or family member instead if that's easier for you – whoever you feel comfortable confiding in when you're finding it tough.



Other things to think about...

- Just because you have swallowing problems, doesn't mean you can't enjoy eating. Hospital food can be pretty bad, so if you're missing your favourite meals and snacks, **speak to your speech and language therapist**. There may be a way for you to have them, or to enjoy something similar.
- Soft foods don't have to be boring. There are lots of **cookery books and online recipes** for tasty pureed meals. Or if you're not able to cook, there are companies that will deliver meals to you that look and taste great. Ask your speech and language therapist or dietitian if they have any recommendations.
- Medication comes in different forms, including liquids, patches and inhalers. So if you're struggling to swallow your tablets, **speak to your doctor or pharmacist** to see if your medication comes in a different form that may be easier for you to take.

Sometimes it's possible to crush tablets and put them in food or water, but not all medication can be taken in this way. So make sure you talk to your pharmacist first to check that it's safe.

Where can I get help and support?

If you're concerned about swallowing problems, then speak to your **doctor** or **speech and language therapist**. If you don't notice problems until you've returned home, then speak to your GP.

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 meet with you and your family and 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 Helpline on **0303 3033 100**
- email **info@stroke.org.uk**
- visit **stroke.org.uk**
- write to us at Stroke Information Service, Life After Stroke Centre, Church Lane, Bromsgrove, Worcestershire B61 8RA.

Other organisations that can help

Below are some other organisations in the UK that may be able to help. Contact our Stroke Helpline if you'd like to know about others in your area.

The following **NHS websites** can tell you more about swallowing problems and how they are diagnosed and treated.

NHS Choices

(England, Wales, Northern Ireland)

Website: www.nhs.uk/conditions/Dysphagia

NHS Inform (Scotland)

Website: www.nhsinform.co.uk/health-library/articles/d/dysphagia

Easy Info page: www.nhsinform.co.uk/Easy-Info/HealthConditions/Dysphagia

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, regular newsletters and invitations to local meetings. Full membership normally costs £5 a year.

Website: www.pinnt.com

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

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

Tips for family and friends



It can be difficult to know how to help someone with swallowing problems. So here are some tips to help you.



Always check

It's difficult 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 your friend or family member feel better.



Give them time and privacy

Swallowing problems can make people feel very self-conscious. So make sure your friend or family member has some privacy when they're eating. Even if it's just pulling the curtain round their bed or asking visitors to pop out for twenty minutes while they eat. Time is also really important. Eating probably feels stressful enough for them, so rushing is only going to make it worse. So **encourage them to take their time** and enjoy their food.



Ask for help if you need it

Coping with swallowing problems can feel very overwhelming. So don't be afraid to ask for help. Before your friend or family member is discharged from hospital, **make sure you know who you can contact** if you have a question once they're home. Talk to your GP if it's getting too much and ask what support you can get.

It may also help to talk to someone else about it, especially someone who's gone through a similar situation. There will probably be a **carers' group** in your area or you could try your local **stroke club**.

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

Do

- Allow plenty of time.
- Show them what they're about to eat or describe it to them. 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 you to present pureed 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.

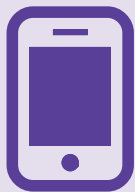
We're here for you. If you'd like to know more, please get in touch.

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

Email: info@stroke.org.uk

From a textphone: 18001 0303 3033 100



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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.

Together we can conquer stroke

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