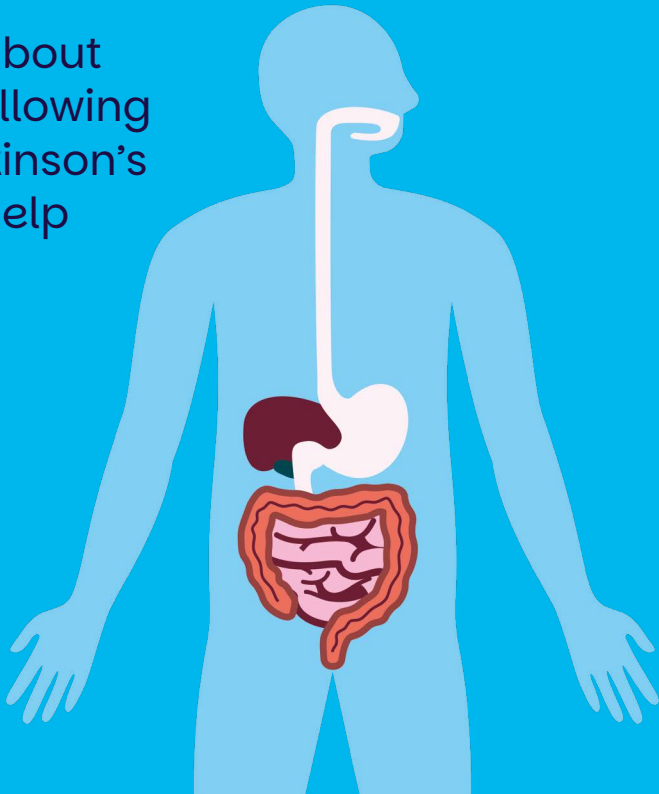


Eating, swallowing and managing saliva in Parkinson's

Symptoms

Find out more about eating and swallowing issues with Parkinson's and what can help



Eating, swallowing and managing saliva in Parkinson's

Some people with Parkinson's have problems with eating, drinking and swallowing. Some might find it difficult to swallow and control their saliva and may experience drooling. Other people may feel like their mouth is too dry, which can affect how they eat.

This information looks at the issues you may have, why they happen and what help is available. We also share practical tips for family, friends or carers.

Swallowing problems (dysphagia)

Some people with Parkinson's have trouble swallowing. This can be because of Parkinson's itself or as a side effect of some Parkinson's drugs.

Why do I find it difficult to swallow?

Stiffness and slowness in your jaw muscles

Parkinson's can cause the muscles used to swallow and chew in your jaw and face to become slower and stiff, or rigid.

This may make it more difficult to:

- swallow
- chew
- move food around in your mouth.

Sometimes we swallow automatically, without needing to think about it. In Parkinson's, this may happen less frequently because of the stiffness and slowness of your swallowing muscles.

Problems with tongue muscles

Your tongue is important for swallowing. You use it to move food around and push it to the back of the mouth, to swallow it. Parkinson's can also cause problems in your tongue muscles, such as a tremor in your tongue, or trouble unsticking your tongue from the roof of your mouth.

Some people have a symptom called "tongue pumping", which is when the tongue moves back and forward in the mouth, making it difficult to swallow food.

Problems with throat muscles

Parkinson's can weaken the muscles, reflexes and sensation in your throat which affects how effectively you swallow. This means that food or drink can be at risk of going down the wrong way and entering your airway.

Some research suggests that breathing difficulties may also affect how safely you can swallow. However, more research is needed to confirm the link between breathing and swallowing.

What symptoms should I look out for?

Swallowing difficulties can develop over time and you may not notice them at first. So family, friends or carers should know what to look out for too.

You may notice:

- drooling
- coughing food back up after you've tried to swallow it
- food sticking in your chest or throat
- a gurgly voice
- coughing when you eat or drink
- choking on food, liquid or saliva
- problems swallowing medication
- pain when swallowing.

This can lead to problems such as:

- losing weight
- not eating enough to stay healthy (known as malnutrition)
- not drinking enough, which can lead to dehydration
- worrying about eating and drinking because you're afraid of choking
- finding it difficult to eat certain foods
- chest infections.

Choking

If you have problems swallowing, there is a risk of choking. Severe choking, where you can't breathe, cough or speak is a medical emergency. If your airway is still blocked after trying to clear it, someone should call 999, ask for an ambulance and follow the operator's instructions.

If you are worried about choking, ask a healthcare professional to show a friend or carer what they could do to help you.

Food and drink going into your lungs (aspiration)

Swallowing problems can sometimes cause food or drink to enter your windpipe, rather than your food pipe (oesophagus) as it normally would. This is called aspiration.

Your body normally coughs to stop food or drink going into your lungs. But sometimes, people with Parkinson's experience "silent aspiration". This is when food, drink or saliva enters your windpipe and goes down into your lungs, without you coughing or choking.

Aspiration can cause the lungs to become infected and inflamed. This is called aspiration pneumonia.

If your cough reflex is weaker, you could be at a higher risk of aspiration pneumonia.

Symptoms of aspiration pneumonia include:

- chest pain
- finding it difficult or painful to breathe
- a cough (you may notice phlegm or blood in your tissue)
- a fever.

You will normally be treated with antibiotics. If you've had problems swallowing and you have symptoms of aspiration pneumonia, contact your healthcare team straight away, or call NHS 111 if they aren't available.

Who can help with swallowing problems?

Speech and language therapists

Speech and language therapists (sometimes referred to as SLTs) work with people with swallowing problems. Your GP or Parkinson's nurse can refer you, or you can refer yourself.

It can help to be referred by a healthcare professional, because the speech and language therapist can contact them for any medical information they need about you. Not all speech and language therapists are specialists in Parkinson's, so, if possible, check that you're being referred or self-referring to a service with specialist skills. Medical referrals are sometimes required for swallowing assessment and treatment.

Dietitians

If you've made big changes to your diet, or you're losing weight without trying to, ask your GP or Parkinson's nurse to refer you to a dietitian. A dietitian can help you make changes to your diet in a safe and sustainable way.

Your specialist or Parkinson's nurse

If you struggle to swallow tablets, your specialist or Parkinson's nurse may suggest a patch or liquid instead.

Find out more: see our information on speech and language therapy, diet and Parkinson's and drug treatments for Parkinson's.

Seeing a speech and language therapist for swallowing problems

What happens when you see a speech and language therapist?

Your speech and language therapist will ask about what difficulties you've noticed when swallowing and if there's any difference between swallowing food or drinks.

They may want to examine your mouth and watch you take small mouthfuls of food or drink, or eat a meal. If necessary, they may refer you for further tests. These include:

- Fibreoptic endoscopic examination of swallowing (FEES) – a small flexible tube with a camera at the end (an endoscope) is passed down the nose into your throat¹ to watch food and liquid as you swallow it.
- Videofluoroscopic swallowing study (VFSS) – this test is done in an X-ray department. You'll be asked to eat and drink foods mixed with a substance that shows up on an X-ray. VFSS is also called videofluoroscopy (VF).

Clinical guidelines say that people with Parkinson's who have problems with swallowing or managing saliva should have access to speech and language therapy.

¹<https://pubmed.ncbi.nlm.nih.gov/18939710/>

We recommend that you speak to a therapist as soon as you can after you've been diagnosed. Even if you aren't having any specific problems, a speech and language therapist can give you useful information about problems that may happen in the future and what can be done about them.

They may spot changes before you do. This will help you cope with the problem before it becomes more difficult to manage.

A speech and language therapist can also give advice about food if you're finding it difficult to eat.

You may be referred to other health professionals, including:

- an ear, nose and throat (ENT) specialist
- a dietitian
- a gastroenterologist - a doctor who specialises in the digestive system.

Treatments for swallowing problems

Following an assessment, your speech and language therapist will work with you and other healthcare professionals, such as a dietitian, to come up with a self-management plan to suit your needs. This might include:

- changing your sitting posture and head posture when eating or drinking. This can help you make sure you swallow your food safely and avoid aspiration
- changing your diet to make food and drink easier and safer to swallow. This may include avoiding hard, dry or crumbly food, or moving on to softer, moist or chopped food

- avoiding taking mouthfuls of food or drink that have different consistencies together, like cornflakes and milk, or peas and gravy. Having a sip of water in between bites may help clear any leftover food too. Your dietitian can help you identify any meals or snacks that might need adapting
- eating more slowly and reducing the size of your bites
- talking to your specialist or Parkinson's nurse about the timing and doses of your medication. They'll be able to tell you more about which medications you can take with food or if you should wait between taking your dose and eating.

These are examples of what might help. The most important thing is to see your speech and language therapist, who will come up with a personalised treatment plan for you.

Swallowing aids

Swallowing aids are tools to help you to remember to swallow. For example, you might use a timer that prompts you to swallow.

Downloadable apps, such as "Swallow Prompt", may be helpful. It can help you retrain yourself to swallow more frequently by sending you reminders for when you need to swallow. You can find out more at speechtools.co/swallow-prompt

Your Parkinson's nurse or speech and language therapist can help you find a device that is right for you.

Expiratory muscle strength training (EMST)

EMST is a type of training which may help to strengthen the muscles you use to breathe out, which are important for swallowing and coughing. Coughing is important to eat, drink and swallow safely.

To do EMST, you'll be given a device and shown some breathing exercises which, used together, may help strengthen the muscles you use to swallow and cough. Improving the strength of your swallowing muscles can make your cough stronger, helping you swallow food and drink more easily. This may reduce the chance of food, drink or saliva going down your windpipe.

More research is needed to work out how helpful EMST can be in improving issues with swallowing.

Ask your speech and language therapist how EMST might be able to help you. They can show you how to use the device and set up an exercise plan for you.

Support for families and carers

Speech and language therapists can also work with your family, friends or carers. This could be especially helpful if swallowing problems are making mealtimes difficult for you. Sometimes the people around you may not realise that swallowing problems are affecting how you eat and drink. Helping them understand your problems and giving practical advice on what to do can help make everyone feel less anxious and make mealtimes easier and more enjoyable (see Eating and drinking on page 16).

Not making enough saliva: dry mouth (xerostomia)

Saliva is important for good mouth health. It helps you to:

- taste your food
- swallow and digest food
- keep your mouth clean.

Without enough saliva you may have a dry mouth. Dry mouth can be a symptom of Parkinson's or a side effect of Parkinson's medication.

A dry mouth can lead to tooth decay and gum disease. You might also have bad breath or dry or chapped lips.

If your mouth feels dry, tell your dentist. They can discuss options which might help. They may ask you what medication you take, so take a list to your appointments.

You should also speak to your specialist or Parkinson's nurse as they may be able to prescribe different treatments that don't make your mouth feel dry.

The following tips may help reduce dry mouth:

Do:

- try to take frequent sips of cold water
- chew sugar-free gum or suck sugar-free sweets
- use lip salve or balm to protect your lips if needed
- remove dentures at night to give your mouth a chance to recover
- cut down on caffeine - it can make your mouth dry.

Don't:

- smoke – you can find out more about free NHS services to help you stop smoking at [nhs.uk/live-well/quit-smoking](https://www.nhs.uk/live-well/quit-smoking)
- use mouthwashes that contain alcohol
- frequently sip sugary drinks – this will also increase tooth decay
- eat spicy, salty or acidic foods (such as lemons). If you usually enjoy eating foods like these, a dietitian can help you look for some alternatives.

We have more information about looking after your mouth and teeth, including if you wear dentures, on our online magazine at [parkinsons.org.uk/dental-care](https://www.parkinsons.org.uk/dental-care)

Find out more: see our information on mouth and dental issues in Parkinson's.

Saliva substitutes

Saliva substitutes help replace your natural saliva and keep your mouth moist. Ask your dentist or pharmacist which saliva substitute products are best for you, as some are not suitable for people with natural teeth, such as acidic artificial saliva products. Some of these are available to buy in your local pharmacy, and some may be prescribed for you.

Drooling (sialorrhea)

Many people with Parkinson's develop problems with dribbling or drooling.

What causes drooling?

We all swallow many times a day. Parkinson's causes movement to slow down, which can affect how often and how well you can swallow.

If you swallow less, saliva can pool in your mouth and overflow from the corners of your mouth, causing drooling. It may happen without you noticing when you're concentrating on other things, like watching TV or doing chores.

Your drooling might be worse if your Parkinson's symptoms are advanced.

Your posture might make drooling worse. Some people with Parkinson's have a stooped, head-down posture and may find it hard to fully close their mouths. This can make it harder to control saliva flowing from the mouth.

If drooling affects you, you might sometimes feel embarrassed or stressed. You may feel that you don't want to go out or socialise with friends or family.

Drooling can lead to:

- skin infections around your mouth
- your clothes becoming damp or wet
- some of your things, such as books or computers, ending up damp or wet.

It's important to speak to your specialist, Parkinson's nurse or speech and language therapist for the right support to manage drooling.

Tips to prevent drooling

You can try these simple exercises at home in front of a mirror to try to help prevent drooling:

- Closing your lips as tightly as possible and holding for a count of four, relax, then repeating five times
- Smacking your lips together
- Stretching your lips in a wide smile, holding for a count of four and then relaxing
- Bringing your lips together as if you're going to whistle or kiss someone, holding for a count of four, and then relaxing
- Reminding yourself to swallow more often – you could leave a note out at home or set a reminder on your phone.

It might also help to:

- make sure that your mouth is closed when you stand up
- have regular sips of water or another drink, so that you can swallow any excess saliva at the same time

A speech and language therapist can recommend specific exercises for you based on your symptoms.

They'll also help you become more aware of what your lips are doing and how tight you need to hold them closed to keep saliva in.

Find out more: see our information on speech and language therapy and Parkinson's.

If drooling is causing the corners of your mouth to become sore or red, using a lip balm, or a cream that has petroleum jelly in it (like Vaseline), is important.

This can help protect the skin around your mouth from infection. Talk to your GP or Parkinson's nurse if you're worried about this.

Other treatments

The following may help control problems with saliva:

- Drugs that can help control saliva (including anticholinergics). UK guidelines suggest that you should be referred to a speech and language therapist before your specialist prescribes any medication for drooling, where possible. If this doesn't happen, you could speak to your Parkinson's nurse about a referral for speech and language therapy.
- Injections of botulinum toxin (Botox) into the salivary glands. This acts on the nerves and the muscles around your salivary glands to temporarily reduce the amount of saliva that they produce. It's important to discuss this with your specialist, as this treatment may have side effects. Clinical guidelines list Botox as a treatment option for people with Parkinson's experiencing drooling so it should be available for you on the NHS, but may not be available in all areas.
- Radiotherapy can reduce the amount of saliva that you produce.
- Surgery for drooling can include removing your salivary glands, or redirecting them, to reduce the amount of saliva in your mouth.

You should talk to your specialist, Parkinson's nurse or speech and language therapist about these treatments, as they're not suitable for everyone.

Eating and drinking

Stomach issues

Parkinson's may slow down and weaken the muscles carrying food down into your stomach. This can make you feel full up even if you haven't eaten much. This could mean you don't get enough to eat.

Also, if you find it difficult to chew and swallow food, it may be harder to get enough fibre in your diet. Fibre works with water to help to keep stools (poo) soft and easy to pass, and helps you to avoid constipation.

There are lots of ways to include fibre in your diet. For example, milled flaxseeds (sometimes called milled linseeds) are high in fibre and easy to swallow, because they have been crushed into powder. You can eat them by themselves or add them to other foods.

Your dietitian can suggest other ways to help you get more fibre into your diet.

Find out more: see our information on looking after your bladder and bowels and diet and Parkinson's.

Practical problems with eating and drinking

Sometimes issues with eating and drinking are more practical.

These may include:

- trouble getting food up to your mouth
- trouble balancing a cup to drink
- feeling tired during a meal or struggling to concentrate on eating.

Who can help?

If you have practical difficulties when eating or drinking, you might find it helpful to talk to a healthcare professional such as an occupational therapist or dietitian.

An occupational therapist can provide advice or equipment to make eating and drinking easier. Your specialist or Parkinson's nurse can refer you. You can also usually contact an occupational therapist through your GP, your local council's social services or social work department, or health and social care trust. It may be possible for an occupational therapist to visit you at home.

You can also pay for private occupational therapy. Contact the Royal College of Occupational Therapists (see page 22).

A dietitian can give advice about eating a balanced diet and about types of food that may be easier to swallow. If you're struggling to eat a balanced diet or are losing weight, they may recommend nutritional supplements. Your specialist or Parkinson's nurse can refer you.

Find out more: see our information on occupational therapy and diet and Parkinson's.

Equipment to help with eating and drinking

There is a variety of equipment to help you eat and drink more safely and comfortably.

For example, adapted cups are shaped so you can drink without tilting your head. You can also buy weighted cutlery, which may be easier to grip and use if you have tremors while you're eating. You can usually buy specially designed cutlery in high street mobility shops.

Your speech and language therapist or occupational therapist can tell you more about the equipment available.

Find out more: see our information on daily living equipment for Parkinson's.

Tips to help with eating and drinking

It may help to:

- Take small mouthfuls. This will give you more control over your chewing and swallowing and will reduce the possibility of food slipping to the back of your throat before you've chewed properly.
- Avoid taking another mouthful until you're sure you've cleared your mouth and throat.
- Take your time.
- Sit upright in a chair that supports your body.
- Reduce distractions while you eat, such as watching TV.
- Refill your cup or glass when it's half empty. This means you don't have to tilt your head back to drink, which can make food or drink go down the wrong way.
- Try naturally thicker drinks, such as smoothies or shakes, which move more slowly and are easier to control, so are less likely to go down the wrong way. If you find these helpful, ask your speech and language therapist for an assessment to see if powdered thickeners are appropriate for you. Powdered thickeners need to be recommended by a speech and language therapist and added to your prescription. They will explain the pros and cons of having drinks thickened with powdered thickeners and how to drink them safely.

Eating out

Some people with Parkinson's find eating out with family and friends difficult. You might worry about being unable to cut up your food or control it on your fork or spoon. Reading the menu in advance could help you choose foods that you find easier to eat.

When eating away from home, it can be useful to take any drinking or eating aids, like your own adapted cup, plate or cutlery, out with you. You could also phone the restaurant first to make sure they can provide what you need.

If you eat slowly, other people may sometimes think that you've finished your meal. Because of this, staff may take your plate away before you've finished. If this happens, remind restaurant staff that you need to take your time.

Families who find it difficult to eat with a relative who has Parkinson's should talk about the problem. If there are children with you, explain that their relative hasn't changed as a person, but their Parkinson's can make eating hard for them and they need support, time and understanding.

Here are some tips to help you get the most out of going out for a meal:

- If you can, time your meal for when your medication is working most effectively. Then you can better focus on your food and catching up with friends and family.

- If you go to a buffet, ask for help carrying your tray back to your table.
- Bladder problems are common for people with Parkinson's. You might need to go to the toilet suddenly. If you're worried, ask for a table with easy access to the toilets.
- If you find it easier to eat from a bowl rather than a plate, or a mug rather than a bowl, don't be afraid to ask the waiting staff to arrange that for you.
- If you prefer sitting in a chair with arms, you could call ahead to the restaurant to arrange this.
- If you're worried about eating slowly, you may feel more comfortable having smaller portions, such as ordering a starter as a main course. However, make sure that you're getting enough to eat and don't be afraid to take your time. Eating more slowly can give everyone more time to chat and enjoy themselves.

If you have a sunflower lanyard, you could wear it to let a restaurant know that you might need some understanding and support during your visit. You can find out more about the hidden disabilities sunflower lanyard at **hdsunflower.com**

More information and support

Association of Speech and Language Therapists in Independent Practice

How to find a private speech and language therapist.

www.asltip.com
office@asltip.com
020 3002 3704

British Dietetic Association

How a dietitian can help and how to find one..

www.bda.uk.com
info@bda.uk.com
0121 200 8080

Royal College of Occupational Therapists

How an occupational therapist can help, and how to find one near you..

www.rcot.co.uk
hello@rcot.co.uk
020 3141 4600

Royal College of Speech and Language Therapists

How a speech and language therapist can help and how to find one near you.

www.rcslt.org
info@rcslt.org
020 7378 3012

Parkinson's UK information and support

Whatever your journey with Parkinson's, you're not alone.

From the moment you or someone you care about is diagnosed, we have information and support for you.

Speak to one of our friendly expert advisers, including specialist Parkinson's nurses, care advisers, and benefits and employment advisers. We've got information and advice on all aspects of living with Parkinson's.

Get help managing your diagnosis. Our information packs, webinars, courses and support groups can help you and your loved ones understand your Parkinson's diagnosis and better manage your symptoms.

Read our up to date, reliable health information. Our website, booklets and magazines can help you better understand Parkinson's. They're full of tips and advice on managing your condition and supporting a loved one.

Find ways to get active, stay active and live well with Parkinson's. Whatever your fitness level, we'll help you find the right activities for you.

Connect with other people with Parkinson's, families, friends and carers. Across the UK, in your local area or online. We'll help you meet others who understand what you're going through, because they're going through it too.

Find out more

- Call our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk** to speak to an expert adviser.
- Visit **parkinsons.org.uk/information-and-support** to read our information or find support that's local to you.
- Call **0330 124 3250** or visit **parkinsons.org.uk/order-print-booklets** to order free printed information.

Thank you

Thank you very much to everyone who contributed to or reviewed this information:

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people affected by Parkinson's who provided feedback.

All of our information is checked by experts and other
people with Parkinson's, so you know it's information
you can trust.

Feedback

If you have any comments or feedback about our
information, please call **0800 138 6593**, email **feedback@parkinsons.org.uk**, or write to us at Parkinson's UK,
50 Broadway, London, SW1H 0BL.

If you'd like to find out more about how we put our
information together, or be part of the team that
reviews our health content, please contact us at
healthcontent@parkinsons.org.uk or visit our
website at **parkinsons.org.uk/health-content**.

Can you help?

At Parkinson's UK, we are totally dependent on donations
from individuals and organisations to fund the work that
we do. There are many ways that you can help us to
support people with Parkinson's.

If you would like to get involved, please contact our
Supporter Care team on **0800 138 6593** or visit our
website at **parkinsons.org.uk/donate**.

Thank you.

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We're Parkinson's UK,
the charity that's
here to support every
Parkinson's journey.
Every step of the way.

Free confidential helpline **0808 800 0303**
Monday to Friday 9am to 6pm,
Saturday 10am to 2pm (interpreting available)
Relay UK **18001 0808 800 0303** (for textphone users only)
hello@parkinsons.org.uk | parkinsons.org.uk

Parkinson's UK, 50 Broadway, London SW1H 0DB



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