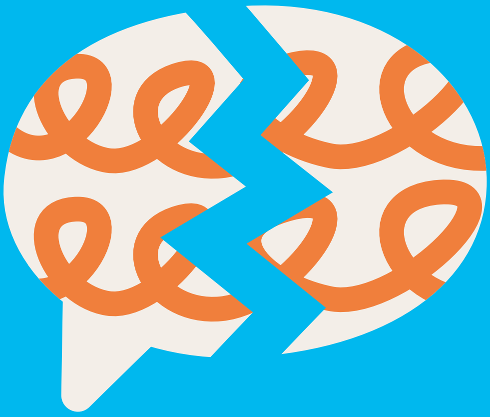
Parkinson's UK

Speech and communication problems in Parkinson's

Symptoms

Find out more about speech and language problems in Parkinson's, and ways to manage symptoms



Speech and communication problems in Parkinson's

Speech and communication problems are common for people with Parkinson's.

They can include problems with your voice, body language, having conversations and your handwriting. But with the right help and support there are lots of ways you can improve symptoms.

This information looks at the symptoms you may have, what causes them and what you can do to manage them.

Why do people with Parkinson's experience speech and communication problems?

Changes in the brain in people with Parkinson's mean that movements become slower, smaller and less forceful than before.

Rigidity, when your muscles become stiff, can also cause problems with communication. This can lead to problems with your speech, body language and facial expressions.

You may have trouble making sure your voice is loud enough, pronouncing words clearly and controlling the pitch (high or low quality) of your voice.

Some people with Parkinson's find that they can't process thoughts as quickly as they need to, which can also affect communication.

This includes difficulty:

- finding the right word
- understanding what other people mean straight away
- getting your thoughts together in time to reply to someone in the flow of a conversation.

Find out more: see our information on thinking and memory changes in Parkinson's.

Speech refers to the way we say sounds and words. But it's not the only way in which we communicate with other people. Things like your tone of voice, hand gestures, body language and facial expressions all help you to get your point across.

Problems with speech and voice (including hypokinetic dysarthria)

You may find your speech sounds too quiet or unclear, or that you have to slow down to make yourself understood. You might notice that you are speaking more slowly or more quickly without trying to, or that the speed of your speech changes as you speak.

Your voice can also change. It may sound:

- breathy, like you are sighing and talking very quietly
- hoarse or harsh, like you have a sore throat
- quieter than before
- flat, like you're talking with the same tone and volume a lot of the time.

You might hear these symptoms referred to as hypokinetic dysarthria.

Problems with the volume of your voice (hypophonia)

A quieter voice is common in people with Parkinson's. A quieter, softer voice, which may sound breathy, is called hypophonia.

You might not realise that you're talking more quietly. In fact, you may think you are shouting and so speak at a lower volume. If you're often asked to repeat yourself, your voice might be too quiet.

If you're unsure, you could ask a friend or family member what they think. You could also record yourself on your phone and listen back to check the volume of your voice. Apps can help too, such as Speak Up for Parkinson's, which has a volume meter to check how loud your voice is.

Speak Up for Parkinson's is currently only available on Apple products like iPhones, iPads or MacBook computers. A speech and language therapist can recommend other apps.

We have more information about apps, devices and technology on our website at: **parkinsons.org.uk/tech**

If you're worried your voice has become quieter, talk to your specialist or Parkinson's nurse. They may be able to refer you to a speech and language therapist for support (see page 9). Your Parkinson's nurse may also suggest downloadable apps to help you communicate while you're waiting for a referral to a speech and language therapist.

Making conversation

These changes to your speech and voice can make it difficult to do everyday activities like talking to friends or making phone calls. In conversations, you may find it hard to:

- take your turn or interrupt naturally to express your opinion
- follow fast-changing topics
- get your thoughts together in time to respond
- take the lead or change the focus of the conversation
- produce a clear, loud voice
- stress the right words or part of a word
- speak for a long time
- make yourself heard the first time you say something.

You may also feel like you have to put more effort into talking and that it’s harder to start talking with confidence. People can find joining in with the conversation difficult, especially in a group. You may sometimes feel isolated or not fully part of a conversation.

Parkinson’s can affect everybody in a conversation: the person with Parkinson’s and their colleagues, family and friends. Everyone involved can help to make communication easier. If family members or close friends join in some of your speech and language therapy sessions, you can all get support to have more successful conversations.

Problems with facial expressions and body language

Facial expressions, body language, hand gestures and posture are important parts of communication. They help others to understand extra information about what we mean.

Facial masking (hypomimia)

Parkinson’s can make it more difficult for you to make facial expressions to show how you’re feeling. This is due to the muscles in your face becoming more stiff (or rigid).

Some people with Parkinson’s have a “masked face”, sometimes called a “Parkinson’s mask”. The medical name for this is hypomimia. It can give you a blank expression, even if you're actually experiencing a strong emotion.

A Parkinson’s mask may stop you showing your emotions, even though you are feeling them. It can mean that other people might not understand how you’re feeling. They could think you are bored, low or unhappy, even if you don’t feel that way.

You might also find that you are blinking less often, or more slowly than before.

Masking can make it more difficult to move your face on purpose - like smiling to encourage someone else to continue talking. It also affects movements that would usually happen without you thinking about them - like smiling when you hear a joke or greet a friend.

Body language

You might have problems with how you move your body, including stiffness and slower movements.

This might mean that other people miss physical signals like hand gestures or a shrug. If you also have a quieter voice because of your Parkinson’s, this could make communicating overall more difficult, so it’s important for you and those you communicate with regularly to get support.

A speech and language therapist can help you to make everyday communication easier (see page 10).

Problems with handwriting (including micrographia)

People with Parkinson’s may have problems with their handwriting. It may become “spidery”, crowded or difficult to read.

Some people's handwriting gets smaller. This is called micrographia.

Some people notice that their handwriting has become generally smaller. This is called consistent micrographia. For others, their writing starts off normally, but becomes smaller and more crowded as they write. This is known as progressive micrographia.

You may also find that you write more slowly than before.

Both motor (movement) symptoms of Parkinson's and changes to how you think can lead to problems with handwriting.

These include:

- tremor
- muscle stiffness (rigidity)
- moving more slowly (bradykinesia)
- difficulty controlling small movements, such as doing up buttons (known as fine motor skills)
- thinking problems caused by Parkinson's.

You might find it more difficult to write if you're trying to do something else at the same time.

Find out more: see our information on tremor and thinking and memory changes in Parkinson's.

Speech and language therapy

Speech and language therapists are healthcare professionals who can measure how well you communicate and give you advice to help. They can look at your speech, use of technology, facial expressions and body language. They can also help you with techniques for breathing.

Clinical guidelines say that people with Parkinson's should have access to a speech and language therapist if they need it. We recommend that you speak to one as soon as you can after you've been diagnosed.

This is important because you may not notice small changes to your speech and communication. But a speech and language therapist can monitor any issues or symptoms you have and help you manage them.

Your first speech and language therapy appointment is likely to involve an assessment. This will give your therapist an idea of what treatment you need. The therapy and the number of sessions you have will depend on your individual needs, preferences, personal goals and the resources available in your area.

It may be helpful to have regular check-ups with your speech and language therapist. This will allow them to monitor any changes with your speech or communication issues and recommend specific exercises or programmes to help.

Family members or friends can go to sessions with you to get advice. They can also help you communicate with the therapist during your sessions.

Clinical guidelines suggest that your healthcare team considers recommending equipment to help you communicate if you need it.

Speech and language therapists can recommend equipment or apps to help you communicate (see page 21). This might include devices such as:

They can look at your speech, use of technology, facial expressions and body language. They can also help you with techniques for breathing.

- voice amplifiers, to make your voice louder
- alphabet boards or charts which let you spell out what you'd like to say.

It may be possible for your NHS speech and language therapy service to give you equipment they have recommended, so you will not have to pay for it. But this might not be available in every area of the UK.

In some areas, it might be possible to borrow equipment from your speech and language therapy service, so you can try it before deciding if it is right for you longer term.

Types of speech and language therapy

There is no standard type of speech and language therapy across the NHS. The type of support you receive will depend on your symptoms and what would help you most. Your therapy should be designed to help you achieve your own communication goals, in the areas that matter most to you.

Types of speech and language therapy you may receive include:

- attention to effort therapy. Your speech and language therapist will ask you to pay close attention to the effort you make when you're speaking. This can help you to speak more slowly and pronounce words more clearly. The Lee Silverman Voice Treatment (see page 12) was developed from attention to effort therapy.
- speech pacing therapy. Pacing therapy encourages you to slow down your speech, which may help you to speak more clearly. Sometimes physical or digital aids called pacing boards are used, so you can count out your words more slowly. Pacing boards sometimes have conversation prompts or sentences to practice pacing your speech.
- expiratory muscle strength therapy (EMST). EMST involves using a breathing device and a set of breathing exercises. EMST may help to strengthen the muscles you use to breathe out. This may help strengthen the muscles you use to swallow and cough, which may help you to communicate. Your speech and language therapist will show how to use the breathing device and create the breathing exercises for you to try.
- Lee Silverman Voice Treatment (LSVT).

Your speech and language therapist can tell you more about each of these options. Depending on availability of a certain therapy in your area, you can decide together which options are best for you.

The Lee Silverman Voice Treatment

The Lee Silverman Voice Treatment is a type of structured speech therapy developed specifically for people with Parkinson's.

The programme helps people to recognise when their voice is too quiet and trains them to speak more loudly. It is an intensive treatment programme with 16 sessions over a month, each lasting up to an hour. There are tasks to complete at home between the sessions too.

Research has shown the Lee Silverman Voice Treatment to be effective for people with Parkinson's and that it can have benefits for your voice that continue after the treatment has finished.

Unfortunately, it isn't available everywhere – check with your speech and language therapist if it's available in your area. It also might not be the most suitable treatment for everyone.

Although research has shown the benefits of Lee Silverman Voice Treatment, the important thing is to get support tailored to you from a speech and language therapist with knowledge of Parkinson's.

Some people with Parkinson's have shared their experience of Lee Silverman Voice Treatment on our online magazine. Read more at: **parkinsons.org.uk/lsvt**

Remember, the support you will be offered will be personal to you. Your speech and language therapy plan will be put together with your goals and needs in mind.

These could include:

- speech or voice exercises tailored to help with your symptoms
- tips to improve your conversations
- devices or apps to assist communication
- group sessions so you can practise communication techniques with others.

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

Other types of therapy that can help

Physiotherapy

A physiotherapist will use physical treatments, including exercise, to help you manage any stiffness in your joints and restore the strength in your muscles. This may help improve your movement and make it easier to control your body language, posture and breathing, which are important for communication.

Your specialist, Parkinson's nurse or GP can refer you for physiotherapy. In some areas, you will be able to self-refer. If you're referred to an NHS service, there may be a waiting list for treatment.

You can also choose to see a physiotherapist privately, which you will need to pay for. The Chartered Society of Physiotherapy can help you find a private physiotherapist (see page 26).

Find out more: see our information on physiotherapy and Parkinson's.

Occupational therapy

An occupational therapist can help you make everyday activities easier. This includes giving you advice to support your handwriting.

You can usually contact an occupational therapist through your:

- GP
- social services or social work department
- health and social care trust in Northern Ireland.

It may be possible for an occupational therapist to visit you at home. NHS services may have a waiting list.

You can also pay for private occupational therapy. To find a private occupational therapist in your area, contact the Royal College of Occupational Therapists (see page 27).

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

Parkinson's medication or surgery for speech and communication problems

Medication

Levodopa could help with your speech problems.

Levodopa is often prescribed for the movement (motor) symptoms of Parkinson's generally, but more research is needed to work out how effective it is at improving speech and communication problems specifically.

People who use levodopa long-term may experience "wearing off". This is when your drugs wear off before you can take the next dose, and your symptoms get worse. This can happen very suddenly - some people compare it to a light switch being turned on and off. As well as your speech, wearing off can affect your body language and make it more difficult to make hand gestures.

Your voice may be loud and easy to understand when you're "on" but quiet and difficult to understand when you're "off". This can be frustrating. If your medication is creating speech and communication problems, speak to your specialist or Parkinson's nurse. They may be able to adjust your dose or suggest a way of taking your medication, such as using a patch on your skin, that might lessen the effects of wearing off. But don't stop taking any prescribed medications without speaking to your doctor first.

Find out more: see our information on Parkinson's drugs and on wearing off/involuntary movements.

Surgery

Deep brain stimulation (DBS) is the main type of surgery used to treat Parkinson's symptoms. It is usually only considered if Parkinson's medication is no longer controlling symptoms well. Research suggests that it generally has no effect on speech and that it may have a negative effect in some cases. However, it may improve any motor symptoms that you have. If you are considering DBS, talk to your specialist to discuss whether it is right for you.

Our information on DBS can also help you understand the benefits and risks of the procedure and consider what questions to ask your specialist.

Find out more: see our information on deep brain stimulation.

Practical tips to help your speech

It's always best to see a speech and language therapist and use any specific strategies they've given you to manage your speech problems.

The general tips below can help promote effective communication:

Getting ready to speak

- Try to relax. Make sure you're sitting or standing comfortably before speaking, with a posture that helps you take in a good breath.
- Take a deep breath before speaking and at the start of each new sentence.
- If you're planning to have a conversation, try to reduce background noise.
- Clear the saliva from your mouth before speaking, if possible.
- You might find it helpful to plan what you might talk about before meeting with people, or keep notes of things of interest that you could bring up in conversation.

Tips for when you're speaking

- Every time you speak, imagine you're speaking (but not shouting) in a big room, to people right at the back. This will help you speak clearly and at the right volume.
- Try to make each word as clear as possible, and speak slowly.
- You may find it useful to practise saying things in a simpler way. For example, try to keep sentences short so you don't get out of breath.
- If you can, have important conversations at a time of day when you have more energy.
- Try to stress the key words in your sentences. This will help your listener to understand what you're talking about.

Getting regular speaking practice

- It's important to stay social, keep doing things you enjoy and speak with other people. This will give you regular opportunities to practise your speech and improve your confidence.

- Keep practising your speech. If you're on your own, don't feel embarrassed to talk out loud to yourself. If you have pets, you could try practising talking to them too.
- Singing can be a good way to exercise your voice and breathing muscles, which may help your speech. Many people with Parkinson's tell us it increases their confidence in their voice, and that it's sociable and fun. There are singing classes all over the UK for people with Parkinson's. Some are run by Parkinson's UK local groups. You can see if there's a local singing class or group in your area at **localsupport.parkinsons.org.uk**

Finally, be open about how others can help you. For example it might help you to meet in a quiet space, or if others give you more time to talk.

Practical tips to help with handwriting

Not being able to write as well as you used to can be frustrating, but there are some things you can do to make it easier:

- Use pens and pencils with a thick or padded cover to help you get a better grip.
- If you have a tremor, a weighted cuff may give you more control. This is a heavy padded strap that you wear around your wrist. Living Made Easy can advise you where to get one (see page 26).
- Use a clipboard or a non-slip mat to stop your paper slipping.
- Write on lined paper, so it's easier to keep your writing straight.
- Take your time to write, so it is not as tiring.
- If your voice is loud and clear you could record voice messages instead of writing things down. Try using your mobile phone or a dictation machine.
- If you need to sign a cheque or document, ask someone else to fill in the details for you, so you just have to add your signature.

Practising your writing can help too. It may help to practise writing bigger letters, or to write in capital letters, if you find that your handwriting is difficult to read.

Alternatives to using a signature

Writing your signature on things like cheques or bill payments can be difficult, but there are ways to get around the problem:

- **Use a credit or debit card template.** This is a plastic guide with a hole where the signature should be. They can help make it easier to sign in the right place. Ask your bank if they can send you one.
- **Change your signature.** Speak to your bank about accepting a simpler signature. For example, you might find it easier to write your first initial and surname, instead of writing your name in full.
- **Use a photo identification card.** Some banks offer credit cards with your photo instead of a signature. In some cases you can also use a passport or driving licence as proof of identification.

- **Use a rubber stamp.** You might find it useful to use a signature stamp. Some banks provide them and you can buy them in most stationery shops. In Scotland rubber stamp signatures are not accepted in all banks, so check before using them.
- **Avoid using cheques for payments.** Use Direct Debit or standing orders to pay regular bills, subscriptions or donations. Many utility companies give a discount for payment by Direct Debit too. Always check whether Direct Debit is the best option for you financially though before you make any changes.
- **Use telephone or internet banking.** Many people manage their finances in this way and it avoids the need for signatures. You can set up internet banking on your computer or download your bank's app to use on your phone.

Our helpline can give you advice on practical tips like these. Call free on **0808 800 0303**.

How technology and apps can help with communication

Computers, tablets, smartphones, the internet and email can be useful ways of staying in touch with people.

- Internet forums are online discussion sites. You can talk to other members by posting messages, and find discussions on topics you're interested in. You can ask other members a question, comment on another member's post, or simply share your experiences on a certain issue. Forums are a great way of meeting people, especially if you don't go out often or live in a remote area. Parkinson's UK's online forum is a space for you to chat to people who know what you're going through. Visit **forum.parkinsons.org.uk**
- Social sites such as Facebook, X (previously called Twitter) and YouTube are good places to start having conversations, get updates on news and find out about local or national events.
- Voice recognition software helps you use your computer without a mouse or keyboard. When you speak into a microphone, it changes your words into text. You can use it to write documents or emails, to search the internet, or to find files. Newer versions of Windows and Apple computers have in-built voice recognition technology. You can buy other software, such as Dragon, online. Usually the software needs to be "trained" to recognise your voice and accent, which can take time to get right.

There are apps for your phone or tablet that can remind you to talk louder and more slowly. Your speech and language therapist may also recommend apps that can record your sentences for you, which you can play out loud later if you need to.

Find out more: see our information about apps and devices for people with Parkinson's at **parkinsons.org.uk/tech**

Not everyone feels confident using electronic devices or getting online. We have a list of organisations which can help you use tablets and smartphones, set up assistive technology like voice recognition and learn key digital skills at: **parkinsons.org.uk/stay-online**. If you're not sure how to do something, you could ask a family member or friend to help you get online or set up assistive technology on your devices.

Our helpline can give you more information and support about technology too. Call free on **0808 800 0303**.

The Parkinson's UK Tech Guide

There are a lot of devices and apps available that claim to be useful for people with Parkinson's. Some are free, or prescribed on the NHS, and some you have to buy yourself. Deciding if a particular device or app is right for you isn't always easy.

Our Parkinson's UK Tech Guide is a reliable source of information about devices and apps for people with Parkinson's.

Each product in the Tech Guide is tested for several weeks by people living with Parkinson's, who give their honest reviews. These reviews should help people with Parkinson's and their families, friends and carers to decide whether an app or device could improve their quality of life, before spending money or time on it.

You can find the Tech Guide on our website at **techguide.parkinsons.org.uk**

You can request a free printed copy at **techguide.parkinsons.org.uk** - fill in the form in the "Get the newsletter" section of the webpage and select print edition.

You can also sign up for email updates with new product reviews.

Conversation tips to share with others

The following tips are for people around you - you might want to show the next page of this information to them, or use it as a starting point for a conversation about how to support you.

Tips like these could also be helpful for other people in your life who you see regularly, like your GP, or your hairdresser or barber. If you're working, it may help to share them with your employer or manager, as well as your colleagues, to help everyone to communicate better at work.

If a family member, friend or colleague of yours has Parkinson's, there are things you can do to reduce their frustration and make conversations easier.

It's important to ask your family member, friend or colleague how they like to be helped in conversation. Some people like to be helped if they can't find a word or finish their sentence, but others will prefer to do this themselves. Everyone is different and asking people directly about their preferences is the best way to help them.

If you know the person with Parkinson's well enough, you could encourage them to use any strategies recommended to them by their speech and language therapist.

The tips below may help too.

Thinking about where and when to have conversations

- Plan to have difficult or important conversations in a quieter place with fewer distractions.
- Avoid speaking above noise, such as a TV or radio. Try to be in the same room when you are talking with each other.
- Plan in a bit more time for your conversation when possible, so you and the person with Parkinson's don't feel rushed.
- Try to have difficult or important conversations when your friend, family member or colleague with Parkinson's is feeling good and not during an "off" period.
- Make sure you and the person with Parkinson's can see and hear each other. Facing someone with Parkinson's can be particularly important to help them communicate clearly and understand you. You don't need to shout.

Listening to your family member, friend or colleague

- Be patient. Give the person the opportunity to get involved in a conversation, but don't pressure them to speak if they don't want to. They may need extra time to respond, so try not to interrupt or walk away.
- Take time for the person to respond to a question. Try to wait without asking lots more questions.
- Be reassuring and help them to relax, if you can see they're stressed.

Replying during a conversation

- Ask them to repeat themselves more loudly and slowly, if you don't understand what they say. If it's just a key word you've missed, ask them to repeat that word. It's helpful to let the person know what you have understood, so that effort isn't wasted repeating a long sentence unnecessarily.
- Avoid pretending that you've understood if you haven't. If you think you know roughly what the other person is talking about, you could say "So you're talking about … is that right?" and then try to clarify what has been said. Try not to talk for the person or finish their sentences, unless it's absolutely necessary or you have agreed this with them.
- Don't accidentally ignore the person by asking someone to speak for them.
- Suggest that the person could write a word or phrase that might help to get their point across if you haven't understood something they've said.

- Don't forget that their facial expressions might not match how they're feeling, due to "masking" (see page 6). Facial masking can make face movements slower and stiffer than before and limit the number of facial expressions a person with Parkinson's can have. If you're not sure how your friend, family member or colleague feels about what you've said, don't be afraid to ask.

More information and support

Useful contacts

AbilityNet

A charity that can help you adapt and adjust your computer to make it easier to use.

0800 269 545 or **01926 312 847**
enquiries@abilitynet.org.uk
www.abilitynet.org.uk

Living Made Easy (previously called the Disabled Living Foundation)

A charity providing free and impartial information and advice on aids and equipment such as products to help with handwriting.

lme-enquiries@shaw-trust.org.uk
www.livingmadeeasy.org.uk

The Chartered Society of Physiotherapy

For details of qualified physiotherapists in your area.

020 7306 6666
www.csp.org.uk

The Royal College of Occupational Therapists

Has more information about how an occupational therapist can help, and how to find one near you.

020 3141 4600
www.rcot.co.uk

The Royal College of Speech and Language Therapists

Has more information about how a speech and language therapist can help, and how to find one near you.

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

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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Thanks also to our information review group and other 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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INFOB1046
Speech and communication problems

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

Trusted Information Creator
Patient Information Forum

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