

# Communication and Parkinson's

**P**eople with Parkinson's may find that they have problems with different kinds of speech and communication, including facial expressions, writing and finding the right words to express their views.

**This information sheet looks at what difficulties you may experience, why they happen and what can be done to help. It also includes information and tips for family and friends.**

## Speech

If you have Parkinson's, you may find you have some problems with your speech. For example, your speech may be slurred, your voice hoarse, unsteady, or quieter than it used to be. You may find it hard to control how quickly you speak or you may find it difficult to start talking.

People with Parkinson's may find their voice sounds monotonous. These problems can make everyday activities, such as talking to friends or using the phone, difficult. Taking your turn to speak, following fast-changing topics or interrupting conversations may be hard. You may find it difficult getting your thoughts together quickly enough to follow a fast conversation, so you end up just giving minimal responses. Taking the lead in conversations may also be challenging.

## What can help?

### Speech and language therapy

Speech and language therapists are healthcare professionals who can help with all aspects of communication, from facial expression and body language to speech and communication aids.

Guidelines on Parkinson's for the NHS in England, Scotland and Wales recommend that speech and language therapy should be available to everyone

“At a meeting I noticed that when I spoke, the people around my table all leaned forward. They weren't hanging on my every word, it was my voice losing its strength. I often have to make two attempts to get a reasonable sound out.”

### **Caroline, diagnosed in 2003**

living with Parkinson's. We recommend you try to see a speech and language therapist as early as you can after you've been diagnosed. Even if you aren't experiencing any specific problems, a speech and language therapist can give you some useful information about possible problems that may arise, how to spot them and what can be done about them before they have any negative effects.

The speech and language therapist may also spot any subtle changes that you may not be aware of. This will help you manage the problem before it becomes difficult.

You may find it helpful to have regular check-ups. This allows the speech and language therapist to monitor whether there are any changes with your speech or getting your message across. If there are, they can recommend specific exercises or programmes to help you. There are a few tips (see Tips to help your speech) that may be helpful, but they are no substitute for getting specialist assessment and advice. If your speech does become really difficult, speech and language therapists have the expertise to support you or to advise on alternative ways of communicating using various communication aids.

In most areas, you will be able to get in touch with a speech and language therapist through the speech and language therapy department at your local hospital, local community health services or social services or social work department. Referrals can also be made through your GP, specialist or Parkinson's nurse.

You can also contact your Parkinson's UK local adviser to find out details of speech and language therapy services in your area. Contact details for your local adviser can be found on our website at [parkinsons.org.uk/localadvisers](http://parkinsons.org.uk/localadvisers) or by calling our helpline on **0808 800 0303**.

**Find out more:** see our information sheet [Speech and language therapy and Parkinson's](#).

### **Medication**

For some people with Parkinson's, medication for their condition, such as levodopa, may help improve the volume and clarity of their speech.

However, there is a potential side effect of levodopa and some other Parkinson's medication, known as the 'on/off' syndrome. 'On' means your drugs are working and symptoms are well controlled and 'off' is when there is no response to medication and your symptoms become much more of a problem. As well as affecting your movement, the 'on/off' syndrome can affect your speech and body language. For instance, your voice may be louder and easier to understand when you're 'on', but be quiet and difficult to understand when you're 'off'. This can be frustrating, but there are ways to adjust your life around 'on/off' periods.

For many people, medication has no effect on everyday speech, so it's important to get advice from a speech and language therapist on other ways of making your speech clearer.

**Find out more:** see our information sheet [Wearing off and involuntary movements \(dyskinesia\)](#).

### **Tips to help your speech**

You can try to train your voice by following a few simple rules. This can take a bit of work at first, but practice will help.

- Difficulty when speaking can be frustrating. Make sure you're sitting or standing easily and comfortably. Stay relaxed so you can put effort into your speech.
- Try to imagine you are speaking (not shouting) in a big room and you are speaking to people right at the back. This will help you to speak clearly and loudly. Many people with Parkinson's don't realise they are speaking quietly. So if you think you're talking at the very top of your voice, you're probably speaking 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. Make sure you stress key words.
- Don't feel embarrassed about your speech. It's important to keep speaking and stay sociable. People will still value your views. Hobbies such as singing might help as they are fun, provide social contact and general exercise for your voice and breathing muscles.

### Computers and the internet

Sometimes, instead of speaking, you may find it easier to use other methods of communication. For example, if you have access to a computer, using the internet and email can be a useful way to stay in touch. Some people find electronic typewriters and word processors can also be useful.

There are computer programs that record your voice and type what you speak. They allow you to send a typed conversation by email or the internet. However, it may take a while for the program to 'learn' your accent and may not work so well if your voice has become very quiet or your speech is unclear. An occupational therapist can advise you on ways to customise your computer so it's easier for you to use.

**Find out more:** see our information sheets *Occupational therapy and Parkinson's* and *Using computers and the internet*.

### Tips for family and friends

Difficulties with communication can be upsetting and frustrating for the person with Parkinson's and for those around them. But there are some basic things family and friends can do, to make life a little bit easier.

These tips may not work for everyone, so it's important to consider the best thing to do in your situation:

- Be patient. Give the person affected the opportunity to get into a conversation and time to say their piece. They may need extra time to respond, so try not to interrupt or walk away.
- Give them the opportunity to talk and encourage them to join in the conversation if it's appropriate, but don't put pressure on them to speak.

- Talk normally, as you would with anyone else and don't shout.
- Listen carefully. Their speech may be unclear or their voice may be quiet, but the message is there.
- Make sure they can see and hear you and you can see and hear them.
- Try to avoid speaking above noise, such as a TV or radio. Try not to be too far away, for example, in another room, when talking.
- Be reassuring and help them to relax if you can see they are stressed. For example, they may like it if a family member or friend holds their hand if they are having trouble speaking.
- Vary the tone of your voice and relax. Stress can be heard in your voice.
- If you don't understand what they say, ask them to repeat it louder and slower. If it's just a key word you have missed ask them to repeat that word. Try not to pretend you have understood if you haven't.
- Try not to talk for the person, unless it's absolutely necessary.
- Avoid finishing their sentences.
- Don't accidentally ignore the person affected by asking someone to speak for them.

A speech and language therapist will be able to give you more advice on what you can do to make communication easier.

**Find out more:** see our information sheet *Speech and language therapy and Parkinson's*.

### Facial expressions and body language

We pick up a lot of information from a speaker's facial expression and their general body language and posture. These may all be affected by Parkinson's. Listeners may misinterpret your mood or your feelings about a topic because of your reduced facial expression or your altered hand gestures and body posture. They may miss signals you are trying to give to show that you wish to join or stay in a conversation.

For some people with Parkinson's these issues are present all the time. For others, it may be just at certain times in their medication cycle or if they have a poor response to their drugs.

Some therapies for Parkinson's may include working on these aspects of communication – increasing facial expression, using body language to signal you have a point to make in a conversation and making sure your hand and arm gestures match the mood you wish to convey.

**Find out more:** see our information sheet *Wearing off and involuntary movements (dyskinesia)*.

## What can help?

### Speech and language therapy

A speech and language therapist can help with your speech, voice, facial expressions and communication in general.

**Find out more:** see our information sheet *Speech and language therapy and Parkinson's*.

### Physiotherapy

A physiotherapist will use physical treatments, including exercise, to help manage any stiffness in your joints and restore the strength in your muscles. This may help improve your ability to move and make it easier to control your body language.

**Find out more:** see our information sheet *Physiotherapy and Parkinson's*.

### Parkinson's alert card

This is a small plastic card you can carry with you to tell people you have Parkinson's. It's useful in case of emergencies, or when you're having problems with movement or communication. You can order an alert card by calling **0300 123 3689** or by emailing **resources@parkinsons.org.uk**.

## Writing

You may experience problems with your handwriting. It may have become spidery or difficult to read. You may also find your writing starts off normally, but becomes smaller and smaller. This is known as micrographia. It can be caused by tremor, lack of co-ordination, stiffness, a difficulty controlling small movements and difficulty putting enough 'power' into movements.

## What can help?

### Occupational therapy

An occupational therapist will be able to give you advice about handwriting and suggest ways of overcoming particular problems. They can be contacted directly or a referral can be made by your GP, specialist, Parkinson's nurse, local community health services, social services or social work department.

**Find out more:** see our information sheet *Occupational therapy and Parkinson's*.

### Practical tips

Difficulties in writing can be frustrating, but there are some things you can do to make it a bit easier:

- Use pens and pencils with a thick or padded barrel to help you get a better grip.
- If you have a tremor, a weighted cuff may give you more control. The Disabled Living Foundation can advise you on where to get one. The contact details are on page 5.
- Use a clipboard or a non-slip mat to stop the paper slipping and write on lined paper.
- It's important to take your time. After writing a line, try to stop and relax.
- If your voice is loud and your speech clear enough, you could try using a dictation machine or tape recorder to record voice messages instead of writing things down. Some mobile phones are also able to record and play back speech.
- If you need to sign a cheque or document, you could ask someone else to fill in the details for you, so you just have to add your signature.

## Alternatives to using a signature

Writing your signature on things such as cheques or bill payments can be difficult if you have problems writing, but there are some things you can do or use to tackle the problem.

### 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. Talk to your bank about whether they provide these.

“My handwriting used to be fine, but since my diagnosis it has become almost impossible to read. I use a computer now because it allows me to continue communicating.”

**Ali, diagnosed in 2005**

### Changing 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.

### Identification cards

Some banks offer credit cards that can show your photo next to the signature. You might also use a passport or driving licence as proof of identification.

### Rubber stamps

You might find it useful to use a signature stamp. Some banks provide them and you can buy them in most stationery shops. Please note that in Scotland rubber stamp signatures are not always accepted in all banks, so do check before using them.

### Avoid using cheques for payments

Try to use Direct Debit or standing orders to pay regular bills, subscriptions or regular donations. Many utility companies give a discount for payment by Direct Debit, so it may be useful to make enquiries.

### Chip and PIN cards

Although the main purpose of the Chip and PIN system is to cut credit card fraud, it may also help people who have trouble writing their signatures.

### Telephone or internet banking

Many people manage their finances in this way and it avoids the need for signatures.

## More information and support

### AbilityNet

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

Call (from home) **0800 269 545**

Call (from work) **01926 312 847**

Textphone **01926 312 847**

**enquiries@abilitynet.org.uk**

**www.abilitynet.org.uk**

### Disabled Living Foundation

Provides information and advice on aids and equipment to help with handwriting.

**0845 130 9177** (Mon-Fri, 10am-4pm)

Textphone **020 7432 8009**

**centre@dlf.org.uk**

**www.dlf.org.uk**

### Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at **parkinsons.org.uk/nurses**

## Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**.

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can put you in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

We have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you, visit **parkinsons.org.uk/selfmanagement**

Our website **parkinsons.org.uk** has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at **parkinsons.org.uk/localtoyou**

Visit **parkinsons.org.uk/forum** to chat to other people with similar experiences on our online discussion forum.



## Thank you

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

**Professor Nick Miller, Lecturer/Honorary Speech and Language Therapist, Institute of Health and Society, Speech and Language Sciences, Newcastle University.**

**Dr Richard Grunewald, Consultant Neurologist, Division of Clinical Neurosciences, Royal Hallamshire Hospital, Sheffield.**

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

## 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 Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

## Our information

All of our most up-to-date information is available at **parkinsons.org.uk/information-support**. If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/ordering-resources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**



## Communication and Parkinson's (FS06/2012)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to **Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**, or email **publications@parkinsons.org.uk**. Thank you!

### 1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in   I care for someone with Parkinson's  
 I have a friend or family member with Parkinson's  I'm a professional working with people with Parkinson's  
 Other (please specify)

### 2. Where did you get this information from?

- GP  Specialist  Parkinson's nurse  Parkinson's UK local group  Parkinson's UK local adviser  
 Ordered directly from us  Call to the helpline  
 Other (please specify)

### 3. Has it answered all your questions?

- Yes, completely  Yes, mostly  Not sure  Partly  Not at all

### 4. How easy was it to understand?

- Very easy  Easy  Not sure  Quite difficult  Very difficult

We're the Parkinson's charity that drives better care, treatments and quality of life.

## Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK  
215 Vauxhall Bridge Road  
London SW1V 1EJ

Free confidential helpline **0808 800 0303**  
(Monday to Friday 9am–7pm, Saturday 10am–2pm).

Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **www.ngts.org.uk**

**hello@parkinsons.org.uk**  
**parkinsons.org.uk**

Order code: PKFS06

Last updated September 2012. We review our information within three years.  
Please check our website for the most up-to-date versions of all our information.

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### 5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

It helped a lot  It helped a little  No change  It didn't help  It made things worse

### 6. What is your ethnic background?\*

Asian or Asian British  Black or Black British  Chinese  Mixed  White British  White other  
 Other (please specify)

\*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

### Want to hear more from us?

I would like a response to my feedback  I would like to be a member of Parkinson's UK  
 I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you?  Email  Post  Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at [parkinsons.org.uk/termsandconditions](http://parkinsons.org.uk/termsandconditions)