PARKINSON'S UK
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Talking to people about Parkinson's

If you have Parkinson's, you may be thinking about the best way to talk to others about your condition, whether it's those closest to you or people you've just met.

This information sheet looks at telling people you have Parkinson's, including when you may want to raise the subject, ways to do it and how to handle people's reactions.

Preparing to talk to people about Parkinson's

You may be someone who is naturally open and finds it quite easy to talk about Parkinson's when you need to. Or you may be more private, or find it hard to come up with the right words.

Even if you are an upfront type of person, it may be daunting to explain Parkinson's to people you meet in everyday situations.

Thinking about these issues and being prepared will make it easier each time you want to talk to someone about your condition.

Talking with children and young people about Parkinson's

This information sheet looks at discussing Parkinson's with adults. If you want to bring up the subject with children or young people, you may want to read some of our other resources:

- *Talking to children about Parkinson's* information sheet
- *My Dad has Parkinson's, My Mum has Parkinson's, My Grandad has Parkinson's* and *My Gran has Parkinson's* – illustrated books for children aged three to seven
- *Parkinson's in your life: a guide for teenagers* – online information for children aged 13 to 19 **parkinsons.org.uk/guideforteenagers**

Why should I tell people about Parkinson’s?

It’s up to you to decide whether to tell people you meet that you have Parkinson’s. You may never want to tell people you have the condition. You don’t owe anyone an explanation and you may want to keep this information private.

There may also be times when you want an escape from thinking about Parkinson’s.

If you’ve just been diagnosed, you may need some time to absorb the information yourself before you talk to others. But choosing not to tell other people may make you feel isolated. You may find that opening up to people can be a positive thing and can widen your support network.

> “My boss did notice something was amiss a couple of weeks after I was diagnosed. I chose to tell him – there seemed no point in lying, though I did ask him not to mention it to anyone else.”
>
> **Semele (forum user)**

If your symptoms are quite noticeable, you may find it easier to tell people about your condition.

At work

You may want to feel you can go about your business without feeling defined by other people’s ideas about Parkinson’s. For some people, this can be important at work.

In most cases you don’t have to tell your employer you have Parkinson’s, but you may feel it is helpful to do so. This is because your employer has a legal duty to give you ‘reasonable’ support and make ‘reasonable’ changes where necessary. This can include adapting your work space or giving you modified equipment.

You do have to tell your employer about your condition if there are health and safety issues relating to parts of your work – for example if your job needs lots of physical effort or quick reactions. You need to consider any risk to your own safety, as well as to other people around you.

You may want to mention you have Parkinson’s when you need people to understand how the condition affects you. You may need to take more frequent breaks than other people at a meeting, for example.

There may be times when you need to sit down, or get up and walk around. You may feel you need to tell people that you may have an ‘off’ episode, or explain why they will see you taking medication.

Find out more: see our booklet *Employment and Parkinson’s*.

Legal requirements

You must tell the Driver and Vehicle Licensing Agency (DVLA) in England, Scotland and Wales, or the Driver and Vehicle Agency (DVA) in Northern Ireland about your diagnosis. You will also need to inform your insurance company.

Find out more: see our booklet *Driving and Parkinson’s*.

Other unavoidable situations

There may be other times when it is crucial to tell people you have Parkinson’s. For example, our helpline has received calls from people who have had to explain their symptoms or medication as they’ve passed through airport security. In such situations, it can make all the difference to have a frank explanation ready to hand.

We have two resources that may help you in situations like this.

- Our Parkinson's medication card allows you to write down all the medications you take and contact details for healthcare professionals.
- Our credit-card sized Parkinson's alert card is something to show people when you want them to know you have Parkinson's, but don't want to have to explain yourself. You can carry it in case of emergencies or when you're having movement or communication problems.

You can order these using the contact details on page 9. You may also want to carry a letter from your Parkinson's specialist, which confirms your diagnosis.

When should I tell people I have Parkinson's?

Opening up to someone else about Parkinson's is a very personal decision. Not everyone needs to know, and not everyone needs to know straight away, so wait until you are comfortable.

> "The worst people to tell are the ones who see me doing OK one day, then see me struggling the next day. I get comments, such as 'He is putting it on' and 'He was OK before'. I do not bother to tell them about having Parkinson's, but my wife takes offence if she hears people making rude comments or assuming I am drunk in the middle of the day. She tells them to mind their own business."
>
> **Pete, diagnosed in 2000**

Once you've decided to tell someone about Parkinson's, try to choose a moment when they are not preoccupied or don't have a lot of time. While family celebrations may be a good time to talk to a number of people at once, it may not be the best place to talk to people for the first time about Parkinson's.

Sometimes you may not be sure if you should mention your condition to people. But if you've spent more than five or 10 minutes feeling uncomfortable about whether to say anything about Parkinson's, and the thought is very distracting, it may be time to say something.

How do I tell people I have Parkinson's?

Talking about Parkinson's will get easier with practice. Once you've told a few people you're likely to feel more confident. You may find it easier to talk about your feelings and experiences with those closest to you first.

Being prepared can help you to be more positive when you're talking with others, which is more likely to result in a supportive response. You may also find it useful to think in advance of a good way to start the conversation.

Whoever you're talking with may have their own ideas about what Parkinson's is and who it affects. When talking about your diagnosis, it may be helpful to explain the symptoms and how quickly the condition develops are different for each person with Parkinson's. You are the expert on Parkinson's, so talk to the person about how it affects you.

You may find it useful to imagine you are meeting an old friend you haven't seen for 10 years. What are the things they will notice about you? This can help you explain the visible ways that Parkinson's affects you.

In some situations you may want to keep a check on your emotions, but there may be times when it feels right to show your feelings. Your emotions may also change quickly – for example, you may find laughter quite quickly turns into tears without much warning.

It may help you to have some leaflets with you. You can use these to help you explain, or you can leave them with the person to read later.

You may find the following useful:

- *A quick introduction to Parkinson's* leaflet
- *Parkinson's and you* booklet (this is an introductory guide for people with Parkinson's who are newly diagnosed. It is useful in answering some common questions about the condition)

See page 9 for details of how to order these resources.

> "I am much more comfortable telling people I have Parkinson's in writing than verbally."
>
> **Sheryll, diagnosed in 2012**

How do I tell people without becoming the centre of attention?

If you'd like someone to know that you have Parkinson's, there are different ways to do this. You may want to think about this in advance if you're worried people may react by offering help you do not need.

For example, if you're joining a new group or class and want everyone to be aware that you have Parkinson's, talk to the leader beforehand. Decide between you how to inform the group. You may want the leader to do it, or perhaps want to explain yourself. You may prefer to talk to people individually.

If you have a group of friends, you may want to tell them together or one at a time. You may ask people not to tell others, or you may be happy for them to pass the information on.

Let your friends know how you want to share the information with others, and whether you're happy for them to talk to you about Parkinson's directly. Even if you don't want this at first, as time passes and your needs change, you may want to raise the subject again. This will be easier if you've occasionally mentioned your Parkinson's in conversation, showing your friends that it is OK to talk about it too.

Talking about Parkinson's to people you meet can be one of the challenges of living with the condition. Finding ways to do this that work for you will ensure it doesn't become a barrier between you and what you want to do.

How will people react?

You may be unsure about how other people will respond when you tell them you have Parkinson's. There can be lots of different reactions. A person may get very upset or angry, or feel guilty they didn't notice your symptoms earlier. They may worry that Parkinson's is a life-threatening condition and what that means for the future.

If you're in control of the conversation and try to approach it with a positive attitude, you'll be in a better position to manage other people's reactions.

To do this:

- choose when to tell people
- decide what you want to say
- try to anticipate what they'll want to know. This may include questions such as "Is it hereditary?", "What causes it?", "What effect does it have on you?", "Is there anything I/we can do to help?" or "Can you still work?"

How may Parkinson's affect communication?

People with Parkinson's may find they have problems with communication, including speech, facial expressions and writing. This can make it harder to express yourself.

If you have stiff facial muscles, which may give you a 'mask-like' expression, people can sometimes mistake this for a lack of interest, boredom or depression. This can be difficult when you're trying to look friendly when meeting new people.

You may have problems getting words out, or your voice may be quieter than it used to be. These problems may be more noticeable if you are anxious or worried. A speech and language therapist may be able to help with this.

Try not to let communication issues be a barrier in talking to people about your condition. In fact, if you experience these symptoms, you may be able to use them to explain how Parkinson's affects you. You may find this helps people understand the condition better and avoid any misunderstandings or miscommunication in the future.

> "People react differently to being told. Some ask how it affects me, others are shocked and don't know what to say. As I'm in my thirties, answers often include comments about having Parkinson's so young. I usually reply with a positive statement like, 'Yes, I've had Parkinson's for 10 years now, but it doesn't stop me doing my job effectively, or enjoying life!'"

Nicola, diagnosed in 2005

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

Tips for talking with people about Parkinson's

- Talk it over with someone you're close to first, so you're prepared. They may be able to help you talk to others.
- Try to stay in control of when, where and how you want to tell people. But be prepared for the possibility of an unavoidable situation where you need to tell someone.
- Whether it's you or someone else talking about Parkinson's on your behalf, be very clear about what you do and don't want other people to do. Say what they need to be aware of and how they should treat you.
- You may choose to take a friend or relative with you for support when you are telling someone about your diagnosis. Be clear about their role beforehand to avoid them talking over you or on your behalf. Remember you are the expert on how Parkinson's affects you.
- If you need time to respond to a question during a conversation, take as long as is necessary. Don't feel pressurised to respond quickly.
- Give clear examples of any practical assistance that is or isn't helpful. Misplaced helpfulness often stems from nervousness. Knowing what to expect, and understanding what you actually need, can help to put you and other people at ease.
- You may want to direct people to our website if they would like to learn more about the condition, its symptoms and how it can affect daily life – **parkinsons.org.uk**
- You can meet others who have been through similar experiences at your local Parkinson's UK group or on our online forum at **parkinsons.org.uk/forum**. Talking with people going through the same thing can be a great source of support. It can help you to get your own thoughts in order, which may make it easier to talk to others. They may be able to give you advice on how they've told people about Parkinson's.

- Our information and support workers can help you in talking with people about Parkinson's. They can also see carers or family members on their own. To find details of your local informationa and support worker, visit **parkinsons.org.uk/localtoyou** or call our helpline.
- You may find it easier to use printed information to help you talk about Parkinson's and life with the condition – or to explain things further if you don't want to. We produce a range of booklets, information sheets and DVDs that can be ordered for free or downloaded from our website at **parkinsons.org.uk/publications**

More information and support

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:

Vicky Travers, Parkinson's Disease Nurse Specialist, Royal Lancaster Infirmary and Westmorland General Hospital

Anne Eaves, Information and Support Worker, Parkinson's UK

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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/informationsupport**
If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/orderingresources** 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**

Talking to people about Parkinson's (FS88/2014)

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

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**

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

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

Parkinson's UK
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

Helplines Partnership

Last updated May 2014. We review our information within three years.
Please check our website for the most up-to-date versions of all our information.
PKFS88

Health & care information you can trust

The Information Standard Certified Member