

Talking to children about Parkinson's

If you have Parkinson's and have children or grandchildren, you may be thinking about how to talk to them about your condition. Maybe you're worried about how to start the conversation or how they'll react. You may also be concerned about how your Parkinson's will affect family life.

This information will help you to think through these questions and prepare for talking to the children in your family about your condition.

Should I tell the children in my family about my Parkinson's?

Yes, when you're ready. It's natural to want to protect children from knowing about serious health issues in case it scares, upsets or worries them. But keeping it from them isn't the answer. This is because:

- Children are very aware of what's happening around them. Even if you try to hide your condition, they're likely to pick up that something is 'wrong' – from snippets of conversations or from changes in the mood or atmosphere at home.
- Not knowing what's wrong may mean that children come up with their own theories about what's happening – and these may be worse than the reality.
- As Parkinson's progresses it will become more and more difficult to hide your symptoms and your children may find out from someone else. It's much better that they hear about it from you. If not, they may feel resentful or worried about why you didn't tell them.
- Trying to keep Parkinson's hidden from your children may be difficult and exhausting for you.
- You may feel relieved to tell your children. Speaking about your condition to your family may help to 'normalise' your situation and make it less frightening for everyone.

Who should tell the children?

If you're a parent with Parkinson's, it would be best if your children hear the news from you and your partner (if you have one). Be aware, though, that how you discuss it will be influenced by the way you feel about your Parkinson's – you may need support with your diagnosis before you're ready to tell them or you may need other family members around at the time.

If you're a grandparent with Parkinson's, you may wish to tell your grandchildren yourself or tell them with their parents around too. Alternatively, you may think it's best for the children's parents to break the news, and you speak to them afterwards.

When is a good time to tell the children?

There's usually no such thing as the perfect time, but it's helpful to think ahead about when and where could be a good opportunity.

Try to tell your children as soon after your diagnosis as you feel you can. You don't have to make it a big occasion, but make sure you're in a calm environment, free from distractions. Give yourself and your children the time and space you need. Leading up to the initial conversation you may feel worried about how to do it, but often the thought is worse than the actual event.

Try not to think of talking to your children about your Parkinson's as a one-off event. Think about it as an ongoing conversation – there's no rush to tell them everything in one go.

As your Parkinson's progresses, and as your child gets older, you'll need to talk about different aspects of your condition. Starting the conversation as openly as possible will help children feel that it's OK to talk about your Parkinson's as time goes on.

What should I tell them?

You can tell children about Parkinson's at any age, but what you tell them will depend on what they are able to understand. The younger your child, the simpler the information needs to be. But even for older children, it will be helpful to keep the information simple to start with.

For younger children (under the age of around seven), try to avoid medical terms. Even with older children, try to describe new words or ideas in an accessible way without using medical language. Try to use the same words or kinds of words your child uses when they ask questions or talk about their feelings about your condition.

Take the lead from your children about how much to say – they may not be able to take everything in at once. Afterwards, check with them what they've heard and make sure they've not misunderstood anything.

How much the condition currently affects you is probably a good place to start. You might ask if they have noticed any changes in you. Or you might start by saying something like, "Mummy has something called Parkinson's, which is why her arm is sometimes shaky." Make sure children understand that Parkinson's affects people differently, and it may affect you differently to other people they know or have seen in the media with the condition.

Be specific and clear in describing your condition. Be honest in what you tell them – children may feel mistrustful if they discover later on that you haven't told them the truth. Also, don't assume anything. For example, you may know that Parkinson's is not contagious, but do they?

Older children may want more information – and may even have questions you don't know the answers to. That's OK. Remember you don't have to discuss everything in one go. Just try to get the message across that it's OK to carry on talking about Parkinson's.

Encourage your child to ask questions – not just when you speak to them, but at any time. This way they can really join in the conversation and feel listened to. They'll also feel more involved and able to share their worries.

Whatever the age of the children in your family, don't forget to remind them that although you may not be able to do everything you used to do, you still love them just the same.

Common questions children have

- How did you get Parkinson's?
- Why do you have Parkinson's?
- Will I get Parkinson's too?
- Will it go away?
- Can the doctors help you?
- Does it hurt?
- Are you going to die?
- Is it a secret?
- Will you still be able to take me to football/music/drama/ballet/etc?

Are there any resources that may help me?

Parkinson's UK has resources to help you explain Parkinson's to your family. For children aged three to seven, we have a range of books available called *My grandad has Parkinson's*, *My gran has Parkinson's*, *My mum has Parkinson's* and *My dad has Parkinson's*. Older children could also read these alone.

We also have online information for teenagers that explains Parkinson's in an accessible way and offers advice on how to handle difficult emotions.

You can find this at parkinsons.org.uk/teenagers.

We have information for young carers too, at parkinsons.org.uk/youngcarers.

You may also find our *Easy read information about Parkinson's* booklet useful. It explains Parkinson's simply by using easy language and pictures.

Don't forget you can call our free, confidential helpline on **0800 800 0303** at any time to discuss any worries you have about Parkinson's, including talking to your children or grandchildren. Your Parkinson's local adviser will also be able to offer emotional support and advice – call the helpline or visit parkinsons.org.uk/localadvisers to find out how to contact them.

Find out more: see 'Our information' for details of how to order our resources.

How might my children react?

Being told that a loved one has Parkinson's can affect a child's emotions, behaviour and even their performance at school. Every child will react differently, even those in the same family.

Try to prepare yourself for the following emotions:

- worry
- anger
- embarrassment
- frustration
- resentment
- relief
- fear
- sadness
- grief

Let your children know that it's normal for them to feel any of these emotions – and make sure they know it's OK to talk about them.

You should also look out for children trying to hide their feelings. They may do this because they think their reaction might worry you. If you think they're hiding their feelings, carry on talking and encourage your child to talk to others too. You may want to tell other adults who your child has regular contact with, such as family members, family friends, teachers or childminders, about your Parkinson's, so that they can keep an eye on your child and be another source of support. But only if you're ready to talk openly about your Parkinson's.

Children may also want to do something positive to help you. Perhaps you could start a new activity together, such as walking or another type of exercise.

Although it can be hard for them to cope with Parkinson's, children are incredibly adaptable and, with the right support, they may surprise you with how well they can adjust. It may be one of those things in life that helps them become more responsible, independent, patient, mature, open and aware.

Who else can help?

There may come a time when you think your child needs extra help – or they may tell you they're finding things difficult. Although it may be useful for them to speak to another family member, sometimes it can be better to talk to someone not involved in their family life. This may be a friend, a teacher or their GP, for example. If they still seem troubled or depressed, you could arrange for some counselling – for the child alone or with the whole family.

If you would like more help for your child, the first step is to talk to your GP. They should be able to explain the different kinds of help available and refer you to an appropriate service. There are also several organisations for children and young people that offer confidential phone support – see below. Some of these organisations, for example YoungMinds, also have a helpline that parents can ring for advice.

Remember, every family is unique and you'll find your own way of living with Parkinson's. If you have any concerns about talking to your children about Parkinson's, call our helpline on **0808 800 0303** or speak to your Parkinson's local adviser – contact the helpline or visit parkinsons.org.uk/localadvisers to find out how to contact them.

More information and support

Carers Trust

The Carers Trust works to improve support, services and recognition for those caring for a family member or friend, including young carers.

London office 0300 772 9600

Glasgow office 0300 772 7701

Cardiff office 0292 009 0087

info@carers.org

www.carers.org

Carers UK

This organisation provides information, advice and support to carers. They also develop projects and campaigns on behalf of carers and have several young carers projects.

0808 808 7777

advice@carersuk.org

www.carersuk.org

ChildLine

ChildLine is a free 24-hour helpline for children and young people in the UK. Children and young people can call the helpline about any problem at any time – day or night. ChildLine counsellors listen and help them find ways to sort things out.

0800 1111 (24 hours)

www.childline.org.uk

The Children's Society

This charity's young carers initiative raises awareness of young carers' needs, campaigns for policy change, supports schools, and works to see that these young people get the future and support they deserve.

03000 303 7000

www.youngcarer.com

Depression Alliance

This organisation works to relieve and prevent depression by providing information and support services to those affected by it.

info@depressionalliance.org

www.depressionalliance.org

Disability, Pregnancy and Parenthood

This organisation promotes better awareness and support for disabled people during pregnancy and as parents.

info@disabledparent.org.uk

www.disabledparent.org.uk

Family Lives

This organisation offers help and information to all parents and guardians. They also run a freephone helpline for anyone concerned about the children they look after.

0808 800 2222

www.familylives.org.uk

Young Minds

This national charity is committed to improving the mental health of all children and young people. It has a free, confidential helpline which provides information and advice to any adult with concerns about the mental health of a child or young person. It also has several useful publications that help young people, parents and professionals understand when a young person is feeling troubled, and explains where to find help.

0808 802 5544

parents@youngminds.org.uk

www.youngminds.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:

Gillian Carey, Parkinson's nurse

Michelle Hampson, Chartered Psychologist and Registered Educational Psychologist

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**

Talking to children about Parkinson's (PKFS66/2018)

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



Last updated November 2018. We review our information within three years.
Please check our website for the most up-to-date versions of all our information.
PKFS66

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