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. You may be 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 sheet is designed to help you think through these questions and help you prepare for talking to the children in your family about your condition.

Should I tell the children in my family about my condition?

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 the news from your children 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 are 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 develop their own theories about what is 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 – and it’s much better that they hear about it from you. 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 are 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 are ready to tell them or you may need other family members around at the time.

If you are 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 probably no such thing as a ‘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 it’s in a calm environment, free from distractions and 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 on-going conversation – there is 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 Parkinson’s. Starting the conversation as openly as possible will help children feel that it’s OK to talk about your condition 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 approachable 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 have heard so that you can make sure they’ve not misunderstood anything.

As Parkinson’s affects people differently, 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.” 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. 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.

**Parkinson’s UK resources that may help**

Parkinson’s UK has many resources to help you explain Parkinson’s to your family. For younger children aged three to seven, we have a range of books available called *My grandad has Parkinson’s, My mum has Parkinson’s, My dad has Parkinson’s* and *My gran has Parkinson’s*. These could also be read by older children alone.

*Parkinson’s in your life: a guide for teenagers* explains Parkinson’s in an accessible way and offers information on how to handle difficult emotions. There are also sections on our website aimed at young people who know someone with Parkinson’s and for young carers – [parkinsons.org.uk/teenagers](http://parkinsons.org.uk/teenagers) and [parkinsons.org.uk/youngcarers](http://parkinsons.org.uk/youngcarers)

You may also find our *Quick introduction to Parkinson’s* leaflet useful for facts about the condition, and our easy read *Information about Parkinson’s* booklet, which 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 local information and supporter worker will also be able to offer emotional support and advice – call the helpline or visit [parkinsons.org.uk/isw](http://parkinsons.org.uk/isw) to find out how to contact them.

**Find out more**: see page 8 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

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<th>Common questions that children may have</th>
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<tr>
<td>How did you get Parkinson’s?</td>
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<td>Why do you have Parkinson’s?</td>
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<tr>
<td>Will I get Parkinson’s too?</td>
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<td>Will it go away?</td>
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<td>Can the doctors help you?</td>
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<td>Does it hurt?</td>
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<td>Are you going to die?</td>
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<td>Is it a secret?</td>
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<td>Will you still be able to take me to football/music/drama/ballet/etc?</td>
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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 them trying to hide their feelings. Children may do this because they think their reaction might worry you. Even 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 family members, friends and your children’s teachers about your Parkinson’s so that they can keep an eye on them or be another source of support – but only if you’re ready to do so.

Although it can be hard for children to cope with a loved-one’s 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 responsible, independent, patient, mature, open, aware or less self-centred.

Who else can help?
There may be a time when you think your child needs extra help – or they may tell you they are finding things difficult. Although it may be useful for them to speak to another family member, sometimes it can be better for a young person to talk to someone who is not involved in their family life. This may be friends, school teachers or their GP, for example. If they still seem troubled or depressed or if interaction between your family is affected by Parkinson’s, 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 telephone support – see the ‘More information and support’ section below. Some of these organisations, for example Young Minds, have a helpline that parents can ring for help and advice too.

Remember, every family is unique and you will 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 local information and support worker – contact the helpline or visit parkinsons.org.uk/isw to find out how to contact them).

“Shortly after my diagnosis, my daughter and I decided that the best thing to do was for her to explain to her boys, aged nine and 11 at the time, a little about what made Granny’s hand shake and what made it difficult for her to cut up her food sometimes.

She chose her moment with care and explained simply. Her boys listened intently, clearly understanding what she was saying, but asking very few questions at the time. After a short while, they started thinking about the next event in their lives – supper and what they were having. This was clearly more important than a detailed explanation of symptoms, at this stage.

However, they obviously absorbed the information because, since then, they’ve often offered to help me with things they can see I find difficult.”

Su, diagnosed in 2013
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 who is ill, frail, disabled or has mental health or addiction problems.
0844 800 4361
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 (Monday–Friday, 10am–4pm)
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 hour)
www.childline.org.uk

The Children’s Society
This organisation believes that children and young people are shaped by the communities they live in, and by the people who surround them. The organisation concentrates its resources on tackling the root causes of any problems children and young people face.

The society has a young carers initiative that seeks to create a national focus for young carers, their families and people who work to support them across the UK.
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 International
This organisation promotes better awareness and support for disabled people during pregnancy and as parents. They have a quarterly international journal dedicated to disabled parenting and a UK information service.
0800 018 4730
info@dppi.org.uk (Tuesday, Wednesday and Thursday, 10.30am–2.30pm)
www.dppi.org.uk

“When my children were introduced to the idea that grandad had to live with a condition that he would not die from but may perhaps limit certain aspects of his life, they simply took it in their stride. On occasions my five-year-old will shake his hands slightly or walk stiffly, and when questioned about it he says it’s so grandad doesn’t feel left out by being the only one with shaky hands. Dad chuckles at this!”
Joanna, whose dad has Parkinson’s
Disabled Parents Network
The network can put you in touch with other parents in a similar position to you, has a helpline staffed by other disabled parents and publishes a quarterly newsletter.
07817 300 103
information@disabledparentsnetwork.org.uk
www.disabledparentsnetwork.org.uk

Family Lives
This organisation offers help and information to anyone parenting a child (whether they are the parents, grandparents, step or foster parents, other relative or friend). 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 is a national UK charity 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 feels troubled and 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 also put you in touch with one of our local information and support workers, 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 spent ages thinking through how we would talk to the children about their dad’s Parkinson’s, what difficult questions they might ask and when would be the ‘best’ time to tell them. In the end, it happened quite naturally when their dad was taking a while to put his shoes on. It seemed like a good time to tell them about the reasons for his slowness. They seemed to take it completely in their stride and over the next few days more questions came out.””

Karen, whose husband has Parkinson’s
We also 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/localtou

You can also visit parkinsons.org.uk/forum to speak with other people in a similar situation on our online discussion forum.
Thank you
Thank you very much to everyone who contributed to or reviewed this information sheet:

Carolyn Edwards, Clinical Psychologist
Michelle Hampson, Educational Psychologist
Thanks also to our information review group and other people affected by Parkinson’s who provided feedback.

Talking to children about Parkinson’s (2014)
If you have comments or suggestions about this information sheet, we’d love to hear from you. This will help us ensure that we are providing as good a service as possible. We’d be very grateful if you could complete this form and return it to Editorial and Creative Services, Parkinson’s UK, 215 Vauxhall Bridge Road, London SW1V 1EJ. Or you can email us at publications@parkinsons.org.uk. Thanks!

Please tick...

☐ I have Parkinson’s. When were you diagnosed? ..............................................................................................................................................................
☐ I’m family/a friend/a carer of someone with Parkinson’s
☐ I’m a professional working with people with Parkinson’s

Where did you get this information sheet from?

☐ GP, specialist or Parkinson’s nurse ☐ Information and support worker
☐ Parkinson’s UK local group or event ☐ Ordered from us directly
☐ Our website ☐ Other ..............................................................................................................................................

How useful have you found the information sheet? (1 is not useful, 4 is very useful) ☐ 1 ☐ 2 ☐ 3 ☐ 4

Have you found the publication easy to read/use? ☐ Yes ☐ No

Has this resource given you information that might help you manage your condition better?

☐ NA ☐ It hasn’t helped ☐ It has helped a little ☐ It has helped a lot

What aspects did you find most helpful? ...........................................................................................................................................................................................
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Were you looking for any information that wasn’t covered? ..............................................................................................................................................
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Do you have any other comments? ..........................................................................................................................................................................................................
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If you would like to become a member of Parkinson’s UK, or are interested in joining our information review group, please complete the details below and we’ll be in touch.

☐ Membership ☐ Information review group (who give us feedback on new and updated resources)

Name ..........................................................................................................................................................................................

Address ..........................................................................................................................................................................................

Telephone ..........................................................................................................................................................................................

Email ..........................................................................................................................................................................................

What is your ethnic background? ☐ Asian or Asian British ☐ Black or Black British ☐ Chinese ☐ Mixed
☐ White British ☐ White other ☐ Other (please specify) ..................................................................................................................................
We’re the Parkinson’s support and research charity. Help us find a cure and improve life for everyone affected by Parkinson’s.

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 020 7932 1303 or visit our website at parkinsons.org.uk/support. Thank you.

Parkinson’s UK
Free* confidential helpline 0808 800 0303
Monday to Friday 9am–8pm, Saturday
10am–2pm. Interpreting available.
Text Relay 18001 0808 800 0303
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk
*calls are free from UK landlines and most mobile networks.

How to order our resources
0845 121 2354
resources@parkinsons.org.uk
Download them from our website
at parkinsons.org.uk/publications

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will 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.

References for this information sheet can be found in the Microsoft Word version at parkinsons.org.uk/publications