

Talking to Children about Parkinson's

A diagnosis of Parkinson's disease is hard enough, but if there are children or grandchildren, there are many other issues to be considered – particularly around a child's reaction to the illness, what you should say to them about your condition and its likely effects on your family's current life and future.

You will need to be very aware of the effect of Parkinson's on a child's emotions, behaviour and academic performance. Children may feel all sorts of emotions in relation to a loved one's Parkinson's: grief, fear, rejection and embarrassment. Some may become weepy, obstructive or withdrawn. The likely reactions may even differ among children of the same family.

Gerry was diagnosed five years ago, aged 35. He and his wife, Jo, have two children, now aged 15 and 12. Gerry says his children react quite differently:

"Our son (the younger child) is very supportive, keen to know more and happy to help out where he can. For example, if we go for a walk he helps me, and he asks if I've taken my drugs. He acts in a carer's role. Our daughter, on the other hand, has taken it much harder, she hasn't really accepted it at all. She is at a more difficult age; she gets more embarrassed in public, at school and so on. If I have a bad Parkinson's day, you can see it having a direct effect on her."

The fatigue and 'on/off' fluctuations associated with Parkinson's can be a big problem. It may mean you cannot spend as much time with the children or get involved in all their activities.

"Looking after an eight-year-old, running the house and just trying to keep up with everyday life means I do get exhausted," says Tara who has a daughter, Yvonne.

"There are times when I'm just waiting for her to get into bed, so I can get to bed straight afterwards! Anything that involves an excursion (a walk or swimming) is very hard, especially as I mostly use a wheelchair when we go out, and we need another adult to come with us. On the other hand, she gives me the motivation to carry on when my Parkinson's is bad, or when I'm feeling down."

Importance of communication

It is important to be open and honest. Do not keep your condition a secret. Tell children soon after the diagnosis, and maybe over several occasions. Remind them that although you may not be able to do everything you used to do, you still love them just the same. Be specific and clear in describing your condition. Don't assume anything. You may know that it is not contagious, but are they 100% sure? Be extra aware of the communication difficulties you may have and that you may have to explicitly express your feelings more than usual.

Gerry says of his children:

"They knew something was wrong, as we did, well before diagnosis. I had all the classic symptoms, but it took a while before Parkinson's was confirmed. We told them immediately, to put them at ease. There had been talk of a brain tumour, so the most important thing was to make it clear that it was not and I was not going to die."



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Tara was diagnosed with Parkinson's three years ago, and told Yvonne within a couple of weeks. Yvonne had been aware that something was wrong.

Tara's first move was to buy a book with simple pictures, including one of a body showing a 'big brown blob' for the brain which had 'thought bubbles' emanating from it, with the words 'eat', 'run', 'swim', etc. "I explained to her that the brain controls everything you do. Part of my brain is not working properly, so that is why I have a shaky arm and I cannot walk or talk properly sometimes. Once it was explained to her, Yvonne found it easier to explain my condition to her friends if they asked."

Parents, grandparents, guardians, relatives or friends may find the following rule of thumb helpful: tell them as much as you think they want to know, make it simple and appropriate to their age and maturity, and do not overload them. Tell them they can talk to you at any time. And keep talking. Talk about the future too, and what will happen when they leave home.

Some ways of coping

With everything that children, especially teenagers, have to cope with, Parkinson's can be a very difficult extra burden to handle.

"I don't know how they manage really," says Gerry. "I try to put myself in their shoes, a child with a parent with a condition like this, but I can't really imagine how I would cope. They have all the normal concerns of school, exams, peer pressure, but Parkinson's too. In the early days we used to cope a lot through laughter, and we still laugh a lot – my son can mimic perfectly all the Parkinson's symptoms – he's

got my dyskinesias down to a tee! That's one way we manage. However, my wife Jo now does a lot of the parenting – going to parents' nights, football matches, etc – as I am less able (and keen) to go out."

This is just one example of how humour has helped one family cope with Parkinson's. Each family is unique, and with good communication and some forward planning you can help your child cope and live well with a parent with Parkinson's.

"We have taken them to a couple of YPN [Young Parkinson's Network] Scotland meetings, but they did not enjoy it much. It would be great if they could meet other children of their age group in the same position". Tara wants Yvonne to meet others too. "I'd love for her to be able to meet children in similar positions, to show her she's not the only one."

Gerry is concerned that his children do not know anyone of their own age in the same situation. He is afraid there is some resentment about how Parkinson's is taking over the family.

To prevent such resentment from building up, the roles and duties of individual family members may have to be re-negotiated, as Parkinson's progresses. It may be a good idea to have regular get-togethers to go through how everyone is feeling and coping. These can be helpful for people to air and share their feelings rather than keeping them bottled up.

"Yvonne is very caring," says Tara. "She's always asking, 'do you need this, can I get that,' but I do not want her to become a carer. She is very willing to help and will run to fetch my sticks, for example, when I need them, but



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I always try to do everything I can, and only let her help when absolutely necessary.”

Children are often naturally very keen helpers, and are likely, like Gerry's son, to want to get involved. Remember, though, to show and tell a child regularly that you deeply appreciate them and their efforts to help. However, be aware of depending on them too much, and try not to overload them with responsibilities. They need time to be nurtured rather than always playing the part of the nurturer.

Individual or family therapy

Individual or family therapy is an option if a child seems troubled or depressed or if interaction between family members is affected by Parkinson's. It is important to recognise that children and young people cannot necessarily make sense of their feelings on their own. They may find it hard to articulate or recognise what they are feeling, either because they are too young or because they do not want to upset people close to them. They may also keep fears or worries to themselves and, as a result, it may be difficult for an adult to recognise the fact that they are experiencing difficulties.

Depression in children is more common than many people realise and can easily go unrecognised. Any child or young person who is depressed needs someone to talk to, or problems can build up. Getting help early on can help avoid long-term problems which may be harder to solve. Although family members may be able to help, it can sometimes be helpful for the child or young person to talk to a neutral person who is not involved in their family life. In this case, a therapist may be the answer.

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Tara has found therapy useful in helping Yvonne to deal with her feelings about her mum's Parkinson's.

“Anything Yvonne needs to ask me, she can – about Parkinson's or anything else – but sometimes she also needs to talk to someone neutral. Therapy was suggested by my GP. I was quite nervous about it at first. It was hard to admit that we needed help. However, I would recommend it to anyone. I am sure some people would find it hard to ask for help because of the fears and associations people have about counselling and mental health problems. Therapy is nothing to be ashamed of. Everyone needs someone to talk to. If you are a parent with Parkinson's and feel isolated, imagine what it must be like for your child.”

Individual therapy for the child, or family therapy for all members, is designed to be appropriate to the age of the child and gives the child a safe environment to express and explore feelings.

“I think Yvonne found it really helpful to talk to the therapist. Often they talked about general things, like school, TV, friends and what Yvonne was interested in, but the therapist was able to pick up on any feelings or situations Yvonne was finding difficult and to explore that with her in an unthreatening way. Although the therapist saw Yvonne on her own, I was always involved in the therapy, and could discuss any problems with the therapist. Sometimes the therapist would identify problems that I was not aware of; by discussing these with the therapist, I was able to either talk to Yvonne to reassure her, or sort it out without Yvonne being aware that I knew there was ever a problem.”



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Talking to your GP is probably the first step, as Tara found. The GP should be able to explain the different kinds of help available and refer you to an appropriate service. There are also several national child and young people-centred organisations that offer confidential support by telephone to children and young people. (See the end of this information sheet for contact details.) Some of these organisations, such as Young Minds, have a helpline that parents can also ring for further help and advice.

Encouraging children and young people to talk to family members, teachers and friends is important too. However, explaining to others can sometimes be difficult. Tara says:

“I've had mixed experiences with trying to explain my condition to Yvonne's teachers. One teacher may be interested, but another might not want to know. What those teachers need to appreciate is that you can't separate a child from their home life. If she went to school saying she was upset because Mummy was slumped in a chair, hardly moving when she left, then teachers need to understand that.”

The positive side

There are benefits for the children too. They can become more responsible, independent, patient, mature, open, aware and less self-centred. They will probably develop a finer sense of humour and a greater sensitivity and understanding of others. This independence and awareness can build confidence and self-esteem.

Tara says:

“Yvonne is much more open-minded than other children of her age. If she sees other

children making fun of anyone 'different' (in any way) she will tell them off firmly. She is also very keen to help others. If anyone is upset in the playground, she likes to mother them. She has one friend whose mum has just gone through a difficult time with breast cancer. She said to the little girl: 'I know the other children do not understand when your mum is not well, but I do and you can talk to me'.”

Remember, too, that how you cope with Parkinson's will be a powerful influence on how your child deals with their own challenges. If you are bitter or depressed much of the time, get help – if not for yourself, for the child's sake. Consider getting involved in some fundraising work, it may help encourage hope for the future.

Further information and advice

Publications

The publications below were used in the preparation of this information sheet:

- *Parkinson's Disease: A Self-help Guide for Patients and their Carers*, M Jahanshahi & CD Marsden (1998) Souvenir Press Ltd, ISBN 0 285 63317 1
- *Parkinson's: A Personal Story of Acceptance*, S Gordon (1992) Branden Publishing Company, ISBN 0 8283 1949 9

The Parkinson's Disease Society (PDS) has developed the booklet *One in Twenty* for people of working age diagnosed with Parkinson's. It sets out to answer the common questions that younger people have, provide general guidance, and share experiences of living with Parkinson's. In doing so, it covers



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topics such as relationships, employment, parenthood and staying independent. Useful sources of information and support are also listed in the booklet, including websites, other organisations and publications.

The PDS also publishes resources for children which you may find helpful:

- The books *My Dad has Parkinson's*, *My Mum has Parkinson's*, *My Grandad has Parkinson's* and *My Gran has Parkinson's*, aimed at 3- to 7-year-olds.
- *Our Mum has Parkinson's*, an illustrated story written by a teacher who has Parkinson's, which describes how Megan copes with her mum's Parkinson's – for 7- to 10-year-olds.
- *Parkinson's: The Facts*, a guide for young people aged 11–17 years.

Useful organisations

YPN

The Younger Parkinson's Network is the PDS's group for younger people with Parkinson's.

YPN

PO Box 33209,
London SW1V 1WH

Tel: c/o the PDS Helpline (0808 800 0303)
who will put you in touch with a YPN member
Website: www.yap-web.net

PDKids

PDKids is an email mailing list for children and young people (under 18) who have a parent or relative with Parkinson's. It was established as a forum for kids affected by Parkinson's to have a place to share with each other. Kids may discuss anything they wish in confidence

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(to the extent that an internet list will allow). PDKids is a joint project between the American Parkinson's Disease Association (APDA) Young Parkinson's Information and Referral Center and the Adrienne Coles Memorial Trust. Simon Coles, the administrator of the Adrienne Coles Memorial Trust, is an adult 'PD kid'.

The list is only for those under the age of 18 – subscriber names and personal email addresses will automatically be deleted from email headers posted to the list to ensure confidentiality. If the reply button is used to respond to a member's post, the email will go directly to the PDKids list, not to an individual member. There is a light adult presence on the list (provided by the APDA Young Parkinson's Information and Referral Center and Simon Coles), providing technical guidance and to ensure that the conversation remains constructive. For further details see the website:

www.coles.org.uk/Current_Projects/Lists/pdkids.htm

General

Carers UK

32–36 Loman Street
Southwark

London SE1 0EE

Tel: 020 7922 8000

Fax: 020 7922 8001

Email: info@carersuk.org

Website: www.carersuk.org

Provides information, advice and support to carers as well as developing projects and campaigning on behalf of carers. Has several young carers projects.



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ChildLine

Helpline for children and young people.
0800 1111 (24 hour) – can get busy but keep trying and you will get through.
Website: www.childline.org.uk

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. The ChildLine counsellors will listen and help them find ways to sort things out.

The Children's Society

Edward Rudolf House
Margery Street
London WC1X 0JL
Tel: 0845 300 1128
Website: www.childrenssociety.org.uk

This organisation believes that children and young people are shaped by the communities they live in, and by the people who surround them. Their prospects can become bleak when these influences let them down. The organisation concentrates its resources on tackling the root causes of the problems these children and young people face.

It has a young carers initiative which seeks to create a national focus for young carers, their families and people who work to support them across England and the UK. The young carers website has details of young carers projects across the UK:
www.childrenssociety.org.uk/youngcarers

Crossroads – Caring for Carers

10 Regent Place
Rugby, Warwickshire
CV21 2PN
Tel: 0845 450 0350

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Email: communications@crossroads.org.uk
Website: www.crossroads.org.uk

Provides care attendants who come into the home to give the carer a break. 180 autonomous schemes throughout England, Scotland and Wales through ten regional offices. Also has some young carers projects.

Depression Alliance

212 Spitfire Studios
63–71 Collier Street
London N1 9BE
Tel: 0845 123 2320
Email: information@depressionalliance.org
Website: www.depressionalliance.org

National charity that supports people with depression. Provides information on depression in children and young people. Also operates a young members pen friend scheme for young people aged between 12 and 24 years.

Disability, Pregnancy and Parenthood International

National Centre for Disabled Parents
Unit F9, 89–93 Fonthill Road
London N4 3JH
Tel: 0800 018 4730
Email: info@dppi.org.uk
Website: www.dppi.org.uk

Promotes better awareness and support for disabled people during pregnancy and as parents. Has a quarterly international journal dedicated to disabled parenting and a UK information service, and develops projects, often working with the Disabled Parents Network (see below), such as a National Centre for Disabled Parents and a support worker.



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Disabled Parents Network

Address as for Disability, Pregnancy, and
Parenthood International
Telephone helpline: 0870 241 0450
Email: information@disabledparentsnetwork.org.uk
Website: www.disabledparentsnetwork.org.uk

Can put you in touch with other parents in a similar position to you, has a helpline staffed by other disabled parents, publishes a quarterly newsletter and develops projects.

Parentline Plus

Helpline: 0808 800 2222
Website: www.parentlineplus.org.uk

National charity offering help and information to anyone parenting a child (whether they are the parents, grandparents, step or foster parents, other relative or friend). Parentline also runs a freephone helpline to anyone concerned about children they are looking after.

Princess Royal Trust for Carers

Unit 14, Bourne Court
Southend Road
Woodford Green
Essex IG8 8HD
Tel: 0844 800 4361
Fax: 0844 800 4362
Email: info@carers.org
Website: www.carers.org

Provides information, advice and support to carers through over 100 carers centres in the UK and through development work. This includes work with young carers.

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Young Minds

48–50 St John Street
London EC1M 4DG
Tel: 020 7336 8446
Fax: 020 7336 8446
Website: www.youngminds.org.uk

Young Minds 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.

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215 Vauxhall Bridge Road, London SW1V 1EJ, UK

Tel: 020 7931 8080 **Fax:** 020 7233 9908

Helpline: 0808 800 0303. (The Helpline is a confidential service.
Calls are free from UK landlines and some mobile networks)

Email: enquiries@parkinsons.org.uk **Website:** www.parkinsons.org.uk

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To obtain any PDS resource, please go online to www.parkinsons.org.uk or contact Sharward Services Ltd, the appointed PDS Distribution House, at Westerfield Business Centre, Main Road, Westerfield, Ipswich, Suffolk IP6 9AB, tel: 01473 212115, fax: 01473 212114, email: pds@sharward.co.uk