

TALKING TO CHILDREN ABOUT PARKINSON'S

Introduction

Parkinson's disease (PD) affects the whole family, not just the person with the diagnosis. It is natural for parents/grandparents to want to protect children from upsetting news or events but even very young children can tell when something is different or "wrong" in their family. When this happens it is common for children to become frightened and worried. To alleviate some of these fears it is important to talk to children about Parkinson's as soon as a diagnosis is received.

Your attitude, the way in which you present the information, and when you have the conversation can make a significant difference as to how your child responds to, and copes with, the information. This help sheet has been developed as a tool to help you talk to children about PD. Below are some suggestions to keep in mind:

Do not keep your condition a secret

- Tell children shortly after you find out that you have Parkinson's. Children are smart and will sense very quickly that something has changed. As a result, they may experience unnecessary stress.

Your attitude sets the tone

- Your approach to your diagnosis will set the tone for the rest of the family. Being appropriately hopeful and positive encourages others to do the same, as does the attitude that "you may have Parkinson's but Parkinson's does not have you." Never lose your sense of humour.

You are still their parent/grandparent

- Children of all ages need the reassurance that PD does not change the fact that you are still their parent (or grandparent, etc.) and it does NOT change how much you love them.

Their questions are welcome

- Children may need reassurance that it is OK to ask anything about PD at any time.

Reconsider your child's initial reaction

- Some children will try to hide their feelings in order to protect yours. Some will not understand and some will retreat into denial. Do not assume anything about their reaction or understanding of the situation and ask them what they think of your diagnosis more than once.

"Magical thinking"

- Be alert to children believing that they somehow caused the illness. Young children sometimes think that if they had behaved better or tried harder in school that Dad would not be sick. They may need to hear that PD is absolutely not their fault in any way.

Feelings are OK

- It is important to recognize that children cannot necessarily make sense of their feelings on their own. They may find it hard to recognize or articulate what they are feeling. Encouraging them to talk about their feelings often will help them pinpoint their emotions. Whatever their reaction, let children know that their feelings are normal and OK.

Broadening the circle

- You may want to tell your child's friends about PD. Clear explanations can alleviate discomfort or awkwardness and encourage friends to be supportive.

Additional responsibilities within the family

- It may become necessary for children to take on more responsibilities in the home. Many children are natural helpers while others become resentful and angry. In other instances children may start to over-function, taking on more responsibility than is appropriate for their age. Balance their new roles appropriately and resist overloading them with responsibilities. How your child will react often depends on existing family dynamics. If children are having a difficult time adjusting, family counselling may be an option.

Getting help

- Depression in children is not uncommon and can easily go unrecognized. Talking to an impartial person who is not involved in the family can be very beneficial. School counsellors and other forms of support, such as a therapist or trusted family friend, are good options for helping your child cope with having PD in the family.

Responding to common questions from children about Parkinson's

“What is Parkinson's?”

- Very young children may be satisfied with an explanation like: “There is something wrong with a tiny part of Mum's brain and that is why she shakes sometimes.” Tell them as much as you think they want to know and keep the information simple. Older children will likely ask for more information and the PSCNO website (www.parkinsoncno.ca) is an excellent source of information.

“Are you going to die?”

- Children of all ages need reassurance that PD is not a terminal illness and that you are likely to have many years of good quality family life ahead of you.

“Will you get better?”

- PD lasts forever but there are many medications that can help with symptoms. Children likely need to know what you are doing to stay as well as possible. It is also helpful to explain that even though there is no cure at present, scientists all around the world are working on it.

“Why do you shake? Why do you look so sad? etc.”

- Do not hide your symptoms. Explain what is happening to you so children are not alarmed by changes they can see. The following are some possible explanations:
 - **Freezing:** “The message from my brain to move my legs just doesn't get through which sometimes makes me unable to keep moving.”
 - **Stiffness:** “It is kind of like the sore muscles you get after playing sports.”
 - **Tremors:** “The parts of my brain that send messages don't always work like they should. My shaking may look funny, but it doesn't bother me that much.”
 - **Facial/vocal expression:** “My face and voice are not as expressive as they once were but that doesn't mean I am sad or angry. Feel free to ask if you are not sure how I am feeling”.

“Why are you taking pills?”

- Very young children are generally content with knowing that your medication makes you feel better, similar to when they are given medication. Older children may need more specific information, particularly if they notice new and different prescriptions. It can be helpful to ask your doctor if they would explain your PD medications to your children.

“What will happen?”

- Talk about future hopes, plans and dreams just as you would without PD. Some adjustments will be needed along the way but many things are still possible.

“Will I get Parkinson’s?”

- It is important to let children know that PD is not contagious. Older children may ask about genetics and the potential of developing PD. Only a small number of cases of PD are inherited.

“How did you get PD?”

- We do not know how or why most instances of PD develop. Even the doctors don’t know but they are working very hard on finding out!

Sources:

I’ll Hold Your Hand so You Won’t Fall, Rasheda Ali

Talking to Children, Parkinson’s UK

http://www.parkinsons.org.uk/Docs/is_talkingtochildren.doc

Talking to Children About Parkinson’s, Parkinson Society of Southern Alberta

<http://www.parkinsons-society.org/LivingWithParkinsons.aspx#three>

Talking with Kids About Parkinson’s Disease, Lisa Lieberman, MSW, LCSW

Parkinson’s Resources of Oregon

What’s Wrong with Grandpa?

Parkinson Society Canada

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