

# Caring in Parkinson's Helping Children Cope with PD



It is often said that Parkinson's disease (PD) is a family affair. Among those impacted are children of all ages, from young children to teenagers to young adults. Children have unique needs when it comes to coping with Parkinson's in the family. In cases in which a parent lives with the disease, the impact on a child will be of particular concern. But in any family where a close member has been diagnosed, children have concerns that can and should be addressed. The good news is that children often adjust well to a loved one's diagnosis of PD. And we can help them not only to adjust, but also to thrive.

## How Does PD Affect Children?

Research into the impact of Parkinson's on children is still new, but we are starting to learn about their unique needs, and how those needs change as PD progresses.

The good news, which turned up in a recent survey, was that the majority of the children who have a parent with PD reported that they had someone to talk to about their feelings. We also learned that a child's outlook was strongly tied to that of his or her parents. If a parent was hopeful, often the child was too. Lastly, we found that the experience of facing Parkinson's disease in the family can lead to positive outcomes, such as personal growth, enhanced empathy and coping skills.

In terms of challenges, we learned that just as symptoms vary for each person with PD, so do the emotions of each child. Among the common emotions reported were anxiety about developing PD themselves; confusion about the changing roles of family members; guilt about being a burden to parents; loneliness in reaction to the parent without PD spending more time with the parent with PD instead of other family members; sadness over changes in the family; and self-consciousness about the appearance of the loved one with PD.

How can you help a child who experiences these emotions? First, we can communicate regularly about PD and the child's feelings. Second, we can offer family and peer support to meet each child's individual needs.

## Communicate Openly and Frequently

Children have many questions about PD and adults may be unsure of how much information to provide. We may think that holding back information is helpful — because we fear that it will be scary or unpleasant — but in the survey, we learned otherwise. In fact, many of the children who had a parent with PD said they did not have enough information, and that a better understanding of PD would help them feel more secure.

We need to remind ourselves that children are observant, and if a parent does not share news of a PD diagnosis, they may fear that something worse is going on. Also, children do not have the same sources of information that adults do, such as doctors and support groups. This means that they often rely on the family for information.

What then should we be telling them? A good rule is to offer information using language that is appropriate to their age. For example, all children need to know that PD is not fatal, that they did not cause it, and that it is not contagious. Beyond that, depending on their questions, we may want to offer information about symptoms and other aspects of PD, at a level that they can understand. We might also tell them that scientists are working to understand the causes of PD and find new treatments.

We should encourage opportunities for discussion, so that new questions can be answered as they come up. At the same time, we should avoid pushing children to talk about their feelings if that

*(over please)*

is not what they normally do; some children cope introspectively and that is okay.

At every opportunity, try to replace fears with knowledge, by providing reassurance and acknowl-

### Help Children Adjust to PD

- Share the PD diagnosis with children, and explain symptoms in simple terms.
- Let children know that PD is not fatal, they are not responsible for it, and it is not contagious.
- Talk about research into new treatments and the specialists who are available to help.
- Bring children to a neurologist's appointment so they can learn about PD.
- Preserve the parental role of the person with PD, in discipline and setting boundaries. The "well" parent should not shield the parent with PD.
- Encourage children to talk with relatives, teachers, coaches and yourself.
- Empower children – for example, by helping them to organize a fundraiser, or to raise PD awareness.
- Help children to make connections with others of their age who have a parent with PD.
- Monitor changes in behavior, but be mindful that children are going through life stressors that have nothing to do with PD!
- Reassure children that they can and should have fun and lead their own lives. Not only is this okay; it's important to their healthy development.
- Hold family meetings to talk about changes resulting from a parent's PD, and discuss worries.
- Maintain family life, while remaining flexible with the changes that occur.
- Consider counseling but ensure the counselors have experience with children or teenagers.

edging feelings. Children model their parents' attitudes. Approaching PD with a positive attitude will help children to do so as well.

### Encourage Healthy Coping and Support

If your family is touched by Parkinson's, how can you help children to cope? There is no single model that works for every family. But the following ideas may help.

**Build a Personal Team:** Reach out to teachers, coaches, neighbors and family — and provide them with information about PD. These adults observe your child in different situations, and may be able to provide important insights to you if and when they see changes in the child's behavior. Communicate with this team about your attitude toward PD and the attitudes you would like to see encouraged around your child.

**Promote the Child's Interests:** Children should be encouraged to live their own lives as normally as possible — including retaining their own interests and hobbies. This helps them learn early on that it's okay for them to live their own lives and to take care of themselves.

**Encourage Peer Support:** Most children with a parent with PD do not know any other children who have the same experience. Yet, children may benefit from interacting with peers who have similar experiences. Suggest that children connect with others of their age who have PD in the family. Do this through local PD groups or online.

### Conclusion

There is no doubt that when a child finds that a parent has been diagnosed with PD, he or she will face challenges. But remember, some changes can be positive, and families that address PD together may find their relationships are strengthened. Know that by approaching children with honesty, communication and a positive attitude, you can help them to adjust and to thrive.

*This article is adapted from an online seminar first presented by Elaine Book, M.S.W., of the University of British Columbia, in November 2014.*

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice. This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.

Adapted from the PDF News & Review, Spring 2015

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