Parkinson's disease (PD) is a family affair: everyone in your family is affected. As a parent of a young child or teen, it is important to consider how PD might affect your children and what can be done to continue to live a full family life with PD.

Whatever age your children are, consider telling them you have Parkinson's. Children always seem to know if something is not right, and they often imagine much worse things than the truth. Explain Parkinson's to them, as well as your best understanding of what might happen. Remember to use age-appropriate language. A better understanding of the condition can actually lead to less distress.

Adolescents have access to a lot of information via the internet. This can be constructive if what they find helps them cope, but it can be devastating if the information is misused or misunderstood. Consider asking your teen what they know about PD and where they got their information. Ask if they plan to get more information, and from where. You might want to go online together to sites that you know are reliable, like Parkinson.org, rather than simply Googling “Parkinson's.”

A parent’s illness can present challenges for a family, but it can also provide opportunities for children to grow in ways they may never have experienced without the health issue. They can become more self-sufficient, confident and independent.

It is vital for children to continue to see their parent with PD as a parent first and foremost, with the same expectations and approaches to parenting, enforcing the same discipline and boundaries. The “well parent” should not try to shield the PD parent from involvement with the children. Stability and consistency will create a sense of security.

Privacy for your child/teen and for you

Your children may not want to talk to you about PD. This is ok, but it is important that they have someone to talk to, whether it is another relative, friend, parent of a friend, teacher, coach, clergy, or other person in their lives.

You may not want your diagnosis or disease process to be shared with the entire community. To meet your needs for privacy and your child/teenager’s need for support, discuss what information it is ok to share and with whom.
What can you do?

» It is generally recommended to share with your children’s school any changes in your home. The staff at the school, along with sports coaches or leaders of other extracurricular activities, can be your allies in watching over your children’s emotional health and looking out for signs of distress. Sharing accurate information with the other adults in their lives will help ensure that messages are always communicated in a similar way.

» Create opportunities for your family to regularly address issues and worries, along with what is working well. Consider holding a regular family meeting. You may use one of the books about Parkinson’s written for kids as a jumping off point for the discussion. A list of some of these books is below.

» Encourage your kids to continue their involvement in favorite activities, interests and hobbies. They should have fun and live their “normal” lives as much as possible.

» Help your children find peer support. They are not the only ones with parents with PD. If you are in a YOPD support group, ask other members if they have children and if they might want to arrange an activity where the kids could meet and interact.

» Demonstrate a positive attitude. Children learn a lot about coping from their parents. Remind them that there are teams of specialists and researchers working on treatment and symptom management.

Final thoughts

Remember that you are the experts on your children. If you sense that something is wrong, you are probably right. However, childhood and teenage years are times of social and emotional development, and their distress may not be related to PD.

Children, like adults, may have to grieve changes in their life and ongoing losses. They should be given permission to do so. Your children might have to work through their sadness before they can adjust to a new reality.
Parkinson's Books for Kids

The following books were written to facilitate discussion with children about Parkinson's disease. The books offer age-appropriate information about PD and perspectives to help children and teens better understand important issues in the PD world. This is not a comprehensive list of available titles, but it's a great place to start. All the books below are available on Amazon.com and other online retailers.

» *I’ll Hold Your Hand, So You Won’t Fall: A Child’s Guide to Parkinson’s Disease* by Rasheda Ali, with a foreward by Muhammad Ali

» *Carina and Her Care Partner Gramma* by Kirk Hall

» *Carson and His Shaky Paws Grampa* by Kirk Hall

» *My GrandPa’s Shaky Hands* by Dr. Soania Mathur

» *Parkinson's in the Park: For Children of Parents with Parkinson's* by Jessica Christie

» *Shaky Hands: A Kid’s Guide to Parkinson’s Disease* by Dr. Soania Mathur

» *The Tale of a Parkie Princess: A Chronic Illness Described in a Fairy Tale* by Annie Konopka

By Elaine Book, MSW, RSW
Pacific Parkinson’s Research Centre