

Talking to Children and Teens about Parkinson's

*A Practical Guide for Parents,
Grandparents and
Adult Family Members*



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

Bryan Roberts, a person with young-onset Parkinson's, was diagnosed around the time his daughter was born. He worried that Parkinson's would affect his daughter's childhood. But Bryan's perspective changed when he heard Michael J. Fox's son, Sam, say, "Growing up, it wasn't Dad who has Parkinson's disease. Dad was just Dad." Now Bryan understands that, "My daughter won't know what I was or what I am not, she will just know that I'm her father." He adds, "Parkinson's may sometimes feel like a disease of diminishment, but it doesn't have to be. Some roles, like that of a parent, are too big to be diminished."

In some families, children never know their parent or grandparent without Parkinson's disease (PD). For others, the diagnosis is a defining moment in everyone's life. No matter when or how Parkinson's enters a child's world, there will be questions about the disease and also likely fears or misinformation that need to be addressed.

Every family communicates differently. The most productive discussions are thoughtful and open. Use this six-step guide to help you have conversations about Parkinson's with your family and the children in your life.

Practical Tip #1: Adjust to the Diagnosis, Then Plan Your Conversation

People accept the diagnosis of Parkinson's in different ways and on different timelines. Some are ready to share the day they're diagnosed; others take longer. Take time to digest the diagnosis and organize your thoughts so that you can be clear and confident, and lead children to greater security about aspects of life with Parkinson's that may feel worrisome or uncertain. If you are confident in how you feel about the

diagnosis, it will help others feel more comfortable processing their reactions and feelings.

It is important to talk openly with children, because this prevents an atmosphere of secrets, which can be frightening and even harmful. When children see change they don't recognize, they create stories to explain it. Your conversation is an opportunity to proactively shape understanding and provide facts.

Choose a time to talk when your child isn't distracted, having a bad day or going through a significant transition (the start or end of the school year, for example). Give plenty of time for discussion, questions and time to sort through the information. And say that this can be the first of many conversations to come.

Practical Tip #2: Agree on Common Language and How Much to Share

Common Language: Meet with the most meaningful adults in the child's life and agree on the best way to explain Parkinson's. Both parents will likely want to use the same words to describe



Parkinson's to children, and grandparents may want to agree with the child's parents on which terms to use.

With younger children you may want to call Parkinson's disease "PD" or tremors "the shakes." Michael J. Fox has written about the loving nickname his own children bestowed on him, "Shaky Dad." Using descriptive words or a nickname makes an unfamiliar topic feel accessible, and provides a vocabulary for children to ask questions. For older children and teens, more technical medical terms — along with guidance on how to research the topic online and elsewhere — may be appropriate.

How Much to Share: In addition to the basics of Parkinson's, decide how much of your PD you want to share — current symptoms, other symptoms that might develop, how symptoms might change over time, and what concerns you might have about how disease progression may affect you and those around you.

Some people focus on the here and now; others look more broadly at what might happen in the future. What you talk about depends on your comfort level, your relationship to the child, and the child's age and maturity.

Practical Tip #3: Tailor the Conversation to the Child's Age

No matter how old the child, Parkinson's is likely a new topic, and it can be scary for children to learn that an adult they rely on is now experiencing a medical issue. But as children grow, they understand and process information differently. Use everyday language to describe Parkinson's, give concrete examples of what they might see, and suggest ways they can learn about or get involved with the Parkinson's community. This can decrease anxiety and make a PD diagnosis feel less daunting.

Parents might ask the child's pediatrician or a school counselor for guidance as these professionals have experience handling a variety of scenarios and life events with children of all ages. Grandparents might look to friends or support groups for advice.

What follow are tips for age-appropriate conversations. Remember the initial talk will be one of many. Keep your part of the discussion short and give children time to ask questions and digest information.

Preschoolers (3-4 years old)

- + Use simple language and specific examples. "My hands are shaky." Or "It's hard for mom to walk fast." Describe how Parkinson's could impact your activities. For example, "It might take longer for me to tie your shoelaces when my hands are shaky."
- + Consider visual aids such as books with pictures and few words to help explain Parkinson's and its symptoms. (See Resources, pg. 6.)
- + Ask the child to draw a picture of how they feel.

School-age children (5-9 years old)

- + As with preschoolers, use concrete examples. "Some days I'll have a harder time playing catch with you, but other days I'll feel just fine."
- + Depending on the child's age and your level of involvement in the Parkinson's community, you may want to suggest activities, such as bake sales or walks, in which you can fundraise for PD together.

Adolescents/Teens (10-19 years old)

- + Use more common medical terms, especially with older teens. For example, "I have Parkinson's disease. That means my brain makes less of a chemical called dopamine, which causes tremor, or shaking, in my hands, stiffness in my muscles, and slowness of my movements."
- + Start broadly and leave room for questions and further explanation.
- + Acknowledge and validate emotions, which can range from sadness to anger to fear. Young people typically use less sophisticated emotional vocabulary than adults. It is common for children and teens to use simple language to name feelings, such as "sad" or "mad" — consider this an opening for conversation, but don't press for nuanced or descriptive language. Remember, too, that children may genuinely not know how they feel. In this case, don't pressure them. Leave the door open for later conversation when or if they feel ready. Create a safe space to foster communication about their emotions.
- + Encourage teens, who may not express emotion with you, to share their feelings with a trusted friend, provided you want



to share your diagnosis outside of the family. (Peers are a particularly important part of a teen’s support network.)

- + Give guidance on where they can go for more information. Certain websites and books (See Resources, pg. 6) and people who have Parkinson’s or their children may be good places to start. You might also ask your Parkinson’s doctor if he or she would talk with the child at your next visit.
- + Propose ways in which the child can learn more (school projects or internships, for example) or get involved in empowering activities such as helping to fund research toward a cure (participate in a 5K fun run, for instance).

No matter how old the child is, offer reassurance. Being able to soothe your child may be somewhat difficult, especially when you don’t have all the answers and may be nervous yourself. A phrase such as “We love you and care about you, and we will always love you and make sure you are cared for, no matter how things grow and change for our family,” may provide comfort, and can be repeated over time.

If you have trouble with these conversations, consider engaging a therapist, counselor or social worker. These professionals support children and families working through new situations. They may be particularly helpful if behavioral and emotional changes arise. (Parents of school-age and older children may want to ask a school staff member, such as a teacher or coach, to monitor for emotional and behavioral shifts.)

Practical Tip #4: **Be Open and Model Behavior**

Just as important as sharing information in your conversation is setting the stage for the child to express and manage their emotions.

Be Open: During your conversation, be open about how you are feeling — confused, scared, worried, sad or a combination of emotions. Children may feel the same way. When you talk about your feelings, it lets your child know it’s okay to express theirs as well.

Model Behavior: Children pick up on verbal and non-verbal cues and react to adults’ energy, tone of voice and behavior. Even though you may be sad, angry or frustrated, you can still be calm and in control. (Of course, this requires self-awareness

and time to practice what you want to say.) Children will look to you for security. While this diagnosis signals a change — inevitable in life — children want reassurance about stability and support, and your help to work through whatever circumstances arise.

Practical Tip #5: **Anticipate Questions and Prepare Answers**

One of the wonderful things about children is that, given the chance, they’ll tell you exactly what they are thinking. Often this comes in the form of a question, many times one you don’t anticipate. Provide time and space for questions — many of which will be self-centered — during your initial discussion, and leave the door open for future questions.

Some common questions surrounding a parent’s or grandparent’s diagnosis and suggested responses that can be adapted:

Are you going to die?

Most people with Parkinson’s live full lives and I’m going to do everything I can (exercise, eat right, take my medicine) to do so. My symptoms (shaking, slowness, problems walking) will worsen gradually over time, but doctors generally believe you die with, rather than from, Parkinson’s.

Answering this question also may be an opportunity to reassure your child and convey comfort. If you’ve adopted a phrase (“We love you and care about you, and we will always love you and make sure you are cared for, no matter how things grow and change for our family”), now might be a good time to repeat and reinforce it.

Am I going to get Parkinson’s?

Parkinson’s isn’t contagious, like a cold, so you can’t “catch” it from me. We can still hug, hold hands and share meals together like we normally do.

Is this my fault?

Absolutely not! And it’s not mine either! Scientists are still working to figure out exactly what causes Parkinson’s disease. They think it’s most likely caused by many different factors in our genes and environment.



Does this mean I can't go to summer camp or play soccer anymore?

Encourage your children to continue regular activities and maintain hobbies. To the extent possible, keep them on their usual schedules. Children like consistency and routine and keeping them on their regular schedule will keep them from feeling overwhelmed by a Parkinson's diagnosis.

Should I come home from school?

Older teens who are away at college or living in a different state may wonder whether they should drop everything to visit. Offer reassurance. Describe your current condition, symptoms and feelings. (Use video chat if helpful.) Plan a visit in the not-too-distant future at a mutually convenient time. Meanwhile, encourage them to focus on work, studies or social activities as they had been doing and tell them you'll be living life as you had before the diagnosis, too. Keep the door open for regular conversations.

Being ready for frequently asked questions is helpful, but don't feel like you need a script. You're human. It's natural and okay to fumble in your responses, show your feelings and not know the answer. Replies of "I'm not sure," "I don't know," or "I wish I knew" are perfectly reasonable. But they should be coupled with details about what information you can (or can't) find out and how you can find out together. This builds open communication and paves the way for finding answers together.

Practical Tip #6: Manage Children's Reactions

Children may have the same range of emotions as you did upon learning about your diagnosis. Sadness, anger, withdrawal, worry and indifference are some of the potential reactions. Just as you likely needed time to adjust when first diagnosed, your child will need time to figure out what this means for them and the rest of the family. Some hints as you work together:

Be Supportive: Everyone processes information differently. Children often express their emotions behaviorally, in the way they respond to rules, perform in school, get along with other children or speak to you. This is their way of trying to understand what is happening. Talk to them in a supportive manner; tell them you want to hear what they have to say. And know that there are professionals who can help you and your family through these conversations.

Create a Safe Space: Feelings, and the child's ability to express them, vary widely. Make sure your child knows that feelings are individual and unique, and that there are no right or wrong feelings. Tell your child that you want to talk about any and all feelings they experience. Acknowledge and validate emotions ("I can understand why you feel like that") and reflect them back ("Sounds like you feel pretty worried about grandpa right now") to encourage and clarify communication.

Establish Space to Talk with No Distractions. Give ample time for your child to put in their own words what they are feeling and for you to really hear what they have to say. Observe how they express themselves. Have some flexibility and tolerance for behavioral changes, but don't allow acting out or rudeness. As you listen, watch and talk, it may become easier to help children separate feelings from behaviors.

Ask for Help: When needed, connect with local resources, such as a therapist, your Parkinson's doctor or a support group. There are many willing and qualified individuals who can help you and your children navigate how Parkinson's fits into your family.

Check In: Establish regular check-ins (perhaps around the time of your usual doctor visits) for your children to talk about what they are feeling and to ask questions. This is particularly helpful as symptoms change over time.



About the Authors

The guide was developed by movement disorder specialist Rachel Dolhun, MD; career and professional development consultant Marti Fischer; and behavioral health professionals Mollie Eliasof, LCSW, Aubree Guiffre, PhD, Jessica Moore, PhD, and Ellen Poleshuck, PhD.

Mollie Eliasof: www.meliasoftherapy.com

Marti Fischer: www.martifischergroup.com

Aubree Guiffre: <https://www.linkedin.com/in/aubree-guiffre-phd-b9650a57/>

Jessica Moore: <https://www.urmc.rochester.edu/people/26758312-jessica-a-moore>

Ellen Poleshuck, PhD: Ellen_Poleshuck@URMC.Rochester.edu

Resources

The Michael J. Fox Foundation website, www.michaeljfox.org, offers comprehensive information on the diagnosis and management of Parkinson's disease.

The following books (an incomplete list), may provide a framework for talking with children about Parkinson's.

Carina and Her Care Partner Gramma
by Kirk Hall

Carson and His Shaky Paws Grampa
by Kirk Hall

I'll Hold Your Hand, So You Won't Fall: A Child's Guide to Parkinson's Disease
by Rasheda Ali

Mrs. Wigglesworth's Wiggles
by Pat Erickson

My Grandpa Has Parkinson's
by Margot Grant Evans

My GrandPa's Shaky Hands
by Soania Mathur, BSC, MD, CCFP

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 Soania Mathur, BSC, MD, CCFP

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

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