



Helping Your Children Cope with Your PD

When I was diagnosed with Parkinson's in 2000, I first thought of my three children and of how my diagnosis would impact them. How would I tell them? Would I be able to help my daughter fix her hair and make-up? Would I be able to walk at their weddings?

At first, I chose not to share my diagnosis with my children but I soon realized that I had to tell the older two — Kyle (9) and Erik (6). Their first question was, "Are you going to die?" I reassured them that this disease was not fatal, but told them that sometimes I might need help with small tasks. At the time, neither child asked many questions and seemed relieved to know that I was technically "okay."

As time went on, I could see small but distinct ways that my announcement changed their behavior. When my son Kyle and I would go shopping, he would hold only my left hand. When I asked him why, his reply was that he was trying to stop the shaking. Then Erik decided suddenly that he would become a scientist, and create a bracelet and anklet that would stop people with Parkinson's from shaking.

As I considered how to help my boys understand my disease, I got some wonderful suggestions from my movement disorders specialist. Upon his request, my husband and I brought the boys on a "special" doctor's appointment. The doctor showed us pictures of the brain, explained the disease in simple terms and told us — and the boys — what it is like to live with PD.

While this visit was invaluable to me and my children, I continued to see signs of their struggle with my diagnosis. They were unsure how to answer children at school when they were asked why their mom shakes so much, and I continually had to reassure them that I was not going to die. At one point we decided to seek outside counseling from a psychologist for one of the boys who was having a particularly difficult time adjusting. We found him to be helpful in teaching us how to cope.

For my daughter, Rachel, who was only two years old when I was first diagnosed, living with Parkinson's has raised different issues. Rachel and I both had a hard time dealing with my inability to pull up her long, thick brown hair in a ponytail and have

her look like the other girls her age. At first I asked the stylist to cut her hair short, but now, with adjustments and help from other family members, Rachel is learning to make her own ponytails. It's just one of the many examples of simple things that Parkinson's can take away from you, but which you can take back with a little teamwork.

This problem turned out to be minor compared to what was to come. Just this year, at age 7, Rachel hit me with a bombshell that I will never forget. I was sitting on my porch enjoying a cool day when she sat on my lap, placed her arms around my neck and asked, "Why do you have to have Parkinson's?" I tried to explain, but she kept saying, "I want you to be like you were before. It just isn't fair because Kyle and Erik got to see you like you were before and I never have." It made me realize that my daughter had many questions going through her mind. We held each other, and she asked what the word "cure" meant. We

talked about this, and then she asked the inevitable question — was Parkinson's contagious? I told her that it was not, and that I would be around for a long time to answer any other questions that she may have. I also set up a phone call with my doctor so that he could have the same conversation with Rachel that he had with my boys.

Of course my children continue to have questions. Just last month Rachel asked me how old I was when I started shaking. I replied that I was 30, whereupon she asked if she too would start shaking when she turns 30. As I assured her that she would not, it reminded me that the questions about my Parkinson's disease probably will not end. But at least I know I am here for my children, and plan to be for a long time.

My overall advice in dealing with this disease is to keep the faith and recognize the strength of your family. Expect that they will have questions, and be open to suggestions for dealing with these questions from your doctor, friends and other family. Remember that we are all in this together, and that only together will we win this war on Parkinson's disease.

Michelle Lane is an advocate and founder of the Parkinson's Association of Louisiana.

Tips for Talking to Your Kids

1. Explain your diagnosis in simple terms, including the symptoms and what behaviors to expect.
2. Be prepared to answer basic questions, such as if the diagnosis is fatal, if PD is contagious and if your child will get PD.
3. Encourage your child to ask questions, and be prepared for some of them to be of a sensitive nature.
4. Make a visit to your neurologist to discuss the disease.
5. Let your kids know that there will be some changes in daily living and that working as team will help your family.
6. Explain that people may stare at you because of the disease, and that it is usually because of curiosity and not rudeness.

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.