

TALKING WITH KIDS ABOUT PARKINSON'S DISEASE

Living with Parkinson's disease (PD) presents challenges; being a parent with the disease raises another set of issues. Approximately 10 percent of the 1.5 million people with Parkinson's are below the age of 40. Many of them are in the midst of raising their families. Talking to your children — or even grandchildren — about PD is an emotionally charged, but necessary, task. Patients and professionals agree that understanding is the key to acceptance and moving forward as a family.

COMMUNICATING ABOUT THE DISEASE

Relieve the Uncertainty

Lisa Lieberman, M.S.W., L.C.S.W., is a psychotherapist with Parkinson's Resources of Oregon. When it comes to communicating with children about Parkinson's — or any disease — she believes that knowledge is power. "Lack of knowledge creates more anxiety," she says. "Kids are intuitive. They know what's going on. If they aren't given a way to make sense of it, it just makes it worse for them."

Even the most difficult news, once out in the open, relieves the anxiety that uncertainty creates. The good news is that people living with Parkinson's today have more room for optimism than ever before, so the conversations, while understandably difficult, need not be without hope.

"And it can be an opportunity to talk about the ups and downs of life in a developmentally appropriate way," says Lisa.

The Road to Reassurance

What children need most is reassurance. Sandy R. was diagnosed in June 2003. When she first told her daughter, the 14-year-old was concerned and shocked. "I told her right away that it's not something that's going to kill me," says Sandy. "I could see that relieved her tremendously."

Provide reassurance that, although things may be a little different, you'll continue to be there for them in

ways that matter. Of course, it's important to balance optimism with reality, and not make promises you may not be able to keep. You might want to use words like, "I think I'll be able to. . . I'll try to. . . or I hope to. . ."

Children also need to know that Parkinson's is not contagious. They can't catch it like they can get a cold or the chicken pox. Older children also may be worried that, since they're related to you, they will contract the disease themselves eventually. But with today's research leading in the direction of predisposition combined with environmental factors, you can comfortably reassure them that is not likely to happen.

As unlikely as it sounds to an adult, young children may need to be told that it's not their fault a parent has Parkinson's. Be aware of what child development experts call "magical thinking," which is normal and common. Children can feel guilty when things go wrong around them, and believe that in some way they are to blame. A simple statement such as "It's too bad that I have this problem, but it's nobody's fault. It's just one of those bad things that happen sometimes," can help relieve a child from their perceived burden of responsibility.

Be Prepared to Repeat Yourself

Young children learn by repetition, so don't be surprised if they ask you to repeat your explanations time and time again. This can be frustrating for an adult, especially if you are trying to keep a positive attitude



and not dwell on your problems. Ongoing reassurance and honesty are important to building their acceptance and understanding, so answer their questions as often as they need to ask them.

CONSIDER AGE DIFFERENCES

What is Developmentally Appropriate

Therapist Lisa Lieberman stresses that it is important to make the information available to kids at a developmentally appropriate level. Particularly at first, you may want to talk to each child individually if they have different information needs. A six-year-old may just need to be told that a part of mommy's brain isn't working like it should, and that makes her move funny, but she's going to be okay. An adolescent may need more specific information about the disease.

Outside resources can help in guiding your discussions. The American Parkinson Disease Association, Inc. Young-Onset Information & Referral Center publishes a free booklet called *My Mommy has PD . . . But It's Okay!* Written at a third-grade reading level, it can also be used as a read-aloud booklet for younger children. *What's Wrong with Grandpa?*, published by the Central Ontario Region of the Parkinson's Foundation of Canada, also is useful.

There are a variety of good Web sites with information at all levels. "I showed my teenage daughter Michael J. Fox's Web site," says Sandy. "We talked about how they are spending a lot of money on research, which could help me. That was reassuring to her."

Consider Outside Help

According to The National Parkinson Foundation, "sometimes adolescents can benefit from professional counseling to help ease the struggle of having a parent who is less than physically perfect."

Lisa Lieberman agrees. She says that it is important to try to tease apart the strands in family dynamics, to determine what issues are really due to the general make-up of the individual or family and what is about the PD. The combination of those elements can be a complex interaction that a specialized therapist can help a family work through.

EXPLAINING THE PHYSICAL EFFECTS

Children are naturally curious about — and even frightened by — the physical changes that Parkinson's can bring.

"The jerking from the medicine, or tremors from the disease, the difficulty in moving or stooped posture, these things may be alarming to young children," says Gloria Bock, A.P.R.N., B.C., program coordinator of the Regional Parkinson's Center at Aurora Sinai Health Care in Wisconsin. "But when these things are explained in language they can understand, their curiosity is satisfied and their fear diminished."

Here are some simple ways to explain to children the physical symptoms associated with PD and the effects of medication.

- **Freezing** – The message from my brain to move my legs just doesn't get through.
- **Stiffness** – It's kind of like the sore muscles you get after playing sports.
- **Stooping, Balance or Shuffling** – Using a cane helps make walking easier.
- **Shaking or Tremors** – The parts of my brain that send the messages don't always work like they should. Sometimes it's embarrassing, but that's okay.
- **Mask** – Lack of expression in my face or voice doesn't mean I'm sad or angry, especially at you.



FIRST IMPRESSIONS CAN BE MISLEADING

When you're first talking to the children in your life about PD, keep in mind that their initial reaction may be misleading, and you may not want to take it at face value. In 1993, Jaci Dumler shared her diagnosis with her son and daughter, then 8 and 11 years old.

"We had a family meeting, where we just gave the top-line information — not a lot of detail at first — until the questions started coming." She thought that nothing could affect her happy-go-lucky son. But when they recently reminisced about that conversation, he shared with her how concerned he really had been. "Mom, I was freaking. I didn't know what to do." As every parent knows, children don't always express what they're thinking, and that goes double for adolescents and teenagers.

Sandy, whose symptoms are mild enough to go relatively unnoticed, says at first her daughter didn't seem to express much ongoing worry. "But later I heard from her best friend's mother that she had talked to her about it, and she was really upset and worried." Sandy's daughter was likely trying to protect her mother, fearing that expressing her feelings would make her mother feel worse.

In your conversations, it is important to stress to kids of all ages that their feelings are okay.

EXPANDING THE CIRCLE — FRIENDS AND SCHOOLMATES

Of course, the need to communicate about PD doesn't stop at your doorstep.

"You have to be honest with your kids' friends, too," says Liz S. of California. She works in the classroom with her 8-year-old and talks to the kids about it: "You know how everyone's bodies are different, right? Well, I have something different in my brain, where it doesn't produce the right

chemicals, so sometimes I shake. Just ignore it; it's not a big deal." That's all they need, she says. "They accept it. And then when it happens, they'll help me carry things, and they feel so important."

Jaci D. made it a point to show the deep brain stimulation (DBS) device to her son's friends. "The boys thought it was cool. They called me the bionic mom." On the other hand, her daughter was uncomfortable with that kind of openness, which she attributes to some of the natural self-image issues of being a teenager.

LIVING WITH THE DAILY UPS AND DOWNS

You know that living with Parkinson's means that some days will be better than others. A few practical tips may help your kids cope with the inevitable ups and downs and come to understand that the effects of PD are not always constant.

Allow All Feelings

Lisa Lieberman brings a unique perspective to her work in dealing with family issues related to chronic illness. Her husband has MS and their son is autistic. "One of the tools for my journey is to allow all feelings," she says.

Old parenting wisdom says allow feelings, limit actions. Give your kids a chance to voice feelings, even the seemingly forbidden ones like fear, anger, shame and resentment. "But there's a difference between hating how mom has PD, and how you need to treat her," says Lisa. "Another rule of thumb is to listen, listen, listen."



Be Comfortable With Yourself

We all know that keeping a positive attitude can affect our mental and physical health. So maintaining a certain amount of calm and acceptance about your circumstances can set the tone for your family interactions. If the parent with PD is constantly complaining or embarrassed, kids will pick up on that and act the same way.

Of course, that's not to say that you have to keep everyone's spirits up all the time. You need to experience your own emotions and give them validation. The key is to not get caught up in your emotions and let them drag you down.

Keeping your sense of humor certainly helps. Jaci believes being able to laugh at yourself is a key component to living with PD. "One time I was trying to fix supper and my arm started flailing. Here I am with a big knife, cutting potatoes. We all got a good laugh. You have to stay positive."

Encourage Understanding of Treatments and Effects

Parents with Parkinson's agree that you shouldn't try to hide what you're going through from your family. Doing so can backfire on you.

"It used to be that when I'd have my 'off' periods, I would go into my room rather than subject my family to it," says Joan S. "That was a big mistake, because they needed to see what I was going through in order to understand."

Greg H. has had two successful rounds of DBS surgery since his diagnosis in 1990.* He says his kids have become very sensitive to his needs when he goes in for what he calls his annual "stimulator appreciation day" where the device is turned off for 24 hours. "They see that I'm almost catatonic without it, and they have such an appreciation and understanding of what the technology does for me."

Greg is a vocal proponent of the DBS therapy after it had such a positive effect on his life, and he has advised several patients on the procedure. "I've taken my kids along on those visits," he says, "so they know a lot of people with Parkinson's." That exposure helps them gain greater understanding and openness about the disease.

**Results vary; not every response is the same.*



New Hope for Parkinson's Program

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THE SILVER LINING: UNEXPECTED POSITIVES

As difficult as it can be living with PD and raising kids at the same time, there are some positive aspects that arise for many people.

Raising Compassionate Kids

Joan sees her children developing into more compassionate, caring and non-judgmental people. When she has functions at the house that are attended by people with Parkinson's, her children anticipate their needs and help without being asked. "They are just so much more aware of other people's needs."

Developing Responsibility

When a parent has PD, the tendency can be for kids to help out more with things their parents can no longer do. When Michelle L.'s husband is out of town, her older son helps tie his little sister's shoes and button her shirt, and he feels good about helping. The children are definitely learning independence. "They love that they get to cook certain things, and sometimes even fight over who gets to do the dishes," she says.

Jaci has seen changes in her children. "My daughter has definitely gotten more independent. She does a lot around the house that she wouldn't have had to, and I think it has made her a better person." Does her daughter resent the extra work? "In the beginning she probably did, but now that she's an adult, I think she knows it was good for her development."

Jaci first started having freezing episodes about two years after she was diagnosed. Her son heard her calling for help when she couldn't get out of bed. "He came and helped me by getting my pill. That helped him, to know that he could help me."

Liz agrees, saying that her son likes feeling that he's helping. "Of course, you have to let them be a child," she says.

That idea gets a firm nod from therapist Lisa Lieberman. "It's important not to parentify kids," she says. They may learn more responsibility, but they need permission to be kids, have friends and be normal in that respect. "They are not there to be in charge of everything. They need to have some of the carefree spirit of being a kid." There is a fine line between developing an appropriate sense of responsibility — not pretending that things aren't any different — and putting too much onto their shoulders.

Learning Acceptance

With patience, persistence and openness, families can experience a growing sense of acceptance and matter-of-fact handling of PD in their lives. "The disease is just a matter of course in our lives," says Michelle. "But it has brought us closer in different ways." Her children are very protective of her, and also have grown very close to their father because he's taken over a lot of the things that she can't do.

They have learned what people of any age would do well to learn: Although there are changes in their life, they can work through them together. Issues like this can be an opportunity to teach your kids a basic tenet of life — that what happens to us may not be completely in our control, but how we handle it is up to us.

Important Safety Information

Activa® Parkinson's Control Therapy: Patients should always discuss the potential risks and benefits with a physician.

Indications: Bilateral stimulation of the internal globus pallidus (GPi) or the subthalamic nucleus (STN) using Medtronic® Activa® Parkinson's Control Therapy is indicated for adjunctive therapy in reducing some of the symptoms of advanced, levodopa-responsive Parkinson's disease that are not adequately controlled with medication.

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Warnings/Precautions/Adverse Events: There is a potential risk of tissue damage using stimulation parameter settings of high amplitudes and wide pulse widths. Extreme care should be used with lead implantation in patients with a heightened risk of intracranial hemorrhage. Do not place the lead-extension connector in the soft tissues of the neck. Placement in this location has been associated with an increased incidence of lead fracture. Theft detectors and security screening devices may cause stimulation to switch ON or OFF, and may cause some patients to

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Health information changes quickly. Therefore, it is always best to confirm information with your health care professional.

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