

Parenting Children and Teens

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Parenting, even under the best of circumstances, is a challenging and often stressful endeavor. When one has young onset Parkinson's disease, being an effective parent can be an even greater challenge. You must decide when to tell your children about your condition, what to tell them, and how to best help them cope with changes occurring in the present and those to come in the future. While there is no single or "right" way to address these concerns, the purpose of this article is to provide general guidance in these areas.

Educate Yourself About PD

Having a comprehensive understanding of PD is the first step in not only helping yourself live well with PD but also in helping your children understand and adapt to the changes to come. Actively pursue reliable information about PD. The more you understand about the disease and how it progresses, the better prepared you will be to make the best decisions about your own healthcare, and to accurately answer your children's questions.

Explain PD to Your Children

As a general rule, you should tell children sooner rather than later. Children are perceptive and will likely know that something concerns you. Choose a quiet time when your children are rested and are able to engage in a conversation. If you have children of different ages, you might speak with your older children first. Perhaps the older children will want to help you tell your younger children. Try to have these conversations as close together as possible so that all members of the family are aware of the situation and have a chance to support each other.

When explaining PD to your child, strive for age-appropriate honesty. With younger children, provide information using simple language that your child can understand, such as the name of the disease and symptoms they may initially observe. Over time you can add to their understanding of PD. With older children and adolescents your initial explanations can be more detailed. However, regardless of your children's ages, explaining PD to your children should be viewed as a process that occurs over time rather than a one-time event. Remember also *how* you speak to your children is as important as *what* you say. Using a calm reassuring voice, even if you become sad, will help your children see how you are trying to cope. It will help them do the same.

Discuss with your children the symptoms of PD they are likely to see in you. With young children you should probably keep your description of symptoms focused on what they might be noticing right now, and wait to discuss any symptoms that might occur in the future. With older children and adolescents you might want to discuss potential symptoms in advance to help them prepare for upcoming changes.

Invite Questions

Let your children know that you are available to answer any questions they may have. Try to anticipate common questions your children might ask, and think about how you might respond. Depending on their age, expect them to ask questions such as:

- What is PD?
- What causes PD?
- Is PD contagious?
- Can it be cured?
- What is the treatment for PD?
- Are you going to die?
- What is going to happen to you?
- Can it be inherited?

Younger children often believe that their behavior is powerful and that they may be responsible in some way for your being sick. They may believe that they could have caused your PD by being “bad” or by not being “good enough.” They may wonder (out loud or to themselves) if they behave better will you get better? Reassure them, as often as is needed, that their behavior has in no way caused or contributed to your PD.

Provide enough information to adequately answer their questions, but stop short of giving too much information so they are not overwhelmed. Remember that children, especially young ones, tend to have short attention spans, so do not talk longer than they can listen. Having more frequent, brief discussions may be more helpful and productive than the occasional, more structured, and emotionally intense family meeting. Make your illness part of your family's ongoing dialogue, but try not to have it be your primary family focus.

Help Your Children Deal with Their Feelings About PD

It is hard to predict how a specific child will react to the knowledge that his or her parent has PD. Make every effort to help your children deal with the range of emotional reactions they might have. You can do this by providing support, listening to your children, and discussing their feelings. Some children may resist discussing their concerns or feelings in order to protect their parents from becoming upset. It is critical that children know they can talk to you about any concerns or feelings without fear of being judged negatively or causing you to become overly upset. You should also keep in mind that your child's thoughts and feelings about the illness may change over time. This is why it is important to keep the lines of communication open. Ask your children on a regular basis if they have any questions or issues they would like to talk about. To encourage conversation, try asking open-ended questions (questions that cannot be answered with a one-word response such as “yes” or “no”).

Older children and teens might need additional outlets to express and work through their emotions. Options may include: journaling, poetry, exercise, counseling, or a teen support group. The goal is to find the outlets that work best for your child.

Over time, watch for any emotional changes in your children that might indicate they are stressed from worry. Check to see if they are confused or have misinformation about PD. Sometimes children hear misleading information from other people and have unfounded worries about something that isn't true.

There are also a number of resources available to help children understand PD. The American Parkinson Disease Association publishes a booklet for young children entitled, *My Mommy has PD...But It's Okay! A Guide for Young Children about Parkinson's Disease*. You can also check with your local library, bookstore, or APDA for other helpful resources. It is important to remember that books should be used as a supplement to one-on-one discussions with your child and never as a replacement for talking to your child about PD.

Prepare Your Children for the Reactions of Others

Children often do not know how or what to tell others about their parent's condition. You can help your children by suggesting some simple and concise explanations of the disease and how it is treated. It may help for the parent and child to role-play examples of questions others might ask. Do not avoid doing things

with your child because you are concerned about the reactions of others. Your child needs you to be an active, involved parent, regardless of the presence of PD.

Older children and teenagers may feel self-conscious or embarrassed about having a parent who is “different.” Getting them involved with other children who are also living with a parent who has PD can be a source of encouragement and support. You can find this type of support in a teen PD support group, if one is available in your area. An alternative would be any group that provides support to teenagers who have a parent with a chronic illness.

Teenagers are often more masterful at retrieving information from the Internet than their parents. While you should encourage them to learn as much as they can about PD, it is also important that you help them understand that they must seek out reliable sources online (see *Traversing Technology* section). Provide your children with Web sites you know are sound sources of information about PD, and help them utilize the information they obtain by talking it over with them. It is also important to emphasize that PD affects each person differently.

Be Mindful of What Your Children Can Overhear

Children are naturally curious and will often make an effort to listen in on conversations that go on between their parents. This is especially true if they are worried about something. Avoid discussions regarding your concerns or issues related to PD when your children have the potential to overhear what is being said.

Have Fun with Your Children

One of the best ways to strengthen your relationship with your children is to have fun together. Find interactive activities that you and your children enjoy doing together. Choose activities that will be manageable for you but also bring enjoyment for everyone involved.

Preserve Family Routines and Set Limits

Make an effort to maintain your normal schedule, such as wake-up times, meal-times, bedtimes, and other regular activities, as much as possible. Children typically do best when their daily routines are predictable and consistent. Of course, this is not always possible, but making an effort to maintain regular routines and schedules for all family members will be reassuring to children.

Many parents feel guilty that their children have to endure the consequences of living in a household with PD. As a result, some parents with PD are reluctant to set firm limits and appropriately discipline their children. However, children do best, even amid health concerns, when there are clear boundaries and they know what they can expect from their parents.

Work with Your Children's School

While you attend to the relationship with your child on the home front, it is also important to work closely with your children's teachers. Consistent contact with teachers will give you additional clues about how your child may be adjusting to any PD-related changes in you or in the family dynamics. Is schoolwork being completed correctly and on time? Are there any behavioral problems in class or with peers?

Regular contact with teachers will also allow you insight into how you can best help your child explain to peers what living with PD is like. To help your child, you might do a presentation on PD for his or her class or work with teachers to allow your child to do a research project on PD to learn more about the disease.

In addition, make an effort to keep your children involved in extra-curricular activities and social events. These activities offer another avenue for your child or teen to find support from others such as friends, coaches, and teachers.