

# Talking to Your Teen About Parkinson's Disease: FAQs From Parents of Teenagers

Parenting is one of life's greatest challenges even without a chronic illness. Throwing Parkinson's disease (PD) into the mix can add many hurdles and can introduce a seemingly endless set of questions: *Should I tell my children about my PD? How do I tell them? When do I tell them? What do I tell them? How might they react?* Below are frequently asked questions from the parents of teenagers and some potential answers that may help you navigate life with PD and teenagers, including suggestions on how to communicate the diagnosis, prepare for potential reactions, and ultimately remain an active, involved parent.

**Question:** *Do I really have to disclose my diagnosis? Why would my teens need to know about my Parkinson's disease? Do I have to tell them myself?*

**Answer:** PD is a visual diagnosis which means the people around you may notice your symptoms. This includes your children. It is therefore likely that your children, especially teenagers, have already sensed that something is going on. Telling the truth about your diagnosis may therefore be reassuring to your teens, while *not* telling them can potentially enable them to develop their own theories, which may be worse than the truth. Providing information and education to your teens about your experience with PD will also allow them to confidently explain what is going on and answer questions from friends who might have become concerned about you.

Whether you are the person to tell your teens about your diagnosis ultimately depends on your relationship with them. However, you are the expert in your experience of living with PD. This means you are likely the best person to answer questions about your symptoms and prognosis. Having someone else tell your teens has the potential to make things more complicated. If you're uncomfortable telling them on your own, consider having someone else there with you whom your children trust – a spouse, a relative, or close family friend.

Until your teens know about your diagnosis of PD, it is important to remember to be mindful of conversations you are having pertaining to your diagnosis in their proximity. This will help you avoid disclosing your diagnosis in an uncontrolled manner.

**Question:** *How should I tell them? What should I tell them? When is the best time to tell them?*

**Answer:** How you approach the conversation really depends on your teenagers and what you think will be the best environment or time for them. In some situations, it may be helpful to have a big family meeting. In other families it may be more suitable to have individual private conversations. Keep in mind that there is never truly a “good” or “right” time to have difficult conversations. It is important, however, that enough time is planned in which to have the conversation, so that your teens can ask all their questions. This is not a conversation to rush through. It's best to plan for a time you know your teens will be home for a prolonged period of time. This will help you avoid inciting panic or anxiety, and allow you to keep the conversation casual.

**Question:** *What are the different reactions I can expect? Are there questions I should be prepared to answer? Will we have to talk about it again?*

**Answer:** There are a wide range of possible reactions and these can change over time. Some teenagers may be very scared or worried, while other teens may seem avoidant or dismissive. During the conversation, make sure your teens have the opportunity to vocalize their feelings and ask questions without fear of hurting your feelings. Try not to force the conversation. Teenagers are limited in their life experiences, existing primarily in the here and now. Immediate reactions may seem self-centered and focused on their friends' reactions, or on the ramifications of the diagnosis on their own lives. They may ask: *Can you still drive me to soccer practice? Are you still coming to my dance recital? Does this mean I'm going to have more chores? Is that it, can I go now?* Try not to be insulted or take their initial reactions personally. On the other hand, some teens might get overly concerned about you and be afraid that you are dying. A third possible reaction is concern for their own health. They may ask: *Are you contagious? Does this mean I will also get Parkinson's?* These are all serious questions and should be answered honestly. This is a long-haul disease so disclosing your diagnosis will likely be the first of many conversations. Give your teens the time and space to digest the information and don't push them to talk if they are resistant. But be ready to talk more when they are ready.

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**Question:** *How will my diagnosis of PD impact our relationship? Is it possible to continue life as normal and avoid disrupting their lives? Are there personality changes I can be mindful of? Should I tell their school?*

**Answer:** Teenagers will not often specifically say they need you, but they do. Regardless of your diagnosis or the age of your children, they need present, supportive, and active parents. Disclosing that you have PD does have the potential to build individual and family resilience as well as strengthen bonds. While some teenagers will rise to the challenge, others may withdraw. You should be mindful of your teens' mood and look out for anger, depression, and anxiety. In an effort to try to get ahead of some of these potential personality changes, encourage your teens to ask questions.

PD might make you look or sound different than other parents – you might have dyskinesias (a type of uncontrollable movement) or a soft voice, for example. Your teens may try to avoid you because they are embarrassed by something that may be perceived to them (or by others) as “weird.” Rather than accept avoidance or awkwardness in these situations, it's better to acknowledge the discomfort. If your teens are open to discussing your diagnosis, ask them to let you know if you do something strange or are acting differently.

Early on, your PD should not impact your teens' schedule. Young people thrive on structure and it's important to try your best to maintain established routines. If your teens are athletes, musicians, or actors, continue to support them by going to games and related events. Of course, this may vary across situations and if it's not possible, you should communicate with your teenagers about impending changes. You should continue to engage in family traditions, fun activities, and celebrations as you are able. It may be valuable for you to request patience before outings or events if it may take you longer to move and do things. A positive attitude, optimistic demeanor, and sense of humor can make an incredible impact on both you and your teens' outlook on life.

As for disclosing your diagnosis to your child's school, you should have a conversation with your teens asking

their opinion on whether to disclose your diagnosis to the school. Ultimately, you want to listen to your teens and respect their decision. If your diagnosis will impact your ability to perform some expected parent duties at or for the school, it may make things easier if the school understands the reasoning behind that.

**Question:** *What is the best way to ask for help with tasks? How can I avoid asking for too much help?*

**Answer:** Most families encourage children to help around the house or assign chores regardless of any illness. If you begin to need help with certain tasks, you can incorporate these new tasks or responsibilities as part of your teens' role in the family. Try to frame additional chores as activities that help the household, not as something that your teens need to do because you have PD. Be reasonable with how much you ask your teens to do and make sure it is within their physical and emotional capability. Consider asking for help from people other than your teens as well (i.e., other family members or relatives, neighbors, etc) so that you're not always asking the same person for assistance and not putting too much pressure on anyone. It is likely that you'll find most people are happy to help.

**Question:** *Can my diagnosis influence my teen's health?*

**Answer:** Yes, it can. While acting embarrassed and distancing themselves from their parents is common in teens (regardless of any illness), it's imperative to be aware of withdrawal, anxiety, depression, or rage. Be mindful about the increased difficulty for your teenagers to relate to their peers. Most of the people they will socialize with in their age group will not understand what they are going through as they will not have had any comparable experience.

In addition, some teens may not want to complain about their own problems if their parent is sick. They may perceive their problems as not significant enough in the face of PD. You should discourage this type of thinking and instead reinforce the importance of your teens communicating to you about their mental and physical health. Just because you have PD doesn't mean they didn't have a terrible day at school and need to talk about it.

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Many patients worry about the possibility that they will pass on a PD gene to their children. In reality, however, the increased risk is small. Your teens can decide on their own whether to undergo genetic testing for PD when they reach adulthood. The field of genetics is ever expanding and by the time your teen enters adulthood, there will be many more PD genes available for testing than there are now.

**Question:** *What about their goals and independence? How does my diagnosis affect my teen's ability leave home? What if my college student/independent wants to come home?*

**Answer:** When your teens reach the time to leave home, they may be eager to do so (as many teens are). If that is the case, you should accept and support their decision. Some teens however, may be more nurturing or feel compelled to stay behind and help if a parent is ill. If that is the case, it is important to have a conversation with them specifically addressing their goals and plans for the future. Remind them that they are responsible for their own lives and their own decisions. If they currently do a fair amount to assist you, you can make arrangements to have those tasks handled by someone else when they move away and reassure them that you will be ok while they are gone. Most parents want their teens to have positive opportunities and are eager to celebrate their successes as they evolve into adults. Your teens should feel supported to create their independent lives.

**Question:** *How can I support my children and help them understand my diagnosis? What resources are available to us?*

**Answer:** It's important to keep in mind that your teens are at an age of rapid emotional changes. You should expect your teens' feelings to change over time, so it is good practice to check in with them once in a while. If you have a teen that is more open and interested in your life with PD, feel free to include him/her in different activities such exercising together. If your teen is more avoidant or disinterested it is okay to acknowledge those behaviors.

You might want to encourage your teens to talk to someone such as another family member, friend, coach, spiritual leader, or therapist. If your teen is open to additional support such as therapy, be sure to help your teen find support and resources. Many schools have a social worker on site or a referral system in place for students who need counseling. There also may be a local support group for children with chronically ill parents. With safe use, social media can be a great tool in connecting people who have similar experiences. Although the internet can be an endless source of information, it's important to remain cautious as the internet is also a source of misinformation, untrustworthy sources, and unfortunately malicious people. Supervision of your teens' online activity will help to ensure their safety and also ensure that the information they are consulting regarding your PD is accurate. If you have teens who are interested in learning more, you can give them direct links to credible websites such as ours ([apdaparkinson.org](http://apdaparkinson.org)) which is a tremendous source of useful information about PD.



Every person's journey with PD is different, and every teenager and how he/she reacts to the news of a PD diagnosis is different. Open and honest communication can make a tremendous difference in how you move forward as a family and will enable you to support each other along the way.

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