

TIP SHEET

My Parent Has Parkinson's. What Does It Mean?

Information for children and teenagers who have a parent or other relative with Parkinson's disease

Parkinson's disease is a slowly progressive disorder. This means it gets worse over time. Parkinson's affects how you move and other functions within the body. Dr. James Parkinson first described the disease in 1817, so it was named after him. One area of the brain that is affected is the substantia nigra, meaning black substance (for how it looks when you cut the brain open!). A neurotransmitter—a chemical messenger in the brain—called dopamine is made in the substantia nigra. Dopamine allows nerve signals to travel from one nerve cell to another, sending messages to the muscles of the body. This is how we move, without really thinking about it. When the cells that make dopamine are lost, Parkinson's symptoms appear. These symptoms, such as tremors and slow movement, are how a doctor knows that someone has Parkinson's and not another disease.

There is a lot of research being done all over the world to understand the cause of Parkinson's. Most scientists agree that the cause includes a combination of genetics the environment. There is also a lot of research being done to find better treatments to improve life for people with the disease.

What does Parkinson's look like?

Parkinson's disease, or "PD" for short, does not look the same in everyone. People can have different symptoms, and problems can show up slowly over time. Here are some of the symptoms that affect people with Parkinson's:

- » Tremor (shaking)
- » Rigidity (stiffness)
- » Bradykinesia (slow movement)
- » Quieter voice
- » Smaller handwriting
- » Body pain
- » Fatigue (feeling tired)
- » Depression and anxiety
- » Difficulty with thinking clearly



How is Parkinson's treated?

Doctors, nurses, physical and occupational therapists, social workers, speech therapists, and other professionals work with people with Parkinson's to help them enjoy happy, active lives.

There are many kinds of medications that can help people with Parkinson's. These medications make it easier to walk, stand up and sit down, and do other things that are part of a normal day. Sometimes the medications that help with Parkinson's can make people dizzy, tired, or have an upset stomach. But most of these problems can be improved by finding the right combination of medications.

How will PD affect me?

Things will change over time as Parkinson's progresses – your parent's Parkinson's symptoms will change, so family plans, finances, and responsibilities will change, now and for the future. Talk with your parents about your concerns. Together you can figure out solutions.

You may have to do tasks in the house that you did not have to do before. You may also have to help your parent with daily tasks or activities, like getting dressed or cooking meals. You may feel you have to do these chores, but you do not have to like it. It is ok to be angry, sad, resentful, frustrated, embarrassed, or guilty.

The things your parent with Parkinson's can do – and the things you can do together – may change over time. It is important to think about different ways to stay connected with your parent and create new activities that you can do together. While your parent will always be your parent, PD might mean that you have to change what you expect of your parent and your family life.

What can I do?

- » **Think about having regular family meetings**, once a month or even once a week. Use this time to share with your parents how Parkinson's makes you feel. They can also explain some of what they are going through. This will help you understand each other better, and you can try to find ways to help each other and reduce stress.
- » **Talk to someone** – whoever you feel a connection with. This could be a friend, relative, teacher, or counselor. You may have concerns or worries you don't feel comfortable telling your parents about. Expressing these feelings might help you feel better, and the person might have good advice.
- » **Get involved.** Sometimes we feel better when we can DO something to improve a situation. Go to a local Moving Day®, organize your own fundraiser to support PD research through Team Hope™, or raise awareness of PD at your school, church, or other community center.
- » **Connect with other people your age.** You are not the only one with a parent with Parkinson's disease. If your parents are in a Parkinson's support group, they might know other people with PD who have kids that would like to talk or hang out.
- » **Try different activities to cope and manage stress:** Exercise, stay involved in your favorite activities, eat well, get lots of rest, and continue to have fun!
- » **Get more information.** Instead of Googling “Parkinson's disease,” check out Parkinson.org. It might be a good idea to look at the website with someone who can help you understand the information, like a relative, adult friend, teacher, counselor, or coach. Maybe you can look at the site with your loved one with Parkinson's, so you learn together.

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