

Sharing Your Diagnosis

Hearing from your doctor that you've been diagnosed with a movement disorder can be difficult. Telling those you love about your diagnosis can be almost as hard. When do you tell them? How do you tell them? What should you say?

When should you share your diagnosis?

You're in control of when you tell people about your diagnosis. Many psychologists recommend that you wait until after you've come to terms with the diagnosis and feel emotionally ready to tell others.

However, waiting also has its downsides. Close family members, friends, or coworkers may notice something is wrong, even if they don't know what it is. They may feel hurt when they later learn that you've been hiding something from them. Plus, the support you receive from close friends and family is important from the start.

So, there are key people in your life that you'll want to tell almost immediately. For others, you'll want to wait and have a strategy in place before sharing the details of your situation.

What should you tell people?

The details you share will differ depending on the person and their relationship to you. But, there are a few basic points you may want to include:

- That you've been diagnosed with Parkinson's/Huntington's/Wilson's/etc disease, which is a type of movement disorder that can affect the ability to perform common, daily activities.
- The disease is progressive, meaning the symptoms will become more noticeable over time.
- My condition affects everyone differently, so there is no way to predict how quickly it will progress or what changes you will see.

People may have questions, and it's okay to tell them that you don't have all the answers or simply aren't ready to discuss them right now.

How you explain your condition to your others depends largely on age and your relationship with that person.

You can explain it to them in simple terms. It can be as basic as, "I have an illness that will affect my movements and I may need help doing some things." You don't have to give them all the details, especially not right away. But it's important to be honest with them and let them know what is going on.

Most people are also capable of finding those details online, so it's best to be open with others and let them hear the facts directly from you. You can also encourage them to come to a doctor's appointment with you, attend a class, or join a care partner support group.

Starting the Conversation

First, have the conversation. That may seem obvious, but many people avoid it. They don't want to burden their child, partner, and friends. The first conversation can be as simple as asking what the other person knows about the condition. It may scare you to ask, but starting with where the other person is in terms of knowledge will be very important. That way, you can gauge what they already know, dispel any myths, and fill in gaps. Second, it can be important to discuss the disease early in the diagnosis. Most people have access to social media and the Internet, more so than ever before. Unfortunately, this access does not always mean accurate information or information presented in an understandable manner. This first conversation does not need to be long or in-depth. In fact, often the best way to handle it is to use the exchange as a way to open the door to future conversations. No pressure, just start the conversation.

Having the Conversation—FAQS:

Below are a couple frequently asked questions to help start and move forward the conversation

Question: What if the person I tell does not want to talk about my diagnosis?

The other person may not want to talk and that is OK. What you are doing by starting the conversation is showing them that it is OK to think about it, talk about it, and ask questions. Here are a few suggestions to help guide the initial conversation(s):

- Provide the space and let them come to you.
- Tell them they can come to you at any time when they are ready.
- Tell them support from your doctor and team is available.
- Make the conversation normal with no pressure. It may take a few starter conversations, but being available and open will help smooth the way to a full conversation.

Question: What if they ask a question I am not prepared to answer?

Think about possible questions, things that make you uncomfortable. How would you like to talk about it? What would make you comfortable? This can be setting, time of day, or other people involved. Show your willingness to discuss difficult issues.

Start with saying something about your diagnosis that makes you uncomfortable, perhaps how something has changed.

For example, "I am sad that I have difficulty doing..."

Answer honestly and don't be afraid to say you don't have answers or that "we will find out as we go along."

How and What to Talk About

You can get the best support possible by planning the conversation. Consider including three items:

- "Process" talk
- Specific problem
- Suggestions for how loved ones can help

"Process" talk means "talking about talking," rather than talking to share information. Prepare your listener for an important conversation by using "process" talk. Here are some ways to begin a process talk:

- "I want to talk to you about something important. I'm not sure how to talk about it, though. Can you just listen to me? I'm hoping I'll feel better after talking about it with someone, but I need you to be patient."
- "There's something going on with my health that I need to talk to you about. I am still not very comfortable talking about it, though, so please know I may ask to pause the conversation if I am getting too overwhelmed."

Concrete examples of what is meant by your condition. Every movement disorder is different. To get the best support possible, share one or two examples of how your diagnosis is affecting you now:

- "The doctor said I have Parkinson's disease. Parkinson's can affect someone's movements and mood at times. Some people may have a tremor, slowed movements, and speech changes."
- "Huntington's affects everyone differently, so there is no way to predict how quickly it will progress or how I will be affected."
- "There is currently no cure for the disease, but there are treatments that can help."

Suggest ways to support you. Family and friends may not know what they can do to help. You can get the best support by asking for specific types of help:

- "I'm not comfortable with talking about my diagnosis all the time, and it especially makes me uncomfortable to talk about what will happen in the future. Can you please respect my wish to not talk about it at certain times?"
- "Please be patient with me."
- "I need a lot of love and support. Can you just tell me you're there for me and give me a hug?"

By telling the right people and suggesting ways for loved ones to help, you can start building a strong social support network. At first, you might be afraid to talk about your experiences. But don't give up looking for support and encouragement from others. You'll discover that many people want to help you.

You don't have to share everything. Decide in advance what parts of your experience you'll talk about and what parts you won't. Stand by your decision. It's perfectly understandable to answer a question with a statement like "I'd rather not talk about that right now."

Set boundaries. Be clear with people about when you want their advice and when you just want them to listen. Also realize that people come with their own opinions, informed and otherwise, so be patient when explaining.

Let them know how they can support you. Everyone has different needs, and different people respond in different ways. Think about your needs ahead of time, about whether this person can support you, and if there are resources that would help them understand what you're going through. Some people may not be able to handle disclosure, so it may be difficult to expect support from them. However, there are many people who will probably feel honored that you shared this with them, and whom will be happy to do what they can.

Provide them information after you talk to them. Pamphlets and books are a good place to start. Your Northwestern team has wonderful resources you and your family.