

SHARING YOUR PARKINSON'S DIAGNOSIS AT WORK

A Practical Guide

Rachel Dolhun, MD

Medical Communications
The Michael J. Fox Foundation

Marti Fischer

Career and Professional Development Consultant
www.martifischergroup.com



THE
MICHAEL J. FOX
FOUNDATION

Every person's path from a Parkinson's disease diagnosis to open discussion is unique.

The decision around if, when and how to bring professional colleagues, in particular, into the conversation is based on many personal factors — and you are under no obligation to talk about your disease at work. Those who have, though, typically say they wish they hadn't kept Parkinson's a secret for so long. Speaking to *The New York Times*, Team Fox member Nancy Mulhearn of New Jersey, a school secretary, said: "I didn't want anybody to feel sorry for me. To have people look at you and start crying — that's not what anyone wants." But, she told the paper, she regretted having waited years to talk openly about her Parkinson's at work.

Still, there are many reasons people do, including very real concerns about what Parkinson's disease (PD) may mean for their working environment and career path. These fears may be perpetuated by widespread misconceptions about who gets Parkinson's and misinformation about

associated symptoms and disease progression. Additionally, people may not wish to explain motor symptoms to their colleagues or mention non-motor symptoms — depression, fatigue or cognitive disturbances — that may potentially affect their work.

If you are thinking about sharing your Parkinson's diagnosis in the workplace, consider these step-by-step guidelines — developed with career and professional development consultant Marti Fischer — to help you outline your strategy, create talking points, deliver your news and navigate your audience's reactions. "When it's time to share your diagnosis, having a solid plan in place will allow you to be proactive and control the flow of communication. Taking time to consider the culture of your organization and the qualities of your audience will help you find a comfortable way to integrate Parkinson's into your work life," says Fischer.



Practical Tip #1:

Get the Facts about Parkinson's Disease

Knowledge is power — the more you understand about Parkinson's, the more you can help others understand and the easier it may be to talk to your coworkers about your diagnosis. You can help dispel myths about Parkinson's and diminish stigma, especially surrounding younger-onset disease. It may be helpful to familiarize yourself with the provisions of the Americans with Disabilities Act. The official website of the ADA (<http://www.ada.gov/>) offers a wealth of resources and information that will be useful when and if you should require accommodations to continue working with Parkinson's disease.

Practical Tip #2:

Decide When to Talk about Your Parkinson's

To direct when you will reveal your Parkinson's diagnosis to your colleagues, create a personal indicator based on your individual symptoms and situation. This could be general, like when you begin taking medication to control symptoms. Or, it could be more defined, such as a specific timeline that takes into account work deadlines and promotion schedules.

Practical Tip #3:

Make a Communication Plan that Reflects Your Workplace

The culture of your workplace can help inform the sequence in which you tell your colleagues and manager. Construct a list of everyone you will tell, in order of when you will tell them. If helpful, make notes about their personal styles and how they might react to your news. Make the invitation to meet informal if that sets an appropriate tone. The meeting itself shouldn't take longer than 15 minutes.

Practical Tip #4:

Craft Your Narrative Ahead of Time

Your conversation can be concise but it doesn't have to be mechanical. Make sure to let your personality shine through. As you build your narrative, the following structure may help you shape talking points:

- » State the facts about your diagnosis.
- » Describe your current symptoms and what you can expect, if you are comfortable doing so.

- » Explain how — if at all — this information will impact your work and your coworkers.
- » Provide an "action step" to let them know how you can best proceed together in this new territory.

Practical Tip #5:

Harness the Power of Positive Non-verbal Communication

Nonverbal characteristics account for more than 60 percent of the factors that create our perception of someone. So creating a positive impression can be particularly challenging in Parkinson's where facial expression may be decreased or body language could be limited by slowness or stiffness. Some tips to maximize non-verbal communication:

- » Relax and take your time — obviously much easier said than done! To reduce tension, practice breathing deeply from your diaphragm, the muscle located just below your rib cage and above your belly button. (Many free online videos can help you learn this simple technique.)
- » Face the conversation with a confident stance. Parkinson's can cause a stooped posture, but just by bringing your intention to standing straight, you will look poised.
- » Adopt a positive, even tone, and don't raise your voice at the end of a sentence.
- » Maintain good eye contact with your listener.

Practical Tip #6:

Navigate Audience Reactions

Once you've delivered the news, give your audience time to process what you just told them. They may be caught off guard; they may possess little or no understanding of Parkinson's. They also could have no idea what to do with this information on a personal or professional level.

Assess the reaction — positive, negative, neutral or, likely, some combination — and respond as appropriate. In the case of positive or neutral reactions, you might ask if there are questions or share something you've learned since your diagnosis. When faced with a negative reaction, you may want to talk less and simply offer to keep the door open for discussion.

THIS IS A SENSITIVE ISSUE FOR EVERYONE. REMEMBER THAT THIS IS ONLY THE FIRST CONVERSATION YOU'RE HOLDING AND IT PROBABLY WON'T BE THE LAST. STILL, IT'S YOUR STORY AND YOU CAN REMAIN IN CONTROL OF HOW AND WHEN IT'S DISCUSSED. YOUR PARKINSON'S DOESN'T DEFINE YOU, AT WORK OR OTHERWISE.

