

SHARING YOUR PARKINSON'S DIAGNOSIS AT WORK

A Practical Guide

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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.



TALKING ABOUT PARKINSON'S AT WORK

A Practical Guide Part Two: Managing Long-Term Professional Relationships

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Parkinson's may now be part of your work life, but it doesn't have to — and shouldn't — be the focus in the workplace.

It may necessitate recurring conversations (as symptoms change or schedules need adjustment), but you have the ability to control the flow of information. Parkinson's is your story. You decide how to tell it.

The very same day he was diagnosed with Parkinson's disease, Dan Kinel, a lawyer in Rochester, New York, confided in his managing partner. Shortly thereafter, with Dan's permission, his managing partner told the other partners in the firm. Dan was fortunate to have his law firm's support as he came to grips with his diagnosis. Still, despite how quickly he shared his Parkinson's disease (PD) diagnosis and integrated it into his professional life, Dan admits that he, his colleagues and his clients had to adapt over time. In retrospect, he wishes he had given it a bit more thought. "I wasn't prepared for the reactions I often received," says Dan. "I remember telling one client within a few

weeks of my diagnosis and she started to cry in sympathy. Another time, I was asked almost immediately whether my diagnosis meant I'd be spending less time on client matters." In hindsight, Dan wishes he had been better prepared for the different reactions and ready to reassure his clients and co-workers that "I wasn't going anywhere, and I was the same person and professional I was the day before my diagnosis."

"A little bit of preparation goes a long way in allowing you to remain in control of how you share your personal information," says Marti Fischer, a career and professional development consultant, "including the how, when, why and with whom you'll engage in further disclosure."

If, when and how you bring your PD diagnosis into the workplace is a personal decision. Making your diagnosis public



may bring relief and lift a burden of hiding or explaining away your symptoms. At the same time, though, disclosing may raise new questions for you and your co-workers, and the reality is that it could change your work-related relationships.

In Part I of this series, Marti Fischer and Rachel Dolhun, MD, vice president of medical communications at The Michael J. Fox Foundation, offered practical tips for sharing your Parkinson's diagnosis in the

workplace, including tools for deciding when, tailoring a plan for your unique work environment, and navigating colleagues' initial reactions. In Part II, we provide recommendations for continuing the conversation and managing long-term professional relationships once Parkinson's has been brought into the open.

Read on for tips to plan for situations you may face in the workplace after sharing your diagnosis.

Practical Tip #1:

Continue the Conversation

In most circumstances, figuring out why people react in a certain way or what they are thinking is a challenge. Navigating reactions related to your Parkinson's diagnosis is no exception. In this regard, your initial disclosure may best be viewed as opening a line of continuing communication. When you first share your news, responses may vary from positive to negative to neutral (or some combination of all three). As daily activities and tasks resume and your Parkinson's is, over time, integrated into the regular workflow, initial reactions may change (for the better or for the worse).

Fundamentally, we are all creatures of habit, and individuals' ability and willingness to cope with change vary widely. For many, when confronted with new information, the most burning question (whether we admit it or not) may be: "How will this affect me?" Preparing for this natural human reaction will help you be proactive and prepare for frank conversations, which may be beneficial to engage in early and often. Changing Parkinson's symptoms could necessitate adjustments in workload, team structure or schedule. Talking with colleagues who will be directly impacted can prevent them from creating their own version of the story or feeling as though they've been left out of the information loop. With the assistance of managers (and, if applicable, human resources staff), these discussions can be productive for everyone. Keep in mind as you communicate changes in professional responsibilities:

- » **Frame conversations from your colleague's point of view.** Begin with the outcome. Directly state what changes in

workload or schedule mean for your colleague and you, and share how you hope these changes will help everyone continue to meet their professional goals. While you may not be certain of long-term plans, share what you know now and promise updates as you have them. Don't assume people know the preparations you are making; describe support strategies and other action items that are, or will be, in place, to help the entire team maintain its pace and volume of activity.

- » **Use positive body language and maintain eye contact.** Keep your head up and your shoulders back, and stand tall (sometimes easier said than done, since posture can be impacted by Parkinson's disease). The nonverbal confidence you convey will direct colleagues' responses to your statements.
- » **Modulate your voice.** Practice what you will say so your voice does not rise at the end of sentences. A rising voice often is perceived as a sign of uncertainty, which can detract from your confident and clear delivery. Parkinson's can make speech softer, less expressive, or even monotone. If you notice any of these difficulties, consider working with a speech therapist to improve communication.
- » **Pause.** Be concise. After you deliver your message, stop talking, take a breath and give your audience time to process the information.
- » **Keep the door open.** Leave room for questions immediately and in the future. Offer yourself, managers and the human resources department as points of contact. (Establish this protocol ahead of time.)



Practical Tip #2:

Manage Expectations

Sometimes when personal information — such as a Parkinson’s diagnosis — is revealed, a perceived shift can occur within the relationship. A colleague may believe that a new level of familiarity has been reached, which may result in awkward conversations going forward. Or a co-worker may choose to ignore the information and quickly return to “business as usual,” which could be equally uncomfortable. Recognize that others’ behavior changes likely have nothing to do with you, but stem from their own personal situations and experiences (e.g., having watched someone else go through a similar illness). Managing expectations in professional relationships over time is critical for maintaining workplace relationships and productivity. Three common scenarios you may encounter:

» **The Oversharing Colleague**

Someone with a relative or personal connection to Parkinson’s may feel a deeper connection with you or greater openness as a result of your disclosure. This colleague may bring up some aspect of Parkinson’s in many or most conversations. Decide your level of tolerance and comfort and, if you do not want to promote this facet of your relationship, be empathic but not encouraging. Don’t overshare in return. Bring the discussion as quickly as is polite back to the work at hand. For example, “I understand how you must feel. Maybe later I can tell you about some good support groups and resources I’ve found. But right now let’s focus on completing this project.” Be clear about your timeframe — “I only have a minute, can we discuss next steps on the project?” It also may be worthwhile to set a mental time limit before meeting with this person (i.e., plan that you will only spend one minute on non-work topics before steering the conversation to work-related issues).

» **The Ignoring Colleague**

Some co-workers act as though you never disclosed your diagnosis. For whatever reason, they may feel uncomfortable or uncertain about how to proceed with this new information. In these cases, maintain your pre-diagnosis working relationship and focus conversations around work and clients. Don’t force PD as a topic of discussion, but when the need for it arises, such as with changing symptoms or workflow adjustments, address the changes factually and succinctly. If you want to connect on a personal level, try inviting this colleague out for a friendly, non-work (non-PD)-related lunch or coffee. People often are more relaxed outside the office.

» **The Solutions-oriented Colleague**

This person is eager to assist in the “fight against Parkinson’s” and may ask regularly what they can do to help. Depending on your relationship, your personal involvement in the Parkinson’s

community and your comfort level, you could propose any number of activities. If you fundraise or host educational activities, you might invite them to participate. Or, you could suggest they volunteer for research (clinical trials need people without PD too), join a charity walk, or share resources with their peers or physicians. Be gracious and thank your colleague for their interest, but be clear that you can’t supervise or coordinate their engagement. (Unless, of course, you want to.) If you’ve chosen not to seek out a role for yourself in the PD community, interactions with this colleague could put you in an awkward position. When approached, don’t feel as though you owe an explanation or a personal invitation. A perfectly reasonable response would be to thank your co-worker for their interest but tell them you’re unaware of any opportunities.

Practical Tip #3:

Create Boundaries

You are the owner of information about your Parkinson’s. You get to choose if and how you share that information. Simply because a co-worker asks how you’re doing doesn’t mean you have to divulge personal details. Decide in advance of activities such as off-site meetings and office get-togethers what level of detail you want to communicate. A bit of planning will prevent you from feeling caught off-guard and disclosing more than you want to:

» **Give real thought to what you are and are not willing to share.**

Of course this varies from person to person, but you may wish to tell others when you were diagnosed or what symptoms you have. More specifically, you may want to explain that your tremor is part of Parkinson’s and not anxiety or “nerves.” Or, there may be aspects of living with Parkinson’s (such as depression or constipation) that feel too personal to talk about with work colleagues. We all have different thresholds for what we are comfortable sharing with people outside of our close friends and family. Remember: There is no obligation to talk about any aspect of your health or illness with your colleagues just because they may be curious. Practice steering the conversation to topics that may feel more comfortable, such as your engagement in the Parkinson’s community, participating in a clinical trial, putting on a bake sale to raise funds for research, or advocating for public policy changes impacting Parkinson’s disease. If you do choose to discuss these topics, be ready to invite others to get involved and be clear about managing their expectations for how you may be part of their efforts.

» **Decide when and how you’ll share.**

Situations that throw you and your co-workers together outside the everyday workplace — such as company outings and holiday parties — merit thought and planning ahead of time. If



the timing for a discussion about your Parkinson's is not appropriate (or you have decided you don't want to talk about your PD with that person), pivot the conversation. Ask them a question about themselves or redirect to another topic. If you have a trusted colleague, consider asking him or her to check in with you periodically to help keep discussions short and allow you to politely excuse yourself if necessary.

Practical Tip #4:

Craft "Push-button" Responses to Frequently Asked Questions

In and out of the workplace, certain questions are likely to arise when people learn you have Parkinson's disease. Having responses ready will help you control the conversation. In the communications field, we call these "push-button" answers. You may even want to practice a time or two with a trusted family member or friend so your answers feel natural (but not rehearsed). Keep your answers short and to the point, perhaps focused around three key points. A few of the most common questions people with Parkinson's tell us they're asked:

» **How are you feeling?**

You don't have to mention Parkinson's at all if you don't want to. "I'm doing well, thanks for asking. Between family activities, book club and how busy work is, life's a little crazy, but I'm good. How are you?" Or, if you do want to bring up PD, "I've got my good days and bad days but that goes for everybody, Parkinson's or not. Exercise really helps so I've been trying a new boxing class called Rock Steady. Have you ever heard of it?"

» **What can I do?**

To answer this question, you may want to first ask about the nature of the person's inquiry. Are they asking if they can do something for you personally or professionally, or do they want help the broader Parkinson's community? Once you've figured this out, ask yourself if you want or need their assistance. A few suggested responses on which to build:

- » "That's so kind of you to ask. I'm fine right now but can I let you know if I need anything in the future?"
- » "Depends on what you'd like to do. Here's a resource/website I use that shows all the different ways you can get involved."

» **Isn't Parkinson's an older person's disease?**

This is a great opportunity (if you want it) to educate others and lessen some of the stigma associated with symptom misinterpretation, especially common in young-onset PD. A good starting point: "That's a really common misconception. It's true that most people are diagnosed with Parkinson's at 60 or older, but Parkinson's does occur in people who are much younger. I was only XX years old when I was diagnosed." If they're interested, you can refer them to educational resources, such as those at www.michaeljfox.org, for more information.

Practical Tip #5:

Frame Your Diagnosis as a "New Fact"

- » To keep things in perspective in the workplace, make sure business and client relationship goals (not your PD) are front and center at all times. If you listed everything that described you — your character traits, relationships, activities, career, etc. — where (if at all) would Parkinson's fall on the list? Parkinson's is one of many things that now contribute to your makeup.
- » No matter when you're talking about your diagnosis (the first time you share it or over time, as symptoms evolve), frame your Parkinson's as a fact about you, such as your height or eye color. The objective is to have colleagues accept this as just another aspect of you, not the totality of you as a person. Remember: You are the sum of all of your parts. Parkinson's doesn't define you, your personality or your work. 🌿

*The information contained in this article is based on a series of hypothetical situations and is intended to provoke thought. It is not and does not contain medical or legal advice. Please note that a Parkinson's diagnosis doesn't automatically qualify one for disability insurance or other coverage. If you have questions about your personal health, please consult your medical provider or other knowledgeable resource. If you have concerns about your personal employment situation, or you suspect you have been mistreated in the workplace or terminated due to your illness, please consult an attorney.

