



Telling Coworkers, Friends & Extended Family: Choosing What to Share, With Whom, and When

One of the most personal decisions after a Parkinson's diagnosis—especially for individuals with **Young Onset Parkinson's**—is deciding **who to tell, when to tell them, and what to share**.

Disclosure is not an obligation. It is a choice rooted in your comfort, safety, and emotional well-being.

You are the expert on your life.

You control your story.

You Choose Who, When, and How Much to Share

There is no single “right” way to disclose.

You may choose to:

- Tell only a few trusted people
- Share more broadly with coworkers or family
- Delay disclosure until symptoms require explanation
- Adjust what you share over time as your needs change

Disclosure is not a one-time event. It is an **evolving process** that may shift with work demands, symptom changes, emotional readiness, life transitions, and family dynamics.

Why Some People Choose to Share

Disclosure can serve practical and emotional purposes.

1. Reduces Misunderstanding

Without context, symptoms may be misinterpreted as:

- Nervousness
- Disinterest
- Laziness
- Cognitive difficulty
- Alcohol or medication effects

Sharing selectively can prevent inaccurate assumptions that affect relationships or work credibility.

2. Increases Support

Disclosure may lead to:

- Assistance when needed
- Patience during symptom fluctuations
- Emotional understanding
- Adjusted expectations

Support often becomes available only after people understand what's happening.

3. Decreases the Emotional Burden of Hiding Symptoms

Many people experience:

- Relief from constant self-monitoring
- Reduced anxiety
- Greater authenticity
- Improved emotional energy

Carrying secrecy can be exhausting. Letting others know—on your terms—can restore emotional bandwidth.

What You Do Not Owe Anyone

You are not required to provide:

- Detailed medical explanations
- Your full treatment plan
- Prognosis discussions
- Reassurance at your own emotional expense
- Optimism for someone else's comfort

You are allowed to set boundaries **without justification**.

Sample Disclosure Language

You can adapt language to fit your comfort level and audience.

Brief & Professional

"I have a neurological condition called Parkinson's that affects movement and energy. I'm still able to work, but I sometimes need flexibility."

Personal but Boundaried

"I've been managing Parkinson's for a while now. Some days are stronger than others, but I'm taking good care of myself."

Family-Centered

"I want to share something important about my health. I have Parkinson's, which affects how my body moves and how much energy I have. I'm still me, and I'm still here for our family."

Boundary-Setting

"I'm not comfortable discussing the medical details, but I appreciate your understanding."

Practicing language ahead of time can reduce anxiety and help you stay grounded during conversations.

Different Audiences, Different Considerations

Coworkers

- Share only functional impact if preferred

- Limit disclosure to select colleagues or supervisors
- Focus on job performance, solutions, and continuity

Friends

- Some may respond with strong support
- Some may not know what to say
- Some may minimize or overreact

Extended Family

- May respond with worry or overprotection
- May offer unsolicited advice
- May seek frequent reassurance

Others' reactions reflect *their* coping—not your responsibility to manage.

When You May Choose to Delay Sharing

Waiting can be a healthy, intentional choice.

You may delay disclosure when:

- Symptoms are mild and well-controlled
- You are still emotionally processing your diagnosis
- The relationship does not feel emotionally safe
- Disclosure would increase stress more than support

Waiting is not dishonesty—it is **self-protection**.

Common Emotional Responses After Disclosure

Even positive conversations can stir complex emotions.

You may feel:

- Relief
- Vulnerability

- Empowerment
- Grief
- Anxiety

Mixed emotions are normal. Disclosure often opens space for both connection and processing.

Managing Unhelpful Responses

Some responses may feel uncomfortable or intrusive.

Common examples include:

- Minimization (“You look fine.”)
- Overreaction (“That’s terrible!”)
- Unsolicited advice
- Predictions about your future

You are allowed to redirect the conversation, reassert boundaries, pause the discussion, or take emotional distance as needed.

A Reassuring Truth

Telling others about Parkinson’s does **not** define you by your diagnosis.

You are still:

- A professional
- A friend
- A partner
- A parent
- A whole person

Disclosure is often an act of **clarity, strength, and self-advocacy.**

When to Seek Additional Support Around Disclosure

Consider added support if:

- Anxiety around disclosure feels overwhelming
- Family reactions create ongoing distress
- Workplace communication feels unsafe
- Emotional processing feels stuck

Counseling, peer support, or coaching can help you navigate disclosure with confidence and care.

A Final Thought

You are allowed to share your story slowly, selectively, and on your own terms. Parkinson's may be part of your life—but **it does not take ownership of your voice.**

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