



WORKING WITH PARKINSON'S

FIVE QUESTIONS

Davis Phinney Foundation YOPD Council August 2020



DAVIS PHINNEY
Foundation For Parkinson's

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1. SHOULD I DISCLOSE MY DIAGNOSIS AT WORK?

If your symptoms are such that you need to ask for an accommodation (that is, you can still do your job but you can't really perform under the same working conditions as you did before), you must disclose in order to trigger your rights under the Americans with Disabilities Act (ADA) and related laws. And you need to know when and how!

If your symptoms are hidden or mild, and you can continue to do your job without accommodation, then the question is whether you should disclose, not whether you must. The answer depends on the nature of your job and your professional relationships, how much good will you have at work, and your particular symptoms. It's helpful to hear other people's stories and to practice difficult conversations before the stakes are real.

Helpful Resources:

- » AskJan.org: [Disclosing Your Condition at Work](#)
- » EEOC: [Your Employment Rights as an Individual With a Disability](#)
- » Davis Phinney Foundation
 - » [Expert Advice on Workplace Issues](#)
 - » [How to Share Your Parkinson's Diagnosis](#)
 - » *Every Victory Counts: Essential Information and Inspiration for a Lifetime of Wellness with Parkinson's Disease*, Workplace Issues, pages 88-97
- » Michael J. Fox Foundation
 - » [Workplace Challenges](#)
 - » [Sharing Your Parkinson's Diagnosis at Work: A Practical Guide](#)



2. WHAT ARE MY LEGAL RIGHTS IF I WANT TO STAY IN MY JOB?

Congress has enacted several laws that may trigger statutory rights in the workplace for people with disabilities or health conditions. One of those statutes is the Americans with Disabilities Act (ADA). Each state has corresponding laws too.

Under the ADA, if your condition qualifies you as a person with a disability, then your employer may not fire you or take some other adverse employment action against you because you have a disability. But this can get complicated. First, just because you have Parkinson's doesn't necessarily mean that you are a person with a disability. Instead, the ADA defines a disability this way:

“A physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.”

So a condition by itself is not a disability – instead, the condition must substantially limit a major life activity, which includes things like seeing, hearing, walking, executive functioning, and performing manual tasks.

And second, even if you qualify as a person with a disability, your job is not protected simply based on that fact alone. Instead, the obligation of your employer is to provide you with a “reasonable accommodation” unless that presents an “undue hardship” for the employer. If you can continue to perform the essential functions of your job with the help of an accommodation which is not unduly burdensome for your employer, then an employer who refuses to provide that accommodation may be violating the ADA.

An accommodation can mean lots of different things – everything from modifying the physical structure of your workplace, to adjusting your work schedule, to providing assistive technologies, to changing work policies. This is really fact-specific and what is “reasonable” depends, of course, on what kind of job you have.

Helpful Resources:

Check out the links in the Helpful Resources on page 2 as well as the following additional resources:

- » AskJan.org - free, one-on-one, confidential guidance on workplace accommodations
- » [Davis Phinney Foundation YOPD Webinar](#): Disability Insurance and Parkinson's, October 2020



3. WHO'S GOING TO HIRE ME WITH PARKINSON'S?

There's no doubt about it - getting a new job even in the best of markets is challenging. And when you pile on the fact that you have Parkinson's, the blow to your confidence that has caused, and the uncertainty around its progression, getting a new job seems pretty far out of reach.

And then there's the global pandemic and the sky high unemployment rate.

That said, if you look around a bit, you'll find a good number of people with Parkinson's who have changed jobs and continue to work. Key to changing jobs are outlook, self-assessment, and self-education.

Outlook. Viktor Frankl was an Austrian neurologist and psychiatrist who survived four concentration camps in the Holocaust, while his parents, brother, wife, and unborn child died. Frankl used his time in the camps to study human psychology under extreme stress and suffering and wrote about it in his venerated book, *Man's Search for Meaning*. His conclusion (highly simplified): all other things being equal, people who turned their suffering inward, asking "why me?" rapidly deteriorated and died, while the ones who survived looked outside of themselves with the mindset, "the world still needs me."

With Parkinson's, you still have a lot to give, and there's no question that this world needs your help and your talents. It's not about you, it's about what you can do to make the world a little better. Adjusting to this outlook (which admittedly is not easy) will reset your confidence.

Self-Assessment. You need to assess your abilities, skills, and values. They may be different than before the diagnosis, but you still have abilities! As the saying goes, "What's wrong with you is beside the point; what's right with you is the starting point." You're at a new starting line, running a different race. Make a list of what you bring to the team.

Helpful Resource: The Department of Labor's [CareerOneStop Self-Assessments](#)

Self-Education. Both the federal and state governments offer special job tracks for people with disabilities and also offer tax credits to private companies for hiring people with disabilities. These programs are real, and they do work. Start here to learn more about them: U.S. Department of Labor, [Job Search for People with Disabilities](#). There are also career counselors and coaches who specialize in helping people with disabilities and serious health conditions.



4. HOW DO I AVOID FINANCIAL RUIN?

The cost of having Parkinson's in the US is enormous, and those costs fall more heavily on families of modest means and low income, who are least able to bear those burdens. According to *The Economic Burden of Parkinson's Disease*, a research paper recently published by The Michael J. Fox Foundation, the total cost of Parkinson's to individuals, families and the United States government is \$51.9 billion every year, with \$25.4 billion attributable to direct medical costs, (e.g, hospitalizations, medication) and \$26.5 billion in non-medical costs such as missed work, lost wages, early forced retirement, and family caregiver time.

This fear of financial ruin is legitimate and needs to be approached like any fear. That means we have to first find the peace of mind to approach our financial situation with a proactive commitment to focus on data, education, planning, and problem-solving, rather than always staying in reactive mode. Any form of mindfulness, meditation, or therapy that works for you should be the starting point to get to that place.

Helpful Resources:

- » [Open Path Psychotherapy Collective](#): Many therapists in this collective offer “pay what you can” therapy while also maintaining their regular practice at full rates for those who can afford them.
- » *Every Victory Counts: Emotional Health*, pages 184-206

Then, get to work. Money coaches and financial planners all follow pretty much the same process: (1) take a realistic inventory of your assets, liabilities, and income; (2) examine your values, beliefs, and blocks around money issues; (3) have difficult conversations with your partner and family if you need to significantly adjust your lifestyle; (4) make a plan to get out of debt and transition to a sustainable lifestyle taking into consideration the financial burden if you have to leave the workforce or take a cut in your income, and (5) find and implement a way to stay accountable to that plan.

Helpful Resources:

- » Davis Phinney Foundation Webinars:
 - » [Financial Wellness and Parkinson's](#)
 - » [How to Reduce The Costs of Your Parkinson's Medications](#)
- » [Financial and Legal Issues](#), American Parkinson Disease Association
- » [Financial Therapy Association](#)



5. HOW DO I CREATE MY OWN INCOME STREAM?

Developing your own income streams can create more security and alleviate the fear of losing a job, while also enabling you to manage your symptoms and make the time for the exercise that is so important to live well with Parkinson's.

That said, the entrepreneurship path has always been hard and risky, and it remains that way despite the seemingly endless information on the internet about how to become rich through passive income and online creative ventures. Side hustles, freelancing, and project work may be worth pursuing, but keep a realistic perspective about how much money you can actually make and how much work the path entails.

Just like when you're looking for a new job, you'll have to start with inventorying your skills, abilities, and interests, and you'll also need to inventory your time. And unlike having a W-2 job, having your own business or doing project work means you have to take care of the legal and tax work yourself.

Helpful Resources:

- » [Small Business Association](#)
- » [Popular Podcasts on Building an Online Business](#)
- » Amazon's [Best Online Business Startup Books](#)
- » Job Boards for Remote, Flexible, Part-Time Work, including Flex Jobs and Indeed
- » [Davis Phinney Foundation YOPD Webinar](#): How to Change Careers and/or Find More Meaning Along Your Career Path, January 2021

WHAT'S NEXT?

Want proven ideas on how to live well with Parkinson's?

Much more can be found in our Every Victory Counts® manual. It's packed with up-to-date information about everything Parkinson's, plus an expanded worksheets and resources section to help you put what you've learned into action. Request your free copy of the Every Victory Counts manual by clicking the button below.

[Request Your Manual Now](#)

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