

Working and Parkinson's: How to Keep Your Job, Find a New One, or Reinvent Your Career

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The Victory Summit® Virtual Event: How to Live Well with Parkinson's

Any conversation about work is a conversation about money, so that needs to be addressed first, before talking about keeping your job, finding a new one, or reinventing your career.

Addressing Financial Uncertainty

The fear of financial ruin as a consequence of losing your continued ability to work is legitimate and needs to be approached like any fear. That means first finding the peace of mind to approach your financial situation with a proactive commitment to focus on data, education, planning, and problem-solving, rather than staying in panicked reactive mode. Any form of mindfulness, meditation, or therapy that works for you should be the starting point to get to that place.

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:

- **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. <https://openpathcollective.org/>
- **Every Victory Counts: Emotional Health**, pages 184-206
- **Davis Phinney Foundation Webinars:**
 - Financial Wellness and Parkinson's: <https://davisphinneyfoundation.org/webinar-recording-financial-wellness-and-parkinsons/>

- How to Reduce the Costs of Your Parkinson's Medications: <https://davisphinneyfoundation.org/reduce-cost-parkinsons-medications>
- **Financial and Legal Issues, American Parkinson Disease Association:** <https://www.apdaparkinson.org/resources-support/living-with-parkinsons-disease/financial-legal-issues/>
- **Financial Therapy Association:** <https://financialtherapyassociation.org>

Disclosing Your 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:** https://askjan.org/topics/Disability-Disclosure.cfm?csSearch=2622789_1
- **EEOC: Your Employment Rights as an Individual with a Disability:** <https://www.eeoc.gov/publications/ada-your-employment-rights-individual-disability>
- **Davis Phinney Foundation**
 - Expert Advice on Workplace Issues: <https://davisphinneyfoundation.org/expert-advice-on-workplace-issues>
 - How to Share Your Parkinson's Diagnosis: <https://davisphinneyfoundation.org/share-parkinsons-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: <https://www.michaeljfox.org/news/workplace-challenges>
 - Sharing Your Parkinson's Diagnosis at Work: A Practical Guide: https://files.michaeljfox.org/100915_MJFF_WORKPLACE.pdf

The Legal Landscape

None of us has a constitutional right to employment, but 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.

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 a “reasonable accommodation,” then an employer who refuses to provide that may be violating the ADA.

An accommodation can mean lots of different things – 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.

In addition to the Helpful Resources linked above, there's no better resource than AskJan.org - free, one-on-one, confidential guidance on workplace accommodations and disability employment issues provided by the expert consultants at JAN.org, a grant-funded service provided by the DOL's Office of Disability Employment Policy.

Finding a New Job

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. 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 Career One Stop Self-Assessments:**
<https://www.careeronestop.org/ExploreCareers/Assessments/self-assessments.aspx>

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:
<https://www.dol.gov/general/topic/disability/jobsearch>

There are also career counselors and coaches who specialize in helping people with disabilities and serious health conditions. Feel free to contact me and I can put you in touch with several.

One tip for finding employers who are interested in hiring people with disabilities is to go to websites that are designed for employers, rather than employees. A good website is AskEarn at <https://askearn.org>. The Employer Assistance and Resource Network on Disability Inclusion (EARN) is a free resource that helps employers tap the benefits of disability diversity by educating public- and private-sector organizations on ways to build inclusive workplace cultures. EARN offers information and resources to empower individuals and organizations to become leaders in the employment and advancement of people with disabilities. According to EARN, a common question they hear from employers is “Where can I find qualified job candidates with disabilities?” The answer is found on this page:
<https://askearn.org/topics/recruitment-hiring/finding-candidates-with-disabilities>.

EARN helps not only employers, but also prospective employees. See this page:
<https://askearn.org/resources/job-seeker-resources/>.

Finding and Working with a Lawyer

Disability law is highly specialized. When choosing a lawyer, recognize that there are lawyers who practice exclusively (or near exclusive) in disability law, and there are lawyers who practice in multiple areas, only one of which is disability. There's even a big difference between Social Security Disability law and the law of private long-term disability that may be offered to employees through their employer benefits. Many people hire two different lawyers: (1) one to advise on private employment-based disability; and (2) another to pursue SSD benefits. Workers' compensation law is different and specialized in its own right. Some lawyers practice both workers' compensation and disability benefits law. Common advice in this area is to look first for a lawyer who practices exclusively in one area, although there are many good lawyers who practice in multiple areas.

Some things to think about when deciding on a lawyer:

- If the lawyer charges a fee for an initial consultation, **don't use that lawyer**. It's not illegal or unethical to charge a fee, but the best lawyers offer free consultation.
- A healthy lawyer-client relationship should be client-driven, transparent, and based on frequent and clear communication. When talking to a lawyer at the vetting stage, ask the lawyer what the lawyer's practices are regarding client communications and what the time frame is for what you're hiring the lawyer for. If the lawyer's message is "don't worry about a thing, I'll take care of everything," don't go with that lawyer. The lawyer is an agent of YOU, and you should be making the decisions every step of the way (within reason) with the lawyer's guidance.
- Lawyers will have different personalities and practice styles, ranging from warm and comforting to aggressive to smooth-talking. None is right or wrong but choose a style that you want and that you think would work best for whatever situation you're hiring that lawyer for.
- Lawyers are expensive. Ask up front what the fees are. In major metropolitan areas, it's not uncommon for hourly fees to range from \$250 to \$900 an hour. Some lawyers charge a flat fee for whatever matter they're handling for you. I prefer a flat fee because there aren't as many surprises as with an hourly fee (think of hiring a contractor for your home improvements). When it comes to SSD, many lawyers will take the case on a contingency fee basis, which means they won't charge you anything out-of-pocket, but if they win the claim for you, they'll take a cut of your benefits. This is also a good way to go, as long as the percentage is reasonable.

It may be helpful to contact a nonprofit disability rights organization first. They are staffed with lawyers who know everything about disability law and they often will answer a lot of questions and may be able to refer you to lawyer they know and trust. They are usually only permitted to directly represent low-income clients, but that may vary, and you should explore that inquiry with them. To find a disability rights organization near you, do an internet search. For example, in the Washington D.C. area, here are Virginia and Maryland disability rights organizations: (1) Disability Rights VA, <https://www.dlcva.org/>; and (2) Disability Rights MD, <https://disabilityrightsmd.org>.

Reinventing Your Career

A serious health diagnosis often brings with it the pull to make a working life more meaningful. If you have the means to do so, finding your purpose may just be one benefit of having Parkinson's.

I have found several books and podcasts inspirational to help lead in certain directions, which I have listed below. There are many others that other people recommend. The key to reinventing your career is to block off a large chunk of time to get to know yourself again. If you're interested in helpful self-coaching inquiry, I have included one below.

My favorite books and podcasts to help inspire reinvention:

Books

- *Callings: Finding and Following an Authentic Life*, by Gregg Levoy
- *Flourishing*, by Maureen Gaffney
- *Wishcraft*, by Barbara Sher
- *Mindset: The New Psychology of Success*, by Carol Dweck
- *The Gifts of Imperfection*, by Brené Brown
- *Choose Yourself*, by James Altucher

Podcasts

- There are so many! And different styles will speak to different people. I enjoy Chris Guillebeau's Side Hustle School and Christine Kane's The Soul-Sourced Entrepreneur, but if you do an internet search using "podcasts about reinventing yourself," a long list will come up. It's a good idea to sample some to find what speaks to you.

Self-Coaching Inquiry (a/k/a Ten Questions to Ask Yourself About the Rest of Your Life)

Many people who seek change in their life start with the question, "What do I want to do?"

But that's not the right question.

Besides the fact that many of us have no idea what we want to do, that question is wholly disconnected from real lives of financial pressures, family responsibilities, and other often intractable challenges and limitations.

Plus, asking that question as a starting point gives us no bearings from which to set a course.

The better question is, "Given my challenges and limitations, what am I willing to give up to get what I want?" That grounds the inquiry in our real lives and establishes checkpoints along the way so we can adjust our sails and stay on course.

Question #1: How Much Money Do I Have?

You know it makes sense to do this. But for several reasons, none of us want to. This is the worst homework assignment ever! If you're like me, not only will it confirm that we have awful organization skills - I don't even know where half my financial records are - but I suspect that the truth will hurt and the only result that will come out of this process is that we will be faced with hard and irrefutable proof that we've made poor financial choices and can't take any of them back and now it's too late and so all we're going to get out of answering this question is regret, shame, and anxiety!

But we also know that if we don't do this first, none of our decisions about how we want to live the rest of our life will be actionable. They'll have no foundation and will be subject to collapse. And that's got a whole lot more regret, shame, and anxiety attached to it than shining a little light on your financial situation.

This question is not about budgeting or investing or saving - it's simply about taking an inventory of your assets and liabilities, along with recurring financial obligations, so you can have some hard evidence on which to gauge the extent of your financial freedom.

Whatever numbers you come to are not, by themselves, significant. What IS significant is what they tell you about your future. When you're thinking about what changes you want to make in your life, you'll be able to use those numbers to decide whether the cost of making those changes is worth it to you.

Step One: Assets

Write the value of each category of asset on the line provided. Don't think too hard here! (This is not the place to decide whether you want to sell your assets, just list them!)

Checking Accounts: _____

Savings Accounts: _____

Investment Accounts (money markets, CDs, mutual funds, college savings accounts, stocks, and any other investment vehicles, not including retirement accounts):

Retirement Accounts: _____

Other Funds: _____

Real Estate (market value): _____

Personal Property (market value, including automobiles):

Other Assets: _____

Total Assets: _____

Step Two: Liabilities

Mortgage Balances: _____

Credit Card Balances: _____

Other Loan Balances (car loans, personal loans, student debt):

Other Liabilities: _____

Total Liabilities: _____

Total Assets: _____

Net Worth (Total Assets Less Total Liabilities):

Contractual Payments (per year, this category includes things like rent, child support, school tuition, senior living payments, and homeowners' or condo association fees): -

Step back and get a good understanding of where any financial buffers, if any, may be in your life.

Question #2: How Would I Describe Myself?

One of the most important drivers of changing your life is knowing (or discovering) who you are and why you describe yourself in the way you do. That often reveals what's important to you at this point in your life and from there, you can work on where you want to go next.

To answer this question, think about what you care about, what you believe in, what principles guide you in your life. And describe yourself from that space.

If you need a little help, here are a few free personality tests - none of them is perfect but they'll get you thinking. You can do an internet search by their names to find them.

Big Five Personality Test: (also known as OCEAN, or scrambled, CANOE), this test is one of the most highly regarded personality tests in the academic research.

VIA Character Strengths: This test is widely used in career advising and management consulting.

16-Factor Personality Test: The 16 factors are warmth, reasoning, emotional stability, dominance, liveliness, rule-consciousness, social boldness, sensitivity, vigilance, abstractedness, privateness, apprehension, openness to change, self-reliance, perfectionism, tension.

Question #3: How Would I Characterize a Life Well-Lived?

This is different for everyone. Living well depends on what your values are. Two people may have achieved the same level of success in their professional lives but if one values risk-taking, for example, and has never stepped out of his comfort zone, then he may feel unfulfilled despite everything he has achieved.

So how do YOU define a life well-lived? Does it have to do with becoming something, compassion, service, family, fun, adventure, risk, helping others, love and friendship, making a mark in the world, creating something, traveling, experiences, responsibility, freedom, wealth?

Do you measure it by external markers or internal virtues?

This doesn't have to be quotable. Nobody has to see your answer but you. Be honest.

Question #4: What Would I Most Regret Not Doing by the End of My Life?

The question is not what you regret now, but what would you regret later if you don't do it now.

Question #5: How Different is My Life Now from My Vision of a Well-Lived One?

What does your life look like now compared to your vision of a well-lived life? Maybe your life now is time-crunched and stressful. You're working full-time, taking care of kids and parents, barely making ends meet, not getting any sleep or exercise, managing your Parkinson's symptoms, and you feel strung out and stuck. You want freedom - to do the kind of work you enjoy, on your own terms. You want to be well rested and have enough energy to exercise and spend quality with your kids and your parents. You want to volunteer for causes you believe in. You want to travel. To read more. To learn to play the guitar. Slow down. You want peace of mind.

To get from here to there, you would need more money, more time, more energy, and more family support. Better health. And a good night's sleep.

It all seems way out of reach.

Question #6: What's Stopping Me from Taking Action?

We have so many problems, in so many different forms. Some we cannot change - like illness, loss, time, age, genes, burdens and responsibilities created by our choices, our relationships, our brains and bodies, our commitments.

Other problems are less concrete but just as seemingly unyielding. Resistance in the form of fear, anxiety, inner critic, low self-confidence, mindsets and beliefs around money, achievement, love, power, identity, and so many other things.

This inquiry is not designed to fix these problems. That would be unrealistic.

List each problem (big and small) that's stopping you from taking action toward your well-lived life. We'll take a closer look at each one and see if there's a way around.

There may not be, and that's important to learn too.

Think of your problems as waves, the kind that smack you in the face, steal your breath, knock you down.



Question #7: What Would Need to Happen to Stop It from Stopping Me?

Let me go out on a limb here and propose that many of us spend a lot of time thinking about and planning for a better life (and this worksheet is guilty of being a part of that) but that when it comes to taking action toward a better life, we freeze. Dip a toe in. Retreat. Keep thinking. Do more planning.

And nothing changes.

Why is it so hard to act?

Fear. Limits. And habits.

Not enough time. Not enough money. Too old, too unhealthy, too tired, too many obligations.

What if you realize that none of those things will change, ever? And that the thing that needs to change is your response to them? We live with those limits our whole lives and we'll die with them too.

So, this question opens up the possibility for change. It requires you to think creatively.

Step One:

For each of your problems, ask yourself, "what would need to happen to stop it from stopping me?"

For example: "I'm drowning in debt."

- I would need to make more money.
- I would need to change my lifestyle in a way that frees up money I already have.
- I would need to create a workable budget to pay off my debt in three years. And also create a plan to position myself so that I'm ready to take action at the end of three years.

Step Two:

For each thing that would need to happen, what are the options to make that happen?

- I would need to make more money.
 - a. Ask for a raise.
 - b. Get a second job.
 - c. Get a different job.
 - d. Create a side hustle.
- I would need to change my lifestyle in a way that frees up money I already have.
 - e. Downsize.
 - f. Move somewhere with a lower cost of living.
 - g. Sell assets.
 - h. Reduce expenses.
- I would need to create a workable budget to pay off my debt in three years. And also create a plan to position myself so that I'm ready to take action at the end of three years.
 - i. Track expenses.
 - j. Create savings goals.
 - k. Commit to interim milestones.

Step Three:

Break it down further – what action steps are involved in each action?

This obviously will take some time, and it helps to have someone to work through it with you. Hang in there.

Because if you address all the things that are stopping you, one inquiry at a time, big breakthroughs can often happen.

When those waves come at you, you don't have to stand there and take the full brunt of their force. You can crouch down, dive under, dolphin dive over, ride them to shore.

Maybe even swim toward them so you can get past before they break.

Question #8: What Would My Life Look Like If I Didn't Take Action?

In three years? Five? Ten?

Question #9: What Do I Need to Best Manage My Energy?

With Parkinson's, as with many serious health conditions, the key to getting anything done is managing your energy. What is it that you need to manage yours? Regular breaks for exercise and naps? Three days of work following by two days off? Only working in the morning? Start with fueling yourself and build your work around that.

Question #10: What Am I Willing to Give Up to Get What I Want?

So here we are at Question #10, and you've done the work to help you make choices about how to live the rest of your life well. You have information about your financial wiggle room, your vision of a well-lived life, the things that are stopping you from living that life, and all the different ways you can take action to get around those blocks, along with the picture of your life if you didn't take action.

How easy is it for us to say that we want a lifestyle that gives us the freedom to work when and how we want, to take vacations, have a financial cushion, travel, have time for exercise and take cooking lessons and volunteer our time to causes we believe in. But all that is just daydreaming unless we also factor in the costs. It's like setting sail with only a picnic lunch and a bottle of wine and hoping for the best.

That kind of daydreaming just wastes time - the only time you have left.

You have all you need in front of you. If your vision is worth the work you have to do and the things you have to give up, then you are fortified enough to set sail fully prepared and with a compass and map to guide your way.

Nice work.

And if you decide that your vision is not worth what you would have to give up, then you've also given yourself a great gift - permission to just ride out the rest of your life, knowing that storms will come and the waves may be brutal, but enjoying the ride anyway because you have

cleared the deck of the clutter of unrealistic daydreams, the what-if's, the should've- could've- would've's, the crazy energy-sucking thoughts, so you can stretch out under the night sky on a warm night and look up at the stars and realize that at that moment, life is unbelievably beautiful.

Everything is your choice.