

Living with Parkinson's: The Pain, the Pressure, and the Person You Become

People think Parkinson's is just tremors. That's the headline symptom. But the whole story runs deeper and darker. It's not just shaky hands or stiff legs. It's the slow, invisible takeover of your body and mind. It's chronic pain, relentless tension, and the way your personality twists under the weight of something you can't control. Living with Parkinson's is living in a body that no longer cooperates and sometimes no longer feels like yours.

The pain is constant. It's not sharp or dramatic—it's worse. It's the kind that grinds into your bones, your muscles, and your nerves. Every part of you clenches. Your back stiffens—your neck locks. Your jaw aches. You try to sit still, but your muscles won't let you. You try to move, and your body resists. No position brings real relief. Relaxation is a memory. Your nervous system doesn't know how to shut off. Even when you're still, you're fighting.

What people don't talk about enough is the tension. The clenching. The internal chaos. It's like your whole body is trying to brace against something that never hits. It builds and builds. You can't stretch it out. You can't breathe it away. And eventually it infects your brain. Chronic pain changes your thoughts. It steals your patience. It shortens your fuse. You start snapping at people you love, not because they did anything wrong, but because your skin is on fire and your mind is drowning.

Parkinson's doesn't just break your body—it messes with your identity. You find yourself becoming someone else. A version of you that's smaller, more withdrawn, more irritable, and more obsessed. You start to fixate. You zero in on things—small things, specific things—and can't let go. You replay conversations. You obsess over routines. You get stuck. There's a tunnel vision that comes with this disease. A kind of mental rigidity that shuts out nuance, flexibility, and sometimes even empathy. It's like your emotional bandwidth narrows. You become less spontaneous and more brittle.

Relationships suffer. You know you're not easy to be around. Your partner tries to help, but you push them away. Not because you want to—because it's easier than showing how much you're struggling. Friends drift off. Socializing becomes too much. Too much energy, too much unpredictability. You stop making plans. You stop reaching out. Eventually, it feels like your world shrinks to the size of your symptoms. Parkinson's is a lonely disease.

The emotional fallout is brutal. It's not just depression—it's a particular flavor of hopelessness that comes from watching yourself change in slow motion. You remember what you were like before. You remember ease, lightness, and movement. And then you look at yourself now—slower, stiffer, moodier—and you mourn your disappearance. The grief is constant. It's like living with a ghost version of yourself that you can't stop chasing.

And the worst part? People don't see most of it. They know the tremor, maybe. They don't see the sleepless nights, the gut problems, the skin crawling with restlessness, or the mental exhaustion of trying to pretend you're okay. They don't see the internal war you're fighting to

show up, to smile, to function. You start to feel like you're performing your life instead of living it.

Fixation becomes a coping mechanism. You cling to routines, projects, rituals—anything that gives you a sense of control. It can be helpful at first. It makes the chaos manageable. But then it turns on you. You become obsessive. You get locked into patterns and can't shift out. It's not just a habit—it's a compulsion. And it keeps people out. When you're fixated, you're not present. You're not connecting. You're managing. You're trying to hold the world together with whatever thread you can still grasp.

Those who stay see the change. They notice the sharp edges, the isolation, and the fixation. Some try to reach in. Some give up. You don't blame them. You're not the same. Parkinson's rewires you. It affects dopamine, the chemical that governs not just movement but also mood, motivation, and even pleasure. When that balance is off, everything gets harder. You're more prone to anxiety. You overthink. You catastrophize. And sometimes you go numb.

But humor helps. Sometimes it's the only thing that cuts through the heaviness. When I freeze up—stop mid-step, locked in place like a paused video—Donna looks at me and says, "You're buffering again." And I laugh, because what else can you do? That joke, that lightness, that shared absurdity—it's a tiny crack in the concrete. It reminds me that I'm still here, still human, still connected to someone who gets it. Humor doesn't solve anything, but it softens the edges. It's a lifeline when nothing else feels solid.

There's no clean way to end this story. Parkinson's doesn't have an arc—it just has stages. There are better days and worse ones, but the trend line is downward. Still, people with Parkinson's find ways to adapt. You find strategies. You hold on to the good days. You treasure moments of clarity and connection. You stop waiting for comfort and start looking for meaning.

Some days, that meaning is in small victories—tying your shoes, getting out the door, having a whole conversation without drifting. On other days, it's just about surviving without snapping. You redefine success. You let go of who you were and try to make peace with who you are. It's not easy. Some days it feels impossible. However, even during difficult times, a certain resilience develops. You endure.

Parkinson's doesn't kill you fast. It wears you down slowly. It chips away at your independence, your confidence, and your sense of self. But inside that struggle is something honest. You stop pretending. You stop wasting time. You see the truth of things. And maybe, on the hardest days, that's a kind of clarity worth holding onto.

This disease is cruel, but it doesn't get the last word. It might rewrite you, but it doesn't erase you. Pain is constant. Tension is brutal. Fixation is real. But so is resilience. So is love. So is laughter, especially the kind that shows up just when you need it most.