

# **PARKINSON'S WRITERS WORKSHOP**

**Essays from experience with Parkinson's Disease**



Parkinson's Writers Workshop  
Six meetings: February and March, 2024

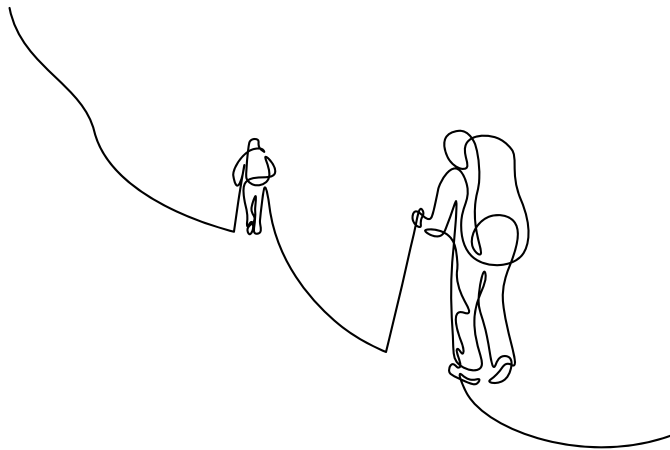
What We May Be  
By Sue Bryant

Parkinson's: Pathway to a Closer Relationship with God  
By Chris Hanna

Four Battles In The War Against Parkinson's Disease  
By Ryan Kelly

Parkinson's: I'll Take Some of That  
By Paul Pate

L-Dopa Hesitant  
By Dan Royer



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## Foreword

The idea for a Parkinson's Writers Workshop first came to me when Kelly McWilliams, the nurse navigator in Corewell's Parkinson's care program, mentioned that while at a recent national conference she heard a speaker presenting on the topic of "narrative medicine." I studied English, language, and writing in graduate school and was a professor of writing at a university for twenty-three years. Though I had not heard of "narrative medicine," I was well acquainted with the power of narrative in our lives as a force for changing ourselves and others. I was intrigued.

I was reminded that everyone I had ever met with Parkinson's had a story to tell. We all share our diagnosis story and after listening to a few, I began to realize what an important landmark they are in everyone's history with PD. Peter Dunlap-Shohl in his graphic novel, *My Degeneration* even introduces an amusing catalog of the types of ways this tough news gets delivered to patients. As far as I can tell, this first conversation with a neurologist has something like a thirty-year half-life. While much else gets forgotten, the diagnosis story endures in our memory.

With these thoughts in mind, I put together a six-week workshop for writers and invited several folks to join me that were in my Parkinson's orbit at the time. As things turned out, the workshop had little to do with "narrative medicine" and little intentional therapeutic aim. What it did have was a social and creative aim, an aim to tap into some creative processes that might help us to begin to write. Our end-game would be to produce a reasonably finished narrative rooted in our experience with Parkinson's disease, our own or others.

So the five of us met each Wednesday night at Kent-Plainfield library in a study room and talked about writing. We read the narratives of others, and we paid particular attention to the work by Michael J. Fox. By the end, we all, with help from each other, forged a piece of writing about our experiences that we are proud of. All of the essays reach beyond the conventions of the "diagnosis story" and explore interesting aspects of the Parkinson's experience. Readers of these essays will be greeted with our self discovery, inspiration, humor, as well as some information about some of the history of the efforts to treat Parkinson's. All of these narratives shine some light on the way that Parkinson's (a formidable foe) resists our best efforts.

**Sue Bryant** guides us through her experience getting diagnosed and the aftermath. Among the writing group, Sue's diagnosis is the most recent. She describes some frustration but also a stubborn effort to keep moving forward and take some risks. Sue has a lot to teach us about empathy. Her essay takes readers on a lively journey through the first several months of a Parkinson's diagnosis.

Whereas Sue leads us through the first six months, **Chris Hanna's** "Pathway" essay takes us through eighteen years. Chris's journey with Parkinson's turns out to be a spiritual journey as well. The two are intertwined for Chris. An astute observer of patterns and purposes in his experience, Chris's essay urges readers to think about their own paths and to pay attention, as he did, and connect the dots.

As we discussed throughout the writers workshop, aim is the lure that guides creativity. For **Ryan Kelly**, inspiration is a primary aim in his essay, and sharing his many years of experience with Parkinson's is the way he achieves this aim. Ryan's essay uniquely delivers the kind of folk wisdom that reminds us of how we move forward when we wage our battles and direct our energy outward towards helping others.

**Paul Pate** is a ten-year early-onset Parkinson's veteran with some early battle scars to show off. I think he'd describe himself not so much as a person with Parkinson's but as a Mirapex survivor. Maybe not, but his essay reveals a fearless spirit who has some funny stories to tell. It seems he often does what he's told to do by his doctors, but he's also been a man with a plan.

I was diagnosed with Parkinson's two-and-a-half years ago. For **myself**, this Parkinson's essay gave me an opportunity to explore some of the history of the drug those with PD have been taking for over a half-century. Levodopa's ability to produce dopamine in the brain was behind Arvid Carlsson's Nobel Prize for Medicine in 2000. But the last fifty years has been accompanied by a variety of surprising hesitations, including my own. But that's not all bad. Hesitation, even error, is the price we pay for progress.

~ Dan Royer

## What We May Be

Sue Bryant

*"We know what we are, but know not what we may be."*

~Ophelia in Shakespeare's *Hamlet*

I knew. It happened and I knew. I was driving to the gym. My left pinky finger started to tremble. I could stop it temporarily but I couldn't avoid it happening again.

The thought snuck up on me: I have Parkinson's. I said nothing to my son sitting beside me.

Weeks later, my internist's attention was riveted to my hand, shaking on the table. I volunteered my suspicions, couched in expressions of doubt. "You need to see a neurologist," he urged kindly. Internal reaction: Oh shit. My surrender: "OK."

Now I was beginning to connect the dots. About four years ago I would joke that everyone else on the gym track passed me by as I did my daily jog. Years before that, my friends would forge ahead of me on our hikes. I urged them, "You go ahead, I can't keep up." For the past three years I've struggled to get up from the lunch table and to begin to walk. "Creaky," I laughed to my friends.

Last year I clung to the hand rail, slowly moving down step-by-step. People streamed by, cascading down the steps after a performance at DeVos Hall. Multiple offers: "Can I help you?"

Walking felt like pushing through molasses. X-rays showed moderate osteoarthritis.

A stint of physical therapy brought many exercises and increased strength. Molasses was as tough as ever.

**H**is countenance stern and serious, the neurologist entered the room. He asked the questions and gave the directions. I tapped my fingers, stood up from a chair, and demonstrated my flawed gait. The doctor entered the evidence into his computer. Then he pulled up a chair facing me. Leaning forward, he asked, "Has your doctor talked to you about Parkinson's?" That opened a door and I described my experiences. He gave me the diagnosis: "Parkinson's Disease."

Shock and relief flooded me. I had no doubts this was correct, and

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***His countenance stern and serious, the neurologist entered the room. He asked the questions and gave the directions. I tapped my fingers, stood up from a chair, and demonstrated my flawed gait. The doctor stood, turned away from me, entering the evidence into his computer.***

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yet I was stunned. The doctor talked further. My listening abilities arrived in time to hear about medication I must take three times a day five hours apart. "I can do that," I squeaked.

"Any questions?" I tried to think of something sensible. I think I asked about side effects and denied having further questions. He gave me a booklet and prescribed physical and occupational therapy.

Then this matter-of-fact man exited the room. My life changed forever.

I took my meds, and gratefully felt my muscles loosen. I walked and generally moved better in the hours when Sinemet was active in my system. My hand tremor retreated and has rarely been seen since. I began to read during the times I felt open to yet more PD information. I told my sister and my sons about the illness. I told my friends. They were positive and caring. I sighed with relief when that was accomplished.

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***Basically, the clinician should strive to build a one-to-one relationship, a positive rapport. This would include listening for the patient's understanding and feelings about the diagnosis, giving assurance that the patient is not at fault for the illness, dispelling any myths, and normalizing reactions such as anxiety, anger, and depression.***

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experience with another person who had the condition. He encouraged me to join the group. Gladly I did just that. I met others with PD, learned about the role of exercise in PD, started to gain more confidence and began to feel I am what I am.

Reading more, I learned much about this complex neuro-muscular disease, from its early history to today's helpful organizations and hopeful research. I was struck by a book and an article concerning the different ways that clinicians deliver the diagnosis of Parkinson's Disease.

Written and illustrated by Peter Dunlap-Shohl, the book, *My Degeneration*, was informative, relatable, sobering, and wickedly funny. He describes his battle with Parkinson's disease, along the way providing information and strategies for coping. His discussion of the initial diagnosis raised the issue of the quality and tone of doctor-patient communication and its ability to crush or encourage. He concedes the difficulty of finding the honest words to describe an incurable progressive

I went for PT and OT evaluations and signed up for the Big and Loud Parkinson's program at Corewell medical center. What was I getting myself into? I got bolder. I saw a notice for the PD Shake Up! exercise group at my gym. There I met Dan. That was the first time I talked about my Parkinson's experi-

and disabling disease and at the same time offering hope and a means of coping well enough to live a decent life. He skewers the clinicians he characterizes as the unrealistic optimist, the doomsayer, the symptom denier, and the know-it-all. He is all for doctors who provide information about exercise, diet, reading, learning and participating.

The importance of emotional support from the day of diagnosis and forward was discussed by neurologist Dr. Indu Subamarian in a paper she presented in a professional journal. Her paper, "Delivering the Diagnosis of Parkinson's Disease-Setting the Stage with Hope and Compassion" presented the concerns of a discussion group which included patients as well as world-wide leaders in the care of Parkinson's.

The group brought up issues about current practices in the delivery of a Parkinson's diagnosis. The consensus was that on the day of diagnosis, the manner of communication is crucial, thought to affect the course of the PD patient's adjustment afterwards. The clinician should strive to build a one-to-one relationship, a positive rapport that can be fostered in later encounters. This would include listening for the patient's understanding and feelings about the diagnosis, giving assurance that PD is a treatable illness, and a discussion of the many supports.

In his memoir, *Blue Eyes*, neurosurgeon Dr. Oliver Grin had a unique take on these issues.

He admitted his "... too-aloof manner" and noted, "... I tended to communicate too matter-of-factly or not at all." He considered his weak areas important enough to hire a nurse to work cooperatively with him to provide patients with better communication and emotional support. While this solution may have been unique, I hope all clinicians would give consideration of their own abilities to provide positive patient support.

On my diagnosis day, I was overwhelmed. I was able to trust the skills and acumen of the doctor, but would have benefited from encouraging words framed in a caring manner.

Now, I've had time to put that diagnostic day in a wider perspective. It was important but only one of many life experiences.

I've shared conversations and experiences with others with the PD diagnosis. I've had time to reflect on our common journey and to appreciate the ways others cope. I've taken advantage of some of the opportunities at Corewell. I've read about the many aspects of this complex disease. I find it encouraging that people such as the writer-illustrator, the physician-movement specialists as well as Parkinson's patients themselves are underlining the importance of meeting the patient's emotional needs for encouragement and hope. I envision the day that the initial diagnosis will routinely include such support, enhancing the ability of people to begin their Parkinson's journey with the optimism of "I can do this."

## Parkinson's: Pathway to a Closer Relationship with God

Chris Hanna

It was early on a spring morning in Lansing, Michigan, the whir of a greens-mower in the background, a hint of fresh cut grass wafted through the room, I had the day off. It was Good Friday and I was sitting at the kitchen table sipping tea with my Bible open preparing to finish Isaiah, Chapter 52 with no idea what was about to occur next. . . .

Eighteen months earlier, my wife, Kathleen and I, had been visiting friends in Texas. The husband, Brian, was a childhood friend of mine. He and I roomed together at Michigan State University. After college, we went our separate ways, but always managed to stay in touch. He ended up building a successful business in Texas. He also went to seminary school and got a degree in religious studies.

During our visit, I shared with him that I had been searching for some spiritual answers to help me deal with the advancing symptoms of my Parkinson. We talked about his path to the seminary and his relationship with God. He told me the story of how he had left a very secure and successful position and partnered with a couple of others to start a wholesale gasoline business. A week after their start-up they received their first shipment of fuel and had it pumped into an underground tank for storage. Later that evening a line of strong thunderstorms passed through the area. Lightning struck the tank and it blew up. Fortunately, no one was hurt, but with a wife and two young children, he wondered if he had made a mistake switching careers. That night he prayed to God asking for guidance and direction and that was the beginning of his journey seeking a better understanding and a stronger relationship with God.

We continued our conversation and Brian likened the gasoline explosion in his life to the Parkinson's explosion in my life. "Sometimes it takes a major event for God to get our attention and get us to focus on what's important. Other times it may be more subtle. For me the explosion and the unknown of what's next brought me closer to God. Close enough that I wanted to learn more about God. Enough so that I went to seminary school."

"I'm not sure I want to go to seminary school," I said, "but I am very interested in learning more about God. Any suggestions for how I approach this?"

"A good way to start is to read some Bible verses. I can point out some that might help. I'll loan you a study Bible if you want. This might help you interpret meanings."

"Would it make any sense to read it cover-to-cover?" I said.

"That would be a big commitment. If you take that route, I would do a casual read and not try to interpret meanings."

"I'm a painfully slow reader so I'll think about it and let you know what I decide."

At this point, he looped back to my original inquiry of spiritual help with advancing Parkinson's, "Your experience with Parkinson's may be an opportunity to help others afflicted with this disease. People that don't have Parkinson's can't understand its impact, but you know first-hand. God has a purpose for each of us, this could be yours."

I told him this is something that I have thought about and I see myself doing after I retire.

On the plane flight home, I reflected on our conversation and decided I would challenge myself and read the Bible from cover to cover. I began my journey the day after we returned from our trip and made steady progress between then and Good Friday a year and a half later.

I finished chapter 52 and began reading the next chapter. As I read the final few words of chapter 53, "and he bore the sins of many and made intercession for the transgressors." I realized that I had just read the prophecy for what Christians recognize as Good Friday which is the fulfillment of the

prophecy in Isaiah. I was stunned. . . . then I recalled Brian's comment from our visit. "Sometimes it takes a major event for God to get our attention and get us to focus on what's im-

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***This may seem like just a simple coincidence to others, but I truly believe it was a subtle nod of confirmation from God that I was on the right path in my journey to learn more about and become closer to God.***

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portant. Other times it may be more subtle." After a year and a half of almost daily reading, including missing the four days earlier in the week being sick, if I had read any more or less on any day, this moment would not have occurred. This may seem like just a simple coincidence to others, but I truly believe it was a subtle nod of confirmation from God that I was on the right path in my journey to learn more about and become closer to God.

With renewed energy, and conviction I plowed ahead with my reading. One morning I just couldn't concentrate on what I was reading in Romans. My mind kept wandering and I must have read the same verses two or three times. As I sat there frustrated with myself, I recalled a text that Brian had sent earlier in the year with encouragement. Maybe some of his earlier words would help. So, I grabbed my phone and opened my texts. When I read his text, I saw that he closed it by listing two Bible passages, Romans 8:28-39 and Hebrews 4:12-16. The passage I was currently reading and rereading was Romans Chapter 8 and I had just stopped out of frustration between verses 28 and 39. Again, coincidence? I think not. Just another nod from God for being on the right track.

Late that year (2019), I completed my read-through of the Bible and was thinking about what I should do next to expand my knowledge. Brian had mentioned in the past that he would be happy to do a Bible study with me if I wanted. One evening I was bored with the football game and it was too early to go to bed. So, I did something I normally don't do in the evening, read and study the Bible, (I like the morning when I am fresher and it's quiet). I had been doing some random reading of Jesus's parables and studying their meaning. After I had spent some time doing this, I got to thinking that there is a better way to approach my studies going forward. . . . I'll contact Brian in the morning and take him up on his offer to do a Bible study with him.

Happy with this thought, I headed for bed, at which point, I took my nightly last glance at my phone and there was a text from Brian, asking if I wanted to do the Bible study he had mentioned months earlier. A coincidence? Nope just another nod.

Shortly after, we started doing weekly Bible study via zoom and we continue to meet weekly.

That brings me to one last story. I recently joined four friends with Parkinson's to participate in a writing workshop. The goal is for each of us to develop a written piece that focuses on an experience we have had with Parkinson's. I had the idea of writing this piece, but was concerned with talking about religion. It can be tricky, a turnoff for some or a sore spot for others. It can be very personal, so I prayed for guidance. I googled Parkinson's and spirituality and the first document I looked at made reference to Romans 8:28:

"And we know that for those who love God all things work together for good, for those who are called according to his purpose."

I thought, interesting message, it kind of fits with what I am going to write about. What didn't register at the time was that this is the same passage that I talked about above. What did register though, was when I glanced down at my watch and it showed 8:28. Coincidence? Come on! One more nod from God.

This whole sequence of events has drawn me closer to God and told me I am on the right path as I participate in a number of Parkinson's centered activities. I thank God every day for the opportunity to help others afflicted with Parkinson's and for the friendships I have made in and outside of the Parkinson's community. I continue to ask God to guide me in directions that help and inspire people and bring attention to the needs of the Parkinson's community.

## Four Battles In The War Against Parkinson's Disease

Ryan Kelley, Ed.D.

I am one of the ten million people that has Parkinson's Disease. I am fifty-eight years old and I have had P.D. for twenty-four years. I have been inspired by the involvement and the commitment of many famous people like Michael J. Fox, Kirk Gibson, and Muhammad Ali. As a result of witnessing their commitment, I have become more active in speaking out at community functions, support groups, and care team meetings. Everyone has a part in this war on Parkinson's. While our brilliant researchers are trying to find a cure, the rest of us need to be developing plans for our current P.D. population. Everyone needs to have hope. Hope that they can maintain their best life for as many years as possible. Listed below are the four battles that we must win.

### Battle #1 - Awareness/Education/Information

All of us need to be aware of the significant number of people affected by PD. Once we are aware of the size we need to promote the purpose of our efforts. What can we do to help the PD community?

Twenty-four years ago, when I was diagnosed, I had a doctor from Yale tell me and my wife to quit our jobs and travel. He could not have said anything worse to my wife, Jody. I am the optimist in our marriage. Jody is the exact opposite. I asked the doctor why he would say such a thing. He said that his mother died from Parkinson's, and he had never seen another illness so bad. The other obvious question that I had was, could he give me a travel loan? After all, we were 35 years old, with three young children and not much in the savings account.

### Battle #2 - Inspiration

I can honestly say that I am a better person because of my experience. Now I am humble, forgiving, understanding and caring. I will still be the first in line to receive the cure, but in the meantime, I will try to continue to become a better person. We cannot sit around and wait for a cure. We need to keep moving, keep thinking, and keep fighting. We need to maintain a positive attitude and a proper perspective. As the care teams develop their plans, an underlying goal is to see their loved ones being happy. However, most of us are uncertain of what happiness is and how to obtain it. I'm reminded of the following letter that was written by a frustrated elderly man:

*We convince ourselves that life will be better after we get married and have a couple of babies. Then, we are frustrated that the kids aren't old enough and we will be content when they are. Then, we're frustrated that we have teenagers to deal with. We will certainly be happy after they get out of than stage. We tell ourselves*

*that life will be complete when our spouse gets his or her act together, when we get a nicer car, when we are able to go on a nice vacation or when we retire. The truth is there is no better time to be happy than right now. If not now, when? Your life will always be filled with obstacles, and time waits for nobody.*

### **Battle #3 – Personal success plan developed by care team**

A significant amount of time and thought must be put into the development of a care team success plan. Here are some components of my plan:

- Medication - Carbidopa/levodopa (2 pills, every 2 hours), Amantadine (1 pill, 3 times daily), and Pramipexole (1 pill daily in the early afternoon)
- Surgeries – DBS (deep brain stimulation) and SCS (spinal chord stimulation)
- Exercise – cardio (treadmill or stationary bike – 15-20 mins), weights (dumbbells and free weights – 10-15 mins), stretching and balance (10 mins)
- 35 - 45 mins per session
- 5 days per week
- Weekly total (175 – 225 mins)
- Reduce the amount of sugar in diet, drink a lot of water, and eat more fruits and vegetables.
- Continue to be active with educating the community on PD.

### **Battle #4 – A cure**

To all of the people with PD, I can honestly say that I am a better person because of my experience. I will try to continue to become a better person. We also need to educate those within the PD community. I frequently speak to the newly diagnosed patients. At first, they seem to have given up hope for a better tomorrow. They feel like they have received a death sentence. I make it very clear that Parkinson's will change your life, it will not end your life. We still have a lot of work to do, but we are making progress. However, until we

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***Each patient and their care team must develop and implement a plan for success. We cannot sit around and wait for a cure. We need to keep moving, keep thinking, and keep fighting.***

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have a cure, we need to keep up the fight. Our first line of defense is bringing awareness to the challenges and limitations of PD. Second, we need to maintain a positive attitude and a proper perspective. Third, each patient and their care team must develop and implement a plan for success. We cannot sit around and wait for a cure. We need to keep moving, keep thinking, and keep fighting.

The first “cure” will be achieved when we are able to prevent the

disease from progressing any further. The patient will not have the disease advance any further, but will not get back to “as good as new.” The second “cure” will be defined as when the patient, regardless of how long they have had Parkinson's, returns to their previous normal self.

How should our “best life” be defined. To me it should include some of the following: people furthering their education, working hard, staying positive, treating people with respect, and being trustworthy. Be the kind of person that

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brightens up a room when entering, not when leaving. Be an inspiration. Be a person who wants to attack Parkinson's Disease and is willing to fight, fight, fight. Continue to participate in some of your social activities – golf, cards, watching grand kids activities, etc. Have a legacy to be remembered as a person who fought the disease with a positive attitude, a thirst for knowledge, daily exercised his/her mind and body, kept things in the proper perspective, and was always willing to help his fellow Parkinson's friends—whatever their needs might be! Every Parkinson's patient is different, so each of them will have a plan that is specific to their symptoms. Their care team must be involved in the process.

**A**s the care teams develop their plans, an underlying goal is to see their loved ones being happy. We cannot sit around and wait for a cure. We need to keep moving, keep thinking, and keep fighting. However, most of us are uncertain of what happiness is and how to obtain it. Don't let Parkinson's be your only reason for not being happy. It certainly can be a reason for having a bad day, but don't let it be the sole factor that dominates your life.

If there ever was a group of people who deserve some relief in the form of happiness, it's the 10 million people with Parkinson's Disease and the millions of caregivers. The daily challenges that our Parkinson's community faces can be overwhelming. But we can't give up and sit around while we wait for a cure. We each need to continue to work on being the best we can be.

I believe that every family and every individual should reflect on their lives on a regular basis. Get up every morning, asking what you can do to give you purpose and to help others. One thing that everyone can do is pray for the Parkinson's Disease doctors, nurses, and patients. Also, read about all of the research that is taking place, that is bringing renewed hope to the Parkinson's Community. Being one of those who has the disease, I plan on continuing to live my life one day at a time. I will dedicate my life to maintain purpose by helping others.

As I reflect on my life, I hope that I was able to live a life that allowed me to help people to overcome obstacles. I hope that I served a purpose that was aligned with the phrase “it’s not where you start that’s important, it’s where you finish.” I want to know that I am still growing and learning. You must live your life with gratitude. Be thankful for everything that you have.

## Parkinson’s: I’ll Take Some of That

Paul Pate

It was 2013, my wife Erin and I were sitting on the couch. She was watching my left thumb twitch a little.  
“That’s not normal.”

Picture one of those neon signs on a motel that says “Vacancy,” and it flickers as you drive up. The sign was shining right in the middle of our living room, snapping with the sounds of crickets and skeeters.

*\*That’s Not Normal\* \*That’s Not Normal\**

Erin is not the type of person to utter those words lightly. She married a rather eccentric dude. She gives a wide berth to “normal.” Upon hearing those words from her, I figured I should go get it checked out. I really didn’t want to, but I probably should.

Fast forward a year and I’m 44. I’m sitting in the office of a neurologist. I had no clue really what a neurologist was or did. I mean, I was athletic, healthy,

and always tried to take good care of myself. I didn’t really care about doctors. After a series of about fifteen or twenty really weird questions like, “Do you have bad dreams?” and “How

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***Picture one of those neon signs on a motel that says Vacancy, and it flickers as you drive up. The sign was shining right in the middle of our living room, snapping with the sounds of crickets and skeeters: That’s Not Normal. That’s Not Normal.***

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is your sense of smell?” These were weird, random, seemingly unrelated questions. The neurologist said, “You have Parkinson’s, man.”

### Mirapex

That was a gut punch, and a right cross to the eye. I was stunned. I had no idea. Parkinson’s? You mean like Muhammad Ali? Michael J Fox? Before I left the office I had a prescription for Mirapex. That’s what they give you when you’re diagnosed with Early Onset Parkinson’s. They told me how and when to take it. They told me how to ramp up the dosage and the side effects to watch out for. Within days I had my bottle of pills. Each and every day: *I guess I’ll take some of that.*

The side effects of Mirapex can be terrible. They aren’t for everybody, but they were for me. Right away it made me nauseous. It also made me sleepy. I was sleepy before I started taking it. Man! This was not good. They warned me about depression. I needed to eat healthy and exercise. I already liked to do those things, so I just needed to keep it up. I needed to keep a great attitude and just do what I was supposed to do. The truth was, I was scared. I was afraid of what my fu-



ture held. I didn't know what to do, other than what the doctor told me.

My great attitude pushed me through about three years taking Mirapex. I had developed fourteen out of the fifteen bad side effects. I gained 50 pounds from obsessive eating. My car was a disgusting mess full of candy wrappers, fast food bags, and a smell you could see. I suffered from insomnia and depression. I had a bout of paranoia. That was wild. I was a terrible mess. One night, after I had snapped at one of the kids, Erin said, "you're being a jerk!" Again, the flickering neon sign. Erin does not say those kinds of words unless it is dire. This time the sign had some letters that were burnt out. Not good! I needed to try something different.

### Marijuana

Deep into my Mirapex era, when I was really struggling, I worked with Bob. Bob was an interesting cat for a lot of reasons. For one he was really into marijuana. He wasn't a burn out or anything like that. He wanted to grow marijuana and maybe run a dispensary. He was learning all he could about it, the different types and all its uses from medicinal to recreational.

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***I was headed up the first hill of a giant roller coaster. Clickety clack, clickety clack. The white and red lights from the other cars were long straight lines guiding us down the track. As we drove through our little town I had the sensation we were driving straight up into the sky.***

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Bob saw me struggling to stay awake at work and suggested I try some of his "stuff." I had never tried marijuana. I was a health nut. Marijuana was not in the mix for me, but I was really struggling. My health was shot. I figured it wouldn't

hurt to try. I gave Bob a hundred bucks and he gave me a bunch of different little treats. There were about four or five different candy bars and he gave me the rundown on each one.

I took my stash home and told Erin as I hid it in a closet away from the kids. The next Friday came along, and I thought I'd try some when I got home from work. I broke off a little piece and ate it. It was little, barely a bite. I didn't even get a chance to tell Erin about it before I started feeling funny and laughing. I fell asleep on the couch and forgot to ever mention it.

The following Friday the plan was to have a beer at our cool little bar in the basement. We'd talk and laugh about whatever. The problem was, I'd always fall asleep slouched onto the bar and Erin would end up talking to the top of my head. Maybe she could drink a beer and I could try one of those edibles. This time I'd just eat a tiny little piece,

half the amount I had eaten before (and never told her about). We talked it over and that was the plan.

We needed a few things from the store. I suggested I would take my little treat before I ran off to the store. She could crack open a beer when I got back. Erin thought that sounded fine, but wanted me to let our son Ryan drive. He was fifteen at the time and was taking driver's training. He needed to get some practice in, plus he wanted to buy a video game at Meijer. I agreed and we headed out.

Ryan and I strolled into the giant store, groceries on the left, everything you could ever possibly want on the right. I grabbed a cart and pushed it over to the greeting card section.

"You go buy your game and I'll pick up a few things. Meet you right back here," I told Ryan.

"Sounds good." He had no clue, such a nice boy.

Five or ten minutes later Ryan returned, the video game purchased and in a bag. It coulda been an hour and ten minutes later for all I knew. I had not moved.

"You didn't get anything?"

I looked at my empty cart. "Nah. Let's just go home."

"Okay," Ryan said, a little confused, but still clueless. He was happy to get in the car, drive home, and play his new video game. He followed me out the door as I left the empty cart stranded in the greeting card aisle.

By the time I buckled up in the passenger's seat, I was feeling pretty weird. It was dark out and the bright parking lot lamps hovered around like flying saucers. When we pulled out onto the main road, Ryan asked me how he was driving. At this point I couldn't tell if we were going forward or backward, but he had gotten us there. He was definitely our best shot at getting us home in one piece. "You're doing great, buddy." I remember gripping down on the sides of my seat like I was headed up the first hill of a giant roller coaster. Clickety clack, clickety clack. The white and red lights from the other cars were long straight lines guiding us up the track. As we drove through our little town, I had the sensation we were driving straight up into the sky. I just closed my eyes and hoped for the best. My dad had me driving across the country at fourteen. Ryan could get us home from Meijer. He was fifteen, for goodness sake, and I was high as a kite!

### Sinemet

The marijuana story is funny in retrospect, but not a good experience. My experience with Mirapex was even worse. It was terrible, in fact. It was getting so bad I didn't know how much longer I'd be able to work. I wasn't even fifty! In consultation with Erin and my doctors, I decided to quit taking Mirapex. The drug had become worse than the disease. The scary part was that you had to take like six months to wean off the medication. The warnings of depression and suicidal thoughts terrified me. I didn't feel confident I could do it, but I needed to get off that

drug. It was killing me.

As soon as I started taking less Mirapex, I started feeling better. I started feeling like myself mentally and emotionally. By the time I had stopped, my tremor was pretty significant and my body was super stiff. My coordination was bad and it was hard to exercise. But I was happy to be alive.

It just so happens that my mom had been to the Mayo Clinic some years before. My sister had asked me if she minded if she tried to get me in. She'd fill out all the paperwork and stuff for me. My sister is my guardian angel. I figured it couldn't hurt and then I forgot about it. I had only been off Mirapex a few months when I unexpectedly got an appointment with a doctor at the Mayo Clinic. He was not surprised to hear about my experience with Mirapex. I didn't tell him my marijuana story.

Right away the Mayo Clinic prescribed a medicine called Sinemet. It would help with my tremors and not have any of the side effects. *I'll take some of that!*

### I Can Move Again

The Sinemet helped right away, perhaps just thirty minutes. Mirapex is a drug that builds up over time. It takes weeks before it can effectively and efficiently ruin your life. Sinemet isn't like that. It runs through your system quickly and creates dopamine in your brain. My tremor stopped and I felt coordinated, like I could run or dance. It wears off after a few hours and I'd have to take more. I take it three times a day now.

The great thing about Sinemet is that it helps me feel like I can move and exercise. Exercise is the number one thing a person can do to slow the progress of Parkinson's. *I'll take some of that!*

### Life

As I write this I'm ten years beyond my Parkinson's diagnosis. The disease progresses, but I'm pretty lucky to be doing alright. I fight back by getting exercise and trying to live a rich and fulfilling life. I need to do more exercise and less "rich and fulfilling," but I'm trying. The hardest part of hearing, "You have Parkinson's, man," is the fear. What will life be like in ten years? I still have that fear today, but I think most people do to some extent, Parkinson's or not. I can look back at the past ten years and all the things I've tried, and honestly tell you having Parkinson's is just life. Just like anything in life, Parkinson's will force you to respond. You will have to make tough decisions and try different things. Your response will reveal who you are. I feel pretty okay about who I've been the last ten years. It's life. *I'll take as much of that as I can.*

## L-Dopa Hesitant

Dan Royer

The discovery of the importance of a chemical called dopamine in 1957 by Swedish scientist Arvid Carlsson eventually led to the treatment of Parkinson's disease with levodopa, and in 2000 he was awarded the Nobel Prize in Medicine. Neuroscientists at that time viewed dopamine as a mere building block or "precursor" of other more important molecules. Carlsson was the first to realize that dopamine itself was a critical neurotransmitter responsible for, among other things, our ability to move.

The story begins when Carlsson was experimenting with an antipsychotic drug and injected it into some rabbits. He expected this drug to block some im-

portant neurotransmitters and, sure enough, it paralyzed the rabbits. His next hunch was to try to wake them up by injecting them with L-Dopa, a molecule that was believed to be a mere precursor to known neurotransmit-

ters like norepinephrine (adrenaline). It worked, but not for the reasons many at the time would have suspected. Upon deeper investigation, Carlsson realized that it was dopamine that had emerged in the rabbits' brains, not just the other transmitters he expected, and it was dopamine that was responsible for reversing the rabbits' paralysis allowing them to move again.

Within ten years, L-Dopa was being given to patients with Parkinson-like symptoms, and the effects were astonishing. Progress was cautious and stuttered at first, but FDA rules were not strict in the late 1960s (FDA approval for levodopa came in 1969; carbidopa-levodopa was FDA-approved in 1975) and by the late 1960s, experiments on humans had begun. The most famous of these early experiments with L-Dopa was documented by Oliver Sacks and published in his book *Awakenings* (1972), a collection of case studies with thick descriptions of fifteen patients suffering with Parkinson-like symptoms (so-called "Sleeping Sickness") in a Bronx care facility. The results seemed miraculous: after being administered L-Dopa, his patients emerged from, what was for many, decades of deep catatonic isolation, awakening to a new and joyful life. It was hard to believe.

A 1990 film, "Awakenings," starring Robin Williams and Robert DeNiro dramatizes this miraculous change and the astonishment of

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the doctors and patients. It also captures the limitations and intolerable side effects of these first efforts to produce dopamine in the brain by way of L-Dopa in the gut. Reading Sack's account confirms that Hollywood was not exaggerating. His careful case studies pull back the curtain to reveal a lot about the inner lives of these suffering patients whose ability to move and communicate had nearly ground to a halt because of their loss of dopamine.

But despite all of this initial excitement over L-Dopa, the claims of the near miraculous, the astonishment of patients having endured, for some, decades of catatonic stupor, when the opportunity presented itself, some patients were hesitant.

Dr. Sack's reports in *Awakenings*,

*The good news spread quickly. By March 1967, the patients at Mount Carmel had already heard of L-Dopa: some of them were eager to try it at once; some had reservations and doubts, and wished to see its effect on others before they tried it themselves; some expressed total indifference: and some of course were unable to signal any reaction.*

Indeed, Sack's himself was hesitant:

*I could, despite its cost, have started a few of our patients on L-Dopa after reading Cortzia's paper. But I hesitated—and hesitated for two years. For the patients under my care were not 'ordinary' patients with Parkinson's disease: they had far more complex pathophysiological syndromes, and their situations were more complex, indeed without precedent, for they had been institutionalized and out of the world for decades—in some cases since the time of the great epidemic<sup>1</sup>. . . . Thus there was an element of the extraordinary, the unprecedented, the unpredictable. I was setting out, with my patients, on an uncharted sea . . . (Sacks, 78)*

I see in my own early experience with Parkinson's an L-Dopa hesitancy that arose from these same fears and concerns. I was in a clinical trial for the first fourteen months after my diagnosis, and this trial required that I not be on any medication. But after the trial the opportunity to take L-Dopa was available. I felt oddly, vaguely, hesitant. I was not able to muster any arguments about the unprecedented or the unpredictable. My neurologist told me that about six-percent of Parkinson's patients did not respond to levodopa, but fifty-five years after these early experiments, carbidopa-levodopa had a very good track record. Nevertheless I had my doubts and reservations. I was vaccinated and not particularly averse to medication. Perhaps I wanted to

<sup>1</sup> *Encephalitis lethargica* assumed its most virulent form between October 1918 and January 1919. In the United States the epidemic peaked from 1920 to 1924. It is estimated that as many as one million people were diagnosed with *encephalitis lethargica* during the epidemic period. (Wikipedia)

observe its effects on others before committing myself. My concern was really not a rational concern.

Sitting in my doctor's examination room, I contemplated the decision to begin this gold-standard medication; I felt something like a lack of courage or confidence. What would I really be getting myself into? My identity would forever be tied to this small yellow tablet. It seemed to me that if anything

signaled that I really had Parkinson's disease, it was L-dopa. This drug would address the pesky motor symptoms—my right-hand and right-leg tremor—but not the weighty non-motor symptoms that disrupted my life much more. I could

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***“The scrambled eggs tumble off my fork,” I remarked. “My handwriting is terrible.”***

drink fine and not spill with my left hand, but the achy anxiety that migrated from my chest to my spinning brain would be unaffected by the levodopa. The disease was very powerful; the drug must be even more so!

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***“So, yes, It's a quality of life issue,” the doctor explained.***

***I left the doctor's office without a prescription and remained L-dopa hesitant for six more months.***

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“The scrambled eggs tumble off my fork,” I remarked. “My handwriting is terrible.”

“So, yes, It's a quality of life issue,” the doctor explained.

I left the doctor's office without a prescription and remained L-dopa hesitant for six more months.

In between the annual visits with my neurologist, I was scheduled to visit with his assistant, Angela. At this point, six months after starting a daily dosage of an SSRI—a chemical method of increasing serotonin in the brain, another important neurotransmitter—I was a true believer. Extra serotonin caused me to feel as if I had been living life with one arm tied behind my back. Things got easier.

“So, no levodopa yet,” she observed looking at my chart.

“No, not yet, I was thinking that maybe I should start with a MAO-B inhibitor, you know just to get things going in that direction,” I said.

“Ah, but that would interact with the SSRI you are such a big fan of,” she countered.

I mused for a long moment. I was not ready for that one. Here I was. The small office remained still for another moment while my brain searched for a bunny trail to escape.

“It's really no big deal,” Angela finally said.

I held that phrase in mind a bit, “No big deal.” It had a finality to it as if all other responses were beside the point. There was a clarity and a simplicity in her words that I experienced as compelling.

“No big deal.” “Well, maybe not to you” I thought to myself but I could feel the sense of her words. I mustered a bit of courage and confidence and I left her office and shoved off on an uncharted sea. The first pill down the hatch on an empty stomach . . . I waited and watched the clock. Thirty-five minutes later I experienced about an 85% reduction in my right-hand tremor.

### The L-Dopa Hesitant Physicians

The first thirty years of L-Dopa use for Parkinson’s patients coincided with the development of other drugs that were also found to be helpful. Dopamine agonists (think, “dopamine helpers”) like Pramipexole (Mirapex®) and Ropinirole, for example, were used to mimic the effect of dopamine. Other medications were also used to provide symptomatic relief for Parkinson’s patients. As clinical trials matured, debates grew up in the medical community about the best or optimal sequence of treatment options for persons with PD. Two influential clinical trials in 2000 captured the attention of movement disorder specialists by suggesting that the use of these agonists should be the first treatment option because of the belief that L-Dopa was toxic, that it had too many side effects, and, the belief that endured the longest, because it had a limited period of effectiveness that should be saved for when symptoms got worse.<sup>2</sup>

Later clinical trials undermined these conclusions, and a more balanced view has emerged in clinical practice. Nevertheless, this belief about a limited treatment window for L-Dopa remains one of the most common reasons that person’s with Parkinson’s might have for wanting to delay the use of carbidopa-levodopa. It is no longer a belief held among movement disorder specialists as it commonly was in the first fifteen years of the 21st century, but beliefs that were once suggested by clinical trials still sometimes prevail as myths among some who are unfamiliar with more recent medical literature.

My friend Paul was caught in this transition period given that he was diagnosed in 2014. Many doctors in this period were L-Dopa hesitant and the prescription for Paul would start with Mirapex. Paul believed this strategy would preserve the use of L-Dopa for when he could get most from his limited opportunity with it. During his first three or four years post-diagnosis, Paul experienced, as he tells it, 14 out of the 15 possible side effects of Mirapex. It turned out to be a disaster; side effects were far worse than the disease itself. But by his fourth year after diagnosis, 2017, the tide began to turn and doctors, no longer L-Dopa hesitant, took him off Mirapex and switched him to L-Dopa. It was life changing. Ten years post-diagnosis, L-Dopa is still effectively managing Paul’s symptoms.

<sup>2</sup> Revisiting the Medical Management of Parkinson’s Disease: Levodopa versus Dopamine Agonist (2016). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4876591/#R39>

An excellent and readable description of this “Levodopa Phobia” phenomenon, including four illustrative case studies, appeared in a 2018 article in *Nature (NPJ)*<sup>3</sup>. These short case studies are excellent illustrations of how, even after years of clinical trials suggesting the contrary, levodopa phobia is still common.

### In Medicine, to be Hesitant is a Virtue not a Vice

I have been suggesting above that what I refer to as L-Dopa hesitancy based on lingering historical misperceptions was, and still is, a problem to be solved. But it’s important to keep in mind that in the world of medicine—as a researcher, clinician, or patient—to be hesitant is a virtue not a vice. All of science moves forward with hunches, experiments, skepticism, doubt, and second guessing, that is, with some hesitancy. In science, error is the price we pay for progress. It seems that in every realm, overconfidence is the conspicuous menace of our current times, and it can be pernicious in a world where quality of life and even life itself is at stake. As patients, we want to see our nurses and doctors be confident, but not overconfident.

The full history and complexity surrounding the historical shift in views of the optimal treatment strategy, starting treatment with dopamine agonists like Mirapex vs carbidopa-levodopa, is an ongoing story. An excellent review can be found in *Current Neuropharmacology* (2016) “Levodopa Phobia: a Review of a Not Uncommon and Consequential Phenomenon.”

What we might now describe as myths were first suggested by serious clinical trials. But, again, error is the price we pay for progress. Clinicians now have a more complete and nuanced understanding of things. As the authors of the review cited directly above conclude, “A balanced perspective is needed as there is a place for both drugs in the management of PD.”

Oliver Sacks had an illustrious career as a neurologist, documenting in various books his case studies of the experiences and inner lives of his patients. He had an empathetic genius for the uniqueness and “neurodiversity” of his patients. He was curious and confident, but not overconfident. Robin Williams, playing Sacks in the role of Dr. Sayer in *Awakenings* (1991) commenting near the end of the film says something very much like Sacks himself might have said given Sack’s awareness of both the miraculous potential and sometimes unexpected limitations of drug treatments:

*What we do know is that . . . the human spirit is more powerful than any drug—and that is what needs to be nourished: with work, play, friendship, family. These are the things that matter.*

<sup>3</sup> ‘Levodopa Phobia’: a review of a not uncommon and consequential phenomenon. <https://rdcu.be/dAGcF>

