

# Parkinson's and me



## Frederic Platt, MD

Dr. Platt is a retired primary care internal medicine physician living in Longmont, CO.

### Who was I? Who am I now?

I have a liberal arts education from Northwestern University and medical training at Stanford, the Universities of Chicago and the University of Colorado.

I practiced primary care internal medicine for 50 years and taught at the University of Colorado as Clinical Professor of Medicine with a special interest in doctor-patient communications. In all those years, I rarely saw a patient with Parkinson's disease, until I became one.

Now, I am fully retired, have moved to Longmont, Colorado, and spend my time reading, playing bridge, and going to doctor appointments. I do little these days with medicine except when I am the patient.

### Rapid eye movement dreaming

In 1990, my dreams began to toss me about at night. I dreamt of arguments and fights, and threw myself from side to side, punching and grabbing my opponents. I grabbed the bedside lamp post, knocking it down, and more than once I grabbed my wife, who would struggle and shout, "Let go," waking me. Twice I fell out of bed while dreaming.

I never had real fights like the dream ones, and did not want to harm my wife, so I made an appointment for a sleep study at a local hospital.

After what seemed to me to be a pleasant, undisturbed sleep in the laboratory, I learned from the technician that

I had climbed out of bed, answered a non-ringing phone and conversed with imaginary callers. The scalp leads showed REM sleep, thus dreaming. The sleep expert said I had a problem called REM sleep disorder that suppresses sleep paralysis, the function of the brain that keeps dreamers immobile. He said it could be managed with a benzodiazepine called Clonazapine, and added as an afterthought, "Sometimes, it's an early sign of Parkinson's disease."

Turns out that "sometimes" means "all too often," 12 years later, when I was 75 years old, that time had come.

Current estimates of the frequency that Parkinson's is linked to REM disorder are much higher than the sleep expert thought. In 10 years, more than half of REM disorder patients will have been diagnosed with Parkinson's disease. By 15 years, the number rises to 70 percent. Fifty percent of Parkinson's patients have a history of REM disorder.

### Then what?

Over time, I seemed to be getting tired more easily, needed occasional naps, and developed aches and pains in my back and my limbs. I have several other health challenges: heart disease, bladder cancer in remission and diabetes mellitus, with neuropathy that rendered my feet numb and probably led to loss of proprioception, the sixth sense that tells us where we are in space. I was weaker, had more difficulty balancing, and began to use a cane while walking. Occasionally, I would experience a jerking movement of my arms, and sometimes a tremor of my hands.

In 2013, my wife and I went to visit a neurologist in Denver. I thought that perhaps all the troubles I cited

could be blamed on diabetic neuropathy but my blood sugars and my A1C hemoglobin levels were doing quite well on minimal insulin dosage.

The neurologist did an examination and then asked me to walk up and down the office hallway. He then asked me if I “always walked that way.” I asked, “What way?”

He said “Your arms don’t swing, but don’t worry about it.”

I thought that was a silly thing to say. I was a doctor. I knew what arms not swinging meant. So did my wife. She said, “You must have Parkinson’s disease.”

My neurologist, on satisfying himself about the diagnosis, started me on a little pink pill, carbidopa/levodopa. The tremors diminished remarkably. However, the drug has a short effectiveness period so I needed to take a Dopa tablet every four hours to suppress the tremor. If I miss a dose, my tremor increases and I become incapacitated because of the shaking.

Unfortunately, the drug did not restore my energy, relieve the aching pains, or help my balance.

### **What else is happening?**

If you read a list of symptoms shortly after being given the diagnosis of Parkinson’s disease, you may find the growing list frightening and depressing. Fortunately, Parkinson’s disease is not a fatal illness. I will probably not die of this disease, but as I age, other disorders and side effects will probably limit my activities, then my life.

Parkinson’s disease was first noted to provoke tremor and increase muscle tone and weakness, but it also has major effects on the gastrointestinal tract. Like others with Parkinson’s disease, I have intermittent severe constipation with rock-hard, implacable stool. Once, I went to the emergency department for relief of the obstipation and discovered the value of occasional doses of polyethylene glycol, a powerful laxative, I now dose myself with a daily handful of prunes.

Another distressing complication is a paralyzed bladder that refuses to empty until more than full. The bladder paralysis may be the result of diabetic neuropathy, but could also be a visceral neuropathy caused by the Parkinson’s disease.

As I grow older, I realize that any number of physical and cognitive changes may be caused by Parkinson’s disease. My wife and I recognize the loss of volume in my speech, and a growing lack of facial gestures as signs of Parkinson’s progression.

### **What of the tremor?**

What most people know or what they might ask about when discussing Parkinson’s disease is the tremor. For me, the tremor varies from a mild, almost unnoticeable, slow, pill-rolling movement to a violent shaking and jerking, and an irremediable total body shaking and quaking. I often feel out of control, as if I were on a small ship at sea in a moderate storm. Nothing in the world, as I perceive it, remains at rest. In less distressing times, my fine motor control is simply absent and I cannot use a pen, turn the pages of a book, or eat with a fork. No physical action is dependably controllable.

The Parkinsonian tremor is usually said to be present when one is at rest and may be somewhat controllable by effort, but my tremor, simply ubiquitous and difficult, is likely to be out of control with intentional action or at rest.

### **Why is it hard to diagnose Parkinson’s disease?**

When two Parkinson’s disease sufferers meet on the street, each one asks, “When was your diagnosis first made? and, “What symptoms first appeared?”

Both tell the same story.

## **On and off**

We go ON and OFF.

ON means drug is working,  
usually C/L Dopa,  
and we can move,  
maybe not freely,  
but somewhat.

OFF means the drug has worn off  
or never worked at all  
and we are stuck in place,  
“frozen,”  
or the tremor has increased  
and we are equally broken down.

We are the puppets  
that the drugs we take  
can switch what is left of us  
ON or OFF.

## How are we doing?

We Parkinsonians arrive  
for our exercise class,  
some with walkers, some with canes,  
some just shuffling in.

We greet each other,  
“How you doing?”

Then we lie  
and everyone says,  
“Pretty good,” or “Not bad,”  
until Rich says, “Incredibly good!”

Then we all laugh and agree that's how  
we're doing.

We're all just incredibly good.

Symptoms for 10 years, but diagnosis only the last five, then a guess like, “Perhaps my doctor wasn't the expert I needed.”

Some diseases are visible, and some diseases have markers; the PSA tells us about prostate cancer, and a positive HIV gives away its secret. Parkinson's disease lurks, creeping up on us. Our grandkids notice that we no longer smile? We lose our sense of smell, and our appetite falls off. Walking through a door, we freeze and begin to shuffle. This phantom transforms us.

### Rigidity

As a medical student I learned that one of the key features of Parkinson's was the increased tone or stiffness of the muscles. I was taught to test for the disease by holding hands with my patient and rapidly moving my arms up and down, noting that the patient's arms didn't move freely but more as if they were stuck in heavy-weight oil. The patient would say they felt slowed down as if walking in molasses.

For me, as a patient with the disease, I don't feel stuck in molasses, just tired.

### What is a typical day like?

I may wake feeling pretty good, but two out of three days I have pain in my back and legs. My calves cramp up, and I have some thigh and buttock cramping. I do calf and thigh stretches holding onto the bed. The leg pains will usually diminish once I am sitting up but I am still slow and hardly able to move. After sitting for a few minutes, I have another burst of hope, “Maybe I'm still going to have a really good day.”

Dr. Pavot (AΩA, Virginia Commonwealth University School of Medicine, 1999), my neurologist, recommends sitting for a few minutes before standing. When I stand up, I experience a lack of balance and have to hold onto something—my three-legged walker or a piece of furniture. I am wobbly enough that I expect to fall, but fortunately, so far, have had no falls and no injuries.

Obeying Dr. Pavot's recommendation, I have to stand holding onto the walker or the furniture for several minutes, then try to walk to the bathroom. Walking is hard at first; legs and feet refuse to follow my orders. I am frozen in place. I try stamping my feet, starting with the one that feels most stuck until they seem willing to move. Then, I feel my way into the bathroom. There, I go through the morning ritual: wash a bit, maybe shave, take myriad pills, and inject a dose of insulin. Bowels and bladder are a major priority for the next hour.

Back in the bedroom, getting dressed requires numerous steps. I use a shoe horn, even for slippers. I don clothing by going from sitting to standing to sitting, using a maneuver taught by Sarah, my physical therapist. While sitting, I kick up one leg, and, on its return, can throw my torso back up. This maneuver follows Newton's third law of motion.

I am still very wobbly and sense an impending fall so I keep holding onto my three-wheeled walker, and as I move about, I grab the door frames for security. We have placed several grab bars at strategic spots enroute, invaluable for progress and safety. Then I walk downstairs for breakfast, using the two bannisters, one on each side of the stairs.

### Dementia

One variant of Parkinson's disease includes dementia as its main feature, and is ascribed to Lewy bodies in the brain—packets of a protein that seem to diminish all thinking ability. Parkinson's disease patients have few features of dementia, yet fear that complication of the disease above all others. My benchmark for judging cognitive alertness is my ability to sort a bridge hand and to do the crossword in the daily newspaper.

Dr. Tom Graboys (ΑΩΑ, New York Medical College, 1992, Alumnus), in his book, *Life in the Balance*, describes his decline into dementia as the worst part of Parkinson's disease for him, saying that he was often angry about his mental deterioration. My friend, Irv Press, suffering from Parkinson's, says he is angry at his body for having failed him.

I recognize feelings of sadness and loss in myself but not so much of anger. There is nobody to blame, not even myself. Sometimes I feel shame. When I see that I am walking with my head down and with short shuffling steps, speaking almost inaudibly, uncertain and shaky, I feel embarrassed, ashamed, and want to hide.

Parkinson's is a tricky disease. It usually lets us live for a long time with the many symptoms. And it surprises us with new symptoms whenever we think we've had them all. I have had some loss of sense of smell, loss or blunting of taste, gradual loss of voice volume and liveliness, and what I call "minor hallucinations," the sense that I almost was able to see a squirrel that had just run across my living room floor but never could hold in my vision for more than a moment or two.

I am aware of the many losses I've incurred and the embarrassment I've experienced. I consider my Parkinson's evidence of nature—in this case, biology—taking its course. My feeling about the affliction is less one of self-pity than of self-compassion. I see a human being bent, but determined. I feel the loss of that young man who worked hard, ran daily, and pursued myriad interests. I have experienced an opening toward others, a feeling of acceptance that is new and that may be a feature of the disease.

There is no good answer to the puzzle of causation for Parkinson's. Lewy bodies may cause the tremor and the dementia, but we still don't know why a person might get those Lewy bodies and another avoid them.

And, along with those painful feelings of shame and all the physical symptoms, I still have a lot of happiness and joy.

### **My pleasures**

I get pleasure from weekly internet bridge games with friends.

We have two daughters, two grandchildren, and two beloved dogs. Most beloved, and most helpful, is my dear wife, Connie. She is everything to me and helps me in every way. She helps me work my computer and

## **Prognosis**

Lying quietly in the morning  
I am sure that I am whole and well.  
I will get up soon and move  
easily, I am sure.  
All the symptoms  
must have gone away while I slept.  
I am healed!

No, no, no...  
I was wrong.  
I rise and wobble.  
I stagger to the bathroom, then sit to dress.  
I take my walker to the stairs  
and head down,  
carefully.

I will shake and wobble  
for whatever time is left.  
This is me.

balance my checkbook, a task newly difficult because I cannot read my own entries in the transaction register. She trims my toenails to avoid the Howard Hughes look, runs the household, cooks our meals, and laughs with me. Most of all, she listens to me as much as she is able. She is an introvert, and I am a sharer, a dynamic that results in a tension we have to balance. I try not to exhaust her resources.

Reading has remained my major activity. I read fiction and non-fiction. This last year, I reread a half dozen science fiction novels by Ursula LeGuin. I read Isabel Wilkerson's *Caste*, a brilliant sociological book about how we put people in a hierarchy of social power from high to low. The concept of caste has been used to categorize ethnic and cultural groups. As Wilkerson observed, the elderly have been assigned a lower caste status, more so if we are disabled by symptoms of Parkinson's.

I have read and reread four fine books about Parkinson's. I read and re-read Graboys' memoir and the encyclopedic *New Parkinson's Disease Treatment* book by Eric

Ahlskog of the Mayo Clinic. As a side benefit of my reading Ahlskog, I am less worried about dementia. I discovered the Davis Phinney Foundation and read *Every Victory Counts*, a great collection of expertise and ideas. I've watched Phinney doing interviews on YouTube programs. He is intelligent and thoughtful but looks like the rest of us—facial blandness, tremor, shuffling gait, quiet voice. I enjoy hearing him talk about exercise—once a world class bicyclist, now his favorite exercise is vacuuming the rug.

### What tools do I have?

I have several devices to help me navigate Parkinson's disease.

Our bed is king-sized with remote devices controlling each side. I lower the upper half of the bed when I am trying to get in, and raise the head when getting out, thus borrowing a little help from gravity. My son-in-law recently anchored two PVC pipes to the bed frame to aid me in pulling myself in and out of bed.

I use a cane with a large foot for help with balance, one that comes apart so it can be packed in a carry-on

bag for travel. The cane signals my disability to others, so I frequently get extra help. At first, I felt a bit guilty in accepting these preferential services but now I realize that without some help I would find it hard to leave home.

At home, I have two walkers, one on the main floor and one on the second floor, where our bedroom and master bathroom are located. The first-floor walker provides better balance than a cane, and a shelf for carrying books or other necessities. I can even turn around and sit on the shelf for a bit of rest.

Another aide that I initially was hesitant to use but now accept fully is the disability tag for my car. I obtained the tag by taking a brief note from my doctor to the vehicle license bureau. I have a tag for each of our two cars.

At home, there are two short staircases between floors, a total of 18 steps. When we bought the house, the stairs had one bannister on the left side of each staircase. We found a woodworker to design, make, and install bannisters on the other side, a glorious help. Even with bannisters, it is often difficult for me to climb the stairs if encumbered with a book or food items. My Parkinsonian tremor makes it hard to hold anything besides the railing. I find that I can hang a library bag with loop handles around my neck, freeing my hands for getting up or down.

The first item to add to a house for disability use must be grab bars. We have added nine chromium bars but we should add several more. Our marital discussion often features me wishing for more hand holds and my wife voting for a less clinical appearance. We negotiate. Lacking a grab bar every few feet as I negotiate my way through the house, I use ledges in the door frames and furniture. Usually, just a touch is enough for balance, more if I am trying to hoist myself from lying to sitting, or sitting to standing.

Our cordless house phones have an intercom function so we can talk to each other when we are at opposite ends of the house or on different floors. That saves shouting. Of course, we both have cell phones and the portability of the cell phone, when I remember it, can find it, and keep it on its charger, enables me to have a computer at hand.

People are helpful and I am grateful for their aid. As one's circle narrows, the good will and competence of those who remain close are particularly important. Most turn out to be helpers: my neurologist, my neighbor who organizes bridge, the neighbor who shovels our drive when it snows, the physical therapist who organizes weekly workouts for me and other Parkinsonians, our Longmont daughter and her husband, our housekeeper, our dogwalker, and our dogs. The dogs follow us from room to room and never forget their roles as lap dogs, especially during

### Davis Phinney vacuums the rug

Davis Phinney, on a YouTube interview tells how he vacuums the rug.

Being an Olympic cyclist, he was never asked to pick up crumbs and unpopped corn grains or wash the tubs or sweep the porch but he imagines getting useful exercise and now he's found one.

He says he's especially happy seeing the little ruts in the carpet where his Bissel has gone over and over. Then he feels stronger and more lithe.

It's almost like being on the Tour de France again.

our daily half hour of meditation, an activity introduced by Connie.

Writing this little summary of patient-hood was possible because of Connie's careful and kind editorship. I am ever so lucky to have her love and her attention. She also has introduced me to the NYMBL program, a short daily cognitive and movement exercise that claims to help my balance.

### **Writing as therapy**

Parkinson's is an on and off affliction. During my on days I can do at least two activities, even sit down to do

some writing. On my off days I do little more than read and rest and report to the table for meals. So I take advantage of the odd burst of ambition and sit down to what used to be a daily pleasure to me: writing and reflecting.

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## **My last dog**

Clyde is surely my last dog.  
We found him at an animal orphanage,  
the MaxFund,  
with lots of larger, more attractive  
dogs, nothing like what we wanted,  
but he climbed in our arms and told us  
that for him, we were the people he needed.

Ah well, perhaps he chose us and not the  
opposite,  
but now we are together. His fifteen pounds  
include a touching attraction for both of us.

When we moved to Longmont, I worried  
if Clyde would still sit on my lap  
at breakfast? Would he be able  
to leap up to the alcove bench?  
Will the stairs daunt him?

Silly me. He's undauntable.

We've always had a dog. Sometimes two.  
Now it's Bobby and Clyde, one for each of us.  
We've saved the best for last.