

Music Without a Melody

Music Without a Melody

Living Inside a Body with Parkinson's Disease

[A Partial Book]

Robert A. Harris

.:Virtual**Salt**[®]
PUBLISHING
Tustin

Music Without a Melody

Living Inside a Body with Parkinson's Disease

[This is a Partial Book, a work I did not have time to finish. I believe there is some valuable information here, so I am posting it on my Web site. Readers have permission to download and print a copy for personal use. Selling copies is not allowed.]

VirtualSalt® Publishing

Tustin, California

© 2020 Robert A. Harris

All Rights Reserved

ISBN 978-1-941233-28-3

Notice: Nothing in this book is intended to constitute medical advice. Consult a licensed physician before following any of the behaviors or regimens described here.

www.virtualsalt.com

VirtualSalt® is registered trademark of
Robert A. Harris

Contents

Introduction.....	2
My Parkinson's Story Part 1.....	9
My Diagnosis And Treatment	15
When Is a Symptom a Symptom?	22
A Menu of Symptoms	29
Movement disorders	31
Attack of the Sialorrheans.	35
Emotions	38
What Causes Parkinson's?	43
For the Recently Diagnosed	49
My Name Is Bob, And I Don't Have Parkinson's .	55
Interlude.....	57
Ten Things Parkinson's Disease Has Taught Me..	61
My Parkinson's Disease is Not Progressing	73
Got Pills?	77
Parkinson's Devotional Notes	83
Lemonade for Parkinson's.....	91
Parkinson's Prayers.....	94
Making Money from Parkinson's.....	99
On the Benefits of Parkinson's Disease	103
When Bad Things Happen to Christian Parkies .	109
What's in a Word?	117
A Parkinson's Prayer.....	124
Update to April, 2020	127

Update to November, 2020.....	137
-------------------------------	-----

1

Introduction

Blessed are those who endure when they are tested. When they pass the test, they will receive the crown of life that God has promised to those who love him.

—James 1:12 (GW)

I got the idea to write a book about Parkinson's Disease from my discontent with other materials about it. The symptoms and the long-term prognosis of the disease, together with the side effects of the treatments are too often couched in vague, euphemistic language. And that might be okay, or even good, since doing so aims at protecting the patients.

However, I am a rather blunt person, for better or worse, so I thought a more direct explanation of the disease would be

welcome by those who are looking for that frankness.

A second motivation to do this book was the realization that most of the Parkinson's neurologists don't actually have the disease, so they are describing symptoms, side effects, and psychological states by generalizing from their patients. And such generalizations are of singular value for helping both patient and doctor to understand. But I think a treatment of the disease and its adjuncts from the standpoint of a Parky himself, someone who lives with the disease—or rather, as my subtitle indicates, someone who lives in a body that has the disease—would be of interest, just as specific examples provide valuable particulars standing next to wide generalizations.

And so, when the opportunity arose, in the form of an assignment in a Parkinson's support group meeting, I was ready. We were asked to write a short essay on the topic, "What are three things you would tell someone who was newly diagnosed with Parkinson's?" This was somewhere about 2015 or so, my 15th or 20th year of having the disease. For some reason, when I was first diagnosed, I just wasn't all that curious about the disease. So, for this assignment, I actually had to do some research to find out about it—and

to compare myself with what the literature said Parkies were like.

Having been a teacher of writing for 25 or 30 years, and having pretended to be a competent writer myself for nearly a dozen years, I reacted to much of the available literature as cold, off-putting, ambiguous, dry, unencouraging and sterile. The trouble with official, voice-of-authority materials is that they think the professional way to approach a subject is in a formal, humorless way. After all if the doctor (or brochure) must tell you that you have a disease without a cure, then conveying that information in either an incomplete way or a slowly revealed way seems best for sensitive people. You never know how the patient will react. For example, here is the soft, kind approach:

SCENARIO 1

Doctor Gentle: "Well, Mr. Feemster, you are in reasonable health for your age, though you do have some issues."

Feemster: "Why, what's wrong?"

Doctor Gentle: "Well, you have mildly elevated cholesterol, and you should watch the size of the desserts you eat."

Feemster: "Oh, that doesn't sound so bad."

Doctor Gentle: "Yes, not too bad. Oh, and then you have PD."

Feemster: "PD? What's PD?"

Doctor Gentle: "That's Parkinson's Disease."

Feemster: "What is that?"

Doctor Gentle: It's a chronic condition like high cholesterol, without a current cure."

Feemster: "So then I'll have it for the rest of my life?"

Doctor Gentle: "Well, a cure might be possible, some day."

Feemster: "Whew! For a minute there I was afraid I had something serious. Doc, I'm going to recommend you to all of my friends."

And then there is this type of reveal, championed by doctors who believe in getting to the point, or "full disclosure":

SCENARIO 2

Doctor Blunt: "I'm sorry to have to inform you, Mr. Jones, but you have Parkinson's Disease."

Jones: "What's that?"

Doctor Blunt: "It's an incurable, progressively debilitating terminal disease with dozens of humiliating symptoms. The medicines will not cure you but will have embarrassing side effects. And they will cost you a fortune."

Jones: [Running from the doctor's office] "AaaaaHhhhhh!!!! Noooooo!!!"

Doctor Blunt: “Don’t forget to pay your bill on the way out. And I’ll see you again in six months!”

The materials I read in the course of murdering my curiosity about Parkinson’s were much like the tone and clarity of Scenario 1. The book you now dare to hold in your hands, on the other, um, hand, embodies a straightforward presentation similar to that of Scenario 2 (or maybe a *little* less frank). I think that people with Parkinson’s want to know the truth.

I also believe that Parkies (welcome to the club) like to laugh, too, so why not lift our feelings by laughing at the disease? You will find in these pages that I have a somewhat odd sense of humor. I hope you will discover, as I have, that Parkinson’s is much less daunting when facing it with a little satire.

Thirdly, as a committed Christian, I have found comfort, insight, and hope through the Biblical and spiritual concepts that for me render Parkinson’s a much more endurable challenge.

So why not combine all of these ingredients into one tasty mix? Mix the honey and the medicine to allow both to benefit the reader.

Parkinson's Disease is a set of symptoms interacting with your body, attitude, and spirit.



One of the classical values informing most literary works until the 19th century was that of *dulce et utile*, the idea that an author should create a reading experience that provided both enjoyment (*dulce* or sweetness) and something worthwhile or even edifying (*utile* or useful). Since both my personality and my formal training resonate with this concept, I have endeavored to make this book both entertaining and useful. So here you will find information about Parkinson's—delivered by someone who has it and has had it for many years—in addition to my attempts to amuse you.

Much of the material here was written at first in article form for varied audiences without any thought of immortalization (or coherence) in the form of a book. In the process of writing something useful, interesting and accurate enough to provide a good understanding of Parkinson's Disease I have sometimes made the book longer and more expensive by repeating myself.

This is a casserole of a book. It joins together biography, analysis, humor, philosophy, Christianity, and pontificating all in a tossed salad. But whether my metaphor mixes casseroles with salads, my hope is that you'll find the book informative and comforting. Feel free to wrinkle a brow, crack a smile, or shed a tear, as the context moves you.

I ask you for indulgence for those passages (or the entire book) that appear disconnected, wandering, or repetitive. I have reached the point in the disease that my medications have given me ADHD, so I, like many Parkies, suffer from organizing and focusing problems. Besides that, I also like coffee ice cream.

2

My Parkinson's Story Part 1

I have told you this, so that you might have peace in your hearts because of me. While you are in the world, you will have to suffer. But cheer up! I have defeated the world.

—John 16:33 (CEV)

So I was working along as an instructional designer in 2005 at the ripe old age of 55, when I noticed that I seemed to have ***lost my sense of smell***. Call me slow to catch on, but eventually I noticed that I could no longer smell a pot of freshly brewed coffee, or that distinctive odor of a meadow after a rain, or a bouquet of flowers, or the perfume wafting from a young woman's newly shampooed hair.

A reduction in the sense of smell is **hyposmia**. The complete loss of the sense of smell is **anosmia**.

Occasionally the whiff of an aroma would sweep by me momentarily, making me think that perhaps I had just misplaced my odor detector temporarily and that it would return in full force in the near future. But it didn't. For the most part, my nose was shot. But because I was only 55 years old, I thought it would be a good idea to run this discovery by my primary care doctor to see what she thought.

Her fear was that I had developed a brain tumor. I was quickly scheduled for an MRI. When I saw her again, she said, "The MRI shows that you have lots of wrinkles in your frontal lobes, which supposedly means you're smart, but you don't have a brain tumor. I'm going to refer you to an EENT to see why your nose is so dry."

So she sent me to an EENT (Eye, Ear, Nose, and Throat) doctor who also found nothing wrong with my nose, other than its dryness. He prescribed Requip,¹ one of the medicines used to treat Parkinson's. Unfortunately, the Requip caused me very nearly to faint at work. I could tell that things were not right when my vision started to blur. I looked a coworker and

¹ Generic name, ropinirole. It is a dopamine agonist (makes dopamine work better).

said, “Do I look pale to you?” and then almost fainted. By the time I was in the process of lying down, I began to recover.

However, The ever-cautious folks at work called the paramedics in spite of my protests, and it wasn't long before three strong men arrived and applied their instruments to me. Soon I was on the way to a nearby hospital. Anyone who has been to the Emergency Room in a hospital knows that *emergency* in this context relates directly to its root in Sanskrit, meaning, “to blend gradually by stages that blur distinctions.”² This means that



you sit in the Emergency Room hour after hour until you blend into—merge with—the furniture. My “almost fainting” occurred in the morning, and I sat in the Emergency Room for observation the rest of the day (five or six hours).

Eventually, I told a staff member that I had not eaten anything since breakfast and I was hungry. A tuna sandwich arrived a little while later.

Then the hospital doctor thought I should stay overnight to make sure nothing bad had occurred, such as starvation,

² Merriam Webster Collegiate Dictionary, 11th Ed., merge 3:

neglect, furniture merging, or death by boredom. (Indeed, the only thing less exciting than waiting in the ER is waiting at the Department of Motor Vehicles. It's far worse than waiting to be called for service from the Jury Room.)

Finally, a nurse said, "They've decided to keep you overnight, for further observation."

To which I said, "In the past six hours, no one has observed me yet." No, I didn't actually say that. But I did suppress the thought.

Well, now, the decision to keep me overnight started another adventure. After another hour—perhaps they were waiting for a patient to pass on and make room—a nurse came and told me that the hospital was full, and that I needed to be transferred to another hospital nearby.

I am convinced that the definition of *nearby* was written by the same person who defined *emergency*. At any rate, I was put into an ambulance and driven thirty miles from the hospital in Cypress to one in Mission Viejo. On arrival, I was wheeled into a room where the staff hooked me up to blood pressure, EKG, inflatable leg compresses and I don't know what else.

Since there was nothing wrong with me, other than the side effect from Requip, I was discharged the next morn-

ing. To my pleasant surprise, a thoughtful coworker had kept in touch with my situation and when she got the green light, drove the 30 miles down to pick me up. Now that I write this in recall, I should have rewarded her somehow.

As you might imagine, I quit taking Requip and things returned to normal. But as time passed, I noticed that ***I was losing dexterity in my right hand.*** Buttons had become my enemy, and I could barely button my dress shirts. Buttoning the left sleeve was sometimes impossible. And even though my handwriting had always resembled scratches in the dirt made by drunk chickens, and even though it had fully earned the D given it in 6th grade, I was now also concerned that my ***handwriting was getting smaller and smaller,*** making impossible, rather than simply difficult to read.

Tiny handwriting, known as **micrographia**, is a common symptom in Parkinson's Disease.

Some far seeing institution could have given me a degree in medicine without the need to earn it, since my prescription pad technique had already been perfected.

So in 2011, my doctor sent me to a neurologist (we will call him N1), who tested the electrical function of the nerves from my neck to my hand. He said they were working normally and at normal speed.

3

My Diagnosis And Treatment

Whether it was my complaint about **poor sleep**, or **constipation** (both common in Parkinson's), my primary care doctor must have begun to suspect that I might have Parkinson's Disease. In her office visit notes, the mysterious letters *PD* began to appear along with my other conditions (high blood pressure, high cholesterol, kidney disease, BPH, and so on). Then in 2012 she sent me to another neurologist (call him N2), who immediately diagnosed me with the disease, just by observing **my uneven walk, my lack of blinking, and**



my blank facial expression.³ He prescribed carbidopa-levodopa, Mirapex®, aka pramipexole dihydrochloride (a dopamine agonist), and Azilect® aka rasagiline (an MAO-B inhibitor). I had this doctor for several years, although I didn't think he kept up with the cutting edge in Parkinson's treatment.

For example, I researched pramipexole and discovered that the drug manufacturers had found no added benefit for daily doses larger than 1 mg. I was on 2.5 mg. This finding was significant because I had almost fallen asleep while driving my truck around in nearby cities. (Falling asleep while driving is one of the common side effects of pramipexole, as well as some other Parkinson's drugs.)

I also researched rasagiline and learned that the dire warnings against eating tyramine-containing foods, such as cheddar cheese, did not apply to MAOI-B drugs like rasagiline.)

After some time, my healthcare provider changed, and I had to change neurologists. So in 2013 I went to a doctor (call him N3) who had me walk down the hall, touch my fingers together, lie on a bed and turn over as fast as I could, and

³ This doctor also took one look inside my mouth, ("Say Ahh") and asked me if I had sleep apnea. I said no, went in for a test, and was put on a CPAP machine. My apnea was mild, but it was there at the time.

so on. He doubled my medication. I stayed with him for some time, when my plan changed once again, requiring me to get yet a different neurologist. So in 2014 I went to a new guy (call him N4). He was actually N1, now treating Parkinson's instead of testing general patients for neurological problems.

By this time I was married, and my wife accompanied me to doctor visits. She was quite disappointed with N4, even though he had a PhD in addition to an MD. He was a time passer who merely asked how I was doing and said, "See me in six months." I asked him what percentage of his patients were Parkinson's, and he said, "About 15%." He was not a movement disorder specialist. My wife said, "We need a new neurologist."

My recommendation to all Parkies to get not just a general neurologist, but one specializing in movement disorders, one trained and certified in the area, and who knows Parkinson's Disease.

So, on the recommendation of several other Parkinson's patients we had met in meetings and seminars, we signed up with an amazing movement disorder specialist, (call her N5) in 2018. She actually

listened, knew the available treatments, and remained curious about advances in disease practice. As you might guess, just as I was complaining that the her appointments were too far between, she said she had decided to move forty miles further down the coast, and out of the coverage area for my insurance.

Choosing another new neurologist was once again the task at hand. Too bad there were only a few in-network, move-



ment disorder neurologists to choose from. Neither of the new doctors we wanted was connected to the maze-like, Byzantine interconnectedness of the health plans (Medicare, Advantage, Senior Plan, HMO), contracting with

an IPA (independent practice association), and an IPA subgroup with doctors connected to specific hospitals, and agreeing on some cost-control affiliation with a family practice association.

Somewhere along the line (please don't hold me to a strict chronology of all these events), I was having one of those five-test tube blood draws, so to pass the time as she filled up the little bottles, the phlebotomist and I were talking along about an olla podrida of gallimaufry when, out

of my usual curiosity, I asked her how she decided to choose a career of draining blood from people. (I ask every phleboto-mist that same question.) This one said she wanted to become a nurse, and was sticking needles attached to vacuumed test tubes into people and draining their blood just for cash flow.

I interjected a few comments about myself, and eventually mentioned that I have Parkinson's Disease.

"I know," she said. "I was about to ask you to be sure."

"How could you tell?" I asked.

"By your face. You have a rather blank expression."

Since then, a few other people have told me that the expression on my face makes me look bored, or angry, or depressed. That explains a lot about my difficulty making friends with girls (in the days when I was in the market). At my 50-year high school reunion, some of my classmates mentioned that they remembered me as angry or bored rather than shy. And in other venues, I have been told, "Don't look so serious."

The scientific name for masked face or blunted affect, or poker face is **hypomimia**.

So in 2019 I was forced to sign up with the only choice left, a neurologist (call him N6) who was apparently world famous. He had framed and posted magazine and journal covers featuring his photograph and a headline about some study he had done that revolutionized the world



of neurology. Unfortunately, his fame had gone to his head and he knew all the answers before the patient did. Example:

Bob: "I also have myoclonus, which often attacks me at around 10 pm while I am lying on my back."

N6: "No, it attacks you at 3 am."

And he was too busy and important to ask for consent:

N6: "You don't sleep well? Nurse, sign him up for the clinical sleep experiment."

This neurologist also had a habit of talking all the time, and his speech verged on incoherent because of his heavy accent. Worse, not only could I barely understand him because of his accent, but his constant stream of words made it difficult for me to ask questions and describe symptoms.

Bob's recommendation to all doctors, nurses, medical specialists, medical technicians and the like: It would be great if, at certain intervals during your diagnostic interview in the office, you would stop talking and let the patient tell you what's wrong. You might even ask a question of two to help the patient know what to focus on. And try your best not to jump to conclusions or to hear what you want to hear.

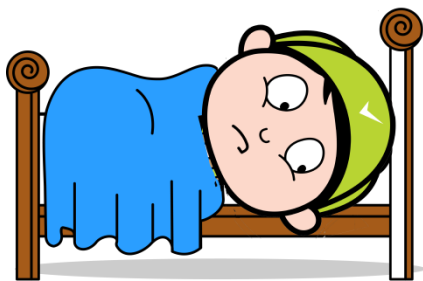
4

When Is a Symptom a Symptom?

When I taught critical thinking to college students, one of the activities we pursued was a series of differential diagnoses based on collections of symptoms. In these activities, the problem solver is faced with a set of symptoms (or in the case of a criminal investigation, a set of clues). The solver must decide which symptoms point to the most likely condition or which clues support the working hypothesis and which do not.

The symptoms pointing to a diagnosis of Parkinson's Disease are sometimes present very early on in a Parky's life, but only by looking back can they be understood as indicators. At the same time, many of these same behaviors that appear to be precursors of PD occur so early or so commonly in "normal" people that they are not considered as warning signs of the coming disease.

For example, you and I now know that I have Parkinson's. It is also true that among the symptoms of PD—just to name a few—are **trouble sleeping**, **excessive sweating**, and **dizziness**. Long before



anyone connected the dots to identify me as having PD, I had these symptoms.

I have had quite a life of **insomnia** since I was 8. In Corona, from age 10 on, I used to shove my pillow into a cubby hole in my bed frame, push my head into it, and pretend that I was driving a truck all night long. The source of this creativity was that in the summer at night, my father turned off the air conditioning and with the windows wide open, we could hear the gravel trucks hauling decomposed granite from the quarry up the road.

Another characteristic of many Parkies is also a characteristic of many ordinary, nervous people. Since about the age of 15, and until just a dozen or so years ago, I regularly drenched my shirts with **excessive perspiration**, especially when teaching. Even though I wore an undershirt below my dress shirt, both ended up

soaked every day. Some of those who develop PD later in life suffer from this embarrassing discomfort many, many years earlier (as if did). Is that an indication of Parkinson's coming thirty or forty years later, or is it just an indication of a nervous personality who happened to get PD later on?

How this question is answered lies at the center of understanding of the relationship between cause and effect. Perhaps the largest mistake made by investigators, analysts and just plain folks is mistaking correlation with causation. True causation is an event that necessarily comes before the effect. That's true. But it is not enough to say that sweating in Olympic quantities years before I developed PD is evidence that I would someday be eating carbidopa/levodopa pills like M&Ms. No, *just because* my nervous personality resulted in soaking my shirts when stressfully teaching my students, we can't logically conclude that water leaking from under my arms caused the disease. Now, if you wanted to make a case for nervousness related to stress related to underarm water falls, related to Parkinson's, that might be ask-



ing a worthwhile question. For we all know how harmful stress is on our lives.

In my early forties I took a girl to the beach for a fun and relaxing time. As usual, I was nervous and anxiety ridden.

By early afternoon, my shirt, my entire shirt, not just the usual wide swath spreading well beneath my armpits, was soaked with nervous (or Parkinson's?) perspiration. All over my back, my shirt was totally wet.

Excessive sweating's official term is **hyperhidrosis**.

One year I flew to Canada several times to train the faculty of a few universities how to detect plagiarism and how to teach students to avoid it. Several of the schools videoed my PowerPoint talks. At one of them, for some reason I perspired quite a bit, and the shirt I was wearing didn't help hide it. (I usually wore white shirts to help hide the wet stains.) After an hour so, the host said, "Shall we take a break?" and pointed to the restroom, where I ran the heated air hand dryer on my armpits for ten minutes to dry them out. (I can only imagine that the video looked like.)

So, Dr. Sweat Arms: Is all that water from Parkinson's or from my high-stress personality?

Another possible symptom of Parkinson's is **vertigo (dizziness)**. In my twenties and thirties, I often suffered from bouts of vertigo, which tended to come on suddenly and at night. For a long time, I could not pinpoint the trigger that set off the reeling floor. Sometimes the attacks were mild and sometimes they were severe.

One time on another trip to Canada to present a lecture on plagiarism to faculty,



I had just finished a relaxing bath on the night before the presentation when the room began to spin wildly and I couldn't tell which way was up. I couldn't stand; I could

barely crawl. By 3 AM or so, I was desperate, so I called the front desk and asked for some nausea medicine. They generously sent someone to the store and got me some meclizine. I had to take 50mg and, when I arrived at the lecture, told my host that I might not be able to make the presentation. She was very un-

derstanding and told the faculty my situation. I persevered and at the end, one of the faculty said it was the best presentation on plagiarism she had ever heard.

The question is, was that dizziness connected to my coming Parkinson's, or was it unrelated? I later did some research and discovered that there is a sodium-potassium cascade in the inner ear that can set off vertigo. I began to take a potassium supplement every night at bedtime and since then have not had any more trouble. I mentioned this to a church member one time and she later said the potassium cured her, too.

Don't confuse vertigo (dizziness) with faintness. Fainting occurs when the blood supply to the brain gets too low and causes a loss of consciousness for a while. Vertigo is the sensation that the room or environment is spinning around nauseatingly.

Bottom Line: As with any diagnosis or conclusion, you must be wise and circumspect in order to draw an accurate picture. With Parkinson's medications, the same prescription might cause constipation in one patient and diarrhea in

another. Or you might try a medicine that relieves your dizziness but causes pain in your back.

“Cure one, cause another,” is the doctor’s mantra about pills.

“What’s the big deal?” a teenager asks. “After all, that’s why they call it a *medical practice*. The doctor is just practicing.”

Sometimes a symptom or clue will fit in with your diagnosis or conclusion, when it is not really connected to the disease or the crime.

“How do you know you’ve got Parkinson’s?” asked the farmer’s friend.

“Well, my left elbow always hurts when rain is coming.”

“You imposter!” screamed the friend. “An hurting left elbow means that snow is about to start. Pain in the right elbow means the temp will drop below freezing tonight.”

5

A Menu of Symptoms

Parkinson's has the widest variety and number of possible symptoms of any disease I have studied. Some are more common than others. I have many of the common ones. Surprisingly but informatively, I don't have (yet) some of the most common ones. Let's see what else there is.

Perhaps the most famous saying among Parkinson's patients, neurologists and caregivers is, "When you've seen one Parkinson's patient, you've seen one Parkinson's patient."

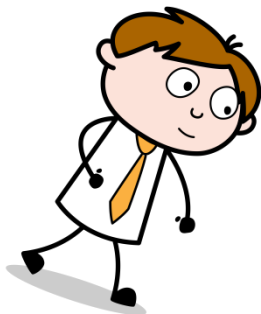
Tremor. One of the earliest and most common symptoms of Parkinson's is a tremor (a rhythmic shaking) of the hand or fingers. If your thumb, finger, or right

hand shakes gently when your hand is at rest, you have a possible sign of PD. However, tremor can instead be caused by some other neurological condition such as stroke, hyperthyroidism, or damage from too much alcohol. On top that, a person with tremor might have *essential tremor*, a malady whose cause is not known but which is often inherited.

As I've said, I have had PD for 15 or possibly 20 or more years, and yet I have never had this most common symptom.

Stooping or bending over when standing or walking. Even though I am taking all kinds of dopamine, dopamine agonists, dopamine mimics, dopamine protectors, and so on, I still have periods when I walk or stand with a stoop. This usually occurs during my wear-off time, when the supply of fake dopamine in my body is low. I cannot stand up straight without my back bothering me.

My theory about this is that my lower back muscles aren't getting their share of neurotransmitter signals from my brain. As you well know if you have ever had back pain, virtually everything we do muscularly goes through the back. Walk, bend over, sit



up, push a door open, whatever, you'll feel it in your back. Does this mean that the back muscles are trying to hog a limited supply of dopamine, but can't get it? Maybe.

Consider this. On one of my visits to a neurologist, he had me try out a new product that involves inhaling powdered dopamine, bypassing the digestive tract and entering the bloodstream right away. In what seemed like seconds, my posture shot upright and my back pain was gone.

So? So if you have PD and you find yourself stooping when you stand or walk, talk to your movement disorder specialist about your medication.

Movement disorders

Neurologists who specialize in Parkinson's are often referred to as "movement disorder specialists" because the loss of dopamine producing and receiving brain cells makes the muscles more difficult to control. Hence, PD is "movement disorder." Here are some manifestations of that:

Freezing. Some Parkies develop difficulty starting to move. They can stand there and think, "Okay, legs, get moving," and the legs will just answer, "You can't make me."

The Parky will then say, "Feet, take a step," and the feet will reply, "As if."

What seems to happen is something of a brain stall, where the foot movement command center of the brain can't decide which foot to move first. The command center tries to get a signal all the way from the brain down to the legs and feet, but what the extremities hear is something like, "Okay, left foot, move, no wait. Make that a right foot, or is it left foot—right leg, no, both feet, no, cancel that. Get moving."

And the feet and legs say, "Are you talking to us?"

One remedy that works for some people is to use a cane or a walker that shines a laser line in front of the Parky as a mental stimulus. The person says, "Okay, feet. I dare you to cross that line."

And the rebellious feet say, "Well, okay, but we're doing it voluntarily." And the walking begins.

Bradykinesia. As you might imagine, when your brain is basically unhappy talking to your muscles, your muscles respond reluctantly. This means that you can't do anything fast (unless your meds are working well). If you want an impactful, clarifying analogy, go to YouTube and search on "Three-toed Sloth." That how we Parkies feel when we "run out of gas"—run low on medication.

Bradykinesia combines the scientific words for slow (*brady*) and movement (*kinesia*).

Getting up off the floor, out of the bathtub, out of bed, out of a car—all these activities that we used to take for granted and do quickly and unthinkingly, we struggle with to varying degrees.

Festination. As a participant in this strange drama known as Parkinson's Disease, I have experienced many of its symptoms and have developed my own explanations for some of them. Festination is the tendency to take smaller and smaller steps, often faster and faster, together with a forward lean of the body.

This behavior makes perfect, rational sense to me, because it is my brain's way of preventing a fall. **Parkies have a tendency to fall** because, while the signaling from the eyes and inner ear to the brain might move quick enough, the commands from the brain to the appropriate muscles needed for maintaining balance might be weak. In other words, **trouble with balance** is another symptom of PD.

You can observe this sensible behavior anytime a Parky has to go through a narrow doorway, or, with me, whenever I must pass between people standing around after church, or moving through a crowded store. My body automatically

goes into tiny-step mode, to make sure that I maintain my balance as I weave through the maze of folks focusing on each other or on the fantastic buy-one-get-one-free super sale.

And then a Parky might experience

- Constipation
- Depression
- Fatigue
- Hallucinations
- Drooling
- Insomnia
- Rigidity
- Unstable posture
- Walking difficulties (shuffling)
- Dystonia
- Soft speech
- Impaired or lost sense of smell
- Diminished thinking ability
- Weight loss
- Lightheadedness
- Vertigo
- Difficulty urinating
- Sweating
- Eye changes

6

Attack of the Sialorrheans.

The night was cold and dark; the wind howled like a pack of not-so-distant, angry wolves. Window shutters banged, tree branches broke off and thudded to the ground, and icy air pushed its way into the bedroom through every crack.

The storm had caused Robert to suffer a troubled and broken sleep. He tossed and turned, shoving the blankets onto the floor as he resisted an attacker in his wild dream.

Suddenly, a particularly loud crash woke him. Robert felt cold. And then he noticed that his face was colder, almost wet. No it was wet. He put his hand between his face and his pillow to get a little bit more comfortable. Then he felt it. His pillow was wet.

Leaping out of bed, Robert shuddered with terror. It was the sialorrheans. They had dared to move their attack from the kitchen table to his easy chair—and now

to his bed! Would these monsters ever relent?

When a Parky like me tries to get up out of a chair and flops back down, or when he festinates through a crowd, he's probably not embarrassed. That's part of having PD. But when we drool on a pillow, a shirt, or a table, we are indeed embarrassed. It is unsightly, unsanitary, and makes the drooler look like someone not in possession of all his faculties.

Drooling, or **sialorrhea**, is inadvertent and that's why it often occurs during sleep. The poor Parky (that is, me) wakes up in the night to a wet section on the pillow or blanket or whatever was under his gaping, dripping mouth. We get upset over such minor is-



ssues, all things considered. But we are like most other people, much too vain to want anything like a drip of saliva on our shirt to take away our dignity. And a Parky won't dare take a nap in public. No one wants to see the Frimpkins report covered with slobber.

If you know a Parky troubled by nighttime drooling, ask whether he or she has ever tried to put a towel over the pil-

low to catch the waterfall. I know I've tried, many times, and the towel never stays put. Chalk that one up to my restless sleeping.

Dysphagia deserves its own moment of fame in this book because of its potentially sinister consequences. If you meet dysphagia on the street, he will tell you reassuringly that he is only a slight difficulty in swallowing, a discomfort, an inconvenience. Not to worry, he says. And yet he can sometimes be the first link in a chain of events that will be the last chain of events a Parky ever experiences.

Practice safe swallowing.

To swallow medications safely, follow these steps.

1. If you have more than four or five pills to take at once, divide your total into groups of four or five.
2. Put the first group of pills into your mouth and take sip of water. Do not swallow.
3. Slosh the pills around in the water in your mouth to make sure they are all wet all over (to reduce the possibility of sticking in your throat).
4. When they are all wet, swallow them by tilting your head down so that your chin gets close to your chest. Swallow the pills and water.
5. Take a couple of extra sips of water to make sure there is enough flow to move the pills all the way down.

6. Follow steps 2 through 5 above until all the pills have been swallowed.

7. Finally, eat a small handful of raisins and wash them down with a few sips of water. (This practice assures that there won't be any pills sticking, nor will there be any "after-sticking feeling" that can sometimes occur.

Note that it is the gelatin-based capsules more than the tablets that are the most likely to stick in your throat if not watered and swallowed properly.

Swallowing carelessly (laughing, talking, swinging upside down on the high bar while eating) can result in inhaling some of the food you intended to swallow. Ordinary people can usually cough up the food, but Parkies often have an impaired ability to cough. As a result, food, laden with bacteria, lodges in the windpipe, gets infected, enters the lungs, and causes aspiration pneumonia. Too many Parkies who develop aspiration pneumonia are unable to recover

Emotions

I gradually became aware that sometimes when speaking to a group of friends or faculty or a Sunday School class, my voice and throat would suddenly and un-



expectedly choke up with emotion, even though I didn't feel emotional otherwise. The choking started mildly and occasionally with brief instances around 2011. My bosses' boss noticed that this happened while I was giving some PowerPoint presentations about the many awards the company had received (most of which I had written

the applications for). He thought that my revealing how much I cared about the company and its awards would impress the prospective clients, so he invited me to several sales presentations. I eventually noted that the choking up seemed to be connected to ideas and events that I felt strongly about or that involved successes where "the good guys won."

It meant a lot to me. As time went on, the emotional impacts increased. I began to notice that when something "good" happened on a TV drama, such as when the hero wins or when the villain is exposed, I would start to sob for about 20 or 30 seconds.

Now, when I talk or read aloud, quite uninvited, all of a sudden, I will choke up and have to stop talking, because I cannot be understood, so firmly does the emotion choke off my voice.

The reaction is unpredictable. Recently my wife and I were watching a biography of economist Walter Williams. The narrator mentioned that Walter was highly influenced by Frederik Hayek. I started sobbing uncontrollably and the crying lasted for over a minute. My wife was surprised and confused. She didn't know how to console me.

After I regained my composure, I explained that Frederik Hayek was one of my brother's favorite economists. Before he became ill, my brother earned a degree in economics and was fond of talking about Hayek and his theories regularly. After my brother succumbed to schizophrenia, I took care of him for many years as he suffered horribly, afraid of assassins, poisoning, bomb attacks, thieves supposedly stealing his ideas, and so on. The unexpected mention of Walter Williams and his interest in Frederik Hayek brought a rush of memory to me about my brother and how his life, career, and accomplishments were destroyed by his disease. The emotions swept over me and I sobbed.

Needless to say, when this outburst of emotion, half crying, choking, and so on arrives in the middle of my calm and ordinary conversation to strangers, and even to acquaintances, I feel like a fool. I want to say, “Hey, I’m not really that worked up about putting Christmas lights on the eaves of the house, it’s just my Parkinson’s brain that thought the idea was extremely moving.” But as I said, the reaction stops me from talking. If I try to talk anyway, my words emerge distorted and drenched with what appears to be uncontrollable sorrow. I usually make a strong effort to stifle down the emotion, but most of the time I simply have to be silent for a minute or two.



I understand what’s happening when a woman is told something that produces an emotional earthquake (happy or unhappy) and breaks down in sobs. It’s a brain and brain chemical reaction.

Now, in 2020 as I write this passage, I am becoming convinced that there is some personality characteristic connected with the emotional welling up. For example, if someone asks me a question, or if I am recounting a positive event or outcome, the emotion sometimes wells up and I can’t make an answer.

This is all so odd. For most of my life I was thought of as a stoic—emotionless, too tightly wound. The mother of one the girls I invited out in high school told me, “Bob, if you would just learn how to relax, you’d be able to enjoy life.” But now I’m becoming a sporadic emotional wreck.

Nor does the long-term prognosis seem especially bright. I know another Parky who can barely speak at all without his voice choking up. But then, as they say, “When you’ve met one Parkinson Patient, you’ve met—one Parkinson patient. It’s impossible to generalize or form expectations based on observing other Parkies.

7

What Causes Parkinson's?

The search is on to find the cause of Parkinson's Disease. Because someone can get it many years before any symptoms are evident, connecting the real cause can prove difficult.

So is it a genetic defect whose broken DNA will be exposed once the investigators are sufficiently funded to find it? Or perhaps it is a genetic vulnerability that lies dormant in the body until an environmental trigger sets it off?

Or perhaps genetics has nothing to do with the etiology of the disease. Perhaps there is an environmental cause. When I was a kid, I did a lot of dumb stuff that could have caused or contributed to the inception of the disease.

Toxic fumes? When I was about 10 or 12, I bought a propane torch to do some soldering. But as a kid, I also decided to



see what happened when various items met the 3,600 degree flame from the torch. The question was, “Will that melt”? So, for several years I put the heat on bugs (no need to tell you what happened to them), soda cans, tuna cans, clock gears, and lots of other items.

One item that might have been harmful to me was a small oil can—plated with **cadmium**. Cadmium is a toxic metal, and it becomes more toxic when heated into fumes.

So, was it toxic fumes that started the long incubation of my PD? Maybe.

Poison? While I was still a young kid (about 6 or 7) living in Inglewood, three or four boys from the neighborhood (at ages 12 to 14 and therefore more mature than I, or so I thought) handed me a tin can a little less than half full of **some dark liquid**. They all urged me to drink it.

I hesitated for a while, but what 8-year-old can resist the possibility that he will be invited to “run with the big kids” and enjoy the accompanying social prestige?

So I tasted a sip—it was apparently the juice squeezed out of green almond hulls—and stopped. The boys encouraged me to drink it down, but it tasted so dis-

gustingly horrible that I had to say, "No, thanks." I had to attend to the burning in my throat, so I excused myself while the boys went about their fellowship, their exclusivist cabal, and visited various Spots of Meaning such as Fence the Flesh Ripper, Gouge the Gorge, and One-Foot-Nail, the latter of which was only a weathered plank with a rusty nail sticking up out of it.

Bug Spray. But I'm thinking that the most likely cause for my Parkinson's was the bug spray I used at Corona.

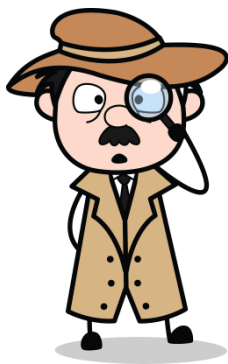
We moved to a new house in Corona when I was 10. The ants quickly invaded the area, attracted by the moisture from the watering of the newly planted landscape.

We bought a few aerosols at first and used them up quickly. One problem with them was that they leaked around the spray button, getting bug spray all over my index finger. Naturally, as a fool kid, I didn't wear gloves, and didn't wash my hands after they got drenched with bug spray. Soon we were buying the one-gallon containers of bug spray. These required pumping up and spraying the lightly pressurized bug killer on the ants.

It became a game for me. The ants moved their eggs whenever the watering got too (from the sprinklers, for example), or when the day got too hot and the ants

needed to find a cooler spot for the eggs. I would go outside to play and see a long stream of ants, perhaps six to eight insects wide, stretching thirty or forty feet. I would “call in air support” and grab a jug of ant spray. That became the attack plane that made a low pass along the line and wiped the ants out.

On other occasions, I would be digging around in the garden, and when I turned over a pile of leaves, thousands of ants would be exposed. Once again, air support was needed—in a hurry, because the ants panicked when they realized they had been exposed to the military might of the United States of Bobby. I would run to the workshop, grab the gallon sprayer of highly effective (did I mention highly toxic?) bug spray, pump up the handle, and attack and attack and attack until there were only a few ants left in the trembling throes of death, amid the completely still bodies of thousands of others.



So what? Well, have you ever thought this through? Bug sprays contain chemicals that are neurotoxic to bugs. A neurotoxin kills the brain cells and other parts of the bug's nervous system. And do you

think those same chemicals are vitamins for humans? What do you make of those warning labels that say, "Toxic to fish and wildlife"? or "Keep away from pets"? Do they also say, "Great for quenching kids' thirst"? or do they perhaps say, "Harmful or fatal if swallowed," and "Avoid contact with skin," and "Wash hands thoroughly before eating or smoking."

A miscellany of Parkinson's Triggers. And there are many more acts of stupidity that could have contributed to my Parkinson's later in life:

Playing with mercury. Some neighborhood kids and I wandered onto a vacant lot one day, where we discovered some old chicken incubators (or so they seemed to us). Since they were abandoned and in decline, we figured they were in the public domain (foolish kid thinking) and took the thermostats to harvest the mercury.

As every little kid knows, mercury is just a fun thing to play with. It is liquid at room temperature, weighs a lot, and can be used to coat the surface of a silver coin to make it incredibly shiny. (Back then, many dimes were still silver.)

Oh, and did I mention that mercury is very toxic?

What about lead? Give me a blow torch and a lead fishing weight, and I will have lots of fun. Melting lead without any

reason to do so was always fun. Give me some fishing weights (nearly all made of lead in those unthinking days) and I could melt and pour lead all over place. And when I soldered some wires together (using lead-based solder, of course), I always inadvertently managed to get in the smoke trail from the built-in flux.

And toluene? Benzine? Gasoline? I played with them all. Ever spill gasoline on yourself while pouring it on a bug you want to light on fire?? And of course as a one-time operator of a go-kart, two-stroke weed trimers, chain saws, and more, I was virtually awash in gasoline in my youth.



Bottom Line: Parkinson's Disease is caused by a deficit of dopamine, dopamine producing cells, and dopamine receptor cells in the brain. As the progresses, these brain cells continue to die off, resulting in a need for more replacement dopamine.

The factors that produce the loss of dopamine and related cells have not been convincingly identified yet. However, there may be several possible causes, each of which by itself or in combination with others can cause the disease.

8

For the Recently Diagnosed⁴

Three Things I Would Tell Someone Who Was Recently Diagnosed with Parkinson's Disease

At a Parkinson's seminar in 2016, all of us Parkies were asked to write down three things we would tell a recently diagnosed Parky.

1. Everyone experiences the disease differently.

Let me use myself as an example. As of now, I've had Parkinson's for about fifteen years. My first symptom was that I seemed to have misplaced my sense of smell. Then I noticed that the buttons on the cuffs of my dress shirts had begun to conspire against me and my right hand and were making it nearly impossible for

⁴ Original version published August 24, 2016.

me to push them through the button-holes.

Then my handwriting, which would never have won a prize in a calligraphy contest, went from ridiculous to completely illegible. That was—and is—a huge frustration. I've always loved the feel of writing. I bought ballpoint pens by the dozen, always in search of the smoothest writing experience. I kept a pad of paper (sometimes a clipboard with full size 8 ½" by 11" paper in it) next to my bed. With the aid of my chronic insomnia, I would generate ideas, organize content, and edit sentences. That worked out well while my writing could still be made out, even after some puzzling.

But now, even though my mind continues to generate ideas at random intervals, and even though I attempt to write them down, I can't read what I wrote. And I can't use the excuse of darkness or sleepiness, because no matter when I try to make a note, all I get is scribble. Every day, there's another brilliant concept lost to humanity, forever! Or at least a list of what I need at Walmart or Home Depot.

Thank God for keyboards and voice input. While my accuracy is abysmal with both, at least I can get my thoughts down.

To continue. After my nose went on strike and my hand began to write in

Sanskrit or something, things seemed more or less to stabilize for many years. Okay, it's true that eventually all the other buttons on my dress shirts joined their comrades on the cuffs and began to resist mightily my efforts to push them through the buttonholes. Sometimes it would take me ten minutes to put on or take off a button-up shirt.

Once again, you probably won't have exactly these same experiences. Your right hand might remain as useful as ever. But there will most likely be something odd happening to your body that will seem strange. A few of the more common developments (and I have them all) include these:

Being told that you are very soft spoken.

Now, I know it's tempting in a society like ours, where everything bad is someone else's fault, to turn to those who ask us to speak up and to tell them in an appropriate tone of voice just to turn up their hearing aids. However, not only is that impolite, but it doesn't go over well when the person remarking on your soft spokenness is only ten years old and doesn't even know what a hearing aid is.

Being told that your face is expressionless.

Blunt affect, someone told me. I'm always tempted to scrunch my face into a

psycho killer expression, and say, “You’re next!” but then, I don’t want to be invited downtown where I can spend a little time in a room with mattresses on the walls.

Experiencing balance issues.

Some people with PD have difficulty with their sense of balance. I, for example, often stand with a slight stoop to help maintain my balance. And while the stoop does keep from stepping backwards and from falling over backwards, it does quickly give me a backache. (That, by the way, is what they mean when they say life is a series of trade-offs.)

Again, your experience may not be like mine. You may go for many years experiencing only minor symptoms. As they say, your mileage may vary. So, if you’re just starting down the road, remember that you are embarking on your own personal life adventure. Just as travelers on the same itinerary visit the same locations but have different experiences, so too you’ll have some of the same complications but you will handle them differently.

2. Remember that you are not your body.

One of the dismaying things about Parkinson’s is that you—the you who lives inside of your body—will probably be

watching your body become more and more uncooperative as time goes on. You'll start to wonder why your legs grow increasingly rebellious when you want to get out of a chair or put your undies on. And don't even ask me about getting out of a bathtub. But it's your body that's not following your commands. There's nothing wrong with you.

And it's possible that one day you'll be leaning over a nice salad or taco mix, stirring it up really well, when all of a sudden a stream of drool will land in whatever you're doing. Your first reaction will be surprise. "Did I just drool in the salad?" you'll ask, astonished. The answer is, No, you didn't. Your body, suffering from Parkinson's Disease, did.

Eventually, you—I mean, your body—might start walking with small, shuffling, oddly flopping steps that make you self-conscious and, to be frank, embarrassed. But it's your body that's embarrassing you. It's not you. Your body is a temporary habitat you live in. You are not your body. And remember: we get new bodies in heaven.

3. You and the Lord need to open a lemonade stand.

Parkinson's is something of a lemon, all right. But with God's help, you can persevere and even flourish through your

illness. It's the sweetness of your response to personal challenges that turns lemon juice into very tasty lemonade. What better way, what better reason to bring your heart and mind and soul closer to God? People are watching to see how faithfully you respond to the burden that has come upon you. So don't throw lemons at them, offer them some lemonade.

In the short story "Youth," by Joseph Conrad, the character Young Marlowe faces a series of increasingly disastrous events: the ship catches on fire, the captain goes mad, the ship blows up. Each time, Young Marlowe says, in effect, "This is great! I can handle this! I feel so alive! I can't wait to see what's going to happen next!" His attitude should be ours.

Or as the apostle Paul would put it, "I can do all things through Him who strengthens me" (Philippians 4:13, NASB).

I'll let our Partner in the lemonade business sum up for us:

I have told you all this so that
you may have peace in Me. Here
on earth you will have many tri-
als and sorrows. But take heart,
because I have overcome the
world.

—John 16:33, NLT

9

My Name Is Bob, And I Don't Have Parkinson's

So they look at me and notice some things about me and say, "You have Parkinson's Disease, don't you?"

To which I say, "No. I don't have Parkinson's Disease."

And they say, "Then why do you take little shuffling steps and sometimes freeze and can't decide which foot to step out with next?"

And I reply, "Oh, I understand your confusion. My legs have Parkinson's. That makes them often uncooperative. I don't like it when they shuffle like that, but what can I do?"

So they say, "Well, if you don't have Parkinson's, then why do you sometimes slur your speech and drool and talk too fast and so softly that people can barely hear you?"

And I answer, "Don't you see? All those effects are the result of my mouth having Parkinson's. I keep telling it not to slur or talk too fast or too softly, but it just doesn't pay attention. I just have a disobedient mouth. That's common in mouths with Parkinson's Disease. Unco-operative to the core."

So they say, "Oh, I get it. I suppose the reason you no longer have a sense of smell is not because *you* have Parkinson's, but because *your nose* has Parkinson's; and the reason you have tiny, unreadable handwriting is not because *you* have Parkinson's, but because *your hand* has Parkinson's."

And I say, "Yes, you're catching on. Now you understand when I say that I don't have Parkinson's."

And they say, "Then what's wrong with you?"

And I say, "Nothing is wrong with *me*. After all, I'm still me. I'm not my body. I'm Bob."

That is why we never give up.
Our physical body is becoming
older and weaker, but our spirit
inside us is made new every
day.

—2 Corinthians

4:16

10

Interlude

A Parkinson's Prayer



Dear Lord:

We come to you with hearts overflowing with gratitude for all the help and guidance, blessings and mercies, forgiveness and grace you have lavished on us throughout our lives. Yes, we have now been called to bear the difficulties of Parkinson's Disease, but those pains amount to little more than irritants compared with the many years past when our lives were filled with so much happiness, so much joy, and so much love. Over those years filled with such unending goodness, we have learned to trust you for each day, whatever it might bring, and

to trust you for our future, not just on earth but in heaven. Yes, compared with the promise of eternal life with you in heaven, our current illness is nothing but a sneeze. And that knowledge and trust allows us to carry over the joy and love we have always enjoyed from your bounty, redeeming the time of our current distress.

As the Bible says, “No eye has seen, no ear has heard, and no mind has imagined what God has prepared for those who love Him” (1 Corinthians 2:9). And further, it says, “I am sure that what we are suffering now cannot compare with the glory that will be shown to us” (Romans 8:18).

So our past was good—we thank you for that—our present is good, in spite of our disease—because you help us to flourish—we thank you for that— and you keep reminding us that our future is glorious—and we certainly thank you for that.

But frankly, Lord, we don't care very much for Parkinson's Disease, neither those of us who have it nor those of us who are caregivers for someone burdened by it. We ask, therefore, that you will give us the ability to bear this burden with cheerfulness, and to be content with our lives. As Paul says, “I have learned to be content in whatever circumstances I'm in. And I can endure everything with the help

of Christ, who strengthens me" (Philippians 4:11b,13).

Yes, Lord, may this ridiculous disease, that makes us drool on our pillows and shuffle when we walk, may this disease be used by you to improve our character and our spiritual walk. As the debilitating conditions continue to mount, give us the understanding of what's truly important and what is not. Help our suffering to lead to hope, as Paul says: "And not only this, but we also exult in our tribulations, knowing that tribulation brings about perseverance; and perseverance, proven character; and proven character, hope; and hope does not disappoint, because the love of God has been poured out within our hearts through the Holy Spirit who was given to us (Romans 5:3-5).

Even more than helping us to grow, dear Lord, we ask that you will make each of us a quiet witness to the world, turning our suffering to account by making us model Christians, a light for others, both saved and unsaved, that all may see our commitment to you our God. Make us examples of faithfulness and trust in you, relying on you with all confidence, resting cheerfully in you as we persevere through whatever may come. For "we know that God causes all things to work together for good to those who

love God, to those who are called according to His purpose" (Romans 8:28).

Thank you again, dear Lord, for giving us an opportunity to live in this world and to be saved from it. May we always reflect our gratitude for being who you are and what you have done for us, remembering that

In our weakness, you give us strength,
In our suffering, you give us hope,
In our sorrow, you bring us joy,
And in our struggles, you bring us peace.

In Jesus' name we pray. Amen.



11

Ten Things Parkinson's Disease Has Taught Me

Bob Harris ♦ July 13, 2016, revised March 16, 2020

Yes, Parkinson's Disease has taught me many valuable facts, about myself and others. Indeed, a Parky can see the world and others in it in a totally unique way (and that's not just because we are stooped over when we stand or walk). Anyway, here are some things I've learned, courtesy of having PD.

10. I'm on the way to becoming irresistible to women.

They say women are attracted to men who are tall, dark, handsome, and soft spoken. Everyone keeps asking me to speak louder. And when an attractive young woman looks at me and says, "Huh?" I understand that to mean that she is quickly growing romantically inter-

ested in me because I'm being so polite as not to yell or whistle at her. (Leave that to the construction workers.) After all, why else would she pretend not to hear what I said, when she's only three feet away? That must mean I am indeed soft spoken. And that's already one-fourth of irresistibility. All I need now is elevator shoes, hair dye, and a little plastic surgery. Then again, I guess I'll pass, because I'm already happily married. (And she regularly says, "Huh?", "What was that?", "Say that again," "Say that over," and so forth. How she must love me!)

9. Even with a blunted affect, I still can't play poker.

A blank facial expression might be good for poker, but for me, it makes people think I'm uninterested or bored, when the fact is, at best, I'm quite interested and at worst, I'm usually only thinking. And I don't even know how to play poker. I just have the same poker face all the time. Except when I laugh. I need to laugh more often.

Oh, another thing I've learned from having PD is that many things have several names. (Have you ever read a Russian novel, where each character has at least three names?) "Blunted affect" is also known as "masked face," "facial masking," "blank facial expression," and by

professionals, “hypomimia.” Developing this symptom of PD can be somewhat unsettling when the Parky learns unexpectedly that he or she has it. “Have you met Bob?” “Not formally. He always looks completely bored.” “Oh, I think he always looks angry.” “I wish he knew how to smile.” “If he would just look interested once in a while, maybe people would think he is less stuck up.”

8. I am not my body.

The person I’m talking about when I use the word *I* is not the same as my decrepitating body. I have to live inside it, and let me say it used to be a much more fun and comfortable home than it is today. Not only is the house showing wear from 65 plus years of weather and neglect, but Dr. Parkinson has come in and is in the process of smashing up the place. But I’m still sitting by a warm fire in spite of a drafty house.

To change metaphors, my body is a car and I am the driver. The car is an older model, so that today, the radiator leaks, the engine isn’t running on all eight anymore, and the tires are going flat, but the driver is still fine. The driver just can’t go as fast as he used to. Sometimes he can barely get out of the driveway.

7. Feeling frustrated doesn't make anything better.

You know, it's kind of aggravating when my mind tells my legs to lift me up and all they can say is, "That's above my pay grade. Let the arms do it." I tell my legs that they are very muscled, but they say, "What's it to ya?" And that chronic back pain; that gets old after a while. And then there's my diminishing ability to use my beloved tools. My right hand is getting increasingly uncooperative, so now I can't seem to make a pair of pliers do what I used to do with them. And the left hand has to help the right hand just to screw in a light bulb. But getting upset over all this doesn't make a difference, so why bother to get upset? Besides, not many people like a grump.

And let me tell you a bizarre truth. Some of the antiparkinsonian drugs can cause compulsive behavior, such as eating all the time, gambling—and shopping. That's me, the shopper king. For a long while, I soothed my compulsion by regular visits to the dollar store. But I've noticed that as time goes on, I have the irresistible urge to buy tools, just as my ability to use them diminishes. I refuse to tell you how many screwdrivers I have.

My wife sometimes tells me,
"You don't need another set of

drills or screwdrivers, or pliers..
You have, how many? Five or six?"

So I simply say, "I think you should cancel your shopping trip. You don't need any more towels or blankets or sofa pillows. After all, how many do you have now? Twenty or thirty?"

Then she says, "Well, you do have Parkinson's. Do you need a ride to the hardware store?"

6. I don't take anything for granted.

My handwriting is already comical. Maybe I'm writing in secret code and I just don't know it. I dare you to try to decipher it. But how much longer will I be able to type, even with my clumsy, disobedient fingers that insist on leaving out some letters and doubling others—even in the same word.

But I can still type, sort of—if you don't mind three g's in every word and maybe an extra f or two. (You can surmise how much editing I have to do on everything I type). But the amount I can still do is a blessing. And then there are those rebellious buttons that fight me every buttonhole. True, they no longer cooperate the way they did years ago, but, eventually, I can still button a shirt. This, too, is a blessing. In fact, I see every good thing as a distinct blessing, and not

as an entitlement. Life is good—increasingly awkward, but good. Whether I eat a 99-cent taco or a prime steak, I'm content—no, make that happy. Grateful and happy. Some people take their health for granted. Big mistake. Next time you're glum, just sit down and count your blessings. Let's see, safe water supply, sewer system, reliable electricity, cell phones, bubblegum, paved streets, "warehouse" stores, green olives, first-world medical care, the beauty of nature, potato chips, air conditioning, and on and on. Your life stinks? You have hot and cold water, available on tap, soap, washrags, shampoo, towels, clean clothes. . . .

5. I have a lot more compassion for the handicapped.

I've learned that we shouldn't judge others by using ourselves as the standard of measure. We can't fully understand what others are going through unless we ourselves have the same situation. I feel as if I've been put into a body that doesn't belong to me. I ask, "Why is my body stumbling around?" and "Why does my tongue stumble, too?" and "Why is my handwriting so small? Is there a paper shortage only my hand knows about?" Or is my body being my friend, knowing that my handwriting is illegible, so might as well make it small. It serves no purpose

other than to fool the speaker into thinking I'm taking notes. And Yes, I feel awkward and conspicuous when I walk around. Slight stoop, uneven small steps. Now I know how other people feel who aren't young and agile and "normal." God bless them. So, less judgment, more empathy.

4. There's no "Why me?" here.

When something bad happens to some people, they ask, "Why me?" when the real question is, "Why not me?" We're told that in this world we will have tribulation. And while we're quick to ask, "Why me?" when we get sick or hurt ourselves, how come we never ask, "Why me?" when we're eating lobster on a vacation cruise or even licking an ice cream cone at home? Maybe we should all get into the habit of answering the "Why me?" question with, "Because you're special," or "I guess because you seemed like a good choice."

3. We can't predict the future.

Seems as if every time we expect a high fast ball, we get a low curve ball instead. Here we are, afraid of a future that probably will never come, and completely unaware of what is really going to happen. The fact is, only God can see around corners; we can barely see in a straight

line. Maybe we should take the hint and trust God for our future instead of trying to outguess him. Of the 100 things you grind over with worry, angst, and insomnia, only one or two will ever be likely to happen. But all 100 will hurt you as you stress and complain over them. Remember, if fortune tellers could really predict the future, they wouldn't have their businesses in tiny, old buildings in the not-so-glamorous areas of town. They would be living in Maui or Switzerland and playing the stock market—or currency futures.

2. I am now more aware of my mortality, and that's a good thing.

Did you ever notice that when people get all worked up (courtesy of the media) and begin to panic and run around like chickens with their heads cut off, all they can do is stockpile food and weapons and toilet paper? And when you ask them what's the worst case scenario, they say, "We're all gonna die!"

Yep, we're all gonna die. They are absolutely right. But we knew that already. We just haven't been thinking about it that much. And until or unless the Lord calls our attention to it in a quite personal way we won't get a clue. But when you get a NOTICE of COMING DEATH, you have the opportunity to do some planning and thinking, and communing with your

maker. Gonna die. Check. Got it. Getting ready.

12

1. I still have hope.

I was at a meeting a little while back when someone asked me, “How can you have hope, knowing that you suffer from a terminal disease?” My first answer was, “Life is a terminal disease.” But the better answer is that I have hope in God, who made me, owns me, and can unplug me whenever he wants. Learning to trust God, and to place your hope in him, might require a lengthy effort, but once you get there, you can find joy in any circumstance. So, I have hope—not that I will be cured, but hope for the kingdom of God. And hope for strength during the remainder of my stay here. It is said that instead of asking God to remove the mountain in front of us, we should ask him to teach us to climb mountains. And in the meantime, put our hope in the peace and rest we’ll find at the top.

Hope. Many of our personality and philosophical and spiritual traits must be tested and developed and refined by experience in order to mature and gain strength. We understand good character by observing it in others, of course, as models are always useful to some extent. But those traits (call them virtues) become deeply fixed into ourselves—our selves—most robustly only as we ourselves practice and embody them. The depth of sympathy is reached more deeply not just by seeing a sympathetic character in a movie, but by admiring that character, by modeling that character, by becoming that character.

Okay, so what's the point? The spiritual characteristic most needed to be strengthened and developed in most of us is hope. Hope is pretty flabby and tired in many people. They have put their hopes in worldly people, possessions, power, fast tracks, short cuts, sure things and (surprise) been repeatedly and profoundly disappointed. One of the most needed and for some the most fragile spiritual attribute is the possession and exercise of hope.

Having been introduced to the subtle and not-so-subtle features of Parkinson's at a typical age (60 is common but my age 55 is not uncommon), I thought I could use my remaining 10 or 20 years to help oth-

ers who have not yet learned to face this
mala

The Bible is a good place to find out
about our hope. Isaiah tells us:

Do not fear for I am with you;
do not be afraid, for I am your
God.

I will strengthen you; I will help
you;

I will hold onto you with My
righteous right hand.

—Isaiah 41:10 (HCSB)

13

My Parkinson's Disease is Not Progressing

Bob Harris, Original: August 22, 2017, update, March 16, 2020

They have it all wrong. In fact, they've got it backwards. And I find that positively repulsive. (Did you get that joke? Huh? Huh? **Retropulsion** is the fancy term for those little backward steps some of us Parkies take, to prevent us from falling over backwards.)

Sorry for the pun on retropulsion and repulsive, but this terminology zoo we are in is positively confusing. (Or is it negatively confusing?)

For example: It's one thing for me to notice that I've become a bit more unstable on my feet, or that I'm beginning to slur or stutter occasionally, or that my muscle control is lessening a bit. But when I'm told that this means that my

disease is *progressing*, it gives me a headache.

I mean, look up the word *progress* in the dictionary. "Progress: gradual improvement, betterment, moving forward, ascension, advance, enhancement." Enhancement? *This* describes my physical diminishment? In that case, then, eventually I will likely be enhanced so much that I won't be able to move.

Wouldn't it be better for me to choose a word instead that indicates a decline or loss or worsening? What about decrepitating? You know, like that old car you kept too long? I could say, "My Parkinson's Disease is decrepitating"?

Or how about, dilapidating? Like that old gas station that between thieves, kids, and the weather, gradually just fell apart. Imagine working as a Walmart greeter.

"Welcome to Walmart. How are you today?"

"Oh, I'm still dilapidating. Thanks for asking. How goes it with you?"

Maybe declivitating is the right term. Picture this:

"Welcome to Denny's. How many guests?"

"Two non-smoking and one declivitating, please."

I mean, let's be realistic and use the right words. Saying that our Parkinson's is *progressing* makes it sound as if it's go-

ing to conquer us. And we won't let it do that.

We trust the Lord that the best part of life is ahead, because we get new bodies in heaven, and they will obey our commands. They'll walk easily, speak clearly, and feel full of energy. That confident hope sustains us, no matter how much our disease "progresses."

The fact is, the more our disease begins to take over our executive functions, the more grateful we become, not just for the health we enjoyed (I still remember the smell of coffee, the aroma of perfume, the thrill of driving a nice car—or even a crummy, old Datsun 210 that we took on the road to Hana in Maui when I was only twenty something.)

What now grow even more grateful for the future where our hope lies. For in our future lies our joy.

Behold, I tell you a mystery; we will not all sleep, but we will all be changed. For this perishable must put on the imperishable, and this mortal must put on immortality.

—1 Corinthians 15:51, 53

In the world you have tribulation,
but take courage; I have overcome the world.

—John 16:33b

14

Got Pills?

Bob Harris, March 17, 2020

Scene 1

My father, who was a medical doctor in his prime about seventy years ago, used to say about someone he found utterly distasteful, “He is just a pill,” or “That woman is a pill.” I use the word “distasteful” intentionally. Many pills in those days were just stamped out of powdered ingredients and sold uncoated to the hapless public. Needless to say, they weren’t exactly crafted for taste. Yes, pills tasted horrible, no matter how quickly you tried to swallow them.

(If you want to share the experience of patients of yesteryear, next time you have a headache or an aching back, take two uncoated aspirin, like the ones you can get from the dollar store, and chew them up before you swallow. Mm, mm, good.) So when my father said, “That last pa-

tient was a real pill,” listeners could nod in knowing agreement. They knew bitter as a reality, not just as a metaphor.

Scene 2

But you know, in those days it wasn't so bad. First, in the old days, when someone had a headache, they were often prescribed the inhaling of coffee vapors. In the era after that, if you had, say, a bullet wound, you were offered a stiff slug of whiskey and the soft lead end of a bullet to grit between your teeth (hence the expression, “bite the bullet”). After that, when aspirin became available, it was sold in powder form. You had to be really sick in order to want to run a mouthful of that stuff across your palate. Still, that was a leap forward for the medical profession, and soon coffee aromas and lead-and-whiskey applications were forgotten. So the availability of the drug in pill form was considered a major advance. Think of how many billions of APCs (aspirin, phenacetin, caffeine) were consumed by the military (until the 1960s, when phenacetin was banned because it can cause kidney disease and cancer).

Scene 3

In my fifties, I worked as an instructional designer for the call center of a mail order pharmacy, where I created

training materials for the customer service representatives. Since our reps were mostly in their twenties, we knew that visuals were important to keep their attention. So I scoured the Internet for stock photo companies, looking for just the right pictures that would make an impact. Since exaggeration is a significant method of gaining attention, I looked for images with hyperbolic content, making a point by going way beyond reality.

One of the images I found showed an older man peering from slightly behind a stack of eight or nine pill bottles. He looked concerned, befuddled, overwhelmed. “What could all these pills do? How can this poor man keep them straight?” I thought. “What a great satire on modern medicine! Inflate the situation to make a point.” We used that slide to discuss topics such as drug interactions, pill-taking difficulties, missing medication times, and so on.

Scene 4

Now that I’m pushing up against seventy, I have to admit that the photo of the man buried behind a mass of pill bottles is not actually satire, after all. It is a picture of reality. And rather than exaggeration, it is an understatement. Indeed, ***I have become that man in the photo.*** For I have not eight or nine, but twelve or

thirteen bottles—of pills, capsules, gelcaps, tablets. I've got dopamine, stuff that pretends it's dopamine, stuff that makes dopamine work stronger, stuff that makes dopamine last longer. And that's just the Parky meds, unless you want to add the stool softener, needed because all the other meds and Parkinson's itself constipates the heck out of many of us. (Do I recommend the stool softener? It works great. Instead of feeling as if you're passing chunks of concrete, it's just feels like passing hardened asphalt rubble.)

So what? Well, my pill regimen requires that I take various pills five times a day. So who has time to eat? And who has an appetite anyway? It's almost a good weight loss program, except that I can't chew the pills, depriving me of chewing satisfaction. At least the pills that would otherwise be horribly distasteful are coated now.

In an effort to reduce the whole pill-taking nightmare, the pharmaceutical industry has begun to explore other routes of administration. Instead of (or in addition to) swallowing, you can now take your medicine by inhaling, injecting, pumping, or infusing it transdermally (that is, by skin patch).

At any rate, we have come a long way from those days when the doctor's assistant said, "Anesthetic, did you say? Sure.

Here, drink some of this whisky and then bite down on this bullet. I'll have your leg sawn off in no time. And if your stump doesn't get infected or cause unendurable pain, and if you don't bleed to death, you'll be fine—eventually.” (Of course, that also depends on what your definition of “fine” is.

Maybe the meds we have are not so bad after all.

“Christ gives me the strength to face anything.” —Philippians 4:13 (CEV)

So, check your attitude by reading the following story I wrote many years ago.

The Limit

One day a man was walking through a forest and got lost.

“Nothing could be worse than this,” he said. Then it got dark.

“Lost in the dark. What could be worse?” he asked.

Then it got cold. “Now nothing could possibly be worse,” he said as he shivered and stumbled around.

But then it began to rain. “How could anything be worse than this?” he asked himself.

But then the rain turned to snow and the wind came up.

"This is absolutely the worst possible thing that could ever happen," he said. "There's nothing left."

But then he fell and broke his arm. "Well, that's it," he thought. "This is the worst of all."

But as he lay in the snow, a tree branch broke off and fell on him, breaking both his legs. "This is worse than the worst," he thought. "But at least nothing else can happen."

But then he heard the sound of wolves coming his way.

The noise was so startling that the man awoke and discovered that he had been dreaming.

"What a dream I had," he said, shaking himself. "Nothing could be worse."

❖❖❖

15



Parkinson's Devotional Notes

The Fall

Recently, I fell over backwards in the workshop. It could have been pretty bad, because there are all kinds of sharp, pointed things poking out here and there as well as metal and wood things not designed to cushion a fall comfortably. But by God's grace, I landed in an area near the door where I crushed an empty cardboard box and knocked over a five-gallon bucket fertilizer (that didn't spill) together with a few other items.

Why?

Falling down reminded me that the universe was severely damaged by two other falls, one by Satan and his minions

and the other by another man long ago. These are the falls love my fault a place Satan is running amok for a time, throwing us both physically and spiritually on-to the ground over and over. And I also realize that I am part of the fall since I related to Adam.



Dear Lord, keep me from falling physically or if I do maybe a soft place. And more importantly keep me from falling spiritually but instead if I fall physically, to rise up spiritually all the farther.

Mat 7:24 "Therefore everyone who hears these words of Mine and acts on them, may be compared to a wise man who built his house on the rock.

Mat 7:25 "And the rain fell, and the floods came, and the winds blew and slammed against that house; and yet it did not fall, for it had been founded on the rock.

1Co 10:12 Therefore let him who thinks he stands take heed that he does not fall.

1

Mat 10:29 "Are not two sparrows sold for a cent? And yet not one of them will fall to the ground apart from your Father.

Mat 10:30 "But the very hairs of your head are all numbered.

Mat 10:31 "So do not fear; you are more valuable than many sparrows.

Mat

The children's nursery rhyme:

Ring-a-round the rosies,

A pocket full of posies,

Ashes! Ashes!

We all fall down.

The Bed, or God Is My Strength

I've gotten to the point that sometimes I can barely turn over in bed, and takes me sometimes a couple of minutes to get out of bed, which is interesting since I have to get up to go to the bathroom several times at night and I sometimes wonder whether I make it to the bathroom on time. When my medication is off as they say I simply don't have strength that I used to.

So what?

When my strength fails, sometimes all I can do is turn to God and thinking for all the times when I had strength for all the blessings and in the past my whole life. More important than that however is that I remember that God is my strength and spiritual strength in the strength of God to help me spiritually to grow to serve to worship that is the strength is important. Serving God I am strong stronger than ever.

Psa 22:15 My strength is dried up like a potsherd, And my tongue cleaves to my jaws; And You lay me in the dust of death.

Ps

sa 37:39 But the salvation of the righteous is from the LORD; He is their strength in time of trouble.

Psa

Psa 73:25 Whom have I in heaven but You? And besides You, I desire nothing on earth.

Psa 73:26 My flesh and my heart may fail, But God is the strength of my heart and my portion forever.

Psa

Psa 84:5 How blessed is the man whose strength is in You, In whose heart are the highways to Zion!

P

Mat 9:6 "But so that you may know that the Son of Man has authority on earth to forgive sins"--then He *said to the paralytic, "Get up, pick up your bed and go home."

ct 9:32 Now as Peter was traveling through all those regions, he came down also to the saints who lived at Lydda.

Act 9:33 There he found a man named Aeneas, who had been bedridden eight years, for he was paralyzed.

Act 9:34 Peter said to him, "Aeneas, Jesus Christ heals you; get up and make your bed." Immediately he got up.

Act 9

Can you smell that? No I can't.

One of the first symptoms years and years ago that I have Parkinson's disease was that I lost my sense of smell. They can no longer smell coffee or perfume cooking food. They can no longer smell bad orders either. I'm waiting patiently to enter the kingdom to give my sense of smell back since it was important to God have a sense of smell. In the Old Testament is much mention of smell of incense and the sacrifices bring on the altars and please God that pleased God.

If someone asks, Do you enjoy your five senses? I answer, do you mean my four senses?



Write that.

Lord, it is true I got a D in handwriting in the sixth grade. But now my handwriting is worse than chicken scratch I cannot even read it myself. They used to be pretty fast accurate typist, but now I'm lucky to get three or four letters in a row right. So I'm using voice dictation, how long will that last? Is a speech goes to.

Buttons are my enemy perhaps the second symptom of Parkinson's I noticed was that buttons had turned against me. Buttoning my dress shirts gradually became more and more difficult, until I could barely get dressed. The shirt front buttons were pesky rebels, but my cuffs became nearly impossible. Using my right hand to button my left cuff was, and often still is, the source of frustration. Occasionally I left the left

sleeve unbuttoned because I had to get to work.

Never have it, never miss it. If I had been born unable to button my shirts, the lack of ability to do so would not have been missed, or else would have been the source of only mild discontent. This shows us how much we take for granted in life. We are so spoiled with blessings. The minute one is gone, we whine and complain

I have told you all this so that you may have peace in Me. Here on earth you will have many trials and sorrows. But take heart, because I have overcome the world."

John 16:33 NLT

On suffering

"What's wrong with you?"

"What do you mean?"

"You walked stooped over and take little tiny steps."

Why do I have Parkinson's?

2107. Pain is the stylus that writes meaning into our lives. Pain keeps us from loving this life too much. Pain, suffering and death remind us that life is serious, not a place for endless self-indulgence or entertainment. Pain, suffering, and death re-

mind us of the seriousness of sin. Sin implies guilt, and we run from guilt by denying sin—until we meet the consequences.

2701. Why isn't life after salvation perfect and painless? God is supposed to love and care for us. That's exactly what he is doing when he allows trials and disasters to visit us. When suffering arrives, we realize that we can't endure it alone. So we ask God for help. This act of realizing that we need God's help humbles us. And since pride is our greatest enemy, every act of humility improves us.

Then the young woman will rejoice with dancing, while young and old men *rejoice* together. I will turn their mourning into joy, give them consolation, and *bring* happiness out of grief.

—Jeremiah 31:13 (HCSB)

16

Lemonade for Parkinson's

Parkies Partnering with the Lord.

Parkinson's Disease is something of a lemon, all right. Bite into a ripe lemon and you'll know what I mean. But we can join with God, using his help to flourish even in the face of debilitation. With God's help, we can persevere, then flourish, and finally live with joy through our illness.

How? Haven't you heard the saying, "When life hands you Parkinson's, make lemonade." Here's the recipe:

Parkinson's Lemonade Recipe

Whenever a Parkinson's lemon falls off the tree and rolls up against your shoe:

- ❑ Pick it up and squeeze it hard, until all the juice is expelled.
- ❑ To the sour juice, add the sweetness of your attitude.
- ❑ Mix with the Living Water of Jesus.

*Enjoy the delicious lemonade,
And drink as much as you like.*

It's the sweetness of your response to personal challenges that turns bitter lemon juice into very tasty lemonade. What better way, what better reason to bring your heart and mind and soul closer to God? People are watching to see how faithfully you respond to the burden that has come upon you. So don't throw lemons at them, offer them some lemonade.

In the short story "Youth," by Joseph Conrad, the character Young Marlowe faces a series of increasingly disastrous events: the ship catches on fire, the captain goes mad, the ship blows up. Each time, Young Marlowe says, in effect, "This is great! I can handle this! I feel so alive! I can't wait to see what's going to happen next!" His attitude should be ours.

Or as the apostle Paul would put it,

I can do [endure] all things
through Him who strengthens
me.

—Philippians 4:13, NASB

I'll let our Partner in the lemonade business sum up for us:

I have told you all this so that
you may have peace in Me. Here
on earth you will have many trials
and sorrows. But take heart,
because I have overcome the
world.

—John 16:33, NLT

17

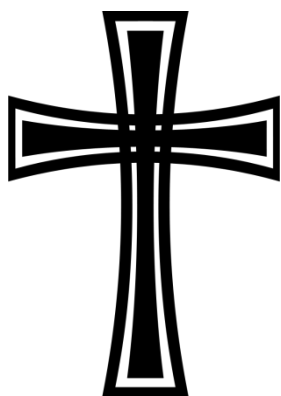
Parkinson's Prayers



Dear Lord, thank you so much for filling our lives with so many blessings. Truly, we are too little grateful for the many gifts you have heaped upon us, gifts that we possibly have never thanked you for because we took them for granted. Now that our Parkinson's disease is beginning to diminish some of those gifts, we can realize what a treasure-filled life we have had and be grateful.

Some of us Parkies were able for many years to enjoy our sense of smell. We relished the aromas of freshly brewing coffee and pizza hot from the oven and perfume

calling attention to someone and food sizzling on the barbeque and flowers in the field or in a bouquet and cherries and oranges and other fruit and hot chocolate



and the air after lightning and the soil after rain and the ocean mist as the waves pounded on the shore and the pine forest as the gentle breeze hummed through the branches of the trees. Now many of us can no longer smell any of

these things. And we thank you for that, Lord, because the loss makes us so deeply grateful for such a wonderful and delightful gift we enjoyed all those years. Thank you Lord.

In our losses with Parkinson's, we celebrate the gains we used to have. How many abilities, activities, and senses you gave us that we took for granted. As David says in the Psalms,

I will give thanks to You, for I am fearfully and wonderfully made; Wonderful are Your works, And my soul knows it very well. (Psalm 139:14, NASB).

So we are grateful to you today, Lord God, for taking an unhappy disease and bringing joy and thankfulness out of it. As Paul says,

And we know that God causes all things to work together for good to those who love God, to those who are called according to His purpose. (Romans 8:28, NASB)

Thank you for finding the positive in the midst of our challenges and for reminding us of the gratitude we owe you. We thank you and praise you with all our heart. In Jesus' name. Amen.



Dear Lord, it is true that everyone has something; I have Parkinson's Disease. But I also have your love, which is greater than Parkinson's. If it might please you, make my brain behave and produce the chemicals and nerve cells it needs that will allow me to function normally again.

If that is not your will, I ask that you will give me the perseverance I need to

endure this disease. I might be physically weak, but I am spiritually strong. I will always trust you through my future until we meet on the other side in your kingdom, where I will be able to run and jump for all eternity.

Thank you for being my strength, my hope, my God, and my friend in this and every other challenge in this life. I joyfully pray this in Jesus' name. Amen.

For every child of God defeats this evil world, and we achieve this victory through our faith.

—1 John 5:4



Dear Lord, we come to you with thankfulness, thankfulness for the many blessings, protections, guidance, and friends you have given us over the course of our lives here, while we wait for our translation into your presence in glory.

Even though we face the challenge of Parkinson's Disease, we are encouraged

by your sustaining strength, together with the hope you keep alive in our hearts.

We remember the words of the Apostle Paul, who wrote to the church at Corinth during their suffering:

Therefore we do not give up. Even though our outer person is being destroyed, our inner person is being renewed day by day. For our momentary light affliction is producing for us an absolutely incomparable eternal weight of glory. So we do not focus on what is seen, but on what is unseen. For what is seen is temporary, but what is unseen is eternal.

—2 Corinthians 4:16-18

Lord, we make Paul's words our own and pray that you will continue to live in our hearts and keep us looking forward to an infinitely better life. In Jesus' name.
Amen.



18

Making Money from Parkinson's

Bob Harris, October xx, 2016

Enough of this gloom and sadness about having Parkinson's. Though it's no wonder people get depressed when they get their diagnosis. You go to a strange doctor called a neurologist, thinking that he's going to give you something for your nerves that makes you feel just oh-so-fine. Or maybe he will prescribe many sessions with a Swedish masseuse, who will also make you feel just oh-so-fine. Whatever he prescribes, you will soon be cured of your hand tremor or your slow walking gait.

Instead, The Conversation takes place:

DOCTOR: "Yup. Sorry to have to tell you this, but you have PD."

YOU, surprised, and glancing at your body to see if anything is leaking or missing: "I do? Uh, what's PD?"

DOCTOR, looking around furtively and whispering: "Parkinson's Disease."

YOU, in a tone that reveals your total ignorance: "Sounds serious. Is there a pill for that?"

DOCTOR, chuckling: "A pill? Oh, yes, a pill." For some reason, the doctor finds your question amusing. "A pill, you say?" he continues. "Oh, my, yes. There are many pills."

YOU, still clueless: "So, how long does it take to cure? A week? I could probably put up with taking a few pills for a week or so."

DOCTOR: "There is no cure. You have to take the medicine for the rest of your life, or until it stops working."

YOU, shocked, just shocked, with disbelief: "But then, what exactly is Parkinson's Disease? Is it like nervous indigestion?"

DOCTOR, looking at you as if he thinks you are a country bumpkin who has just fallen off the turnip cart: "No, Parkinson's Disease is an incurable, idiopathic terminal neurodegenerative disease caused by a chronic malfunction of the dopamine-neuronal brain communication system that prevents your dead brain cells from telling your muscles what to do."

YOU: "Oh."

Now, doctors who say things like this often cause their newly diagnosed patients to run from the room screaming, or jump through a nearby window. (If the

doctor's office is on the 44th floor of the medical building, the patient's diagnosis is no longer a critical issue.)



But there is a better way for a doctor to present his patients with the news of a PD diagnosis. He can share with his patients some ways to monetize the illness. Imagine these scenarios:

DOCTOR: "Parkinson's Disease produces a number of symptoms that you can turn into employment opportunities. Because you have or are developing some unique characteristics as a result of your rare ailment, you can monetize them rather handily—er, profitably."

YOU: "I don't get it."

DOCTOR: "Well, consider these:"

Tremor. If your Parkinson's causes your hand to shake, you are qualified for one of these jobs:

- Bartender. If James Bond walks into your bar and orders a Martini, "Shaken, not stirred," you're the qualified expert.
- Home Depot Paint Department. You can save the store time and money by simply holding those quart cans of custom mix paint. No need to use the store's shaker equipment.

- Walmart greeter. Not only can you say hello, but you can offer an unforgettable handshake.

- Server at a salad restaurant. Virtually every bottle of salad dressing says on the label, "Shake well before using." You have a unique talent here.

Stoop.

19

On the Benefits of Parkinson's Disease

Bob Harris ♦ September 12, 2016

If you've just been diagnosed with Parkinson's Disease, you might be thinking that your life has screeched around the bad-to-worse corner. The fact is, having Parkinson's actually provides several benefits. Here are some of the ones I've been experiencing.

1. Handwriting benefits. Okay, I admit I got a D in handwriting in sixth grade, but at least I've usually been able to read most of what I have written (except for those notes scribbled in the middle of the night on my bedside pad). But now, as is common among Parkies, my bad handwriting has also become nearly microscopic. I must take off my reading glasses in order to make it out, and even then, I'm lucky if I can read fifty percent of what I've written. The good news is that I'm saving paper: a single sheet of paper lasts all day!

Additionally, seeing a page filled with one-quarter-size handwriting is actually quite impressive. It creates the appearance of saying something wise or intelligent. That appearance must come from our life experience. We see little children writing great big letters as they develop their muscles and the hand-eye coordination. Gradually, their writing gets smaller. Graduate students no doubt have quite small writing, the more intelligent among them, the smaller the writing. If you look at my handwriting, and if writing size is the indicator, I must be a genius.

And the people who see it but can't read it either assume that it says something profound or pretend to be able to understand my wonderful insights. It's a case of the Emperor's New Manuscript.

Finally, if you have this phenomenon in your own situation, you can not only show your friends ("Oh, that's deep," they will say), but you can impress them with a new word. "I have micrographia," you can say.

"Is it contagious?" they will ask.

2. The unpleasant is made pleasant. At our house, I'm in charge of following our aging Chihuahua around on his morning rounds and withdrawing whatever deposits he makes on the neighbor's lawn. The good thing about this is that the very first

symptom of my getting Parkinson's Disease many years ago was that I lost my sense of smell. True, I cannot smell the perfume on an attractive young woman—but that's good because it keeps me from temptation.

So, pick up after the dog, fix a clogged sewer pipe, get with several friends and chow down on chili and bean burritos before watching the game together in a crowded living room—none of that bothers me.

Besides, you can drop another new word on your friends. "I have anosmia," you can say.

"Have you tried some of the over-the-counter sleep aids?" they will ask.

3. All my food is mouthwatering. You know the expression. Delicious food is mouthwatering. It gets the saliva going in anticipation of something truly tasty. Well, my mouth waters (please don't call it drool) all the time. And if I'm not careful, I will water whatever is beneath my chin. The good part, at least in theory, is that when I go to a friend's house for dinner or a party, the hostess thinks I'm really enjoying the food. "Look at him! He's drooling over the food. It must taste especially delicious tonight."

This one comes with a double bonus: You can tell your friends, “I have sialorrhea.”

“I always use the pink medicine for that,” they will say.

“But sialorrhea isn’t the runs. It’s hypersalivation.”

“Wow,” they will say. “I never knew anyone with a disease fifteen letters long. Wait till I tell the gang at the office.”

4. My expression makes me look deep.

The medical folks like to call this feature of Parkinson’s Disease “blunted affect” or “masked face,” or “hypomimia,” or “poker face,” but I like to think of it as a pensive, thoughtful, philosophical expression.

“You look so serious,” my friends will say. “What’s on your mind?”

“Just thinking over an issue related to quantum entanglement,” I might reply. “Can’t you tell by the expression on my face?”

“Quantum?” they will ask.

“Yes,” I’ll say, giving them a sample of my handwriting. “Here’s something I’ve written on it.”

“Quantum, huh?” they will say again, shaking their heads and handing back the writing after a brief squint. “We had one of those once, but it was always in the shop and the gas mileage was terrible. You have one now?”

5. I'm the envy of the room with my soft voice. Parkies like me supposedly speak very softly, even though our speech volume sounds perfectly normal to us. At a party, we can blab to our heart's content, and the other guests will be too polite to ask, "Would you say that again?" or to say, "What?" "Huh?" or "I can't hear you." Two benefits derive from this.

First, the person or people you are speaking directly to will pretend to agree with you and nod their heads as if in agreement. Not knowing what you're saying, they won't interrupt or contradict you or ask questions you can't answer.

Second, the other guests, noticing that your auditors are leaning in and struggling to hear you, will naturally conclude that you are whispering, which leads to the obvious conclusion that you are telling secrets, gossip, or secret gossip. This thought will drive the entire party wild with curiosity and you will be sought out eagerly for as long as you want to stay at the party.

The truth is, of course, that Parkinson's is not really much fun. But I've always trusted God with my life—and I've been really blessed—so I see no reason to change now. And if I can continue to

trust God with a positive attitude, I can endure the future.

“Remember that the greatest honor you can pay to the author of your being is by such a cheerful behavior as discovers a mind satisfied with his dispensations.”

—Samuel Johnson

20

When Bad Things Happen to Christian Parkies

Pray for Health and Protection,
But Realize that God is Not an Insurance
Policy

Through many tribulations we
must enter the kingdom of God.
—Acts 14:22b

How many times have you heard someone say, “I’m a Christian, so I know God will protect me from illness, accident, and crime”? What does the Bible say? Jesus himself tells us to pray for our needs, such as food, for forgiveness for our sins, and for protection from Satan:

So this is how you should pray:
“Our Father in heaven, we pray
that your name will always be

kept holy. We pray that your kingdom will come—that what you want will be done here on earth, the same as in heaven. Give us the food we need for today. Forgive our sins, just as we have forgiven those who did wrong to us. Don't let us be tempted, but save us from the Evil One.”

—Matthew 6:9-13, ERV

But Jesus doesn't say we will not have any disease, accident, injury, or other suffering and evil visit us. We are in a fallen world, where, until Jesus returns, Satan rules the world through his evil adherents, both demonic and human. Jesus tells us this himself: “I will not talk with you much longer, because the ruler of the world is coming. He has no power over Me” (John 14:30). What *does* Jesus say about challenges and sufferings? He says, “I have told you all this so that you may have peace in Me. Here on earth you will have many trials and sorrows. But take heart, because I have overcome the world” (John 16:33, NLT).

So what does this mean for the daily life of a Christian?

Let's look at an example. Who in the Bible was chosen by God to write more than a

dozen books of the Bible and to record and spread the Christian message throughout the entire Roman world? Who was honored to visit dozens of cities, towns, and villages, preaching to both Jews and Greek-speaking peoples?

Yes, it's the Apostle Paul. You can imagine how God must have protected and smoothed the way of such a dedicated, strong, faithful, consecrated, energetic, obedient believer. Or, maybe not. Let's see. The book of Acts records much of Paul's evangelistic and nurturing work. While preaching the Gospel,

- Paul and Barnabas are persecuted and driven out of Pisidian Antioch (Acts 13:50).
- Jews and Gentiles attempt to stone Paul and Barnabas at Iconium (Acts 14:5).
- Paul is stoned at Lystra and left for dead (Acts 14:19).
- Paul and Barnabas get into a major disagreement and split up (Acts 15:39).
- Paul sees a vision calling him to Macedonia. He goes there and his reward for obedience is to be stripped, beaten with rods and put in the stocks in prison (Acts 16:22-24).

- A mob searches for Paul in Thessalonica, so Paul must escape by night to Berea, but when he arrives, he is forced to flee from there, too (Acts 17:13-14).
- In Corinth, God appears to Paul in a vision and tells him that he won't be persecuted in that city. Paul stays there 18 months (Acts 18:11).
- Paul's ministry is interrupted by a riot in Ephesus (Acts 19).
- Some Macedonians plot to kill Paul, causing him to leave Macedonia for Troas (Acts 20:3-6).
- The Holy Spirit tells Paul that imprisonment and affliction await him in every city (Acts 20:23).
- Some believers warn Paul that persecution is ahead of him in Jerusalem (Acts 21:4, 11).
- Paul is seized by a mob in the Temple in Jerusalem and beaten until soldiers arrive (Acts 21:30-33).
- More than 40 men plot to kill Paul, but their plan is exposed (Acts 23:14ff).
- Paul is kept in prison for more than two years (Acts 24:27).
- On the voyage taking Paul to Rome, an enormous storm rises and tosses the boat around for two weeks. Then the ship hits the rocks and is destroyed (Acts 27).

- Paul is bitten by a poisonous snake, but he shakes it off into the fire (Acts 28).

In Paul's own words:

Are they servants of Christ?--I speak as if insane--I more so; in far more labors, in far more imprisonments, beaten times without number, often in danger of death. Five times I received from the Jews thirty-nine lashes. Three times I was beaten with rods, once I was stoned, three times I was shipwrecked, a night and a day I have spent in the deep. I have been on frequent journeys, in dangers from rivers, dangers from robbers, dangers from my countrymen, dangers from the Gentiles, dangers in the city, dangers in the wilderness, dangers on the sea, dangers among false brethren; I have been in labor and hardship, through many sleepless nights, in hunger and thirst, often without food, in cold and exposure. Apart from such external things, there is the daily pressure on me of concern for all the churches. Who is weak without my being weak? Who is

led into sin without my intense concern?

—2 Corinthians 11:23-29

(NASB)

Huh? What happened? Is that the life a dedicated servant of Jesus can expect? Well, maybe, and sometimes. The history of Christianity is filled with martyrs who were tortured, burned, disemboweled, ripped apart by horses pulling in four directions, stoned, beheaded—and more. So, pray for deliverance, but don't expect to be granted a privileged life just because you signed on to the Christian program. Read God's word in the Bible and get a realistic picture of the life of a believer. Then you won't be surprised when your life takes an unhappy turn. You will realize that your cushy life with its minor challenges is really much better than the life experience of most people.

And when you do experience something pretty bad, please don't wail or complain, or ask, "Where is God?" And don't pray, "Oh, God, why are you doing this?" Instead, pray, "Dear Lord, help me to endure this suffering. Deliver me from it if that is your will, or if not, help me to persevere through it. And may every event in my life, good or bad, be used by you to produce good, because "we know that God causes all things to work together for

good to those who love God, to those who are called according to His purpose" (Romans 8:28).

Stay alert! Watch out for your great enemy, the devil. He prowls around like a roaring lion, looking for someone to devour. Stand firm against him, and be strong in your faith. Remember that your Christian brothers and sisters all over the world are going through the same kind of suffering you are. In His kindness God called you to share in His eternal glory by means of Christ Jesus. So after you have suffered a little while, He will restore, support, and strengthen you, and He will place you on a firm foundation.

—1 Peter 5:8-10

Remember that faith is trusting God when you don't understand.



May the Lord God who made the heavens and the earth and all that is in them, convert everything meant for evil into good, and may he continue to shower his children with blessings, hope, and endurance. In Jesus' name. Amen.



September 22, 2019

21

What's in a Word?

The English language is impossible to make any logical sense of, and therefore does not admit itself of creating a sensible set of rules. We have already looked at the nonsensical use of progress to describe the worsening of Parkinson's Disease.

“Two years ago, I could speak, write, and type. If a great idea came to me at midnight, I could just grab a pen and a pad of paper and jot it down—without a nightlight or glasses.

But now my disease has “progressed” as the crazies like to say, so my speaking is often interrupted by wells of emotions that choke off my sentences, my typing has more wrong letters than correct ones, and my handwriting is completely illegible. This is progress?

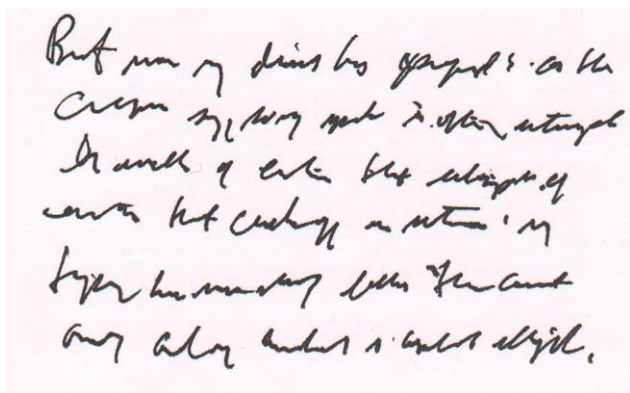
Here, in early 2020, is the previous paragraph typed right through without any corrections:

But now m dedisease has “pro-
gressed” as t e cazies like o sa,
so m speaing is oftgen
intgerfrupted by wells of emot-
gioisn tghatg hsocioeof
sentgences, my opin has more
wrog lees tgan coec ones k, and
by handwriting is compleely
ileltible. hisis rogamss?

And this sample doesn't include the number of backspaces, spelling corrections offered replacements, and the number of repeated incorrect letters. such as typing *tgh* for *the* and *forf* for *for*.

that I can barely write two words that make sense

And while I'm at it, here is a sample of my handwriting, same sentence as above:



Imagine a poor schoolchild trying to learn:

Teacher: "Some words are made clearer if they include another, short word as a helper.

"He burned to ask her for a date."

"She did a slow burn when she heard his name."

"Their house burned down yesterday."

"My car burned down last year."

"No, cars bun up, not down."

Many of you no doubt, as you "progress" in your PD, have noticed that when you walk

exceptional

cleave

progress

shuffle

Sinemet®, vs carbidopa/levodopa

off period

Why Me?

why did God do this?

Why did God want this?

Why did God allow this?

secret sin

Why me? Why you? Why not you?

Why don't we ask, "Why me?" when good happens?

Why are we so deluded by the idea that Christians are immune from all harm? Is Jesus a vaccine, inoculating us? Believe in Jesus and you'll never get sick or be harmed in any way. Then something bad happens, oh, say Parkinson's. I've heard that some people run screaming from the room when they first hear the diagnosis. Later they ask in resentful and maybe even disbelieving tones, "Why didn't God keep me from getting this? And why doesn't he heal me now? We exist in a realm with genuine good and genuine evil. A powerful spiritual battle is being fought. Whose kingdom? The devil is roaming around. The Lord's prayer: may your kingdom come; may your will be done. Think of the suffering of Christians and others through history. and now you?

My hope is confirmed twice a day. I usually have two off periods each day, when I feel totally without any energy. My will is drained and I don't want even to attempt to get up out of bed. But then, two hours later I can get up and work, feeling almost human.

I have not kept the good news of Your justice hidden in my heart; I have talked about Your faithfulness and saving power. I have told everyone in the great assembly of Your unfailing love and faithfulness.

LORD, don't hold back Your tender mercies from me. Let Your unfailing love and faithfulness always protect me.

—Psalm 40:10-11

As an example, brethren, of suffering and patience, take the prophets who spoke in the name of the Lord.

We count those blessed who endured. You have heard of the endurance of Job and have seen

the outcome of the Lord's dealings, that the Lord is full of compassion and is merciful.

—James 5:10-11

Dear brothers and sisters, when troubles come your way, consider it an opportunity for great joy. For you know that when your faith is tested, your endurance has a chance to grow. So let it grow, for when your endurance is fully developed, you will be perfect and complete, needing nothing.

—James 1:2-4 (NLT)

We ought always to give thanks to God for you, brethren, as is only fitting, because your faith is greatly enlarged, and the love of each one of you toward one another grows ever greater; therefore, we ourselves speak proudly of you among the churches of God for your perseverance and faith in the midst of all your persecutions and afflictions which you endure. This is a plain indication of God's righteous judgment so that you will be considered worthy of the kingdom of God, for which indeed you are suffering.

—2 Thessalonians 1:3-5
(NASB)

God blesses those who patiently endure testing and temptation. Afterward they will receive the crown of life that God has promised to those who love Him. —James 1:12 (NLT)

22

A Parkinson's Prayer



Dear Lord, thank you so much for filling our lives with so many blessings. Truly, we are too little grateful for the many gifts you have heaped upon us, gifts that we possibly have never thanked you for because we took them for granted. Now that our Parkinson's disease is beginning to diminish some of those gifts, we can realize what a treasure-filled life we have had and be grateful.

Some of us Parkies were able for many years to enjoy our sense of smell. We relished the aromas of freshly brewing coffee and pizza hot from the oven and perfume calling attention to someone and food siz-

zling on the barbeque and flowers in the field or in a bouquet and cherries and oranges and other fruit and hot chocolate and the air after lightning and the soil after rain and the ocean mist as the waves pounded on the shore and the pine forest as the gentle breeze hummed through the branches of the trees. Now many of us can no longer smell any of these things. And we thank you for that, Lord, because the loss makes us so deeply grateful for such a wonderful and delightful gift we enjoyed all those years. Thank you Lord.

In our losses with Parkinson's, we celebrate the gains we used to have. How many abilities, activities, and senses you gave us that we took for granted. As David says in the Psalms,

I will give thanks to You, for I
am fearfully and wonderfully
made; Wonderful are Your
works, And my soul knows it
very well. (Psalm 139:14,
NASB).

So we are grateful to you today, Lord God, for taking an unhappy disease and bringing joy and thankfulness out of it. As Paul says,

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

—(Romans 8:28, NASB)

Thank you for finding the positive in the
midst of our challenges and for reminding
us of the gratitude we owe you. We thank
you and praise you with all our heart. In
Jesus' name. Amen.

23

Update to April, 2020

This account is accurate as of April, 2020. Since PD is a “progressive” (I hate that word) disease, who knows what I will be (or have been) like by the time you read this. Anyway, I hope it is helpful to you in some way.

Sleeping.

My wife and I slept together in our California King sized bed for years, until my Parkinson's and other ailments made me move. I have always had a restless sleep, with lots shifting and turning over, back to stomach, stomach to side, side to stomach, and so on. The arthritis in my spine prevented me from resting in one position for any period of time. Most positions produced pain after only a few minutes, requiring me to shift around until I fell asleep. Unfortunately, our mattress was too soft, so not only did it make shifting around more frequent, but it also made it more difficult. What is an almost

unthinking flip for a normal person can be a prolonged struggle for a Parky. Many times I have needed to change positions, only to grunt and groan and put monumental effort and attention into making a change, only to have my body respond with the equivalent of a yawn. Often, I have to gather up my grunt power and make an all-out effort to move. Along the way, I discovered that sleeping without PJ's made turning over somewhat easier, because the friction between the sheets (cotton most of the time) and the PJ material (often cotton as well) was high enough to feel as if someone had put on the brakes to turning.

Next, I developed myoclonus, an involuntary jerking of the arms and legs, occurring at night, in my case. This added to my wakefulness and difficulty in sleeping. Myoclonus could be related to Parkinson's, but the connection is not definitive at this point.

As my Parkinson's progressed, my thrashing got more wild. Then one night I fell out of bed while moving around. That was a two-and-a-half-foot drop to the floor. I wasn't hurt, but it was something of a last straw. As time had gone on, my sleeping in the King bed had become more and more problematic. Getting out of bed grew increasingly difficult (in the middle of the night, dopamine levels are

lower), making it a challenge to get up and go to the bathroom—which was necessary anywhere from two to five or six times a night. Getting out of bed at night was so difficult that we bought one of those elevating beds (for a huge “investment”). The bed was okay, but it wasn’t the panacea we had hoped for. And then when I fell out of bed, we said that was it.

So, while lying on my King bed put me about two-and-a-half feet above the floor, lying on my new bed puts me about four or five inches above the floor. It’s a custom job: two one-inch thick exercise mats 24” by 72” hooked side by side, one three-inch-thick twin-sized memory foam mattress, one twin comforter and one microfiber blanket. Plus six or eight pillows and a couple of microfiber throws.

This new arrangement has several benefits. First, the farthest I can fall out of bed is four or five inches. Next, my new floor bed is positioned between the foot of the King bed and the armoire. Both of these pieces of furniture allow me to grab onto something (the footboard and a drawer) when I want to get up. I can leverage my body and combine what little strength my arms have with what little strength my legs have.

I also discovered that I could reduce the myoclonus attacks by sleeping on the flat floor on my stomach.

Answering Nature.

A few years ago, we were visiting the widow of a Parky, and she was telling us all the things her husband had done while he was still able to make the house more useful for himself after he had continued to debilitate. For example, he had installed support bars, also called grab bars, around the bathtub and toilet. I followed his idea and installed two 18-inch stainless steel grab bars, each two feet from the back wall and 36-inches from and parallel with the floor. Even though I am not yet so debilitated that I would have to use them for potty visits, I still use them because they are handy and helpful. I can secure my balance when performing the standing requirement, and I lean on one of them while contemplating the transitioning of processed food.

Night Light.

Those kiddie night lights that feature a superhero blocking the light, and those adult night lights that pump unusual smells into the room while pushing a few feeble lumens up against the darkness are not adequate for an extremely near-sighted, wake-up-and-got-to-go Parky who has to struggle to get on his feet and then negotiate the path to the blessed flush-the-slush machine. (I really do thank and praise God for flush toilets and

water treatment plants. If you don't do that too, either travel more, visit a mountain campsite, or look up world sanitation practices—and their lack.)

As I was going to say, a sturdier night light is needed for midnight commuters, so, Mr. Thrifty that I am, I found an LED desk lamp at Walmart for \$2.50. Now I can get up easily and find my way to the necessarium without peril.

Go Tub.

One of my favorite things to relax my aching back and painful spine is to take a hot bath just before going to bed. And that raises another challenge for a Parky: how to get into and out of a bathtub. Actually, getting in is less problematic than getting out. Get in: Walk over, brace yourself, step in to the tub. Get out: Now you are lying down, so you first have to sit up, scoot your body into position, get a grip on something, and pull yourself up. For a while, I had a helper bar, consisting of a U-shaped steel bar, secured to the tub by a screw-tight mechanism. This worked quite well for a couple of years, until the occasional retightening of the bar cracked the fiberglass tub, and the bar had to be exiled.

Too Fast

As I write this now, in about the 15th or 20th year of my endowment⁵ with PD, I notice that I am increasingly exhibiting some of the characteristics of ADHD (Attention Deficit Hyperactivity Disorder). Since I'm not trained in psychology or mental diagnosis, I'm merely saying that some of the characteristics of ADHD appear to have joined my symptom group.

The main reason I have come to this conclusion is that I ***do most things too fast.***

Write too fast. I have always loved the feel of a ballpoint pen in my hand and the pleasure I got from writing notes, letters, ideas, term papers, and so on. My parents gave me an electric typewriter as a welcome-to-college gift when I went away to the university, and I used it to type up my papers. But—and the secret is—I actually drafted them completely by hand before typing them up. The same was true all through graduate school.

I have spent many years buying cheap ball point pens, looking for the ones with the least resistance to my ideas, pens whose ink would flow effortlessly onto the page as I prosecuted yet another great contribution to Western Civilization. My writing was slows and deliberate. I could

⁵ See? Your attitude is crucial to a successful negotiation of the disease. Don't get all mopey and lose heart.

pause for reflection as often as I wanted, availing myself of another sip of coffee at will.

My transition from hand drafting to typewriter drafting was never very successful. Then the first computers set up as word processors became available. I remember that the English Department at UC Riverside obtained a used Lexitron machine around 1980 or so. The Department kindly allowed the graduate students to use this dedicated word processor after 6:00 in the evening. I signed up for it and immediately fell in love. I even wrote some (mock) romantic poems to it.

The Lexitron was not the solution to all difficulties, and in fact it had some quirks. To insert something into the middle of a document, you had to shove every page after it down in order to make room. There was no auto-insertion feature. But I quickly transitioned from pen to Lexitron, mostly because the machine had a backspace key that I could use to back up over mistyped text and repair it. (Even then, at age 30, I was a lousy typist, who had to correct many typos.)

I enjoyed using this machine so much that I called the Lexitron folks and asked how much they cost. "We have a used one for \$9,300," they said.

"Thanks," I said. "I'll be in touch."

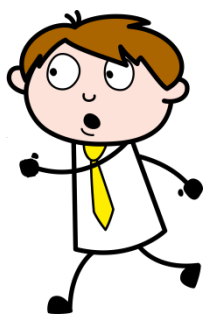
Back then, in the early 1980s, I typed and wrote at “normal” speed. But in the last year or so, I have discovered that I write too fast—or rather, I try to write too fast. Currently, there is no purpose to attempt to write something with a pen (though I still try, remembering the pleasures of the past). When I do, my illegible scribble becomes little more than pathetic graffiti. And don’t tell me to slow down. I try to go slow but it doesn’t help. My hand still wants to run at full speed and more.

Type Too Fast. As I have indicated elsewhere, my toping is almost as bad as my writing, except for the fact that I can wear out the backspace key and correct the errors.

Speak Too Fast. People around me are always telling me that I’m becoming impossible to understand because I speak too fast, shoving all my words together into an incoherent stream. I find myself tripping over my words because my brain is delivering them to my mouth faster than my mouth can enunciate them. Many times, I have to stop my verbal blast, wait a few seconds, and then try to speak slowly whatever idea had just flooded all the speech circuitry.

Eat Too Fast. I’ve always been a purpose-focused eater, never a dawdler who enjoys long conversations when there’s a

double cheeseburger sitting in front of me. In the last couple of years, or so, it seems that I have changed from a fast scarfer to an inhaler of my food. People notice. "Slow down," they tell me.



Walk Too Fast.

"You're always running through the house and outside, too," my wife tells me. "Slow down or you will fall and hurt yourself." I used to say that I have a lot to do, but that didn't go over well, so now I do try to slow down a bit.

Move Too Fast. There is the regular sound of glass shattering in the kitchen of our house, as I continue to knock glasses and dishes off the shelf while attempting to retrieve one or put back another. I have suggested to my wife that get some drinking glasses and other dishes from the dollar store, but so far no go. At my desk or the kitchen counter a poorly planned low sweep of my hand in pursuit of a pen or notepad can knock a coffee mug, juice glass, or perhaps even a vase with costly floral décor in it onto the always unforgiving tile floor, resulting in a ten-minute break from my desired activity.

Seek the LORD while He may be found;
Call upon Him while He is near.

Let the wicked forsake his way
And the unrighteous man his thoughts;
And let him return to the LORD,
And He will have compassion on him,
And to our God, For He will abundantly pardon.

"For My thoughts are not your thoughts,
Nor are your ways My ways," declares the LORD.

"For as the heavens are higher than the earth,
So are My ways higher than your ways
And My thoughts than your thoughts."

—Isa 55:6-9

24

Update to November, 2020

Well, all you literature and classics majors will no doubt recall that literary epics traditionally have 24 books to them (chapters, we might call them today). And how many chapters does the work you are reading have? Just sayin'.

So, what is my life like today? Here are some random descriptions.

Thyroid to the Rescue. The biggest change since the last update (previous chapter) has been in the discovery that my thyroid hormone was below normal. My Primary Care doctor found this in a routine blood test and put me on levothyroxine 25 mcg once a day. It immediately made a huge difference. I no longer feel completely exhausted most of the time. I do get tired and need to rest or nap a couple of times a day, but the totally wiped out feeling is generally gone.

So Parkies, if you feel utterly exhausted much of the time, ask your doctor to check your thyroid in addition to having your Vitamin D checked.

Sleep. The latest iteration in my sleep is the removal of the 3-inch memory foam pad. My floor mattress is now built from the 1-inch exercise mats (two 24-inch wide pads side by side) and a thin comforter (\$6 at a closeout), two side-by-side body pillows (aka Dutch wives) and a microfiber blanket. I sleep under a microfiber throw. Sleep is pretty good compared to the past. Instead of 4 or 5 trips to the porcelain water repository each night, I make 3 to 4 trips. Sleeping on my stomach is still my best position, shifting mostly between two positions:

1. Head facing left, left leg pulled up about half way, right arm down my side or sometimes under my hip, left arm pulled up near mouth.

2. Head facing right, right leg pulled up about half way, left arm down by my side, right arm by face.

3. Occasionally I move to one side or the other for a few minutes.

4. Sleeping on my back works only until the myoclonus starts.

Handwriting. Hah! Since I cannot read even my most careful notes (with rare exceptions), I have moved my work to the keyboard, mostly, and have recently

installed Dragon Naturally Speaking Version 15. It's amazingly accurate if you enunciate carefully and speak a bit slowly. When my meds are working happily, I still prefer the keyboard. I will type until I start making two or three typos for every word. Then I switch over to Dragon.

Cognition. I can tell that more than just my dopamine manufacturing cells are dying. I have sensed a bit of a decline in my mental capacity. (So I do puzzles for a few minutes a day, and read, write, and think to keep the circuits going.)

I'm experiencing increased difficulty in word-finding (as they call it) and name finding. Once maybe a year or so ago, I couldn't remember a family member's name. Finding the word I want is sometimes difficult, and that's an irritant for someone who is writing all the time. (By the way, I know what the word is that I want, but I can't think of it. Sometimes I will run down the alphabet, trying to match the first letter of the word. This is a relatively important fact, because it shows that we are not controlled by our words: thought precedes words.)

Hallucinations. As Parkinson's advances, or as the medication you take increases in dosage, hallucinations are possible. I went for many years without any. Then one day about two or three years ago, I was looking out over a parking lot

when it suddenly rippled up and back down in a big, curving wave. That was all.

Now, out of the corner of my eye, I occasionally see the silhouette of a person walking by in my peripheral vision. Each one of these lasts only about a second or two.

Emotional Speaking. I'm still suffering from sudden emotional washes that prevent me from continuing to talk (or if I try, my voice is drowned in feeling). Again, these are unpredictable and a nuisance.

This is a Partial Book. I am putting many of my unfinished books online so they can benefit people in case I'm called home before I could finish them. Look on my Web site for more: www.virtualsalt.com.

Last edited and updated: November 19, 2020.