

A sunset over a beach with a person walking in the distance. The sun is low on the horizon, casting a long, bright reflection on the wet sand. The sky is filled with soft, golden light and some light clouds. The overall mood is serene and contemplative.

My Journey with Parkinson's Disease

The Good, Bad & Ugly

Kenny Phipps

My Journey with Parkinson's Disease – the Good, Bad & Ugly

by
Kenny Phipps

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*I dedicate this book to my lovely wife Evon,
for putting up with me and the disease that has caused her
more than one sleepless night.*

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Forward

The beginning of my relationship with Parkinson's started in the late 1990s. I noticed that my right hand always appeared to be shaking, and my penmanship became noticeably smaller. The constant drooling and shuffling walk would not arrive for several years, but trust me; they also became part of my life.

I knew something was wrong with my body but did everything I could to keep from seeing a doctor like my wife, Evon, had been constantly trying to get me to do. "Aw, it's just too much coffee or sugar from all the candy bars I had shoved down my throat for all of these years." So, I quit drinking coffee and stopped eating chocolate. No change. I was still shaking almost constantly, especially my right arm. I must add at this time that I am right-handed. Not just a little bit right-handed, but totally right-handed. I can't button a button or unzip a zipper left-handed, and that's led to several embarrassing accidents when the rush to operate the zipper is the one on my Wrangler jeans.

I knew something was wrong, but I wasn't sure I wanted to know what it was. After all, there is a long list of bad stuff out there to get. The problem with delaying the dreaded doctor's office visit is it won't get better on its own and by delaying treatment the damage may raise exponentially. The other problem is like when you were a kid and you did something wrong. Nobody knew but you. So here you have this secret and you know when it is discovered by Mom, Dad, or your teacher there is going to be some kind of punishment. And the longer you pondered what the judgment would be, the more scenario's your mind created, each worse than the one before, until you decided to confess your sin and accept the sentence passed down to you, which usually wasn't as bad of what you had dreamed up.

So one day, I decided I needed to face my fears find out what was happening inside my body. I agreed to visit a neurologist in the fall of 1999, and he diagnosed me with Parkinson's disease. I was only forty-four, and to say the news that I had Parkinson's was shocking is an understatement. I went through a variety of emotions, which include but are not limited to denial, anger, crying, and self-pity. I tried cussing, throwing fits, and holding my breath like a child, but none of them worked.

Why me? I asked myself over and over. I was in the prime of my life. I had a beautiful wife and three wonderful kids. I had a very good job for which I traveled all over this great country of ours. My life had always been filled with adventure. I had been a scuba instructor, a private pilot, an ex-rodeo cowboy (who still roped with my sons), and won the Baja 1000 off-road car race. How could I live without the things that gave me fulfillment and defined me as a person?

What was my future? Would I be an invalid in a year? Five years? Ten years? No one knew, and I hated the thought of being a burden to my family whenever the unimaginable idea of being one-hundred percent dependent entered my mind.

In this little book I am not going to say, "I know how you feel." That is one thing that can launch me into a tirade that I normally regret later. When someone tells me they know how I feel I reply, "No, you don't. You don't have an incurable disease that robbed you of your way to make a living and took many of your favorite hobbies away. Don't tell me you know how I feel unless you have a disease that may make you an invalid in a few short years, or unless you have ever been embarrassed in public, whether in a restaurant eating salad with a spoon or shaking like you had just seen a ghost."

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So, I will not insult you by saying I know how you feel. There are too many personal dynamics that create our thinking to know how anyone feels. It is okay for someone to say, "I understand why you would feel that way," but please never tell me you know how I feel.

I am not going to give you any cures for this nasty disease. I have been offered many cures over the years by well-meaning friends and family that have no scientific support for what they saw on some television talk show. Most of them are pretty exotic and require a pretty good imagination, which I have, but they have no medical or scientific background or testing. So if they help at all, it is in one's mind. Now when someone offers me a "cure" I smile, say thank you for thinking of me, and toss it in the trash later. The truth is that there is no cure. There are drugs and treatments that may lessen the effects Parkinson's has on you, but there is no cure. The good news is; it won't kill you. It can and will make life more difficult, but it won't kill you.

I subtitled this little book *The Good, Bad & Ugly* after the old spaghetti western starring Clint Eastwood because there are several phases or ways Parkinson's can affect you. And while it affects people in different ways, we all have similar experiences. This is my story of how I came to cope with, accept and actually realize that many aspects of my life have improved since Parkinson's tried to destroy my way of life, and worse than that, my spirit for living.

I want to make clear that these are some of the experiences that have happened to me and my thoughts about how to deal with them. Everyone is different and may not have the same symptoms or areas of concern that I have. My wish is to give the reader especially if they are new to the Parkinson's disease family or have a loved one recently diagnosed with Parkinson's disease what they may expect ahead with Parkinson's from an ordinary guy's point of view. And more importantly the assurance that this diagnoses is not the end of the world.

The Bad

Emotional Stress

Another issue directly linked to the uncontrollable shaking, or tremors as the doctor called it, was the emotional stress. To a look-fate-in-the-eye guy like me, I felt that by not being able to control my body, I was weak and vulnerable, and I did not like that for a moment. I felt that people were staring at me. Little kids were whispering about me and pointing at me. The helpless feeling that ran over me like a tsunami, nearly consumed my being.

A few people that were really rude, stupid, or both, openly teased me about the tremors. However, in time I got a bit tougher and ignored how people reacted to my condition.

Still on occasion, I have someone who not out of kindness or concern asks me, "Why are you shaking?" To which I reply, "I'm scared."

"Of what?" they always ask.

"I don't know. I just don't know."

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Most of the negative thoughts I had, originated in my mind and were not actually meant to be harmful or rude by other people. I was the one who was doing myself harm by the way I interpreted the meaning of what someone said or did. I finally realized one day that I needed to be less defensive when talking to people and disregard negative comments.

Public

I got to the point that I hated going to restaurants, which was a major issue since I traveled six to nine months a year with my job. I'd order a pizza or eat fast-food instead of dining at a little healthier establishment because most of the food I ordered ended up on my shirt or on the floor. Eating scrambled eggs with a fork just wasn't going to happen. I now carry a weighted spoon and fork with me that helps counteract the tremors. Special plates can be purchased that have a rolled edge, and that makes it easier to trap your food.

I have never been completely comfortable as a public speaker, but now when I'd have to address an audience, I would be shaking before I stood before them. I really started shaking when I felt they were paying more attention to the tremors than my message. I now start my presentations by explaining to my audience that I have Parkinson's. I believe it eases their minds as to why I'm shaking. I know it helps me because now I know they know I am not as nervous as I look.

Drooling

One of the symptoms of Parkinson's disease is drooling. Now drooling is cute when it's a six month old baby cutting their first tooth, but a fifty-five year old man, slobbering so much he has to carry a napkin or handkerchief, is uncool. I don't know how the body can produce so much saliva. It constantly seeps from both corners of my mouth. The good side of drooling is that I can swallow any number of pills without needing water to wash them down.

Sleep

What the heck is that? I haven't had a full night's sleep in ten to twelve years. I've tried sleeping pills; which may as well be M & M's, booze; which just made me drunk, and even marijuana. A friend told me if I'd smoke a little dope I would surely sleep all night. I would have tried anything to get a full night of sleep. Well my friend was kind enough to provide some quality herb which I smoked on my back porch before going to bed. The results were that I didn't sleep a minute longer than before, but I ate everything in the refrigerator. So, I quickly decided that since I was breaking the law, and I was going to gain two-hundred pounds by emptying the fridge every night; this experiment would last just one night.

I take time every day to take two or more power naps. They don't take long, usually five to ten minutes each, but refresh me better than any over-the-counter energy supplement. When I drive, I pull over and take a nap, even though I may be five minutes from home. The long term effects on other people's lives or mine are not worth the risks of falling asleep while driving.

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Crying

I'm not going to tell you I am a tough guy. I have been in my share of physical scrapes, but I don't go looking for fights. However, since my journey with Parkinson's began I have become a crybaby. I get choked-up watching a movie. If I am talking to someone about any number of topics my voice may start to quiver and I may even tear up. It drives me crazy. I always think of Tom Hanks in "A League Of Their Own." "Crying, there's no crying in baseball." I am not sure how many men with Parkinson's this affects but, "Crying, there is crying with Parkinson's."

Voice Control

I have never had a deep, booming voice that can be heard above jet aircraft or rock bands, but I could usually communicate well enough to be heard. Early on in my journey with Parkinson's I noticed, or my wife noticed for sure, that my voice volume was barely loud enough to be heard. If I am facing away from you, all you will probably hear is a mumbled bunch of words or what you think are words coming from me. I try to say every word clearly and loud enough to be heard, but it is something I have to work at daily.

There are now workshops now that Parkinson's patients can attend that help you train your voice to be understood better by whomever you are communicating with. It also helps to be facing the person you are talking to.

Penmanship

As I said in the forward of this book one of my first clues that something wasn't right was my penmanship went from large to tiny. Soon it progressed to barely legible. There are so many things we take for granted, and the ability to write is one of them. If someone wants directions, or me to write them a note, I tell them to write for me so they can translate them later.

Balance

The next two symptoms to impede my pursuit of happiness were shuffling my feet, much like a wino down in the slums, and losing my balance. I looked like the old men I saw in nursing homes. Add to that malfunction of my motor skills, I started falling. I used to be like a cat, when knocked off my balance I could easily regain it. Now, I would fall at least once a day when walking across level ground. My wife told me she was going to make me start wearing a bicycle helmet. For a guy that used to ride bulls and broncs in rodeos, this was a bit hard to digest.

Living Day to Day

Simple things like threading new line onto a fish-hook or writing a short note for someone became major tasks. Typing on my computer was annoying, but kind of funny. I tell people my right hand can type seventy-five words a minute and my left hand thirty-five, you just can't tell what my right hand says.

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Driving

There are folks who believe I am at an increased risk when driving a vehicle due to having Parkinson's, especially in high volume traffic areas. Their theory is that due to loss of motor skills, my reaction time to any number of traffic scenarios could either cause an accident, or cause me to not be able to avoid an accident. In my heart, I understand their concerns and might be able to accept not driving in downtown Dallas or some other test track for maniac NASCAR wanna-be's. I may be as dangerous as that guy who just passed me while texting his soon-to-be widow or that lady who was putting eye-liner on while in the HVO (high vehicle occupancy) lane. But, I am far from being ready to relinquish my keys while driving in my rural Oklahoma countryside.

Hallucinations

For a couple of years, my neurologist asked me on every visit if I'd experienced any hallucinations. I always replied honestly that I had not. Then, they started. They normally appeared when I was tired and working or playing games on my computer. The figure in my hallucination would be right at the edge my peripheral vision, just out of full view. I could just see a being there. Don't know if they were male or female, adult or child. They were just there.

"There they are," I'd say to myself. I would slowly turn my head away from where they were, then when I'd think they weren't paying attention, I'd snap my head back as fast as I could, hoping to catch them. I never did. My experiences with hallucinations were mild and kind of amusing to me, but I have talked to many people who had all-together more sinister experiences with them. So, beware of these possibilities.

The Ugly

I am not a doctor, a pharmacist, or a psychiatrist; therefore, I am not going to attempt to give scientific support or documentation on the following subjects. These are my own observations feelings, experiences, and explanations I have personally lived through, and some of them are ugly. There is also information I have discovered on the internet. This may be the toughest chapter in this small book for me to write. For this book to have integrity, honesty, and truly help someone besides me; I have to be frank and honest with myself and the reader.

Drugs & Side Effects

There are demons that accompany most high-powered drugs that are taken to help control a medical or physical issue. These are called side effects. When the possible side effects are stated during a commercial for a drug, I often ask myself, "Why would someone take a drug with so many adverse side effects?" The answer is actually quite simple. The person taking the drug has had enough of the medical condition that they are affected by and are willing to take the chance, usually a small chance, of one or more of the negative side effects occurring to them. We must also realize that with the liability laws in the United States, drug manufacturers must list every possible side effect that has ever happened to a lab rat that was given one-hundred times the dosage you or I would ever take, to protect themselves legally.

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Unemployable

Believe it or not, I was one of those guys who loved his job. My thirty-one years as an independent claims adjuster took me all over the United States and introduced me to many interesting people, some of whom are now life-long friends. I witnessed or worked in the aftermath of many of the largest natural disasters in history. And, I actually helped people. My attitude was if you had the correct insurance coverage, then my job was to help you get all of the money required to repair your property back to pre-storm conditions.

I was diagnosed with Parkinson's disease in 1999 and continued to work until 2007. My loss of balance made it extremely dangerous to climb ladders, and that was a daily requirement. Also, the inability to legibly write due to my hand shaking made it very difficult to decipher even my own notes about the claim that had to be transferred to a computerized estimate later.

Disabled

One of the hardest things I have ever done was to accept the fact I needed to file for Social Security Disability. You are going to say, "Why would that be so hard?" It's true that I had paid into the program for years, but pride and self-respect was incorrectly telling my brain that I was a bum for not being able to care for my family.

Accepting that I had this incurable disease was one of the biggest hurdles I had. But when I did accept that fact and realized it was through no fault of my own, applying for assistance became less of a guilt trip. I now look at it as my retirement.

Addictions

Some of the drugs used to combat Parkinson's disease can lead to over-indulgence of certain activities, especially those that trigger exciting or compulsive stimuli to the brain. Two of these are gambling and sexual addictions.

Gambling

I have always enjoyed playing cards, especially blackjack or 21; and honestly, I believe I am pretty good at it. The issue is that I have gambled with money I couldn't afford to lose, and that is a problem.

Now, I play poker on-line only for free games. This may be more fun because now I can bet whatever amount I want, and there is no pain if I lose.

Sexual

I have looked at sexually explicit sites on the internet. Has it got me in trouble with my wonderful wife? The answer to that is yes. I have not always used good judgment about my sexual thoughts, fantasies, and actions.

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Costs of Medications

This is an easy topic to discuss because all I have to say is; the price of meds used to treat Parkinson's disease is outrageous. At a time my wife and I should be enjoying retirement and our grand-babies, she has to have a job just to keep health insurance to keep me in dope.

I used get angry with myself every morning my wife went to work while I stay at home. Then I started focusing on how lucky I was to have a life-long partner who was willing to go down this path with me. I discovered I enjoyed cooking. I could tolerate cleaning the house and other chores I had taken for granted. The only real issue is that most men (okay, me) don't take time to separate the colors from the whites.

The Good

I intentionally shuffled the order of the title so I could end my story with the positive effects Parkinson's disease has had on my life. By getting this terrible disease, I discovered my life did not end, but in many ways started renewed and fresh.

During one visit to my doctor, I saw a young girl with some neurologic disorder that made mine look pale. "What am I grieving about?" I asked myself. "Parkinson's ain't gonna kill me. I can't eat scrambled eggs with a fork, but who cares? It may make my life a bit more difficult, but right now the future still belongs to me."

So from that day forward, I started a new approach to Parkinson's. I decided that I was not going to learn to live with Parkinson's; it was going to learn to live with me. I am not naive enough to think I am going to outlive Parkinson's, but it is not going to control my life.

Humor

I started to make fun of the tremors. Even though I could not prevent the obvious symptoms, I could control the way I handled them in private and public. During one of my first visits with my neurologist, we had an interesting conversation that left my wife embarrassed and gave both my doctor and I a new understanding of each other and a sample of how I was going to deal with Parkinson's for the next several years.

My doctor was a really nice guy from a country in Africa, who, as hard as he tried, could not quite get his point translated to me, nor mine to him, due to language barriers. About the third or fourth visit, he asked if I had considered any of the more radical treatments involving Parkinson's.

"What have you got, Doc?"

"Well, one option is a new procedure called deep brain stimulation." He proceeded to tell me that two electrodes could be placed into my brain. That would stimulate the production of dopamine that, in turn, would eliminate or reduce my tremors and shaking.

"Two electrodes in my brain?" I certainly was not prepared at that time to consider brain surgery. The thought of it scared the heck out of me since I knew, or thought I knew how catastrophic a mistake could be. "Sorry Doc, you're going have to try something else."

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He then told me about another new procedure involving transplanting stem cells from a pig into my brain. If they bonded with my brain, dopamine would be produced.

“Brain cells from a pig in my brain?”

“Yes,” he said. “Pigs are the closest animal genetically to man, therefore, we can use their brain cells to insert into your brain. If they are not rejected, your brain will produce dopamine and you’ll stop shaking.”

What happened to man coming from monkeys, I thought to myself. I then asked the good doctor. “Would I be able to eat bacon without crying?”

With a puzzled expression he asked, “What?”

“Would I be able to walk past a mud puddle without rolling in it?”

He looked over at my wife who sat with her hands covering her face. She looked at me with that, “I’m going to kill you in your sleep” look and apologized to the doctor saying, “I’m sorry. He does this.”

“When I laugh, will I snort like a pig?”

I then asked him, “What if I became a Razorback fan?” which to any true Oklahoma boy would be an unforgivable sin?

At this point he started catching on, but he appeared to be very cautious with his choice of words from there on. We decided to make surgery a last resort option. Soon thereafter, he left my small town and went into research where I am sure he is now making an impact on finding a cure for all of us.

I began using humor more and more to fight my battle with Parkinson’s disease. After I finished throwing tantrums, stomping around the house, blaming everyone and everything on why I had been chosen to receive this disease; I finally had to accept the fact that I did have Parkinson’s. This was pretty tough to do without crying or cussing God, but eventually I accepted the fact that I did have Parkinson’s and would for the rest of my life.

While I do not want to deny or ignore the effects of Parkinson’s disease on one’s body and mental status, those of us who have Parkinson’s disease must learn to cope with them in order to live life with as much enjoyment as we can.

Creativeness

Five years after I was diagnosed with Parkinson’s disease, the strangest thing happened to me. At the time my family and I owned and operated a horse riding stable in a state park. On a Wednesday afternoon during spring break 2004, I took two ladies, who each had two kids, on an hour-long ride.

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When we returned to the barn, I had this strong urge to write a poem about them. I need to let you know I was not a poet, didn't even like poetry. I just barely passed high-school English. But there I was sitting on the steps of my horse trailer, and I wrote this beautiful poem about these two ladies and the tragedy of divorce.

And suddenly the flood gates opened. Since then, I have written and published two books of poetry and short stories. This gift has been one of the most rewarding experiences of my life. Several of my rhymes are funny and silly; but many are serious and have drawn very heartfelt responses from people whose lives they have touched. I honestly believe God gave me the gift of poetry to help me and other people deal with this disease.

Relationships

I have been told, and according to my experience I believe it to be true, that when one is faced with a life challenging situation that you become more aware of the personal relationships in your life. It may have something to do with having more available time, since I can no longer participate in my chosen profession, but it is more likely to be the result (as in my case) that I realized for the first time that I will not live forever.

When that reality finally slapped me in the face, I became very aware that time is precious, especially time spent with my children and grandchildren. I always tried to be a good father when I was on the road with my career, but I also knew I had missed many of the important events in my children's lives. Having Parkinson's disease has opened my eyes to what is really important in this world and that's relationships. Relationships with family, friends, and God are what truly make this short time on earth worthwhile. Take the time to be with the one's you care deeply about.

Support Groups

Find a Parkinson's disease support group in your community. If you are a new member of our family you can find out first-hand what experiences you can expect in the future. If you are an older member, you can help guide people like yourself and me on this sometimes difficult and bewildering journey that we have no choice but to travel. Be sure to check out websites like the National Parkinson's Foundation or the Michael J. Fox Foundation. They can provide you with a wealth of information about current events and/or treatments for Parkinson's

Doctors & Medications

In the short time since I was introduced to the world of Parkinson's disease there have already been major scientific and medical breakthroughs including stem cell research, deep brain stimulation, and new drugs. And researchers are coming up with something new almost every day it seems.

Doctors are a very important part of our journey. I am lucky to have one of the best in Wayne Wasemiller M.D. He listens to me. He explains what is happening to my body in a way I can understand. He keeps me up to date on new developments for Parkinson's disease. He is an invaluable part of my physical as well as mental battle against the disease.

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Surgery

There are advancements being made almost daily in the way of surgery. Deep Brain Stimulation (DBS) is an incredibly exciting treatment which has given many Parkinson's patients their lives back. Look it up on YouTube and you will be amazed. Here is an uneducated scenario of how it works. Doctors insert two tiny electrodes in the patient's brain, then run tiny jumper-cables under the skin to the shoulder where they install a device that sends electrical impulses to the brain and SHA-ZAM!, the patient all but stops shaking.

Summary

What I hope my little booklet does is give new members of the Parkinson's disease family hope and knowledge that this disease can be dealt with successfully. It is not the end of the world. Life can and will go on. We must not be afraid to continue to live life with every ounce of enthusiasm in our souls. Accept the fact that you now have a life-long companion and although you don't like him, you can still enjoy more good than bad experiences. Time is precious; don't waste it on giving up on life. God gave us this life to enjoy. Make the best out of a bad deal and make every day count.

★★★

Kenny exhibits all of those qualities which I find to be of immense value in my patients—courage, honesty, and humor. The challenges of facing any chronic illness, especially Parkinson's Disease, can be devastating. Through his anecdotes, Kenny reveals his ability to meet the challenge with grace and humor.
Wayne L. Wasemiller, M.D.

For information on how to order copies of this booklet,
or if you are interested in having Kenny speak at an event,
contact him by email:
kenghipps@aol.com