

LIVING WITH PARKINSON'S.

By Rhoda Foust. 11/2016

This is a long post. If you are not suffering any kind of pain, have no health problems, or know of anyone who has, you may not be interested in reading this article, nor sharing it. You might even think of it as a waste of time. This is my way of visiting the afflicted, suffering and lonely, sharing some time and love, with those who are interested. This story is for those who have not had a voice for them, to tell what others do not understand about their problems. I understand, because I am wearing their shoes.

I have Parkinson's disease. I have had Parkinson's for about four years. I have problems writing. I make lots of typing mistakes because I am unable to get my fingers, feet, arms, and vocal cords to do what my brain tells them to do. If not for my editing program I could not be writing this now. Parkinson's is often associated with Alzheimer's but there is a difference in that the latter is much more devastating than Parkinson's. We, who have Parkinson's, are very blessed that our brains are still operating, but not as well as we want. However, we are told if we live with Parkinson's long enough it may eventually become Dementia.

Parkinson's is not something that is passed on by contact, as a disease can be. As far as I know no one in my family has ever had this condition. My Mother lived for 97 years and was healthy most of her life. My Father lived to be 90 and died with a condition he developed shortly before his death, diagnosed as Dementia.

In my search for a reason I have tried a special Parkinson's boxing program, and special exercising programs. I saw different specialists, two acupuncturists, read many articles, medical posts, attended seminars by professionals, who use long knowledgeable words and descriptions about this condition they call "Parkinson's disease". Since I don't understand all of their medical language, as I suspect many of you don't either, I will explain in every day English what I am experiencing.

I will touch on some of my previous life so the reader will know a little about my background, to set a foundation for the condition. It would require too much work, time, and memory to fill in just a small part of my two totally separate lives. This story's primary purpose is to show when, where, and how much of it started.

I, personally, never even heard of the word "Parkinson's" until I was in my 70s. I have had my share of health problems, off and on, while struggling with the normal problems during six pregnancies, being married 27 years, the first time, to an alcoholic husband.

When I was 14 years old my parents allowed me to marry a 20 year old neighbor who looked like a handsome six foot tall man, but actually was an irresponsible boy in a man's body. He died in the hospital from alcoholism in his early sixties. Being of small frame, weight, and height, I was never physically strong, but from an early age I loved to read, and draw. Having gone only to the eighth grade in school, I determined to better myself. After a few years of marriage I started going to night school to finish my

education. My hunger for learning was stronger than ever. I sold some of my art, and built a business tinting pictures. My hunger to learn led me to searching for my place in God's plan. I had attended Business College by the time I met my second husband, and finished shortly after we were married in 1977.

I came into a second marriage with three grown married children, and a ten year old. I had monthly cramps, back problems, migraine headaches, and various other problems, etc. In spite of all this I was one of the happiest people on earth. I was blessed to marry a wonderful husband who loved me who had all the character traits I had longed for in a husband, most of my life.

We both had children by first marriages, but resolved we would never allow problems of combining two families to damage our personal relationship, and we never have. Working together, while sharing the same faith, has had a huge influence in our lives. We were determined to get it right this time. I had back surgery and had that problem fixed. We were very involved in church activity, made new friends, finished building the house he had started, but unfinished. We eventually bought our first rental house, rented it to a couple who (39 years ago) are still renting from us.

Since that time we have acquired several rentals, combined with employment funds, which allowed us to spend ten winters in Florida. Our seven children have all "flew the coop", most are grandparents themselves, making us great-great grand parents.

Now I will write what it was and is like living with Parkinson's, and how it begins, from my point of view. We had bought a small winter house in Florida, with the intention to add onto it, improving its size and comfort. In 2011, while helping my husband lay tile on the new addition my right ankle and leg became very swollen and so painful I was unable to put any weight on it.

My first experience with a medical condition in Florida was pitiful. I could not get in to see a doctor for several days, so I visited a clinic. They did not have the proper machine they said they needed, so they sent me to the local hospital. They, too, did not have the proper machine, and made an appointment for me to see a specialist. By the time I got to see the specialist, over two weeks later, he could not find any kind of problem. No swelling or pain. That was all forgotten until I began to feel very weak and lifeless a few weeks later. Thinking I had contracted a virus of sorts, I dismissed it several weeks later, after feeling improved.

I had a habit of gathering soiled laundry in a basket. Instead of carrying it to the washer I would push it with my foot, across the floor to the laundry room. This particular morning was a beautiful sunny day. I was looking forward to hanging clothes out on a clothesline to dry. So here I go kicking my basket of soiled laundry across the floor, feeling no pain.

What happened in the next few minutes resulted in fourteen days in the local hospital. Even after all these years it is almost impossible for me to find words to describe this experience. A sudden awareness, that I was very near death, hit me like a strong gust of wind. I instantly dropped to the nearest chair, trying to get my breath. The chair would not do, so I made it to the couch. My husband was nearby, he sensed something was very wrong. "What's the matter" he asked, "Are you alright?" Unable to speak I shook my

head. "Do you want me to take you to the doctor?" Again I shook my head. "Should I take you to the hospital?" When I shook my head a third time, he picked up the phone and called for an ambulance. While waiting my husband kneeled beside me and prayed. He followed the ambulance to the hospital. After we arrived I was asked, "Do you smoke, drink, have any disease, been in an accident, etc?" I shook my head to all. After having us sign release papers (in case I didn't make it), they explained the procedure to save my life was a onetime remedy. After ex-rays and examination we were told I had massive blood clots on both lungs. The procedure was too dangerous to ever have it done again. But if it was not done, my problem was so serious I would probable die.

Those fourteen days, unable to raise my head for over a week, with a big needle secured into my neck, an i.v. in my arm, and being pumped with some kind of pain killers, was the worst experience I had ever experienced.

After being neglected for two weeks I was released. I had lost ten pounds, and gradually lost fifteen more within three months of recuperating. When we got back to Indiana, my daughter took one look at me and explained, "Wow! Mom, where is the rest of you?" In four months I had gone from 150 to 125 pounds.

The next thing that happened, still in Florida, the following winter, I developed a painful frozen shoulder. A trip to two doctors revealed I had bone spurs that were destroying tendons, in my right shoulder. Being right handed that was bad news. If I didn't have surgery my right arm would become useless in time. After surgery my arm begin shaking so badly I couldn't even write my name. After going to rehab within time the tremors slowed down. It was several months, after surgery, after returning to Indiana, I gradually began writing by hand, and using the computer again. By 2014 I did a lot of research, convinced I had the symptoms of Parkinson's.

Since 2012 lots of other events in our life caused a lot of stress for both of us: breakins, several very close family deaths, husband's prostate cancer ordeal, and my trembling gradually became noticeable. In 2015 I began having severe pain in my other shoulder. Dr said I have a tear in it, probably due to excessive use while protecting the right shoulder. I am told my bones are too thin to support an operation. Finally after going to three doctors I am also diagnosed with Parkinson's.

This spring, of 2016, one of my doctors suggested I check out a program called "Boxing With Parkinson's". He had heard this program was very successful with some. I asked how this would affect my shoulders. He said they would possibly work around that problem. Well, they tried, but after two months, going twice a week, they gave up, and so did I. The patients were mostly men, in a group of about twenty senior citizens. While there I got acquainted with several patients that attended primarily because they enjoyed friendships, something to do, and the exercise of boxing. It was fun for some, none had shoulder problems. I observed there were many varieties and conditions of individual patients. Some had progressed further than others. I was able to walk much better and longer, than most, and my voice was stronger than those who had advanced more than me. Others could respond much better with boxing, catching ball, games, and things impossible for me to do because of my shoulders. A couple had troubles standing, having halters to keep them from falling. Others had bent necks so they could only look down, unable to straighten up. Occasionally someone would show up, having just recently been released from

the hospital, usually for something other than Parkinson's.

The next thing I tried was a shoulder rehab program, in addition to the two months I had taken while in Florida, which seemed to help my shoulders for a short while. These trips were confining, time consuming, not to mention expensive, without any substantial improvement. I came home and continued doing some prescribed exercising on my own.

Well, "what is Parkinson's disease anyway?", one may ask. As the result of my investigation, and my own personal experience, I have come to understand anyone of middle, any to old age, is likely to get Parkinson's. I do not think it is a "disease", but a "condition" of certain stresses that occur to a brain. It results from damaged nerves to the brain, occurring from overload stress. That is why I started out by giving a preview of my earlier stressful experiences which may have, over time, triggered Parkinson's in my brain. Experimenting is continuing without any proven cure, or proof of why it continues to affect thousands of older people yearly. My conclusions differ somewhat from Ted Noals since I am experiencing the condition myself. He, on the other hand, is taking "specialists" opinions, which may or may not be accurate.

Now back to what my life is like living with Parkinson's. It started out very slow and has become more aggressive recently, during this year of 2016. Even though I suspected I would progress with Parkinson's several months before I was unable to do regular, normal activity, I had no way of knowing how fast it would progress in the following six months. Numbered, gradual to faster progression is as shown below.

- 1) First stage: I began noticing an increase in mild trembling, still able to write rather well.
- 2) Later, I began having mild balancing problems. My stance became slightly noticeable.
- 3) During spring: I had a one time experience while cleaning weeds out of two flower planters, of blacking out, falling face down in the dirt for a few minutes, not knowing what, where, or why it had happened for half an hour. This has not happened again, so far.
- 4) My voice has become weaker, making it difficult to get clear sounding words out. My husband has the same problem and he does not have Parkinson's.
- 5) Next, I began to shuffle slightly when walking. My back started to slump noticeably. Also hard to turn my head in either direction.
- 6) I started losing my taste for foods I usually loved. As a result I began losing weight again. I weighed 120 lbs. by midsummer.

When doctors finally agreed that I did have Parkinson's I was prescribed L-Dopa. It only worked part time. True to its name it made me feel really dippy. By mid summer of 2016 I accepted this unhappy fact, trying other means of treatment while recognizing near weekly changes taking place, in my brain and in my body.

- 7) My fingers not only trembled worse, but began to refuse to obey my brain constantly. I am now unable to button or unbutton small buttons, or perform any tedious activities. I can no longer use my almost new sewing machine.
- 8) Both shoulders became very touchy and painful when used in certain ways, or too often. I require help now bathing and dressing myself.

9) Without using shoulders, getting in and out of bed by myself is very difficult, sometimes impossible. My husband, being the busy man that he is, is not always available, so I have learned different methods of solving my unexpected problems, trying not to make unnecessary demands on him.

10) L-Dopa meds prescribed make me dizzy and sluggish, making movement much slower. I have less to no motivation. I have to force myself to do minor activities that I once loved to do. We take lots of natural vitamins hoping they will help, and I have dropped most of the prescriptions.

11) One day I started to eat, found it too difficult to spoon the food into my mouth, and could not stop crying. We worked through that, though. Fingers work better for most foods. My ambitions have returned since I stopped taking blood thinners, and the other meds, but using my arms makes me so weak every small chore exhausts me.

12) I decided months ago I was unsafe driving. Since my responses are too slow, I no longer drive. This was hard to give up. I have a stiff neck that keeps me from turning my head from side to side. I also have trouble keeping my back straight enough to see forward.

13) I have softer, brittle teeth; I lost one this year. My dentist said my nerves are dying inside my gums causing the teeth to crumble. He was hesitating to do anything at present. I keep wondering what to do about them.

14) I get very tired for no reason; often near exhaustion. It is much harder to stand in one position five minutes than to walk in ten. I tend to fall backward if I don't position my feet just right. So far, so good.

15) I am unable to reach my feet to trim toe nails, or pull on socks or shoes. It is very difficult to care for finger nails, comb my hair, or apply makeup. Sometimes I can, sometimes I can't. I have good days and bad days, but mostly not so good as time goes by.

16) I strangle on liquid very often, and have to eat very cautiously to avoid choking. I tend to want sweet foods, so I avoid raw sugar. I seldom can eat out because salt makes my feet and ankles swell. I know I don't drink enough water, so that is a constant struggle.

17. At present I am.....?? I am too weak to open our refrigerator door, to lift a gallon jug of milk, or unscrew a new bottle cap, to lift my laptop. I am unable to dress myself without help, or reach or rehang clothes, since I have shrunk three inches in the last four years. I am still losing weight, down to 115 lbs. now.

18) I never get thirsty, so I have to keep reminding myself to drink more water to keep from getting dehydrated. My favorite drink is milk. I love butter milk.

19) Recently I have noticed when trying to rest I become unusually tired. I have come to the conclusion by noticing an arm, leg, or body muscle tensioning triggers un-controllable trembling and tiredness. Now I consciously detect limb tenses mostly in my legs and hips. I practice mentally controlling one at a time. It sounds weird but it is the only way I can relax enough to get comfortable...

As a side comment: It is being said that Hillary Clinton has had Parkinson's since 2008. From my experience, and others I have met, compared to hers, she shows very little signs that this is true. That is not to say I think she is the better choice for our president. It is easy to make false assumptions by watching flashing short skits of facial expressions, or comments. Having Parkinson's for three or four years would show in the average person's speech. We all, who have Parkinson's, have a common weakening change in our speech. Most have a memory problem that prevents us from remembering words in the middle of sentences during normal conversation. We also find we are not

capable of doing normal activities because of not thinking ahead. Most senior citizens normally have some aging aches and pains, plus a host of fixable medical problems like hearing, eye sight, decaying teeth, etc that can be fixed. The difference in normal ageing and Parkinson's is until a cure is found it will only get worse, and no one knows how to fix it. It causes us to think differently about many things.

Just recently I was not thinking, I stooped down to organize some papers on a low shelf. When I tried to stand up my knees buckled. I was unable to stand. I knew my husband would not hear me call, he was outside mowing. I had to get pressure off my knees, so I tried to pull up on a nearby rolling desk chair. That didn't work, so I had no choice but to force my painful shoulders to lift my body to a crawling position where I could reach a better place to pull up. Ten minutes later I made it up, another new lesson well learned.

I might add: I have never had long coughing spells, head bobbing, or head shaking, and I haven't vomited in years. In all past four years I only passed out that one time, which happened this year.

I am concerned that my poor husband is so overworked; he is beginning to feel stressed. In addition to his normal work he is also doing everything I used to do outside and inside. He takes care of me, the garden, yard, wood cutting for winter heat, and demands of rental properties, plus grocery shopping, helping others when in need, etc. He has a few health problems, also, but refuses to admit he is 77, not still 50. Some nights he actually cries with leg cramps.

The above are the negative list. In spite of all these things there are some very positive things that I am so-o-o thankful for. Most of my pain is from exhaustion, which usually stops after I relax in a comfortable position.

I have occasional minor aches and pains, normal for an eighty-two year old. Once I get comfortable I feel no pain, and I sleep very well. Even though I tire easily I can walk short walks without a walker. I do use one for balance. If we take longer trips, my husband pushes me in a wheel chair. I am able to read, and type, with the help of my spell checker, I do amazing well, considering. In addition to that I have a wonderful, loving, care giver, which has devoted his life to me.

Recently, our visiting insurance doctor informed us, after two hours of tests and questions, that I was the healthiest person with Parkinson's he has ever known. He assured me that every problem I have, aside from my shoulders, is strictly the

Symptoms of Parkinson's. He also offered, because of that, I was a perfect candidate for participating in the experimental studies being done with cell implants to the brain in the search of finding a cure. He could tell that was not something that excited me, so he left me a phone number to call if I should consider it.

But most of all I thank God He has let me live 82 years, let me know His undying love for me, and everyone, who choose (eternal) life according to His instructions. I could write another story about all the prayers we have had, and are still having, answered. We have had many healings and miracles preformed in our lives. Our Heavenly Father has guided us in making many decisions that have been wonderful

blessings in numerous ways. Most know of all the many bible studies we have shared with so many loving people around the world. We have been blessed with a large family, many friends, our web page, (where we invite anyone to visit at "www.foust.info") and lots more. These are all wonderful gifts from our Father. I have already received more than my share of love. We are so blessed for the sacrifice our older brother, Jesus, made that opened up the gift of eternal life to us all.

I sincerely thank all of you who have offered up prayers for my healing, but it may just be my time to go, you know? Do you know Jesus said death is better than this life, and death is a blessing to the righteous, when we will rest from our works? Even knowing that is a wonderful blessing, too. Paul said we can't even imagine what a wonderful future God has prepared for those who love Him. He even tells us how He wants to be loved, too. It is not hard to do, either. To know Him is to love Him, who first loved us.

THE HAPPINESS BANK

A friend shared this with me. I thought it was a nice way to end this topic.

The 92-year-old, petite, well-poised and proud lady, who is fully dressed each morning by eight o'clock, with her hair fashionably coifed and makeup perfectly applied, even though she is legally blind, moved to a nursing home today.

Her husband of 70 years recently passed away, making the move necessary. After many hours of waiting patiently in the lobby of the nursing home, she smiled sweetly when told her room was ready.

As she maneuvered her walker to the elevator, I provided a visual description of her tiny room, including the eyelet sheets that had been hung on her window.

"I love it," she stated with the enthusiasm of an eight-year-old having just been presented with a new puppy.

"Mrs. Jones, you haven't seen the room; just wait."

"That doesn't have anything to do with it," she replied. "Happiness is something you decide on ahead of time. Whether I like my room or not doesn't depend on how the furniture is arranged.. it's how I arrange my mind.

I already decided to love it. It's a decision I make every morning when I wake up. I have a choice; I can spend the day in bed recounting the difficulty I have with the parts of my body that no longer work, or get out of bed and be thankful for the ones that do.

Each day is a gift, and as long as my eyes open I'll focus on the new day and all the happy memories I've stored away just for this time in my life.

Old age is like a bank account: you withdraw from what you've put in.

So my advice to you would be to deposit a lot of happiness in the bank account of memories. Thank you all for your part in filling my Memory bank. I am still depositing." I say AMEN!!