

W. Stanton Smith
Rosalind Lewis-Smith

Still
Waving
Goodbye to
Parkinson's
Disease

a journey of hope



Still Waving Goodbye to Parkinson's Disease: a journey of hope

W. Stanton Smith with Rosalind Lewis-Smith

Copyright © 2020 W. Stanton Smith, LLC

ISBN: 1986065812
ISBN- 13: 978-1986065818

All rights reserved.

Except as permitted under the U.S. Copyright Act of 1976, no portion of this book may be reproduced in any form or by any means, including electronically, without express written permission from W. Stanton Smith, LLC.

A previous version of this work, *Waving Goodbye to Parkinson's Disease: A Journey of Hope*, was published in 2012. It is no longer available.

This book can be downloaded *free of charge*. In lieu of book payment, please be generous and make a donation to the Greenville Area Parkinson Society.

www.gapsonline.org

CONTENTS

How To Read This Edition

Acknowledgements

Introduction 7

Chapter 1: My PD Timeline – the first 6 years 8

Chapter 2: Catching the LifeWaves® - the second 6 years 12

Chapter 3: Catching the LifeWaves® - the third 6 years and beyond 16

Chapter 4: A Wife's Perspective as Care Partner 21

Chapter 5: Eyewitnesses: What to Expect from Others Who Observe You 26

Chapter 6: A Word of Encouragement 31

Appendix 38

About the Authors 49

How to read this edition:

This update builds on an original publication in 2012. The Acknowledgements have been amended to reflect additional help we've received for this update. An entirely new chapter 3 has been added to reflect on the period since the original book was published. The new chapter 4 has an addendum from my wife. Each of the Appendix items has been updated and a new item added regarding non-Traditional therapies such as Kinesiology and AIS.

Acknowledgements

My sole purpose in writing this book with my wife, Roz, is to give a realistic account of: 1) what has transpired since being diagnosed as a Person with Parkinson's (PWP); 2) the steps I've taken to restore my health to the greatest extent possible; and 3) my wife's role as Care Partner (CP) in this process.

I am grateful to the many people who have helped me throughout my life. However, I want to especially acknowledge my late mentor, Dr. Herry O. Teltscher. He was instrumental in providing the tools to change the way I looked at the world and gave me a fighting chance to grapple with PD. Words fail to express how much I appreciate the positive role Herry played in my life. In addition, I want to gratefully acknowledge Dr. Irving Dardik, the inventor of LifeWaves, and my coach, for his help and selfless service to others. He continues to coach me with enthusiasm and optimism.

As you will see in this book, I am blessed with an exceptional wife who has always been at my side and shown resilience and loyalty that goes far beyond the call of duty. She is the definition of a life partner and best friend. I am grateful to her beyond words.

I have been given the gift of many concerned and loving friends and colleagues who have accompanied me on my PD journey. It is not feasible to name them all, but you know who you are, and I am very grateful to you.

Many thanks to Dominic Conde of Oleonmedia for his cover design ideas and skills in laying out the original book. Regarding this update, my thanks to Kate Weaver for her editing expertise, and to Glenn Weaver for his new cover design, formatting expertise, and in helping me navigate the process of creating this new edition.

Another person deserving thanks is Dr. Mary Hughes, one-time head of the Department of Neurology for the Greenville Health System (GHS), now in private practice in Greenville. She was most supportive of the efforts of the Parkinson's Support Group of the Upstate (PSGOTU), which became the Greenville Area Parkinson Society, and my writing this book. I will add that GHS (now Prisma

Health) is an impressive organization of people dedicated to serving the Greenville, SC community in a caring manner. It is a privilege to work with Dr. Hughes' successor, Dr. Fredy Revilla and his talented, caring staff.

Additional gratitude goes to the leadership team at Deloitte LLP from which I retired as a principal in 2009. This team was supportive and accommodated my situation creatively. I am very aware of how unusual this type of support is nowadays in business. Special thanks to true partners of mine: Sharon Allen, Jerry Leamon, Barry Salzberg, and Jim Wall for their unwavering and essential support.

Finally...

Over the past 8 years I have been blessed with new friends who have entered my life and made a huge positive difference. Pat Sullivan, co-founder with me of the Greenville Area Parkinson Society (GAPS) has shown me what true partnership is as we build GAPS. Manisay Gabbard, co-owner of MG's Grand Day Spa has applied her superior knowledge and skilled application of AIS principles in a manner which most probably saved my life. I appreciate Dr. Fredy Revilla. His quick and effective actions in dealing with the rare and serious side-effects of an inadvertent and extended overdose of a prescription med probably saved my life, as well. In addition, he has led the support of GAPS by GHS, now Prisma Health. Laryn Weaver, the Executive Director of GAPS, Kamber Parker, Associate Director, and Glenn Weaver, Creative/Communications Director, have both brought a burning concern for PWPs and CPs to their respective roles. Consequently, GAPS is experiencing strong growth.

W. Stanton Smith - January 2012 (updated January 15, 2020)

INTRODUCTION

Does the world need another book by someone diagnosed with Parkinson's Disease? What is there left to be said? The answers: *yes, and plenty.*

I was diagnosed with Parkinson's Disease (PD) in November 1999, only a few days short of my 51st birthday. For the first six years my condition worsened significantly. For the last 14 years my condition has improved dramatically (with, of course, the usual ups and downs). How did this happen? Can People With Parkinson's (PWP), their care partners (CP), friends and relatives, and other interested parties take away something helpful from my experience and that of my wife? I believe they can.

I intend this book to be a quick read that will motivate my fellow PWP and their CP, as well as friends and families. By telling my story as a PWP and my wife telling hers as a CP, we sincerely hope that you will not only feel uplifted but learn something new that will help you.

Most importantly, we want you to:

- Realize that you are not alone in this struggle with PD.
- Be encouraged that a fellow PWP has found a way to make some progress against PD and that there is something you can do.
- Be motivated to treat exercise ~~as just~~ as importantly as taking your medications daily and on time.

I also hope that health care professionals will read this and increase their understanding of how better to care for PWP and CP.

W. Stanton Smith
January 15, 2020

CHAPTER 1: MY PD TIMELINE – THE FIRST 6 YEARS

It was the fall of 1999. I was looking out into a beautiful forest full of color from an office in suburban Connecticut. I'd changed jobs about 18 months before and was settling into this new opportunity. But something seemed seriously amiss. I was "stiff as a board," dragging my right leg, and beginning to shuffle when I walked. My leg muscles, especially the quadriceps and hamstrings were so tight and often my equilibrium was so uncertain that when I stood up to leave my office, I was not steady on my feet. I hoped that no one would see me struggling.

I dreaded leaving the confines of my office. Once I started moving, I thought that I looked and felt like the 1,000-year-old man. But some days were better than others, so I tried to put it out of my mind. I told myself "just focus on doing this big job," which I held as a principal in a global professional services firm.

When I got home, I was so exhausted that I often had to take a nap for up to an hour before I could even eat dinner. My wife, Roz, expressed concern about this seemingly endless fatigue. Finally, the combination of exhaustion, shuffling around and putting my head in the sand was too much for Roz. She obtained a referral for me to see a local neurologist around my 51st birthday in December 1999. It didn't take long for him to give a tentative diagnosis of Parkinson's Disease (PD) and prescribe some medication. I left the office unable to accept the diagnosis and completely in denial.

Determination is admirable but putting blinders on and not paying attention to reality is harmful to yourself and others. I learned this the hard way by trying to fake it at work. In my denial I thought that no one would pick up on my preoccupied manner, the shuffling, or the stiffness, or the increasing instances of briefly falling asleep during meetings. This fantasy world came crashing down at a meeting in Orlando, Florida in August 2000 about nine months after the initial diagnosis.

It was time for the annual performance review of partners, principals and

directors. Delivering the review was one of the two partners instrumental in hiring me. The review began with the words, "You're going to have trouble hearing this." By the end of the discussion it was clear that I'd fooled only myself.

Very much to the credit of the firm's leadership, a real effort was made to find a job I could do effectively. More importantly they were able to refer me to a highly respected neurologist in New York City. I recognize that many businesses would not have accommodated me. I will always be grateful for this support.

Once I was properly medicated and began acknowledging publicly that I had PD and that I was a Person with Parkinson's (PWP), life proceeded more smoothly.

I still worked long hours. Therefore, I exercised after 9 pm in the evening usually with a long walk around the neighborhood. I even started to jog. Neighbors were inspired by my devotion to walking regardless of weather.

During this 18-month period, I began to feel as good as I had before. Walking alone and getting a little extra rest with a job requiring less travel all seemed to be adding up to a reasonable accommodation for PD, at least in my mind. In fact, I began to view PD as an annoyance and began to believe that I'd dodged a bullet. My tremors, while evident, were manageable, my stamina was improving with exercise, and my outlook was more positive than at the beginning of my diagnosis. I attribute this positive outlook to my meditation routine which calmed me and granted me a more balanced frame of mind, as well as the unswerving support of my wife.

A False Spring

This 18-month period proved to be a false spring. My neurologist had alerted me to the tenuous nature of my improved condition, but I didn't focus on this cautionary counsel at the time. What he said was that any significant health related crisis could weaken me considerably and that it would be difficult for me to recover fully. He added that two such events might be too much for me or anyone to handle. I asked for clarification on "too much...to handle". His answer: "there would be a high probability of death." I was not reassured by this, but I appreciated his candor.

In May 2002 the nature of this false spring became evident as a growth appeared on my neck. It grew into the size of a tennis ball. Thanks to the quick action of both my general practitioner and ENT, I was hospitalized and operated on by an extraordinary surgeon. I say extraordinary because what started as a 30-minute procedure to drain an abscess became a 90-minute race to "vacuum up" an infection that had spread just short of my brain and heart. The eradication of the infection required an 8 eight day stay in the hospital during which my PD meds stopped working completely. I would lie in bed shaking almost without respite with an IV in my arm, and wondering what the next shoe to drop would be.

I continued working from my bed and then my home office. Due to an excellent staff reporting to me and support from Deloitte's leadership, as mentioned earlier, I was able to stay productive professionally. Thankfully, my mental powers and stamina were not materially affected, allowing me to work, albeit more often from home than before.

But there was one major consequence of this hospitalization. I could no longer walk any distance at all. My legs felt weak and my gait became halting. I started using a walker at home and a cane when I was out in public.

My motor skills began a noticeable decline. It took longer and longer to get dressed, to take a shower, to do anything that was physical. I could do little to help with household chores as I couldn't stand for very long and was unsteady on my feet.

Another False Spring

I now had descended to a lower plateau of life quality which lasted about two years. My frame of mind began to decrease in positivity. My wife had to increasingly assume responsibilities for our life together. This was a strain for her that I could do little to ameliorate. This powerlessness to do my part preyed on my mind.

I threw myself into my work with what energy I had, leaving little for anything else. Professional success was at least keeping my focus on the positive aspects of life and diverting me from self-pity and general negativity which can so often afflict those of us with PD.

On the brighter side, my physical condition had improved enough to travel with Roz to Venice for an international conference in the summer of 2004. I made a presentation about an innovative career guidance program which I'd played a major role in designing and implementing since 2002. I was feeling that I'd attained some modus vivendi with PD. This "truce" with PD would prove to be yet another false spring.

Yet Another False Spring

About four months later in November 2004, my neurologist changed my primary medication. The medication I had been taking for the last 4+years had caused heart problems in enough cases to merit concern.

The transition from the old to the new medication was disastrous for my health. My reaction to the new drug made me bed ridden for about eight weeks. I could not get out of bed without assistance.

With a full-blown crisis on our hands, my wife set about to get a neurologist closer to where we lived in Scarsdale, New York. This turned out to be a good move as I was evaluated as to be under-medicated and in need of physical therapy.

Nonetheless, I was fast becoming an invalid, even though I was still able to

do work from home. Thanks to the help of a dedicated fitness trainer who visited me and stretched me once a day for nearly 2 months and a chiropractor who visited a couple of times a week to adjust me, and the services of my Kinesiologist, I was able to very occasionally go to the office both in Manhattan and suburban Connecticut. However, the handwriting was on the wall. We had to prepare for me going on disability and doing so in a lower cost location.

Serendipity

It was June 2005 when a serendipitous event occurred. Roz and I had scheduled a dinner in Manhattan with my nineteen-year-old godson and a business colleague and her two college age children.

I was having a bad day, feeling very stiff and shaking continually. With my discomfort obvious to all at the table, my colleague's daughter asked her mother if her uncle could help me. It turned out that her uncle was Dr. Irv Dardik, a respected cardio-vascular surgeon. One of his research interests was a kind of interval training exercise program, which had been of value not just to people with optimal health but also individuals with diabetes, MS, and even cancer. Although she believed the possibility to be a long shot, my colleague agreed to ask her brother-in-law if he'd be willing to take on my case. Meanwhile, Roz and I were looking at houses in the vicinity of Greenville, SC. Any house that we liked was measured for a wheel chair. The episode with the medication change and adverse reaction had eroded nearly all my physical and psychological reserves. I was sinking fast.

As my condition seemed to worsen almost by the day, the words of my first neurologist came back to me. The episode with the new medication had constituted the second major health crisis from which it would be very difficult to recover. In other words, this was strike two, and for all I knew strike three was on its way, and I was standing in the batter's box with no bat.

Meanwhile, it was becoming difficult for me to get through meetings without nodding off or losing concentration. I began to wonder if I could do my professional work much longer even with the first-rate staff that I had to support me.

Neither my wife nor I were happy about moving away from our supportive circle of friends, but we felt we had no choice but to face the inevitable. For the first time, having run out of options and now facing the real possibility of succumbing to PD, I began to feel angry at with my condition. While I was open to talking to Neale's brother-in-law, I was skeptical about there being anything practical that could be done to halt my evident decline much less improve my prospects for a better quality of life.

CHAPTER 2: CATCHING THE LIFEWAVES® - THE SECOND SIX YEARS

On a humid summer day in 2005, Roz and I had our first meeting with Dr. Irv Dardik. Irv explained the theory behind what had become “LifeWaves® Cycles Exercise® Program.” Interestingly, Irv spent most of his time talking to Roz. He was assessing whether Roz would be supportive of devoting time to the program. His experience told him that without spousal support there was little hope that I would stick with the program.

Dr. Dardik explained that his original interest in interval training started when he was co-chair of the U.S. Olympic medical committee during the 1970s and the 1980s. It seems that many athletes became ill after ending their Olympic training and competitive regimens. He concluded that we were very good at training peak performance, but we largely ignored the body’s need to recover after challenging it to perform. Therefore, he developed the concept behind the LifeWaves®Cycles Exercise® Program to emphasize a balanced approach to exercise.

Dr. Dardik retired several years ago. With his retirement, this program is regrettably no longer available to the public. Consequently I have not included any program details in this revised edition. I still work with him on an informal basis as he wants to continue to track my long-term progress.

I continue to attribute a good deal of my good quality of life after 20 years of PD to Dr. Dardik and LifeWaves®. To recap, here is the timeline of improvement from my starting with the program in August 2005. Nearing the end of year 6 of PD diagnosis (summer of 2005), I could no longer:

- Tie my shoes.
- Tie a neck tie.
- Button a shirt.
- Reach for something without fear of falling forward.
- Walk without a walker or cane.
- Walk across a room without extreme concentration in order not to fall.

- Run or jog.
- Walk any distance without fatigue or danger of falling.
- Dress myself without major assistance.
- Stand in the shower.
- Stand long enough to put dishes in the dishwasher or wash/dry by hand.
- Stand at a kitchen counter or at a bathroom sink without holding onto the counter or sink top “for dear life”.
- Write “large” or write legibly regardless of the size of the letters.
- Stand or sit with proper posture.
- Execute basic household chores like changing a light bulb or standing on a ladder.
- Concentrate for long periods of time.
- Easily make expressions with my face, due to having the “Parkinson’s mask”.
- Go up and down stairs readily.
- Drive a car for more than fifteen minutes comfortably.
- Sleep more than 4 four hours per night.
- Sing for very long with control or proper breath support.
- Utilize a conventional knife, fork or spoon.
- Carry a coffee mug or a full glass of water safely

This is a long list of everyday activities that I could no longer do. When was the last time I couldn’t do anything on the list above without assistance? The most likely answer is before age five. The problem I had was that I had the awareness of someone in his early to mid-50s but with the motor capabilities of a pre-kindergartener, which engendered in me a desperate, claustrophobic feeling to say the least. Had I made the right decision to start LifeWaves®? Had I sent myself and my wife on a fool’s errand? Was I wasting our money? Could the quality of my life really improve? All these doubts assailed me. So, I looked carefully to see if anything was improving.

I soon learned that while I didn’t see gradual improvements, others did. And as they related their excitement at seeing these improvements, the more excited I became and the more convinced that I was on the right path.

Chronicle of Improvements

So, by the end of the first year of LifeWaves® (August 2006), I was showing some noticeable improvement in my physical mobility. People who hadn’t seen me in months commented that I had more energy and better color in my face. Progress showed in enhanced flexibility, less spasticity and more alert behavior. This feedback made me increasingly hopeful.

By the end of year three (August 2008), I was able to walk without a cane or

walker. I have a video of me jogging around a parking lot, walking unaided into an office, and tip toeing backwards in the same parking lot. By now I was beginning to believe that I might actually be able to turn things around with continued effort.

By the end of year five (August 2010), I was able to do everything on the list above, perhaps not at the same level as prior to the PD diagnosis, but certainly adequately and without continual assistance. Now I had completely lost the sense of fear and desolation I had felt over the past ten plus years.

By year six (April 2012), improvements in mobility continued. I am now able to undertake activities that I haven't been able to do for ten years. For example:

I am now able to walk up a steep road nearly three tenths of mile long and rising 200 feet over that length. This road leads to the top of a ridge where we lived. This feat is recorded on video.

I am now in a fitness program having finally achieved enough physical capability to be able to engage in body conditioning exercises while continuing with the LifeWaves® program.

Now here are some facts drawn from analysis of six plus years of charting my heart rate using the Polar watch and belt:

1. My average resting heart rate has lowered from about 100 beats per minute to about 80 beats per minute and moving into the 70s. This level is still higher than optimal but a significant improvement, nonetheless. The goal is was to get my resting pulse on average to be in the 60s. Now, once the edema was cured, my resting heartrate is consistently in the low to mid-60s.
2. My heart rate variability is higher in the morning than in the afternoon which means that it is in sync with the circadian rhythms. This means that, among other things, my metabolism is functioning within a normal range now for the first time since the initial PD diagnosis.

Money Matters

There is always the subject of what it costs monetarily to engage in a LifeWaves® or other high-quality fitness program. I have had several conversations with PWP's who focus on the cost of fitness programs. Their concern is that devoting themselves to such a program will require both a time and money investment that many PWP's feel unable to undertake.

I do appreciate the need to scrutinize all expenditures. I also know for sure that the quality of my life and that of my wife has been greatly enhanced by my investing time and money in taking advantage of the tools I had access to such as LifeWaves®, Kinesiology and Neurologists. That said, when fellow PWP's say that they can't afford this level of investment in health, I reply, "How can you

afford not to do it?"

A Thought Before Moving On

In my opinion, being under stress continually and living without heeding circadian rhythms over many years contributed to my losing my health. The good news is that within a year of devoting time to LifeWaves® some relief occurred and year after year more improvements followed. By year seven, much functionality has returned with the promise of more to come.

Do the nearly seven years of grinding it out with LifeWaves® seem worth it? Yes! The remarkable improvement I've experienced with LifeWaves® makes the seven years seem much, much shorter than the six years of continuous decline I experienced after the PD diagnosis.

CHAPTER 3: CATCHING THE LIFEWAVES® - THE THIRD 6 YEARS

As 2012 ended and 2013 began, I felt confident that improvements in my health would continue. However, this was not to be. Early in the summer of 2013 small lesions began appearing on my calves. They would burst and drain down my legs. Discoloration of the skin began occurring. My GP diagnosed this edema to be treated by wrapping cold towels around my legs below the knee. The cold towels drew out the heat in the lesions. With more lesions appearing every day I became very concerned. Doing my own research, I learned that left untreated, edema can lead to heart disease and/or gangrene. My GP suggested that I look on the internet to learn about possible side effects of each of my PD medications.

I started with Pramepoxole, a medication which extends the life of dopamine in the brain. The answer, to my consternation, was very clear: the daily dose of Pramepoxole should not exceed 1.5 mg and I had been taking upwards of 8-9 mg per day for about 10 years. The good news about the overdose was that it combined with the exercise made me very high functioning when I was on, but this high functioning was being purchased for at a very high price.

Research on the side effects of Amantadine, another dopamine extender, provided me with further bad news, although this was much easier to correct. I had only taken twice as much as I should have. This overdose just added fuel to the fire, so to speak.

Why didn't my neurologists in White Plains, NY or in Greenville recognize the overdose? I don't know, and I didn't ask because 1) once I learned of the extent of the overdose and what it meant, the bond of trust with both neurologists was severed; and 2) I realized that "it takes two to tango." I was getting the high function results I wanted, and I clearly didn't want to look too closely. Therefore, I never did any research on my own as to what the ideal dosing levels might be or the nature and health implications of possible side effects.

Fortunately, I was acquainted with Dr. Fredy Revilla from an advisory

committee that we both served on at GHS (Prisma Health). I sought him out for an independent opinion of my condition. It turned out that Dr. Revilla had significant clinical experience in dealing with overdoses of these two medications. He laid out a very deliberate program to reduce the dosage back to proper levels. It would take nearly 24 months to transition (fall 2013 to the fall of 2015) to the proper dosage levels. A measured pace was necessary to avoid another crash as the body was addicted to the previously high levels.

Legacies from the Overdose

Once the transition had occurred, it became apparent that the overdose of these two meds had covered up dyskinesia which is a symptom some PWP's develop. I noticed a marked increase in restlessness in my legs and an involuntary twisting of my body.

Simultaneously, we were in a crisis mode with the edema. I had gained over 50 pounds due to water retention. My kidney function was showing very concerning numbers and my glucose readings indicated the possibility of incipient Type II diabetes.

The body needed to be drained of the excess fluids. A stagnant lymph system was a ticking time bomb of further infection.

What viable options did we have? There was very little to be done with medication at this point. Physical therapy seemed the best alternative. However, I needed some technique that would work effectively on draining the lymph system. It was a race against time as the backup of fluids could cause damage to the heart, if not a heart attack. The pressure of the excess fluids on the circulation system could cause noticeable damage to the nerves in the feet and legs. In worst case, neuropathy could result.

Periodically, I had been visiting a local massage therapist, Manisay Gabbard, who was trained in the Mattes Method or Active Isolated Stretching (AIS). See the appendix for a more complete description of this technique.

For the nearly twenty-four-month transition period, I had AIS sessions; bi-weekly at first and then for the final fifteen months on a weekly basis. This technique produces very satisfactory results, but it requires willingness to endure some physical discomfort over the forty-five minutes each session takes as blockages of energy throughout the body are broken up and the lymph system drained. A combination of proper levels of the medication and timely AIS therapy resulted in my losing fifty pounds and keeping it off. I am grateful to Manisay for her highly professional and caring approach which she brought to these AIS sessions.

A bonus to the weight loss was the return of my "kidney function numbers" and blood glucose levels to within normal ranges.

The improvement in my blood chemistry was not mirrored in the dyskinesia. Since dyskinesia is a side-effect of prolonged use of Carbidopa Levedopa, I find

myself on the horns of a dilemma: to have any semblance of a normal life, I must take a significant dose of this medication daily. The extenders that I take (Entacapone, Pramipexole and Amantadine) act as a much needed, if modest, brake on the dyskinesia.

Working with Dr. Revilla, we have crafted a plan to take my medications evenly throughout the day. For example, where I took five pills three times a day, I smoothed out the dosage to take the same total daily amount every sixty to ninety minutes.

This experiment has been a limited success as I do have a more consistent energy level throughout the day. In addition, I no longer appear subject to the steep changes in energy level that I had before this plan. However, the dyskinesia does return after about sixty to seventy-five minutes after taking one of the doses, although at slightly lower levels of intensity than before.

This result is a disappointment, but I am confident that we can find a better balance of medications. Why? Because, within reason and in conjunction with my neurologist, I must be willing to treat myself as a "Science Project". In other words, I must be willing to gather data on my reaction to each pill, timing of the doses and intensity of the dyskinesia. This paying attention to detail should foster further scientific research that is needed.

We continue to adjust the LifeWaves® routine to see if we can further minimize the dyskinesia. The daily cycles follow a pattern of one day of strong cycles followed by a day with light cycles. The theory is that the lighter cycles on what was the "off day" rings the bell and reminds the body that it can sustain the "normal" function, and as a result, the body is active when it needs to be active and relaxed when it is not active.

What have been the results so far? The intensity of the waves of dyskinesia has been lessened by about 20%. (Statisticians cite 20% as the typical amount of change that needs to take place before an individual will state that they can really recognize a change that has been made.)

You may infer correctly that I plan to take steps to greatly limit the meds that I currently take. This brings us to Duopa™. This product is a combination of carbidopa and levodopa in a suspension form (gel) that is delivered directly into the intestines by a pump for up to sixteen hours. Duopa bypasses the stomach and delivers a continuous infusion of carbidopa-levodopa into the duodenum of the intestines, which often reduces or eliminates the fluctuations for many patients.

With Duopa, a procedure is required to make a small hole (called a stoma) in the wall of the stomach to place a PEG-J tube for delivery of the carbidopa/levodopa suspension. PEG stands for percutaneous endoscopic gastrostomy, and the J stands for jejunal, the upper part of the small intestines. The PEG-J tube is connected to a cassette containing Duopa and a pump, which moves the medicine from the cassette through the tube. This method of delivery

also results in most users experiencing a 50% decline in the amount of carbidopa/levodopa pills daily. This reduction of pills is especially helpful to those who are having trouble swallowing.

The cons include the inconvenience of keeping the incision dry. This means that the pack must be taken off every time one showers, swims and at night before bed when the PEG-J tube must be cleaned. But the inconvenience factor could be overlooked if there were a good chance that the dyskinesia frequency and intensity could be materially lowered, but to date there has been no consistent positive effect on the solving of the problem of dyskinesia.

In early 2019, I researched this product extensively. With the assistance of the highly professional Duopa help desk, I developed a good understanding of the pros and cons. While there are some attractive pros as mentioned above, there are significant cons. I concluded that Duopa was not for me.

This is not to say that the product is not what someone might need. It is that I find the cons to outweigh the pros.

Research continues on solutions which can help the medication bypass the stomach and enter directly into the bloodstream. I am currently (December 2019) beginning to participate in a fifty-two-week study designed to test a less intrusive and more efficient way to get the medication into my bloodstream. This involves a miniaturized version of the Duopa delivery pack.

Another method/procedure known as Deep Brain Stimulation is an operation which seems to work very well for those with bad tremors and/or severe dyskinesia. The procedure takes off the top of range of symptoms and fills in the bottom. In other words, it levels off or averages out the symptoms. That is the good news. The bad news is that there is no way of telling what the average will look like post-operation. In one case I researched, the individual received some relief from the dyskinesia, but the clarity of his speech deteriorated noticeably, and he gained fifty pounds due to the reduced physical activity resulting from the steep fall in dyskinesia. Another patient also had the side effect of much poorer speech clarity but was relieved of the terrible tremors he had before. Given these tradeoffs, I have not taken advantage of DBS, but it was worth going through the vetting process so it can remain a viable option.

More side effects of the medication

As if all the foregoing weren't enough to think about, there is the following unpleasant fact: The high level of "dry mouth" created by the medications, especially Carbidopa/Levodopa, has caused on-going and marked deterioration of my teeth. This is despite diligence on my part coupled with receiving high quality dental care over a twenty year period,

The condition of my teeth is such that with the completion of oral surgery in early 2020 to remove several teeth, most of my dental work will be implants.

I realize that this is not good news for any of us people with Parkinson's. All I

can recommend is to you keep your body as hydrated (with water) as it can be and keep your mouth environment as clean as possible.

CHAPTER 4: A WIFE'S PERSPECTIVE AS CARE PARTNER

In the Beginning

The care partner (CP) of a PWP also “has Parkinson’s.” Probably as stressful, if not more so, is being a part of the life journey of a PWP. This role of CP is one that is often overlooked. In this chapter, my wife, Roz, will reflect on how my being a PWP has affected her. She also gives some tips on how to cope with this role that truly no one “signed up” for.

The Diagnosis

When Stan went to the first neurologist in 1999, he went alone. BIG MISTAKE! I had to take his word for it that he “might have PD” and that the pills “might help.” When the pills didn’t agree with him, I couldn’t persuade him to call the doctor back or to see him again, even when Stan’s condition was clearly getting worse. I insisted on going with him to the second neurologist in New York City to hear what the doctor said and to “keep Stan honest.”

Following the second diagnosis, we both took PD seriously. I needed to know more about the disease, what my role would be, and what to expect in the future. So, I bought several books on PD and sat down to read them. Another BIG MISTAKE! The books began with a list of all the horrible things that probably would happen to the patient with PD.

I never got past the first few pages. I became depressed, thinking about what our lives would be like, wondering when the next stage would happen. This dominated my thoughts for quite a while. Then I snapped out of it, realizing that there was no way of knowing exactly what would happen, or when. Stan had his challenges, but he was OK for now. I threw away the books.

Beginning to Deal with PD

Stan was having difficulties not only with walking (he was dragging his right leg and his arm wouldn’t swing freely), but also with fine motor control in his right hand. For some things he was able to use his left hand but getting dressed was a slow and difficult process.

Being a good wife, I wanted to help him in every way. Stan said no, he wanted to do it all himself as much as he could. It was difficult watching him struggle with buttons and shoe laces, but it was the right thing to do. Neither of

us wanted him to become dependent on my help.

The way I could help without doing it for him was to purchase some items to aid him in dressing: shoes with Velcro closings, a long shoe horn combined with a hook to help lift clothing to the upper level in the closet. Other products are available, but these were the ones I chose for starters.

Stan was still able to do many household chores: he was able to go up and down stairs, so he continued to do the laundry (I have arthritis in my knees), and he was able to clean up the kitchen after dinner. He also helped with grocery shopping.

Dealing with the “Crash”

Stan was stabilizing on the combination of the medication prescribed by the second neurologist and walking thirty to forty-five minutes a day. Then came the “crash,” and there being new evidence of a problem with the first medication, the neurologist decided to change his medication.

The process of weaning himself off the first medication and onto the second caused a “crash.” Suddenly Stan’s legs became weaker and weaker until after about a week he was confined to bed.

I was scared. It was terrible watching him struggle to move his legs. He was uncomfortable, and I couldn’t fix that. The second medication appeared to be causing a bad reaction. His neurologist was away and the one on call did not have a viable suggestion.

What could I do? I had no experience caring for someone who was helpless. I had no support group.

I purchased a walker. I lifted Stan’s legs to get him settled in bed and to get him started walking when he got up. (Legs are really heavy!) I called Stan’s chiropractor, and he came over several times to help move Stan and get him up. Stan called his trainer, and he came over to stretch Stan’s legs and help him get up and started walking.

Meanwhile, Stan wasn’t taking any medication at all. The next thing I did was to insist that he see another local neurologist who had been recommended to me by a friend. It took several days to convince Stan to do this. I asked him just to go with me and make up his own mind which neurologist to continue with. After being prescribed a combination of medications and learning he had been under-medicated, he decided on the new one. I had a stair chair installed so Stan could safely get down to the garage, so I could take him to the neurologist.

Stan began to improve slowly with the new medication. I had to be on call 24/7, and so staying at home became a necessity. This was difficult for me, as I was used to a free schedule. Luckily, I had already stopped working.

I called on a few friends who grocery shopped for us. I called on a couple of Stan’s friends who came over and sat with him so I could go out. Eventually, I was able to leave him at home if he had a phone nearby to call me if he got into

trouble, although he never had to.

Amazingly, Stan continued to work during this period. I brought his laptop to him even when he was confined to bed, and he had his cell phone to make calls. FedEx delivered papers he needed. Much of his staff were in other states and he worked with them over the phone and via email.

The period of the “crash” lasted nearly two months and exhausted me. I wish I could have had a PD support group to talk to, but I didn’t really know of their existence. Now I know that if anything like this ever happens again, I would hire a home care service to help me out. I just didn’t know where to turn.

Recovering from the “Crash”

Stan became able to walk with a cane instead of the walker. He wore sweatpants and T-shirts around the house, so dressing wasn’t a chore. Of course, he no longer could help with laundry and cleanup. After about two months he needed to go to the office, so I drove him the hour and a half round trip.

Stan was having trouble managing a fork and knife. I began cutting up his food for him, and eventually I cut things like chicken into bite-size pieces before cooking it. I used short pasta shapes like penne rather than strands like spaghetti or linguini. I bought eating utensils with large, weighted handles that were easier for him to manage. I bought lightweight plates and bowls that he could carry back and forth from kitchen to table, and plastic glasses. I looked for anything that would help him feel more independent.

Stan began driving himself to work when he needed to be in the office, but it was difficult for him. He still worked at home as much as he could. The situation was far from ideal.

Moving to South Carolina and Beginning LifeWaves®

Five months after the “crash,” Stan wanted to move to South Carolina for warmer temperatures. The cold causes his legs to tighten up, and snow and ice are treacherous to walk on. He still wasn’t very stable and needed his cane all the time. We thought he was headed for a wheelchair. So, when we looked at houses in SC, I measured doorways for wheelchair access.

One month before we closed on our new home, Stan and I met with Dr. Irv Dardik to learn about LifeWaves®. It was a fascinating meeting. Dr. Dardik explained that he believed the system could help with PD and had conducted a sixteen-week research study with PD patients a few years earlier which gave some indication that it could help. Stan took a leap of faith and decided to sign up for the program. At this point, he was so frustrated with his condition that he was willing to try any reasonable approach.

Little did I know that Dr. Dardik was interviewing me as well as Stan. We found out later that he would not have agreed to start Stan on the program if he had not felt that I was supportive and would not interfere with Stan’s staying on

the program.

Progress and the Breakthrough

We purchased a stationary bicycle for Stan to use for the exercises, and he also used the staircase as an alternate method. Staying on the exercise schedule was a challenge, as it took up to an hour every other day; however, Stan managed to organize his work around the exercise schedule, even when he had to travel back to New York City for meetings.

Progress was slow. Changes in Stan's stability were barely discernible for a long time. He had to grab onto the kitchen countertop to avoid falling when he lost his balance. Despite this continuing instability, Stan was feeling better.

Sometimes when you see someone every day, it is difficult to see the changes. But our friends in New York could see the improvement in Stan, as they only saw him every six months or so.

After a while Stan reduced his dependence on the cane. One day, about four years after Stan started LifeWaves®, we were walking down a hallway and I was several steps behind him. He had his cane with him, but he was not using it. Suddenly, I realized that he was walking evenly, not limping or dragging his right leg. I stopped him and hugged him, even though hugging him standing up could put him off balance, I told him what I had just seen.

Around the same time, because his balance had improved, Stan began to do the dishes and load the dishwasher after dinner! To this day, he always cleans up the kitchen. For me, that was a great victory.

As Time Went On

I no longer worrying about him constantly, but it is always somewhere in my mind that Stan has PD. I trust him to know whether he is feeling well enough to drive, limiting his driving to forty-five minutes. If we are going somewhere together, I always do the driving.

There are times when Stan has problems walking or standing up for a period of time, especially first thing in the morning. However, he knows if he climbs a set of stairs once or twice, his legs will loosen up and he will be almost back to "normal."

If he is dressing in a hurry, I will help him with collar buttons and straighten the shirt collar after he puts his tie on.

He doesn't need the special utensils to eat, although he still uses the lightweight plates most of the time.

For a while, the side effects of some of his medication caused him to have nightmares, but he has been able to adjust his dosage and that rarely occurs now.

Side effects, as described above, have caused me much distress. I began attending all his doctor's appointments, both so I would know what was being

discussed, and so that I could answer many of the doctor's questions from an observer's and care partner's point of view.

I am relieved that the edema caused by overdose of some of his medications has been solved. The dyskinesia is varying in intensity. When the intensity is at its highest level, it is difficult to sit next to him, as he often moves side to side. But, as the dyskinesia can be much noticeably reduced by modifying the medication levels, I considered this as a great weight off my mind.

A Final Word

There will be times that CPs will need help. I would suggest joining a support group even if you don't feel you need one now. You will make friends in the group and will be able to turn to them for support when you are in need. Accept help when it is offered by friends or neighbors if you need it. For example, we have neighbors who will help with some household chores that we are unable to do, such as change overhead light bulbs or carry heavy objects. In times of extreme need you may receive offers to grocery shop or even provide meals. Their offers are sincere and heartfelt, and they want to help you.

CHAPTER 5: EYEWITNESSES AND WHAT TO EXPECT FROM OTHERS WHO OBSERVE YOU

If you've ever been eyewitness to an accident of some seriousness, you know that it leaves images in your mind that can be lasting. A welter of conflicting emotions sweeps over you: fear, revulsion, a desire to help, confusion, a desire to deny the reality of what you just saw.

As PWPs, we are witnesses to the "train wreck" which is PD, while also being witnesses to the many and varied reactions that we see on the faces of those who observe us. We see faces reflecting concern and kindness countered by faces reflecting contempt, fear, and irritation at us and our slow movements or seemingly "deformed" looks.

For some of us PWPs, the final indignity of PD is the reaction of others to our appearance. If we were to follow our feelings, we would avoid public contact to avoid the discomfort or even humiliation.

In my experience, withdrawing from life only adds to the pain a PWP feels. To help PWPs and CPs deal with eyewitnesses, I've developed four expectations or "the four E's." Through the four E's I've tried to capture what to expect from others and what can be done by PWPs and CPs to remain positive.

The Four E's

- 1) *Expect a visceral reaction of fear and even disgust from some people. Take this as an opportunity to educate them.***

At a large PD Symposium in April 2011, the crowd of PWPs, CPs and health professionals was beginning to leave the main event room of the Convention Center in Greenville, SC. One of the Boy Scouts assigned to help anyone in need stood near me as I watched over the Parkinson's Support Group of the Upstate information table. His eyes were bulging out of his head. He tried several

times to talk, but his mouth could only open part way and no sound emanated.

Finally, after much of the PD community had exited, he summoned up the courage to speak. He asked, "How do you catch Parkinson's?" There was real fear in his facial expression. I asked, "Are you freaked out by what we with Parkinson's look like?" He nodded yes. "And you're afraid that you could catch this disease by being in contact with us?" Another nod yes. I said, "You can relax because PD is non-communicable. You can't catch it from someone else."

He looked relieved and walked away to help the PWP's and CP's as requested. Later, a fellow PWP and I rode down the elevator with this scout and another. My fellow PWP is a tall imposing man. He smiled and looked at the scout and his buddy and asked, "are you going for Eagle Scout?" They both nodded yes. My fellow PWP then said, "I was an Eagle Scout too. In fact, the youngest in the state ever at that time."

My scout who seemed to be handling this encounter so well to this point suddenly had a relapse. Learning that my fellow PWP had been an Eagle Scout seemed to fill him with terror all over again. He and his buddy acted as if they were trying to become a part of the elevator wall. When the door opened, it looked like a "jail break" as they left the elevator as fast as they could.

My fellow PWP and I were amused. However, this is a microcosm of how some may react to those of us with PD. This type of reaction can be hurtful unless we develop a sense of humor and a readiness to educate others about PD.

2) *Expect friends, especially at first, to be uncomfortable around you and even avoid you. Take this as an opportunity to show understanding and reach out to them.*

Avoidance of situations which make us uncomfortable is natural. So, expect it and realize that friends and colleagues are struggling just like the Boy Scouts above.

What follows is a good friend's story in his own words about his struggle to accept PD's impact on me:

Scott Salik— (a long-time friend):

I have known Stan Smith since the early 90's, well before he was showing the obvious signs of Parkinson's. The length of our friendship has allowed me to experience the before, during, and after of his evolution of the disease.

Since I only see Stan from time to time, the changes in his mobility were obvious with each visit. I am not proud of the fact that I found it difficult to see the deterioration of his body, and at first would try to shorten the time of each interaction with him. But there came a point where I started to see beyond the physical signs and realize that it was the same old Stan behind the costume of

Parkinson's.

The great part of getting to that point was that I was able to experience his miraculous devolution of the disease's evil symptoms. When the disease set in, he always needed help to get around. You could see him carefully planning his path across the room. He would spot the points in the room where he could pause to get his footing, or take a rest, or catch himself if he began to fall. Even when he relied on his cane, when I was around Stan, I always was prepared to catch him.

Then a funny thing happened. You could see he made less planning in his path, less worry about his stability and less reliance on the cane. With each visit life became less of an issue for Stan and he would volunteer to get something if someone needed it. And then, even the cane was gone, and his footing became surer and more stable. I would even say that there are days now when I forget he even has Parkinson's.

These are pretty amazing results for the hard work he has done on this new therapy, not to mention how inspiring the evolution has been.

3) *Expect others to be watching how you handle PD. Realize that you can impact others (for better or worse) by your example, especially younger people.*

Here are representative examples of eyewitness statements from two young people under thirty to give you a flavor of the principle I'm illustrating.

Joe Zakierski – (mentee, now a business executive):

Stan is a true career facilitator. I was able to witness firsthand his ability to connect colleagues with each other in order to improve the overall organization and its individuals. He is an incredible role model for people with Parkinson's and other types of diseases because of how much he has achieved since being diagnosed. He has helped me understand that with hard work and determination anything is possible.

Kiira Benzing – (business colleague):

While working on my documentary film, *The Wave Maker*, a film about Dr. Irving Dardik, I met Stan Smith. It was the fall of 2008 and Stan had been on LifeWaves® for about three years. Just before his interview he had done the exercises for that day. We then proceeded to film Stan for an hour and a half.

Throughout the interview I noticed Stan's right hand tremble consistently. During the interview, Stan mentioned that if he concentrated on making the trembling stop, he could, and as he spoke this, his hand stopped trembling. We filmed Stan getting dressed as he readied himself for a business meeting, and his right hand functioned in aiding him.

About two years later I flew down with my crew to film Stan at his home residence. Surprising to me, Stan's stride had improved, and I noticed far less trembling in his hands. Stan carried on doing daily activities like driving, walking, writing, and attending choir rehearsal. I also listened to Stan sing opera, and I was amazed at the vocal range he exhibited. Stan's perseverance and optimism should be inspiration to us all, and I look forward to including his story in my film.

4) *Expect others to want to help you but not know quite what to do. Take this opportunity to connect with them by accepting help while also letting them know when you won't accept help.*

My experience is that it is important to be clear about when we PWP's need help and when we need to do it ourselves, so we can maintain physical capability and sense of self-esteem. We PWP's understand that there is no worse feeling than having a sense of helplessness and dependence. On the other hand, I've learned to see the love behind gestures to help even if they aren't welcome sometimes. As in all matters in life, a balance is required between stubbornly believing that we can do things that any observer knows we can no longer do and becoming totally dependent on others.

You may ask, "how do you show that you are willing to help but are being sensitive to PWP's or CP's feelings at the same time?" I'll answer it by giving the example from one of our current neighbors. He has made it clear that he will do any housekeeping chore such as changing lights bulbs or alarm system batteries or carrying a heavy box downstairs or run an errand. He is never insistent but is persistent by frequently asking what he or his wife can do to help.

A logical follow up question is, "Then what are the most useful actions you can take to help out a PWP and/or CP?" The answers are: 1) anything that gives the CP a break from being constantly vigilant. It could be giving the CP some time to do some shopping or go to the hair dresser or just take a nap or play a round of golf. It is important for the CP to be able to do something for himself/herself on a regular basis. Otherwise fatigue and resentment can build to dangerous levels; 2) anything that helps maintain some orderliness and cleanliness in the home or other space in which the PWP and CP are living; and 3) provide transportation to doctors, place of worship or venues outside the home.

One final tip to PWP's and CP's. Make a list of what tasks would be helpful when you need help. Each time someone asks how they could help, give them this list and tell them to choose what they'd like to do. Everyone likes to feel that they have choices, and this gives them that chance.

A Thought Before Moving On

Look at the appendix for more eyewitness accounts. I've included them not only

to offer more proof of my improvement but to suggest a model for how you can keep track of your progress on all fronts. I've found that friends are willing to tell you the truth if you ask and are receptive to their input.

I realize that retreating is what we PDs feel like doing much of the time. However, humans are not intended to bear burdens alone. Trust that others will respond if you reach out. This will ease your journey.

CHAPTER 6: A WORD OF ENCOURAGEMENT

I hope that I've whetted your appetite to further investigate ways to take more control of your destiny. PD can rob us PWP's of our sense of confidence leaving us with a sense of futility, hopelessness and frustration. I believe that my experience provides hard evidence that PD's progress can be dramatically slowed, and quality of life vastly improved by taking the right steps to exercise properly as well as to develop a positive mindset.

I hope that you've seen how your willpower can trigger improvement that is substantial if you choose to exert such willpower.

The 6 B's

As a parting word of encouragement, I'll leave you with six thoughts that I hope you'll keep in mind as you continue on your journey with PD, whether you're a PWP or CP. Living the 6 B's creates a positive wave of energy that builds on itself and makes physical progress much more likely. *These 6 B's are:*

1. Be knowledgeable about PD, but not obsessed with how bad it could be.

When I was diagnosed with PD, my wife purchased many books related to the disease. She began to read them avidly and reported to me what she found. The result was depression and a sense of hopelessness that began to overtake us. There was an air of inevitability that was essentially paralyzing.

To have simply stopped reading the bad news would have been to continue the denial process. On the other hand, to have continued to feel hopeless and depressed was unacceptable also. So, we reached for a middle way which was to educate ourselves on the condition in order to create a basic framework within which to operate. This approach accepted the facts that PD is a degenerative disorder and that certain "bad" things would more than likely happen over time. However, there was no need to sit and wait for these bad things to occur. We learned to acknowledge the facts and get on with living life as best we could.

2. Be compassionate towards yourself and those close to you.

As PWP's and CP's know, PD is a disease with clear outward signs. As a result, everybody we come in contact with is affected: the clerk in a store who sees you moving uncertainly through the aisles; a friend who asks with concern whether or not you can negotiate a set of stairs; the individuals who help you through the airport security screening; your spouse or partner who may have to do chores around the house because you only can stand up for short periods of time if at all or don't have the steadiness of hands to even use a knife in order to cut a piece of fruit. All these "others" in your life either are filled with some anxiety and/or assume extra duties because of your condition. This naturally can lead to others feeling put upon even while feeling sympathetic to you. Further, all the inconveniences can lead to resentment, anger and generally a negative environment at home.

What's a reasonable solution for all concerned? On my part it was developing a sense of gratitude to others for accommodating me: friendship must be accepted as a gift from others. On the part of others who interact daily with PWP's, I would ask for some forbearance on your parts. Why? We PWP's sometimes freeze and don't respond immediately even if we want to do so. Patience oils what could be unrelenting friction between those who are able and those who are disabled. Nevertheless, no one must put up with moodiness on the part of a PWP.

I recognize the reality that many a relationship falters under the strain of PD. CP's and other family and friends can wind up feeling put upon, which is the phrase often used by CP's who are "bailing out," is meaning, "I didn't sign up for this."

This phrase sounds reasonable, but I've concluded that whenever I am tempted to say, "I didn't sign up for this," I find that I am avoiding responsibility for my life. Something good, even great, can come out of adversity but it requires a willingness to find the learning point in every situation. I ask myself, "What is the situation teaching me and how can I activate my reasoning power, willpower and activities to do the right thing for all involved." Without objectivity, I become angry, resentful and closed off from others, lost in self-absorption. It is not fun to acknowledge how I've contributed to a negative situation but there is no forward movement without a commitment to the truth about my role in every situation in life.

Life truly is what happens while we are making other plans. If I bloom where I'm planted, the odds of a more satisfying life substantially increase. An added benefit is that others will be glad to be around me as I'll be a point of light in their lives.

3. Be active and optimistic in choosing to fight your condition.

This is a tall order as you feel yourself slowing down, getting tighter physically, and unable to do simple motor actions like button a shirt or more complex actions like playing a sport or engaging in an enjoyable pastime like singing in a choir.

I found that extreme emotional swings would occur. I would swing from feeling that I could handle PD to absolute despair when I was in a hospital bed being treated intravenously for an infection with none of the PD medications working or even more intensely as I was laying in an easy chair unable to stop shaking during an adverse reaction to a change of medication.

All these feelings of despair and frustration were very real, but I was determined not to let them rule me. I used my practice of meditation and affirmations to get me off the floor and get back to some functionality. To survive I realized that I had to “spiritualize” my life.

What does this spiritualization mean to me? The answer comes in two parts. Firstly, I've learned that humans are basically goal seekers. We have a desire and we work to obtain the desired thing. It follows that an effective tool to build a more satisfying life on all levels is to set a positive stretch goal.

Secondly, I define religion and spirituality as differing concepts but with some overlap. Religion, unfortunately, is too often associated with hierarchy and dogma, and a tendency to exclude.

In contrast, spirituality connotes a tendency to include, and an awareness of the interconnectedness of all. This in turn leads to recognition that we are a part of a greater whole and that we live together most harmoniously when we keep each other's best interests at heart.

An extension of this line of thinking is to affirm I am not my diagnosis. I am consciousness that exists regardless of how my body feels. Does this seem too “out there” for you, just mental gymnastics? All I can say from my experience is that this viewpoint leads to actions which improve the quality of your life and the lives of those around you.

4. Be a lifelong “un-learner” as well as a learner

Along the way I've learned to “unlearn.” This is no easy feat, and I must constantly work at it. For example, I would have been unable to see the possibilities in LifeWaves® were it not for unlearning the limiting, cynical thought processes that I once strongly held. In the process of developing a world view of my own, I had to unlearn negative self-talk, raging about how I was being treated by others, and always expecting something to go wrong.

What is unlearning? Unlearning consists of two steps. The first is stopping a behavior and forgetting how to repeat it in the future. The second step is to

replace the unlearned behavior with a positive behavior. In my case, I worked to replace a cynical, suspicious outlook on life with a positive set of values which helped me help myself out of binds I ~~get~~ got myself into. It gave me some precepts by which to avoid old negative patterns and increased my chances of having a fulfilling life despite PD.

Focusing on PWP's specifically, unlearning means dropping all the negative mantras like "why me?," "I didn't sign up for this," "I can't change," "It's too hard to push myself to be physically active," "What's the use?," and "Why can't I swallow a pill and be cured"?

What replaces these mantras? The void is filled with mindfulness, i.e., paying attention to the little successes in a PWP's life such as tying a necktie even if it takes five minutes now or buttoning a shirt even if it takes much more time than it used to. Mindfulness is acknowledging improvements and paying attention to the details of life. This keeps your mind active and alert to the many opportunities to enrich your life.

Mindfulness also includes paying attention to how your medications affect you. Some PWP's complain that neurologists don't warn them of a side effect or what to expect from the medication or what the next step in the progression of PD might be like. Perhaps the neurologist didn't meet patient expectations, but to be balanced about this, neurologists face several conundrums: 1) they see a patient infrequently and have no way of knowing if the patient is having a good or bad day unless the patient tells them; 2) patients may not share the details of how they are reacting to medication; and 3) neurologists often are not kept in the loop about major life events like being hospitalized for some condition unrelated to PD. Such an event could have an indirect impact on a PWP's PD symptoms that the untrained eye would not see.

Human nature seems to lead us to talk to everyone but the doctor about problems encountered with treatments prescribed by a doctor. You can help educate your neurologist and create a team approach to your care. I'm pretty sure that he or she will appreciate it, and you'll be doing yourself a favor.

5. Be committed to exercising consistently in a variety of ways to keep yourself interested and motivated in improving your health.

For me exercise goes beyond the physical workouts to improve mobility. It encompasses keeping my voice in shape. Earlier in my life, I had extensive voice lessons, and I depend on what I learned then to assist me in this regard. In addition, for the first eighteen years of my PD diagnosis I regularly sang in a church choir and have, along the way, created a CD or two of Broadway songs with limited distribution to friends and colleagues. The purpose is not just creative expression but to track the health of my voice.

You say that you couldn't carry a tune in a bucket. Perhaps, but if you can

sing at all, I urge you to sing. There is research that indicates that PWP's who sing have a greater sense of wellbeing and even experience a decrease in tremors. If you really can't sing, I suggest the LSVT Loud speech treatment therapy as one that will help you cope with the deterioration of vocal capability which all of us PWP's experience. (For more information go to www.LSVTGlobal.com).

I also urge my fellow PWP's to make interval training a part of your daily life. Why? Because it provides a proven approach toward exercise which is anti-inflammatory and as we PWP's know "swollen," "inflamed," and "stiff" are three words which describe our condition all too well.

Yes, any kind of exercise will help you feel better, but the innovative type of interval training I've undertaken can help make you better. LifeWaves® training is designed to create "health", i.e., helping the body reverse course and move towards whatever being healthy would look like if you were your age without PD. But this reversal towards health is not an overnight process. There must be ongoing dedication and commitment. With these two attributes as a base to work from, the PWP has the tools to make life with PD increasingly reasonable.

To my mind, there is also a direct correlation between devoting myself to LifeWaves® and a turnaround in the notable deterioration of my vocal capability. The quote below is from Dr. John King, Minister of Music at Hitchcock Presbyterian Church in Scarsdale, New York. It is Dr. King's take on the impact of interval training on my voice.

"I have known Stan Smith for over 20 years. When I met him, he was a picture of good health. After he was diagnosed with Parkinson's, I watched his health deteriorate over the years. His hand tremors became more severe and he became less and less mobile. I even noticed a decline in his singing—his voice did not have the same control or range. However, since he has started his current regimen, I have noticed a miraculous turn around. I spent time with him recently, and I observed that his hand tremors were almost undetected, his step was virtually without stagger, AND his singing voice is more focused and supported."

If you still believe that interval training is not a feasible path for you, there are other ways to stay active and have fun. Nintendo's Wii video game products (baseball, tennis, bowling, and other activities) can involve not just you but family members in entertaining and useful physical exertion. In addition, Pilates classes and other regimens which require focused and controlled movement such as Hatha Yoga and Tai Chi increase your powers of concentration and mobility.

I have also found chiropractic treatments to help. Special mention is in order for Kinesiology, which my chiropractor has utilized in treating me over the years, in particular the first six years of my PD diagnosis. (If you are interested in

learning more about what Kinesiology can bring to the table, see the transcript of an interview that I conducted with Dr. Robert Frey about how he treats PD.)

Also, therapeutic massage has been essential to my health. The Mattes Method also known as AIS or Active Isolated Stretching is particularly effective in my case. So, when all is said and done, don't wait for a pill to cure PD. Such a cure may well come in time. In the meantime, take steps to assertively improve your health. I can attest that when you see the very positive improvements from a concerted effort to physically exercise (in my case interval training), your outlook on life will improve substantially, including the improvements in your physical health that you'll experience.

6. Be active in a Parkinson's Disease support group

A PWP colleague once told me that a doctor had advised him not to join a support group because it was "just a group of people crying on each other's shoulders." Putting aside the offensive emotional tone deafness that this statement conveys, I would say this is a perception that holds back PWPs, CPs, family members and concerned friends from availing themselves of a source of much needed support.

Another belief that holds PWPs and CPs back is encompassed in a statement made to me by a PWP. He said, "I'm young onset and I don't want to see what I'm going to look like in a few more years. It's too depressing!"

My recommendation to both PWPs was that they attend support group meetings and compare and contrast their mental states before and after attending a meeting. I stated my belief that they were cutting themselves off from a source of emotional strengthening as well as information which would be very helpful to them.

PD is hard enough to contend with without adding isolation from others to the list of negative disease-related events in your life. Remember that humans are social beings. We are to be together and interact. As mentioned earlier, the body itself needs interaction in order to function properly much less our psyches.

If there isn't a support group in your area, take the initiative and start one. It need only be an hour over coffee and cookies at your home or in a room at a community center. The agenda can be simply each person talking about their experiences and learning from each other. If this is crying on each other's shoulders, then let the crying begin because support groups are proven to help participants cope with serious life issues.

Of course, such a support group if successful will grow to where you can have guest speakers to talk about a variety of topics that are germane to PD. The support group we belong to is the Greenville Area Parkinson Society (GAPS). It has peer group meetings that are facilitated by trained professionals. There is one group for PWPs and a separate one for CPs. The feedback is that it is a

relief to be able to talk about the wrenching changes that occur in your life when you are diagnosed with PD, and, most importantly, to realize that you are not alone and you are not the only one who feels the way you do.

Is a support group a crutch? I'd say yes, and what's wrong with using a crutch if that's what reality calls for? If you have a broken leg, but could walk if you had a crutch, why would you refuse to use the crutch? To resist help which is available is simply continuing the denial of the seriousness of the disease condition.

Concluding Thoughts and What I Have Learned So Far

My goal has been to show that there are tried and true tools for PWWs (and sufferers of other major diseases, for that matter) to deal effectively with their condition. I have shared my experience with the LifeWaves®Cycles Exercise® Program as an example of an exercise program which can turn your life around if you commit to it. In addition, we've offered a CP's perspective on PD.

Ironically, PD has been one of the best things to happen to me because it made me focus my energies, opened me up to the high level of goodwill, of which humans are capable, showed me what a miracle the human body is and what impressive results can be produced by the mind when concentrated on a positive outcome. My hope is that the contents for this book have inspired you, whether you are currently ill, or are in perfect health, to a new level of respect for what we each can achieve if we align our reason, will and determined activity to achieve a worthwhile goal.

Another way to put this is: "What I've learned to date." At the time I published *Waving Goodbye To Parkinson's Disease* in 2012, I was very optimistic about my physical condition and what I thought were high odds of having PD under control and becoming largely symptom-free over the coming years.

This expectation has been tempered by 3 side effects of the primary Parkinson's Disease medication, namely levodopa. 1) it loses its effectiveness gradually but inexorably over the long-term; 2) it is the cause of dyskinesia; and 3) it in combination with the other meds such as Amantadine, Pramipexole and Entacapone causes an extremely dry mouth. Add to that the acidity of the meds themselves and the result is long-term deterioration of the teeth.

My dentist compared x-ray photos of my teeth in 2005 and in 2019. In 2005 she found a mouthful of teeth in very good to excellent condition, In late 2019 she finds that, despite aggressive care, I have lost about 50% of my teeth to cavities or put another way the aggressive dental care has saved half of my teeth. In light of my experience, I urge PWWs to make dental care a high priority.

Am I still optimistic? Yes, I am. I don't expect a cure. I expect to continue to find ways and means to live a high quality of life despite Parkinson's Disease.

APPENDIX

Kinesiology-An Interview with Dr. Robert Frey

The following is an interview I conducted with my chiropractor of many years, Dr. Robert Frey. Through his knowledge of chiropractic and his talent in applying the concepts of Kinesiology, he has been instrumental in my road to improved health despite the challenges of PD.

In my opinion, Dr. Frey's ideas about causes and treatments of PD to be worth considering as both those with PD and their physicians contemplate next steps in treating PD. Nothing in the interview should be interpreted as offering a cure. No approved medical claims are being made by Dr. Frey or me.

Please tell us about your background

I am Dr. Robert Frey and I have practiced Kinesiology in Westchester County New York and in New York City for almost 30 years.

My specialties are Chiropractic, nutrition, homeopathy and acupuncture. I hold a BA in psychology SUNY Buffalo and a Doctor of Chiropractic from Life University, Marietta, Georgia

When did you begin treating me?

You became my patient in 1997 about two years prior to your PD diagnosis. What are the major shifts in my health that you've observed?

You've gone from deteriorating motor skills and liver and heart issues to improving motors skills, no liver chemistry problem and a "normal" heart examination.

From a Chiropractic/kinesiological viewpoint, what is Parkinsons Disease (PD)?

PD is a disease of oxidation; effectively an acceleration of the aging process in the specific areas of the brain which are responsible for dopamine neurotransmission. The process of oxidation can be compared to a lighted sparkler (like on the 4th of July) which comes into contact with a living cell and burns it. The process of oxidation changes the DNA of the cell causing distortions in the cell's genetic functioning. With this damaged cellular function, toxic proteins are abnormally created by the oxidized brain cells, and Lewy bodies are formed. Since function follows form, if the form is distorted then so will be the function.

It is oxidative stress which overwhelms the body's ability to cope normally. The stress can come from toxic heavy metal and carbon pollutants which gain entrance into our bodies through eating, drinking and inhaling them. They can be transmitted in the womb from mother to baby in utero prior to birth, and can be generated by stressful situations, sun exposure, and even by excessive exercise.

One intrinsic pathway of toxicity is through the "leaky gut phenomenon" aka stool toxins leaching from the large intestine back into the body. In a healthy large intestine the fat soluble waste of the stool can leak back into the body at a rate of 7%. A healthy liver can handle this through the P450 cytochrome pathway which converts these fat soluble toxins into water soluble toxins which are easily excreted as urine. However, leaking at a rate over 7% challenges the liver function and over a period of time the liver loses its ability to convert fat toxins to water soluble toxins. Consequently toxins can't leave the body and as they circulates through the blood system, they cross over through the blood brain barrier and enter into the central nervous system where the toxins are stored as fat by brain cells.

When the body can't turn fat soluble toxins into water soluble toxins, they can't excrete without harming the body and the body will store the waste as fat. The normal detox pathways include exhalation, stool, urinating and sweating, however the toxins must be in the proper chemical state so they can be released without harming the body. Otherwise the toxins are reabsorbed and not excreted.

As fat soluble toxins pass through the blood/brain barrier into the brain, they can infiltrate the substantia nigra, the part of the brain where dopamine is created. Here, as the neurons become toxic, they abnormally form proteins called lewy

bodies which build up and destroy dopamine metabolism. With these negative changes, nerve energy flow becomes disrupted which leads to major challenges in the synchronized movements of the locomotive system as well as an overall decrease in the life energy of the entire body. This disrupts the sophisticated movements of the fine motor skills; making writing, walking, talking and even tying a shoe lace increasingly difficult if not impossible.

What role does exercise play?

It is essential as it engages the body in action and reaction. It causes the eliminative processes of exhalation, urinating, sweating and stool elimination to work properly. The lymph system is stimulated by exercise and blood flow to the brain and all vital organs increases.

As exercise increases blood circulation to the system, the delivery system of valuable oxygen and antioxidants as nutrition is more available to the cells; in particular anaerobic training stimulates antioxidant activity. It resets the system and enables the body to perform more efficiently and effectively.

Could a pill cure PD?

Yes, this is possible if the pill does the following:

1. protects the body from oxidation by decreasing toxic loads in the system. This preserving of the mitochondrial cell function permits the cells to go about the business of making dopamine which would be beneficial to the health with anyone with a dopamine challenge.
2. stops the process of oxidation; it is not sufficient to just manufacture more dopamine, while oxidation continues unabated.

So what do you treat first?

Treat the large intestine first so its normal flora balance can prevent a leaky gut. Next, treat the liver for its effective detoxification efficiency is vital for the brain's health. Once the large intestine and liver become healthy and are cooperating properly, we can prevent oxidative stress to the brain by preserving its neurochemistry and enhancing normal immune responses of the brain to prevent further sources of toxic loads. These toxic loads suppress the immune systems creating subclinical infections. In turn, these infections use up nutrients and cause further oxidative stress.

The Chiropractic Kinesiologist looks for ways to monitor PD and does so by getting feedback from the brain through a series of muscle strength tests which can yield specific information of what nutrients are needed specifically for the patient's specific profile of oxidative/toxic challenges. A specific regiment of nutrients is then recommended to support the PD patient over time.

I got very sick with PD meds at first. Why was that?

As RX medications which treat PD symptoms are taken, the level of dopamine begins to increase. As this occurs an increase in dopamine function enhances the body's ability to find toxins and to detoxify them. If you find the toxins but can't chemically detoxify through the many pathways of excretion, your body could get acute or sub-acute toxic reactions from taking the medication thus making you sick. Your body at the time couldn't handle the toxins already in the body. My job was to nutritionally support the liver function. As it gradually improved so did your ability to take and absorb your PD meds.

Why is dementia often a long term symptom of PD?

As dopamine function decreases, its impact on other neurotransmitters creates various effects. The specific effect of decreased Acetylcholine function slows the speed of the brains function. The same toxic environment that increases the lewy bodies can also increase the brains production of Tau proteins and a myriad of proteins which altogether lead to dementia and overall decreased central nerve system functioning.

Final thoughts

Knowledge is information but wisdom is to know when and how to use it. Kinesiological testing techniques can not only reveal valuable information about the body's functioning but can also indicate what is needed to remedy the situation.

The Mattes Method (aka Active Isolated Stretching or AIS)

The Active Isolated Stretching (AIS) method of muscle lengthening and fascial release is a type of Athletic Stretching Technique that provides effective, dynamic, facilitated stretching of major muscle groups, but more importantly, AIS provides functional and physiological restoration of superficial and deep fascial planes.

Over the past few decades many experts have advocated that stretching should last up to 60 seconds. For years, this prolonged static stretching technique was the gold standard. However, prolonged static stretching actually decreases the blood flow within the tissue creating localized ischemia and lactic acid buildup. This can potentially cause irritation or injury of local muscular, tendinous, lymphatic, as well as neural tissues, similar to the effects and consequences of trauma and overuse syndromes.

The AIS Technique Deep, Superficial Fascial Release Performing an Active Isolated Stretch of no longer than two seconds allows the target muscles to optimally lengthen without triggering the protective stretch reflex and subsequent reciprocal antagonistic muscle contraction as the isolated muscle achieves a state of relaxation. These stretches provide maximum benefit and can be accomplished without opposing tension or resulting trauma.

Myofascial Release Achieve Optimal Flexibility

Aaron Mattes' myofascial release technique, which also incorporates Active Isolated Stretching, uses active movement and reciprocal inhibition to achieve optimal flexibility. Using a 2.0 second stretch has proven to be the key in avoiding reflexive contraction of the antagonistic muscle. Without activating muscle group contraction, restoration of full range of motion and flexibility can be successfully achieved. Find out more about AIS on line at: www.stretchingusa.com/active-isolated-stretching

Additional eye witness reports...

Lynne & Merrell Clark-longtime friends

Stan Smith has done remarkable things despite Parkinson's Disease. We think it was a miracle, but one that resulted from extremely hard work.

We saw Stan diminish dramatically when his PD was initially diagnosed. He and Roz bought a new home in the Southeast where living would be easier.

When they visited us in Scarsdale, NY, we were happy to see old friends, but sad to see Stan so diminished. More stooped, needed a cane for balance, found it difficult to climb stairs, walked with a shuffle. He needed help: with his coat, with food, carrying things.

He described his prognosis then as a downward series of plateaus, not up. But several years ago, the prognosis changed dramatically.

When we saw Stan recently, he was much stronger than he had been before Parkinson's Disease. He walked erect, briskly, without shuffling and needed no cane. His grip was strong. His voice was strong. He was living a new life.

We have witnessed this hard-won miracle, as if an eagle with a broken wing had healed and now was soaring higher than ever before.

Dr. Robert Frey-Kinesiologic Chiropractor

Stan, you became my patient in 1997 about two years prior to your PD diagnosis. You've gone from deteriorating motor skills and liver and heart issues to improving motors skills, no liver chemistry problem and a "normal" heart examination.

Ellen Galinsky-business colleague

When I met Stan Smith in 2002, he had tremors in his hand and was walking slowly, stiffly, and hesitantly, using a cane to steady himself. In 2007, my organization (Families & Work Institute) honored Stan with a Work Life Legacy Award and although he was still walking with a cane, he was much more vigorous for all the events surrounding the honor. Three years later, the cane was gone, and he could stand and walk for long periods of time. Today's Stan bears very little resemblance to the person I met long ago. Rather than Parkinson's progressing, it seems to be receding. It has been an amazing transformation.

Neale Godfrey-business colleague

I met Stan Smith over fifteen years ago. During a first meeting, the obvious thing that strikes you about Stan is his brilliance and vision. He is a man who can see into the future of the workplace and into the needs of our next generation. In life, there are moments when you meet someone who can finish your sentences. Stan was one of those people. But I could see that Stan's body was not keeping pace with his mind. It was holding him back.

His voice was tentative and without affect. His hands were trembling, and he sort of shuffled along and dragged his feet. He said that he was also a singer, but really didn't do much singing anymore. He spoke of his voice in the past tense. Stan would dose-off in meetings.

Stan diligently follows the LifeWaves® Program. He does it on time and when and how he should. I think that may be one reason the effects are so

dramatic. Stan is committed to his health. He is committed to not being his disease.

I have watched the transformation with both smiles and tears of joy. Stan, Roz and I have become dear friends. I have watched Stan go from walking with a cane and shuffle to walking with a gait which outpaces me. The cane is gone. Stan's broken voice is fixed...in all ways! He has written two books, cut a CD of show tunes and Roz and I wept when he stood, yes stood, to sing a performance of Messiah.

Stan is a role model for all of us, certainly for me. Stan is truly committed to life.

Artie Maier-mentee now business executive

Stan has been a good friend and mentor of mine for over 20 years, and I've personally witnessed the incredible health transformation that he has achieved with the help of his doctor and his workout regime; it's been nothing short of inspirational to behold. Considering that Parkinson's is a progressive and degenerative disease, by all logic, it should get worse over time, but somehow, against all medical odds, Stan has found a way to make significant improvements in his quality of life through sheer willpower, sweat, and a positive mental attitude that just won't quit.

Years ago, before he started working out with the LifeWaves®Program, the physical symptoms of the disease were hard to miss. Stan and I would often go to lunch to talk about life and philosophy, and although I tried hard to ignore it, it was clear that he had trouble performing some seemingly simple tasks, like picking up silverware and navigating food into his mouth. The telltale "tremors" in his arm seemed to never stop. Walking and even speaking seemed to require a great deal of focus and effort, and as a result, I believe he learned how to choose his words carefully, because he simply did not have the energy to waste on rambling or nonsense. Our conversations were always thought-provoking and rich, and I was always impressed at how he always managed to stay positive and see the bright side of things, even when his condition took turns for the worse. I believe that positive attitude was perhaps the keystone of his transformation. It provided the fertile grounds required to sow the seeds of change and reap the benefits down the line.

Seeing him now, it's like a whole new Stan! After just a few years of working with his Doctor, he was able to walk around (without a cane), stand up, sit down, crack jokes, and generally move about with a sense of comfort and ease that I had never seen in him before. I can hear the difference in his voice; he speaks faster, with more energy, and without pause. He's always been passionate about his work, but now it seems like he has the energy to tackle the big problems. This has been by no means a cure for Stan. He still has Parkinson's, and he lives with it every day, but I'm happy see that this program has given him back somewhat

of a "normal" lifestyle, and that's better than the best medicine on the market has to offer. I'm so happy for him, and hope he keeps up the good fight.

Gina Martindale-business colleague

I have known Stan Smith since I began working for him in 2007. Since that time, I have witnessed a complete physical metamorphosis.

When I joined Stan's team, he struggled to put on his jacket without some additional assistance, walked with a cane and at times fought to maintain alertness throughout a meeting agenda.

In fact, some of our team members would joke that if Stan could accomplish all he had done with Parkinson's, imagine all that he could do if he didn't have Parkinson's!

I have always admired Stan Smith and never doubted the power of his mind. However, I never imagined that I would witness the transformation that he was able to achieve in the years that I have known him. My most recent visit with Stan was a breakfast meeting where he met me out in the parking lot (sans cane) and walked at a pace where I followed him into the restaurant. I didn't help him with any doors, chairs or his jacket and he even finished eating his breakfast before me. He was as sharp as a tack and even demonstrated a light jog on our walk back to our cars. He is truly one of the most amazing souls that I have ever encountered, and I am so lucky to call him a friend.

Scott Randall-business colleague

I first started working with Stan when he was a principal at Deloitte LLP. I was immediately impressed with Stan's vision and big picture ideas - and surprised that he would sometimes doze off in the middle of a meeting. As his condition progressed, Stan had problems walking. One day, after not having seen Stan for some time, we had a particularly vibrant meeting and walked Stan to the lobby where he proceeded to practically bound down the stairs to the street level! What a sight to see! Stan really put his mind to what he could do and made it happen. Hooray!

Phillip Roark - business colleague

I first met Stan Smith in November 2000. We worked together on projects at Deloitte for nearly a decade after that date and we are still good friends today. From the time we met it was obvious that Stan was having some sort of symptoms that impacted his daily professional function especially alertness from time to time. Regardless, he was still a vibrant leader and quick thinker. Over the next few years, during our frequent interactions, it was more apparent he was in a type of decline physically. I was concerned for him. His mobility, and especially his quickness of movement changed dramatically.

However, to my surprise and relief this decline slowed. A type of stability

appeared around 2006/7. Since then, he gradually overcame and started to manage and control his symptoms, walking independently and gaining an improved level of health and activity. Writing, singing, speaking, traveling, consulting and being in demand, 12 years later he is an active civic leader, mentor, successful author, businessman and husband.

Megan Turk - business colleague

I have known Stan since 2008. As the partner in charge of my group, he never faltered in his mental ability to lead and drive work, but Parkinson's at times brought him to a dead stop physically. Stan never complained, but the disease forced him to decline work travel and speaking opportunities because of the side effects. I was so inspired to see the video of him at a fast walk, cane free! He never gave up and made it happen for himself and his community. Amazing!

Jim Wall-business colleague

Stan and I have been colleagues and friends for over 15 years. When he was first diagnosed with Parkinson's Disease, we feared the worst and prayed for his recovery and rejuvenation of his body and his spirit. Over the past 6 years, we have seen just that! Gone are many of the symptoms of the disease. Stan's mobility, intellectual sharpness, confidence and sense of optimism and hope have all returned. While his struggle continues, he is a shining example of the power of determination, persistence and faith.

Stewart Watts - mentee, now a business executive

Stan has been a mentor of mine for well over 20 years. Seeing Stan today, when I think back to the low points of his battle with Parkinson's, the memories hardly seem to be credible. Through those times and better times, he has remained dedicated to mastering the illness, as well as his body and mind. Beyond simply stalling the disease, Stan is as sharp and stable now as I have seen him in years.

Jim Wexler - business colleague

One knows immediately that Stan Smith is an idea man. We met many years ago in his role as accountancy/innovator at a Big 4 firm. It's not a typo and not an oxymoron with Stan Smith. He has been instrumental in using both sides of his brain to help these in-the-box guys think out. He'll master the granularity of a business transaction and sing show tunes with professional flair on the same afternoon. Together, we framed a way for the Big 4 accounting firm to become more relevant to the next generation workforce. The bulb that illuminated on this challenge for Stan: Make videogames that engaged them to learn, and overlay assessment criteria that measured them, and build a social relationship with them from the experience.

This was almost a decade ago, before multiplayer game deployments, before

Facebook, and the idea was so advanced that today it appears shockingly fresh. So, for his big brain to have its wiring go haywire was a tremendous loss, for those he touched and those he served. Stan started to need a cane. He'd slip away from a brilliant thought in mid-sentence, appear to doze, and then awaken and complete it. It was bizarre, worrisome, and potentially tragic. So, of course, Stan thought out of the box he was in, and found a way to rewire his essence, his mortal coil. Amazing, unprecedented, but not surprising at all with Stan Smith.

Marlene & Joe Zakierski - longtime friends

Stan and his lovely wife, Roz are our dear family friends who we have had the pleasure of knowing during the last 30 years. When Stan first became ill, it was sad to see how this vibrant man was becoming more and more debilitated as each month passed.

When Stan and Roz moved to South Carolina, he began an intensive program under the guidance of trainers from LifeWaves. Of course, knowing Stan's perseverance and hearing his faith in his doctor's protocol, we held our breath and looked forward to an improvement in Stan's strength, walking ability, speech and overall return to his youthful demeanor.

Stan makes several trips to New York each year and on occasion he and Roz have been our houseguests. During these visits, it seemed as if a miracle had occurred! There seemed to be a total transformation in his walking, speech and range of motion. It has been incredible to witness the return of his strength and stamina.

This major improvement can only be attributed to Stan's ardent adherence to the LifeWaves®Cycles Exercise® Program and Stan's determination and positive attitude.

NEW TESTIMONIALS IN THIS UPDATED EDITION

Paul Hamberis – DPT, Palmetto Physical Therapy (Greer, SC)

As of Mr. Stan Smith's physical therapy evaluation on April 3, 2018 the clinical findings are as follows: observation reveals that there is dyskinesia present which decreases with activity or with increased concentration on balance. Manual muscle testing of both legs results in 4- 4+/5 grossly out of a possible score of 5/5. His standing balance falls between good and normal in that he is unable to maintain single leg stance for 15 seconds on the right and left feet (left foot, 6-8 seconds. right foot, 12seconds). Per the Dynamic Gait Index, Mr. Smith can walk, turn head horizontally and vertically, and change his gait speed, all with no evidence of imbalance along with a fairly normal gait pattern. Based on the Berg Balance Scale, Mr. Smith scored in the 41 to 56 with 56 being top score, meaning he is a low fall risk. Mr. Smith has known of his Parkinson's for greater than 20 years. Considering this I would say he is doing remarkably well.

Jennifer L. Trilk, PhD, FACSM

W. Stanton Smith is *Superman*. And I have the credibility to make this claim, as I am an Associate Professor at the University of South Carolina School of Medicine Greenville (USCSOMG). For five consecutive years, Mr. Smith has guest-lectured to USCSOMG medical students on the physician's essential role in healthy lifestyle counseling (exercise, nutrition, stress reduction, self-care) for persons with Parkinson's Disease (PD). His passion, wisdom, and humor create an environment where our students feel encouraged, inspired, and empowered to use Mr. Smith's teachings for a lasting impact on their patients. And why wouldn't the students listen to him? Every year, Mr. Smith arrives at USCSOMG stronger, leaner, faster-paced, and wittier. Aren't persons with PD supposed to decline in function? How is this man thriving, and proving to our future physicians that health and quality of life can be achieved in the face of a PD diagnosis? Because W. Stanton Smith is *Superman*.

Fredy J. Revilla, Chief Division, Neuroscience Associates, Greenville Health System (Prisma Health), Greenville, SC.

Precious few have had the courage to write on the challenges of living with Parkinson's disease. This is an inspirational work that compiles stories of a personal journey and describes how the author conquers hurdles daily. I applaud the publication of this wonderful book. It is a good reminder of how to be brave and face our daily challenges. The author provides a practical guide on how to

live and defeat Parkinson's disease. May these words inspire patients, caregivers and scientists from all over the world.

Thank you, Stan, for sharing your personal experience with us.

Enrique Urrea-Mendoza, MD., Neurologist
Advanced Clinical Research Associate, Neuroscience Associates,
Greenville Health System, (Prisma Health) Greenville, SC

This book speaks to the relationship between courage and success. To meet Mr. Smith is to be inspired by his bravery and tenacity in the face of his diagnosis.

The description of his journey is memorable as well as fascinating for a neurologist like me working in the research field of Parkinson's disease. This book has inspired me, and I hope will continue to inspire other scientists across the world to continue the race toward the development of new treatments and possible cure.

ABOUT THE AUTHORS

W. Stanton Smith is a Person with Parkinson's (PWP) having been diagnosed in November 1999. He is the Co-Founder of the Greenville Area Parkinson Society, a registered 501(c)3 not for profit and member of the advisory committee to the Neuroscience Institute of the Greenville Hospital System. His wife, Roz, is his Care Partner (CP). They have been married for 40 years and reside in the Greenville, SC area. They are both members of the Westminster Presbyterian Church of Greenville, SC and its Sanctuary Choir. Roz and Stan actively support the Greenville Symphony Orchestra (GSO) where Roz serves as a board member. They are members of the Guild of the GSO of which Roz is a past president.

Stan was in the business world for 36+ years. For most of his career he served in senior Human Resources positions with professional services firms. He was born and raised in Houston, Texas. He received a B.S. in Economics from the Wharton School, University of Pennsylvania, and an MBA from the University of Texas at Austin. Professionally he is a recognized expert in intergenerational communication issues in the workplace.

In November 2010, Stan Smith published his second book, *Decoding Generational Differences: Changing Your Mindset...Without Losing Your Mind*. In this book Stan expands on extensive research conducted during the previous decade to help executives, parents, and teachers understand gen y and how to

effectively communicate with this new generation in the workplace.

Since the founding of GAPS in 2012, Stan has devoted his energies to building awareness of the services that GAPS offers to the Parkinson community in Upstate South Carolina.

Rosalind Lewis-Smith

For nearly 30 years Roz worked as a senior professional in the marketing research business working on major global brands. She was born in China and lived in Washington D.C. and Rome, Italy as a child. She spent her teen years in the Poughkeepsie, NY area and attended the Oakwood School. She holds bachelor's and master's degrees from Cornell University.