



# I Have Parkinson's Disease?! What Now?!

*written by Don Rasmussen*

**T**he title *I Have Parkinson's Disease?! What Now?!* broadly captures my early reactions to being diagnosed. Namely, a reluctant acceptance, but little to no progress on the question of what to do about it. *What now?* would determine the quality of the remainder of my life. Yet, as important as that was and as much as it required my initiative I remained largely unaware of those facts for several years. Then, after coming under excellent care and advice, I have discovered my roles and benefited greatly. I feel compelled to help others do the same.

A recent self-evaluation of my progress in fighting Parkinson's disease clearly revealed that three roles in the fight are not only vitally important, but also misunderstood and underappreciated. I have paid a price for my late appreciation in the form of partially lost opportunities to improve and extend quality of life.

I am a layman, but with over 12 years of personal experience as a Person with Parkinson's (PWP), educational experiences from books, webinars, symposia, CDs and as a member of a very active educational and support group. Additionally, a history of marathon running has taught me to listen carefully to my body. All those miles without winning a race may finally pay off.

The vital roles I refer to are motivation, self advocacy and exercise management. I do not mean to imply that caregivers, doctors, medication and research are not critical, only that they are primarily the roles of others and that we PWP have very important roles of our own to play. I must be clear, fail to appreciate and fill these three roles and you are complicit with the disease. Eagerly address them and you open opportunities to improve and extend quality of life.

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There is a risk here of being too encompassing and losing focus. So let's address the three vital roles I identified and little else. If and when they are well received, I would be willing to address less critical, yet important, additional topics.

Let's first address motivation. I have always believed that everyone has a responsibility to themselves to maintain a positive attitude. However, I acknowledge that remaining positive and motivated is a lot to ask someone who has only recently been diagnosed, is in the middle of the grieving process and knows little about the disease.

Of those of you who have Parkinson's, how did you progress from the disappointment of your diagnosis to becoming motivated, even inspired, to tackle PD head on? I know you can do it because I see much success. Unfortunately, I also see others, apathetic or misdirected, succumbing all too early. Did your family members encourage you? Did you observe others successfully fighting? Did you see educational materials? Did you dig deeply into yourself and find a spirit unwilling to yield to what is likely the greatest challenge of your life? Was your doctor forthcoming, if not inspirational?

The neurologist who diagnosed me offered little educational material, no mention of exercise and his only advice was "Do you have a bucket list?" He told me I had only five good years left ... that was 12 years ago. It sent me into a pity-party funk, which only exacerbated my symptoms. I lost three years of quality life before Michelle Haub, Leader of the Meadowlark Parkinson's Program, rescued me. Don't let a similar delay happen to you or those you know with PD.

In the interest of understanding how to motivate

ourselves, let's consider various aspects of motivation.

- ⇒ It is a condition that moves us to act.
- ⇒ It can be stimulated in us by another person, but to be genuine and most effective, it needs to grow from within.
- ⇒ In the absence of motivation little can be achieved because little is tried.
- ⇒ The incentive to act in response to motivation must be strong.

⇒ The path forward needs to be seen as achievable.

Applying this to issues at hand:

- ⇒ The degree of motivation felt by a newly diagnosed PWP is often low to negative.
- ⇒ The "progressive" label on PD at first sounds unforgiving and final.
- ⇒ Many PWPs exhibit depression and apathy.

Although I have not experienced them myself, I can easily see how the challenges of PD can be overwhelming. Additionally, PD research reveals that while reduced dopamine production in the brain is the most commonly acknowledged hallmark of PD, it is not the only brain chemical that shows abnormalities in PWPs. Some of these are believed to result in mood alterations. Do not dismiss feelings of depression and apathy. Rather, see them as possible legitimate symptoms of PD and worthy of forthcoming discussion and treatment with your doctor.

- ⇒ It is very important that optimistic and inspirational thoughts prevail as soon as possible after diagnosis.
- ⇒ The promise of a better quality and extended life provides a strong incentive to the PWP to self-motivate and reach out for help.

**"I lost three years of quality life before Michelle Haub, Leader of the Meadowlark Parkinson's Program, rescued me."**

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⇒ How, then, can we PWP's best promote our own and others confrontation with PD? I suggest through communications like this one, education and support groups, awareness events, fundraisers and information dissemination by doctor's offices.

I and my fellow PWP's, absent a cure, have long awaited a means to reduce symptoms and maintain a degree of control. The good news is that medications that supplement and protect your own limited dopamine production have partially met that desire.

The next major treatment advance and even better news have been found and reproduced in numerous studies over the past several years. It is reliable, inexpensive and its side effects are largely positive. Have you heard about it? It is called *exercise*. Much more on that later. The entire PD community agrees! For the first time PWP's can see a very desirable result with a means to get there. What a motivational boost! Let's together understand and promote motivation as a critical first step of all PWP's in launching their fight with PD toward a higher quality and longer life.

The following motivational tid-bits resonate with me.

Adopt those you like or create others that fit your situation. Own your motivation and be vocal. It will kick start others.

⇒ I have PD and it is not going away. Self pity and apathy are counterproductive. Therefore, I choose to embrace the opportunity I have been given to understand and fight this disease. It adds purpose to my life and assistance to others!

⇒ I am not defined by PD, rather by my fight with it!

⇒ I choose to view my fight with PD as an adventure, as unique in symptoms as a snowflake!

⇒ We are miraculously given life and dealt a set of circumstances. There is no re-deal! Our reaction should be one of overwhelming gratitude and a search for purpose.

⇒ Every hand is a winner and a loser. Play your hand well!

⇒ Our fight with PD is like a boxing match. The first and

last rounds may be predetermined but I will win all the other rounds!

⇒ If I didn't have PD I wouldn't have the opportunity to speak with you today!

⇒ Pain is inevitable, suffering is optional!

⇒ Use it or lose it!

⇒ Design your future; do not let it simply happen to you.

⇒ My health is my job!

⇒ Motivation is contagious, catch it and pass it on!

Progressive can thankfully now refer only to continued reduction in dopamine production by our bodies, not to inevitable physical deterioration. A well designed and faithfully executed exercise program has been shown in multiple studies to reduce motor symptoms of PD.

Continued use of that program can extend motor performance beyond what it would have been without exercise. Performance cannot understandably be held flat in the face of continued reduction in dopamine production. Never-the-less years of better life can be "banked." Spread the good news!

Although the success of exercise has been established beyond question, its adoption, broad communication and faithful use will continue to be challenging. This or similar motivational communiques need to find their way to the offices of every neurologist and motor movement disorder specialist in the state. I'm attempting to do that with this material. I will also target PD education and support groups. I personally find the group to which I belong to be educational, inspiring and extremely valuable in exchanging coping techniques.

The reward clearly justifies the effort and the time is now. Yes, the commitment is a bit frightening ... but not nearly as much as the alternative. To do nothing doesn't maintain the status quo. Rather it accelerates

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decline. Symptoms rapidly worsen and life becomes shorter and more difficult. **We have no alternative but to fight! Are you in it with me?** I fervently hope so.

In summary, concerning motivation, the important role of the PWP is to understand its critical importance and champion its use, espousing motivational tid-bits similar to those previously listed. The incentive to fight is great and the exercise route makes it achievable.

Let's move on to the second vital role of the PWP, self advocacy. Behind that benign sounding word lurks very substantial duties.

Throughout our lives we have experienced illnesses that are reasonably straightforward in that their diagnosis is near certain, their symptoms standard and measurable, their frequency high, their treatment well established and their duration short. For these, our family doctor or at most one specialist cures us, with little effort or uncertainty. We were only asked to drive to the doctor's office. A layman's knowledge of the illness is sufficient for us. We needed no advocate other than the doctor. Contrast this with the far greater complexity and lifelong duration of PD. None of the preceding characteristics remain true!

Many PWP's don't fathom what that means to them. I certainly didn't. That created uncertainties that delayed me and influenced the quality of my fight plan. Looking back I can now quickly list 37 bothersome to disabling symptoms of PD (appendix 1) and 14 often needed medical specialists (appendix 4). No wonder advocacy catches many off guard. I have included these lists principally for effect at this point while acknowledging they are not intended to be exhaustive. We will return to these later.

With the breadth of duties, contacts and duration now before us, it becomes obvious that the PWP himself or herself (where possible supplemented by the caregiver) is in by far the best position to serve as advocate, in

this case self-advocate. And a big job it is, encompassing education, resource identification, medication management, monitoring and general coordination of all aspects of PWP care. PWP's, I know you don't want to hear that; I didn't either. Do your best, the life you extend will be your own.

The advocate's first duty is that of education. He or she will need to converse with a number of specialists. While that may occur in layman's language, it needs to be insightful and command respect to be effective. There are several educational tools available, including books from your local library, publications and CDs from the National Parkinson's Foundation, Michael J. Fox Foundation and the Davis Phinney Foundation, to mention a few. One caution, note the publication dates. Understanding of PD, particularly with regard to the effectiveness of exercise has changed markedly over the past 10 years. The advocate identifies the resources that are likely to be needed beginning with a neurologist and ideally, a movement disorder specialist (MDS), both of whom need to have a strong reputation and experience with diagnosing and treating PD. Be aware that too few MDS exist today to serve the needs.

General Practitioners are seldom qualified to diagnose PD and only a portion of neurologists have sufficient training and experience to treat PD. In selecting a neurologist, you are making a very important decision, one that you will hopefully maintain for many years. With care in selection, you may be able to retain a neurologist knowledgeable in PD research. I suggest you scroll through the list of healthcare professionals (appendix 4). It may sound surprising that PD's impact and range of treatment is so broad, but I and many others can attest to that fact. Select other healthcare professionals as needed for your



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My sisters supporting my adventure with PD.

particular symptoms. If you later find that your selections are not serving you well, do not hesitate in making changes. Remember, these are decisions of life-long impact. Communicate well, promote a “team” atmosphere, and be watchful for members who may not be inclined or dutiful in coordinating with others.

Advocacy continues beyond resourcing to strategizing, medication management, raising questions and providing feedback to specialists. Recall that the uniqueness of each patient’s symptoms and response to treatment makes advocate observations and feedback all important. Prepare thoroughly for doctor visits.

The third and final vital role of the PWP that I will address is exercise management. Although considerably simpler to describe than advocacy, its importance cannot be overstated.

As noted previously, there is no longer any doubt that exercise is extremely effective in delaying and reducing motor symptoms and thereby recapturing and extending quality life. I’m not, however, talking about a “going through the motions” type of exercise. Rather I refer to routines, intensity and duration that result in a good sweat selected to address specific problematic motor symptoms of the PWP, as well as general overall motor functions.

I’m now going to take you to what appears to be “off topic,” but in fact helps to tie all of this together. We are all familiar with the muscle strengthening results of exercise in the absence of PD. Research shows that these results continue to be available, even to those that come to display symptoms of PD (typically when ones’ dopamine production drops by roughly 80%). Yes, exercise becomes more difficult with PD, but it is still rewarding. This suggests that mechanism at play is that the production and use of dopamine and the capability of muscles are two participants in a sequence of events that take place to complete a motor function. Decrease in one factor in the series can be more than offset by an increase in the other.

At this point, I would expect you to ask, “Why not simply continue to increase medication dosages?” The answer is that many PD medicines are fraught with serious side effects, particularly at higher dosages (appendix 3). Let’s turn our attention back to the symptoms list, this time noting specific health services that may be needed. I appreciate that is quite a challenge, particularly to PWPs in low population density locations. Motor function performance can be substantially increased by targeted exercise. The more demanding the exercise regimen, the greater (to reasonable degree) the increase in performance. I have come to understand that the negative impact of reduced dopamine availability with disease progression can be more than compensated by the positive impact of a strenuous exercise program. Further, it has recently been observed that exercise itself provides an extra bonus in that it promotes the production of additional dopamine.

Those symptoms categorized as “motor” are easily observable, even measurable. Exercise effectively reduces these symptoms, particularly when targeted to problematic muscle groups.

For those symptoms categorized as “non-motor,” the principal treatments are medication. However, core

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exercise appears to substantially contribute to improved performance. That shouldn't come as a surprise since a closer observation reveals that each involves muscle actions, fine as they may be.

Note that some on the non-motor list (appendix 2) are principally side effects of PD medications. Tradeoffs between the positive influence of certain medications and their negative side effects is a hallmark of PD treatment. This situation demands close observation, record keeping and feedback between the PWP and healthcare professionals.

One caveat: as dopamine availability reduces with disease progression, motor performance will ultimately be negatively affected, but to a lesser degree than would be experienced without exercise. In the absence of exercise, both motor and non-motor performance deteriorates rapidly, raising the risk of various diseases.

A set of suggested exercise criteria follows to help you design your program.

- ⇒ Frequency: Most experts agree on five or more sessions per week, each lasting 30 to 45 minutes.
- ⇒ Composition: Identify and select exercise that you enjoy while ensuring that they reasonably and equally address strength, stamina, flexibility and balance. Consider running, fast walking, treadmill, Theracycle, Nu Step, resistance training, weights, LSVT BIG and LOUD, yoga, Rock Steady Boxing and handwriting.
- ⇒ Leadership: A personal trainer can bring increased accountability, guidance concerning exercising and injuries and suggestions on content. Expense and availability may be downsides. I find that using a personal trainer once or twice a week while retaining ownership of the overall program works best for me. Do not allow the expense or proximity of a personal trainer be an excuse to not exercise.
- ⇒ Exercise with others: Consider seeking out a group that exercises together and that has skill levels near

your own. That creates mutual accountability and takes the "work" out of "workout."

- ⇒ Restart exercises that you used to enjoy.
- ⇒ Find exercise DVDs specific to PD like those offered by the Davis Phinney Foundation.
- ⇒ Speech & related: Don't overlook exercises that address deep breathing, vocalization (intonation, articulation, loudness and pitch), facial muscles and swallowing. Recall that the leading killer of PWP is aspiration pneumonia. Consider a speech pathologist, at least until you familiarize yourself with speech-related exercises.
- ⇒ Exercise your brain with puzzles and games. Insist that the scorekeeper be you. Combine mental and physical tasks. Help dispel the common belief that when you look a PWP in the eye you find the lights on but nobody home. Active facial muscles, voice elements and cognition can beat that rap!

To this point I have encouraged strenuous exercise leading to a good sweat. That is where observations of my own exercise results and more recent publications lead me. One might ask, is it really all or nothing? I would never advise that modest exercise is worthless. At minimum it establishes a habit in the correct direction. Yes it is better than nothing. But I hasten to add that it doesn't fit the generally accepted wisdom for the motor improvement mechanism at play.

Also, please note that all things are relative and that "strenuous" for one person who may be advanced in their fight with PD will appear to be modest to a more fit individual. It is the effort level, not the appearance that we are striving for. Year by year I more appreciate my favorite running shirt which has a turtle on the front and a claim of "I am running" on the back. The right time to start your exercise program is now! It is never too late.

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One final observation about exercise. I have witnessed several people who have for some reason (like being hospitalized or severely injured) found it absolutely necessary to suspend their exercise regimen. Without exception, while exercise was suspended their PD symptoms and fitness level markedly deteriorated. In some cases the PD related medications have been suspended by hospital staff. More frequently the previously established timing for PD medications has been altered for hospital convenience. Advocate! You play a most important role at this time to maintain medication timing and prompt resumption of exercises, if only in a limited way.

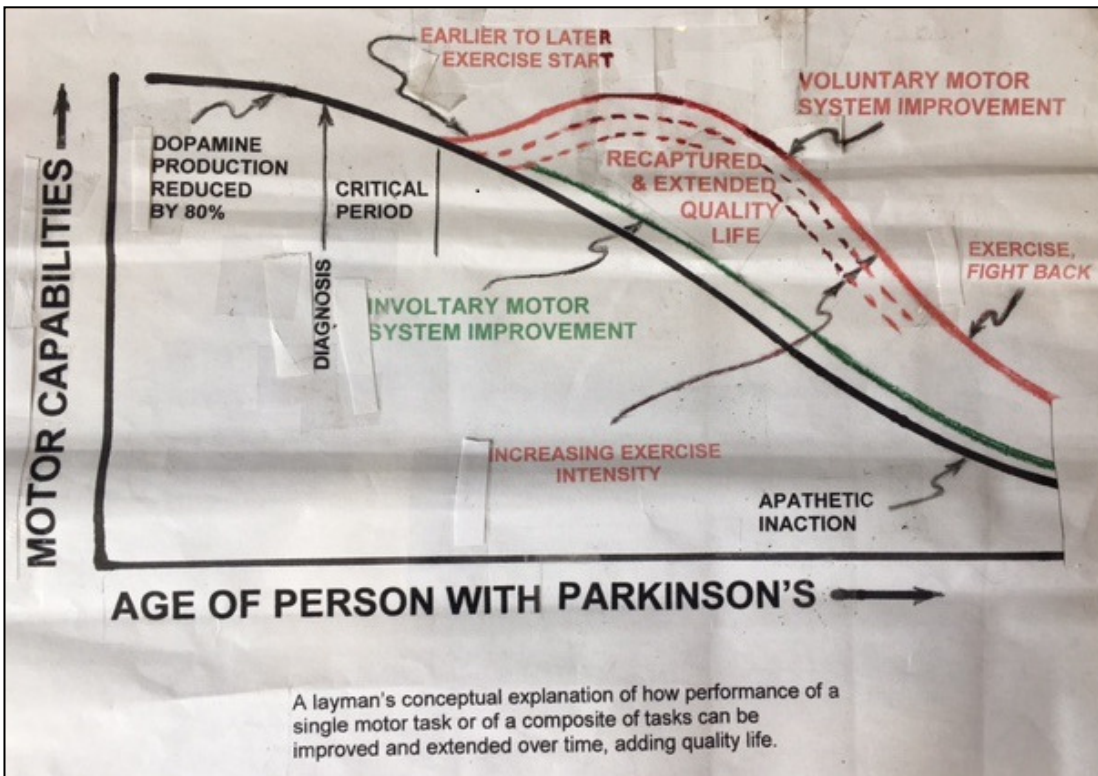
My engineering background led me to attempt to relate the several parameters of this subject in a way that I haven't found in literature. Find the resulting diagram below. It attempts to conceptually convey that over the latter stages of our lives we with PD can recapture and extend motor function performance through vigorous exercise. Performance is plotted against age (non-specific) and with and without exercise. Modest involuntary system contributions are acknowledged. The effect of earlier or later and modest to robust regimen is suggested by

overlay. I offer it with the hope that it may prove useful to others as we continue to understand PD and exert a degree of control over it.

If we PWP's do our job in filling the three key roles and we wisely select healthcare professionals for services and medications, then we will recapture and extend our quality life.

I can't resist the opportunity to add a plug for my education and support group and the Meadowlark Parkinson's Program in Manhattan, Kansas, which currently meets the needs of 125 with broad range services. These fellow PWP's are my heroes, fighting for better quality lives. They motivate me to fight back even stronger. We recognize each other's efforts, celebrate each other's success and buoy each other's spirits. We are a formidable education and motivation force. It is not necessary to reside at Meadowlark Hills (as I do), to be qualified to participate in the program. However, I can vouch for the fact that it is very convenient to do so.

Fellow Persons with Parkinson's, I wish you wisdom, discipline, perseverance, success and serenity (in that order) in our shared fight with PD. Let's never, never, ever give up!



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## Appendix 1 Motor Symptoms

- ⇒ Bradykinesia (slowness)
- ⇒ Rigidity (stiffness)
- ⇒ Resting Tremor
- ⇒ Postural Instability (later)
- ⇒ Hypomimia (masked facies)
- ⇒ Decreased blink rate
- ⇒ Soft, hoarse voice or slurred speech
- ⇒ Aching/pain/cramping
- ⇒ Dysphagia (swallowing difficulty)
- ⇒ Sialorrhea (drooling)
- ⇒ Shuffling, short step gait
- ⇒ Festination (short, fast steps)
- ⇒ Freezing
- ⇒ Micrographia (small handwriting)
- ⇒ Stooped posture, leaning
- ⇒ Difficulty turning in bed
- ⇒ Reduced arm swing
- ⇒ Dragging of foot

## Appendix 2 Non-Motor Symptoms

- |   |  |
|---|--|
| <b>Abnormalities of Sensation</b>                                     | <b>Neuropsychiatric Issues</b>   |
| ⇒ Olfactory dysfunction (smell)                                       | ⇒ Bradyphrenia (slowed thinking)   |
| ⇒ Visual dysfunction  | ⇒ Executive dysfunction (attention, organization, planning, concentration, memory) |
| ⇒ Pain, paresthesia (tingling)  | ⇒ Dementia   |
| <b>Autonomic Abnormalities</b>  | ⇒ Apathy (lack of motivation)  |
| ⇒ Orthostatic hypotension (dizzy when standing)                       | ⇒ Depression   |
| ⇒ Gastro-intestinal dysfunction (constipation, reflux, bloating, gas) | ⇒ Anxiety  |
| ⇒ Urinary dysfunction   | ⇒ Hallucinations   |
| ⇒ Sexual dysfunction  | ⇒ Psychosis  |
| ⇒ Thermoregulation (hot seems hotter, cold seems colder, sweating)    | <b>Other Non-Motor Symptoms</b>  |
|   | ⇒ Sleep dysfunction  |
|   | ⇒ Seborrhea (red, itchy, dry skin)   |
|   | ⇒ Weight loss  |

**Note from the author:** This material, in various forms (pamphlet, PowerPoint or personal presentation) is intended to increase awareness on the part of the persons with Parkinson's (PWP) that their interests in fighting and living well with Parkinson's are achievable and best met by taking specific lead roles in their fight. It is targeted at those who have been diagnosed with Parkinson's and their caregivers and is offered by a fellow PWP who fervently wishes to increase and speed other's success. Visit [www.meadowlark.org](http://www.meadowlark.org) to learn more about the Parkinson's Program and access video of this presentation.

## Appendix 3 Common Side Effects of PD Medications

- ⇒ Sleepiness
- ⇒ Hallucinations
- ⇒ Swelling of ankles
- ⇒ Drop in blood pressure (when standing)
- ⇒ Confusion
- ⇒ Involuntary movements (dyskinesia)
- ⇒ Nausea

## Appendix 4 Health Care Professionals

*Commonly needed to successfully work with PWP and caregiver in "team" atmosphere*

- ⇒ General Practitioner
- ⇒ Neurologist
- ⇒ Motor Movement Disorder Specialist
- ⇒ Speech Therapist (including voice, breathing, swallowing, facial muscles, cognition and memory)
- ⇒ Occupational Therapist
- ⇒ Physical Therapist
- ⇒ Counselor/Social Worker
- ⇒ Dietitian
- ⇒ Optometrist/Neuro-ophthalmologist
- ⇒ Dentist
- ⇒ Urologist
- ⇒ Gastroenterologist
- ⇒ Phycologist/Psychiatrist
- ⇒ Personal Trainer & Exercise Leader