



Stay Engaged – Do what you CAN still do. You will find that you can do many things that give you some measure of joy. The more active you are, the better off you will be.

Uncover your Purpose – You have a purpose. Your higher power has a plan. You are part of that plan. You need to fulfill your role in this plan. It may be to help others with your condition, it may be to help find a cure. Heck, it may be to write a book, teach at a university and travel the world bringing hope back to people who have lost hope.

And one last thing to do is to stay positive. Go and see as many inspirational speakers as you become aware of, especially ones who have Parkinson's (JohnBaumann.com). In addition, read as many positive, self-help books as you can or listen to as many positive readings of such books as you can, especially ones written by someone with Parkinson's ("Decide Success – You Ain't Dead Yet" is available from Amazon in written and narrated format).

**Staying positive will give you strength.  
Love will give you strength.  
Faith will give you strength.**

**John Baumann, World Parkinson's Program  
(Chair of the Patient Mentorship Program),  
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WORLD PARKINSON'S PROGRAM

### DID YOU KNOW?

Millions of Parkinson's patients suffering from poverty around the world

- Cannot afford to buy their medications
- Cannot afford to purchase a cane, walker, or a wheelchair
- Cannot obtain educational literature about Parkinson's in their language
- Are not able to afford consulting a neurologist and remain undiagnosed and untreated

### OUR SERVICES

We provide unique services for Parkinson's patients including:

- Parkinson's medications to those patients who can't afford to buy them
- Canes, walkers & wheelchairs to prevent falls
- Parkinson's educational brochures in 15 languages
- Free electronic educational newsletter
- Free Parkinson's clinics
- Chapters of World Parkinson's Program & Parkinson's Education Clubs in various parts of the world

### JOIN THE FIGHT AGAINST PARKINSON'S

**TO DONATE, VISIT PDPROGRAM.ORG**

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Acknowledgments: John Baumann

## Living Well with Parkinson's disease since 2002

## If I Knew Then, What I Know Now: A Definitive Guide for Those Newly-diagnosed with a Chronic Illness

*John Baumann, World Parkinson's Program*



WORLD PARKINSON'S PROGRAM

[www.pdprogram.org](http://www.pdprogram.org)

*"Those who fight Parkinson's with knowledge always  
find solutions"- Dr. Rana*

I remember the fateful day like it was yesterday. The doctor came into the waiting area took one look at me and said those fateful four words that changed my life forever, “You have Parkinson’s disease.”

She went on to say that I had all the classic, what they call, motor symptoms or manifestations: my right hand was trembling, my left arm did not swing when I walked, my face showed no expression (called facial masking), I did not blink, my handwriting was illegible, and my voice was no louder than a whisper.

Upon diagnosis, there are so many “first” things to do, it is mind boggling, so we put together this brochure that doctors can distribute to patients, especially those newly-diagnosed with Parkinson’s or other chronic illnesses.

You need to not look at this as a horrible death sentence. It is horrible, no doubt, but there are things that you can do to have a decent, if not amazing, quality life for many years, if not decades, with Parkinson’s. Take a breath. I recommend that you do what you can to shut down your feelings and emotions for now, there will be time for that later. Right now, you must go into warrior mode.

First, I recommend that you research and contact the World Parkinson’s Program ([pdprogram.org](http://pdprogram.org)) to obtain information and also contact a local patient support organization. Ask the staff for the names of “Movement Disorder Specialists.” Discuss with them how to tell your family (one of the emotional heartbreaking things you will ever do). If you are still working, ask them if they have the names of employment lawyers that have experience with Parkinson’s. Ask them also if they have a list of benefits and elder law lawyers.

Second, make an appointment with the Movement Disorder Specialist that you choose (after researching the list) as soon as possible.

Third, if working, you should meet with an experienced employment law attorney to discuss what rights you now have and which ones you think you might have, but don’t. You should discuss if, when, and how you will inform your employer. For example, if you live in the US, ask about “reasonable accommodations” under the ADA and “intermittent leave” under the FMLA.

It is never too early to research and choose a disability attorney, at the very least to know how the process works. In the US, there are waiting periods for social security disability and Medicare. Be sure and consult with the disability and employment attorneys that you have identified before taking any action.

Your diagnosis likely is a “shock” to your system and you may not be able to make decisions as well as you did before. You may need to run your decisions by someone you trust before taking action. Meet with your, or find a, financial advisor. Parkinson’s progresses at different rates depending upon your age, your physical fitness, what you eat, where you live, the disease itself, etc.

Some medications have side effects that could result in addictions: gambling, sex, etc. Making your financial advisor aware of this may prevent you from losing your life’s savings. Knowing this may help you resist, or seek help for, newly formed obsessions.

You need to realize that Parkinson’s may have an effect on your ability to multi-task and your short-term memory. Maybe turn some responsibilities over to your trusted care partner or financial advisor.

Recognize that, although Parkinson’s is a progressive, degenerative disease, eating a healthy diet and extensive exercise has been thought to, in some individuals, slow the manifestations of the disease. So, get a plan together, with the assistance of a nutritionist, fitness trainer, therapist, etc. to improve your lifestyle and stick to it.

Finally, it is time to deal with the feelings that you repressed in order to get through the practical issues. You likely are experiencing, or will experience, denial, anger, sadness, depression, fear, uncertainty, loss of self-esteem, loss of perceived self-worth, lessening of self-image, and reduction in self-confidence. You may need a good therapist. Again, contacting your local support organization for a list of doctors familiar with Parkinson’s is a great start.

There may also some non-motor issues that may present themselves at an earlier age than is “normal.” These include: eyesight issues, bathroom issues, rounded shoulders, back problems, non-specific irritability, restless leg syndrome, trouble driving, and bedroom issues (both sleeping and sexual), to name a few.

Some of these can be treated or, at least, lessened with therapy (especially deep tissue massage), rest, a healthier diet, changing up your daily exercise routine (as supervised by your fitness instructor) and sometimes medications specific to an issue (as prescribed by your doctor).