

Five Ways I Advocated for Myself While Battling the Symptoms of Parkinson's Disease



The Wake-up Call

My first inkling that something was not right with me was probably in graduate school. It was challenging to lift and turn in bed. I knew something wasn't right, but I ignored the signs. I experienced debilitating fatigue, but I attributed it to the fact that school was rigorous. I did not connect the dots, nor did I pursue a diagnosis or treatment at the time because I didn't have the money. It wasn't until I was an intern in graduate school that I had some wiggle room financially; that is when I sought medical attention. Muscle cramps, also called dystonia, reared their ugly head in South Carolina in 2003. You can't walk very well with muscle cramps, so I knew I had to get it examined. That was the beginning of a nightmare story of trying to get diagnosed. It was a difficult time for me. I had to change the trajectory of my life, so I developed a plan to advocate for my health; I implemented it and was victorious. Here are the five ways I advocated for my health.

Find a Primary Care Physician That You Trust

I dealt with my symptoms for a long time. The muscle cramps started in my right leg, but eventually, years later, my other side was affected.

It took so many visits to doctors to diagnose my condition; I don't even have an estimate. I saw doctors, including rheumatologists, orthopedics, and specialists in muscular dystrophy before I even reached a neurologist. I even had a biopsy, and a huge chunk was cut out of my leg and was tested to see if I had muscular dystrophy. At one time, I was very close to having back surgery, although it was not needed.

That is why it is so important to find a primary care doctor you trust so that they can help guide and help you to find the best care or the best specialist.

I chose about three doctors in my area and read their bios to find the doctor that best fit my needs. These are some of the questions I had in mind when I was researching:

1. Has the doctor treated patients with similar symptoms?
2. Does the doctor research the patients' symptoms during his office hours?
3. Is the doctor open to collaboration with other doctors?
4. Is the doctor open to using innovative technology in their approach to treating patients?



Become a Partner

Partner with your health care system by volunteering to serve on the board or patient advisory committees. Participating in these committees helps the doctors better identify the needs in your demographic. We can positively influence how we are treated as patients and improve the quality of our lives and our fellow patients by taking a seat at the table. A great example of this is my participation on Emory's Parkinson's (PD) Patient Ad Board; we are working on a research project looking at smartwatches. We are trying to determine if smartwatches have positive impact on patients by motivating patients to be active. I'm also a very active member of the PD Foundation Georgia Advisory Board, where I strongly advocate for my African American community and our needs as we plan PD community programs. Also, I have really enjoyed speaking on panels at Emory and for the PD Foundation, because I know that sharing my journey gives patients and our community hope.

Be Proactive



I was 35 when I got the diagnosis, but I had lived with the symptoms for a long time and made peace with them. Prior to me getting a diagnosis and after I lost my first baby, I knew that I had to make a change and take better care of myself. There was a point in 2010 when I could barely walk, and at that stage, the doctors and physical therapists were no help. That's the moment I decided I had to help myself. First, I researched illnesses similar to PD because many of the symptoms matched the symptoms that I had experienced. As I researched, I looked for information that would help me develop a wellness plan. The intent of this plan was to improve my overall wellness and mobility.

At first, I created my own exercise regimen and began eating lots of green leafy food. Then I began juicing and working out with a trainer and a cycling coach five days a week. Within about five months, the doctors and I noticed improvements. I was better and getting stronger, and when I was finally diagnosed in 2013, I began taking the medications carbidopa/levodopa and Mirapex and that just catapulted my improvements.

Find Your Voice

PD does not give you the luxury of having time to sit in your medical appointments with your mouth closed. If you have PD, you are in a race against time. The sooner you take action, your quality of life will be better. You must advocate for yourself faster than the illness is chipping away at your mobility. To do that, write your questions or concerns down and bring them to your appointment. This will help you and your doctor make the most of your visit.



One of the things I did that was very helpful was to give the doctor detailed information about my symptoms, including when and how long they occurred. Also, collect any information on your family's history that may help the doctor. In my case, I did not have much information about my family experiencing neurological problems. The person in my family that was experiencing issues did not want me to share the history with the doctors. However, having this information will help you get your diagnosis sooner.

Seek Support

I would strongly suggest that you link up with positive individuals, that are impacted by PD that you can relate to. I chose not to do that, instead, I bonded with individuals that I worked out with. I also found amazing support and lifelong friends in church and in a group called MOMS AND MOPS, a support group for moms. Many moms in these groups were health enthusiasts and I learned a lot about healing your body naturally through them.