

PARKINSON'S WARRIOR'S VIGNETTE

ED PIPER

Written By: Ed Piper

Ed Piper is a Pacing for Parkinson's team member.

Tell us a little about your relationship with Parkinson's Disease.

Parkinson's Disease appeared to me as a wake-up call while going out one morning for a five mile run. Suddenly my left arm stopped swinging on my left side and started to stiffen up. I scheduled an appointment with my primary care physician, who referred me to a neurologist. My first neurologist delivered the news to me in a shocking way I'll never forget. He told me, "yes you have Parkinson's. There is no cure for it. By the time you're 60 you'll be in a wheelchair pretty much for the rest of your life!" I walked home from the doctor's office and attempted to tell my now-deceased wife the bad news while she was on the porch. I told her that I have Parkinson's and she slammed the door in my face.

I decided to get a second opinion and learned that consistent levels of stress will aggravate symptoms of Parkinson's and that it was up to me to regulate my schedule, exposure to stress, diet, and exercise. At the time I was serving as a university chief of police and was also a 19-year adjunct faculty member with Johns Hopkins University. My condition began to deteriorate rapidly and I had to make some very hard decisions in conjunction with recommendations of my physicians. I had resigned from both positions in one month. I'll never forget the pain associated with giving up the two positions that I loved very much in order to try to regain my health.

Despite the fact that my body and my nervous system were being negatively affected by Parkinson's, I decided to go after some things I never pursued before because I was always working. One challenge for

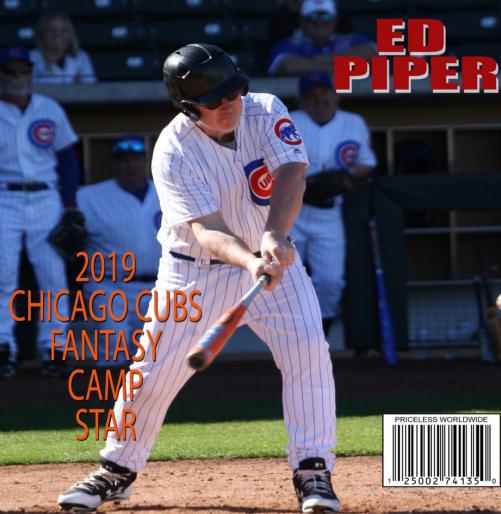


Above: Ed Piper with his Punching Bag

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Above: Ed playing in the Chicago Cubs fantasy program

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BEING A PARTNER OF A PERSON WITH PD OR FAMILY CARETAKER OR EVEN DEALING WITH AN EMPLOYER REQUIRES LOVE, COMPASSION, AND UNDERSTANDING.

me was to run the Rocky stairs [at the Philadelphia Museum of Art] and film it. As a matter fact, it was the Rocky theme music and movies that often kept me motivated to exercise and fight back against PD. Due to camera mishaps I had to run the stairs three times in order to get it filmed.

I also decided that I wanted to play for the Baltimore Orioles in their fantasy league program. Despite the fact I have Parkinson's, the Orioles gave me a waiver, and believe it or not I was able to hit the ball and run quickly to first base and usually beat the throw. I tried so hard to play my best that the Baltimore Orioles awarded me the True Grit award for perseverance and consistency.

Growing up in Chicago, I was also a Chicago Cubs fan, and so I also wanted to play for them. So I played two seasons with the Chicago Cubs fantasy program also, and I was given the game ball for my performance.

Parkinson's forced me to realize my own mortality and the fact that I was not always in charge of my body anymore. I look for inspiration from my fellow veterans disabled due to war injuries. I also look at historical figures such as Lou Gehrig and FDR. Though I have a new master, I am determined to fight it with everything I have!

When you think of the Parkinson's community, what word comes to mind?

The word love comes to mind. I say this because being a partner of a person with PD or family caretaker or even dealing with an employer requires love, compassion, and understanding. I could not do any of the things that I tried to do since the beginning of my Parkinson's journey without the support of my wife. She is an angel that always builds me up and gives me the courage I need to fight the negative challenges that face all of us with PD.

What's one piece of advice you would give someone with PD and their community?

Parkinson's Disease is too powerful to face by yourself, and it requires a community made up of family members, medical professionals, psychological advisors, spiritual advisors, and at least one or two totally dependable friends with whom you can share anything. As the Barbara Streisand song "People" says, "People who need people are the luckiest people in the world!"