

SHAKEN, NOT STIRRED: Living with Parkinson's Disease is the story of a reluctant hero navigating the trauma of a lifealtering diagnosis. Despite the seriousness of his illness, Linton is living a life that is more rewarding, fulfilling and meaningful after his diagnosis than before. Reading this inspiring book will transform your life, too.

SHAKEN, NOT STIRRED

Living with Parkinson's Disease

by Larry Linton

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Larry Linton SHAKEN, NOT STIRRED: LIVING WITH PARKINSON'S DISEASE



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This book details the author's personal experiences with and opinions about Parkinson's Disease. The author is not a healthcare provider.

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Introduction

In 1969, Elizabeth Kubler-Ross wrote in her book, "On Death and Dying" that grief could be divided into five stages: denial, anger, bargaining, depression, and acceptance. Although originally devised for people who were terminally ill, the stages have been adapted for other experiences with loss, too.

Forty-three years later, in 2012, confronted with a life changing diagnosis of Parkinson's disease at the age of 49, I went through the same stages. Each stage was experienced, but not necessarily in order. Sometimes, I felt like I went through all five stages in one day. Other times, my day would start with depression, but as the day progressed, I became frustrated, and angered. Some days, I could not actually define what stage I was experiencing. I just knew that I was not myself.

You may have picked up this book because you have recently been diagnosed and struggling to cope with such an unexpected life changing event. You may be the caregiver who has now been, unexpectedly, shouldered with the burden of the condition, too. You are feeling

overwhelmed with all the incessant questions flooding into your head, but you don't have any answers. You lie in bed fretting about your career, your home, the well being of your family.

This book purposefully avoids subjects like the possible causes and risk factors of Parkinson's disease, the pharmacology of the disease, the various stages of the condition and its progression. Instead, the book essentially starts with the premise and a fundamental question: you've got it, now what?

To answer that question, and the underlying reason for writing this book, is to

share with you my own experiences through the same stages of grief. More importantly however, this book gives you a look into my life before my diagnosis, the dark days that followed "the day of," but then, more importantly, how I managed to start to enjoy a life that is, in many respects, more rewarding, fulfilling and meaningful AFTER my diagnosis, than before. My sincere hope is that it helps get you to the same stage far sooner than me, so that you can regain control and continue to enjoy a life that is worth living, and to do so for many years to come. Parkinson's disease does not control or define me. I want the same for you.

CHAPTER ONE Diagnosis Delivered

"The diagnosis can be done in about two lines. It doesn't engage anybody" - David Foster Wallace

"Parkinson's disease is a chronic and progressive neurodegenerative disorder for which there is no cure."

I read that on an information pamphlet in the waiting room at my first appointment with a neurologist. All I could focus on were the words: Chronic. Progressive. No cure.

Three years before the appointment, I became conscious of a slight, but continuous, twitching of my small finger of my right hand. It was the first thing that I noticed every morning when I woke up, lying in bed after the alarm clock went off. Then, a few months later, my right leg started dragging, and I noticed that I was walking with a sort of flat, dropped foot. I didn't have a natural heel-to-toe gait, it was more like a slapping motion. I saw my GP to discuss these issues but, in his opinion, I was anxious. I was too young to have Parkinson's disease. It was all in my head. I came up with excuses: too much coffee was causing the twitching in my

hand. My dragging leg was a result of too much running, I pretended to myself.

I saw a Chinese herbalist and he told me I should live near water and prescribed something to drink that tasted as bad as it looked. Sessions at a physiotherapist, hypnotist, acupuncturist, and herbalist followed. Three years later I had developed a resting tremor in the whole of my right hand. I could hardly walk, let alone run.

Even years before, I noticed tremors in others: I watched the HBO series "Real Sports with Bryant Gumbel" interview with Freddie Roach (the trainer of the boxer Manny Pacquiao) talking about how he

confronted living with Parkinson's disease. I focused on his right hand. My hand had a similar tremor. Before coaching, he had been a professional boxer and took blows to the head. That's why he got Parkinson's disease, I convinced myself to think.

I saw Muhammad Ali light the Olympic Flame during the opening ceremony of the 1996 Atlanta Games, his left arm shaking uncontrollably as he did so. He was in the advanced stages of his fight against Parkinson's disease, a fight that he unfortunately lost in 2016. I rationalized that, again, it must have been all those years of taking blows to his head that caused him to get the disease.

Then, of course, I saw Michael J. Fox. I have always liked Michael J. Fox. On my first trip to the United States, and after seeing him in "Back to the Future," I had to find those same red striped, white leather Nike sneakers, as well as a pair of Original 501 Levi's that his character, "Marty McFly," wore in the movie. Later, watching him on "Family Ties," I tried to adopt the same preppy look of "Alex P. Keaton" as a young law student at the University of the Witwatersrand in Johannesburg, South Africa, right down to the same tanned executive briefcase that he used in the show.

Years later, when he announced that he had Parkinson's disease, I was sad for him.

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Little did I know, I would have something more in common with him besides sneakers and jeans. He told a similar story about a resting tremor in his left hand as the earliest symptom and the start of his journey with Parkinson's disease. He was 30 years old at the time, working on "Doc Hollywood," his fifth film in three years. He was a busy actor, not a professional boxer! I was neither, but I had the same tremor.

The appointment with the neurologist comprised of a full medical history including the checking of my vitals, like blood pressure, pulse check, heartbeat, lungs and the usual "prod and poke" around the abdomen. The examination quickly progressed to a brief

neurological examination and observation for balance, coordination, tapping and extending the fingers, and the writing of a sentence. All of this lasted 30 minutes before I heard it officially: "It's my opinion that you have Adult Onset Parkinson's disease."

But what I really heard was: Chronic. Progressive. No cure.

So, just like that, after 3 years and 30 minutes, I finally had a diagnosis. At long last, I knew what I had, and didn't have to bother about trying to get an opinion from another list of health providers. The doctor recommended one drug to start (Mirapex) to

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be taken three times a day and wanted to see me again in a month. That was it.

Chronic. Progressive. No cure.

No mention was made of those three topics. Nor did he address his history of treating patients with Parkinson's disease. Nothing on his overall treatment philosophy. It was all very clinical, and unemotional.

Waiting to finalize my next appointment with the receptionist, I noticed that the waiting room had filled up. I looked at some of the faces and I wondered how many would be getting the same news that I had just received. How many other lives would be impacted and forever changed from that

day forward? What does it all mean? What happens now, today and tomorrow? I had no answers. My only focus was on the words: Chronic. Progressive. No cure.

Returning to the office, and to the pile of files on my desk, no longer seemed important. I needed to be at home. When I got home, I poured myself a whiskey - it was 5:00 PM somewhere! I booted up my laptop and typed into Google and YouTube, "Parkinson's disease." I was traumatized at what I read and watched. I had no terms of reference or any understanding of what I reading or seeing - "freezing," was "dyskinesias," "dystonia," "dopamine agonists" were words that were suddenly added to my

vocabulary, but with no real understanding of what they meant.

The images that I saw terrified me. People sitting in chairs, shaking uncontrollably, some walking with flailing arms and legs, some with expressionless faces, others drooling. Was I looking at my future self? How was I going to live with an old person's disease at the age of 49? How was I going to provide for my family as the principal wage earner?

That day was the start of another traumatic period of my life.



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