

DEFYING DESPAIR

*Feed the Mind
Train the Body
Nourish the Soul*

Anthony Scelta Jr.

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FOREWORD

There has been an explosion of books on Parkinson Disease, including two of my own: *Shaking Up Parkinson Disease and 100 Questions and Answers about Parkinson Disease*. About half of the books are by doctors giving patients and care-givers information on treating Parkinson Disease, and about half of the books are by patients giving information on coping with Parkinson Disease. Why is this book different? It's different because Anthony Scelta was diagnosed with Parkinson Disease before he was 25 years old! He has lived a life, for all intents and purposes, knowing only Parkinson Disease, with a brief memory of what it was like to live without this malady. Most people in his shoes would have drowned in despair. Anthony has not! Somehow through will, through physical conditioning, through sheer “guts” he gives all of us a message of hope in adversity. This is definitely a book worth reading!

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Internationally recognized expert on Parkinson Disease,
author of five books on the topic,
and National Medical Director of the National
Parkinson Foundation.*



INTRODUCTION

Out of the one and a half million Parkinson's sufferers in this country, I am one of the few to have developed the disease by the age of twenty-five. Before I reached thirty years of age, I displayed most of Parkinson's worst symptoms, including debilitating fatigue, extreme rigidity with muscle spasms, slowness of movement, tremor, and insomnia. While dealing with the emotional issues of having a failing body, I needed to handle the practical problems of being the single dad of a newborn. Adding insult to injury, my disability prevented me from continuing my livelihood as a personal trainer. Flat broke, overwhelmed, and despondent, I sank into the abyss. This invisible foe called Parkinson's Disease had dismantled my life. At my darkest moment, I knew I had to make a decision: Give up on living altogether and waste away, or fight to get my life back.

I chose the latter. But who was I fighting? How does one fight an insidious and intangible adversary like Parkinson's Disease? I didn't know exactly how, at first, but I was determined to prevail. No matter what, I would not let it beat me. Instead, I would defy it!

Earlier in my life, the solution to most of my problems was somehow always related to fitness—my whole world revolved around it. Fitness, in one form or another, was my

livelihood, my source of self-esteem, and my passion. If I was going to defy despair, exercise needed to play a big role. However, in the poor physical condition that I was in, it was hard to fathom ever being fit or even simply feeling good again. I realized that training my mind, as well as my body, was the only way I would truly feel whole again. That is when my spiritual journey began.

After much exploration, study, and reflection, I realized that three essential ingredients in facing monumental challenges are Faith, Inspiration, and Tenacity. With the insights that I gained, I built a foundation of inner-strength to face what was before me. Suddenly, my obstacles were no longer barriers, they were challenges. As my mind was getting stronger, my body was following suit. The mind-body connection was more profound than I had anticipated. The realizations that I made through study and introspection were helping me emotionally. Additionally, my new outlook allowed me to fight past my physical limitations in order to strengthen my body. Becoming fit, in turn, further fortified my emotional and mental state. It was a powerful cycle that gave me my life back.

Now it's time to create your own success story. Defying Despair can help those who want to:

1. Find meaning in their lives, particularly in their suffering.
2. Overcome any adversity while reveling in the good things that life has to offer.
3. Strengthen their mind, body, and spirit.
4. Feel healthier and fitter than ever before.

Introduction

Part I of the book contains a light-hearted account of my struggles with Parkinson's, and the events leading up to my metamorphosis. From denial to depression, this section describes my experiences with the same issues that plague all of us during times of crisis.

Part II sets forth the cerebral portion of my mind-body strategy for defying despair. In it, you will learn to be F.I.T., by building a foundation of Faith, Inspiration, and Tenacity. Whatever the source of your despair—divorce, illness, loss of a loved one—you will discover that all of us have the same battle to fight. Despair is our common enemy, and the F.I.T. strategy is the common battle plan.

Part III describes the role physical fitness plays in preventing and managing illness. The emphasis of this part is on the benefits of exercise, and how it can strengthen the mind as well as the body.



PART I:

*The Harbinger
Of Despair*



CHAPTER ONE

The Bomb Drops

Plan To Be Surprised

“**W**hen we make plans, God laughs.” I heard this Jamaican proverb many years ago, but at the time, I paid it no mind. You see, in my early twenties, I had it all planned out. As far as I knew, nothing could stop me from personal training clients, having fun, and basically flying by the seat of my pants. Vibrant, and in peak physical condition, I wanted to enjoy life to its fullest. I was young, brash and seemingly invincible—I didn’t think there was anything beyond my reach. That’s when God let out a guffaw that sent a shockwave through my life. My life’s vision had been snuffed out, and replaced with a nightmare that was unimaginable. Despite all my planning, developing Parkinson’s Disease at the age of twenty-five was definitely not something I had anticipated.

My first symptom was tightness in my left shoulder and arm. I was even having difficulty putting on a jacket because of it. At the time, I figured it was nothing more than a minor, sports-related, shoulder injury. Shortly after I experienced my

first symptom, something happened at the gym. In between sets of a shoulder exercise, my whole body started to tremble. My legs were so wobbly that I could hardly drive home. I figured I must have been glycogen depleted—when the body is deprived of sugar—due to overexertion. Within days of that incident, my left hand started to tremble quite visibly, for no apparent reason. I didn't know what the heck was going on. All I could think of was that I had developed some sort of sensitivity to caffeine. So I eliminated it from my diet. Finally, on one occasion, during a heated repartee between me and a crooked car salesman, my left arm shook very violently and uncontrollably. It was then that I decided to see a doctor.

The first doctor I saw dismissed my symptoms as “probably stress related,” but tested for a possible thyroid condition just in case. When hyperthyroidism was ruled out, and my tremor persisted, I was referred to a neurologist. Like a Ping-Pong ball, I was bounced from one specialist to the next. Comments like, “You're okay, you're probably just depressed,” coupled with questions such as, “Are you gay?” made the process terribly frustrating. What on God's green earth did my sexual orientation have to do with anything?

Then came the real fun and games—the testing. First, I went for an MRI, then for a CAT scan, and then for another MRI. These exams were my own little tubular tunnels of torture: Forty-five glorious minutes of being entombed in a temporary casket, with loud thumping noises walloping my eardrums. If I would've known then that the torture tunnels would be the most pleasant of all my tests, I might have tried to enjoy them more.

A nerve conduction test, called an EMG, was by far the most harrowing of the lot. Before the test even started, I

knew I was in trouble. You know how it works. When the doctor tells you, “This won’t hurt a bit,” you know it’s going to hurt. If he says, “This may hurt a little,” it’s going to hurt a lot. Well, the doctor performing the EMG said to me, “This is going to hurt quite a bit.” So you do the math.

During this procedure, I was given the opportunity to do my best impression of a voodoo doll. First, the doctor would stick a large needle into a particular muscle in my arm—the muscle between the index finger and the thumb, for example. Then I had to tense up that muscle, and hold it for about thirty to sixty seconds. So, while the needle was jabbed between my index finger and my thumb, I was told to make a fist. The pain was excruciating. After being probed approximately thirty more times, in various parts of my arm, it was almost over.

By then I was exhausted, and severely nauseated. But the fun continued for another half hour, with unbearable electric impulses being applied to the same traumatized parts of my arm. At least if I ever get electrocuted, I’ll be prepared. When I was done being tortured, I was hoping they could at least tell me something; anything. But they couldn’t.

A year of more probing and testing finally led to the initial diagnosis. Frankly, I thought the doctor was nuts. Besides, he didn’t even sound convinced of the diagnosis himself. Believing that the diagnosis had to be wrong, I got three more opinions, the last of which was given by a renowned doctor at the National Parkinson’s Foundation in Miami. At that point, I finally believed it.

The unequivocal words, “You have Parkinson’s Disease,” left me numb. As I left the office, I replayed the

doctor's description of the illness in my mind. "It is a progressive, neurodegenerative disorder that eventually leaves the patient debilitated. And there is no cure." In essence, part of my brain was dying, and there was nothing they could do to stop it. It was just too surreal to process. I wasn't scared, sad, or angry; just totally stupefied.

Breaking the News

That night, when the time came to tell my girlfriend of the official diagnosis, the stark reality of the situation hit me like a ton of bricks. I had heard the doctor utter those two dirty words that afternoon, but somehow, when "I have Parkinson's Disease" came out of my own mouth, the realization set in. I had never uttered those words before. There was always that suspicion, or hope to be precise, that the first three doctors were wrong. But I had finally run out of wiggle room. There were no more "maybes." I had Parkinson's Disease....period. That night, my girlfriend and I, both cried ourselves to sleep.

Mustering up the courage to tell my older brother and my mother didn't come until a week later. My mother made an effort to be strong, and offered many supportive words. My older brother, however, went into immediate denial, despite the second, third, and fourth opinions. It was his only way to cope with the pain. I actually waited an entire year to tell my father, fearing he wouldn't be able to handle the situation. Despite the immense pain he must have felt upon hearing the news, he hid it fairly well. For him though, my particular condition was especially hard to accept. All my life, my body and athleticism had been a source of great pride for him. It was a rare occasion for him not to "feel my

muscles” during one of our visits. So he had to get used to the fact that his son was no longer that guy with the muscles. For me, the pain my illness was causing my loved ones was much harder to bear than the disease itself. Outside of my family, I only told my closest friends.

It was very strange, but every time I broke the news to someone, I felt as if I was letting them down. It felt like I was telling them that I just paid off a gambling debt with the deed to their house. I think it’s common for people who become ill to feel guilty in some way. Whether my feelings came from the guilt of not being able to fulfill certain expectations, or from the guilt of causing other people pain, or something else entirely, I do not know. It was probably all of the above. This guilt, however, was only a harbinger of the many extra burdens to come.

Assimilating the Unimaginable

The future was suddenly uncertain and ominous. I could no longer entertain pie-in-the-sky fantasies of all the great conquests that were in store for me. Instead, they would be supplanted by the realities of surviving day-by-day. I handled the next few weeks relatively well, considering the doctor’s diagnosis occupied my every waking and sleeping thought. It was literally overloading my brain.

But, I am invincible

Then, suddenly, after a few weeks, I became totally at ease. I barely gave my condition a second thought. I guess my mind just shut down, in a sense. With this, came a new attitude. For some reason, I could not fathom being affected by this disease—or anything else for that matter. Not only was I

physically fit, but my symptoms were minor. And after I was prescribed my first medication, I felt even better. To my delight, the tremor and stiffness had been minimized. In my mind, no obvious symptoms meant no disease.

I guess my attitude was to be expected. After all, I spent twenty-five years thinking I was invincible. Why should that change in just a few weeks? My past was replete with stupid stunts, all of which left me unscathed. So who could blame me for thinking my good luck would continue?

When I was a teen-ager, a friend and I used to get drunk, and speed through New York City's Central Park in the middle of the night. Most of the time, one of us would be hanging half-way out of the sun roof. How we didn't fly out of the car taking sharp turns at 70 mph is a mystery to me. Years later, when I was in Costa Rica, I also exhibited poor judgment that put my life in danger. Very late one night, I was roaming the streets in search of a particular discotheque that was located in an extremely dangerous area, especially for tourists. It was so bad that even the cab drivers wouldn't stop in that neighborhood. So being as prudent as I was, I attempted to find the club--on foot. I never found it, which meant my stay in the bad part of town was brief. Luckily, my arrogance didn't get me killed that night.

These examples provide only a glimpse into the moronic adventures of "yours truly." When I look back on my past behaviors, I really can't believe how untouchable I thought I was. Okay, so I'm being euphemistic. I know "stupid" is probably the description you had in mind.

I had to be invincible to survive all the hairy situations I put myself into. What else could I think? Well, it was several weeks after a diagnosis of Parkinson's Disease, and

wouldn't you know it, I still thought I was invincible. Even though I felt that nothing could touch me, I did not pretend that my illness didn't exist, however. I did do my homework. I read up on the disease and discovered that some people have lived very well with Parkinson's. Since the disease affects everyone differently, I was certain that I would have the milder form of it. And in some cases, the disease can progress very slowly. Again, I took it for granted that I would belong to this elite group. So I had a reason to hope. However, I also discovered that younger patients—only five percent of Parkinsonians develop symptoms before the age of forty—tend to have a more variant form of the disease. Furthermore, side-effects from medications tend to be more severe in younger patients. To top it all off, most research studies excluded patients under age forty, because they are so rare, and their progression is so unpredictable. But this information conveniently floated over my head. After all, none of it could possibly apply to me. I remained sure that I was physically too strong to succumb to the same symptoms that plagued other Parkinsonians.

Strength or denial?

My air of invulnerability actually seemed to work for a while. Everybody that knew of my diagnosis marveled at how well I was coping with my fate. I would frequently hear, "I don't know how you do it," or "You are so strong." I didn't think I was being particularly strong at all. Given my warped sense of reality, I honestly thought it was no big deal. That's because like most people facing a loss of some kind, I was heavily entrenched in denial. I guess it was my mind's defense mechanism, to give me some time to assimilate all the ramifications of my illness. And in retrospect, I definite-