



# Find Your Roar

A Memoir of Life, Health,  
and Living with  
Parkinson's Disease

**DEE GIBSON**

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## Dedication

To my one true love, Kathy Gibson, whose life has been a testimony of her love, passion, and patience for me.

And to my three adult children, DeeAnn Hanlon, Andy Gibson, and Denae Green, along with their spouses, and our four incredible grandchildren, Adelyn, Lydia, Gibson, and Marshall, whose love for me has made living with Parkinson's disease less of a challenge.

Thank you all for your unwavering support and encouragement!

Sample Chapter

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# INTRODUCTION

It was a crisp fall afternoon just after Thanksgiving in 2019. The sun was peeking in through the sliding glass doors and I was sitting at the kitchen counter “talking” with my son, Andy, about what had become one of my biggest challenges—my speech. The house was silent except for some music playing quietly in the background. There was a scented candle burning in the kitchen with the warm, aromatic smell of vanilla and sugar. It was just the two of us, one of those father and son moments dads always dream of, except that the circumstances that brought us here were less than ideal.

Andy and I were in similar circumstances—well, sort of! Being a leader of a nonprofit in South Carolina, he had just returned home from a time of sabbatical. We were both trying to discern our respective futures. Andy was trying to decide if he was going to stay at his current job, and I was trying to plan for a future that included my recent diagnosis of Parkinson’s disease (PD) and figure out how to enjoy my retirement in the meantime. Although I wasn’t completely convinced of it, I had been dealing with similar symptoms of PD for over three years. I was still moving pretty well, having just returned from a trip to Washington, D.C., where I had walked and walked and walked some more. But as far as my voice was concerned, it was difficult to speak loud enough to be heard. Andy would lean in whenever I spoke, often putting his ear close to my face to hear what I was saying. Even with the good relationship we had, I was frustrated with him being so close to my face just to hear my voice. I was still holding out hope for a different explanation for my symptoms.

For most people with PD, their voices become softer. In my case, however, I have a hard time getting my words out to begin with. And when I feel stressed or anxious, they often become garbled and almost unintelligible.

As we talked, he shared that he'd been praying for me and believed God would help me "*find my roar.*" Andy felt He would heal my voice, and I prayed he was right. But I also believed God would help me find it in another way. Since that fall afternoon at the kitchen counter with my son, I knew that one day I'd write this book sitting before you now, even though its contents weren't yet fully clear to me in that moment.

This memoir is the record of my journey with Parkinson's disease. Through the depths of my pain, I have had extraordinary experiences with God, my wife Kathy, and my children, which have radically changed the way I live and how I love those around me. In the pages that follow, those suffering with PD, as well as their families and caregivers, will discover that hope can be found even if healing in this life doesn't come. I've learned that a person with this disease can lead a full and meaningful life. In fact, life can be more impactful because chronic pain and suffering keep us more grounded and focused on what is most important in our lives. Despite the circumstances, surrounded by my family's love and being in a right relationship with God reminds me that everything is going to be okay.

*Find Your Roar* is a book divided into three parts. The first is about my personal journey with Parkinson's. I've heard it said, "*If you've ever met a person with Parkinson's disease, that is exactly what you've done: You have met a person with Parkinson's disease.*" You see, what I have learned is that Parkinson's disease, like many other neurological conditions, is very hard to diagnose because it's difficult to discern exactly what is happening with a patient. There are no blood tests or x-rays that can give an exact diagnosis, which can be incredibly frustrating. It is possible many are left wondering, not weeks or months, but often years in trying to determine their exact illness. Not having a firm diagnosis can be more stressful than officially finding out itself.

If this is your diagnosis, I imagine you feel both bewildered and uncertain about your future as well. The unfortunate reality of the situation is it can be extremely difficult to manage your emotions



through it. I understand. In part one, I trust that my words and story will help you find hope, peace, and joy in your life.

The second part is about the role and importance of caregivers. I've had the privilege of speaking to a number of those living with PD and those who ultimately provide their care. It's not one person's affliction, but rather a disease that affects an entire family. And as you will see, the closer you are to the person with it, the more your life is changed as well.

The third and final part is about the all-important question of immortality. Is there a purpose in our pain? While this book is primarily for those dealing with PD, I am confident anyone facing a life-altering hardship, suffering, or affliction will find help here. Although this last part of the book is not a deep theological treatise on the question of immortality, it is most definitely a question I have had to wrestle through personally. And I hope anyone who takes the time to read it will find both answers and encouragement. This book is ultimately about hope, healing, and living a life filled with purpose and passion, not in spite of, but because of one's circumstances.

Thank you for going on this journey with me and helping me find my roar. Suffering doesn't have to be the end of the story; rather, it can be the beginning of a new one. My hope and prayer for you is that this book might inspire you to find your *own* roar.



PART 1

**Finding  
My  
Roar**

Sample Chapter



## CHAPTER 1

# My Journey Begins

It was early 2015, and I had gone to my primary care doctor for what I thought was a routine office visit. He had known me for years as a big, strong guy. I always prided myself on being physically fit and active, participating in high school sports, running track in college, and playing basketball and lifting weights until my late forties with work colleagues. Even in my early sixties, I retained the athletic build I'd always had. But my doctor had seen some changes. My movement was slower, and my speech had gotten quieter.

“Dee, I want you to go see a neurologist,” he told me. “I want to make sure there’s nothing going on here.”

He knew of patients who could only say a certain number of words in a day, and he didn’t want that for me. Some years later, he indicated that because he hadn’t seen me very often, he noticed stark changes in my slow movement and gait, what I know today as *bradykinesia*.

I can’t say I summarily dismissed his assessment because I went to a follow-up appointment with a neurologist, but I didn’t necessarily buy what he was selling, either. In fact, I nearly dismissed the whole notion of having PD after my first visit, primarily because *that* neurologist gives all neurologists a bad name.

As I remember our first visit, he was very cold and distant. He asked me my name and date of birth, then just sat there fiddling

around with his ink pen, taking it apart and putting it back together again. He never once looked me in the eye or did any kind of assessment. As I was leaving his office, I considered that a huge waste of my time. I was, and obviously still am, put off by his behavior.

It wasn't until some months later that Kathy, my wife of nearly fifty years, noticed changes in my demeanor as well. We were sitting at the dinner table one evening early in 2016 when she saw I was eating very slowly.

"Dee, are you feeling okay? You remind me of Jim," she said. Jim, my brother-in-law, has waged his own war and battled brilliantly against the same dreaded disease. At this time, I was still an active chief executive officer of a twenty-million-dollar nonprofit called Josiah White's, one of the greatest charitable childcare organizations in the country. It was established in 1850 and created to care for troubled youth in a residential setting. Today, it's one of the largest childcare institutions in Indiana with a vast array of services, including residential treatment, therapeutic foster care, and home-based services for teens and their families. On top of my work there, I was still jogging (albeit ever so slowly), swimming laps, and weightlifting.

As time progressed, I noticed changes in my ability to swim laps. My arm motion was not as smooth or flexible as it had been earlier. Until a few years ago, our family would often go out in the boat at the lake to swim and bathe during the summers. We would take shampoo and lather up, and then jump into the lake for our daily bath. I am now, however, like a beached whale because I must watch from the boat. I can no longer swim well enough to stay afloat or get in and out of the boat with ease.

I have a very good friend, Jim, who, for a couple of years, worked in a senior living community with a swimming pool. After Jim retired from the Federal Motor Carrier Safety Administration, he was a life-guard at the pool and assisted elderly people, a number of whom had PD. He told me he would often have to put ankle weights on clients so

they wouldn't lose their balance and end up upside down in the pool. I hate to say it, but for a season in my life, I dismissed Jim's comments because I felt what he was saying didn't apply to me. Now, however, it makes perfect sense. As my Parkinson's has progressed over the last six years, what originally was slow movement became muscle rigidity and is now postural instability.

A second early warning sign was my quiet voice, although it was still much louder and more understandable at the time than it is today. Other people had commented on my tone and volume as well, but I shrugged it off as possible nerve damage from a throat surgery some years prior.

Yet another early sign was my handwriting, but then again, I've always had terrible writing skills, even from a young age. I was a south-paw (left-handed), which meant I constantly wrote over the top of words I'd just written. My handwriting was so poor I often quipped that I wrote like a third grader. Truth be told, my grandson, who *is* a third grader, has great penmanship. But today, my handwriting is so poor that I avoid writing as much as I possibly can. As an adult, however, there are times when writing my name, address, phone number, and email address are unavoidable. This has turned into one of my biggest embarrassments because I write so small it's utterly unintelligible. Even with some occupational therapy, nothing has proven helpful to date. Thank goodness I can still type reasonably well, which has been a godsend when it comes to my communication skills!

And finally, a fourth early warning sign was a "frozen shoulder" which can be very painful. Going back close to fifteen years, I had the first of two secondary shoulder impingements. Simple daily tasks can become almost impossible to do—things like putting on a belt or coat or tucking in your shirt. But I can tell you as painful as these things are, the treatment modalities are worse and downright barbaric.

I believed at times that my physical therapist was a sadist. There are fibers that grow together and restrict your movement, much like a

rubber band that is pulled tight all the time. They impede your arm's ability to move freely in the joint. My physical therapist's job was to break these rubber band-like structures in my arm to allow for freedom of movement. The problem wasn't so much the therapist as it was the home treatments he assigned, which involved things like broomsticks and Kathy using her leverage to manipulate my arm in ways it simply didn't want to go. Although she hated putting me through the pain, we had some fun with the whole "broom" thing, specifically when I accused her of being the "wicked witch of the west." Actually, Kathy would be an excellent physical therapist. She liked to say, "I know this is going to hurt, but do it anyway!"

The formal definition of a frozen shoulder is when the humeral head isn't centered within the shoulder joint, causing impingement when the arm is moved. Common causes include specific upper body exercises, poor posture, or muscle imbalances such as rotator cuff weakness. The working theory is that this condition is due to a change in the arm swing of people with PD. The good news is that if you are willing to go through the pain of rehabilitation, my experience has been that you can recover from a frozen shoulder, even with a Parkinson's diagnosis.

Because of Kathy's concerns, I went to see another neurologist at the Indiana University Medical Center, but I still wasn't convinced. They explained the difficulty in diagnosing PD, primarily because the symptoms are so varied and elusive. He was not prepared to give a conclusive finding, especially given that my symptoms were so mild then. He did, however, suggest I consider Rock Steady Boxing. It's a nationally recognized program in Indianapolis, and it's known to benefit those with Parkinson's.

Kathy and I stopped by the gym on our way home. One of the original founders was a lady who showed me around, and she proudly proclaimed they were known as "the badasses of PD." The Rock Steady Boxing program has four different levels; the lowest level is designed for those with only mild symptoms. I was impressed with the entire program. They had good facilities with all the equipment needed to



teach boxing, but most of all, they had the right attitude towards the disease. I even joined another location closer to my home and attended classes regularly for the next year until my thyroid cancer surgery. I went weekly to the Level One class, where we did all kinds of boxing drills which I had never done before, but I really enjoyed the training. I used the heavy bag and beat the snot out of it. Fortunately, for everyone involved, there was no live contact between clients.

Although I don't remember much about those early months in the class, I can recall with clarity the founder's comment about being a badass. I felt like one and didn't realize how much I needed it. In fact, that comment means more to me today, given the progression of the disease I've seen in my own life. Still, throughout 2016, I struggled to accept the reality of the disease, in part because my symptoms were so mild and because the neurologist at the IU Medical Center hesitated to give me a firm diagnosis. Soon, however, I wouldn't be able to ignore the signs any longer.

Sample Chapter



## CHAPTER 2

# Mad As Hell

It was a cold, wintery night on the twenty-eighth of February 2017. It was three o'clock in the morning, and I was lying in a hospital bed recovering from the second of two surgeries to remove my thyroid. I felt unsettled in my spirit—not so much afraid, but anxious! Emotional! Worried! I wasn't even certain about what.

I suspect part of my anxiety was a lack of sleep. The night before the surgery, I showered with a special soap to prevent infection, which only added to my anxiety. It was the moment I realized this was not a standard routine procedure. And then I had to be at the hospital before dawn.

After surgery, and throughout the day and night, the nursing staff came into my room checking my vitals and all the tubes attached to my body. I had been pricked and probed in every way imaginable and felt like a proverbial pin cushion. But hey, at least I knew the ropes. Two weeks earlier, I'd had the exact same surgery. The first was to remove just half of my thyroid, in hopes the cancer would be contained in the nodule itself and a full thyroid removal wouldn't be necessary. But it was.

**I HAVE THYROID CANCER!** There is something very sobering about hearing the words, “You have cancer,” that causes a person to stop and evaluate their life. This was a gut check moment . . . when I realized I was getting older and as the Good Book says:

## FIND YOUR ROAR

*“You’ve limited our life span to a mere seventy years, yet some you give grace to live still longer. But even the best of years are marred by tears and toils and in the end are nothing more than a gravestone in a graveyard! We’re gone so quickly, so swiftly; we pass away and simply disappear.” (Psalm 90:10 TPT)*

Up to this point in my life, I had felt pretty good. Sure, I’d had some health concerns, including the suspected PD a year earlier, but overall, it had not yet seriously affected my life. But now, with my thyroid removed because of cancer, I was taking inventory. I came to understand all too well the truth of this verse. My days are numbered.

I’ve never considered myself a poet but had limited exposure to it through some of our students at Josiah White’s. They were young, teenage men from troubled backgrounds, and they wrote incredible poetry under the guidance of house parents who had worked with a professor at Manchester University. Reading their words, I determined that when I retired, I would write some poetry too. Little did I realize these first two would take on such a significant role in my life. The following poem, titled “Mad as Hell,” was written over the two weeks following my first surgery—starting at three o’clock in the morning on that lonely, hospital bed in the Indiana University Medical Center.

Sample Chapter

## ABOUT THE AUTHOR



**Dee Gibson** has dedicated his life to serving others for forty years, twenty of those as chief executive officer at Josiah White's, a 170-year-old organization and one of Indiana's oldest and largest nonprofit social services agencies. He has served on numerous boards and committees dedicated to the welfare of children including the 2004 Indiana Commission for Abused and Neglected Children and their Families. Dee finished his remarkable career receiving one of Indiana's most distinguished awards, The Governor's Sagamore of the Wabash, recognizing individuals who make significant contributions to their commu-

nities and whose qualities and actions endear them in the hearts and minds of Hoosiers.

Dee is a graduate of Marion College (now known as Indiana Wesleyan University) in Marion, Indiana, and has a graduate degree from Ball State University in Muncie, Indiana. He is a licensed social worker in Indiana as well. In 2019, Dee was commissioned as a Colson Fellow, from the Colson Center for a Christian Worldview. This is a ten-month deep dive into culture and how it relates to a Christian worldview that provides Colson Fellows with clarity, confidence, and courage to effectively engage the world.

Although Dee struggled with symptoms of Parkinson's disease for several years prior, he was not formally diagnosed until 2019. Since then, he has suffered numerous setbacks. But with the incredible support of his wife and children, he has continued to make "lemonade out of lemons."

Dee and Kathy Gibson have been married for fifty years. They have raised three children, DeeAnn Hanlon, Andy Gibson, and Denae Green, and share four grandchildren together. Today, they reside in Sweetser, Indiana, and continue to live a vibrant life dedicated to their families and serving others. They attribute their lives, legacy, and journey through Parkinson's to their relationship and faith in Jesus Christ.

Sample Chapter