

# Little V's Hope

Journals + Letters

by Vita Coffey with Käj Jorgensen

*Live like you're alive. Act like you're living. Let your heart soar. Hope.*

—Vita Coffey

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# Foreword

At first, I had no idea Vita was a multiple sclerosis patient at all.

I had known at least six patients with MS, most of whom were wheelchair bound, or struggling with a cane, or complaining about numbness, lesions, and lumbar punctures; but when I first met Vita at an Apple Store in Omaha, Nebraska, she was incredibly lively. More *alive*, in fact, than most of the completely healthy people I know. More hopeful, more willful, and more driven.

She told me a story of loss, survival, and hope unlike any I'd heard: she'd gone from being unable to walk, see, or think clearly to being able—as best I or anyone else could tell—to live a full life without the constant burden that MS forces upon most of its sufferers. Vita was both lucky and empowered. And it was no accident that she appeared to have overcome her disease.

The work of editing and focusing the story she tells in this thirteen-year chronicle of journal entries, thoughts, and letters was not easy; despite her poor condition, Vita wrote prolifically during her first thirteen years with MS, maintaining a blog and multiple books of handwritten journals, writing to friends and family, and receiving letters. To get the full picture of what Vita experienced, we decided to include the most trying periods of her journal as well as the most important letters she wrote and received—including those she decided not to send.

Using the bulk of Vita's handwritten journals meant asking her to reread and type them, as her handwriting was largely illegible during the most severe attacks she endured. As her partner on this project, I sometimes felt guilty making such a request; reviewing feelings from the most trying period of one's life is something a person shouldn't have to do too often, if ever—yet I asked her to do it for more than two years straight.

In the process of editing and assembling Vita's book, though, I learned a few things. First of all, whatever I have to complain about, it's *not all that bad*; I have my health to be thankful for. Second, Vita makes clear the importance of family and close friends; they're the ones who help a person through the hard times and, hopefully, the ones who stick around to help celebrate the good. Not all friends are *true* friends, and it often takes something difficult—like debilitating disease—to filter out the ones who can handle fair weather only. Realizing this in the throes of such a time, Vita found hope instead of despair; something to pray for as opposed to something to give up on. She faced more challenges than most ever will, yet emerged an emphatic survivor.

Thus, *hope* became the theme of our project.

Vita's story is full of its ups and downs: loss, loss, and more loss, followed by a glimmer of hope, followed by more loss. It is not an easy account to read, but ultimately an empowering, uplifting one. Although her story brings both tears and laughter, the message here is overwhelmingly positive, and one that can be poignantly captured by the age-old adage "where there's a will, there's a way."

Vita's will found her the way. May her strength also empower her readers.

Thank you, Vita, for the honor of contributing to your book.

—Käj J. Jorgensen

## Introduction

When Vita Coffey's doctors informed her that she was in the early stages of multiple sclerosis, she knew very little about it. With symptoms ranging from a "droopy mouth" to waking up unable to walk or feel one side of her body, she was expecting to be diagnosed with a brain infection, or cancer, which she was all-too familiar with after witnessing several family members suffer over the years. Multiple sclerosis, though, was not a disease she'd directly faced before, and definitely not one any family member had endured. From what little she understood at first, Vita feared paralysis, numbness, slowly wasting away; she worried about friends' reactions, burdening her family, things changing. And as Vita's symptoms grew worse, many of her worries became quite real.

Following her diagnosis in 2000, Vita endured many attacks or "exacerbations" at the mercy of her disease, each incident leaving her hospitalized for days or weeks, heavily medicated and, very often, alone.

It was her suffering, though, that motivated Vita to learn about multiple sclerosis while she still could—particularly in the realm of treatment. In her exhaustive research, Vita sought not only a better quality of life for herself, but also the more than two million other multiple sclerosis patients<sup>1</sup> worldwide. Understanding her disease became a way for Vita to subdue her fears and confront the inevitable.

The process of diagnosis for a person in Vita's condition is manifold; not only do several forms of multiple sclerosis exist, but many of its symptoms—numbness, fatigue, slurred speech, tremors—occur in other diseases of the central nervous system as well. A proper diagnosis typically requires a neurologist, who

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<sup>1</sup> The National Multiple Sclerosis Society

assesses a patient's medical history, monitors the progression of early symptoms and, if necessary, performs tests.

One such test, magnetic resonance imaging, or MRI, is used to detect plaques, which are "sclerosed" or hardened areas of scar tissue located at multiple sites throughout the central nervous system. Although higher numbers of plaques tend to be consistent with more advanced forms of the disease, the name "multiple sclerosis" describes the system-wide accumulation of nervous system damage present in all MS patients. Because this damage occurs variably from patient to patient, however, the disease affects everyone differently; and although MS is believed to be a result of the immune system attacking the central nervous system, the medical community remains unsure as to *why* this happens in the first place. MRI, in short, is merely a method for determining the severity of a patient's case, not the cause of the disease or which form it might take.

For Vita, MS took the form of *relapsing-remitting*, wherein symptoms arrive as part of an acute exacerbation, followed by recovery and remission that can last for months or even years. Each attack, though, is unpredictable and can require days or weeks of hospitalization. New symptoms may arise in one attack, but not appear in another; two attacks might occur only weeks apart, followed by a third months later. The course of *relapsing-remitting* MS is unpredictable, but periods of relapse do offer relief.

Beyond *relapsing-remitting*, MS can develop more aggressively in its *primary-progressive* form, moving steadily from early symptoms of numbness to severe disability with little or no remission in between. Some patients may require a wheelchair soon after diagnosis, while others might continue to walk as they always have, never needing so much as a cane. Whatever the form of MS a patient has, its symptoms stem from the same problem: hardened scar tissue in multiple areas of the central nervous system that inhibit communication between the brain and the body.

Unsure of how deeply MS would affect her life, Vita began exploring treatment options new and old. She learned about drugs, chemotherapy, highly-selective research studies, homeopathic remedies. Some were promising, but many, as Vita later learned first-hand, came with a bevy of undesirable side effects often more unpleasant than multiple sclerosis itself.

Finding the best treatment for herself and others—through much trial and error—became the focus of Vita's new life as an MS patient.

# Prologue

*“In three words, I can sum up everything I've learned about life: it goes on.”*

—*Robert Frost*

Friday, October 16th, 2009 was the day of my bone marrow biopsy.

In my research I had read how painful these biopsies could be, how much they can hurt; I hardly slept the night before just thinking about the needle. Would it be long or would it be short? How fat could it be? How long would the torture last?

I had a slight problem because I was not supposed to do this procedure without a caregiver. Monica, my first caregiver, had not arrived yet, so I had to convince one of my neighbors in the condo, Rob, a former paramedic with post traumatic stress disorder, to come into the clinic physically and take me home after the procedure. He was supposed to stay with me the rest of the day and night, but he dropped me off at the clinic instead. A very kind nurse practitioner, Rebecca, took me back to the exam room where she explained everything down to the last detail.

“Where does the needle go? My hip? My femur?” I asked.

“It goes through your hip, but I numb it locally and give you some drugs to help you relax. You shouldn't feel much,” Rebecca reassured me. Her words were comforting, and she totally relieved my anxiety. When I started to feel loopy from the drugs, Rebecca and I had funny conversations about our families and what our lives were like at home. Rebecca lived with a cute three year old with curly blonde hair and a hippie husband who had multiple tattoos and played saxophone with a jazz band.

In the end, the needle wasn't as long as I thought it would be; it wasn't nearly as bad as I had read. When the procedure was over, Rebecca called Rob; and as much as he hated to go into the clinic, he came in and helped me get into a wheelchair and rolled me out of the clinic and back to the condo, where I went straight to bed. I slept most of the night away. And although Rob and his fiancée Cheryl checked on me often, I understand now how foolish I was not to have a proper caregiver. I was in a lot of pain, which I had normally, but I hadn't thought the first two weeks would be as difficult as they had been. It was hard to be in the condo alone, as I was afraid of falling. The drugs from the biopsy made me dizzy, so I had to hold onto every wall I could. I was vomiting every night, and as soon as the pain meds would wear off, I'd be in a lot more pain, which made it hard to walk—even when leaning into the walls. I really could have hurt myself, and I was more alone—more depressed—than I'd ever been.

Rob became my caregiver for the next day's procedure in Dr. Bowen's office. After my spinal tap was done and enough spinal fluid collected, once again, Rob came into the office to wheel me away. This was when my body became so stressed that I had an exacerbation, or what some call an "MS attack." Besides my headache from the spinal tap, the pain in my legs had almost become unbearable. I had to put my head down or rest as much as possible because my nausea was constant, I had double vision, and was ataxic, always leaning to the right. So once again, my doctors put me on five days of 1000mg IV steroids. My stem cell transplant was pushed back a few weeks.

Receiving multiple sclerosis as a diagnosis was difficult; I was endlessly very scared and always sad. Fatigue had taken over my life, the right side of my body was numb, and my face and legs were in constant pain. My condition helped me understand how important friends and family truly are; little things—especially simple acts of kindness—made such a profound difference in my life, I realized. I needed to stop and smell the roses. I needed to appreciate what I had, no matter how small it seemed or how big it could become. I needed to have hope.