

Stories of Hope, Vol. 1

STORIES OF HOPE, VOL. 1

Reflections on Resilience

Laura Quirk, Project Editor

Conestoga College

Kitchener



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Introduction

This project came out of an “aha” moment I had about five years ago. I had made it through some very difficult times in my life and people often asked me what my secret was. I wanted to make my story available to others because I believe shared stories allow us all to heal.

This first volume includes an essay about my journey of dealing with multiple sclerosis. It is about my mother’s story, as she also had MS. And it’s about my own story of MS from diagnosis to the present. It is about the depths of despair that such a diagnosis can create and it’s about the possibility that people can come out of dark places and realize the joy that can be found in life – in spite of, and because of, the challenges that health concerns can create. This story reinforces that without MS, I would not be the person I am today.

But I want to do more than just share my story of hope. My journey is only one such story of why and how we can move through in life in ways that require us to dig deep and find hope—somehow, somewhere. So, I have invited others to contribute their experiences to this project. My vision is to add art, poetry, videos, graphic novels, or whatever form other stories need to take. In other words, I want this to be about so much more than my journey. My story is just the first step. I knew from the beginning that I wanted this resource to be free and open, therefore the fact that publishing an open education resource achieved both goals was very important to me.

As a learning resource, this volume and future volumes can be used in a variety of programs in different ways. In this volume a variety of topics are covered, including (but not limited to) resilience, multiple sclerosis, symptoms and treatments of MS, dealing with depression, education, love of work, and the concept of hope.

The learning assessment included in this volume is aligned with a course in the occupational therapy and physiotherapy assistants’ program at Conestoga College, but it is also relevant to other healthcare programs, such as nursing, paramedics, personal support worker, massage therapy, etc. Because this essay does not only discuss the *medical* struggles I have gone through,

it could also be relevant to students in disability studies, psychology, sociology, social work, criminology, policing, and other related programs.

Call for Feedback

If you would like to provide feedback on this project, or you have suggestions about further content ideas, I welcome your thoughts. Additionally, if you are an educator who has used this OER in your course, I would love to hear how. Please contact me at lquirk@conestogac.on.ca.

Call for Contributors

Stories of Hope is an ongoing project and I invite all readers to consider becoming part of it. Just because I tell my story in essay format doesn't mean that others need to do the same. If you are interested in sharing your own story of hope and resilience, please know that contributions of poetry, visual arts, audio recordings, video, or other media are welcome. Educators are also invited to develop and contribute learning materials for the resource.

Note that any contributions will be published under a [CC-BY-NC-ND](https://creativecommons.org/licenses/by-nc-nd/4.0/) open license.

I am eager to see this project grow and expand and thus I welcome contributions. Please contact me at lquirk@conestogac.on.ca to discuss your ideas.

Disclaimer

The essay in this volume is the personal story of the author and is not meant to be a scholarly work or to offer medical advice. The work is based on the author's own lived experiences and understanding and has not been reviewed by medical professionals.

Acknowledgments

Land Acknowledgment

At Conestoga College, we would like to acknowledge that in Kitchener, Waterloo, Cambridge, and Brantford, we are located on the Haldimand Tract, the land promised to the Haudenosaunee people of Six Nations, which includes six miles on either side of the Grand River. This is the traditional territory of the Anishinaabe, Haudenosaunee, and Neutral peoples. Recognizing the land is an expression of gratitude and appreciation to those whose environment we reside in and a way of honouring the Indigenous people living and working on the ground for thousands of years.

Author's Acknowledgments

I want to thank a few people who have been instrumental in my healing journey since MS first made its presence known in my body – Cathy Wordley, Kim Farrar, and Doug Cameron. It would have been impossible for me to reach this level of healing if you hadn't had a huge hand in helping me through the worst of times and celebrating the best of times. I have no words for what your love and support mean to me.

I want to thank Gino Innamorato for helping me to push myself to include elements in this essay that I never would have thought to add because they were so personal—your ideas helped make it better. I am beyond grateful for our connection.

I want to thank my dear friend Marg for being such a support in everything I do, not just this project. We are lucky to share so much of our lives with one another—including the dog sitting of each other's animal friends!

I want to thank Sunil Kuruvilla for being an early editor of this essay. You were so encouraging and helpful, and it meant more than I can say.

I want to thank my chair Adam Miller for your support in this project. I know that this essay

inspired the idea of introducing a minor in disability studies at Conestoga College and I so appreciate your trust in me in this endeavour.

And I need to thank Kimberlee Carter and Rachel Stuckey in Conestoga College Open Learning for making this project go from my own first draft to this exciting publication. I cannot express how much it means to me to see this idea launched. I cannot wait to see where we go from here!

— Laura Quirk

Attributions

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Accessibility Statement

Conestoga College Open Learning is committed to producing open educational resources that are accessible to as many learners as possible. We encourage our authors and contributors to adopt a [universal design for learning approach](#) and aim to comply with the accessibility standards of the AODA and WCAG.

If you experience challenges accessing this resource or have suggestions for how we might improve accessibility in our OER, please contact us at openlearning@conestogac.on.ca.

For more information about how we strive to meet accessibility standards, please review the [Conestoga College Accessibility Statement for OER Projects](#).

About the Contributors

Project Editor

Dr. Laura Quirk

Laura received her doctorate through the Tri-University doctoral program, which utilizes the expertise of the University of Waterloo, Wilfrid Laurier University, and the University of Guelph. Her PhD is in history with minors in archaeology and gender. She has been a professor at Conestoga College since 2010 and has developed many courses for the college, including history of art I and II, archaeology, history of living memory, gender, Canadian history, and ancestry, as well as a travel course to London and Paris.

Laura is the author of the first essay in *Stories of Hope*: “When Hope Is All You Have Left.” She is also the project’s editor; having created the initial concept, she is now soliciting further contributions.

Call for Contributors

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Please contact Laura at lquirk@conestogac.on.ca to discuss your ideas.

When Hope Is All You Have Left

Laura Quirk

Dr. Laura Quirk is a professor of history at Conestoga College in Ontario, Canada. She was diagnosed with multiple sclerosis in 1988. Since then has struggled with her physical health and faced mental health challenges related to her condition. In this essay, she writes about her experience with the disease and the development of her career as a professor.

Learning Objectives

After reading this essay, you should be able to:

1. Describe some symptoms of multiple sclerosis (MS).
2. Identify different ways in which MS symptoms can impact a person's everyday life.
3. Describe how an MS diagnosis can impact a person's mental health.
4. Discuss the role of hope in Laura Quirk's journey after diagnosis.

Before You Read

Reflect on and answer the following questions before you read this essay.

1. What do you know about multiple sclerosis?
2. Do you know the difference between a visible disability and an invisible disability?
3. Have you ever experienced a challenge so great that you did not believe you could overcome it?

Content Warning: This essay discusses substance abuse, child neglect, and suicide ideation.



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Part One

Laura Quirk

My name is Laura Quirk. I was diagnosed with **multiple sclerosis (MS)** in 1988. Although, it is likely that I had the disease for several years without knowing it. Since then, my body has gone on some scary and complicated rides. My mental, emotional, and spiritual states have also been shattered by this disease. But as I have learned—often the hard way—hope is sometimes all any of us have left. I want to tell you about my journey with MS and what finding hard-fought hope means to me.

The Early Years

As hard as she is to talk about, or sometimes even think about, I must begin my story with my mother. She also had MS. I was six months old when she got sick but I was eight years old when she was officially diagnosed. By that time she had difficulty walking, and my parents told me she'd broken her leg. I was not convinced. She shuffled when she walked, and her speech was hard to understand; even I knew that wasn't what having a broken bone looked like. She was also blind in one eye.

I pestered my mother to tell me the truth until she finally told me she had MS. Of course, I didn't know what MS meant (but then, almost no one did at that time). Back then, diagnosis was a long and arduous process that included **spinal taps** and observation to see what sorts of symptoms a person experienced—because the symptoms varied from person to person, it was often years before an official diagnosis could be made.

Back then, diagnosis was a long and arduous process that included spinal taps and observation to see what sorts of symptoms a person experienced.

Some of my earliest memories of my mother are her sick in bed and needing care most of the time. At eight years of age, I was taken out of school for three weeks to look after my mother.

My father went to work, and I presume that my sister (who was four years older than me) could not miss school because it would be harder to catch up in grade seven than it was in grade three, making me the logical choice. In hindsight, I have often wondered why we didn't have a nurse or PSW come to the house to take care of her, but for whatever reason, that didn't happen. I remember trying to clean, cook, and grocery shopping. I remember bringing the groceries home on the bus one day in those old paper bags that didn't have handles—I wasn't strong enough to carry them. I recall sitting on the sidewalk crying as I tried to pick up the bags and carry them home. Eventually, a bus driver parked the bus and helped me carry the bags to my house. I wish I knew who he was, as I have often thought of him with gratitude and wished I could thank him for his kindness.

The Road to Diagnosis

I was always told that MS was not genetic and that I had no chance of getting it. Imagine my surprise when a doctor hinted that my vision loss, at age 23, might be because of MS. At that time I was walking normally, so how could MS even be an option? I didn't shuffle like my mother did. I was in every other way "normal." I was sure they were wrong, particularly when my vision improved and I could see as I had before. It was only when I lost my vision again six months later that the doctors began looking for answers and I was sent to see a **neurologist**. That doctor immediately performed a spinal tap. But because I wasn't in an MS attack at the time, it came back negative. So, I spent the next six months being poked and prodded and even given electric shocks to see how the messages travelled through my body. None of the tests were **conclusive** so they sent me to London, Ontario, to the MS clinic there. The neurologist read my chart and told me that I was "classic MS," but he did an **MRI** anyway, just to check. Sure enough, the doctor confirmed that day that I had MS.

You might be wondering what MS is. I am not a medical doctor, but I have lived with the disease for more than half my life, so I believe I can speak to the basics without misleading you. MS is a disease of the central nervous system, or the brain and the spinal cord. This system includes the complex network of nerve cells responsible for sending, receiving, and interpreting information from all parts of the body. MS attacks the **myelin** that surrounds the nerve. The myelin's job is to help transmit messages along the nerves from the brain to your arms, legs, eyes, mouth, organs, etc. Myelin damage can occur anywhere in the spinal cord or brain, which is why MS symptoms vary so much from person to person. Typical symptoms include loss of balance, muscle spasms, weakness, tremors, bowel and bladder problems, vision loss, hearing loss, facial pain, brain issues such as memory loss, sexual issues, and problems with speaking and swallowing.

No matter what symptoms a person with MS might have, the one constant is fatigue. Of course, everyone experiences fatigue, but MS comes with a unique form referred to as nerve fibre fatigue. Essentially, this means that the messages are working hard to get from the brain to somewhere in the body, but because of the damage caused by MS, the messages can't get where they are trying to go, which causes parts of the body to shut down. This fatigue can manifest as (temporary) paralysis for some. For me, it's more like being tired to the core of my being, or "bone tired." For others, it may just mean they need a nap.

To simplify the story of MS and myelin, let me give you an analogy. Myelin is like a big sleeping bag that is cuddling a strong fibre (the nerve). MS comes in with a big pair of scissors and cuts the sleeping bag, sometimes with only a small nick but other times shredding the sleeping bag in the process. In people with MS, the myelin spontaneously fixes itself (sometimes fully) until the age of about twenty to twenty-five. As a person ages, their body is not as capable of fixing the problem. So, MS diagnosis is usually between the ages of 20 and 40.

Going back to my analogy, when the body begins to heal after an MS attack the body starts to sew up the tears in the myelin sleeping bag. Sometimes the repair is so good that the person is almost like they were before, with barely perceptible changes in their body. But sometimes the sewing job leaves small holes or even gaping holes in the sleeping bag, leaving the nerve unprotected. So, the messages transmitted along the nerve are slowed down or interrupted—the result is changes in ability, commonly known as an attack (or an exacerbation).

In medical terms, a buildup of scarring on the myelin is known as **sclerosis**. When there are many such sites, it is known as *multiple sclerosis*. Damage to the myelin can be on a spectrum from permanent to medium to minimal, with minimal damage leaving no obvious signs of the disease at all.

MS can attack the body in a number of ways. The most common is with the arms and legs—causing anything from mild numbness to paralysis. About fifty percent of people with MS have numbness in their body, usually the arms and legs, and about fifty percent have pain in those same areas. I have both. The second most common type of MS attack is in the brain stem-cerebellar area, making up approximately thirty-five percent of all relapses. I have had many attacks that come from this area in the brain. The most common symptoms from these attacks are speech difficulties, compromised balance, and vision issues. You can also experience acute pain in the ear, swallowing disturbances (which can lead to choking) and trouble with facial muscles and nerves.

“But You Look Normal”

From my story so far, it may be obvious why it's difficult for people in my life to understand MS. You may have seen me last week and I looked perfectly “normal” but today I look and act differently. The difference might be that I'm using a wheelchair, or a scooter, though sometimes it might be a cane. Sometimes I have trouble seeing, sometimes breathing is a concern, sometimes my ability to speak is challenged, sometimes I've difficulty using my hands; sometimes I even have trouble peeing. In other words, MS has impacted me from the top of my head to the bottom of my toes and almost everything in between. The other difficulty is that the average length of an MS “attack” is between 8 and 24 weeks. At one time I had between three and four attacks a year, which mean I was always in an attack.

I am also not an average person with MS, which is one of the biggest challenges of the disease. Some people have only one or two symptoms in their entire life, having what's known as a **benign** form of the disease. While others have permanent damage and are identified as “**chronic progressive**” patients. The most common type of MS called the “**relapsing/remitting**” type, which means that the disease comes and goes. When I was first diagnosed, I went steadily downhill with chronic progressive MS; after about five years, I was “upgraded” to a relapsing-remitting type. It must have been odd for people to see me in a wheelchair one time and the next time walking confidently down the street. Or remember having a normal conversation and then finding they could not understand my speech at all.

But perhaps the most frustrating aspect of MS is that many of the symptoms are silent. When you look at me, I may seem “normal” (oh, how I hate that word!), but I may not be able to see, or to pee, or even breathe properly (I have what's known as MS-induced asthma). Or I may be experiencing intense pain or numbness in my body. All these symptoms are “silent” to the observer, but not to me. So, when I heard people say something like, “oh but you look so good,” I would be screaming inside that I was anything but “good.” Yet it was so much “easier” to just smile and say, “thank you.”

Being Mannerly

Politely they inquire,
“How are you?”
Politely I answer,
“Fine, thank you.”
But inside I scream,
“I AM NOT FINE!”
To them I seem well enough,
But can't they see it?
The inner struggles,

The uncontrollable shaking,
 The weakness, the pain,
 The numbness, the fatigue,
 The feeling of helplessness,
 The fear...
 It occurs to me
 That my own half-truths,
 And my need to be independent
 And strong,
 Silence me.
 Okay, starting today,
 As my own acceptance
 And understanding grow,
 I will attempt to share my feelings,
 So that my silent screams
 Can be heard.
 — Laura Quirk

My Mother and MS

My mother, from what I have been told, was extremely bright. She had a terrific sense of humour, and she held a master's degree in psychology. She actually ran the psychology department at a hospital near where I grew up in Toronto. When she first had MS, I gather they thought she had some odd, transitory paralysis and she was expected to make a full recovery. But, as it turns out, it is very common for women to have MS symptoms crop up for the first time after they have given birth—which probably explains why I never knew a healthy or “normal” mother. For as long as I can remember, she was strange to me. She didn't walk or speak or even make dinner like my friends' mothers did. And perhaps most importantly, one of her symptoms was memory issues, so she often had no idea who my father, my sister, or I were.

I remember that when my sister and I would go to school, for instance, she would sometimes call a locksmith to change the locks. She couldn't figure out what these small strangers were doing in her house. She also did extraordinary things like introduce herself to new neighbours and ask them to keep our good silverware because she didn't trust us and was sure that we would steal it. Yes, that made for particularly awkward moments when these confused neighbours would quietly go to my father and return the silverware. To be honest, my mother embarrassed and perplexed me on a regular basis.

It was not a surprise when my mother sued my father for divorce when I was twelve and the three of us (my father, sister, and I) moved out of the family home. We all thought it was best because she was more and more lost and confused and her turmoil made the three of us feel like we didn't know which way was up. You might think us heartless for leaving her. But from my

perspective as a kid, it was just too hard to understand why she didn't know who I was. After all, I was her daughter. In truth, I thought sometimes she was just being mean and pretending she didn't know who I was. It was only when I became an adult and began to unravel what it all meant that I found some compassion for her and realized how scary it must have been for her. Perhaps you can better appreciate my horror when I was told I had MS. I thought that if I had the same disease, I must be a genetic reprint of my mother and would eventually forget those I love and worse, I'd hurt them along the way.

When There Is No Fight Left

Interestingly, I have since been told that my diagnosing neurologist labelled me as "together" and "able to handle it." That couldn't have been further from the truth. After my diagnosis, I was suicidal for the one and only time in my life. I began to drive around wondering how I could crash my car without hurting anyone else. I would look at a bridge and think "what about there?" Or I'd see the wall of a shopping mall and think "how about there?" Each time, I stopped myself after thinking, "what if that bridge gets knocked down?" Or "what if that wall caved in and it hurt people inside the building?"

I was just so deeply sad that living didn't seem like a viable option. And I was determined not to hurt the people that I loved by forgetting who they were. I just couldn't do that to them. Fortunately, some voice inside me stopped me from crashing my car. But I came close, many times. I was in a very dark place. So dark that I felt like I was in a deep well without light. I did find myself looking for light, somewhere, anywhere. But for a number of years I just couldn't see it. In hindsight, it is interesting to me that while I couldn't see any light in my very dark place, I somehow still knew it was there. I just had no idea where or how to find it.

There is No Fight Left

There is no fight left.
There is only sadness.
I am profoundly, deeply
And unmistakably sad.
This is not depression.
It is a kind of quiet unfathomable grief.

I am passed outward tears now
But inside I weep still.
It doesn't stop the pain
Or change the feelings.
It's almost as if my sadness
Is the residue that is left
After the storms of pain

Have subsided.

Nowadays, people look at me
And think I am coping well.
They think that I am strong.
The truth is
There is only sadness
And there's no fight left.
— Laura Quirk

Part Two

Laura Quirk

The Turning Point

Tired of being tired, saddened by always feeling so sad, I sought the help of a counsellor. I had to work hard to understand that I was not a genetic reprint of my mother, although, as it turns out, we had the same first symptoms as one another. My life-saving counsellor suggested that I try to track down my mother's neurologist and ask him about her early years with MS. By then, I had had no contact with my mother for a number of years. It was just too hard to see her when she had no idea she even had a daughter—her memory had deteriorated permanently by then, and seeing her was like watching the scariest horror movie I could imagine come to life before my eyes. So, for my own sanity, I avoided seeing her.

When I finally found her neurologist—and explained that I had MS, I asked if he could shed any light on whether I would lose my memory. He bluntly asked me, “Are you an alcoholic?” I remember being stunned by the question, then answering “no.” He then said, “Your mother was an alcoholic and essentially pickled her own brain. So, if you're not an alcoholic, you'll probably be fine.”

It was an oddly comforting conversation. I did know about my mother's alcohol abuse at a very young age. I had grown up uninterested in being drunk or in using recreational drugs. I enjoyed wine and beer but did not drink hard liquor and I usually stopped drinking even before I was tipsy, never mind getting drunk. But it had not occurred to me that MS and alcohol don't mix. When I hung up, I realized that the mental deficit my mother had was not necessarily a foregone conclusion for me as well. So, I decided then and there to go on living, but to hold in reserve suicide as an option if I ever believed I was heading down my mother's path. Before that happened (if it ever did), I wanted to embrace life, seize the day, and live for each day as it came.

The First Steps in Healing

From that point on, I began searching hard for the light in the darkness. I had been told by doctors that there was no hope for MS. They had no cures, and all they could offer me were experimental drugs. I realized early on that those experimental drugs had to be tested on real people with MS, so I agreed to take the drugs, believing that if there was any hope it would be found in the doctor-gods who prescribed them.

Like so many people with chronic illnesses, I began to identify myself with this strange body of mine that was in constant flux. I quickly learned that I couldn't count on this body that was no longer doing what I told it to. I began to think "I am MS. MS is me"—which by extension, meant nothing was ever going to be normal again. It was a strange process of starting to believe that my physical body was the most important part of who I am. I learned that people wanted a healthy Laura. For example, some friends suggested that if I couldn't play tennis with them anymore then perhaps we had nothing in common.

I began to think "I am MS. MS is me"—which by extension, meant nothing was ever going to be normal again.

And so I let the doctors give me the experimental drugs, believing that they knew my body better than I knew it myself. In fact, one early neurologist told me, "You are not as well as you think you are. I have tests to prove it." Although one small part of me believed him, there was another part ready to fight; I answered him, "You're wrong. I am exactly as well as I think I am. No better and no worse." He was blatantly skeptical and let it show. I remember thinking, "I'm not an idiot." I knew I had the disease, but I also knew that I was exactly as well as I thought I was. Sadly, it didn't stop there. He told me to, "go home and eat all the chocolate you want, don't bother exercising, you're going to die young anyway." In spite of those words, I knew I wasn't finished with life, and I was not going down without a fight.

I have no idea what sort of motivation the doctor thought he was providing me in that exchange, but what that did for me is provide the spark that was missing. I did begin to see the light at the end of the tunnel, so to speak. I began saying to myself that if I could afford it, I would try anything to get healthy. And by that I don't just mean "afford it" financially. Bee stings were suggested as one method to control pain. Apparently one needed ten bee stings per day to get pain relief. I remember thinking I couldn't "afford" that emotionally, so I said no to that one. Otherwise, I began seeking out all kinds of non-chemical, non-invasive therapies that might give me pain or symptomatic relief.

Finding My Voice

One of the dangerous symptoms of MS happens when my brain stem is swollen, which impacts my speech. It is dangerous because, from what I understand, the brain stem is in a small space and when becomes inflamed there is only so much room for swelling. Someone once explained that it was like the brain stem was a balloon that was being pumped up in a small box. After a while, it can go “pop.” The effect of this swelling for me was difficulty swallowing and difficulty in speaking clearly. I was hospitalized to receive very high doses of **prednisone**, in **intravenous (IV)** form. The neurologist said they didn’t know if I was going to make it because they couldn’t get the brain stem swelling to stop or slow down. I remember grabbing a piece of paper and writing “I am going to prove you wrong.” Obviously, I did.

The next time I had a problem with my speech, I decided to seek out the help of a different neurologist. That doctor told me that my speech difficulties were all “in my head.” In other words, it was **psychosomatic**. You might imagine, my first thought was, “Is it time to kill myself? Am I going crazy like my mother?” But I decided to go to a speech pathologist to find out if my speech issues were really “all in my head.”

It wasn’t. She told me that my speech was only 17% intelligible because my palette was not lifting, my esophagus wasn’t closing properly and the air was therefore coming out my nose (and not my mouth). My speech sounded similar to that of some deaf speakers, even to my own ears. And there was a danger of choking to death if I wasn’t careful.

It was a very strange world for me. I had a brain full of ideas and thoughts and little way to express myself. I used even more extravagant gestures than I normally do, and I took to writing things down. My hands were not working as well as I wanted and so my handwriting was slower and more laboured than my “normal.” It was an intensely private and personal place to be. Working so hard to communicate led me to I start asking myself what I had been saying that I shouldn’t have said, and perhaps more importantly, what I had not said that I needed to say. Looking back, I know that was when I promised myself that I would no longer be silent. My silences had not saved me from anything.

Being silent was part of being the “lady” my grandmother always wanted me to be. She was one who always wore dresses and pearls and had visions of me doing the same. I could not be the silent lady she wanted, as I could not face the possibility of dying without having spoken my truth. I learned that while I never intend or desire to hurt anyone, I also need to be as truthful as any situation will allow. I have since been told by the closest and dearest people in my life that I am sometimes very blunt and sometimes it hurts, but that they never wonder where they

stand with me. It is often a challenging balance for me between being honest when situations are delicate and recognizing when I need to hold back. Again, those who love me know that I am often the “bull in a china shop,” but they also know I never mean to be hurtful.

Art and Archaeology

Around this same time, a different, well-meaning neurologist (who confirmed that the speech issue was also not “in my head”) told me that I needed to think about what I wanted to do with my life because, he said, “No one will hire you.” (Looking back, I honestly do believe he was trying to be helpful.) I was still young and the thought of dying young and never working again did not sit well with me. So, I decided to go back to university.

When I left home at 17 years of age, years before my diagnosis, I had planned to attend university and work at the same time. I had enough money saved for one year, so I started a psychology program at the University of Waterloo. As it turned out, I loved every course I was taking except psychology and I couldn’t afford to go on, so I quit school to work full-time at an art gallery. I quickly discovered that I loved the art world and I decided to buy a small art gallery rather than return to university. I reasoned that I could always go back to school but wouldn’t have another opportunity to own an art gallery?

My first career, therefore, was as an art gallery owner. I loved it. Along the way I did take whatever university courses interested me, at night, but mostly I had thoughts of someday having a second gallery and of living my life in the art world. Then MS struck.

Let’s face it, it is hard to see artwork when you’re blind or frame pictures when your hands aren’t working. And when the speech problems hit me hard after eight years of owning the gallery, I realized I had to give it up. There is more to the story than that, but it was then that I decided to go back to university and do something with my mind, because so far, it was the only part of my body that had not let me down.

It struck me as odd, even at the time, that I elected to study the one thing that makes no practical sense for a person with MS—I decided to study **archaeology**. It had long been a passion of mine and one that I was determined to master. I knew that there are two different types of archaeologists: There are the dirt archaeologists, who look for evidence in the ground and there are the so-called armchair archaeologists who study and assess the artifacts that others dig up. I thought I could become the latter type.

While working on my undergraduate degree, I had trouble walking, seeing, talking, and moving my hands, and I was experiencing extreme fatigue. Despite that, I won the gold medal for arts and science the year I graduated. Not surprisingly, what that taught me was that I could

do this. But I also knew I needed more than an undergraduate degree to do what I dreamed of doing—teaching historic archaeology. I knew I needed to keep going and complete a doctorate degree. I wasn't sure my body would let me, but I knew if I didn't try, I'd never know.

My First Master's

I applied to the University of Western Ontario to do a master's degree in anthropology and was accepted into the program. It was a two-year program and I drove from Waterloo to London on class days. It took me four years because of my health, but I did it.

In addition to concerns I might have had about the physical demands of MS, after I finished my master's I had other concerns about my future. I began reflecting on whether I really thought I'd get a job teaching archaeology. Because the field is very small in Ontario, I realized that my chances were slim. But I did think there was a greater chance I would be able to teach history, so I decided to change directions and do a second master's, this time in history.

At the same time, I realized that ever since my startling diagnosis I had been grieving the loss of the body I had known. While I was busy in school, I had not yet been able to work through the grief process and allow myself time to move out of that dark place and into the dawn of each new day. I realized I had been feeling sorry for myself and it had been getting in the way of living. And like so many in my position, no one had told me that what I was feeling was grief or that it was okay to grieve. I thought I should just "snap out of it" and get on with it. Isn't it funny how hard we are on ourselves? I had to learn to face it and let it go. So, I began to do something that I still do to this day when a new symptom shows itself, or an old one revisits again. I give myself one day to feel it: to wallow in self-pity and to recognize that it is not fair, it is not right, and it's not okay. But when that one day is over, I tell myself, "Enough, no more." I make myself think about today, this moment, and living.

Quiet Moments of Healing

I have just experienced quiet moments of healing.
It began with my feet.
They were rough and tired of their own awkwardness
But I soothed their roughness.
As I thought of how often I have stumbled
And the life lessons I have learned
Just because my feet were awkward,
I realized how well my feet have led me.

I next thought of my hands
And how their lack of strength betrays me,
How painful and awkward they can be.
But then I thought of how creative they are,

How gentle, how tender.
Then I realized I saw my hands as strong.

I next thought of my vision
And of how terrifying the darkness was.
Then I thought of all the things
I now see clearly.
I see how lucky I am.
I see myself as whole, not broken.

And then I realized
That I am strong
And proud to follow the path
That my feet are leading so well
— Laura Quirk

My Second Master's

It was during the year of my second master's that I began saying a mantra out loud, every time I thought of it. I would say, "I feel healthy. I feel happy. I feel terrific." I admit, it was sometimes said through gritted teeth, but I figured that my brain would hear my own words and would begin to believe them. It is something that I still say today, although not as often through gritted teeth. I also sought out massage for my spastic muscles, physiotherapy to help me walk again, a brace for my left hand that was so curled up my fingernails would literally cut my palm.

I also went to energy healers to help the parts I couldn't touch. I remember one very helpful healer telling me that I was viewing my body as the most important part of myself. He wasn't wrong. I had been paying my physical body so much attention that I hadn't given myself time to look at the spiritual, mental, or emotional parts of myself. I began to realize that they were all equally important and that I had been privileging the thing that was yelling the loudest but that was not necessarily the way to be healthy.

It was also during this time that I started a new experimental drug that was administered by daily injections. By then I realized that a balanced approach was best for me, and it was time to reintroduce Western medicine into my goal of getting healthier. I was still interested in trying anything, as long as I could afford it, financially, or emotionally. (Ironically, there was a time when I said to myself, "At least I don't have diabetes because I don't think I could inject myself every day.")

In the end, it wasn't self-injection that was the problem, it was just the wrong drug. I kept having what was referred to as a "911 response." After I injected, I would literally drop to my knees, gasping for breath, and the pain around my chest was crushing. This always lasted about 20 minutes. I never did call 911, but I did finally say—after twelve such episodes—that I could

no longer emotionally “afford” this medication. And I gave up again on the idea of Western medication.

The Road to Becoming a Doctor

After my second master’s was completed, I decided to follow a lifelong dream to get my **PhD**. Again, I wasn’t sure I would be able to do it, but I thought I simply had to try. I was accepted into the Tri-University Doctoral Program in History. This program uses the expertise of the history departments at the University of Waterloo, Wilfrid Laurier University, and the University of Guelph. Rather than graduate from all three universities, candidates graduate from the university where their main advisor works. My main advisor, Dr. Cynthia Comacchio, was at Laurier. I knew from the beginning that she and I would work well together, and more importantly, that she would see me for myself and not for this strange body that I inhabit. I was very fortunate to have found her as a mentor and guide. I am sure my journey would have been very different without her support and encouragement. Thank you, Cindy!

It is always interesting the things that derail you when you least expect it. It was during the early stages of my PhD that I was having increased pain in my body, and it was becoming more and more challenging to do simple tasks like typing (a requirement for papers and proposals within my PhD program). I had, for many years, existed on **Tylenol 4s** and other pain medications but ultimately stopped them because they made me feel “stoned” all the time and I was still in pain. But that left me with few alternatives.

The pharmaceutical industry is always coming up with new and different options, but these drugs were increasingly not masking the pain. So, I approached my doctor and asked if she would be willing to prescribe medical marijuana. I had never tried it recreationally, but a friend had given me a pot cookie to try, and it had given me the most pain relief I had had so far. After doing some research, my doctor gave me the prescription, then I had to go to the police to get the legal license. The process struck me as extremely odd. At this time, possessing pot was legal with my license, buying pot was still illegal.

It is always interesting the things that derail you when you least expect it.

I didn’t like the idea of buying through an illegal dealer, so I ordered marijuana from the government instead. When my order arrived, I was slightly surprised to receive a large box, within which I found a slightly smaller box, then a slightly smaller box again, and finally a wee little envelope that contained some seeds and no instructions. What did I know about the growing

and harvesting of pot? Nothing! I did plant them but then I found out that I wouldn't be able to harvest the plants for four to five months, so I turned to my friends in search of anyone with organic pot.

My doctor had agreed to prescribe marijuana only if I promised not to smoke it, since I had MS-induced asthma. I planned to bake cookies. I eventually found someone who said her pot was organic. Soon, I was eating a pot cookie every other night at bedtime. I slept fairly well but didn't love how the drug made my body feel. Over time, I developed some odd symptoms, but I wasn't used to pot so I didn't know what I was feeling was a stronger high or something else.

Long story short, four months later, I went to bed after eating my pot cookie and suddenly went into convulsions. It truly was the oddest thing I've ever known: My body was involuntarily twitching and flipping. I had the oddest feeling that I was not really experiencing my own body but watching someone else going through it.

I finally got the attention of my housemates, who called 9-1-1. It took almost two hours for the ambulance to arrive, which I have always assumed was because marijuana was mentioned in the initial call. The attendants were nonchalant, until they took my blood pressure and realized it was dangerously high. They whisked me off to the hospital, did some tests, and it was discovered that I had formaldehyde poisoning. The doctors determined I had all the symptoms of poisoning, except coma and death. It took about two weeks for the convulsions to fully stop.

It was a very difficult time; needless to say, I stopped taking pot cookies immediately. I found out that the grower of the pot didn't realize that if she sprayed her plants with insecticide, which was 99% formaldehyde, that the pot wasn't organic. As you might imagine, I was genuinely perplexed, and I remember asking "what exactly do you think organic means?" I never did receive a satisfactory answer. Ironically, I found out that had I smoked the pot, it would have burned off the formaldehyde but by eating it, it was potentially lethal.

Not long after that, my neurologist told me about a new pain medication that was a **neuropathic pain** reliever. I tried a sample of the drug and it worked. I have been taking it ever since. I also began taking new medications for **spasticity** and for asthma. I felt like a walking, legal, pharmaceutical experiment.



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Part Three

Laura Quirk

Finding Tools to Help Me Succeed

So far, I have told you about some of the medications and therapies I've pursued. But that's not all that gave me assistance as time went along. I also have a scooter, which was a very scary idea at first. I thought if I used a scooter, I would forever be attached to it and that my "new normal" would be a label that included the term "disabled." I was, therefore, quite reluctant to get into the seat of the scooter.

What I can tell you is that my scooter was purchased by eleven lovely friends who wanted to help me defray the cost and also, I think, to metaphorically "hold me up" in the scooter seat. It worked. Instead of seeing my scooter as the enemy, I saw it as a tool of love. It was a life-changing time for me because the scooter gave me back my independence and motivation—I could even drive a van after a scooter lift was installed.

I also became involved with Freeport Hospital, the **rehabilitation** campus of Grand River Hospital, and their augmentative devices department. If I needed it, I could get tools that would speak for me and computers that would type for me. In addition, there was help if I was unable to see—books could be read to me.

What all of that told me was that if I needed it, help was there. I could pursue my dream of teaching. And so, I began teaching part-time at the university, just to see if I could do it. Of course, it was a shock to students to see me looking healthy in class one day and using a scooter another, but they quickly learned to adapt to my changing body. I also learned to share my story with them so that they would be more comfortable when I came into the classroom with a mobility device. It was a scary and invigorating place to be.

MS and Remission

One thing that I have so far neglected to talk about is the fact that MS can go into **remission**.

Multiple sclerosis is thought to be an autoimmune disorder. In autoimmune diseases, immune factors attack the body's own cells. In the case of MS, the immune system attacks the tissues that make up myelin. The damage to myelin, and nerve fibers (axon), is caused by overactivated T cells. T cells are a type of white blood cells called lymphocytes. In my case, blood tests always show a very high white blood cell count. So high that any new doctor invariably wants to put me on antibiotics, and I have to convince them that I didn't have an infection. That was my "normal."

In the first twenty years I had MS, I had not once been in clinical remission and the disease had been very active in my body. But at around the twenty-year mark my family doctor asked me to see a new neurologist; she had heard this specialist speak at an event and thought I'd like her and be able to trust her. And, as my family doctor rightly pointed out, I had had amazing recovery after experiencing so many symptoms over the past twenty years, but the long-term effects were likely to become more challenging if I didn't at least try to stop the progression of the disease. I had refused all such offers up to that point because I had bad luck with neurologists. But I trusted my doctor, so I agreed to go.

When I met this neurologist, I was immediately impressed with the fact that she was a human being and she treated her patients as human beings as well. I will admit that a good bedside manner is not terribly important to me, but it was such a relief to find someone who was positive, strong, interested in the latest research, but not a risk-taker with the lives of her patients. I did trust her and she quickly put me on an injection drug called **beta interferon**. The medication is believed to work by suppressing the inflammatory factors in the immune system that are associated with the attack on myelin. In other words, the drug would suppress my immune system and hopefully bring my white blood cell count to normal levels. And surprisingly, it did just that. Within four months of regular injections, I was, for the first time, in clinical remission. I couldn't believe it. That was in April of 2008. It was then that I knew I would pursue my goal of teaching at a post-secondary level.

I will admit that a good bedside manner is not terribly important to me, but it was such a relief to find someone who was positive, strong, interested in the latest research, but not a risk taker with the lives of her patients.

In early January 2010, I successfully defended my PhD dissertation and officially became a "doctor." I cannot explain what a victory that was for me, but suffice it to say, I knew I could do anything. The next day I was exhilarated that my dream had come true, but I found myself staring at my computer and asking out loud, "now what?" I had fulfilled my dream and I didn't know how to take the next step.

Almost immediately, the phone rang, and I had a phone call from the chair of liberal studies at Conestoga College. He told me that he was looking for someone to immediately fill a vacancy teaching Canadian history at the college. In fact, the semester had already started, and the students had missed two classes already. He asked if I was interested. What a question!

Without a second's hesitation I said "yes." I had only a couple of days to prepare, but I wasn't alarmed. I knew my topic, I had taught before, and I was eager to prove that this would be the job for me. And once again I had to say to myself, "If I never try, I'll never know."

It quickly became apparent that Conestoga College was a terrific fit for me. My boss had a talent for giving his faculty assignments that would keep them interested and I was no exception. I began branching out and teaching new courses. I even began developing my own courses that focused on my unique academic training. One of my favourite experiences was developing and teaching a course called The History of Art. In that course, I could include not just my knowledge of history and archaeology, but also my experience as an art gallery owner. I was thrilled and delighted with the opportunities I was being given.

Where I Am Today

In 2011, I was still in solid remission, and I knew that the college was looking for a full-time history professor. I was momentarily in a dilemma. Should I apply? What if I was in an MS attack? Would my students suffer for it? How would I manage MS in the classroom? In reality it was a very quick decision. I had been in MS attacks before when I'd been teaching part-time and I managed to teach with help from various aids. I knew that I could do it. I wouldn't have applied if I didn't think that. And yes, I got the job. I have since been working full-time and loving every minute of it. I have often thought of that neurologist who told me I'd never work again because no one would hire me. I wish he had added, "*Unless they know you and your work.*"

This brings me to today and while I am not currently in remission, MS has mostly subsided. To look at me, you would never know that I have MS. I usually walk normally, talk normally, and generally feel pretty great.

I know I have MS every day, but I take various medications that keep me going and help with the pain and spasticity. It impacts my ability to socialize at night because I take most of my medications with dinner (and I can't drive afterwards). But life is sweet. I have seen that the light, the spark that started so many years ago, has turned into a burning flame. I am thankful every day to be alive and to be so full of hope for my future and for the future of those living with multiple sclerosis.

In the end, I have realized that my life is about hope as a verb and not as a noun. Hope is an

action I must do, not a *thing* I just have. Hope is about trying to see beyond what the doctors and specialists say about my life. What matters is that we all find ways to live our lives to the fullest, whatever that means for us individually. Perhaps what I need to say, more than anything else, is that to hope isn't about being blind to the world, or about being uninterested in how we got here. The ability to hope is hard-won and it drives us forward against all odds. To hope is about resilience no matter the cost and it is about looking for light when hope is all you have left.



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Learning Assessment

Reflection Questions

After reading this essay, reflect on the following questions.

1. What have you learned about how multiple sclerosis affects a person after reading Laura Quirk's story?
2. Laura does not use the term "disabled" until the end of her story. Why do you think that is?
3. In her conclusion, Laura talks about the difference between *hope* as a verb and *hope* as a noun. What do you think about a difference between the action of hoping and simply having hope?

Discussion Questions

1. How has Laura's story helped you to understand MS in new or different ways?
2. Laura wrote poems as part of her storytelling. How do these poems help you understand her experience as a person with multiple sclerosis?
3. Given how Laura describes her life experience, would you use the term "disabled" to describe her? Why or why not?
4. What have learned from Laura's story that will help you in your everyday practice?
5. Describe what you now understand about "disability" that was not clear to you before reading Laura's story.

Learning Assessment: Health Conditions

Learning Objectives: Health Conditions

After reading this chapter, you should be able to:¹

1. Explain in basic terms how MS affects the structures and functions of the central nervous system.
2. Identify some signs and symptoms of MS.
3. Discuss the role of pharmacology in the author's management of MS, including both successes and failures of different treatment protocols.
4. Describe some of the limitations and participation restrictions caused by MS.
5. Discuss how the author has overcome different limitations and participation restrictions.

Check Your Understanding



An interactive H5P element has been excluded from this version of the text. You can view it online here:

<https://ecampusontario.pressbooks.pub/storiesofhopevoll/?p=49#h5p-1>

1. These learning objectives and the associated assessment align with the course and unit outcomes of OPA1255: Health Conditions 1 in the [Occupational Therapist Assistant & Physiotherapist Assistant program at Conestoga College](#).



An interactive H5P element has been excluded from this version of the text. You can view it online here:

<https://ecampusontario.pressbooks.pub/storiesofhopevoll/?p=49#h5p-2>

Critical Thinking Questions

1. Are the symptoms that Laura experienced typical for MS? How are they similar and how are they different?
2. Describe the diagnoses that Laura experienced 30 years ago. How does this compare to the process that is followed today?
3. In what ways has PT and OT helped Laura manage her condition? How have PT and OT been ineffective?
4. Identify the instances of pharmacological management in Laura's story?
5. Use clinical reasoning to discuss the management of MS based on what you've learned in Laura's story.
6. What do you want to know about Laura's condition that was not discussed in her essay? What questions would you ask if she were your client or patient?

Glossary

archaeology

the scientific study of human culture through human remains, artifacts, and other evidence

benign

the quality of being harmless, or not carrying disease; i.e., a benign tumor is not cancerous

beta interferon

a drug that acts to suppress the immune system

chronic progressive

description for a condition that is continuous (chronic) and gets worse over time (progressive)

conclusive

describing information that cannot be interpreted a different way; giving a conclusion to a question

intravenous

entering the body through a tube inserted into the veins with a needle

MRI

magnetic resonance imaging test

multiple sclerosis

a disease of the central nervous system that impacts basic coordination and body functions

myelin

the membrane that surrounds the nerves

neurologist

a medical doctor specializing in the nervous system

neuropathic pain

the pain caused by nerves described as burning, shooting, numbness, or tingling

PhD

abbreviation of "doctor of philosophy," the highest graduate degree (different from a "doctor of medicine" or MD)

prednisone

a steroid drug used to reduce inflammation

psychosomatic

describing a physical health condition that may be caused by a person's psychological health condition or emotional disturbance

rehabilitation

the restoration of health through training or therapy

relapsing/remitting

description for a condition that returns (relapses) and goes away (remits) unpredictably

remission

a temporary or permanent halting of active disease in a body

sclerosis

the scarring and an abnormal hardening of the myelin

spasticity

an abnormal increase in muscle tone and stiffness caused by damage to the nerves that transmit messages to and from the brain

spinal tap

a medical test in which a large needle is inserted into the back to remove spinal fluid for testing; also known as a lumbar puncture

Tylenol 4

a brand name prescription pain reliever that combines 300 mg acetaminophen and 60 mg codeine, a mild opiate