

BEATING MULTIPLE SCLEROSIS

Empowering Stories of Self-Healing and Thriving

AGOTA NAWROTH
& PAIGE NEWSOME

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To my loved ones,

This book reveals the transformative path of my MS journey and daily dedication required for a healthy life. I'm taking care of myself, so you don't have to.

To the multiple sclerosis community,

May our stories empower and inspire, fostering understanding, compassion, and progress. Together, let's navigate the challenges of this journey, knowing that we are never alone.

With love and deepest admiration,
Agota Nawroth

ACKNOWLEDGMENTS

I would like to express my deepest gratitude and appreciation to everyone who has contributed to the creation and completion of this book.

First and foremost, I extend my heartfelt thanks to Paige Newsome. Without you, this book wouldn't exist. Your belief in this project, constant motivation, and endless hours of work have been a driving force. You shaped this book in ways I couldn't have imagined.

I would like to extend my heartfelt gratitude to all the remarkable individuals who graciously shared their heartbreaking stories for this book. Your bravery in opening up about your journeys will undoubtedly resonate with others who find solace and strength in knowing they are not alone. I am honored to have had the opportunity to give voice to your stories and express my deepest appreciation for your invaluable contribution.

Lastly, I extend my gratitude to my followers, readers, and supporters. Your enthusiasm, feedback, and reviews inspire me to continue sharing my story and the knowledge I've acquired along the way with the world, raising awareness about diseases that can be prevented.

To all those mentioned above and the countless others who have contributed in various ways, your presence in my life has made this book a reality. Thank you for being a part of this remarkable journey.

With heartfelt appreciation,
Agota Nawroth

AUTHOR'S NOTE

Many individuals are searching for a diagnosis while struggling with various symptoms. For those of us already diagnosed, having answers can be a relief but also adds a lifelong burden. At times, this weight can feel overwhelming. I wish a book like this had been available when I was first diagnosed four years ago. It would have made a world of difference. Back then, I wouldn't have felt so alone and lost. I wouldn't have had to search through numerous books to connect the dots. My goal with this book is to provide you answers and give you practical guidance to regain control and steer your life back on track.

The stories in this book showcase the remarkable potential within us as human beings. We can heal our minds and bodies, making full recoveries from autoimmune diseases when we cultivate the right mindset and well-being practices. I haven't encountered anyone who thrives with a pessimistic outlook. Our minds are incredibly powerful. It's crucial to remember that the path to healing often begins there. While change can be a challenge, it's a necessary step for those seeking a healthier life.

So, who is this book for? It's not exclusively for people with MS. This book is filled with ideas to improve the lives of anyone, diagnosed or not, who is facing symptoms. Each chapter is a glimpse into someone's life, flourishing despite the diagnosis. My hope is that you'll discover a story or two that resonate with you. Please share this book, help us spread the message, and raise awareness about this complex condition. It doesn't have to lead to life in a wheelchair.

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Final Note

“Wellness is the complete integration of body, mind, and spirit – the realization that everything we do, think, feel, and believe has an effect on our state of well-being.”

– *Greg Anderson*

DISCLAIMER

The stories shared in this book provide personal perspectives and experiences, reflecting individual accounts. These stories should not be construed as professional medical advice or recommendations.

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Story by

CLARE McKENZIE

Diagnosed in 2019

Currently 50 years old

Lives in United Kingdom

Instagram: @ms_jellylegs

*“Start at the beginning, continue on, and when you reach the end, stop.”
-Lewis Carroll*

My name is Clare, and I live in Burnham-on-Crouch, in the UK, with my partner, Gary, plus our cat, Cosmo. I hope you enjoy reading my story. I’m sorry to start on a somber note, namely, with my elder brother who took his own life at the age of forty-three. He had suffered from multiple sclerosis (MS) since he was twenty-six. I dedicate this story to his memory with the hope that it may make a difference to other MSers’ lives and to avoid anybody feeling the need to take the same tragic path as Ian.

It was December 1994 when my brother was diagnosed, after a spot of double blurred vision. That was the first time I had really heard about the condition. My family never spoke about this with me again; nothing was said. Life went on. At that time, I was twenty-one years old and just

starting out in my sales and marketing career in publishing in London.

When I turned thirty, my brother tried to take his own life. I received the news by phone. Nothing more was said. That year (2003), I took part in a charity called Moon Walk for Breast Cancer, walking twenty-six miles through London.

Fast forward to when I was thirty-five, and my walking became disrupted. I began to notice a significant decline in the distances I could cover, and I started experiencing increased fatigue. Despite those challenges, including the occasional trip and fall, which I managed to turn into a comedic act to make everyone giggle, I carried on...

On July 10, 2012, I attended a London Ambassador training event in London. I felt something was wrong, and I had a tear in my eye between 8:30am and 9:00am. My brother had taken his own life at the age of forty-three. I was thirty-eight. No one talked about this either, just like when he was diagnosed. In my family, illness was never allowed to be out in the open, nor was the MS support landscape as developed as it now is. The result was that my poor, poor brother got very little in the way of psychological help, and he struggled with severe, clinical depression for almost twenty years, from which he never emerged.

I am now forty-five, and I have just organized a charity walk, in aid of Cancer Research UK, for my team at Wolters Kluwer, in Canary Wharf. I knew this would be a challenge. I was barely able to walk thirty minutes by this point. Upon returning to the office, I face-planted onto the marbled floor of my reception. It hurt. That's when I thought I should make a doctor's appointment. This was during October 2018.

After three magnetic resonance imaging (MRI) scans, I was diagnosed with Relapsing-Remitting Multiple Sclerosis (RRMS) in March 2019, by my general practitioner (GP). As you might expect, my brother's tragic experience scared me, but not in the way you might think. I became acutely aware of the importance of being open about my condition and actively seeking out and accepting all the help that was available. I took it fairly well. I started conducting research on RRMS, focusing on exercise and diet. I had already been a pescetarian since the age of eighteen, and I also did not smoke or drink much. Yes, what a bore I am! I do have a fizzy personality though! In a nutshell: my supercomputer (my brain) does not always send messages down my superhighway (my spinal column), and my legs sometimes get in a muddle.

MS is considered an autoimmune disease, as the body's immune system

attacks myelin. This is a fatty substance that insulates and protects the nerve fibers of the Central Nervous System. When myelin is damaged, it becomes difficult for the brain to send signals to the rest of the body and within the brain itself. The symptoms of MS vary from person to person. That's why it is known as the "snowflake" condition. I love that we are all special and unique!

According to the *MS Trust*, an estimated 2,500,000 people in the world have multiple sclerosis. Research suggests the proportion of women with MS is increasing; roughly between two and three women have MS for every man with the condition.

I have a penchant for the book *Alice's Adventures in Wonderland* by Lewis Carroll; it seemed that just like Alice, my MS journey would open many doors. Like Alice, I wanted to stay curious; I would have eaten the proverbial cake and drunk the contents of the bottle just to find out what would happen. Here's what transpired next. I discovered:

- Instagram – I set up my IG account @ms_jellylegs (see what I did there?!) to learn, educate, empower, and inspire others.
- Overcoming MS program – This lifestyle program resonated with me, and I was lucky to stumble upon it only three months post-diagnosis.
- Knives Over Forks documentary
- Mathew Embry's documentary *Living Proof* – A true inspiration. I was lucky to cross paths with Mathew when I reached out and booked him to collaborate with Dr. Gretchen, my MS-Specific Physical Therapist.

Information overload. But here is what I learned: when we give our bodies a break from digesting food all the time, our cells can then focus on other things, like cleaning out damaged cells, in order to regenerate newer, healthier cells. Gut rest can lead to a brain reset. We can also call periods of gut rest, with the intention to reverse chronic conditions, therapeutic fasting. Fasting has been gaining momentum *outside* of the weight loss community due to the multitude of benefits, particularly for the brain. Research in this area is expanding every month and has been indicating that periods of fasting can help reverse or slow down diseases, like diabetes, Alzheimer's, and cardiovascular disease. We now have early hope that fasting may benefit multiple sclerosis warriors, as well.

Preliminary evidence in animal studies has indicated that fasting, or caloric restriction, helps prolong lifespan, and improves MS, by bringing down inflammatory markers, bringing about positive changes to the gut microbiome, demyelination prevention, and axon protection—all while keeping the immune system function optimized. Human data indicating

the benefits of fasting for the brain are on the rise, though studies of the effect of fasting on MS are still limited. However, a new study, released January 2022, offers us some hope of what's to come. In this study, thirty-six people with MS were followed for eight weeks and were randomly assigned to either a daily calorie restriction diet, an intermittent calorie restriction diet, or a weight-stable diet. The intermittent calorie restricted diet, similar to a fasting protocol, was associated with a reduction in memory T cell subsets. Though fasting can feel intimidating to someone who eats three meals and multiple snacks throughout the day, when we slowly compress our eating window, our gut has time to rest and repair, along with all the other cells in the body. If you can start with the goal of not eating after dark and completing a twelve-hour fast every day, it may make a huge difference for you.

I have suffered from non-chronic episodic migraines for years—long before I was diagnosed with RRMS. I do not recognize these migraines as a symptom of MS. Many would argue just that, but not everything is MS-related, right?! My migraines are always around my menstrual cycle, and I have two or three days where I am wiped out. Whether that be from fatigue, light, or food sensitivities—and that's before I mention the roaring migraines. I first discovered Susannah Juteau , a nutritionist and headache specialist, as a guest on the “Multiple Sclerosis Awareness” group via IG, presented by Ritu. I was eager to fix my monthly migraines, so I signed up for the Headaches Bootcamp that I have now completed. I was looking for strategies to relieve headaches without medicine, and understand how I could not only survive, but thrive!

Understanding not just *what* you eat, but *when* you eat is super important if you are embarking on an intermittent fasting program. When you fast, insulin levels drop and human growth hormone (HGH) increases. Your cells also initiate important cellular repair processes and change which genes they express. There are so many benefits associated with choosing an intermittent fasting regime, such as improving heart health, lowering blood pressure, cholesterol levels, and reducing other inflammatory markers. By fasting, your body will trigger a metabolic pathway called autophagy, which removes waste material from cells, improves your brain health, and may help to build new neurons.

Initially, I started with a 12:12 hour fast, and quickly progressed to the 17:7 fast; that's seventeen hours of not eating with a gap of seven hours to eat. I have completed two days of twenty-four hour fasting, which is not that scary when you consider most people naturally do a 12:12 hour eating program. I generally stop eating by 7:00 pm. If you consider relaxation, sleeping, and not eating until breakfast time—that is an easy

twelve-hour window. The process has been super educational. Personally, I need to remind myself the reason “why” I am doing this—that’s my motivation.

I strongly believe fasting is as much of a mental exercise as it is a physical exercise. Dr. Gretchen Hawley – MS Specialist Physical Therapist, always tells me to remember why I want to improve something about my mobility. Quite simply, it is because I want to enjoy myself with my friends, socialize, and feel empowered; that keeps me motivated to exercise. Dr. Hawley released her new book in July of 2023, *The MSing Link: The Essential Guide to Improving Walking, Strength, and Balance for People with Multiple Sclerosis*, which I highly recommend!

The next big thing I discovered was meditation! Did you know that meditation is for the soul? It helps improve your physical AND mental health. I am sure some of you will agree with me that there are many times where you find yourself rejecting the life you must now live; wishing that those weights and burdens did not exist. What if we all had a superpower? An extraordinary gift that you could tap into anytime, anywhere?

Enter mindfulness. In a world that’s constantly forcing you to reach outward (work, fatigue, family, financial worries, illness, etc.), reach *inward* and check in with yourself, using the powerful technique of mindfulness. Meditation is all about relaxation and finding your inner peace. I certainly know what I could do with some inner peace to quiet my pontificating mind!

You need to create a place that works for YOU:

- Find a space with the perfect ambience! Maybe you’re a complete silence kind of person, or someone who needs a little white noise. Taking ten minutes before I start my day does help.
- Get comfy! Grab a yoga mat, a fluffy blanket, or—if staying in bed does it for you—do just that! (Meditation naps are real!)
- Try a new position! Anyone who endures symptoms, such as pain, numbness, or muscle spasms, may have a difficult time focusing, so take the time to find the right position to minimize these symptoms, if possible.
- Keep the distractions to a minimum. Phones (and children) on silent mode, please!

Take a moment to recognize what makes you so extraordinary: your foundation of strength, resilience, and perseverance. Meditation takes practice, and finding the right space for your mindful practice might take a few tries. No space will ever be perfect, but don't let that stop you from trying today!

So, how did I miss MS? I ignored and brushed off symptoms that may or may not have led me to my MS diagnosis, such as migraines, trips and falls, tingly hands in the cold British winter, heat intolerance when living in Curaçao, tingly feet that I thought were caused by my sciatica (don't ask how I got that!), walking distance, and fatigue. They all seemed minor to me, so I just brushed them off and carried on.

Has the diagnosis made much of a difference in my life? Well, it has given me some answers. I am super lucky as my symptoms are mild. Generally, I am in full control of everything that I choose to do. MS has not stopped me, and I feel that I am living my best life right now. I have a lot of things I want to accomplish—one wonky step at a time. It's all about the way you frame it. "What if" can be changed to "even if"! I am super thankful for what I have today. Alice fell down the rabbit hole, as I did during COVID lockdown. But the difference is that I got back up and carried on. The only way is most definitely up!

I have always loved walking. Happily, I'm still a 20,000-steps-a-day person, despite my MS. However, my perambulations haven't been without their moments—some with quite hilarious consequences (in retrospect, at least). I strive to continue living life to the fullest, to not get down about what I've lost, and most of all, to have a jolly good laugh about the curve balls MS sometimes throws at me.

Lastly, I'm happy to announce that as I was writing my story for this book, I received a letter from my neurologist, whom I visited recently, with news that I have to share here. Let me quote: "She has Relapsing-Remitting MS and remains stable through the years, not being on disease-modifying treatment. EDSS score stands at three, and most likely her case, if we consider that the onset of her disease was many years ago, in benign." Hallelujah! Something we agree on—now that my doctor is retiring. So, in no particular order: exercise, diet, fasting, meditation, and not taking DMTs have worked out for me this far. Of course, we do not know what the future holds. Every day is different, and I'm taking it as it comes with a smile and a bag of positivity. My motto is to keep on keeping on; slow and steady.

If you, a member of your family, or a friend have been affected by multiple sclerosis, I highly recommend these sources as a great starting point to find out more:

- Overcoming MS – I am a global Ambassador and founding member of the OMS Essex Circle.
- MS-UK – I support the MS-UK Peer Pod for the Newly Diagnosed on Monday evenings at 7 pm. I am also a member of the Virtual Insight Panel, offering communications and marketing support.
- Doctor Gretchen Hawley – MS-Specific Physical Therapist - The MSing Link.
- MS-Selfie – I am a supporter of Professor Gavin Giovannoni’s weekly newsletter that brings you the latest in scientific discoveries and observations.
- MS Awareness Week – It’s a chance to raise awareness of multiple sclerosis and spread the word. #LetsTalkMS
- shift.ms – By people who get it!
- MS Trust – Great for MS Education.
- MS Society UK – Great for MS research and fundraising.
- talkhealth Partnership – Whatever health concerns you may have, talkhealth comprises a team of like-minded individuals, who are keen to provide the latest health information and support that is currently available. I have submitted articles for the MS Hub, and I am a regular contributor.

FINAL NOTE

"Before you heal someone, ask him if he is willing to give up the things that made him sick." -Hippocrates

As we reach the end of this book, I hope these stories have not only inspired you but also encouraged you to take a moment to reflect on your own life. The purpose of this book has been to shine a light on aspects that deserve recognition and change. It's not just about MS or autoimmune diseases; it's a call to awareness, an invitation to slow down and reevaluate our lives.

Our ancestors had wisdom we can learn from, and with today's technology and knowledge, we can create a healthier, more harmonious world, instead of heading down a destructive path. It's as simple as pausing to take a deep breath, enjoying the smell of flowers, and appreciating the beauty that surrounds us.

We hope you've found this book to be a valuable guide. In closing, remember that while healing isn't guaranteed, it's always within reach. The life you choose to lead is firmly in your hands. Join us on **www.BeatingMultipleSclerosis.com** to explore all the limitless possibilities together.