

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

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

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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

LIEZA

Diagnosed in 2016

Currently 32 years old

Lives in Christchurch, New Zealand

My story is one of resilience, perseverance, and unwavering optimism. Despite facing challenges and setbacks, I never lost sight of my goals and refused to give up. I moved to New Zealand (NZ) from Belgium when I was twelve years old. I'd always loved horses. In NZ, I started competitive horse riding. I loved competing! Eventing (which is what I focused on), consisted of three phases: dressage, show jumping, and cross-country. In the cross-country phase, you have to go fast over jumps for three-to-four minutes. I think I experienced my first multiple sclerosis (MS) symptom (blurred vision) when I was seventeen years old, during the cross-country phase of a horse-riding event. I knew that I had to jump between the red and white flags. Luckily, my horse and I had a strong bond, so he would just jump. I didn't experience blurred vision every time, so I assumed it was just adrenaline from competing.

When I was twenty-two years old, I gave up horse riding as it was too time-consuming, and I needed to focus on my university degree—a Bachelor of Science majoring in Physics. To “relax” from the stress of

university, I took up running. I loved putting on my running shoes and hitting the road. I'd run everywhere. If I felt sad, I'd run. If I felt happy, I'd run. I ran to think about things. I ran to forget about things. Running gave me so much freedom and happiness. Some of my fondest memories are running with my dad on the beach and in the hills of our hometown.

I didn't want to just run; I wanted to be great. I trained six days per week, religiously following a schedule I put together. My dream was to qualify to run the Boston Marathon one day. On trail runs, I'd often trip over tree roots. My dad and I would laugh about how clumsy I was. Little did I know, this was a sign of what was to come. I competed in three full marathons and numerous half-marathons, road races, and trail runs.

When running, I sometimes experienced strange things that I couldn't quite understand. I was not able to completely focus my eyes, and my balance was not as good as usual. I'd slur my words a little afterward, and my feet would sometimes feel heavy—I felt like I was stomping my feet on the ground. These strange symptoms would come and go. I thought maybe my blood sugar was low, so I ate sugary foods during my runs, but that didn't help.

In June 2016, my sister and I decided to run a half-marathon together, aiming for a sub one hour and thirty-minute time. I was doing a lot of treadmill running leading up to it as I was close to submitting my master's degree. By the time I could train, it was dark outside. When I was driving home from the gym, I'd have to cover one eye to properly judge the distance between my car and the car in front of me.

The first three kilometers (km) of the half-marathon were good; then my legs started feeling heavy, and I stomped my feet down on the ground. I kept going but was rapidly giving up on my desired time. At eighteen km, I had blurred vision and could no longer run in a straight line. My sister had to hold my hand. I was stopped by a race marshal and given some soft candies. I was told to rest and wait for the ambulance to arrive. She suspected I may have diabetes.

I got sick of waiting and asked if I could continue. I only had three km left and wanted to finish. She said that I could continue if I walked. I walked for a bit and then decided to run. My legs started feeling heavy, and my vision went weird again. So, I walked the remainder of the course but ran through the finish line, with my sister by my side.

I didn't run again because I feared a repeat of what had happened. I underwent a myriad of tests; none of which provided an answer. Four

frustrating months later, my parents paid for a private neurologist appointment. I explained my experiences to him, and he mentioned something called Uthoff's phenomenon, but no real explanation. He got me into the public health system and ordered magnetic resonance imaging (MRI). No words of MS had been mentioned at this stage, though the neurologist probably had his suspicions.

While I was waiting for the results from my head and neck MRI, I completed my master's degree, and my sister and I traveled around Peru for three weeks. I hiked Rainbow Mountain (5200 m altitude), Machu Picchu, and visited the Amazon Jungle. I didn't experience any strange symptoms during this time.

After my trip to Peru, I started my PhD in Medical Physics. In December 2016, I had an appointment with the neurologist to discuss my MRI results. In NZ, to obtain an MS diagnosis, lesions need to be detected on an MRI, and you must undergo a spinal tap/lumbar puncture. A few days before Christmas, I received my spinal tap. They accidentally punctured my spinal sac, and I spent the weeks around Christmas vomiting and having terrible migraines whenever I stood up. It was performed by a registrar, but I recommend seeing someone who has extensive knowledge regarding the procedure.

In January 2017, at the age of twenty-six, I was officially diagnosed with Primary-Progressive Multiple Sclerosis (PPMS). I remember sitting in the neurologist's office with my mum, not really knowing what this meant, but knowing it wasn't good.

A few months prior to my diagnosis, I began to study for my PhD in Medical Physics. Immediately after receiving my diagnosis, I thought to myself that I'd better get on with my life. I was symptom-free, other than not being able to walk or run quickly. I didn't want to know what could possibly happen; knowing the worst-case scenario is not helpful for me. Ignorance is bliss, right?

The only time I heard from my neurologist after my diagnosis was when she called me to ask if I was interested in participating in a drug trial. I researched the drug and decided no—it wasn't for me. I felt fine; I didn't need medication. I never heard from my neurologist again after that.

So, I continued living my life. Over the next three years, I traveled to China, India, Nepal, Sweden, and visited family in Lithuania and Belgium. I completed my PhD in three years. I had an active social life and met the love of my life. I had MS, and life was pretty good. I was

proud of myself! Even with MS, I was living a life better than I could have imagined.

Fast forward a year and a half. In October 2019, I had the opportunity to live and work in Hong Kong for one year. I loved Hong Kong. My symptoms hadn't changed much since my diagnosis, and I felt very grateful. I couldn't run, so I found refuge in going to the gym for strength training six days a week, but the pandemic took that away from me. My walking deteriorated. Walking from my apartment in Hong Kong to the bus stop (about 500m) was a real struggle. Walking downhill was the worst. My legs would shake and feel like jelly. Walking was awful in the tropical Hong Kong climate, especially with a mask.

At this stage, I was alone. My boyfriend had come to live with me in Hong Kong for six months, but he went back to NZ as he couldn't find a job; Hong Kong is not cheap. I felt hopeless. I was in a foreign country alone, experiencing something that I'd never experienced before. I turned to MS support groups on Facebook for help and advice. I joined quite a few of them, but I felt like none were right for me, as the posts were often negative and quite depressing to read. I felt even more hopeless, like my life was going downhill from here. Then Facebook suggested a group called "Overcoming MS". I joined the group, not fully knowing what it was about—I just liked the name. The first few posts that I read were about people being positive and helpful! I was hooked.

Soon after, I met up with a member from the group, who had MS and also lived in Hong Kong, five minutes away from where I lived. She explained the seven-step Overcoming MS (OMS) recovery program to me. It consists of the following steps: Step one focuses on diet. Step two highlights the importance of vitamin D and sunlight exposure. Step three encourages regular exercise. Step four emphasizes the practice of meditation and mindfulness for stress management. Step five addresses the use of medication. Step six focuses on preventing family members from developing MS. Step seven emphasizes changing your life for life.

She had been following OMS since her diagnosis, and she managed to shrink some of her lesions. Shrink lesions?! How is that even possible? After meeting her, I followed the diet part of OMS 100%. I was taking 50,000IU of vitamin D orally—one capsule per month. Although I didn't feel changes immediately, I did notice that it helped my energy levels. Now, I try to aim for a vitamin D level in the range of 150-225 nmol/L (or 60-90 ng/mL), as per the OMS guidelines. I get my vitamin D levels tested about twice a year: once at the end of winter and once at the end of summer. I also made sure that I exposed myself to the sun as often as I

could. I was doing resistance training in my apartment at home, taking two tablespoons of flaxseed oil a day, and my OMS friend had even convinced me to do yoga.

The amount of resistance training that I did was dependent on my symptoms and mobility level (this was also pre-baby). I used to work at a gym as a receptionist, so I had friends who were knowledgeable and helped me develop my own program. I mostly did strength training with two upper body and two lower body days per week. For my upper body, I trained chest, shoulders, back, biceps, and triceps. For my lower body, I trained my quads, glutes, hamstrings, and calves. My cardio was walking on the treadmill or using the rowing machine. I wasn't really seeing any big changes, but I believed in the science of OMS, and I knew that it would take a long time (years) to see and feel the difference.

My year in Hong Kong was up, and I declined the offer to extend my contract for the sake of my health. At this point, simple tasks were a struggle. Leaving the house was nearly impossible. Every move that I made was calculated. Is it worth it? Is it important? Will I benefit from using what little energy that I had?

I was so happy to get back to NZ, where the climate was cooler, to be reunited with my family and boyfriend, to not have to wear a mask all the time, and to have access to my gym again. I had to do two weeks of managed isolation in a government quarantine facility due to COVID, but that was okay; it was two weeks of rest. I'd managed to organize all my meals to be OMS-friendly, and I even ordered some flaxseed oil from the local health food store. The OMS diet is plant-based, but it also includes seafood, so I got a lot of salmon, rice, and steamed veggies. Life was pretty good.

I'd completed one week of managed isolation when I was reading in my room one morning, and the vision in my left eye started going blurry. A few minutes later, I couldn't see anything out of my left eye. I was experiencing, what I later found out to be, my first bout of optic neuritis. Optic neuritis is often associated with an MS relapse. I had another week stuck in my hotel room all alone! Who could I ask for help? I then remembered that I had a tattered old card in the back of my wallet that had the contact details of my MS nurse on it. I'm surprised and grateful that I remembered I had this.

I was given a five-day course of oral steroids for my eye (I'd had a phone appointment with a neurologist from my isolated hotel room), and I regained some of the vision back in my left eye within two weeks. At this

stage, I was at home with my family and boyfriend in Christchurch. My eye recovered more every day, until my vision finally returned fully.

“Phew, I’m through the worst,” I thought. But MS had other plans. Before the steroids, I could walk fairly normally. I couldn’t walk for long, but what I could do appeared “normal” (except for walking downhill or downstairs). After the steroids, I couldn’t walk straight, my balance was all over the place, my legs would shake and felt like jelly, and I had a limp. I’m not blaming the steroids; it was probably just my MS progressing. I felt awful, embarrassed to be seen, and not like myself. But, as I told you earlier, I’m very stubborn.

Nearly everything that I’d heard and read about MS told me that once you start getting worse, there is no way of going back to where you used to be. I kept following OMS and trusting the process in hopes that it would speed up my recovery. I upped my vitamin D dose three months after starting OMS, from my monthly 50,000IU to 10,000IU a day. I started supplementing with magnesium, and I started meditating daily.

I also went back to the gym. Using the knowledge that I’d gained on my own and from my personal trainer that I’d had in Hong Kong, I started training myself. Initially, I couldn’t walk on the treadmill without holding the sides with both hands (since the treadmill felt narrow and required balance for me). Then, I gradually transitioned to holding on with one hand for one minute, and then the other hand for the following minute. Afterward, I progressed to using alternating fingers for support, followed by fifteen seconds of walking without holding onto anything. Now, I am proud to say that I can walk on the treadmill for five minutes without holding on to anything. That was in the space of about six months.

When I first came back from Hong Kong and was able to drive with my eye, I started working full-time at the medical imaging company that I had worked for prior to moving. Parking is bad where I worked, so I had to walk about one km to work and one km back every day. In the beginning (November 2020), that walk was so difficult. It felt like a walk, or hobble, of shame. My limp was so noticeable.

After I’d finished my job for the day, I’d make myself go to the gym (three times a week). Then, I’d come home and cook myself an OMS-friendly meal. At the end of the day, I was exhausted. “Was it all worth it?” I asked myself. Some of my family members thought that OMS was too restrictive, especially concerning the limited saturated fats. I also lost

about ten kg when I first started, but then I got pregnant while following OMS, and that was that.

After a few months, my limp that occurred while walking to work in the morning disappeared. I transitioned back to walking like a “normal” person, at least for a few hours. A few months later, I noticed that my limp wouldn’t start until the walk back to my car in the evening. Presently, my limp only shows up when I’ve done something “wrong”.

Following my discovery of the strong link between gluten and inflammation, I have embraced a gluten-free lifestyle as part of the OMS diet. I also repeat a lot of the same foods to make it easier on myself as I can prepare in bulk. For breakfast, I have scrambled tofu, beans, potatoes, and spinach with two tablespoons of flaxseed oil drizzled on top. Or I eat rice flake cereal (like porridge) with cocoa powder, maple syrup, and banana with flaxseed oil drizzled over the top. For lunch, I have vegetable lasagna/pasta, vegetarian sushi with miso soup, salmon with vegetables and rice, or curry. I typically eat the same foods for dinner that I eat for lunch. My go-to snacks are bananas, toast, and rice cakes with tahini and honey.

In August 2022, I found out I was pregnant. My pregnancy was very good, and my MS was very well behaved. I’d heard this might happen; nine months of bliss. I was not completely symptom-free, but I had definitely improved!

On May 1, 2022, I gave birth to a beautiful baby girl. I probably didn’t eat as much or as well as I should have (still 100% OMS compliant with my diet though). I definitely didn’t get as much sleep as I needed. I didn’t exercise or meditate regularly. My daughter was my number one priority. But I quickly learned that you can’t pour from an empty cup. About three months after the birth of my daughter, my MS symptoms got worse. I think old symptoms were flaring up. Months of sleep deprivation and my crazy hormones were probably the cause. I was, and still do, exclusively breastfeed my daughter, who is nearly fourteen months. I decided I would do everything it took to get better for my daughter. She was my “why”. I was still following the diet portion of OMS faithfully, I started meditating again daily, supplementing with vitamin D (I never stopped this), and I also became a paying member of the MSGym. The science behind the MSGym really resonated with me, and it made so much sense! I highly recommend you check it out, regardless of your abilities. There is a lot of free information, as well as paid membership options.

I don't currently take any MS medication. There is no medication funded for people with PPMS where I live, but even if Ocrelizumab/Ocrevus was available, I'm not sure if I'd take it. The main reason being that so little is known about MS, so how can they develop effective medication for it? I wish more research was focused on finding ways to better the lives of people living with MS today, rather than solely pursuing an elusive "cure". I prefer lifestyle changes as opposed to medication being the first thing that is offered. Lifestyle changes and medication can coexist. Why do some neurologists see them as being mutually exclusive? Can't you do both?

I don't undergo regular MRI's because I don't believe they are necessarily an accurate representation of MS progression. There are two reasons behind my skepticism. Firstly, so little is known about MS, and new research is constantly emerging. It raises questions about why individuals without detected lesions on an MRI scan still experience disease progression. Is there another underlying factor at play? Lesions alone may not provide the complete picture. Secondly, an MRI machine's ability to detect lesions could be limited by its resolution. This means that different scanners might yield varying results, further challenging their reliability as a diagnostic tool.

To prioritize my health, I engage in several activities that have been beneficial for me (in no particular order). I follow the OMS diet and take vitamin D3 supplements. I include two tablespoons of flaxseed oil in my daily breakfast routine. Getting good sleep, natural sunlight, meditating daily, and engaging in regular physical activity are also part of my health regimen. For meditation, I use apps like *Calm* and *Balance* for guided sessions. I practice breathing exercises for relaxation (non-sleep deep rest) and energy boosts (cyclic hyperventilation/Wim Hof techniques). These habits contribute to my overall well-being.

I've found cold baths to be very beneficial for my well-being, and I incorporate them into my routine whenever I find the time (three-to-four times a week), both in the morning and evening. I stay in for two-to-four minutes at a time. They help to improve my mood, energy levels, sleep quality, and mobility. I feel great whenever I take them. I recommend listening to Andrew Huberman's podcast, as it offers a lot of information about cold exposures. I've noticed that taking a cold bath before a hot shower helps me tolerate the heat better during and after the shower.

Am I grateful to have MS? Yes and no. No, because I wish I could still run on the beach and in the hills. But yes, for so many more reasons. Being diagnosed at a young age made me become a “yes” woman. I say yes to things without overthinking and sorting through all the possible outcomes. I deal with issues as they arise because 85% of what you worry about won’t happen anyway, so it’s just a waste of time and energy. Everyone has something “wrong” with them; MS is just my thing. I am not symptom-free. My gait is affected, and my left hand has unauthorized parties (among other symptoms). I can do 98% of what a “normal” person can do. Some things I can’t do as fast as others, but I get there in my own time.

Life, regardless of whether you have MS or not, is full of ups and downs. I know that I will probably have another “down” period in my life, but I also know that I have tools to fight whatever comes my way. I will never give up; I will continue to learn and educate myself. I will live a life that I have decided, not a life MS has decided for me.

Through my continuous research on neuroplasticity and the power of the mind, I am convinced that the mind can heal the body. Things are looking up. I will leave you with a few things that I have learned on this crazy journey so far: never compare yourself to others, especially considering the unique effects of MS on each individual. While improvement with MS is very possible, there are no quick fixes. Stay consistent and persistent. Take care of your body with nourishing food and positive thoughts. Remember, your subconscious mind is always listening.

Having MS has made me even more determined and resilient. I want to prove people wrong. Pursuing a Ph.D. despite English being my second language and dealing with an MS diagnosis? No problem. Completing it within three years, while managing MS? Absolutely achievable. Residing and thriving in Hong Kong? Yes, indeed. Embracing the joy of motherhood? Certainly. As for running again, just watch me exceed all expectations.

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.