

MY INVISIBLE BATTLE

With Multiple Sclerosis (MS)

SHRUTI GHATE



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please contact:

BLUEROSE PUBLISHERS
www.BlueRoseONE.com
info@bluerosepublishers.com
+91 8882 898 898
+4407342408967

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What does this title signify?

Why This Title?

"My Invisible Battle" is not just a title — it is my truth.

It's the story I carry in my veins,

The war waged silently within me,

Where the scars don't show on skin,

But run deep through nerves, emotions, and moments lost.

Multiple Sclerosis doesn't wear a face that others can easily see.

There is no bandage for numbness,

No cast for fatigue,

No visible wound for loss of control.

Yet every day, I fought.

Sometimes with strength,

Sometimes with surrender,

But always with a will to live beyond my diagnosis.

This title speaks for all of us fighting battles no one else sees —

Those who smile through pain,

Work through weakness,

And hope through uncertainty.

If you're reading this and you, too, are fighting something invisible —

Know this: your courage is real.

Your strength counts.

And you are not alone.

Why "My Invisible Battle"?

Because not all wars leave scars on the skin.

Some battles are fought in silence, beneath the surface,

With strength that doesn't scream — but survives.

MS may be invisible to the eye,

But it has changed every step I take, every breath I fight for.

This is the story of a war you cannot see — but I feel, every day.

I chose the title "My Invisible Battle" because MS doesn't show on the outside. People see me smile, walk, speak — but they don't see the numbness, the fatigue, the quiet tears. This title holds all the pain, the courage, the isolation, and the strength it takes to live with an illness that hides behind a mask of normalcy.

My Invisible Battle is more than a title — it's a truth many live with. MS may be unseen, but so is resilience. This book is not just about the struggle, but the strength it takes to rise through it. I own my story, and through it, I hope others feel less alone in theirs.

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Chapter 1

The First Signs

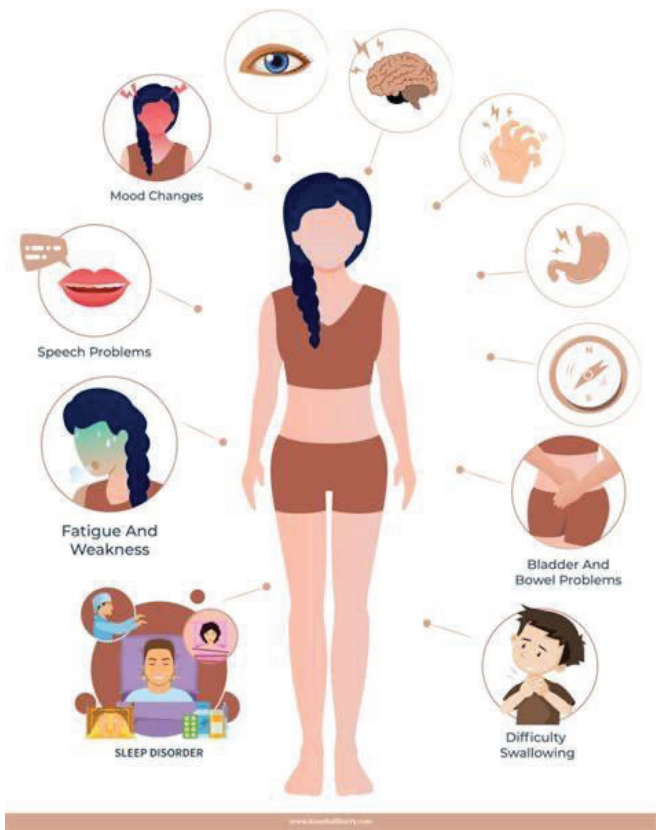
It started with tingling sensations in my feet. Initially, I thought it was only temporary, maybe it'll get better after some rest or a good sleep. But these initial symptoms never got better. Later, I understood it was called Neuropathy. Very soon, it turned to burning my feet, initially for a few months only one, and then both feet.

Later, I found it appropriate to talk to my GP (typically called a family doctor in India), hoping to get answers to my questions around my symptoms. It seemed he got the hint from my symptoms, and he immediately asked me to get an MRI done. I never knew then that this would be only followed by more such MRIs in my coming life.

What is MS?

Multiple Sclerosis (MS) is a degenerative neurological condition of the central nervous system. It disrupts the transmission of nerve impulses between the brain, spinal cord, and optic nerves. This disruption can lead to a wide range of symptoms — muscle weakness and Spasticity, reduced balance, sensory changes such as numbness and tingling, chronic pain, overwhelming fatigue, and cognitive impairments.

One common progression of MS begins with Relapsing-Remitting MS (RRMS), characterized by flare-ups followed by periods of remission. Over time, many individuals transition into Secondary Progressive MS (SPMS). In SPMS, relapses become less frequent, but there's a steady decline in neurological function. This shift often brings new challenges, both physically and emotionally, as the disease advances with fewer recovery periods.



Recognizing Early Signs of MS

What's Commonly Seen Early On :

- Vision disturbances: Blurred vision, double vision, or pain when moving the eyes—often due to optic neuritis.
- Sensory changes: Tingling, numbness, or "pins and needles" in the face, arms, legs, or trunk.
- Muscle weakness & spasms: Difficulty moving limbs, weakness in arms or legs, and painful muscle spasms.
- Balance, coordination & dizziness: Feeling unsteady, stumbling while walking, or experiencing vertigo-like sensations.
- Fatigue: Persistent exhaustion that interferes with daily life.
- Bladder/bowel issues: Difficulty controlling or frequent urges—common though often overlooked early on.
- Cognitive and mood changes: Brain fog, memory or concentration problems, and mood shifts like depression.
- Other possible symptoms: Occasional feelings like electric shock when bending the neck (Lhermitte's sign), speech changes, or swallowing difficulty.

Why Early Recognition Matters

Early symptoms may be subtle or fleeting. For instance, blurred vision or numbness that seems to resolve can still

warrant attention if recurring or accompanied by other symptoms.

- Many first symptoms occur years before diagnosis.
- Prompt recognition and evaluation help neurologists initiate treatment earlier, possibly slowing disease progression.

Bottom Line: The early signs of MS are highly variable and often overlap with other conditions. If you're noticing these symptoms, it's best to talk to a healthcare professional—even if they seem mild. Early diagnosis and care can lead to better outcomes.

A neurologist may perform diagnostic tests like MRI, blood work, and physical assessments to investigate MS or rule out other conditions. Till now, MRI is the only way to detect this illness or monitor the progress.

Chapter 2

The Diagnosis Begins

I still remember my first MRI scan. My mom was with me inside that chilly room. We were both equally scared — the sterile air, the strange machine, the unknown future. At that moment, we thought it was just one scan to find out what was wrong. Little did we know, it was only the first of many. That machine and I would meet again, and again, and again.

The journey stretched on for over a year. Scan after scan. Symptom after symptom. Then came another major blow — bladder issues. Suddenly, something so basic, so automatic, was no longer in my control.

They fit me with a catheter — a tube to help me pass urine. Silly me! I thought this was just temporary. I thought it was a short-term fix, and in a few weeks, I'd be back to normal. But life had other plans.

Take 2 — the catheter became permanent. A forever solution to a symptom that stubbornly refused to go away.

And let me tell you — catheters are not as simple as they sound. There's excruciating pain when it's time for a change. Retention pain feels like a cruel urgency, as if your body is screaming to go, but you're forced to wait. I've spent hours in hospital rooms, waiting for nurses to help change the

catheter, only to go through more discomfort as the old one is pulled out and the new one is inserted.

The pain wasn't just physical. It was emotional. It was humiliating. And yet, I smiled. I cracked jokes. I acted okay. Because what else do you do when your body betrays you — and you still have a life to live?

Although earlier, physiotherapy and exercise physiology used to leave me tired, weak, and fatigued, gradually, I started enjoying it when I realized it was waking up my otherwise exhausted and lazy muscles. At first, each session felt like a monumental effort, a battle against my own body. I would leave the clinic feeling drained, as if I had just run a marathon, and the thought of returning for another session often filled me with dread.

But something shifted within me over time. I began to notice subtle changes — a flicker of strength in my limbs, a slight increase in my endurance, and a newfound sense of mobility that I hadn't experienced in a while. It was as if my body was slowly awakening from a long slumber, and with each session, I was rediscovering parts of myself that I thought had been lost forever.

I remember one particular day during a session when my physiotherapist encouraged me to push a little harder. "You've got this," she said, her voice filled with encouragement. I hesitated, feeling the familiar wave of fatigue wash over me, but something inside me stirred. I took a deep breath and decided to give it my all. As I moved through the exercises, I felt a rush of adrenaline. It was exhilarating! I realized that I was capable of more than I had given myself credit for.

With each passing week, I found myself looking forward to my sessions. The exercises that once felt daunting transformed into a source of empowerment. I began to appreciate the way my body responded to movement, even when it was challenging. I discovered that the tiredness I felt afterward was a sign of progress, a testament to the work I was putting in to reclaim my strength.

I also started to explore different forms of movement outside of my physiotherapy sessions. I ventured into gentle yoga, where I learned to connect my breath with my body, finding a sense of calm and balance. I took walks in nature, allowing the fresh air to invigorate me and the beauty of the surroundings to uplift my spirit. I even tried dancing in my living room, letting the music guide my movements and filling me with joy.

As I embraced this new relationship with movement, I found that it wasn't just about physical strength; it was also about mental resilience. Each time I pushed through the fatigue, I felt a sense of accomplishment that transcended the physical realm. I was learning to trust my body again, to appreciate its capabilities, and to celebrate the small victories along the way.

I also began to connect with others who shared similar experiences. I joined support groups and online communities where people discussed their journeys with MS and the importance of movement in their lives. Hearing their stories inspired me, and I felt a sense of camaraderie that further fueled my motivation. We cheered each other on, celebrating milestones and offering encouragement during setbacks.

Through this journey, I learned that movement could be a form of self-care, a way to honor my body and my spirit. It

became a ritual of empowerment, a reminder that I was not defined by my diagnosis but rather by my determination to thrive. I began to see my body as a partner in this journey, one that deserved kindness and patience.

As I continued to engage in physiotherapy and exercise physiology, I found a rhythm that worked for me. I learned to listen to my body, to recognize when to push and when to rest. I embraced the ebb and flow of progress, understanding that some days would be harder than others, and that was okay.

In the end, what started as a daunting challenge transformed into a source of joy and strength. I discovered that movement was not just about physical fitness; it was about reclaiming my life, nurturing my spirit, and awakening the vibrant energy that had been dormant for too long. I was no longer just going through the motions; I was dancing through life, celebrating each step of the journey with gratitude and resilience.

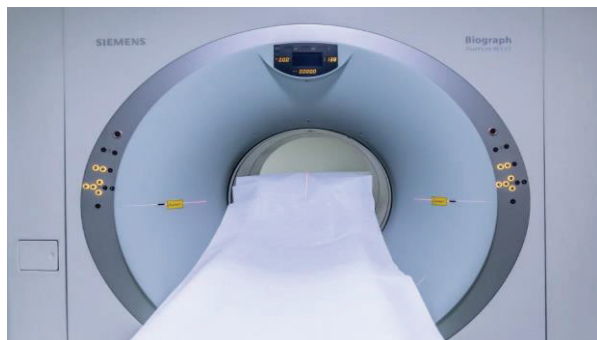
I was waiting for my first MRI result. Little did I know what was in store for me. I was made acquainted with many new terms, new processes, and new doctors. My GP obviously couldn't explain to me about my present or my future. So, he sent me to a Brain surgeon for a stop-gap symptomatic treatment. All the while, the doctors had slowly started understanding this was something rare and not easy to cure.

I was later told the nerves in my brain and spinal cord were going through demyelination. Another new word in my dictionary and a new experience. It simply meant that the myelin sheath around my nerves was getting damaged. To put it simply, when the covering around any electric wire gets

damaged, there's a disruption in the signal that passes through that wire. My body was going through something similar. The signal that goes from the brain to the rest of the body was distorted.

Every doctor I was referred to, I visited only with the hope of getting better. But all I got was a referral to yet another specialist. They all had hopes of treating my case and making me better. I kept trying treatments, first Ayurvedic, then homeopathy, and then ended up taking steroids. Steroids gave me temporary relief from my symptoms, till I was a patient of Relapsing Remitting MS. My MS started with RRMS form, but after a few years, the symptoms refused to go away in spite of me taking steroids once a year. When the symptoms didn't budge, they turned to Residual Symptoms, and that's when my MS turned into Secondary Progressive form or SPMS.

While I was already going through my physical imbalances and medical journey, I was going through stress in parallel. Although I knew, and I was told, that stress is the primary enemy of MS, it wasn't in my hands to control it always. Although it was a guest I didn't welcome always, but somehow, one thing after another kept happening that ultimately led to this dreadful and incurable illness.



Chapter 3

Parallel Pandemics

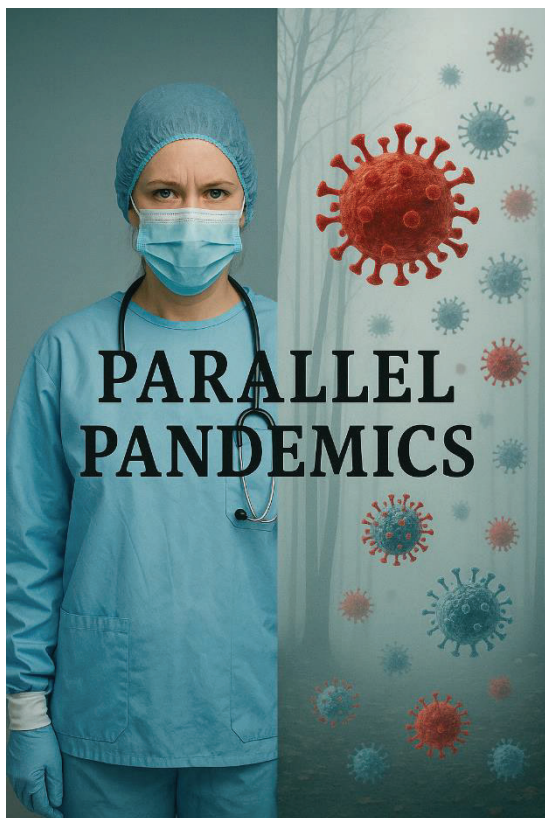
While the world grappled with COVID-19, I was already deep in the trenches of my own silent war. The coronavirus was spreading like wildfire, creating fear and uncertainty across the globe. But inside me, another kind of wildfire was spreading — one that had no vaccine, no official warnings, no worldwide lockdowns — just a slow, invisible invasion of my body by an incurable illness.

When the COVID vaccine was introduced, I hoped it would bring some relief, at least from the external chaos. But I had read and heard that for people like me — with chronic, autoimmune, or neurological conditions — the vaccine could sometimes trigger flare-ups. And that's exactly what happened. The shot that was supposed to protect me instead pushed my body into another spiral. The symptoms intensified. Fatigue grew heavier. And then came a new addition to my reality — a wheelchair.

The first Wheelchair of my life. It felt painful to even look at it, let alone sit in it. But I knew I didn't have a choice. If I wanted to remain mobile and retain some form of independence, this was the only way forward. It was foldable, practical enough to be kept in the boot of a car — yet it carried an invisible weight heavier than its frame. It looked

convenient on the outside, but every time someone lifted it or unfolded it for me, I felt the burden of what I had lost.

It felt like a cruel overlap — two pandemics colliding. The world was isolating, locking down, masking up, while I was being locked inside a body that was slowly turning against itself.



The way COVID crept from city to city, from continent to Continent, is the same way my illness crept through me. It started subtly — a few symptoms here and there — then it spread, slowly but surely, touching my limbs, affecting my

balance, interfering with my bladder, weakening my grip, and draining my energy.

People counted COVID cases by country. I counted symptoms in my body. While the world feared the next wave, I feared the next flare-up. And just like that, while one pandemic raged outside, mine raged within — quieter, but just as devastating.

As the world locked down, I found myself in a different kind of isolation. The news was filled with numbers — rising cases, hospitalizations, and death tolls. But for me, the statistics that mattered were the ones I kept in my mind: the sharpness of pain in my joints, the fatigue that clung to me like a heavy fog, and the unpredictable flare-ups that left me feeling like a stranger in my own skin.

I had been diagnosed with an autoimmune disorder years before the pandemic, but it felt like a cruel twist of fate that my condition would coincide with a global health crisis. While others stocked up on toilet paper and hand sanitizer, I stocked up on medications and supplements, trying to prepare for the uncertainty that lay ahead. The world was adjusting to a new normal; I was just trying to survive my own.

Every morning, I would wake up and take inventory of my body. Was the ache in my knees a sign of a flare-up? Did my throat feel scratchy, or was it just the dry air? I became hyper-aware of every twinge and sensation, my mind racing to connect the dots. I would scroll through forums and support groups, seeking solace in the shared experiences of others like me. There was comfort in knowing I wasn't alone, yet the fear of what could happen next loomed large.

As the days turned into weeks, the world outside my window transformed. Streets that were once bustling with life

became eerily quiet, and the sounds of laughter and chatter were replaced by the distant hum of sirens. I watched as friends and family navigated their own challenges, grappling with the fear of illness and loss. I felt their pain, but I also felt a pang of guilt. My struggles were invisible, hidden beneath the surface, and I often felt like an imposter in a world that was so focused on the visible threat of COVID-19.

I tried to maintain a sense of normalcy. I joined virtual yoga classes, hoping to find some relief through gentle movement. I experimented with cooking, trying to nourish my body with wholesome meals. I even took up journaling, pouring my thoughts onto the pages as a way to process the chaos swirling around me. But the anxiety lingered, a constant companion that whispered doubts into my ear.

What if I caught the virus? What if my body couldn't fight it off? What if the stress of the pandemic triggered a severe flare-up? These questions haunted me, and I found myself retreating further into my own world, afraid to reach out for help. I felt like I was living in a parallel universe, where my battles were overshadowed by the collective struggle of humanity.

One evening, as I sat on my balcony watching the sunset, I noticed a neighbor across the street. She was sitting on her own balcony, her head in her hands, tears streaming down her face. In that moment, something shifted within me. I realized that while my struggle was deeply personal, it was also part of a larger tapestry of human experience. We were all fighting our own battles, each one valid and deserving of compassion.

Gathering my courage, I reached out to her. I sent a simple message, letting her know that I was there if she

needed someone to talk to. To my surprise, she responded almost immediately, sharing her own fears and anxieties. We began to exchange messages, and soon our conversations turned into late-night chats over the phone. We shared our stories, our struggles, and our hopes. In opening up to each other, I found a sense of connection that I had been missing.

As the weeks passed, I learned to navigate my own pandemic with a newfound sense of resilience. I began to advocate for myself more, seeking the support I needed from healthcare professionals and loved ones. I learned to listen to my body, to honor its signals, and to practice self-compassion. I discovered that while my journey was fraught with challenges, it was also filled with moments of beauty and strength.

The world outside continued to grapple with COVID-19, but I found solace in the knowledge that I was not alone in my struggles. I began to count not just symptoms, but also the small victories — the days when I felt strong enough to take a walk, the moments of laughter shared with friends, and the connections forged in the midst of uncertainty.

In the end, I realized that while one pandemic raged outside, mine raged within — quieter, but just as devastating. Yet, through the darkness, I found light in connection, understanding, and resilience. I learned that even in the face of invisible battles, there is strength in vulnerability, and there is power in reaching out to others. Together, we could navigate the storms, finding hope and healing in the shared experience of being human.

Chapter 4

The New Normal

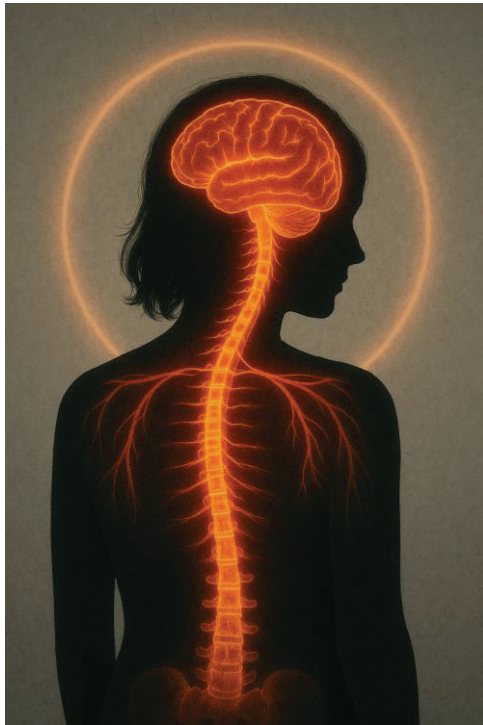
While I was going through all this, my Neurologist also started giving me infusions. Here, I had to visit the hospital every month and get infused with medication to suppress my immune system. Here, the world were increasing immunity to prevent COVID-19 from affecting them. But here I was with an autoimmune illness, and doctors were suppressing my immunity because in this illness, the immune system attacks its own nerves, thinking of them as foreign bodies, and in the process, the myelin sheath gets damaged, thus distorting the signals from the brain to the body.

Although I was taking these infusions for more than a year, the MS was still progressing, and the infusions stopped helping either. Each appointment at the clinic felt like a weight pressing down on my chest, the sterile smell of antiseptic mingling with the anxiety that churned in my stomach. I watched as the nurses prepared the IV, a routine that had once filled me with hope but now felt like a cruel reminder of my body's betrayal.

I had hoped that the infusions would be a turning point, a lifeline that would help me reclaim some semblance of normalcy in my life. At first, there were glimpses of improvement — days when I felt lighter, when the fatigue

didn't wrap around me like a heavy blanket. I reveled in those moments, clinging to the belief that I was on the path to stability. But as time wore on, the progress I had so desperately sought began to fade, replaced by a creeping sense of despair.

The news from my Neurologist was disheartening. Each follow-up appointment brought a new set of challenges, new symptoms to manage, and a growing list of questions without answers. I felt like I was trapped in a cycle of uncertainty, where every step forward seemed to be met with two steps back. The infusions that had once felt like a beacon of hope now felt like an anchor, dragging me deeper into a sea of frustration and fear.



I tried to remain optimistic, to find strength in the small victories, but the reality of my situation was hard to ignore. I watched as friends and family continued their lives, their laughter echoing in the background while I struggled to keep my own head above water. I felt like a spectator in my own life, yearning to participate but often too fatigued or overwhelmed to engage.

In those moments of darkness, I found myself grappling with a profound sense of loss — loss of the life I once knew, of the dreams I had for the future. I mourned the person I used to be, the one who could run for miles, dance without hesitation, and embrace spontaneity without a second thought. The weight of my diagnosis felt heavier with each passing day, and I struggled to reconcile the person I was becoming with the person I had been.

But amid the turmoil, I also discovered a flicker of resilience within me. I began to seek out alternative therapies and support groups, searching for ways to reclaim my agency in this battle. I immersed myself in research, exploring holistic approaches, mindfulness practices, and nutrition that could complement my treatment. I reached out to others who understood the complexities of living with MS, finding solace in shared experiences and the strength of community.

As I navigated this new chapter, I learned to embrace the uncertainty. I realized that while the infusions may not have provided the relief I had hoped for, they were just one part of a much larger journey. I began to focus on what I could control — my mindset, my self-care, and my connections with others. I found joy in the small things: a warm cup of tea, the sound of birds chirping outside my window, and the laughter of loved ones.

Although the road ahead remained uncertain, I discovered a newfound determination to advocate for myself and my health. I learned to communicate openly with my healthcare team, to voice my concerns, and to explore new treatment options. I found strength in vulnerability, allowing myself to lean on others when the weight of my diagnosis felt too heavy to bear.

In the midst of the challenges, I began to redefine what it meant to live fully. I focused on creating meaningful moments, whether it was spending time with family, pursuing creative passions, or simply savoring the beauty of nature. I learned to celebrate the small victories, recognizing that resilience is not always about grand gestures but often found in the quiet moments of courage and perseverance.

And so, while the infusions may have stopped helping, I discovered that my journey was far from over. I was learning to navigate the complexities of my condition with grace and strength, finding hope in the connections I forged and the love that surrounded me. I was not defined by my diagnosis; I was a warrior, fighting for my life and my dreams, determined to carve out a path that honored both my struggles and my triumphs.

I used to be the cheerful one —happy, outgoing, full of stories and songs, the kind of person who lit up a room just by walking in.

Now I sit. Most days in my Wheelchair, some days on my electric bed —motionless, but not resting.

Alive, but not living the way I once did. The hours pass by in silence, broken only by the soft glow of a phone screen, TV voices that don't quite reach my heart, and endless

scrolling through other people's lives —lives still moving, still running, still dancing.

Sometimes I don't even realize how long I've been sitting still. Not because I choose this stillness, but because my body has made the choice for me.

This is not the life I dreamed of —but it is the one I'm learning to find meaning in, even on the days it feels like I've forgotten how.

But I don't like to cry. Not because I'm fearless, but because I've cried enough in silence. I don't want to sit in sadness or let self-pity become my permanent address.

Yes, my normal has changed —drastically, painfully, and without warning. But I've made peace with it. Tears don't heal nerves. Grief doesn't reverse time. The only way forward is to adapt, to bend without breaking, and to shape my life into something that still feels like mine.

So I simplify what I can. I let go of what I can't control. I choose ease over pride, peace over perfection. Because surviving this illness is not about being strong all the time — it's about being smart with the energy I have. And making space for joy, even in a smaller, quieter world.

My new normal was not glamorous.

It was not inspirational quotes.

It was not “you got this”.

My new normal was living with a catheter.

Every single day.

A tube inside my body reminding me constantly that even the simplest biological function — something everyone else

gets to do without thinking — now required medical intervention.

Every 6 weeks I had to go get it changed.

Like clockwork.

I had to plan my life, my outings, my routines, my calendar... around a piece of plastic inside me.

Pain was not episodic anymore.

Pain became part of my architecture.

This new normal also meant I had to accept that the world is not built for bodies like mine.

There were places I couldn't go — not because I didn't want to... but because they were not wheelchair friendly.

Because the entrances were too narrow.

Because the lift was broken.

Because the bathroom didn't have access.

Because independence was not an option — it required someone to accompany me.

My radius of life shrunk.

Everything needed additional planning, approvals, support, coordination and basically a human pass to move through the world.

Sometimes I felt like the world itself had invisible barriers everywhere... and I was constantly being reminded, by architecture and design, that I no longer belonged in many spaces freely.

The hardest part wasn't the catheter.

The hardest part was how much I had to negotiate for basic living.

Every outing became a mental risk assessment.

Will this place reject my body?

Will I need help?

Will I be an inconvenience?

Will I have to explain my medical device again?

This is the part nobody sees when they think “new normal.”

This new normal wasn’t peaceful acceptance.

It was survival acceptance.

It was learning how to live inside limitations I never asked for... while still trying to protect the tiny pieces of who I used to be.

This is what invisible illness takes — quietly, daily, relentlessly.

And yet somehow... I kept going.

THE NEW NORMAL



Chapter 5

My Family, My Strength

My family — the roots of my strength.

In the darkest hours, when my body faltered and my spirit wavered, it was their presence that held me upright. Their love became my anchor, their belief my fuel. I drew strength not from medicine alone, but from the quiet resilience of those who never left my side.

Amidst all these uncertainties came the biggest blow of my life when I lost my mother. I couldn't even visit her funeral or any of her last rites from Australia to India because there were no flights due to fears of COVID-19 spread. I had to accept that and move on.

In the quiet moments of reflection, I often find myself drawn back to the figures who have been my steadfast anchors through life's storms—my parents. Their presence has been a guiding light, illuminating the path even when the shadows of doubt and fear threatened to engulf me.

From my earliest memories of my mother, I can recall her laughter, a melody that filled our home with warmth and comfort. It was in her embrace that I learned the true meaning of love—a love that is unconditional, fierce, and unwavering. My father taught me resilience, showing me that

even in the face of adversity, one could rise, stronger than before.

I remember the countless nights she stayed awake, nursing my fears and anxieties, her soothing words wrapping around me like a protective blanket. She had an uncanny ability to see through my bravado, to recognize the invisible battles I fought within. With her gentle encouragement, I learned to confront my struggles, to understand that vulnerability is not a weakness, but a testament to our humanity.

Her sacrifices often went unnoticed, woven into the fabric of our daily lives. She worked tirelessly, not just to provide for us but to instill in me the values of hard work, integrity, and compassion. I am forever grateful for the lessons she imparted, lessons that continue to guide me as I navigate my own invisible battles.

As I reflect on her influence, I realize that my journey is not just my own; it is a continuation of her legacy. The strength I draw upon in moments of despair is a reflection of her spirit. In every triumph, I hear her voice cheering me on, reminding me that I am never alone.

She was a force of nature, a woman whose resilience seemed boundless. I remember the stories she would tell, filled with laughter and wisdom, each one a testament to her unyielding spirit. She faced her own challenges with grace, never allowing adversity to define her. Instead, she transformed her struggles into lessons, teaching me that every setback was an opportunity for growth.

In the quiet moments of my life, when doubt creeps in and the weight of the world feels too heavy to bear, I find myself thinking of her. I can almost hear her gentle encouragement, urging me to keep moving forward, to

embrace the journey, no matter how difficult it may seem. Her words echo in my mind, reminding me that strength is not the absence of fear but the courage to face it head-on.

As I navigate my own path, I often reflect on the values she instilled in me — kindness, perseverance, and the importance of community. She taught me that reaching out for help is not a sign of weakness but a testament to our shared humanity. I remember the way she would gather friends and family, creating a space where everyone felt seen and valued. It was in those moments of connection that I learned the power of support, and I strive to carry that lesson forward.

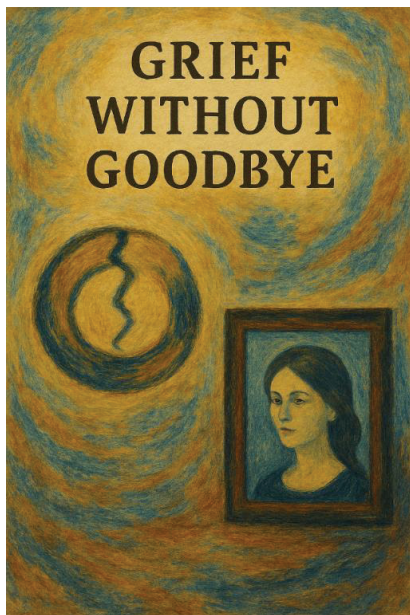
In my victories, both big and small, I feel her presence guiding me. When I accomplish something, I once thought impossible, I can almost see her smile, hear her laughter as she celebrates alongside me. It is a reminder that I am not just achieving for myself; I am honoring her legacy, carrying her spirit with me as I forge my own path.

There are days when the journey feels overwhelming, and the challenges seem insurmountable. In those moments, I close my eyes and visualize her — her unwavering determination, her fierce love, and her ability to find joy even in the darkest of times. I draw strength from that image, allowing it to fill me with hope and resolve. I remind myself that I am a part of something greater, a continuation of her story, and that gives me the courage to face whatever lies ahead.

As I reflect on her influence, I also recognize the importance of sharing her legacy with others. I want to pass on the lessons she taught me, to be a source of strength and encouragement for those around me. I want to create spaces where others feel empowered to share their struggles and

triumphs, just as she did. In doing so, I hope to honor her memory and ensure that her spirit lives on in the hearts of those who knew her.

In every challenge I face, I find a piece of her within me. Her legacy is woven into the very fabric of my being, a guiding light that illuminates my path. I am reminded that I am never alone; she walks with me, cheering me on from the sidelines, a constant source of inspiration. And as I continue my journey, I carry her spirit forward, determined to honor her influence and to live a life that reflects the strength and love she so freely gave.



The strength I drew from my parents was unmatched — not loud or showy, but rooted in endless patience, quiet sacrifices, and unconditional love that never wavered, even when I did. Not all in my family or extended family could

walk this path beside me — even though I know they cared in their own ways. Life pulls each of us in different directions, and not everyone can shift their world in response to mine. Some simply didn't know how to stand still with me in the storm. There is no blame, only understanding. Some stayed close, offering their presence like a steady light. Others had their own limits, or perhaps couldn't see the meaning in this journey enough to stay. And that's okay. Everyone shows up — or steps away — in the way they know best. I've learned to meet that with quiet acceptance.

He never wanted my illness — or the symptoms that came with it.

In truth, he never wanted the version of me shaped by pain, fatigue, and unpredictability. Or maybe, for a while, love tried to fight a battle we didn't know how to win. There were times I felt more like a burden than a partner. Still, we walked through more than twenty years side by side. Maybe it was duty that kept us going. Maybe we stayed for the children, or for the life we had built. Or maybe it was the lingering comfort of familiarity — the echo of who we once were.

A part of us, perhaps, is still reaching for what used to be, not out of hope, but out of memory. Old jokes shared. The way we watched the children grow, moment by moment. The way we celebrated our wins, or quietly sat with our disappointments. So much lived together — even when we felt worlds apart.

But deep down, I always knew — he wanted to rid himself of the illness and, in doing so, of me.

He didn't choose the illness. Not the tremors, not the tears, not the slow unraveling of who I used to be.

He wanted freedom — from hospital walls, from whispered side effects, from the woman who wore pain like a second skin. But still, he stayed. Not always with love, but with a lingering shadow of commitment. Sometimes for the children, Sometimes for the memory of laughter, Sometimes, simply because leaving felt louder than silence.

He didn't want the illness. And in truth, he didn't want the me that came with it. But for over two decades, we danced —between staying and leaving, between duty and distance, between what was and what could never be again. But in all the unreliability, the unpredictability, the words that cut deeper than silence — I was still there. Not because I was weak, but because I chose peace over chaos, forgiveness over fury.

I held space for his absences, made excuses for his cold shoulders, folded his distance into the corners of my strength. Not because he earned it — but because I didn't want to add another storm to the one already raging inside me.

I stayed, not out of helplessness, but to keep my life from becoming another battlefield.

Chapter 6

Immune to Immunity

While dealing with the progression of MS and the emotional burden of losing my mother, the treatments continued. I started learning more about the secondary progressive stage of MS and how unpredictable the disease can be.

The secondary progressive stage of Multiple Sclerosis (MS) is characterized by a gradual worsening of neurological function and disability over time, often following an initial relapsing-remitting phase. This stage is marked by fewer or no relapses, but a steady progression of symptoms.

- **Progressive Disability:** Unlike the relapsing-remitting phase, SPMS involves a continuous decline in neurological function, which may affect mobility, coordination, and cognitive abilities.
- **Unpredictability:** The course of SPMS can vary widely between individuals. Some may experience rapid progression, while others have a slower decline.
- **Symptom Variability:** Symptoms can include increased muscle weakness, Spasticity, fatigue, walking difficulties, bladder and bowel dysfunction. I had it all.

- **Transition Phase:** SPMS typically develops years after the initial MS diagnosis, often 10-20 years later, but the timing varies significantly. In my case, it was 10 years, and it was triggered due to the COVID vaccine
- **Diagnostic Challenges:** Identifying the transition from relapsing-remitting MS to SPMS can be difficult because the progression in my case was subtle and gradual.
- **Symptom Management:** Physical therapy, occupational therapy, and medications can help manage symptoms and maintain quality of life.
- **Disease-Modifying Therapies (DMTs):** Some DMTs are approved for SPMS to slow progression, though their effectiveness varies. That's when my infusions started.
- **Lifestyle Adjustments:** Regular exercise, a balanced diet, and stress management can support overall health.
- **Regular Monitoring:** Ongoing neurological assessments to keep track of the disease progression and adjust treatment plans.

I knew very well that taking immediate actions to manage symptoms after noticing progression in MS is crucial for maintaining my quality of life and slowing disability. Early symptom management included:

- **Physiotherapy:** To maintain mobility, strength, and balance.

- Medications: For Spasticity, fatigue, pain, or bladder issues.
- Occupational Therapy: To adapt daily activities and improve independence.
- Lifestyle Changes: Regular exercise, balanced nutrition, and stress reduction.

I started with proactive symptom management to stay as active and independent as possible despite the challenges of secondary progressive MS. Your prompt response reflects a strong approach to living well with the disease.

Understanding the unpredictable nature of SPMS is crucial to adapting treatment and support strategies effectively. The variability in progression underscores the importance of personalized care and close communication with healthcare providers.

My calendar became filled with medical appointments, hospital visits, medication planning, and physical therapy. There was no space for spontaneity anymore — every decision had to be weighed against fatigue, balance, temperature sensitivity, and pain.

I also started to explore different forms of movement outside of my physiotherapy sessions. I ventured into gentle yoga, where I learned to connect my breath with my body, finding a sense of calm and balance.

I thought of continuing with my singing lessons. Since childhood, I have always had a particular interest in singing, so I started with karaoke songs at home. Also started to learn Indian classical singing. I was always interested in stage performances and never had stage fright, thankfully.

Chapter 7

The Kerala Chapter

Now, if mourning was not an option, healing had to be. I refused to sit still and let the illness define me. I needed to try to search for a sliver of relief in a life that had started to feel like a war zone. I decided I'll leave no stone unturned to heal myself. That's when the idea of traveling to Kerala took root. A land known for its lush green serenity, slow rhythms, and centuries-old Ayurvedic traditions — it called to me like a whisper of hope.

I enrolled in a specialty Ayurvedic clinic, one that claimed to have experience in treating complex neurological conditions like MS. It wasn't an easy decision. The treatment was expensive, and it meant going away — leaving behind my family, my support system, my routines, and everything familiar. But something in me said Go. Maybe it was Faith. Maybe desperation. Or both.

The moment I landed in Kerala, the humidity wrapped around me like a blanket. The air was heavy with the smell of rain-soaked earth and herbal oils. Life slowed down there, and so did my mind. Surrounded by coconut trees and the rhythmic chants of morning prayers, I found a different kind of silence — not the one that echoes with loneliness, but the one that gently holds space for healing.

It was a clinic at a remote place, far away from the hustle and bustle of any city, so obviously it wasn't glamorous. There were no white lab coats or sterile halls — only warm wooden walls, medicinal pastes, and therapists who spoke in Malayalam, which I didn't understand a word! Every day, I underwent hours of therapies — oil massages, steam baths, and herbal concoctions. The treatments were intense. My body ached, rebelled, and sometimes surrendered. But my spirit held on.

There were moments of deep vulnerability — nights I cried quietly into my pillow, missing home, wondering if all this effort would pay off. Was I chasing hope, or just running from despair?

But there were also moments of unexpected grace — the therapists massaged my limbs with care. I spent a good time with fellow patients, and the calm that came from simply being present in my body, pain and all. MS connected us, maybe!

The Ayurvedic doctors didn't promise a cure. They promised balance. And somehow, that felt honest. I began to understand that healing doesn't always mean reversing symptoms — sometimes, it means regaining your strength, power, sense of self, your power to choose, and your courage to keep going.

In Kerala, I didn't find a miracle. But I found something else — a pause. A breather. A sacred space where I wasn't just a patient. I was a person trying to heal, trying to believe again.



Even now, when things get heavy, I close my eyes and think of that clinic — the smell of neem, the sound of the rain, and the quiet whisper that told me, “You are still trying.” And that is enough.

Now, if mourning was not an option, healing was. For healing, I tried an MS specialty Ayurvedic clinic in Kerala, away from family, work, and friends. Although it was an expensive treatment, the hope of getting better made me forget the compromises I made.

Kerala welcomed me like an old friend I didn’t know I needed. The moment I stepped off the train and took in the lush green coconut palms, the spicy scent of the local food stalls, and the damp warmth of the coastal air, I felt a strange mix of calm and uncertainty. I had come here not just for a change in scenery, but because life in the city had started to suffocate me—mentally, emotionally, and physically.

The place where I stayed in Kerala was adjacent to a river (Periyar), with all its calm water and slow pace, which seemed like the antidote to the chaos that had begun to build within me. For the first time in months, I didn’t feel like I was

constantly fighting time. The days were longer here, the people kinder, and somehow, the silence less lonely.

Mornings began with intense therapy, followed by a guilt-free South Indian breakfast always accompanied by a crisp dosa. I started noticing small things again—how the monsoon rain danced on the tiled roofs, how the locals walked barefoot with effortless grace, how even the wind had a rhythm of its own.

I started spending more time with myself. Sometimes, I would lose myself in music, let it carry me to places my body couldn't go. Other times, I found comfort in writing—stories that helped me make sense of the chaos. And on days when I had a bit more energy, I practiced singing, letting my voice rise and fall like a quiet rebellion against the silence that had crept into my life.

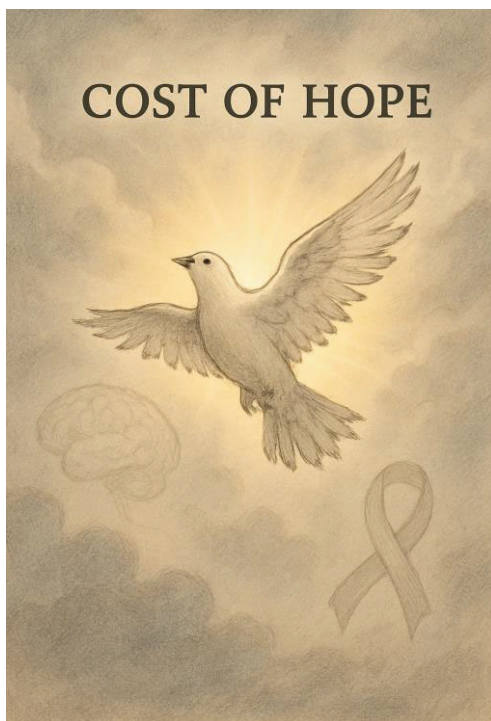
But peace wasn't the absence of problems—it was the presence of healing. My body was still fighting symptoms, and my strength was never what it used to be. Yet, being in Kerala gave me room to breathe. I learned how to live more slowly, and in that slowness, I began to listen to myself. My pain didn't disappear, but it wasn't as loud here.

The locals spoke Malayalam with such poetry that even the most mundane conversations felt like songs. I began journaling again—tiny entries that captured the in-between moments of life, the ones I had previously rushed past.

Looking back, Kerala didn't change my condition. But it changed me. It taught me that acceptance isn't giving up—it's making peace with what is, while still hoping for what can be. That chapter of my life may not have had dramatic progress or miracles, but it gave me something more valuable: a sense of place and a brief, beautiful pause from everything that felt overwhelming.

Chapter 8

The Cost of Hope



Although the treatment was intense, it didn't help much. Staying away from family in a remote place isn't easy, but the hope within makes you do unimaginable things.

I still remember the time I had multiple fractures in my feet from a fall. The cast was still on, but I had already booked my flight to Kerala months earlier—and I wasn't ready to let that go. I decided to go ahead with the plan, even if it meant traveling alone, injured, and uncertain. I chose to take a chance on my hope.

As the therapies began at the Ayurvedic clinic, I was so immersed in the healing process—physically, mentally, spiritually—that I didn't even notice when the fracture healed. It was as if my body responded to the trust I had placed in it. Somewhere in between the oil massages, herbal treatments, and quiet prayers, my bones found their way back together.

Going through all this without a paycheck coming every month to support you is tough. Not being able to go to places you enjoyed independently earlier is tough. Not being able to fulfil the expectations of your family — as a wife, as a daughter, as a daughter-in-law, as a mother—is tough.

Each day felt like a balancing act, like walking on a tightrope between my own aspirations and the weight of familial obligations. The absence of a steady income cast a long shadow over my sense of self-worth. I often found myself questioning my value, feeling as if I was failing not just in my personal ambitions but also in my roles within my family. The pressure to meet expectations loomed large, and the guilt of not being able to contribute financially was a constant companion.

There were moments when I longed for the freedom I once had — the ability to make spontaneous plans, to treat myself to a meal out, or to indulge in simple pleasures without a second thought. Instead, I found myself navigating a world

where every decision was scrutinized through the lens of financial constraints. It was a stark reminder of how much I had taken for granted, and the realization stung deeply.

As a wife, I felt the weight of my partner's expectations; as a daughter, I grappled with the desire to make my parents proud; as a daughter-in-law, I struggled to meet the standards set by tradition; and as a mother, I yearned to provide my children with the experiences and opportunities they deserved. Each role came with its own set of challenges, and the fear of disappointing those I loved was a heavy burden to bear.

Yet, amidst the struggle, I began to recognize the importance of self-compassion. I learned that it was okay to feel overwhelmed, to acknowledge my limitations, and to give myself grace during this tumultuous time. I started to communicate openly with my family about my feelings, sharing my fears and frustrations. To my surprise, their understanding and support were more profound than I had anticipated. They reassured me that my worth was not solely defined by financial contributions or societal expectations.

I began to focus on the things I could control. I sought out small ways to contribute, whether it was volunteering my time, helping with household tasks, or simply being present for my family. I realized that my value extended beyond monetary support; it lay in the love, care, and support I provided to those around me.

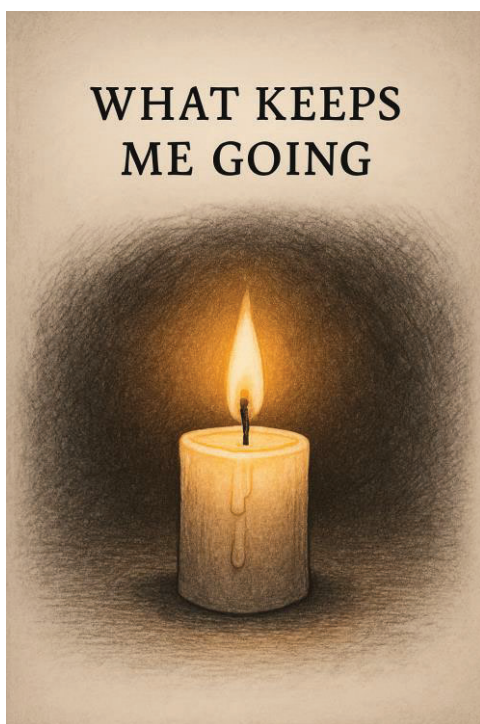
Gradually, I learned to redefine what success meant to me. It was no longer about meeting external expectations but about finding fulfillment in the journey, embracing the lessons learned along the way, and nurturing the relationships that mattered most. I discovered the strength to advocate for

myself, to pursue my dreams, and to carve out a path that aligned with my values, even if it looked different from what I had originally envisioned.

Through it all, I held onto the belief that this chapter of my life was not the end but rather a stepping stone toward something greater. The challenges I faced were shaping me into a stronger, more resilient person, and I was determined to rise above them, not just for myself but for my family as well. Together, we would navigate this journey, finding joy and meaning in the midst of adversity.

Chapter 9

What Keeps Me Going



Despite all the hurdles, I kept going. I had to — for myself, for my family, for the future. Each day was different; some were tolerable, others unbearable. But inside

me, the belief that something better was still possible kept me moving forward.

I often found solace in small victories. A kind word from a friend, a moment of laughter with my family, or even the satisfaction of completing a task that seemed insurmountable. These little moments became the fuel that ignited my spirit, reminding me that hope was not just a distant dream but a tangible reality waiting to be grasped.

On particularly tough days, I would reflect on my journey, acknowledging how far I had come. The struggles I faced were not just obstacles; they were lessons that shaped my resilience. I learned to embrace discomfort, understanding that growth often comes from pushing through pain and uncertainty. Each setback was a stepping stone, a necessary part of my evolution.

I also drew strength from the people around me. My family's unwavering support was a constant reminder of why I fought so hard. Their belief in me became a lifeline, a source of motivation that propelled me forward even when my own faith wavered. I realized that I was not alone in this journey; we were in it together, each of us contributing to the collective strength of our family.

Moreover, I sought inspiration from stories of others who had faced adversity and emerged stronger. Their narratives served as beacons of hope, illuminating the path ahead. I learned that resilience was not just about enduring hardship but also about finding purpose in the struggle. It was about transforming pain into power, fear into courage, and doubt into determination.

As I navigated the complexities of life, I began to understand that my journey was not solely about reaching a

destination but about the growth that occurred along the way. Each challenge I faced was an opportunity to discover my inner strength, to redefine my limits, and to cultivate a deeper appreciation for the moments of joy that punctuated the hardships.

In the quiet moments of reflection, I would remind myself of my dreams and aspirations. They were the compass guiding me through the storm. I envisioned a future filled with possibilities, where my efforts would bear fruit, and the sacrifices made would lead to a life of fulfillment and purpose.

So, I kept going. With each step, I embraced the uncertainty, knowing that the journey itself was a testament to my resilience. I was determined to carve out a life that reflected my values, my dreams, and my unwavering belief that something better was not just possible — it was inevitable.

Chapter 10

Living with Purpose

Now, my entire life revolves around carefully balancing my energy between what needs to be done — and what must be done to keep going.

Each day is a careful choreography of job searching, physiotherapy appointments, exercise physiology sessions, medications to manage symptoms, and targeted efforts to strengthen my muscles, improve my grip, and maintain whatever balance I can.

But it doesn't stop there.

Living with a chronic illness means that even the basics — cooking, cleaning, bathing, getting ready for an appointment — require planning, support, and assistance. I've learned to coordinate with my NDIS Support Workers for the things most people do without a second thought. And while it took time to adjust to accepting help, I now see it as a form of strength, not weakness.

It may not look like the “purpose” I once imagined — climbing ladders, chasing promotions, or ticking off conventional milestones. But this life still holds purpose.

Every small routine I stick to, every day I show up for therapy, every time I advocate for my own care — that is THE PURPOSE .

That day, I proved something to myself: That I don't need everything to be perfect to keep going. That purpose sometimes means showing up despite the pain, not waiting for the pain to end.

Only after that, I visited the urologist to get the catheter checked.

With all that discomfort, I went ahead with my exercise session. I pushed through the stretches, the balance drills, the strengthening routines. Every movement was a reminder that my body may not always make it easy — but my will to keep moving was stronger.

So, I showed up for myself.

But I paused. I asked myself, “Can I still manage today’s physio session?”

The answer wasn’t easy — but it was “yes”.

There are days when even the simplest things turn into battles.

One such day, the catheter refused to cooperate. The discomfort was constant — sharp, unsettling, and distracting. My first instinct was to cancel everything and go straight to the hospital.

Even When My Body Says No

Because living this life, with intention and resilience, is no less meaningful than the dreams I once had. In fact, it’s even more powerful now — because it’s built on survival, strength, and the quiet courage to keep going.

Bleeding from the bladder during catheter replacement is a serious complication that occurs when the bladder lining is damaged, often due to trauma from the catheter insertion. This can happen if the catheter is inserted too forcefully, if the bladder tissue is fragile from repeated catheterizations, or if there is existing inflammation or infection. Such bleeding requires immediate medical attention to prevent further injury or infection. Proper catheterization technique, using the correct catheter size, and managing any bladder infections are important steps to reduce the risk of bladder trauma and bleeding during catheter changes.



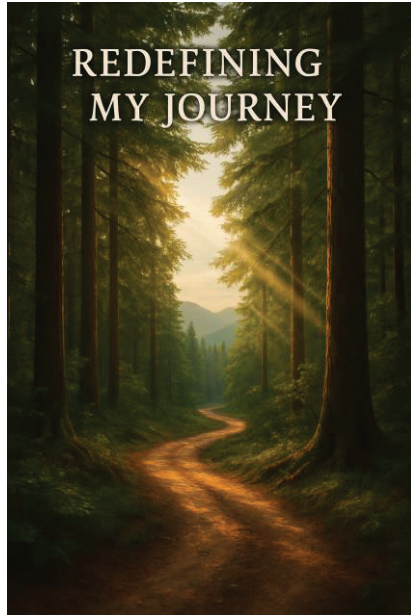
Chapter 11

Redefining my journey

My days are now built around a new structure. A structure I didn't choose but one I've grown into. There's strength in that adaptation — even when it doesn't feel like it. I still find joy in the small wins. I celebrate what I can do, rather than mourn what I can't.

This new rhythm of life includes early morning physiotherapy sessions, where each stretch, each assisted movement is a battle against stiffness and fatigue. But with every session, I remind myself — this is forward motion.

Gone are the rushed office mornings and crowded train rides. Now, my time is measured not by meetings or deadlines, but by therapy schedules, exercise appointments, mobility exercises, and support worker coordination. It's a strange kind of freedom, one I didn't ask for, but one I've come to respect.



Some days I walk a few steps without pain — those days feel like a festival in my heart. Other days, just sitting up and facing the world takes everything in me. But I still show up. And that counts.

Technology and a strong support network play a crucial role in adapting to life after a major health event, such as spinal cord injury or stroke. Digital tools like phone calendars and medical reminders help manage daily routines, appointments, and medication schedules, bridging the gap between past independence and current needs.

The Role of Technology

- Phone calendars organize appointments, therapy sessions, and important dates.

- Medical reminder apps support adherence to medication and therapy regimens.
- Assistive devices and smart home technology can enhance safety and independence for daily activities.

These technologies become essential elements of a personal support system, enabling greater autonomy and reducing the cognitive load of managing complex care routines.

The gentle power of my circle-

- NDIS support workers assisted with daily living, transportation, and community engagement, tailored to my needs.
- Physiotherapists designed and implemented personalized rehabilitation plans to improve mobility, manage Spasticity, and promote recovery.
- Specialists provided medical oversight, customised treatment plans, and monitored my progress.
- Family provided emotional support, motivation, and practical assistance, forming the foundation of long-term well-being.

Combining technology with professional and personal support ensures a holistic approach to rehabilitation and daily living. This integration allows individuals to manage their health proactively, maintain independence, and adapt to new challenges with confidence.

In summary, leveraging both digital tools and a dedicated support network empowers individuals to navigate the transition to a new version of life, supporting both physical recovery and emotional resilience.

But interestingly, I have become part of my own support system. I've learned how to advocate for myself. I've learned how to ask for help, for space, for understanding, and for support.

In this journey of self-discovery, I realized that I didn't have to navigate the complexities of life alone. I began to recognize the strength in vulnerability, understanding that asking for help was not a sign of weakness but rather an act of courage. I reached out to friends, family, and even professionals, sharing my struggles and seeking guidance. Each conversation became a thread in the tapestry of my support system, weaving a network of understanding and compassion that bolstered my spirit.

This life is slower. The hustle and bustle that once defined my days has been replaced by a more deliberate pace. It's a rhythm that allows me to breathe, to reflect, and to truly connect with the world around me. In its stillness, I've discovered depth — a profound appreciation for the little things that often go unnoticed in the chaos of life.

I've learned to savor moments of quiet, whether it's enjoying a cup of tea while watching the sunrise or taking a leisurely walk in nature. These simple pleasures have become my sanctuary, offering solace and clarity amidst the noise. I've found joy in the mundane, recognizing that there is beauty in the everyday moments that make up the fabric of life.

Moreover, this slower pace has granted me the opportunity to explore my passions and interests. I've taken up hobbies that once felt like distant dreams — painting, writing, or even gardening. Each creative outlet has allowed me to express myself, to channel my emotions into something tangible and meaningful. In nurturing these passions, I've

discovered a sense of purpose that transcends traditional roles and expectations.

Through this journey, I've also cultivated a deeper understanding of myself. I've confronted my fears, acknowledged my limitations, and celebrated my strengths. I've learned to listen to my inner voice, to honor my needs and desires, and to set boundaries that protect my well-being. This newfound self-awareness has empowered me to make choices that align with my values, fostering a sense of authenticity that resonates in every aspect of my life.

As I continue to navigate this path, I carry with me the lessons I've learned: the importance of self-advocacy, the power of vulnerability, and the beauty of stillness. I am no longer just a participant in my life; I am an active creator, shaping my narrative and forging connections that uplift and inspire me.

In embracing this slower, more intentional way of living, I've discovered that depth is not just found in the grand moments but in the quiet spaces in between. It's in the laughter shared with loved ones, the comfort of a warm embrace, and the satisfaction of knowing that I am enough, just as I am. This journey has taught me that life, in all its complexities, is a beautiful tapestry woven from both struggle and joy, and I am grateful to be a part of it.

Both my daughters have been with me through everything. They've seen who I was before the symptoms of MS took over—how I used to dance freely at parties with friends, how I rushed every morning to reach work on time. They've seen the changes—from walking independently, to using a walker, and eventually needing a wheelchair. Through all of this, they've stayed by my side. They've

witnessed my struggles up close and never walked away. Their support has been constant and unconditional, and I draw strength from knowing they are with me in this journey every step of the way.

One peculiar thing about MS —

It grants you a strange kind of mercy during pregnancy.

As if the body, knowing it's creating life, calls a silent truce with the illness that shadows it.

No numbness. No flares. No stumbles in the dark. Just a momentary stillness.

A pause in the storm.

For me, pregnancy felt like a miracle, not just for the new life it brought,

But for the quiet it gifted my own.

Even childbirth — that violent, beautiful chaos — was free of the usual betrayals of my nervous system. And for a while after, my body felt like it belonged to me again.

But like all things with MS, this too differs from one woman to another.

What it gives in one chapter, it may take in the next.

Still, that brief lull in the battle remains one of the most mysterious kindnesses MS ever gave me.

Chapter 12

Shifting Connections: When Relationships Evolve

The way I, my routine, and my symptoms were changing, similarly, I could see many known faces changing. That was unbelievably true. Some relations that were part of my support system went through changes and had other priorities eventually. There were times when I faced sympathy, hurt, humiliation, and disbelief from those closest to me. It was a painful realization that the people I loved most often struggled to understand the invisible battles I was fighting. Their reactions, though sometimes well-intentioned, often left me feeling isolated and misunderstood.

As my days unfolded differently—marked by new routines, fluctuating symptoms, and a growing awareness of my own limits—I began to notice subtle shifts in the people around me. Some changes were gentle, like a friend who called less often or a relative who grew distant, their absence explained away by busy schedules or silent discomfort. Others were abrupt, leaving a hollow space where support once lived.

I realized that illness, in its own quiet way, acts as a mirror. It reflects not only our own resilience but also the true nature

of our relationships. Some people, once central to my life and my sense of security, slowly drifted away. Their priorities changed, or perhaps the weight of my struggles was more than they could bear. I felt the sting of sympathy that sometimes bordered on pity, the ache of being misunderstood, and the sharp edge of disbelief from those I trusted most.

Yet, in the midst of these losses, something remarkable happened. People I never expected—acquaintances, distant relatives, even colleagues—stepped forward with kindness and unwavering support. Their presence was steady and genuine. They became my new pillars of strength, offering encouragement, practical help, and, most importantly, acceptance without judgment.

Looking back, I see that these changing faces were not just a reflection of my illness, but of life itself. Adversity has a way of revealing the authentic connections that endure when convenience and comfort fall away. The real ones stood strong, weathering storms by my side. The others simply left, their absence making space for new bonds to grow.

Through it all, I learned that change, though sometimes painful, can also be clarifying. It teaches us who truly cares, who listens without judgment, and who will remain when the easy days are gone. And in that knowledge, I found a quiet strength of my own—a resilience built not just on surviving symptoms, but on embracing the evolving tapestry of support and love that surrounded me.

I remember one particular gathering, a family celebration that should have been filled with joy. As I sat on the edge of the couch, trying to engage in the conversation, I could feel the weight of their stares. I was acutely aware of my fatigue,

the way my words stumbled as I spoke. When I mentioned my struggles with MS, I was met with a mix of sympathy and disbelief. “But you look fine,” one relative said, a hint of confusion in their voice. It was a phrase I had heard too many times before, and it stung like a slap.

In that moment, I felt a wave of humiliation wash over me. How could I explain the fatigue that seeped into my bones, the way my body betrayed me when I least expected it? I wanted to scream that just because I looked fine on the outside didn’t mean I wasn’t fighting a war within. But instead, I forced a smile, nodding along as the conversation shifted away from my reality, leaving me feeling small and invisible.

There were also moments of sympathy that felt more like pity, and I struggled to navigate those interactions. Friends would reach out, their voices laced with concern, but instead of offering support, it often felt like they were placing me in a box labeled “sick.” I could see the way they hesitated to invite me to gatherings, as if my presence would somehow dampen the mood. I felt like a burden, and that hurt more than any physical symptom I experienced.

And then there were the moments of disbelief, when those I trusted questioned my experiences. “Are you sure it’s that bad?” they would ask, their brows furrowed in skepticism. It was as if my struggle was too difficult for them to comprehend, and their doubt only deepened my sense of isolation. I found myself second-guessing my own reality, wondering if I was exaggerating my symptoms or if I was somehow failing to cope.

These experiences weighed heavily on my heart, and I often found myself retreating into solitude. I started to

withdraw from social situations, fearing the judgment and misunderstanding that seemed to follow me. The walls I built around myself felt like a protective barrier, but they also isolated me from the very connections I craved. I longed for understanding, for someone to see beyond the surface and acknowledge the complexity of my journey.

In time, I learned to navigate these challenging interactions with more awareness. I began to set boundaries, recognizing that not everyone would understand my experience, and that was okay. I sought out those who could offer genuine support — friends and fellow warriors who had walked similar paths. Together, we shared our stories, our frustrations, and our triumphs, creating a safe space where empathy flourished.

I also discovered the power of education. I started to share more about my condition with those willing to listen, providing insight into the realities of living with MS. I found that many people simply didn't know what to say or how to react, and by opening up the conversation, I could help bridge the gap between my experience and their understanding.

Through this process, I learned that vulnerability can be a strength. It took courage to express my feelings and to advocate for myself, but it also allowed me to forge deeper connections with those who truly cared. I realized that while some may never fully understand, there were others who would stand by me, offering love and support without judgment.

In the end, the journey of navigating sympathy, hurt, humiliation, and disbelief became a catalyst for growth. I learned to embrace my story, to own my experiences, and to

seek out the connections that nourished my spirit. I discovered that while the road may be fraught with challenges, it is also filled with moments of grace, understanding, and the unwavering strength of community. And in that journey, I found my voice — a voice that refused to be silenced, a voice that celebrated resilience in the face of adversity.

Spasticity often develops gradually in conditions like Multiple Sclerosis, appearing slowly over time alongside other symptoms. It typically starts as mild muscle stiffness or tightness and then progressively increases, making movements more difficult. This gradual onset allows some time to adapt and manage symptoms through therapies and medications, but it can still significantly impact daily activities as it worsens. Early recognition and treatment of Spasticity helps maintain mobility and reduce discomfort as the condition evolves.

Spasticity is a condition characterized by an abnormal increase in muscle tone or stiffness, which leads to involuntary muscle contractions. It commonly occurs in neurological disorders like Multiple Sclerosis (MS), especially in the secondary progressive stage.

What Happens in Spasticity?

- **Muscle Tightness:** Muscles feel tight, stiff, or resistant to stretching.
- **Involuntary Muscle Spasms:** Sudden, uncontrollable muscle contractions can occur.
- **Reduced Movement:** Stiffness can limit the range of motion and make movements difficult or painful.

- **Increased Reflexes:** Reflexes may be exaggerated due to disrupted nerve signals.

Why Does Spasticity Occur in MS?

MS damages the nerve pathways that control muscle movement and tone. This disruption causes the muscles to contract more than usual because the normal inhibitory signals from the brain are impaired.

These are some of the common signs of Spasticity

- Difficulty walking or using limbs
- Muscle cramps or pain
- Problems with posture and balance
- Fatigue due to constant muscle tension

Managing Spasticity or managing those spasms involves a combination of medications, physical therapy, and lifestyle adjustments to reduce muscle stiffness and improve mobility.

- **Physical Therapy:** Stretching and strengthening exercises to improve flexibility.
- **Medications:** Muscle relaxants like baclofen or tizanidine can reduce stiffness.
- **Assistive Devices:** Braces or splints to support affected limbs.

Spasticity can significantly impact daily life, but with proper management, its effects can be minimized to improve comfort and function.

A Path Through Fog

When all around me turns to grey,
And silence swallows what words can't say,
I close my eyes, take one more breath—
Faith walks with me, beyond the depths.
No answers come, no voices guide,
Just inner whispers I cannot hide.
Through trembling hands and aching bones,
Faith says softly, "You're not alone."
It's not the kind with shouts and fire,
But quiet hope that won't expire.
Not always strong, not always loud,
But there through tears, I'm not allowed.
To sink too deep, to fade, to flee—
Faith lights a step I cannot see.
And when the night feels cold and long,
It hums inside—a patient song.
So though the road is steep and blind,
And strength, some days, is hard to find—
I hold on tight, I speak my truth:
Faith is fierce in quiet youth



Chapter 13

The Strength that stayed

Anybody can love you when it's sunshine

The real test is when it's storm

I still remember my first MRI scan when my mom was there with me inside that chilly room. We both were equally scared and confused. Little did we both know back then — this was not the only scan but only the first of many that were destined to follow.

This continued for more than a year. Then came another major symptom — loss of bladder control. They fit me with a catheter that would help me pass urine.

Silly me! I imagined this was just a temporary symptom, and this catheter was a short-term fix for that.

But take 2: The catheter became a forever solution to this symptom that refused to go away.

A catheter is not as simple as it sounds. It comes with excruciating pain when it's due for change, retention pain felt as an urgency — the kind you feel when you know you should go to use the bathroom, but you are made to wait.

I've spent hours waiting in the hospital room for the nurse to help me change the catheter, and then go through pain and discomfort again while they take the earlier one out.

Yet in these painful hours, I was never alone. I saw the pain in my mother's eyes. She tried hiding it, but I could feel it. She held my hand each time. Her presence was my strength. And sometimes, that was enough.

Chronic illness doesn't just change your body — it changes your world.

It filters your friendships, tests your patience, and redefines your sense of worth. Over time, I've learned that healing isn't always about recovery — sometimes it's about learning how to live with what you cannot change.

Not all friends stay. Now I know who truly deserves a seat at my table — and who never did.

Some pretended to care, offering comforting words in passing, but when things got tough, they quietly drifted away. Maybe they didn't know what to say. Maybe my struggle was too heavy for them to carry. Whatever the reason, they couldn't stay.

But in the midst of all the loss, change, and silence, there were the ones who did stay. They didn't always have the right words. They didn't fully understand the illness. But they showed up.

Again. And again. And again.

Through the hospital visits, the breakdowns, the cancelled plans, and the long silences — they stayed. They held space for my pain, my grief, my exhaustion. They reminded me I wasn't alone.

To the ones who stayed: You didn't just support me. You carried me. You helped me survive. And for that, I will always be grateful.

I've learned to stop expecting everyone to understand.

I've learned to release those who chose to walk away.

And most importantly, I've learned to honour the strength it takes to keep going — even on the days when I don't feel strong.

Chapter 14

Revelations from Experience

Chronic illness rewrote my life in invisible ink. I had to relearn how to trust my body, how to listen to what it needs — and how to accept what it can no longer do. Through pain, isolation, and constant appointments, I discovered what truly matters: stillness, compassion, and the quiet presence of Faith.

Listen to your body: MS symptoms are subtle at times — fatigue, tingling, stiffness. Don't ignore the whispers before they become screams.

Build a care team: A good neurologist, physiotherapist, support workers, and a mental health counselor can make all the difference.

Move gently but often: Physiotherapy and low-impact exercises like yoga, swimming, or resistance band workouts help maintain mobility.

Rest unapologetically: Fatigue in MS is not laziness — it's neurological. Rest is recovery, not weakness.

Follow a supportive diet: For me, gluten-free and low-inflammatory foods helped. Track what worsens or improves your symptoms.

Explore all therapies: I tried Ayurveda, Homeopathy, and Integrative Medicine. What works is different for everyone — be open, but cautious.

Mental health is vital: This is a grieving process. Therapy, journaling, music, or art can help you cope and express what words can't.

Know your triggers: Heat, stress, infections, and overexertion can worsen symptoms. Learn and avoid your flare triggers.

Keep Faith and curiosity alive: Medical research is ongoing. Stay informed, stay hopeful.

I now know there's no point in getting embarrassed, ashamed, or guilty about the way my life looks today. I didn't choose this path, but I choose how I walk it — with dignity. There was a time I would hide my struggles, mask my symptoms, or pretend I was okay just to make others comfortable. Not anymore.

If I need support, I ask. If I need to rest, I rest. If I need help with personal tasks, I accept it without shame. Because this is not weakness — this is wisdom born from pain. My body may not function like before, but my spirit has never been more in tune with my truth.

There were days I didn't want to get up, and yet I did.

There were appointments I dreaded, and yet I went.

There were people I lost, and yet I learned to hold onto myself.

I've learned:

- That some people will never understand, and that's okay.
- That asking for help isn't weakness, it's wisdom.
- That rest is not giving up — it's listening.

That Faith is not always loud.

Multiple Sclerosis has no confirmed cause, but it is linked to a combination of genetic, environmental, and lifestyle factors. Based on my research, experience, and discussions with doctors, here are some potential ways to reduce risk:

1. Vitamin D matters: Low levels of Vitamin D are strongly linked to MS. Safe sun exposure and supplementation may be protective.
2. Avoid smoking: Cigarette smoking significantly increases the risk of MS and its progression.
3. Stay active: Regular movement improves overall immune function and brain health.
4. Gut health is key: A balanced, anti-inflammatory diet — rich in fruits, vegetables, whole grains, and healthy fats — can support the nervous and immune systems.

For any party, that potluck, or next birthday celebration, thumb rule - PREFER HOMEMADE FOOD. Can't stress enough.

1. Reduce chronic stress: Stress doesn't cause MS, but it can trigger flares. Learn to protect your peace.
2. Early screening for those at risk: If you have a family history or recurring unexplained neurological symptoms, seek evaluation early.

Stress didn't cause my MS, but it stirred the storm when the skies were already heavy. It whispered chaos into moments of stillness and turned quiet symptoms into loud alarms.

The truth is — my body listens to every emotion I suppress, every boundary I fail to set, every 'yes I say when my soul whispers 'no.' So now, I guard my peace like it's sacred. I walk away from noise that drains me, rest when guilt tells me to push harder, and choose softness — even in a world that demands steel because peace isn't a luxury. For a body already at war, peace is medicine.

Multiple Sclerosis has no confirmed cause, but it is linked to a combination of genetic, environmental, and lifestyle factors. Based on my research, experience, and discussions with doctors, here are some potential ways to reduce risk:

There's healing in the hands that cook with care. In the simmer of spices, the rhythm of chopping, the aroma that fills not just the kitchen — but the soul.

Home-cooked food isn't just about what's on the plate. It's about knowing what goes into your body. No hidden preservatives, no mystery oils, no shortcuts disguised as meals.

When you cook at home, you choose your ingredients, your portions, your pace.

You cook with intention — sometimes even with love. For a gut that's inflamed, confused, or fragile, a home-cooked meal can feel like a warm embrace. Simple, fresh, balanced — that's where healing often begins.

Chapter 15

How I Fought Back

A life reimagined is not less. It's just different. And in that difference, I continue to find purpose

A life reimagined is not a lesser life.

It's simply one that looks different from what I once pictured.

The goals have shifted. The pace has changed. The path is no longer straight — it winds, pauses, bends, and sometimes doubles back.

But it's still my life.

And within this new shape, I've discovered unexpected strength, quiet victories, and moments of deep purpose.

I may no longer chase the same milestones as before — but every step I take now is more intentional, more meaningful, more aware.

A life reimagined is still a life of worth.

And in that difference, I continue to find purpose — not in what I've lost, but in how I've chosen to live with what remains.

I didn't just sit still, waiting for a miracle to happen. I was actively trying to find my way out of this invisible illness that had taken over my body, and every time a treatment gave me even a glimmer of hope, I embraced it.

I tried Ayurvedic therapy and stayed in Kerala, far away from the comforts of home, for two months at a time, twice. The serene environment, dedicated therapists, and traditional treatments gave me some hope — not a cure, but a form of coping. When that didn't yield long-term results, I shifted to Homeopathy, clinging to the hope that something gentler might work on my sensitive system.

Food became medicine. I followed restrictive diets like gluten-free, keto, and paleo. I monitored my intake with utmost discipline. Sometimes it felt extreme, but when your health is deteriorating and no mainstream medicine is giving you permanent relief, you're willing to try it all. I was always ready to switch to the next option when one stopped showing results.

Despite knowing there's no proven cure yet, I kept trying. I followed MS research, new trials, latest discoveries, and even considered clinical research options. Not all of them were accessible or affordable, but the drive to not give up kept me moving.

What truly strengthened me was my Faith in a higher power, in science, in my family's love, and in my own resilience. Even in the darkest nights, I waited patiently

for the dawn. And when it didn't come, I learned to make peace with the moonlight.

The Warrior in Me

They said I'm weak because I sit in this chair.
But little did they know, the strength it took to just be
there.

While my body slows down, my spirit never quits.
In silence, I fight storms and rise after every hit.
With every injection, every test, every therapy I've tried,
I stitched my hope.
To every tear I cried.

No battle was loud, no victory clear.
But I stayed, I stood — Even when frozen in fear. Not
all warriors wear armour, not all battles are seen.

But I've fought in the shadows with courage, quiet and
keen. So when you see me still, know the war is not done.
I may not run like before, but this war — I've already
won!

Faith

It is in these moments — the raw, lonely, quiet ones —
that I found something deeper than certainty: Faith.

- I know the Universe isn't working in my favour It has
given sweetness and spice to all But had given me MS
flavour

- Trust my efforts, know my pain Amidst thunderstorms
and lightning, I'm walking in the rain All you have to do is
have Faith in me.

- The child in me still wants to have fun But the illness
doesn't let me walk or run

- Even I had dreams in tons But now MS has only given
me symptoms

- But I'm not the one to give up Give me a challenge
and I'll take it up

- Although it has robbed me of my health, happiness,
wealth, and love

But it cannot take away my spirit and positivity from me
All you have to do is have Faith in me.

- Although my scans might show lesions or scars, because
those are visible But no one knows the scars given on my
heart and soul, because those are invisible

- Though life is all about medicines, consultations, and
reports now But I know certainly I surely deserve love, care,
attention, time, and support now

- It was never easy for me to accept this But I'd never
give up, I can surely promise this All you have to do is have
Faith in me.

- For an outgoing and extroverted person, it's tough to not attend functions, parties, trips, or walks in person

- But having said all that, I know my hope and my spirit are my only potion simply because there's no other option all you have to do is have Faith in me.

- My only friend who has stood with me through my thick and thin is my Wheelchair If only I could talk with it, I would surely thank it for being my greatest Supporter

- Everyone around here has their own fun, their own life but the most impacted ones, and the ones supporting each other, are the family

- All that I'm going through now was never my wish or my dream but now that I have this unwanted partner, let me be strong and resilient enough to get a grip on

- Yes, I'm giving the best in me All you have to do is have

FAITH in Me

When I look back on everything I've lived through — all the uncertainty, the pain, the shifting relationships, the loss of independence — one thing stands out:

I'm not the same person I used to be. And that's not a tragedy. It's a quiet, powerful evolution. This illness has taken a lot from me. But it has also taught me things I might never have learned otherwise. This isn't the ending. This is me — still learning, still growing, still rising.

Closing Letter

To Anyone Walking a Silent Battle

Dear Reader,

If you've reached this far, thank you. Thank you for walking beside me through every word, every moment, every raw truth.

Maybe you're reading this because you live with an illness too. Maybe your pain isn't visible, but it's still real. Maybe your struggle has no name, no diagnosis — just a quiet weight you carry every single day.

What This Book Is Not About

This book is not about self-victimisation, miracle cures, or do-it-yourself treatments. It does not offer medical shortcuts, quick fixes, stop-gaps, or a way to avoid professional care.

What This Book is About

This book is about walking alongside you in the journey of living with an incurable illness. It is about honesty, resilience, and the daily reality of invisible battles. Through

personal stories and reflections, it offers guidance and encouragement—not as a replacement for medical advice, but as a companion.

Because in any case, seeking medical help, undergoing tests like MRIs, and following professional care are things you cannot escape from—and must be ready for. What you can gain here is the strength, perspective, and courage to face that journey head-on.

You are not alone. Keep going. Keep breathing. Keep being you.

With all my heart,

Shruti