Running Free

What does it mean to live fully when your body feels heavy, swollen, and unpredictable?

Overview / Promise

In *Running Free*, Ashley Sweet shares her 20-year journey with lymphedema — a chronic and often misunderstood condition that challenges the body and the spirit. With honesty, vulnerability, and hope, she takes readers from the first signs of swelling to the daily discipline of management, through grief, resilience, love, and ultimately, healing.

This is not a medical manual. It is a lifeline — part memoir, part guide, part love letter to anyone walking through pain and searching for strength.

Key Themes

Inside, you'll discover:

- How to face grief, anger, and shame with honesty and courage
- The power of routine, discipline, and resilience in daily management
- Stories of love — romantic, family, and self-love — that survive and thrive beyond illness
- How community and connection transform isolation into belonging
- A path toward hope and healing, even without a cure

Emotional Pull / Why It Matters

Whether you are newly diagnosed, a long-time fighter, or someone supporting a loved one, *Running Free* offers comfort, encouragement, and practical wisdom. It is proof that lymphedema may shape your body, but it does not define your spirit.

Closing Line

You are not alone. You are stronger than you know. And you can still run free.

Author Bio – Ashley Sweet

Ashley Sweet is a writer, advocate, and media professional with over twenty years of experience in advertising and communications. Diagnosed with lymphedema in her early twenties, she has spent two decades learning how to balance health, motherhood, career, and self-discovery while living with a chronic condition.

Through honesty, humor, and hope, Ashley has dedicated herself to helping others find strength and meaning in the face of struggle. *Running Free* is her first book, blending memoir and practical guidance to support the lymphedema community and anyone seeking resilience through life's challenges.

Ashley lives in Georgia with her family, where she continues to write, create, and inspire others to live boldly — swollen legs and all.

Dedication

For my mom.

The one who held me when I cried, encouraged me when I doubted, and loved me through every stage of this journey. Your strength and faith taught me how to fight, and your love reminded me why it was worth it. This book is as much yours as it is mine.

Acknowledgments

No journey is ever traveled alone, and this book would not exist without the people who have walked beside me.

To my children — thank you for your laughter, patience, and unconditional love. You remind me daily that joy is possible, even on the hardest days.

To my family and friends — thank you for carrying bags, asking questions, and standing by me when I felt weak. You never saw me as "less than," only as myself.

To the lymphedema community — the warriors, the caregivers, the advocates. You are my inspiration. Each story I've read, each connection I've made, has given me courage.

And finally, to everyone reading this book — thank you for letting me share my journey with you. My hope is that within these pages you find strength, comfort, and the reminder that you are never alone.

Preface – Why I Wrote This Book

When I was first diagnosed with lymphedema, I felt utterly alone. Doctors gave me pamphlets, strangers gave me stares, and my own mind gave me doubts I could barely fight off. I searched for a book that would not only explain what was happening to my body but would also speak to my heart. I wanted someone to tell me: *"Yes, this is hard. Yes, you can still live fully. And here's how I made it through."*

I never found that book.

So I decided to write it.

This is not a medical manual. It's a story—*my story*—woven with lessons I've learned in two decades of living with lymphedema. It's about the fear, the anger, the shame, and the grief. But it's also about the courage, the discipline, the resilience, and the love that I discovered along the way.

This book is for the person sitting alone after a new diagnosis, terrified of what the future holds. It's for the mom wondering how she'll keep up with her kids when her legs feel so heavy. It's for the young woman afraid to date because she doesn't want to explain compression stockings to someone new. And it's for the fighter, ten years in, still searching for hope on the hardest days.

I wrote this book because I believe our stories matter. Sharing them turns pain into power, and isolation into connection. If even one person reads this and feels less alone, every page will have been worth it.

Lymphedema may change our bodies, but it doesn't erase our beauty, our worth, or our ability to live meaningful lives. You can still laugh, love, work, and dream. You can still run toward hope—even if you do it with compression stockings on.

This book is my hand reaching for yours. Together, we will walk through grief, discipline, resilience, love, community, and, ultimately, healing.

Because healing is not about going back. It's about moving forward—with courage, with grace, and with hope.

Title Page:

Book Roadmap: *"Running Free"*

Chapter 1 – Running Free

Begins with your story before lymphedema — childhood, energy, and freedom. Sets the stage for the contrast between life before and after diagnosis.

Chapter 2 – Signs You Can't Ignore

The first red flags: swelling, discomfort, pain. The frustration of being dismissed, misdiagnosed, or misunderstood in the early stages.

Chapter 3 – The Diagnosis

The moment you hear the word "lymphedema." The flood of emotions: fear, confusion, grief. How you began to understand what this disease really meant.

Chapter 4 – Grief and Anger

Processing the loss of your "old body" and the life you imagined. Honest exploration of the anger, frustration, and isolation that follow diagnosis.

Chapter 5 – Discipline and Determination

The turning point where you realize that managing lymphedema requires discipline: compression, wrapping, exercise, diet. How determination became your lifeline.

Chapter 6 – Healing Through Health

Explores anti-inflammatory living, nutrition, exercise, and other wellness practices that made a difference. Guidance for readers on practical ways to support their own healing.

Chapter 7 – Love and Lymphedema

How lymphedema impacts relationships—romantic, family, and self-love. Memoir moments of intimacy, acceptance, and learning that love is bigger than illness.

Chapter 8 – Courage in the Everyday

How courage shows up not in big moments, but in daily choices: wearing compression at the beach, asking for help, showing up despite fear. A guide to building everyday bravery.

Chapter 9 – Resilience and Routine

The role of daily structure in managing lymphedema. Morning rituals, self-care, boundaries, and how small choices build long-term resilience.

Chapter 10 – Community and Connection

Finding strength in support groups, friendships, family, and advocacy. Memoir moments of discovering others with lymphedema and turning isolation into solidarity.

Chapter 11 – Work and Purpose

Balancing career, ambition, and passion with the limitations of chronic illness. Redefining productivity and success, finding purpose beyond a paycheck.

Chapter 12 – Hope and Healing

The conclusion: hope as a daily choice, healing as a journey, and the realization that lymphedema shapes but does not define your life. Encouragement for readers to rise with strength and purpose.

Chapter 1: Running Free

When I was eight years old, I was the fastest girl in my class. Now, that may sound like bragging, but there were only six girls total—still, it mattered to me. I could outrun most of the boys too, and that mattered even more. Running wasn't just something I did, it was something I *was*. There was a freedom in sprinting across the dirt playground, red dust flying behind me, heart pounding like a drum in my chest.

I especially loved to race. Kickball games always ended with someone crying or limping off, so racing became the safer, purer test of strength. Whenever someone called for volunteers, my hand shot up. Most of the time I raced boys, but sometimes Jessica—the tomboy in tight orange shorts and purple suspenders—took me on. She usually left me breathless and beat, except on the days she wore her "uniform," which slowed her down. Those were my victories, and I treasured them.

I had a runner's imagination too. Sesame Street opened with a girl sprinting across a sunset beach, and I swore she was me. The song's cheerful promise—"sunny days, sweeping the clouds away"—felt like prophecy. Running meant escape, joy, possibility.

Through childhood and adolescence, running became my drug and my therapy. When Cal, the cutest boy in seventh grade, broke my heart, I ran. When girls ganged up on me at the pool, I ran. When my dad came home stressed about bills, I laced up my shoes, jammed my headphones over my ears, and drowned out the world with Nirvana's *Territorial Pissings*. My feet hit the concrete until I bent over in exhaustion and glee, body burning but spirit free.

It wasn't just me. Running was a family ritual. Every Sunday after church, we changed clothes, ate lunch, and went to the track. I ran stadium stairs before I even knew who I was. By high school, I was on the track and cross-country teams. My ankles were tiny, like my mother's, and I fell more times than I could count. My coach was old school: ice it, tape it, and keep running. And I did. Because that's who I was—Ashley, the runner.

Looking back, I see how much running shaped me. It gave me confidence, structure, identity. It also planted the seeds of discipline that I would later need in ways I never imagined. Running was the first time I learned that pushing through pain could unlock something deeper: strength.

What I didn't know then was that one day, the very legs that carried me so fast and free would betray me. The same body that sprinted with joy would swell, harden, and ache with a disease I didn't even know existed. My identity would shatter. My freedom would be tested. And yet, the spirit of the runner—the part of me that always believed I could push through—would save my life.

Reflection / Takeaway for Readers:
Your story may not begin with running. Maybe it was dancing, swimming, hiking, or just walking freely without pain. Chronic illness has a way of stealing the things that once made us feel alive. But those early loves never really leave us. They become part of the grit we carry forward. Even if our bodies can't move like they used to, the discipline, freedom, and spirit of that child—running full speed into the horizon—remains within us.

Chapter 2: Signs You Can't Ignore

The body has a way of warning us long before we're ready to listen. At first, the signs were small, the kind you chalk up to being tired, stressed, or clumsy.

In high school, I sprained my ankles more times than I could count. I had tiny ankles, delicate like my mother's, and I was always falling. My coach told me to push through—ice it, tape it, keep running. That old-school philosophy worked for athletes, and it worked for me. Pain was a nuisance, not a message.

By college, those whispers grew louder. I was living fast, running from class to work, staying up too late, eating whatever was cheap and fast. During sorority rush week, I practically lived on Taco Bell pinto beans and apples. I lost seven pounds in a week, fit into a blue dress I couldn't squeeze into before, and thought I was winning. My body was shrinking, but underneath, something else was starting to swell.

The summer before junior year, I worked two jobs—Victoria's Secret at night, classes during the day. On my feet constantly, fueled by saltines and Chick-fil-A lemonade, I started to feel sluggish, weak, heavy in ways I couldn't explain. I brushed it off as exhaustion. Everyone was tired in college. Everyone pushed themselves.

But then came the moments I couldn't ignore. My stomach bloated like I'd swallowed a balloon. My legs felt heavy, thick, different. By November, I was wearing tear-away basketball pants because jeans no longer fit over my right leg. I remember staring at those neon-blue pants, tugging them over my swollen limb, and telling myself it was just water weight, or maybe I'd been eating too much salt. Anything but what it really was.

My father noticed before I admitted it to myself. One night at home, he looked down at my socks and saw the imprint digging into my ankle. "That's not normal," he said. I snapped back

defensively—“Maybe I just had too much salt!”—but deep down, I knew. The sock had left a mark because my body was swelling in ways it shouldn’t.

Still, I ran harder. I worked out more. I starved myself, thinking that if I just pushed enough, my body would go back to normal. That was my answer to everything: work harder, run faster, push through.

There’s a picture I can still see in my mind. I’m jogging with my friend Mary one summer evening in Athens, Georgia. I’m wearing a white tank top and neon shorts, my tan legs glowing in the fading light. We were laughing, carefree, sweaty. Across the street, some guys called out for us to join them after our run. For that brief moment, I felt normal again. Beautiful, strong, alive.

I didn’t know it then, but that night was one of the last times I would ever look down at my legs and see them as they once were. My body was already changing, already signaling that something deeper was wrong.

The signs were there—sluggishness, swelling, fatigue, socks that cut into my skin. But I ignored them, because to acknowledge them was to face something terrifying: that my body was no longer mine.

Reflection / Takeaway for Readers:
Chronic illness rarely arrives overnight. It creeps in with whispers—fatigue, swelling, pain you can explain away. It’s human nature to ignore the signs. To believe that if we just push harder, it will all go away. But our bodies are always speaking to us. Sometimes, the bravest thing we can do is stop, listen, and admit that something isn’t right.

Chapter 3: The Diagnosis

The November air in the Blue Ridge Mountains was crisp, sharp enough to sting my lungs as I stepped out of my boyfriend’s truck. We were camping—his idea, not mine—and by then I was already bone tired. My body felt like it was made of wet sand, every movement heavy and slow. I told myself it was a cold, maybe the flu. College kids got sick all the time. I didn’t want to ruin the trip, so I pushed through, like always.

That night, curled up in a tent, I lay awake listening to coyotes in the distance. My body ached so badly that a wild thought crossed my mind: maybe the animals could carry me away, nurse me back to health like some mythical child of the forest. It sounds ridiculous now, but that’s how delirious I felt—too sick to think straight, too scared to say the truth out loud. Something was seriously wrong.

Back at school, I tried to return to normal, but my leg had other plans. By Thanksgiving, it looked swollen and solid, like a tree trunk. I wore those neon basketball pants everywhere because they were the only thing that fit. I trudged across campus, gallon of water in one hand, books in the other, feeling like a shadow of the runner I once was.

My dad noticed it again before I admitted it myself. Sitting in the family den, he looked down at my socks, tight against the bulging ankle, and said, “That’s not right.” I brushed it off—salt, water retention, maybe stress—but deep down I knew he was right. Something was happening inside me that I couldn’t control.

By spring, I was desperate for answers. My mom had called every doctor in Augusta, begging for someone to see me. Eventually, we landed in the office of a vascular specialist I’ll call Dr. Dick—not his real name, but the name fits.

He was polished, silver-haired, with a smug smile that told me he thought he’d seen it all. My mother poured her heart out, explaining every detail of my swelling, my fatigue, my fear. I sat next to her, rehearsing the story like a robot: when it started, what it felt like, how it was getting worse. He ordered test after test—MRIs, blood panels, scans—and for weeks, I endured needles and waiting rooms, hoping for an answer.

Finally, we sat in his office for the results. He leaned back in his chair, flashing that cream-cheese grin.
“Well,” he said casually, “you’re not going to die.” Relief flooded me for a split second—until he kept talking.
“You do have something wrong with you, but it’s nothing major. We don’t really know what it is. And here’s a little advice: try not to be so vain. So your leg doesn’t look perfect. You’re not going to be a model. Get over it.”

The words hit like a punch to the gut. Vain? My leg wasn’t just “imperfect.” It was swollen, hard, and painful. I could barely walk across campus without collapsing. But to him, it was nothing. To him, my suffering was cosmetic.

I sat there stunned, while my mom’s face drained of color. Part of me wanted to scream, to rage at him for dismissing me so easily. Another part of me crumbled inside, wondering if he was right. Maybe I was just vain. Maybe I should be grateful I didn’t have cancer or organ failure. Maybe I was making too much of it.

But deep down, I knew. This wasn’t vanity. This was my life, my body, unraveling. And this so-called doctor, who was supposed to help, had left me with nothing but shame.

Eventually, another doctor gave it a name: **lymphedema**. A disfiguring, incurable disease where lymph fluid builds up in the body, causing swelling, infections, and chronic pain. A disease almost no one knew about. A disease that would follow me for life.

When you’re twenty years old, you’re supposed to be at your peak—healthy, beautiful, invincible. Instead, I was staring down a future of bandages, compression stockings, and endless questions with no answers.

I left that office with my head spinning, my heart broken, and a single, haunting truth: nothing would ever be the same.

Reflection / Takeaway for Readers:
Getting a diagnosis can be both a relief and a heartbreak. Sometimes the label brings answers;

sometimes it brings shame, confusion, or dismissal. If you've ever been told "it's not that bad" or "you're just being vain," know this: *your pain is real.* You are not imagining it, and you are not alone. The first step to healing is refusing to let someone else minimize your story.

Chapter 4: The School of Pain

When I was first diagnosed with lymphedema, the word "incurable" clung to me like a shadow. Doctors offered little more than shrugs, prescriptions, or lectures about vanity. There was no roadmap, no cure, no promise that I would ever feel normal again. Just swelling, fatigue, pain, and fear.

It's in those moments—when the future feels like a wall instead of a path—that you start searching for meaning anywhere you can find it.

For me, meaning first came from books.

As a child, one of my favorite stories was *What Katy Did*. Katy Carr was a wild, adventurous girl who, after an accident, became bedridden. At first she was bitter and angry, letting the curtains stay drawn and her room grow dusty. But then her cousin Helen, who lived with her own disability, taught her about what she called the *School of Pain*. Pain, Helen explained, was a teacher. A hard teacher, but one that could shape us, deepen us, even grow us in ways joy never could.

That story became a mirror of my own life. Like Katy, I had been full of energy, running wild, unstoppable. And like Katy, I had been stopped in my tracks. Pain forced me to sit still, to face myself, to learn lessons I never wanted to learn. Discipline. Patience. Resilience. Gratitude for the small things.

Later, I found echoes of the same truth in *The Velveteen Rabbit*. The Skin Horse tells the Rabbit that becoming "Real" takes time. You lose your shine, your fur gets worn off, your joints get loose—but that doesn't make you ugly. It makes you loved. It makes you real. Lymphedema stripped away my illusions of perfection, but it made me more real than I ever could have been otherwise.

It's not easy to accept pain as a teacher. There were times I screamed at God, asking why me. Times I closed the curtains like Katy and let despair in. But over time, I realized that pain wasn't just punishing me—it was shaping me. Forcing me to grow stronger, more compassionate, more disciplined than I ever imagined.

The School of Pain is not a school anyone wants to enroll in. But once you're there, you start to realize it offers lessons you can't learn anywhere else. You learn to savor the days when the swelling is low and the pain is quiet. You learn that vanity fades, but resilience lasts. You learn that joy is possible even in the middle of suffering.

Pain became my teacher, but it did not get the final word.

Reflection / Takeaway for Readers:
When chronic illness enters your life, it can feel like a prison sentence. But if you let it, pain can also be a teacher. It strips away the superficial and forces you to focus on what matters: resilience, love, faith, discipline. You don't have to *like* the lessons, but you can still grow from them. And in that growth, there is hope.

Chapter 5: Fighting Back

The summer after my diagnosis, I went home defeated. My body ached, my spirit was cracked, and the word *lymphedema* hung over me like a storm cloud I couldn't escape. I thought I was going home to rest, maybe to hide. Instead, I enrolled in something far more demanding: the fight of my life.

My mother was my first coach. She had always been fiercely organized, and now she channeled that energy into saving me. Armed with binders full of research and articles from the early internet, she charted out therapies, supplements, and routines. She found a lymphedema therapist, a no-nonsense Frenchwoman named Nicole, who wrapped my leg in layers of bandages so thick I looked like a Michelin Man in the middle of a Georgia summer.

It was humiliating at first. I was twenty years old, supposed to be vibrant and free, but instead I was swaddled in medical wraps, hobbling around in oversized pants to hide them. My mom drove me to every appointment, helped me into baths wrapped in trash bags, ironed stacks of bandages every night so they'd be ready for the next day. Her selflessness was relentless. Looking back, I see it for what it was: love in its most practical form.

That summer became a boot camp of sorts. Wake up early. Bathe, carefully. Bandage. Therapy. Walks along the canal, sweating under Georgia's sun while fluid drained and shifted. Classes at the local college, where I wore long skirts to disguise the wraps and tried to keep my head high. Evenings filled with supplements: horse chestnut, rutin, grapeseed, fish oil, a rainbow of pills swallowed with orange juice.

I learned discipline the hard way. No shortcuts, no excuses. Every detail mattered: what I ate, how much water I drank, how faithfully I followed the regimen. For the first time, I realized that while I couldn't control the disease itself, I *could* control my response to it.

Slowly, my body began to change. The swelling reduced. The pain eased. My spirit, once fractured, began to stitch itself back together. By the end of that summer, I returned to school lighter, stronger, armed with new clothes my mom had bought me—pants and skirts that concealed my compression garments, but more importantly, a renewed sense of hope.

I wasn't cured. I never would be. But I had learned something that would carry me through every battle to come: healing is not passive. Healing is a discipline. It's a choice you make every day—to show up, to fight back, to believe that your effort matters.

That summer taught me what no doctor ever could: I had the power to heal myself.

Reflection / Takeaway for Readers:
Chronic illness demands more than medicine. It demands discipline. Healing doesn't come from waiting for a cure—it comes from daily choices: how you eat, how you move, how you rest, how you care for yourself. It's exhausting, yes. But it's also empowering. Because even in a body that feels broken, you still hold the power to fight back.

Chapter 6: Living with the Monster

Just when I thought I had gotten the upper hand, the monster came back.

I had wrapped, exercised, swallowed supplements, and fought my way through the summer. My leg looked better, my energy had improved, and for the first time since my diagnosis, I felt like I had some control. But lymphedema is relentless. It doesn't play fair, and it doesn't stay quiet for long.

The monster's name was cellulitis.

It started with a fever that came out of nowhere. One moment I was fine, the next I was shivering, teeth chattering, drenched in sweat. My leg throbbed with heat, red streaks crawling up my skin like flames. Within hours, I was in the emergency room, curled on a gurney, shaking so hard I could barely speak.

The doctors didn't move fast enough. They didn't understand that lymphedema plus fever wasn't something to watch—it was an emergency. I remember pleading, "I need IV antibiotics now. Please. I've had this before." They nodded, typed on their computers, and left me waiting. My mom sat beside me, her face pale with fear, gripping my hand as my temperature climbed past 103.

That night, lying under fluorescent lights, hooked up to fluids, I learned something crucial: I couldn't just be a patient. I had to be my own advocate. Lymphedema was rare, misunderstood, invisible to most. If I didn't speak up, I could lose more than my dignity. I could lose my life.

Cellulitis became a recurring nightmare. Nine hospitalizations in total, each one burning a deeper scar into my body and my memory. The swelling would explode, the pain unbearable, the fear crushing. Would this be the time it spread too far? Would this be the infection that my body couldn't fight off?

Every ER visit was a battle. Some doctors listened. Many didn't. More than once, I had to beg for the IV, explain the disease, argue with professionals who should have known better. More than once, I felt invisible—just another anxious young woman exaggerating her pain.

But each time, I survived. Each time, I walked out of that hospital battered but alive. Each time, I reminded myself: *I am still here. I am still fighting.*

Living with lymphedema means living with a monster always at your heels. You never know when it will strike—after a flight, a bug bite, a day in the heat. You live with vigilance, packing antibiotics for trips, watching every scratch and bruise like it's a loaded weapon. It's exhausting,

yes. But it's also clarifying. You learn to take nothing for granted: not health, not freedom, not the luxury of a normal day.

I didn't ask for this monster. But in fighting it, I learned the most valuable skill of all: how to speak up for myself, loudly and unapologetically. Because silence, I realized, could cost me everything.

Reflection / Takeaway for Readers:
Living with a chronic illness often means fighting battles that others can't see. You may look "fine" on the outside, but inside you're carrying fear, pain, and the weight of constant vigilance. Don't be afraid to advocate for yourself. Don't be afraid to demand care. Your life is worth fighting for—and no one knows your body better than you.

Chapter 7 – Love and Lymphedema

Love, in all its forms, has been one of the hardest and most healing parts of my journey with lymphedema. Romantic love. Family love. Self-love. Each has been shaped, tested, and transformed by this disease.

The Fear of Being "Too Much"

When you live with a chronic condition that affects your body every single day, it's easy to believe you're "too much" for someone else to handle. The swelling, the wraps, the appointments, the exhaustion—sometimes even I couldn't handle me.

Dating felt like carrying a secret. Do I bring it up on the first date, or do I wait until I've gained someone's trust? I wanted to be seen as whole and desirable, not broken. But lymphedema doesn't always let you hide. The compression stockings, the scars, the swelling—they all tell their own story.

The truth is, real love doesn't shy away from those things. But I didn't know that at first. I had to learn it.

Memoir Moment 1: The First Confession

I remember sitting across from someone I was dating, nervously tugging at my pant leg as if I could hide my swollen ankle forever. My heart pounded as I finally said, "There's something you should know. I have lymphedema. It means my leg swells, I wear compression, and sometimes I'm limited in what I can do."

I braced myself for the look of pity or discomfort. Instead, he leaned back, smiled, and said, "Okay. So what do we need to do about it when you're having a rough day?"

That moment taught me something life-changing: the right people won't see your condition as baggage. They'll see it as part of you—and still choose you, fully.

When Love Tests You

There were times when I felt unworthy of affection. Times when intimacy seemed impossible, when I avoided touch because I didn't want someone to feel the hardness of fibrosis or see the swelling. My confidence wasn't just shaken—it was shattered.

Lymphedema doesn't just affect your body. It affects your sense of beauty, your sense of freedom, your sense of worthiness. I had to face the voice in my head that whispered, *"Who would want this?"*

The people who truly loved me showed me the answer: *"Me. I do. I want all of you."*

Memoir Moment 2: Compression and Compassion

One night, I pulled on my compression stockings before bed, trying to do it discreetly. I'd gotten used to sleeping alone with them, but now someone was sharing my bed. I expected teasing or discomfort. Instead, he reached over, touched my leg, and said, "You're doing what you have to do to take care of yourself. That's strong. That's beautiful."

I cried that night—not because of my condition, but because love had finally met me where I was. No disguises. No shame.

The Right Kind of Love

The partners and friends who made the biggest difference weren't the ones who tried to "fix" me. They were the ones who sat with me while I elevated my legs. Who carried an extra bag when I couldn't. Who didn't flinch when I wore compression garments to bed.

Love didn't make lymphedema disappear, but it gave me courage to keep fighting.

Loving Myself

The hardest love to find was my own. It took years before I could look at my legs and not feel only anger. Before I could wear a dress without worrying about stares. Before I could let myself be photographed without editing out my swelling in my head.

I had to learn that my worth wasn't in having perfect legs or a perfect body. My worth was in my resilience, my humor, my intelligence, my heart.

Self-love didn't come from ignoring my lymphedema. It came from accepting it—and still showing up as me.

Advice for Others

- **Communicate:** The right people will want to understand. Don't hide your needs or your pain.
- **Let people help:** Accepting support is not weakness. It's intimacy.
- **Set boundaries:** Not everyone deserves to know your whole story. Share with those who've earned it.
- **Practice self-compassion:** Talk to yourself the way you would to a friend with lymphedema. You'd never shame them—don't shame yourself.

Love Beyond Lymphedema

Today, I know that love and lymphedema can coexist. In fact, this disease has taught me more about love than I ever could have learned otherwise. Love is not just attraction or romance—it's patience, presence, and persistence. It's holding on to hope when your body feels heavy. It's believing that you are enough, swollen legs and all.

Lymphedema may shape my body, but love—real love—shapes my life.

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The people who truly loved me showed me the answer: *“Me. I do. I want all of you.”*

Memoir Moment 2: Compression and Compassion

One night, I pulled on my compression stockings before bed, trying to do it discreetly. I’d gotten used to sleeping alone with them, but now someone was sharing my bed. I expected teasing or discomfort. Instead, he reached over, touched my leg, and said, “You’re doing what you have to do to take care of yourself. That’s strong. That’s beautiful.”

I cried that night—not because of my condition, but because love had finally met me where I was. No disguises. No shame.

The Right Kind of Love

The partners and friends who made the biggest difference weren’t the ones who tried to “fix” me. They were the ones who sat with me while I elevated my legs. Who carried an extra bag when I couldn’t. Who didn’t flinch when I wore compression garments to bed.

Love didn’t make lymphedema disappear, but it gave me courage to keep fighting.

Family Love: Seen and Accepted

Romantic love is powerful, but family love is the kind that roots you when everything else feels shaky. My children have seen me at my strongest and at my most vulnerable. They've asked questions, carried bags, and even helped me wrap my legs when I didn't have the strength.

At first, I worried they would see me as "sick" or fragile. Instead, they saw me as *resilient*. They learned that sometimes Mom needs rest, and sometimes Mom pushes through. Their love wasn't conditional on how I looked or whether my legs were swollen—it was steady, unshakable, and pure.

And my parents, siblings, and close family members have been part of that too. Sometimes they've worried or tried to "fix" things, but most of all, they've shown up. They've reminded me that family love is not about perfection—it's about presence.

Family love has been a reminder that lymphedema is something I carry, but it does not carry away the love I deserve or the love I give.

Loving Myself

The hardest love to find was my own. It took years before I could look at my legs and not feel only anger. Before I could wear a dress without worrying about stares. Before I could let myself be photographed without editing out my swelling in my head.

I had to learn that my worth wasn't in having perfect legs or a perfect body. My worth was in my resilience, my humor, my intelligence, my heart.

Self-love didn't come from ignoring my lymphedema. It came from accepting it—and still showing up as me. It came from speaking kindly to myself, even on the hardest days. From allowing myself joy, adventure, and beauty, even when I felt like hiding.

And slowly, self-love became the foundation that all other love could stand on.

Advice for Others

- **Communicate:** The right people will want to understand. Don't hide your needs or your pain.
- **Let people help:** Accepting support is not weakness. It's intimacy.
- **Set boundaries:** Not everyone deserves to know your whole story. Share with those who've earned it.
- **Practice self-compassion:** Talk to yourself the way you would to a friend with lymphedema. You'd never shame them—don't shame yourself.
- **Lean into family bonds:** Kids, parents, siblings, and partners can surprise you with their strength. Let their love in.

Love Beyond Lymphedema

Today, I know that love and lymphedema can coexist. In fact, this disease has taught me more about love than I ever could have learned otherwise. Love is not just attraction or romance—it's patience, presence, and persistence. It's holding on to hope when your body feels heavy. It's believing that you are enough, swollen legs and all.

Lymphedema may shape my body, but love—romantic, family, and self-love—shapes my life.

Chapter 8 – Courage in the Everyday

Courage is often painted as something dramatic—a soldier in battle, a hero rushing into danger, a climber reaching the top of a mountain. But when you live with lymphedema, courage looks different. It's quieter, smaller, and far more relentless. It's choosing to keep going when your body feels heavy. It's facing stares when you wear compression in public. It's daring to imagine joy when pain tries to steal your focus.

Redefining Courage

Before lymphedema, I thought courage was about big moments. Now I know it's about persistence in small ones. Courage is:

- Going to the pool and wearing the swimsuit, even when your legs look different.
- Saying "yes" to a night out, even when you know you'll be tired the next day.
- Asking for a seat on the bus when standing is painful.
- Letting yourself cry and *still* showing up for tomorrow.

Courage isn't the absence of fear. It's fear walking hand in hand with faith.

Memoir Moment: The Day at the Beach

I'll never forget one summer day at the beach. I'd avoided swimsuits for years, convinced everyone would stare. That day, I pulled on my compression stocking under a swim skirt and thought, *I can either hide forever, or I can choose joy just for today.*

I stepped onto the sand with my kids, heart racing. I braced myself for whispers or looks. But the only thing that happened was this: my children laughed, splashed, and begged me to play. They didn't see compression or swelling. They just saw *Mom*.

That day, courage looked like a beach chair, sunscreen, and letting love drown out the noise of insecurity.

Building Courage Muscles

Like any muscle, courage grows with practice. The more you use it, the stronger it becomes.

Here are practices that helped me build everyday bravery:

- **Micro-challenges:** Do one thing daily that makes you uncomfortable—wear shorts, explain your condition, ask for help.
- **Celebrate wins:** Notice and honor the moments you showed courage, no matter how small.
- **Anchor in purpose:** Remember who you're showing up for—yourself, your family, your future. Purpose fuels bravery.
- **Borrow courage:** When mine ran out, I leaned on the people who loved me. Sometimes courage is letting someone else carry you for a while.

Courage as a Lifestyle

Lymphedema forced me to rethink what it means to live boldly. It's not about ignoring reality—it's about embracing it and daring to live anyway.

Courage is wearing the stocking. Courage is booking the trip. Courage is looking in the mirror and saying, *Yes, this is me—and I am still worthy of joy.*

Advice for Others

- Don't wait for fear to disappear before you move forward. Move with it.
- Remember that courage compounds. One brave choice leads to another.
- Protect your energy—courage also means knowing when to rest.
- Celebrate visibility. Each time you show up authentically, you open the door for another person with lymphedema to do the same.

Closing Reflection

Courage isn't something we find once and keep forever. It's a daily decision. It's a whisper we choose to believe: *"You are stronger than this moment. You are more than this swelling. You are still here—and that is brave."*

Chapter 9 – Resilience and Routine

Resilience isn't about never breaking. It's about breaking and then choosing, again and again, to put yourself back together. With lymphedema, resilience often shows up not in dramatic

moments but in the quiet rhythm of daily routines—wrapping, compressing, elevating, exercising, eating well.

Routine may not feel glamorous, but it is the scaffolding that keeps resilience standing tall.

Why Routine Matters

When I first started managing lymphedema, everything felt overwhelming. The therapy appointments, the compression garments, the constant vigilance over every little swelling—it was too much. I often asked myself, *How can I possibly live a normal life when every day revolves around this?*

The answer came slowly: by building routines that support, rather than suffocate, me. Structure transformed chaos into something I could carry. It gave me a sense of control when so much felt uncontrollable.

Memoir Moment: The Morning Ritual

I resisted morning routines at first. I wanted to wake up and just *go*, like everyone else. But rushing only led to swelling, pain, and frustration.

Eventually, I created a ritual: I wake up, hydrate, stretch lightly, and put on my compression. Some days I add a few minutes of meditation or gratitude journaling. It doesn't erase lymphedema, but it frames my day with intention instead of panic.

That ritual became a quiet act of resilience. It reminded me that I can't always control my body, but I can choose how I meet the day.

The Power of Consistency

Resilience isn't built in a single victory—it's built in thousands of small choices repeated over time. Routines help us stay steady when life gets unpredictable.

For lymphedema, that means:

- **Compression every day:** Even when it's inconvenient.
- **Movement and exercise:** Gentle, consistent activity keeps lymph fluid moving.
- **Nutrition and hydration:** Choosing anti-inflammatory foods and plenty of water.
- **Rest and elevation:** Building in pauses, even when the world demands constant motion.

These aren't glamorous acts—but they are powerful. Every time we choose discipline over despair, we add another brick to the wall of resilience.

Memoir Moment: Learning to Say No

For years, I said yes to everything—work projects, social outings, helping everyone else before myself. Then I'd crash, swollen and exhausted, wondering why I couldn't "keep up."

The truth? Resilience sometimes looks like *saying no.* Building a routine of rest, of guarding my time, of putting my health first was one of the bravest shifts I ever made. I learned that boundaries aren't selfish—they're survival.

How to Build Resilient Routines

- **Start small:** Add one healthy practice at a time—don't try to overhaul everything overnight.
- **Tie routines to existing habits:** Drink water right after brushing your teeth. Stretch while the coffee brews.
- **Be flexible:** Routines are meant to support, not strangle. If you miss a day, begin again tomorrow.
- **Track progress:** Journals, apps, or even simple notes can remind you of wins and patterns.
- **Honor rest:** True resilience includes knowing when to pause.

Advice for Others

- Your routine is not about perfection—it's about persistence.
- Anchor your day with rituals that bring peace, not just obligation.
- See routines as self-respect, not punishment.
- Remember: resilience isn't about avoiding hard days—it's about meeting them with tools that help you rise again.

Closing Reflection

Routine is not boring—it's sacred. It's the daily rhythm that whispers, *"You are strong enough to live this life."* And resilience is not perfection—it's the steady return, the quiet refusal to give up, no matter how heavy the day feels.

Together, resilience and routine remind us that lymphedema does not define us. Our response, our persistence, and our daily choices do.

Chapter 10 – Community and Connection

Lymphedema can feel like the most isolating condition in the world. It's not something people talk about at dinner parties. It's not splashed across magazine covers or TV commercials. For a long time, I thought I was the only one.

But the truth is this: healing deepens when we share it. Connection multiplies resilience. And community—whether found in family, friends, or fellow fighters—reminds us that we are never truly alone.

The Loneliness of the Journey

In the beginning, I carried lymphedema like a secret. I didn't know anyone else who had it. No one around me seemed to understand the physical or emotional toll. Friends would ask, "Why don't you just elevate your legs?" or "Can't you take a pill for that?"

Their well-meaning but shallow understanding left me feeling unseen. And loneliness can sometimes hurt more than the swelling itself.

Memoir Moment: Finding My First Support Group

One night, after a long day of pain and frustration, I stumbled into an online forum for people with lymphedema. Post after post, I read my own experiences reflected back to me—fear of infections, embarrassment over compression garments, the exhaustion of daily management.

For the first time, I exhaled. These were *my people*. They didn't need me to explain. They already knew.

I didn't realize how much I had been holding until I finally let myself be held by community.

Why Connection Matters

Community gives us three gifts:

1. **Understanding:** People who "get it" without a lengthy explanation.
2. **Encouragement:** Voices that lift you when your own grows tired.
3. **Accountability:** Gentle reminders to stick with the routines that keep you healthy.

Connection doesn't erase the struggle—but it makes the struggle lighter to carry.

Memoir Moment: The Unexpected Friend

I once shared casually with a coworker about my compression therapy. Weeks later, she came back to me with tears in her eyes. Her aunt had just been diagnosed, and she didn't know where to turn. Because I had spoken up, I became a bridge. We swapped resources, encouragement, and hope.

That moment taught me: sometimes your story becomes someone else's survival guide.

Building Your Circle

- **Support groups:** Online or local, these create safe spaces to share and learn.
- **Family and friends:** Educate them gently. Invite them into your world, one step at a time.
- **Healthcare partners:** Find doctors and therapists who listen, not just prescribe.
- **Advocacy and outreach:** Speaking out not only connects you to others—it raises awareness for those still suffering in silence.

Advice for Others

- Don't wait for people to "just know." Teach them. Invite them in.
- Find at least one "go-to" person you can text on hard days.
- If you can't find a group, start one. Connection grows when someone is brave enough to begin.
- Remember: vulnerability builds community. Sharing your truth may open a door for someone else.

Closing Reflection

Community and connection are not extras—they are lifelines. They turn isolation into solidarity, fear into shared strength, and silence into a chorus of understanding.

Lymphedema may be a solitary disease in the body, but it was never meant to be carried in solitude. Healing is multiplied when we walk it together.

Chapter 11 – Work and Purpose

Living with lymphedema means carrying an invisible weight that sometimes feels heavier than the swelling itself: the fear that it might hold you back from living a purposeful life. Work, dreams, goals—how do you chase them when your body demands so much care?

The answer I've learned: purpose isn't about doing everything. It's about doing the right things—things that matter to you, in ways that honor both your ambition and your body.

Work as Identity

For years, I defined myself by my work. Achievements, deadlines, promotions—they were the markers of my worth. But lymphedema disrupted that equation. Suddenly, I couldn't grind at the same pace as everyone else. Fatigue forced me to stop. Medical appointments carved out hours of the workday.

At first, I felt like I was failing. Then I realized: my worth was never in the hours I logged. It was in the value I created, the creativity I brought, and the way I showed up for people.

Memoir Moment: The Presentation

I once had to give an important presentation while managing a bad flare-up. My leg was throbbing, and all I wanted to do was lie down with it elevated. But I stood at that podium anyway. I spoke with passion, I connected with the audience, and no one knew the battle raging beneath my professional smile.

Afterward, a colleague said, "That was inspiring." She didn't know it was *my resilience* that was inspiring, not just my slides. That moment reminded me: my purpose doesn't disappear because of my condition. Sometimes, it shines brighter through it.

Redefining Productivity

With lymphedema, the hustle culture mindset—*always on, always pushing*—becomes dangerous. True productivity is not about burning out, it's about balancing. It's about:

- **Energy management, not time management:** Listen to your body's rhythms.
- **Prioritization:** Do the work that matters most first.
- **Rest as strategy:** Breaks aren't laziness; they are essential maintenance.
- **Advocacy at work:** Communicate openly when you need adjustments. Flexibility is not weakness—it's sustainability.

Memoir Moment: Choosing Passion

There was a point when I had to choose: stay in a safe but draining job, or pivot toward something that lit me up. Lymphedema had stripped away my ability to do *everything*, but it also forced clarity. If I only had limited energy, why not spend it on work that felt like purpose?

That shift—choosing work aligned with passion instead of just paycheck—transformed not just my career, but my spirit.

Finding Purpose Beyond Career

Purpose isn't only about work. It's about living a life that feels meaningful in every corner:

- Raising children with resilience.
- Advocating for others with chronic illness.
- Creating art, stories, or community.
- Simply showing up authentically in your relationships.

Sometimes purpose is big and public. Sometimes it's quiet and personal. Both are powerful.

Advice for Others

- **Don't measure yourself by the old rules.** Redefine success on your terms.
- **Ask for flexibility.** Many workplaces will adjust if you advocate clearly.
- **Align with passion.** Spend your energy where it creates joy, not just survival.
- **Remember balance.** Work is a piece of life, not the whole of it.
- **Let purpose evolve.** As your life changes, so will your calling. That's growth.

Closing Reflection

Work is what we do. Purpose is why we do it. Lymphedema may force us to adjust the *how*, but it cannot take away the *why*.

When we let resilience, creativity, and clarity guide us, we find that our purpose burns brighter—not in spite of our challenges, but often because of them.

Chapter 12 – Hope and Healing

Hope is the quiet thread that has carried me through every dark moment of living with lymphedema. It is the whisper that says, *"This is not the end of you."* Healing, I've learned, doesn't always mean a cure. It means finding peace in the process, strength in the struggle, and light even on the heaviest days.

Healing Redefined

For a long time, I thought "healing" meant getting back to the body I had before lymphedema. I waited for the day my legs would look "normal," for the swelling to vanish and the scars to fade. That day never came.

What did come was a new understanding: healing is not going back—it's going forward. It's learning to love this body, to care for it, to honor it as the vessel that carries me through this life.

Healing is not the absence of pain. It is the presence of peace.

Memoir Moment: The Turning Point

One night, after years of fighting against my body, I sat quietly with my legs elevated. Instead of criticizing them, I whispered, *“Thank you. Thank you for carrying me, for walking me through life, for standing even when you’re swollen and sore.”*

It was the first time I showed gratitude to the very parts of me I had despised. That night marked a shift. My body was no longer my enemy. It was my partner. That was the beginning of true healing.

Where Hope Lives

Hope doesn’t live in false promises or miracle cures. It lives in the everyday:

- In the relief of swelling after compression.
- In the joy of laughter with loved ones.
- In the courage to show up as yourself, scars and all.
- In the knowledge that you are not alone in this fight.

Hope lives in the small victories that add up to a life of resilience.

Healing Practices That Helped Me

- **Gratitude journaling:** Writing down three things I was thankful for daily—sometimes as simple as “my legs carried me through today.”
- **Faith and mindfulness:** Prayer, meditation, or moments of quiet reflection.
- **Creative expression:** Writing, art, or music gave my pain a voice and my hope a shape.
- **Acts of kindness:** Helping others with lymphedema reminded me of my own strength.

Advice for Others

- Healing is not a destination—it’s a journey. Be patient with yourself.
- Hope doesn’t erase struggle, but it makes it bearable. Hold onto it.
- Don’t measure healing only by the body—measure it by your spirit.
- Remember that scars tell stories of survival, not shame.
- Keep looking forward. The future may not be what you imagined, but it can still be beautiful.

Closing Reflection

Living with lymphedema has taught me that healing is possible—even in a body that carries pain. Hope is possible—even on the hardest days. And love, courage, resilience, and community make the journey not just survivable, but meaningful.

This condition may shape me, but it does not define me. What defines me is the way I rise, again and again, with hope in my heart and healing in my hands.

-Ashley Anne.

Epilogue - Surgeries.

When I was first diagnosed with Lymphedema in 2000, I was told that surgery was not an option. The Doctor's said that my only course of relief progressive swelling, deformity and chronic cellulitis and infection was MLD (Manual Lymph Drainage and wrapping in Lymphedema Bandages, wrapped like a Michelin man. I suffered for 16 years without any relief except using a pneumatic pump at night and compression stockings during the day. Manual Lymph Drainage (MLD), is a technique developed by the Vodder's (Dr. Emil Vodder and his wife, Estrid) in 1936 in Paris for treatment of swollen lymph nodes. Lymphatic diseases, especially lymphedema, represent a serious problem in the health community. MLD is a light, skin – stretching massage that helps promote the movement of lymphatic fluid out of the swollen limb. It should not be confused with traditional massage. MLD is specifically focused on the lymph vessels to help the flow of lymphatic fluid. Therapy is applied to your unaffected areas first, making it possible for the fluid to move out of the affected area, or "decongest" the region. MLD helps open the remaining functioning lymph collectors and move protein and fluid into them, as well as to help speed up lymph fluid flow through the lymphatics.

Deep breathing techniques called diaphragmatic breathing are usually done at the beginning and end of a therapy session to help open the deep lymphatic pathways. It's not only relaxing, but it helps increase movement of fluid toward the heart. Other methods exist, including the Casley-Smith Method.

I first met my first lymphedema therapist when I was diagnosed, the Summer of 2000. Nicole helped me to navigate this archaic and almost medieval form of pain relief throughout 2 hour sessions everyday of that disciplined Summer whereby my mom drove me around, taking me to therapy and then to English classes at the local college all because my driving leg was wrapped like a Michelin man and I had a very attractive medical boot on my right foot. Needless to say, this was how I existed or tried to survive for 16 years, hence the reason my leg got bigger and I got sick a lot, especially during the child-bearing years.

In 2015, my mom was on Instagram and discovered a Dr in Orlando, Florida who was doing experimental surgeries with Lymphedema patients. His name was Dr. Richard Klein and he was and is a board-certified plastic surgery who studied in Europe after receiving education at Tufts, University of Michigan. He performed the first Lymph Node Transfer for Lymphedema in Florida in 2013. My mom thought it was promising and the first hopeful news we had heard in 15 years so she passed on his information. Within minutes of our phone call I called to Dr. Klein's office and had an appointment a few month later. I remember feeling hopeful for the first time in a decade and a half. I started getting health again prior to that first appointment, eating better and exercising and drinking lots of water, swimming and wrapping my leg religiously. I live in Augusta, GA so this appointment alone would constitute 12 hrs of back and forth driving and hotel rooms. I met with Dr. Klein and told him my depressing story. He told me he could help me but with the caveat of two things – he wished he had known me 16 years prior and that it would likely take multiple surgeries to see the full affect. I told him I was the clay and he was the artist and to mold me back to my former shape and make me "normal again." My first surgery was VNLT (vascularized lymph node transfer). It happened 6 weeks after that first appointment and the recovery was rough and right before Christmas, putting me in a "Ronald Mcdonald" home for a week with drains coming out of my armpit (where they took the Lymph node) and upper thigh where they put the lymph node. Pain and discomfort are an understatement as I stayed at the medical recovery home by myself while my family took care of the kids and my business. When I first arrived at the medical recovery home I was with my parents and velvet covered stairs/15 of them to be exact were between me and my room. I was sitting on them, blurry eyed and drugged from the surgery. I remember the house attendant saying that I would have to go back the hospital if I couldn't make it up the stairs. I quickly spoke up, probably slurred my words, and uttered, I can do it. I tredged up those stairs and made it to the room, exhausted. My parents had to head back to Augusta. I remember feeling drugged, lonely and kind of scared. I almost fell in the bathtub, drains hanging. I was alone and prayed a lot. I took good care of myself and stuck to a routine, sitting in the during the day and reading "Far from the Maddening Crowd," by Thomas Hardy. I took walks around the hospital after a few days. I had to repeat this surgical routine 4 more times – 1 more VNLT's and 3 SAPLS (Suction-Assisted Lipectomy), a debulking procedure that removes accumulated fat and thickened, solid fibrotic tissue from an affected limb over the course of 2016 – 2020. Without these surgeries and the genius and care of Dr. Klein I would not be where I am today, thriving and healthy and keeping my lymphedema almost in remission. Surgery is not for everyone and insurance is tough, denying procedures and making us patients fight the good fight, but in my case I am forever grateful and willing to tell my story and tout Dr. Klein and his team and how they saved my life.