

# INTRODUCTION

When I was in eighth grade, a few girls started a rumor that I was stuck up. They came to this conclusion because I stand with my left leg slightly bent, and apparently that is the universal symbol for stuck up. Did you know this?

I promise you I'm friendly. My "snooty teen" stance is one of the only visible clues to my diagnosis. The other thing you might notice is that the top joint in each of my thumbs doesn't bend. It's my party trick the schoolyard kids found endlessly fascinating. My fourth grade teacher, on the other hand, was not amused as she struggled to get me to hold my pencil the way other students did during cursive lessons.

## Diagnosis

While these two trivial quirks seem unrelated, they are connected by a disorder my doctor once called "nature's worst malformation." I was born with VACTERL Association, an acronym which stands for the different parts of the body it may affect: *V* for vertebral, *A* for anal, *C* for cardiovascular, *T* for tracheal, *E* for esophageal, *R* for renal (kidney), and *L* for limb. A child has VACTERL Association if she has a malformation in three or more of the systems listed. Piece by piece, my puzzle eventually included all of the letters except for *C*, cardiovascular.

In addition to the thumb thing, here's a rundown of the way VACTERL manifested in my body: my left hip was dislocated, and my spine has some malformed

vertebrae and a slight “s” curve, scoliosis. My reproductive organs, bowel, and urethra were jumbled into a single opening. I have a double uterus. My trachea and esophagus were not properly connected to each other or my stomach. My left kidney was missing, and my right kidney had anatomical defects. Lastly, my left arm and left fingers are slightly underdeveloped and are shorter than on my right side.

I am very fortunate to have been born when I was because medicine had advanced to the level my body demanded. Before I was two years old I’d had ten reconstructive surgeries to put things back into proper working order. Growing up, I endured choking incidents due to the anomalies in my esophagus, pneumonia hospitalizations, experimentation with diet and medication to create a healthy digestive system, and countless doctor visits and tests to monitor the development of my spine and the function of my single kidney.

As the years passed, my family took a collective sigh of relief as it seemed that my health was stable and we were through the worst of it. While I am exceptionally fortunate to be where I am with the start I had, my healing journey continued longer than we hoped. You’ll read about the details of the path I’ve walked throughout the book, but I want to let you know where I’m at today.

I am currently on the national kidney transplant waiting list. I was hopeful that my body would hold off on needing a transplant until science caught up and I could grow my own new kidney in a petri dish, but it doesn’t look promising. The doctors believe I have enough function to last a few more years as my name creeps its way toward the top of the list.

My back gets painfully tired quickly, and I have muscle spasms every six months or so. I also have decreased lung capacity from the anomalies in my trachea and

esophagus that mimics untreatable asthma. You won't see me running a marathon, or more than two blocks, anytime soon. Because of my decreased kidney function and two smaller uteruses instead of one large one, pregnancy is not in my future. If you've dealt with infertility as part of your illness, chapter 10 talks more about my experience with this.

I have been married to Phillip, the love of my life, for ten years. We have moved several times since we've been married, and I mention that a few times as you read along. The succession of our moves is as follows: two years in Colorado, two years in Southern California, four years in Portland, and we're going on three years in Northern California. We live with our furry kids, Abbey and Emma, terrier rescues who bring us joy each day.

## Learning from Illness

When the girls spread the “stuck-up” rumor about me in middle school, I wasn't upset. I wasn't embarrassed. And I didn't try to stand differently to blend in, because I knew that the rumor said more about them than it did about me. My abnormal reaction, for an insecure adolescent, is all credited to my parents.

My parents never ever made me feel cursed, burdened, or unlucky for my health challenges. In fact, I was raised to feel proud of what I had been through. They were encouraged by the capacity of an infant to endure and heal from such tremendous obstacles. They welcomed the journey I was on and worked hard to give me the best chance to live as normal a life as possible.

As I grew up, I knew that if I could be strong and resilient coming out of my first surgery at one day old, then I always had capacity. I felt that my unusual path had a purpose in my life, and I accepted the obstacles

wholeheartedly. With childlike faith, I bounded through my school years believing that my life and my body were just as they were supposed to be. But then came my twenties.

As my kidney function declined and I learned that pregnancy would not be safe, I had to give up things that I wanted. I became less accepting of my health. I started to think maybe I was cursed, burdened, or unlucky. Stress played a bigger role in my life and in my relationship with my body.

I read book after book about healing and the mind-body connection, and I was dismayed that I couldn't heal myself with prayer, meditation, or diet. I misguidedly took on the burden of feeling responsible for my illness. I thought that maybe I was too negative, or karma was following me around creating pain and loss. I shamed myself for the state of my health. It wasn't just that there was something wrong with my body, there was something wrong with me. My body didn't work correctly, and it was my fault. Talk about a burden!

By the time I ventured into my thirties, I was tired of this cycle and ready to develop a new relationship with myself. I reviewed my life and everything I knew about my health. I thought about my childhood, and the version of myself that was too young to feel guilty about getting sick. I saw that not only was she accepting of her body, she was accepting of her emotions and spirit, too. She had compassion for the bumps in the road. She'd cry when she was in pain and bounce on trampolines when she felt good. She wasn't ashamed of or frightened by her scars (both emotional and physical). She had lived what I needed to relearn. From the mirror I'd put up to my life came this book. I titled it *Chronic Resilience* because I realized that to be the essence of gracefully coping with illness. Life is not about figuring out how to be happy and

get your way all the time. Instead, we are called to experience the rollercoaster that is life.

## The Conversations

In addition to sharing experiences from my own life, in each chapter you will meet a unique and insightful woman coping with chronic illness. In chapter 3, Charity Sunshine Tillemann-Dick shares her story of recovering from not one but two double-lung transplants to reclaim her career as a world-renowned opera singer. Chapter 5 will introduce you to Kelly Young, a mother of five who has rheumatoid arthritis (RA). She shares how she adjusts her environment to accommodate RA while fostering her spiritual growth—a “side effect,” she says, of chronic illness. You will meet Sharmyn McGraw in chapter 8. After seven years, and countless doctor appointments with no answers, she researched her way to a diagnosis of Cushing’s disease, which had caused a one-year, one-hundred-plus-pound weight gain. In addition to these three amazing women, there are six more stories profiling: cancer, autoimmune-like disorders, idiopathic pulmonary hypertension, Crohn’s disease, multiple sclerosis, and diabetes.

Each woman I interviewed was generous and honest. They shared the day-to-day struggles and triumphs of dealing with illness while living a full and productive life. They have not been miraculously cured. They have the same fears, frustrations, and hopes that you or I do. They have also learned quite a few things while navigating the rough waters of their diagnosis, and I am honored to bring you their wisdom. The conversations I had with these inspiring women were the most treasured part of putting this book together. Their words lit a path in my life, and I know they will do the same for you as you manage your diagnosis.

## How to Read This Book

As we learn how to become resilient to the challenges and stress of chronic illness, I'll ask you to do more than simply read these pages. Changing your outlook and your life requires active participation, and there is some self-reflection I'd like you to do along the way.

### Journaling

Throughout the book you will find journal exercises. I have journals everywhere. Some are green, some are brown, spiral-bound, and hardback. They hold deep, dark secrets, personal revelations, and my goals for the future. Some have specific functions: this one is for gratitude, that one is to vent. Others are a random mix. I highly encourage you to treat yourself to a new journal and pen. A book can be a bunch of words on a page, or it can be a catalyst to create something new. Open your journal when you see this symbol:



Read the exercise and then take a moment to apply it to your own life.

### Embracing Chronic Resilience

Illness comes with stress—it's a package deal. In these pages I'll show you some ways to rebound from the pressures of having a body that's doing things you wish you could control. We'll explore techniques and philosophies that can help you become a more supportive caregiver to yourself so you can cry when you're in pain and bounce on trampolines when you feel good.

This book is an ownership tool. Each of the ten chapters presents a technique for managing the stress of

illness that you can pull from to walk the journey you are on. Read through the book once, and then pick two or three chapters that resonate with you the most. Reread those with a focus on how you will apply the lessons to your own life. As time goes by you may feel prompted to revisit other chapters, but don't overwhelm yourself by trying to move a mountain all at once. Mountains are moved one rock at a time.

When I asked Charity (chapter 3) how her illness has changed her view of herself, she replied, "It confirmed my thoughts on my extreme specialness!" That is what I pray this book does in your life. Illness doesn't make you less special—it makes you *more* special.

OK, I know you are probably not feeling very special right now; you are probably frustrated, in pain, and dealing with annoying limitations. I'm not asking you to pretend that things are rosier than they are—illness *sucks*. It absolutely does. But you are strong and resilient. There are things you can do to make it manageable, and if you are honest, patient, and compassionate with yourself, these tools can help you feel just how extremely special you are. Trust me. You'll see.

## CHAPTER 1

# Take Ownership of Your Wellness

Why on earth would I want to own a body that is broken? One that has aches and pains, needs medication, ruins plans, and embarrasses me? I would never buy it from a store, order it from a catalog, try to replicate it on my own, or borrow it from someone else. Still, when I wake up in the morning my body is there, ready to be moved through my day, to surprise me at any moment, and to make plans of its own without consulting me. My body is wild, unpredictable, rough around the edges, a pain in the ass (sometimes literally), but it is mine. This is the point that we start from: living with something that we did not choose or approve of.

One moment you're standing on the shore, the next you're swept up by the tide to bob and sway in a churning sea. Control, the one thing so desperately wanted, is lost in the swells. You kick and tread to be cured and supported. Kick and tread to dictate the future. Kick and tread in search of the shore. And then the sea reminds you of the depths you're dealing with and that it's time for a new strategy.

## The *T* Word

My husband Phillip and I moved to Portland, Oregon, in 2006. At that time, I was monitoring my kidney function



through blood tests every six months, so I made sure to find a nephrologist (kidney specialist) soon after we settled in. During my first checkup, my new doctor mentioned that he wanted me to establish a relationship with a urologist (urinary tract specialist) because he would be “on the transplant team.” Everything came to a halt as I wondered, did he really just say the *T* word? In relation to *me*? I could only see the back of the doctor’s white lab coat when he said it; he was typing the urology referral into the computer. I don’t think he realized that this was the first time I had heard the word “transplant” in regard to my kidney. Up until that point, I assumed that my health as a spry twenty-something would mature into my being a spry sixty-something grandma; but apparently I was mistaken. I asked for clarification, and he replied that my level of kidney function would not last for the rest of my life and someday I would need a transplant.

A flood of fear washed over me. My view of my health suddenly changed from “I keep an eye on my kidney and take a few meds” to “I’m sick.” Sick equaled scared. I left the doctor’s office and walked through the dim parking garage back to my car, a flickering orange light illuminating the tears running down my face. Sob after sob, my situation closed in on me. My mind went through crude calculations of how many years it would be before I’d need a transplant, and who in my circle of friends and family was going to be the “lucky” one to donate a kidney. Alone in your car is not a good place to pull yourself together. Facts get fuzzy between the seat and the steering wheel. There is no passenger there to offer reason or a “we’ll get through this” touch. There’s only you, worrying that things are about to get really, really bad.

I was afraid to eat after that appointment. I didn’t know if the thief who had taken my kidney function was hidden in the extra piece of pizza I was known to swipe.

What about the sugar in my lemonade? Or was coffee the culprit? How could something be happening in my body without my awareness or consent? I was supposed to be the guardian of my body, and somehow a burglar had slipped past me. I was determined to not let it happen again.

Up to this point in my life VACTERL had been a challenge, it had upset me and embarrassed me, but it wasn't anything I couldn't work around. There was just something extra dramatic about the idea that I would need someone else's organ put into my body to stay alive. That *T* word was making me tired and out of breath. I was confused and feeling victimized by my own body. In my angst, I sat and watched my power leave in the knapsack of the thief who had just changed my life.

## Why Me?

Have you ever asked yourself, why me? Of all the people, and all the lifestyles, and all the everything, why *me*? You rack your brain for an answer: you think back to what you ate, what you stressed about, and all the snooze-alarm mornings when you only dreamt about the gym. You wonder if God is challenging you, and you question how strong you must be to face something so blatantly crappy.

“Why me?” has a thousand different answers. Philosophers, pastors, priests, revolutionaries, friends, even the random Facebook acquaintance all seem to have an opinion about why things come into our lives when they do and how. The theories run the gamut:

- “The Secret”—You attract your experiences based on your thoughts and feelings.
- “The Karma”—You are being punished.

- “The Guilt”—You are punishing yourself.
- “The Tough Love”—You are strong enough to handle it.
- “The Exorcist”—Disease is evil incarnate and has waged a war on your turf.
- “The Darwin”—It is just evolution, a random draw of the short straw.
- “The Hippie”—You are playing out an archetypal pattern to learn a lesson your soul needs.
- “The Mrs. Fields”—You are too stressed and ate too many cookies.
- “The Evangelical”—You do not have enough faith in God’s healing power.

And the list goes on . . .

Most of the popular answers to “why me?” are ridiculous attempts to pull back the curtain and reveal the wizard, with little aim to provide comfort or understanding. “Why me?” is a complex question—it shows our innate desire to figure life out. Behind that two-word question is a yearning to control. If I could just figure out “why me?” then maybe I could fix what is broken and make things go back to how they were before.

Most often, we look outside ourselves for answers. I have spent many an afternoon sitting on the floor of the self-help section at the local Barnes & Noble, searching for the answer to that “why” question. A title will jump out, and I will think, “That’s it! This book will tell me why my life is messed up and how I can magically fix it.” When I read *The Power of Your Subconscious Mind* by Joseph Murphy, I thought that repeating positive thoughts was going to be the cure. After Eckhart Tolle’s *The Power of Now*, I thought, “Oh, that’s it. I wasn’t living

in the *now*. Once I fully live in the *now* everything will be perfect.” I studied metaphysics, Christianity, and Buddhism. I searched my psyche for feelings and thoughts that needed to be healed. I prayed to increase my faith. I began to see my health as a manifestation of being separated from God, a belief in “dis-ease” that was harming my body. I became frustrated with myself and with my inability to channel healing love as I watched my lab results get worse. My initial question of “why” became a merry-go-round of questioning everything I thought I knew to be true. And so it went, book after book, until I had a bookcase filled top to bottom with answers, none of which seemed to miraculously fix what I envisioned as broken.

Years after I began my quest, I was driving from Sacramento toward the Sierra Nevada Mountains on Interstate 80. The city’s crowded cement and flashy billboards had just left my rearview mirror. I took a deep breath and let my chest sink into the seat as my hands dropped from ten and two to four and six. My mind wandered to the great thinkers that lined my bookshelf. So many of them talk about the idea that we are spiritual beings. To heal and be prosperous, we have to connect with the spiritual side of ourselves, the side that is perfect and complete.

The spiritual journey is described much like my drive. The ego is the city, with its fight to be something. The neon advertisements and cement attempt to build up the prosperous but end up crowding out true beauty. Outside the city, the expanse is vast and peaceful. It is naturally beautiful. The trees don’t need to try to be anything because they already are everything. I wondered why I wasn’t like the trees yet. I had been studying for so long to get out of the city and into the trees, and I was frustrated with myself. The question arose, “why am I still

dealing with the same crap I've been dealing with for years?" Then, without books or seminars or websites or coaches or any guru, an answer came.

The idea was so simple and so obvious you'll probably laugh that I didn't realize this sooner. I realized that *I am human*, and all of the cells in my body let out a collective sigh of relief.

## Being Human

You are born completely dependent. You need to be fed, changed, cleaned, burped, and carried around. Each year you get a bit more independent: you take your first step, you dress yourself in hot pink tights and a green jumper, you hold hands at recess, you learn algebra, you terrify your parents by learning to drive, and eventually you fly from the nest. The gradual grasping of self-reliance gives you the idea that you have control over your life.

Illness laughs at this notion of control. We don't control everything that happens within our bodies because, as I so groundbreakingly discovered, we're human. Part of being human is experiencing pain, loss, stress, and heartache. It is the journey we all take. Each page I turned in all those books was a search for how to get out of being human. I had been looking for a spell that would prevent me from having to live through the tough stuff. I was pushing hard against something that wasn't going to go away.

## Ownership

Imagine with me that you have moved into a new house and the moving crew put your 150-pound dresser on the wrong side of the bedroom. You wanted it to the right of the window, and they placed it to the left. You think, "I'll just move it myself," and you lean into the dresser, but it doesn't budge. You turn around, dig your heels into the

carpet, and try pushing with your back, but that doesn't work either. Then you walk to the other side and pull with all of your might. The dresser is still to the left of the window, but now you are sweating and out of breath. That is stress.

The tension you put against the dresser is similar to the tension you place against illness. Illness is in your life for a conglomeration of reasons, and you can push with your front and push with your back, but it is still something you have to face.

Once you realize that the dresser is staying put, you decide to decorate around it. You no longer have to shove the dresser somewhere else. Tension is gone, and you can move on. The challenge is to figure out how to piece your life together around your diagnosis. The first step is to stop pushing so dang hard.

We push because illness just showed up. It feels like a misplaced tragedy from someone else's life. Like a bad Christmas gift, it doesn't match anything you own. It is unfair that you have to take responsibility for something you didn't choose. Yet, the circumstances of your life are yours to own. No matter what your diagnosis, you've got to go all in, with both feet, completely submerged.

It is important to claim ownership of your health because you already own it. You did not decide to get sick, but you live with your body every day. You are the one who has the intestines that like to play tricks, and you read blog after blog to learn how others shoot back apple cider vinegar and eat macrobiotics.

If you do not take ownership of your health, I can assure you that someone or something else will. Your emotions and thoughts will bounce around like ping-pong balls ricocheting off every opinion, study, test result, article, and sideways look you receive. The especially juicy, dramatic, and horrific thoughts tend to be the ones that

we ruminate on. They also zap energy and impede healing. Not cool.

Becoming ill is a threat—to our lifestyle, and maybe even to our existence. When we feel threatened, it can be easy to cope by giving life the silent treatment. But, responsibility is paramount to every healing process. It is up to you to take on your wellness and live life as fully as possible. There is no person, book, seminar, or tweeted quote that can do this for you. You are being called to own your life.

The day I heard “transplant” for the first time, I wasn’t only processing the idea of needing a kidney

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transplant, which would naturally involve some tears—I was feeding the drama of it. I was letting one word dictate how I was going to feel, mentally and physically. It took me a while to wake up to what I was doing. When my

eyes were open, I saw that nothing had changed with my health except hearing the *T* word. Not my diet, not my exercise patterns. Nothing. Each time I felt out of breath or tired or in pain, I reminded myself of the health I still had and remembered the idea of needing a transplant was, at that point in my life, just one possibility for my future.

A few more months passed, my fatigue decreased, and I was less scared of my own organs. When I was back at that same doctor’s office for my next checkup, he changed his opinion and said, “who knows what’s going to happen; your lab results have been stable every time I’ve seen you.” I had a brief moment of triumph. I had been resilient. I had pulled up my big girl pants and pulled myself together. Problem solved! Or so I thought.

## Ownership Is Not . . .

There is an important distinction to make here. Ownership does not mean that you “own” your disease. If you “own” your illness that probably means it has become your identity. When you begin to identify yourself as “a cancer patient” or say you “suffer from chronic fatigue” or “are a sick person with lupus,” you give a level of importance to the disease—one it does not deserve.

It is completely understandable why we do this. As a society we connect through shared experiences of pain. It’s what we gab about with our girlfriends, it’s what gets us out of work, and let’s face it, when you want your hubby to make dinner, a bit of whining about your aching back never hurt. Illness can cause love and attention to come your way that was otherwise hard to find. Identifying in this way and soaking in the benefits of being ill only keeps us in that pattern. Be honest with yourself about your relationship with your health and body. If you feel you have become entrenched in identifying with your diagnosis, seeing a therapist can help you change that pattern. We will discuss various healing professions in chapter 6.

Ownership is not merely acceptance. It is much bigger than that. Pretend you are on vacation in what is supposed to be gorgeous, sunny San Diego. Unfortunately, a wayward storm has come through, and now everything is all drippy. You can accept that your beach plans have been rained out and spend all weekend sulking in your hotel room watching reruns of *How I Met Your Mother*; or you can change your plans. Visit some of the amazing museums and restaurants in the city. Grab an umbrella and walk through Balboa Park anyway. Likewise, you can accept that you have been diagnosed with an illness and spend all day, every day in bed, or you can use that as a cue



to adjust your plans. With acceptance comes the possibility of giving in and giving up.<sup>1</sup> You may not have resistance to your present reality, but there is no motivation to take action, either. People can let years go by like this, accepting, but also completely disengaged from, life, as if their illness has given them a Get Out of Life Free card.

## Ownership Is . . .

What exactly *is* ownership? How do you take ownership?

Ownership is a decision to take responsibility for your life and your healing. It is that simple and that complex all at the same time. Make a decision to be open to the challenges that are already in your life. Going from clenched fist to open palm releases a lot of tension. Doing that frames every pain and annoyance in a way that makes it easier to deal with. Illness can be an invitation to become a deeper, stronger, wiser, more kick-ass you.

As you open to your experience, you will listen more to your body. It has a story to tell, and an owner learns to listen to her body carefully. When I have pushed myself too hard, my back gives me a gentle nudge that it has had enough. I can listen to that nudge and rest, or I can push harder and spend the next day on a heating pad on the couch. Rather than ignoring what hurts, allow your body a voice in your decisions and actions. This does not mean skipping yoga every time you're tired. Skilled owners can tell the difference between laziness and concerns that need attention. Listen to your body for a few weeks and you will be able to tell the difference between pains that need rest and pains that need to be moved through.

A few years after I first heard it mentioned, the *T* word came up again—this time at a different nephrologist's

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<sup>1</sup> Toni Bernhard, *How to Be Sick* (Massachusetts: Wisdom Publications, 2010), 81.

office, in a different city. I had created a nice illusion for myself. After the Portland doctor declared that I was stable, I assumed I wouldn't need to think about a transplant again. I felt healthy and had stopped obsessing. I was saying my affirmations and eating spinach and tofu. I had “drunk the Kool-Aid,” had fully bought in—I was even giving speeches about attracting health through a positive attitude, for goodness' sake.

The same day as one of my presentations, two hours after leaving the podium, I learned that the kidney disease had progressed. The thief was back for more. The diagnosis had moved from stage 3 to stage 4 (kidney failure is stage 5), and the doctor was starting to float the idea of getting me on the transplant list. It was a blatant reminder that I was, in fact, not in control of this disease or my future. Although books and affirmations eased my symptoms and stress, they had not yet gotten me out of being human.

In an eerie *déjà vu*, I found myself back crying in my car. Our ride home from dinner that evening was an alarming premonition when NPR hosted an hour-long dialysis special to discuss the lifesaving treatment for patients in kidney failure. I pouted, sulked, ate cheesy pasta and loads of sugar, and whined to Phillip. I saw my mind heading back to that first parking garage with the flickering orange light where worry took hold.

A good night's sleep can change a lot, and by the next morning, I was determined to do things differently. This time, rather than indulge in a six-month pity party, I asked a question.

## What Is in My Control?

Being a Harry Potter reader, I know that I'm a “muggle” (human). I didn't get to go to Hogwarts School

of Witchcraft and Wizardry, and I don't have a magic wand to *presto-chango!* control my future, but there is a whole list of things in my control that can influence my response to that future. I can control my diet and exercise habits, and I can control what I focus on.

You take ownership by deciding what is in your control and placing laser-beam focus on that. Ownership is a bumpy ride with lots of twists and turns. As I did, you will be called to learn lessons over and over again—ones

You take ownership by deciding what is in your control and placing laser-beam focus on that.

you thought you had already mastered. You will also get to decide over and over again to be an owner—to step up and claim

the responsibility that is being asked of you. Knowing what is in your control gives you clarity about what your duties as an owner actually are.

After I asked, “What is in my control?” I put a plan together, and I refocused my thoughts and actions toward health. I began researching nutrition; I determined how many days of the week I would work out, and what exercises I would do. I did not give myself the luxury of contemplating the *T* word. Transplant or not, that was not in my control.

After six months of my new routine, I did not have a miraculous recovery; the lab results stated that it was indeed time to begin the evaluation process to be placed on the kidney transplant list. Once again, I couldn't get out of being human! We don't get to choose what life brings us, but we do get to choose what we do with it. My labs indicated that although my kidney function was down, my body was handling it well. I am thankful we have the luxury of being proactive about finding the right donor and preparing for kidney failure and transplant to avoid dialysis.

With all our unpredictable imperfection, illness prompts us to embrace our humanity and learn to get

through our challenges instead of getting out of them. When you are at the mercy of your humanity, look back and think about what is in your control, and in a chronically resilient way, place your attention there.

Here are some things you can control:

- Living by your values (chapter 2)
- Making the most of your time (chapter 2)
- Listening the first time your body says it needs to rest (chapter 2)
- Finally doing what you've always wanted to (chapter 3)
- Learning relaxation techniques (chapter 4)
- Expressing your feelings (chapter 4)
- Turning away from worry (chapter 4)
- Keeping a peaceful home (chapter 5)
- Planning your meals and stocking the pantry (chapter 5)
- Preparing for hospital visits (chapter 5)
- Finding support (chapter 6)
- Being kind to those around you (chapter 6)
- Knowing when to bring in a professional coach or therapist (chapter 6)
- Educating yourself about your diagnosis (chapter 7)
- Finding a kick-butt medical team (chapter 7)
- Organizing your medical records (chapter 7)
- Bringing your thoughts back into the present moment (chapter 8)
- Taking your medications like your doctor thinks you are (chapter 9)

- Sticking to healthy standards: moving your body, keeping up with doctor appointments, practicing deep breathing, etc. (chapter 9)
- Measuring your accomplishments (chapter 9)
- Practicing self-forgiveness (chapter 9)
- Being grateful (chapter 10)

For your first journal exercise, make a list of things you can control. Start now, and add to the list as you continue reading.

#### **IN MY CONTROL**



Start a list of all the things that are in your control.  
Add to it as you read or think of more.

Take back your life—take back responsibility for what is in your control. Owners take action; they lead, they provide motivation, and resolve. They assign meaning and make decisions. They control what they can and trust that they will have the strength and resources to move through the rest.

Is ownership tough? How about when you are tired, sick, and in pain? Yes, at times it is tough. There are times when all your strength is gone and you want to hand the reins over to someone or something else. You want to wallow; you want to cry; you want to get angry and stuff your face with pie. Ownership does not mean those feelings go away; it means you use them as a catalyst to change, to grow, and to investigate who you truly are. Not what the lab results say, not what the MRIs show, but who you are at your core.

I ask again, “why me?” I have an illness because I am human. It requires me to be patient and compassionate

with myself. It challenges me to control what I can and accept what I can't. It helps me see what is important and let go of the trivial stuff. It shows me that I am much more than my body. It is my teacher, and I am here to learn.

## A Conversation with Meredith Israel Thomas, Breast Cancer Warrior

Featured on CBS and NBC, Meredith Israel Thomas courageously shaved her head in front of millions of people prior to starting chemotherapy. She has raised more than \$100,000 for cancer research and continues to advocate for early detection. Visit her at: [www.caringbridge.org/visit/meredithisrael](http://www.caringbridge.org/visit/meredithisrael).

“‘You have some spots. They look suspicious.’ That word [suspicious] to me, now, is the worst word you could ever imagine. Suspicious. More or less, they already know you have cancer.”

The day after her thirty-sixth birthday, Meredith Israel Thomas learned that her diagnosis of stage 2 breast cancer was really stage 4. It had spread into her liver and bones. “He told me stage 4; he gave me less than a year. And that’s when everything hit. To have a doctor give you less than a year to live, and Niomi [her daughter] was only eighteen months old. That night, everyone left the house, and I collapsed in my brother’s arms, and I said, ‘Why is it always me?’”

But Meredith stayed strong, thanks to her mantra, “Kick cancer’s ass!”

That attitude has turned her one-year prognosis into a three-year-and-counting journey of treatments, trials, and living life. As Meredith says, “It’s a stairwell to me. You take one step up, two steps back.”

I learned about Meredith from *The Today Show*, where she took control and shaved her head in front of

millions of people in preparation for chemotherapy treatments. She was going to fight cancer on her own terms. With a voice that conveys the strength of the warrior she is, she spoke with me about taking ownership.

Meredith was visiting her cancer treatment center for the first time, and she was not impressed with her doctor's demeanor. As she puts it, "She was just so forward, and ugh . . . just so harsh. Finally, I turned to the doctor after the next few appointments and I said, 'Listen. I'm a mother and I'm a person, and you need to have some relationship with me.' The doctor turned to me and said, 'I can't be your friend. I have to be your doctor.' I replied, 'Well, you have to talk to me nicer.'" In the end, speaking up for herself proved to be the beginning of a caring friendship with that same doctor.

Meredith attributes her strength and ability to take ownership in her fight against cancer to her earlier battle with postpartum depression. Due to a disorder from her childhood, Meredith was told she would be unable to have children. Getting pregnant with her daughter Niomi was a miracle. When postpartum depression "stole three months" from Meredith after Niomi's birth, she got pissed. "I would sit outside and scream at God that I had always wanted a child and now he's taking [this experience] away from me. So when this [cancer] happened, I just said 'no!'"

Meredith was determined not to lose. Still, she is realistic about the prognosis. As she puts it, "I am not one of those people who sugarcoats it, who says they're going to find a cure. They should have had a cure by now. I am very realistic. The cure is not coming in my time, but that doesn't mean I'm going to roll over like a lot of other patients do. There are patients who just lay down and are done and the cancer wins. It's crazy. I've now known two people who said, 'I'm not going to fight,' and in a week, they're dead." Meredith is determined, more than anyone

I have seen, to squeeze as much life as she can out of her time here.

When I asked her what was in her control, Meredith's first reaction—the reaction a lot of us have—was, “Nothing's really in my control. Physically, nothing's in my control.” After a soft pause, though, she started to make a list of what *was* in her control. Meredith's cancer has spread to her bones, and early on she learned that a hug can crack a rib. The first thing on her list was being careful.

“I know where the cancer's located, and I'm careful. I'm careful with picking up Niomi, I'm careful with heavy packages. I'm in control of mentally staying strong for those around me. The only thing I'm in control of is continuing to live life, because you can walk around with the ‘Woe is me, I'm a cancer patient’ attitude, or you can take it and change your life like I did.

“What I've learned through all my friends is that you have to own it. When I shaved my head, there was no hiding from anybody now. It's fully on display: I'm bald. You can't hide it. I took control of that.”

The highest priority on Meredith's list of responsibilities is staying strong for her daughter. She is fierce about caring for and shielding Niomi from the horrors of cancer. “For Niomi's sake, I need to be in control of how I act in front of her.”

When it comes to controlling the progression of cancer, Meredith turns to her mind. “I have no control except for mentally telling you [the cancer] to get out of me. That ‘I'm going to beat you,’ and talking to it. When I feel a pain, it's like a ping. I sometimes picture the shotguns going right around that area. I think, ‘OK, we're going to blast you.’ Unfortunately, deep down, you have no control, but I do think that from all the survivors I've met, the stronger ones mentally seem to last longer because they're just not throwing in the towel.



“I’ve been very open with everybody; I know when I’m going to throw in the towel. There have been days when the medicine gets to be too much and I’ve said, ‘Enough,’ and I allow myself to cry that day. And then I pick up Niomi from school, and I kick myself back in gear. But I’ve been very clear with everybody, ‘There will be no pain and suffering. I’ve already been through enough and [ask that you] don’t extend my life because you guys need me.’

“I suffer every day. Every morning the first thing I think about is the cancer. I wake up and think, ‘OK. I’m here, and I’m not sick today,’ but it never goes away. So, I guess, I just own my life.”

Meredith knows she can control what she does with each day here on earth, and that’s when the bucket list started. “When I got diagnosed, this bucket list just formed in my head, and skydiving was the first thing I thought of doing. I e-mailed [a family friend and skydiver] and told him, and he said, ‘Get up here!’ My mom was with us, and we went skydiving. And it was my step to kicking it back, saying, ‘I’m still here.’ It was so exciting!”

Also on the list was getting a tattoo. The first tattoo she got before chemotherapy was “warrior” in Hebrew. The tattoo solidarity spread with her mom, cousins, aunt, dad, brother, and sister-in-law all getting them. She says getting a tattoo is “as addicting as everyone says.” Since then, Meredith has added a second tattoo that says “unconditional love.”

“To me, it is so powerful, because I look at Gary [Meredith’s husband], and since Gary met me, between getting pregnant, postpartum depression, moving to New York, buying a house, breast cancer, all of this stuff, I would have run for my life if I were him, and he hasn’t budged. That, to me, is just unconditional love.”

When Meredith learned that hormone therapy hadn't worked and chemotherapy was the next step in her cancer treatment plan, she decided to lose her hair on her own terms. Through her contacts she got hooked up with *The Today Show*. "I really did not want to lose my hair, and I just said, 'I'm doing it,' [shaving my head on TV] and a lot of people disagreed with me. 'Wait 'til it falls out,' 'Wait 'til you lose a chunk.' I couldn't imagine seeing chunks of my hair falling out and shedding. I mean, everyone, including the wig place, said, 'You should be waiting.' Other patients told me I was stupid. I just said, 'I have to do it my way.' I called a couple of survivors . . . and it happened.

"I called my haircutter and said, 'So are you ready to shave it now?' and she said, 'No, but I'm going to do whatever you ask me to do.'

We all gathered, and talked, and there were a lot of tears that day. I just wanted it over with. I got the tattoo, I shaved my head, I got a wig. I did it my way, and I still have no regrets. I didn't fully lose my hair in the end, so that was the joke. But I had bald spots, so I would have had to shave it because I wouldn't have wanted it to be like that."

I'm not as dramatic as I always was. I just laugh at certain things now. We, as Americans, are just workaholics to an obnoxious level, but there is so much more. Now I can't sweat the small stuff.

Meredith says cancer has changed her outlook on life. "I'm not as dramatic as I always was. I was so dramatic. Everything was a drama. I think I changed after the postpartum depression, but I definitely changed after the cancer. I have no patience for dumb stuff anymore. I can't deal with drama now. The other thing I've learned is [about] work. I was always a workaholic, and I'll never forget, with one of my [publicity company] bands or opening up a restaurant, people would start yelling, and

I'd think 'What the fuck? We're not curing cancer here; it's opening a restaurant.' And now I definitely look at it like that. I just laugh at certain things now. I understand work. We, as Americans, are just workaholics to an obnoxious level, but there is so much more. Now I can't sweat the small stuff. I can't deal with drama like that. It's just ridiculous because there's so much more out there."


Meredith's motivation to retain her health is also her wakeup call. "Every morning I hear Niomi's footsteps running from her room to mine, and she pulls the blanket down and says, 'Good morning, Mommy!' I just start laughing. I mean, it cracks me up. When she says, 'I love you' and hugs me, I feel like Niomi's been through so much because of this. She's honestly why I fight. She deserves to have me around. There's nothing like a mommy. She loves her daddy, but there's nothing like a mommy. I use that as my strength, and that's why I've told them, 'No suffering!' I don't want her to ever see that side."

Meredith demonstrates the essence of ownership: living life. She has refused to let cancer take over. She remains resilient "just by living life regularly," and she fills her time doing normal things: going to movies, reading books, and, she confesses, "I'm still a TVaholic." Managing cancer along with running her own publicity company was not possible, so Meredith closed her company to focus on her health. However, she found it was important to have things to look forward to when she was feeling good. She is now volunteering at a children's foundation, where they understand her situation. "They know I might not show up some days, and they know other days I'm going to be rocking it." And rock it she does.

With exceptional courage and grace, Meredith has devoted her life to writing and advocating for cancer

prevention, detection, and research so that one day her daughter will live in a world that has even more ownership over the fight with cancer.

### **HEALTH TIPS**

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- Recognize that challenges are part of the human journey.
  - Take ownership of your body by accepting responsibility for your health.
  - Focus on what is in your control.
  - Take action on things that are in your control.
  - Have compassion for yourself and the journey you are on.