

## PRAISE FOR *ROUGH WATERS*

“Heather’s story is a captivating exploration of how living with a disability is like looking in a mirror showing the unfiltered truth of who you are. Heather defied all expectations by believing in herself.”

—Peta Hooke, host of *The I Can’t Stand Podcast*

“In *Rough Waters*, Markham takes her readers on a journey of loss, transformation, and growth. Her wit, dark humor, and intelligence shine in this memoir about thriving with a progressive disease. *Rough Waters* is for anyone who wants an equally authentic and hope-filled story.”

—Jenny Smith, author of *Live the Impossible: How a Wheelchair Has Taken Me Places I Never Dared to Imagine* and blogger at *Jenny Smith Rolls On*

“[Markham] writes with humor and exuberance. An honest and encouraging narrative about seizing life, no matter your limitations.”

—*Kirkus Reviews*

“*Rough Waters* is the memoir of a young woman who spent years seeking a diagnosis, then continued fighting to survive it with a zeal most of us could not muster. Heather is annoyingly persistent, shamelessly bold, and a tireless advocate for those with disabilities, even as her own body betrays her. The book was impossible to put down as I *had* to know what new and amazing thing she would accomplish in the next chapter. A story of faith and resilience to inspire us all.”

—Ranette H. Halverson, PhD, professor emeritus,  
Midwestern State University, Texas

“I’ve been an occupational therapist who has worked in assistive technology with thousands of clients with all kinds of disabilities for over forty years. Part of the job is to get to know people’s “stories,” so that you know what direction to go in with your recommendation (so the technology will actually work the way the client needs it to). *This* story, the way Heather writes it, is so moving, so funny, so *real*. She takes us on a journey and shares the lessons she learned. She slowly builds upon her inner conversations and experiences as her physical body fails her in a way that allows the reader to understand the turmoil they might never outwardly see in a person living with a disability. I highly recommend this story!”

—Susan Johnson Taylor, occupational therapist,  
ISWP certified, SJT Consulting

“Heather has a way of writing that draws you in not only to her inner thoughts but to the whole feeling of the situation and setting. In sharing her memoir, I felt all the feelings: frustration, laughter, sadness, excitement, and love. For those who may not be familiar with what it’s like to live with a disability, don’t think for a second that you can’t find common ground or relatability. Anyone can get a lot out of reading Heather’s memoir. Through sharing her story, Heather allows us all to glean a greater understanding and empathy for anyone who has a disability. As a medical professional, I feel that by reading *Rough Waters*, I have learned so many things that a degree can’t teach you. Thank you, Heather, for taking yet another exciting risk in your life and making a positive impact through your book!”

—Kelly Twichel, licensed occupational  
therapist, CEO of Access Trax

# **ROUGH WATERS**



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*From Surviving to  
Thriving with a Progressive  
Muscular Dystrophy*

**HEATHER C. MARKHAM**



MAKING WAVES  
FOR GOOD  
PUBLISHING

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This is a memoir, and the events and experiences detailed in it have been presented as the author currently remembers them, to the best of her ability. Some names and identifying details have been changed to protect the privacy of individuals.

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*For Miss Charlotte. Thank you for being the big sister I never had. I will remember for both of us.*





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## PROLOGUE

**I**t was finals day at the AccesSurf Hawai'i Adaptive Surfing Championship, and I was on a twelve-foot surfboard with Ryan preparing to head out to Queen's surf break at Waikiki for our twenty-minute heat. I was lying toward the front of the board, with my chest on the ramp, while he was my adaptive tandem partner. He began paddling, and our pusher and shadow caught up to us. I saw the Diamond Head crater disappear past my left shoulder as we started toward the markers. The professional water-safety guys were waiting for us on Jet Skis pulling tow rafts. When our board was loaded onto one of the rafts by our pusher and shadow, Ryan reached over me and grabbed on to the handles of the raft. Then the Jet Ski roared to life, and we sped toward the giant red inflated markers identifying the starting line for Queen's break, where we would surf. We bounced over the waves, the smell of the ocean mixed with the exhaust fumes from the Jet Ski, and my heart raced with happiness. Even if nothing else happened during the whole heat, I knew that I was having an amazing experience that few people would ever have. I was thrilled.

We caught a few little waves, but nothing of note. At the end of one, the catchers on the inside had turned us around so that we were pointed away from the beach, ready to be picked up by the Jet Skis and taken back out to the lineup. However, we were squarely in the break zone and about to go nose-first up the face of a four-foot wave. I'd been on enough waves over

the years to know that we weren't going to get over it, and as I saw it getting ready to break right on top of us—and in my face—Ryan saw it too. I heard the words he'd said when we started out, but he was calm then. Now, his voice was shouting in my mind: "Your only job is to hold on! You have to stay on the board!"

# **SECTION ONE**

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## **STAND (and Survive) 2002-2007**

“You either walk inside your story and own it,  
or you stand outside your story and hustle for  
your worthiness.”

—Brené Brown





## CHAPTER 1

# LAUGHTER OVER LUNCH

**T**eresa and I had met on the first day at our new jobs in electronic warfare (EW) at Edwards Air Force Base (EAFB). We lived in the same apartment complex and, as we were the first new hires in years, we had naturally gravitated toward each other. We commuted the forty minutes to work and back from Lancaster, California, each weekday, and we explored Los Angeles together on the weekends. She was the best friend I had in town. I loved her energy! Just twenty-three years old and all of five feet, three inches tall, she reminded me of Red Fraggle, one of Jim Henson's Muppet characters, and she embraced silliness, often skipping along or stopping to make pretend snow angels on the bare asphalt whenever she felt like it. But she also had a sharp mind that surprised those who underestimated her.

One day, after we'd been working together for about six months, I asked her to meet me for lunch. We both wore glasses: mine were progressive bifocals, and hers were oval and wire rimmed. We also both dressed casually in jeans, T-shirts,

fleece jackets, and sneakers. But she wore her straight, dark-blond hair pulled back in a ponytail, and I wore mine cropped short. And I was taller, at five feet, six inches, although heavier than I wanted to be.

We chose a tall table so that I wouldn't have to struggle to stand up when we were done. Teresa sat on one side, and I gingerly sat down across from her and put my cane aside. She knew that, although I had lots of good days, I nearly always walked with a cane for stability, and lately I had been having difficulty getting up from chairs.

While we waited for the server to bring our drink orders, the Parkinson's disease-like tremors began—again. The movement started in my hands, went up my arms, and then into my neck and head. My upper body contorted with the shaking, which had been coming and going for nine days, coinciding with the addition of a new medication to the regimen I was already on. Tears began to stream down my face; I had so little control over my own body that I couldn't even hold them back.

Teresa looked at me and said, with bright sincerity, "I'm so jealous of you right now."

"This? You're jealous of this?" By now, my face was wet with tears, and my head, neck, arms, and hands were all visibly shaking, rhythmically but out of sync with each other. I took my hands off the table to keep it from moving.

"Yes, look at all the calories you're burning!"

I laughed. Not a sarcastic, snarky laugh, but one of surprise. That laughter snapped me back to reality. All suicidal thoughts that had surfaced the previous week vanished when I remembered that this wasn't permanent and that the tremors were a side effect. They would go away when I took control over my own care and told the doctor that I wouldn't take any more of that medication.

We sat and waited for the tremors to subside. To distract me, Teresa drank her soda and told me about her weekly phone

call with her family. I barely heard her as I looked at my drink, thirsty but unwilling to pick it up because I didn't trust that I wouldn't spill it everywhere. I knew it would take a few minutes, but the tremors would all settle down soon enough, and while waiting I thought back to how I had gotten here.

## CHAPTER 2

# “YOU BELIEVE ME”

**T**en weeks before, in April 2002, I had walked into the office of a recommended orthopedist with a very slow and awkward gait, like a broken doll, and relying heavily on my cane. I had a lot riding on this appointment emotionally, having endured systematic shaming and ridicule by doctors up to this point. For the last dozen years, they had pronounced incorrect diagnoses and ordered painful and unnecessary procedures, yet here I was today, still barely able to walk. As this new doctor stood at the far end of the hall in his white doctor’s coat, stark against the industrial-blue carpeting with his pale-blue eyes watching me, I worked to close the distance between us. Finally, he decided to meet me halfway.

“There’s something wrong with you,” he said.

My voice choked back a flood of emotion. “You believe me! I’ve been saying it for a long time, but no one has believed me.”

“I don’t have to believe you, or not believe you. I can see it in your walk. There is something wrong, but I don’t think it’s orthopedic.”

I had sent my medical records ahead with all of the previous test results before the appointment, but I didn't know if he'd had time to look at them, and once we settled in the examining room and he asked me for my medical history, I was glad that he wanted to hear it directly from me.

"It's kinda long," I said apologetically, trying to figure out how to summarize the last twelve years. "Maybe I'll just start with the highlights of when I think this started." He said that was a good idea.

"It began in May 1990. I was a senior at Texas A&M and had been working all semester as a full-time custodian at Disney World in Florida, on the College Program. I was fairly fit back then, and my primary job was to roam my assigned section of the park with a dustpan and broom, cleaning up. Each shift also included a trash run, which meant pushing a rolling cart around and collecting the trash from all of the cans in the area. When full, the liners had to be emptied into the compactor, but they often weighed more than seventy pounds each, and the compactor's opening was chest high—higher than I could reach easily. The few times I asked a coworker for help, I was always told that doing it by myself was part of the job requirements. Other times, my job involved what was called a spill run—getting a bucket of hot, soapy water and a string mop and then using repetitive twisting movements to clean sticky messes of old ice cream or whatever from the roughed-up concrete, one after the other.

"On May eleventh, as I was finishing up a spill run, a searing, burning, electrical pain shot down and back up my right leg. Not wanting to get in trouble, I didn't make a sound. I just stood there sucking air until the pain subsided. I'd finished mopping in time for my lunch break, and I hobble-walked to put the mop away and go to the cafeteria for lunch. But at the end of the hour, I couldn't stand up without overwhelming pain. A friend took me to the emergency room, and I ended

up out on Workers' Compensation pay for the rest of the semester. From then on, the pain was chronic but mysterious, and I was launched headfirst into living squarely in the middle of the chronic pain cycle—even though I didn't know what to call it at the time. You know, that whole 'pain creates muscle tension, which reduces circulation, which creates muscle inflammation, which reduces movement and creates pain' thing.

"The first neurologist I saw in 1990 told me I should quit my job at Disney rather than fake an injury, because what he saw during my exam didn't line up with a traditional back injury. I struggled because I had been an athlete and knew my body, but this doctor didn't believe me and told me I was fine. I returned to College Station, Texas, and worked to finish up my degree over the summer, despite the pain while walking across campus and sitting through classes. In July, a family friend helped me get an appointment at the Mayo Clinic in Scottsdale, Arizona. The neurologists there ordered blood work, an electrical conduction study, an MRI, a myelogram, and a sharp-dull pin test, and confirmed compression of the spinal nerve at L5.

"After graduating in August, I went back to Disney because I needed health insurance that would cover my back injury. I transferred out of the custodial department at the first opportunity, but less than a year later, I had more shooting pain—this time while just walking. It felt electrical, and it was excruciating, shooting down my right leg and back up, like before, but this time also going across my low back and then down my left leg and back up. It settled into my low back again like fire. Disney's Workers' Compensation picked up my case again."

He nodded his understanding of all this, and I took that as a signal to continue.

"In 1992, I went to another neurologist—once again in Orlando, Florida—who also didn't see what he expected to

when looking for a traditional back injury. After six months of little improvement through physical therapy, he told me that he would report to Disney that I was faking my injury. I broke down sobbing under the weight of his disbelief, which he mistook for relief at not having to lie anymore. It was crushing. The physical therapist he'd sent me to had measured my calves, and found a one-centimeter difference between them, which she said was notably abnormal. My right calf was atrophying. My back pain was constant, and I found no relief from sitting or walking. But even so, he dismissed me.

"I moved to Fort Myers, Florida, in January 1993 for a new job. At the end of that year, my then-current neurologist did a spinal tap and an MRI and subsequently decided the best way to handle my low back pain was to perform a percutaneous facet rhizotomy, and he burned off the nerve endings next to my bulging disc at L5-S1. He prescribed Thorazine for a week to sedate me post-procedure, which didn't make any sense since it's normally used to reduce manic episodes of bipolar disorder and schizophrenia. It left me drooling and barely conscious for seven days. When I was still in pain afterward, I learned that he'd done the rhizotomy at L4-L5 instead, because that's how he interpreted the test results even though they were in direct contradiction to earlier studies. He became angry and dismissive when I questioned him, and I asked my Disney Workers' Compensation representative for another doctor. She said I'd been seen by all the doctors in Florida that I would ever see, and she wouldn't approve anyone else. I was stuck with him."

I paused to look at the orthopedist. All the color had drained from his face as he listened intently.

"I left Florida in 1995 and moved to New Mexico for a fresh start. A neurologist in Albuquerque said he could tell that my back hurt and that my right calf muscle was atrophying, but that he just couldn't make a connection between them and couldn't do anything for me. In 1996, an occupational

medicine specialist in Las Cruces, New Mexico, prescribed me inhaled synthetic morphine for acute pain and Tylenol with codeine for maintenance but provided no answers. After I moved to Tucson, Arizona, a physical medicine and rehabilitation doctor there continued the medication for me.”

He interrupted. “Inhaled synthetic morphine and Tylenol with codeine, together? How often, and for how long?”

“Refills were every two weeks and every thirty days, respectively, for nine months. The most addictive thing about the morphine, for me, was knowing I could go from lying on the floor unable to move to doing cartwheels in under seven minutes. The codeine just got me through my days, as it was hard to sit or stand for more than an hour at a time, and walking was slow and painful.”

By the frown on his forehead and the dropping of his jaw, I knew he’d never heard a history like mine.

“Workers’ Compensation closed my case in 1996, and I was left without health insurance that covered my back. In the interim, I was seen by doctors for other things, but for this, I’ve been without care for the past several years—until today’s visit.”

As the doctor listened to my account, mostly without interruption, his expression ranged from interest to curiosity to anger to empathy. He then did a routine physical exam, checking my heart and lungs and range of motion in my joints since, as an orthopedist, that was his main area of concern. He confirmed that it was indeed something, but not orthopedic, and gave me a referral to yet another neurologist.