

From the Sidelines to the Finish Line

A Chronic Illness Survivor's
Challenges and Everyday Triumphs

Emily Falcon

Baby Hearts Press
Temple, Texas

“This is the story of a woman with a bad heart who was able to overcome all challenges with tenacity and a good heart. Emily Falcon is a gifted storyteller. The story is packed with action. It is a reminder to value every single day, hour, minute.”

—Dr. Marius Stan, scientist, author, and actor (*Breaking Bad*)

“Perseverance, determination, and a positive attitude toward oneself and the ability to seize opportunity are just a few takeaways from Emily’s personal and heartwarming story.”

—Jack Fleming, President and CEO, Boston Athletic Association

“Emily takes the reader into her tumultuous health journey, which placed her on the sidelines. It culminates in her ability to move from the sidelines into the path of active participation. I shed tears when she described her many experiences with failed cardioversions and ablations and could not begin to imagine the anxiety and frustration that she endured. I rejoice with her now that she can move from the sidelines to the finish line of almost everything.”

—Daphne Davis-Patrick, DNP, Author, Educator, Inspirational Speaker

“A powerful, personal story of a woman fighting for independence and happiness. It’s difficult to talk openly about one’s fears and self-conscious feelings. Emily lets us know exactly what she was feeling. She lets us inside the experience of living with chronic illness.”

—Frank Jaworski, CRNA, father to an adult born with CHD

“I love the uplifting message of this book. It’s so good to have this out there for people who feel their problems are just too much to overcome. Emily is very relatable to anyone who’s struggled with long-term health issues.”

—Hope Angelina, author, *The Story of Hope: A Mother and Transdaughter’s Odyssey of Rediscovery*, to be published in 2024; adult with CHD

“As a heart patient myself, I felt like I was gaining a friend while reading Emily’s book. She described the life and emotions of a heart warrior so well! I was very touched by Emily’s story.”

—Lauren Elizabeth, author, *Lessons from a Broken Heart*, to be published in 2024; graphic designer; adult with CHD

“This is a story of a woman and her team of caregivers’ amazing journey of multiple medical challenges and her successes over them. Emily is a role model for all who face and overcome challenges. Having cared for hundreds of adults with CHD I still found the final race description to be very impactful and I will admit it brought me to tears.”

—Disty Pearson, PA-C

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The names of some people in the book have been changed but not places. The author has tried to recreate events, locales, and conversations from her memories of them.

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Foreword

My brother Rick had cerebral palsy and was a nonspeaking quadriplegic. To communicate he had to type his messages out one letter at a time. One day he asked our father, “Can I run in a race?” and Dad said, “Yes you can!” When they got home from the race Rick wrote on his computer, “Dad, when I am running it feels like my disability disappears.” Dad was hooked, and he had a custom racing chair built in order for them to participate in races. My father, Dick Hoyt, and my brother, Rick, ran the Boston Marathon together thirty-two times. They were known as Team Hoyt, a father-son duo who advocated for people living with disabilities.

The Hoyt Foundation was formed in 1989 and aspires to build the individual character, self-confidence, and self-esteem of America’s disabled young people through inclusion in all facets of daily life. We educate the public about disability awareness and promote the Team Hoyt motto, “Yes You Can.”

Emily Falcon makes our mission a reality. One of her mottoes is, “Just Try,” and ours, “Yes You Can,” shine throughout this book. Falcon tells a stranger, “If I can do it, you can too!” She participates in challenges even when the task might seem insurmountable. Her story enables readers to realize their own potential. Whether it’s going on a walk or running in a race, Falcon demonstrates believing in yourself and never giving up.

Her resilience and determination have allowed her to become a strong athlete, something no one thought was possible. Her obstacles and triumphs are relatable to anyone who has faced and wants to overcome hardships. The advice she gives will make you want to get out there and participate!

Team Hoyt completed more than 1,100 races together. Her race total might someday match my father's and brother's with her strong determination. She will motivate you to achieve your dreams and make the impossible possible because, yes, you can!

Russ Hoyt
President & CEO
The Hoyt Foundation
teamhoyt.com



Emily in 2018, Before the Race

Prologue

In April 2018, I blended into a crowd of 10,000 athletes eager to hear the starting gun for the 5K race to begin. Smoothing out my running leggings and tank top, and glancing down at my runner's bib with my number, I glimpsed my pink and purple chest scar shining brightly. The scar came from my open-heart surgery eight months prior. None of the other participants knew that I had a heart condition or that I had overcome thirty-five years of obstacles to take part in this race. Like everyone else, I was anxious and ready to start running, hoping to do my best.

I had never participated in gym class or sports because of my heart condition, so this was a first for me. In the past, even a set of stairs or an incline could leave me breathless on some days. In the previous few decades of my life, I could never even have contemplated joining an athletic event because I wasn't physically ready to meet the challenge, but I was now attempting it. Trying not to become overwhelmed thinking about what I hoped to accomplish with my newly changed body, I heard the starting gun, and the race commenced.

The elite runners took off. Eventually it was my turn to advance to the starting line, away from my family. As I walked ahead, I took in my surroundings, hearing the cheers of the crowd and seeing the tall Boston skyscrapers shining radiantly against the sunny blue sky. Everything was full of promise. The buildings reflected the green grass of Boston Common and the blur of athletes and spectators. I began to feel more excited than anxious. As I went around the last corner on Beacon Street before the starting line, I saw my family in the crowd. We waved goodbye. Turning on my music playlist, I ran over the starting line and began ...



Emily and Mt. Denali (September 13, 2018)

Introduction

What is it like to experience the strength and vitality of youth for the first time at age thirty-five? This is a story of my personal “Benjamin Button” journey. In F. Scott Fitzgerald’s short story “The Curious Case of Benjamin Button,” Benjamin is born an old man and experiences life in reverse, taking on new abilities as he becomes younger. In my case, as a result of a life-altering surgery, my abilities continue to develop, and I feel younger and more fit every day.

I went from being unable to run more than a few yards to developing as an athlete who participated in my first athletic event, a 5K race, just eight months after open-heart surgery. I chose to move away from the comfort of my medical team and family in Boston to Alaska, where physical challenges were part of everyday life. Whether hiking in Denali National Park, getting lost in the woods, or whitewater rafting in freezing rapids, I found my endurance tested in ways it had never been previously.

I have never had a normal life. At seven weeks old, in 1982, I had a heart attack that destroyed forty percent of the left side of my heart. My heart condition forever altered the course of my life and led to two open-heart surgeries, one at age six and another at age thirty-five.

A little over a year after my second surgery, my cardiac surgeon gave a presentation that featured my medical journey. After the talk, many audience members came up to me and told me they were inspired by my story. I didn’t understand why, or

why they called me a hero. I felt like all I had done was go on living and trying, which I did not feel made me stand out. One audience member shared her fears and hesitation about trying to go on a hike. I responded, “If I can do it, you can too!” Taken aback for a moment, she then agreed to give hiking a try. For the first time, I realized how my story could inspire others.

This book is about my experiences and how I have felt leading a life with complex, chronic medical issues. Unlike many survivors who have experienced sudden traumatic illness or accidents that forced them to live with newly acquired limitations, I have an uncommon perspective, from both a child’s and an adult’s viewpoint, because I have experienced a rare and chronic illness from birth.

At times, it might seem discouraging to read about everything I went through, and it might seem as if life will never improve, but it does. The skills and knowledge of my medical team, endless support from my family, and my own dogged perseverance enabled me to live a life no one ever dreamed was possible. No one and nothing, least of all my body, is holding me back anymore. I want to fully explore my abilities after a lifetime of restrictions and live my motto to the fullest: “Don’t waste a second.” By sharing aspects of my journey, I hope my insights can encourage people who doubt their own resilience.

Today, I live in a different world, one that is full of potential. My wish is to show people who hold back from experiences that maybe they can make a different choice. People with chronic illness can be inspired and learn to advocate for themselves. They can appreciate their level of health and not take it for granted. All opportunities, both big and small, should be embraced. Never waste a moment and don’t let life pass you by!