The Roses Speak

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A Chronic Illness Journey

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To the cystic fibrosis community:
May we never cease to share our stories.
Roses make the world more beautiful.

When the Roses Speak, I Pay Attention

"As long as we are able to
be extravagant we will be
hugely and damply
extravagant. Then we will drop
foil by foil to the ground. This
is our unalterable task, and we do it
joyfully."

And they went on, "Listen,
the heart-shackles are not, as you think,
death, illness, pain,
unrequited hope, not loneliness, but

lassitude, rue, vainglory, fear, anxiety,
selfishness."

Their fragrance all the while rising
from their blind bodies, making me
spin with joy.

—Mary Oliver

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Preface

Discovering My Truth

My father drove me to school each morning during my first year of high school. Traveling in his brown Chevy pickup truck, from the west side of Cincinnati to St. Xavier, took approximately thirty minutes, leaving ample time for father-son life discussions. One morning, I pulled out the most recent edition of *Blueprint*, the school newspaper, which I had hastily thrown into my backpack the previous day. I expected to read the headlines out loud and share the latest school news. As my eyes scanned the front page, I became silent. It felt like a pit in my stomach, and my heart began to race. I was unable to speak as my eyes darted across the page.

Bold letters splashed across the front stating, "Luedeke Battles CF." The article revealed that Mr. Andrew Luedeke, a faculty member at St. Xavier, received a double lung transplant within the past three years because he had cystic fibrosis (CF). Although he had been healthy enough to teach following the transplant, scar tissue developed on his lungs, and he was going to require another transplant to stay alive. The teachers quoted in the article did not sound optimistic about his recovery. One faculty member acknowledged that even being alive in his late twenties made Luedeke "a walking miracle." Another stated, "Most young people die from cystic fibrosis in their mid-twenties. Andy is in his mid-thirties. He's beaten a lot of odds."[1] I reread that sentence over and over, making sure I saw it correctly. My body froze. A chill ran down my spine. I flipped back to the front page to a box with facts on cystic fibrosis. The box read, "Median Survival: 29 years."

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1. Andy Amend, "Luedeke Battles CF," *Blueprint,* March 1, 1996.

I looked toward my father, struggling to find the words I wanted to say to him. “There is a teacher at St. X . . . who has CF. They think he is going to die.” My father remained silent. “And it says here that the life expectancy is twenty-nine. That means . . . I have already lived half my life.” I was processing these words as I spoke. My father quietly replied, “You never know about those things. You could live a long time.” He choked up as he struggled to find a way to support his son who, for the first time, learned that his disease was terminal. For the rest of the day, I was in a trance, going from class to class and occasionally rereading the article. A deep sadness tinged with fear overtook me. I was overwhelmed by the unfairness that I would not get to live as long as my classmates who sat beside me. I felt heavy, moving through the day as if I was stuck in quicksand. The day seemed twice as long as any other, and I just wanted to go home to cry. Each time I pulled the paper from my backpack, it did not change: “Median Survival: 29 years.”

I still remember how I felt reading that newspaper article. I was shocked, afraid, and then felt powerless. That day was the start of a new chapter of my life that dramatically altered how I saw myself, the world, and my future. Two years after reading that headline, I began to develop lung complications, which is one of the more common manifestations of CF. Mucus in my lungs began to slowly destroy the airways. My new and constant coughing was an ever-present reminder of Mr. Luedeke and his need for a lung transplant to extend his life.

Following high school, I moved to Cleveland, Ohio to attend John Carroll University. My new treatment regimen went with me. Luckily, a new advancement for fighting CF had recently become available. It was a vest that would shake a person, causing the mucus to dislodge from the airways so it could be expelled. I also used multiple inhalers while doing these vest treatments to make coughing up the secretions easier on my lungs and muscles. These treatments took an hour each day and kept me relatively healthy during my time in college. However, facing a constant battle to stay alive and completing daily treatments in my dorm made me feel very alone.

By the time I graduated college, my lung issues resulted in a steady stream of inpatient hospital treatments and IV PICC lines[2] to stave off the infections that were slowly killing my lungs. I was losing 3–5% of my lung function per year. Despite being active and adhering to the myriad treatments for fifteen years, by 2019 I found myself meeting with doctors to discuss a lung transplant. As I left that meeting, I thought of Mr. Luedeke. My CF experience was coming full circle. As a high school student, I learned the truly precarious nature of having CF from a newspaper article. Now, I would consider the procedure that gave Mr. Luedeke a few extra years of life before he died.

On January 1, 2020, however, my decline took a dramatic detour. That morning, I took my first dose of Trikafta. Within twenty-four hours, my body began to change. My constant coughing decreased and eventually disappeared. I experienced strength and energy that I had not felt for a long time. I did not realize it then, but that day began a new phase of my life. Nearly twenty-five years after reading the headline in my high school newspaper, I was once again overtaken by emotions and overwhelmed by intense feelings. However, this time it was not about decreased life expectancy, but about a previously unimaginable possibility of a longer, healthier life. In the weeks following my first dose, I saw vast improvements in my stamina. I began to gain weight for the first time since middle school.[3] I eagerly mused about the possibilities for my future.

As I began to embrace this optimism, the specter of COVID-19 overshadowed everything, and lockdowns became a way of life. People around the world feared for their own survival. Especially for those living with a lung disease, 2020 was a frightening time to

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2. Peripherally Inserted Central Catheter (PICC) lines are often inserted in the arm and are advanced to a large central vein near the heart. They are used for long-term IV antibiotic medications.
3. Gaining weight can be especially difficult for those with CF due to malabsorption. Thick mucus can clog the pancreatic ducts, leading to impaired delivery of enzymes and poor uptake of nutrients. People with CF often experience increased energy needs due to infections and increased efforts to breathe while having a decreased appetite.

be alive. Headlines that could have been about CF patients having new opportunities in life were displaced by warnings of an illness killing people every day. I didn't take the time to process what was happening inside of me because there was so much to process outside of me.

I believed at age fifteen that I had lived half my life. I learned that I was going to die. Trikafta has given me a reprieve and extended my life expectancy, but I still live with CF every day. Coming to terms with death is not only a reality for those with cystic fibrosis. Death is the one experience that every human person has in common. Mortality can be a scary realization. It certainly was for me as a teenager. However, a median survival age doesn't define who I am. This book will give insight into the ways having a chronic illness can affect a person. It is an invitation for all people to reflect on mortality and the fragility of existence. This is not only a CF story. It is the human story.

Acknowledgments

This book would not exist without the honesty and vulnerability of the people whose stories you will encounter. I am grateful to those with cystic fibrosis who shared their story with me: Riley Aroche, Morgan Barrett, Grace-Rose Bauer, Ryne Beck, Hilary Becker, Mark Bettinger, Malik Bishop, Emma Boniface, Devin Broadbent, Annabelle Brown, Casey Bruce, Jerry Cahill, Eliza Callard, Erika Castrucci, Talia Cestone, Alexa Ciancimino, Will Corcoran, Maddie Core, Marc Cotterill, Erica Daley, Jaime Dunaway, Teresa Dunning, Tyler Engle, Marina Finnell, Adrian Flor, Justin Goldsmith, Raelene Goody, Lyndall Grace, Caleigh Haber, Steph Hansen, Chase Honeycutt, Anissa Hostetter, Molly Jensen, Kassandra Klemenz, Emily Kramer-Golinkoff, Nick Laing, Jarrod Landau, Emily Lawrence, Andy Lipman, Andrii Lukianets, Debra Mattson, Erin McCaw, Ryann McCoy, Brian McTear, Rachel Meddaugh, Brandon Miller, Joshua Mitchell, Pat Mitchell, Haley Moreland, Beth Morgan, Dylan Mortimer, Ben Mudge, Becca Mueller, Cheri Nel, Maude Perrine, Sonja Petrovic, Jess Pickering, Tricia Polzin, Jess Ragusa, Dugan Reilly, Monique Renee, Adem Riahi, James Richardson, Helen Roper, Kari Rose, Katherine Russell, Rachael Russell, Emily Schaller, McKenzie Schneider, Kathleen Schwartz, Pug Scoville, Sarah Skeffington, Andy Smith, Martin Smith, Reid Jewett Smith, Travis Suit, Zack Swanborn, Martin Tallant, Kira Taylor, Clark Thiemann, Darren Turner, Eric Verdon, Rylee Walker, Stephen Walter, Bryan Warnecke, Tess Weber, Lori White, Lizzie Whitla, Mason Williams, Bonnie-Rose Wise, and Justyna Zaskwara.

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Peck), Beth Vanstone (daughter Madi Vanstone), and Ashley Williams (daughter Aurora Mcarter).

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Writing this book occurred predominantly while I was engaged in Clinical Pastoral Education (CPE) training as a hospital chaplain. I am grateful to my Cleveland Clinic CPE internship group of Stephen Ntui, Diane Rhynes, Natalie Kertesz, and educators, Bob McGeeney and Jim Egolf, for helping me begin to process my own health journey. My one-year residency at Covenant Healthcare, in Saginaw, Michigan, guided me in further exploration of my life. The support of my CPE residency group, Henry Adesiji, Amy Dobyns, Jeremy Lobdell, educator Ron Cooper, and Kathy Bonn, the director of the Pastoral Care Department, was invaluable. CPE was a challenging and beautiful gift that invited me to examine my story while I accompanied others exploring their own.

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I would not be alive today without the love and support of my parents, Ed and Carol, who had no experience raising a child with a chronic illness. They always supported me in every way possible. I am also grateful for the friends in my life who have buoyed me through times of struggle and illness. Finally, this publication would not be possible without the staff at New City Press. Thank you for making it possible for everyone to hear the roses speak.

Introduction

The Extravagance of Storytelling

Dear Diary, I am holding back tears of joy as I write this entry. It's the second day of my high school Kairos retreat. Tonight, I did something I never thought I would do. I had an opportunity to share my story in front of my classmates, and I could feel something inside of me pulling me to stand up. You know how shy I am. Suddenly, I was walking toward the front of the room. It was like my feet had a mind of their own! My heart was pumping so fast. As I approached the podium, I looked out at everyone staring at me. I cleared my throat and began speaking. "My name is Jimmy . . . and . . . I have cystic fibrosis. . . . I want to share my story."

Cystic fibrosis is an inherited genetic disease affecting over 105,000 people across ninety-four countries. Nearly 40,000 of those people live in the United States.[4] As a chronic and terminal illness, there is currently no cure. Cystic fibrosis shares this designation with cancer, multiple sclerosis, Parkinson's disease, AIDS, and many other incurable conditions. Each of these illnesses has unique and debilitating aspects that can make life challenging, difficult, and painful for those with the disease as well as those supporting

4. "About Cystic Fibrosis." *Cystic Fibrosis Foundation*, https://www.cff.org/intro-cf/about-cystic-fibrosis.

them. In the case of many chronic illnesses, those afflicted can find themselves marginalized by the greater population. They may face legal and medical barriers to their care and come to feel they are more of a burden than a person worthy of love and support. They may also feel alone, especially when their condition causes them to endure hardships that no one around them can conceptualize. While this book will focus predominantly on the experiences of those living and dying within the CF community, I hope that people with other conditions will come to discover some of their own story in these pages.

Sixty-Five Roses

Charlie Fry wasn't always a "boy wonder" from the UK. In fact, he wasn't great at football, or as it is known in the US, soccer. His poor lungs held him back. "It made it hard for him to breathe—and he was never hungry. He had to do physiotherapy each day and take a lot of medicine too. If he got ill though, it almost always meant . . . a two-week hospital stay."[5] While walking home one day after a game, he was struck by lightning. Suddenly everything went blank. He woke up in the hospital with a new skill. He saw a target that helped him guide the ball into the goal. Instead of being bullied for his sickly demeanor, Charlie became the star of his team. He still struggled with his chronic-illness identity, wondering why he couldn't be like everyone else.[6] However, he had something that gave him strength and helped him cope. It was the beginning of his self-discovery as an eleven-year-old boy.

Charlie Fry isn't a real person. He is a fictional character in a children's book created by Martin Smith. Martin is in his mid-forties, lives in the UK, and has cystic fibrosis. Unlike Charlie, Martin is not a football star. He was a journalist for fifteen years before his health declined. He began coughing up so much blood

5. Martin Smith, *The Football Boy Wonder: The Charlie Fry Series* (Create Space Independent Publishing Platform, 2015), 15.
6. Smith, *Football Boy Wonder*, 105.

that he was unable to work.[7] No longer healthy enough to continue in journalism, in 2014 he applied his writing skills to a new genre—children's books. Charlie Fry, whose initials are CF, was born. "Everyone who reads it gets a little bit of understanding about cystic fibrosis," Martin explained. Charlie's diagnosis represents more than a reflection of Martin's life living with a chronic illness. It makes a statement about the importance of having a main character who achieves despite a chronic illness. "How often do you see a character in a book or TV series that isn't able-bodied? It rarely happens," Martin expressed. He has been blown away by the support of parents of children with CF who have written to him to tell him how much their children enjoy the series. Charlie represents the challenges of living with a chronic illness, inviting readers to reflect on the ways there may be some of Charlie in all of us.

Although Charlie Fry is fictional, the way Martin describes the life of a person with CF is accurate for some people. There are many nuances to having cystic fibrosis and there is only one thing that is common among all people with CF. People who genetically inherit two copies of a mutated cystic fibrosis transmembrane conductance regulator (CFTR) gene will have cystic fibrosis.[8] Beyond biology, one can speak of common CF indicators, but the disease can vary widely from person to person. Most people with CF experience lung issues caused by the buildup of mucus. This mucus destroys the lung airways, potentially resulting in the need for a lung transplant, like Mr. Luedeke. Many people also have degenerative destruction to their pancreas, which interferes with food digestion and can lead to type 1 diabetes. Other gastrointestinal complications can lead to liver, kidney, and/or stomach issues.

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7. Coughing up blood is known as hemoptysis. It is a common progression of CF due to infection and/or irritation of the pulmonary blood vessels that can cause them to become more delicate over time.
8. "Cystic Fibrosis Causes," *National Heart, Lung, and Blood Institute* (NIH), https://www.nhlbi.nih.gov/health/cystic-fibrosis/causes#:~:text=Cystic%20fibrosis%20is%20an%20inherited,parent)%20will%20have%20cystic%20fibrosis

A person may have any combination of these symptoms in varying degrees. It is also important to know that there are different genetic mutations, which affect treatment. What might work with one group may not work with another.[9]

The treatment disparity based on gene type became heightened with the advent of gene modulators. These treatments are not antibiotics. These medications modulate the CFTR genes. The most recent and successful modulator, Trikafta, has split CF into camps of those who benefit from it and those who do not. The group who has not had their lives changed by Trikafta can be broken into three distinct groups: those who do not have access, those whose gene type prohibits it from working, and those who have access and the operative gene type, but experienced side effects that prevent it from being a viable option. All these categories will be represented in this book through people's stories.

Cystic fibrosis manifestations vary so widely that it is possible for a person to test positive for CF later in life (or never) and to have lived with no outward signs. Pug Scoville, from Florida, was diagnosed at the age of seventy-two. He was being treated for bronchiectasis when one of his doctors decided to test if he had CF because he would cough for thirty to forty minutes each night. "It got to the point where I dreaded going to bed," he recalled. To his surprise, the results were positive for CF. Pug faces unique challenges living with CF in his seventies. For example, he has a pacemaker, and using his therapy vest increases his heart rate and gives him chest pains. "This was the first time somebody with a pacemaker was also using a SmartVest," he explained. After unsuccessful attempts to modify his pacemaker, doctors recommended other forms of airway clearance. Pug also explained that Medicare doesn't give the same financial assistance as other insurers for Trikafta. Luckily, a recent Medicare provision caps

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9. "Types of CF Mutations," *Cystic Fibrosis Foundation*, https://www.cff.org/research-clinical-trials/types-cftr-mutations#:~:text=There%20are%20five%20classes%20of,different%20types%20of%20CFTR%20mutations. There are five major classes of CFTR proteins.

the out-of-pocket maximum for drug prescriptions, making it more affordable. Few people have lived to Pug's age with CF, so funding for Trikafta is a new frontier. He is paving the way for a future where more people live into their seventies.

Because CF can be so devastating, it is difficult for many to imagine living seventy years. Malik Bishop, who lives in Houston, Texas, felt the effects of having CF before he was aware of the world. He was diagnosed at birth and quickly put into a foster home. "I had CF, and my parents weren't . . . equipped to handle that because they were just out of high school," he reflected. Malik considered his disease "moderate" growing up. "I didn't really notice much difference between me and the other kids until I was in the third or fourth grade," Malik recalled. During sports, he would stop to use his inhaler, just as Martin Smith described with the fictional Charlie Fry. To date, Malik's form of CF has focused more on gastrointestinal complications than lung issues, while he contends with constant bouts of pneumonia, weight loss, and mental health challenges. Like some people you will meet in this book, Trikafta has been life-changing for Malik. "It was . . . the difference between night and day since the very first dose," he emotionally shared.

You will read the stories of many people with CF, like Pug and Malik. I invite you to imagine each speaker as a rose, and as the title of the Mary Oliver poem instructs, when the roses speak, pay attention. The rose image is not my own but derives from the story of four-year-old Ricky Weiss. Ricky heard his mother describing fundraising to help find a cure for her son's illness. Ricky heard "cystic fibrosis" and pronounced it "sixty-five roses." Since 1965, "sixty-five roses" has represented CF.[10] Thus, the title of this book combines the image of the rose with the importance of hearing the story told by the chronically ill themselves. I allude to Mary Oliver's poem throughout the book because it tells the tale of the roses who speak truths about what is important in life before

10. "65 Roses Story," *Cystic Fibrosis Foundation*, https://www.cff.org/about-us/65-roses-story.

falling to the ground in death. I hope you find the wisdom of the roses in this book—insights from those who have navigated life acutely aware they are dying.

Sometimes stories are told better without words. Dylan Mortimer, from Kansas City, communicates his CF story through images. He loved art since he was eight years old, which inspired his pursuit of art degrees in college and graduate school. In 2017, when Dylan's health began to fail rapidly, he needed his first lung transplant. Two years later, he needed a second transplant and received a new set of lungs. Dylan explained, "Receiving lungs is a gift that takes you out of yourself, it is very humbling." Following his first transplant, Dylan felt a desire to connect his health issues with his artistic gifts. "It felt dishonest to not bring it in in some way," he explained.

Dylan's artwork now hangs in hospitals and clinics around the country. He feels this is a way to bring inspiration to places where people most need it. He also collaborates with *CF Vests Worldwide*, a nonprofit organization that works to donate therapy vests to people in countries where they may not have access to this lifesaving equipment. When a person is sent a vest, they receive some of Dylan's artwork, which he hopes is a way to combine the "physical aim with a sort of metaphysical inspiration and hope." Dylan hopes that his art will be a "way to engage people, . . . spread awareness, and invite other people into [his] story, . . . [by] connecting [it] to their story and creating community." Dylan's narrative doesn't use words. But it tells his story.

Transformative stories can also be expressed through music. Brian McTear lives in Philadelphia, where he is a music producer, writer, and singer. He runs a widely respected recording studio called *Miner Street Recordings* and a music nonprofit called *Weathervane Music*. The mission of *Weathervane Music* is to advance independent music, art, and the communities around those who create this music. On December 6, 2019, he played his own songs at a holiday concert. Three days earlier, he began taking Trikafta. This concert was his chance for his mother and friends to hear him sing with clear lungs. "The ability to

sing in that concert I had not experienced in fifteen years," he reflected. "The clarity of my breathing [was] pristine. It was virtually overnight," he explained about the hours following his first dose. The name of his first song from that concert was "You paralyze my heart." One can only imagine how his loved ones were paralyzed in shock hearing Brian's new voice, as his unparalyzed lungs were filling and exhaling. What a gift for Brian to be able to sing for his mother, who was sitting in the front row on such a beautiful occasion. Brian's CF story isn't told as a written narrative. It is poetry put to music; the song of new life offered in a community of love.

Music may also provide a metaphor for how to read this book. Different vocal ranges, such as tenor, bass, alto, and soprano, come together to form a harmonious sound. Sometimes these voices seem to be communicating a different message, such as when a choir utilizes polyphony—simultaneously singing different lines. The goal of this technique is not to sound dissonant, but to bring out different aspects of the song. In the same way, people with CF may have very different experiences. The voices may not "sound" the same, and it may be difficult to fathom that they have the same medical condition. However, when hearing the voices communicate together, you will realize their harmony and a united message of singing for the day when CF stands for "cure found."

The Roses Speak is the combined story of many members of the CF community, a glimpse into the world of a chronic illness. It is a representation of people who may feel silenced or ignored because their medical conditions may impair their lives. I am not trying to tell *the* CF story. I am trying to tell CF stories. I invite those with conditions other than CF to see how their journey has similarities to this CF narrative. No one can tell another person's story. No one can truly know what someone else is going through. The best we can do is offer our own story to another and create an environment for storytelling. When that happens, it can be a powerful moment where we come to see the Charlie Fry in each of us.

Data with a Soul

A way to conceptualize the layout of the book is to think of your favorite movie. If someone watched twenty minutes of the climactic sequence, but not the final ten minutes of the movie, it would feel incomplete. You might see the most action-packed part or the big reveal of a mystery, but you would have no idea who the characters are, why the issue exists, or how it concludes. Yes, Trikafta has become a miraculous medication that has saved and transformed lives. It has certainly extended my life far beyond what I expected. However, a fuller picture is needed to appreciate and understand the story of CF in the gene modulator era. Plot, action, and characters develop within a setting and a history. I intend this book to give insight into the "before" and "after" of Trikafta, not just the miraculous present. Appreciating a butterfly is even more amazing when viewed next to a caterpillar.

For those interested in understanding the historical development of CF treatment from the discovery of the CF gene through the early days of gene modulators, I highly recommend *Breath from Salt*, by Bijal Trivedi. Although she does not have CF, Trivedi's well-researched work beautifully tells of the discovery of CF and the vast efforts at care development and fundraising that make gene modulators possible. *The Roses Speak* serves as a continuation of her work. I have chosen to spend less time on historical aspects of CF and CF treatment, as I think *Breath from Salt* has given that to the CF community. *The Roses Speak* focuses more on the psychological, emotional, and spiritual journey told through the eyes of those with CF.

To tell these stories, I needed to find people willing to share, while reflecting on my own story. The method for this research began by emailing more than one hundred directors of CF clinics in the United States. I received roughly thirty responses, with most centers agreeing to advertise in their newsletter. The *CF Foundation* also sent an invitation to their LISTSERV. About 20 percent of the people interviewed came from these two approaches. Around 70 percent of respondents came from the 400 people

I reached out to over *Instagram* who used a CF-related hashtag. The other 10 percent came from personal invitations to others by people who had been interviewed. These interviews occurred virtually, between February 2023 and October 2024.

I never expected how powerful these conversations would be for me. What began as research into CF and Trikafta became research into myself. As people shared stories and created spaces for vulnerability, I found myself sharing my own. I can't recall a single interview where something did not touch my own story. I had only spoken to one person with CF in my life prior to this project. Other people articulated the same form of loneliness. Researching and writing this book were gifts for me; I hope reading it is a gift for you.

During the fifteen months of writing, I was an intern and resident in clinical pastoral education (CPE). My internship was at the Cleveland Clinic, during the summer of 2023, and my residency was at Covenant Healthcare, in Saginaw, Michigan, from September 2023 to August 2024. CPE involves training as a hospital chaplain, sitting with the sick and dying, and hearing their stories. By being present in these times of vulnerability, a chaplain listens for a patient's primary unmet spiritual needs, such as fear when learning a new prognosis, loneliness and isolation, and presence during grief. Once identified, a chaplain attempts interventions, such as guidance in decision-making, reconciliation with others, or finding value in themselves.[11] I found this application for theology incredibly powerful, since I had previously taught theology. A CPE student also spends one day a week in a classroom exploring one's own story and learning tools for pastoral accompaniment. Unlike in movies, chaplains do more than pray with patients. While prayer certainly happens, chaplains also can help a patient explore their innermost feelings and motivations.

11. Michele Shields, Allison Kastenbaum, and Laura B. Dunn, "Spiritual AIM and the Work of the Chaplain: A Model for Assessing Spiritual Needs and Outcomes in Relationships," in *Palliative Support Care* (2015, 13:1), 75–89.

The level of religiosity is entirely up to the patient and the family. Hospital chaplains do not convert or proselytize. They accompany people on the journey of life and help them explore their own stories.[12]

I am very grateful that I was writing this book while learning in CPE. CPE gave me tools to recognize how the CF discussions touched my own story. I grew in my understanding of the importance of listening through the healthcare setting, helping patients to feel seen and heard through the cultivation of skills such as wondering, following, and holding. In *See Me as a Person*, one of the texts used in our CPE training, authors Mary Koloroutis and Michael Trout write, "[Stories] are ways to interpret the past and to be intentional about the future. They can help us move beyond our simple cognitive thinking into accessing our emotional feelings about situations, which can then lead us to new insights and deepen our understanding."[13]

Koloroutis and Trout cite author Brené Brown, who writes, "stories are data with a soul." Another way of conceptualizing this book is through Brown's image. Yes, it is research, and I hope it contributes to the accompaniment and caregiving toward those with chronic conditions. It is also more than research. The "data" you will read is the unfolding narrative of those who have lived with a chronic illness and how these stories are embodied by the individual's way of "wondering, following, and holding" the experience. The Latin word for soul is *anima*, from which we get the English word "animation." When a cartoon is animated, it comes alive, jumping off the page. I suspect there will be moments when this data jumps off the page and, in connecting to your story, jumps into your heart.

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12. To protect patient rights and adhere to HIPAA, stories from my chaplain experience will not contain specific names, ages, diagnoses, or identifying information about patients or family members. Some minor details may be changed as well.
13. Mary Koloroutis and Michael Trout, *See Me as a Person: Creating Therapeutic Relationships* (Creative Healthcare Management, 2012), 20.

At one of my early visits during chaplain residency, I sat with a family of children in their thirties as their mother was dying of complications of cancer and lung failure. Her family asked me to say a few words to her about the afterlife, to "reassure" her in her faith. They explained that their mother, a devout Catholic, had voiced fears the previous night concerning where she would go after her death. As my intervention, I shared words of consolation about God's love, drawing upon her Catholic tradition. She appeared able to hear me as she struggled for breath. She died a few hours later. When I was called to her room, her family asked me to offer a prayer. We gathered around her bedside, held hands, and prayed. We then sat and I invited them to share a story about her as a way to begin their grief processing. What followed was laughing, crying, and storytelling, as they remembered how much she supported each of them in her own loving way. With tears rolling down her cheeks, the daughter nearest me expressed, "I never knew sharing stories about my mother with a complete stranger could be so cathartic." Her observation beautifully encapsulated one way to deal with grief and loss and has stayed with me as one of the more powerful moments of my development as a chaplain. Those stories also helped me reflect on my life, my relationship with my mother, and the empathy I felt toward this family. Their stories were cathartic for me as well.

I hope that the sharing of stories for this book was as helpful to those who told them, as it will be to those who will hear them. I hope you will see, hear, and feel some of your own humanity, vulnerability, and fragility. Perhaps the roses will increase your empathy toward those with a chronic disease or those who are experiencing the debilitating reality of old age. Maybe you will experience hope hearing stories of the miraculous, or you might realize you are not alone sitting with stories of sadness and loss. Finally, I hope this book encourages you to tell your story. No one else can. I describe, in the diary excerpt at the start of the Introduction, when I publicly shared for the first time that I had CF. While on that high school retreat, our leaders told us, "Boldly

be yourself. There is only one of you for all time." Perhaps now I might amend the statement. Boldly tell your story. Only one person can tell it for all time.

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