

Praise for *When There Is No Cure*

“I wanted to cry just reading the table of contents. The author gets it! He understands the lonely path of those of us with chronic illness.”

—*Elizabeth, a patient with lupus*

“This is a book that I wholeheartedly recommend for fellow sufferers of a chronic disease. It takes the reader on a journey that covers many of the concerns a person with a chronic disease has—such as how you can handle your illness, how to interact with doctors, how to handle other people’s responses to your illness, and how others can help. I will use this as a guide in my journey with my chronic disease.”

—*Lisa, a patient with dermatomyositis*

“You can feel the pain of his maladies and yet the author’s powerful commitment to not allow it to affect the responsibilities of a father, a husband, or an educator. Most of all, I was moved by his heart in honestly sharing the journey that it might offer encouragement to those who find themselves similarly afflicted when there is no cure. This book should be required reading by every medical student.”

—*Edward Langston, MD, family physician (retired)
and former chairman of the Board of Trustees
for the American Medical Association*

“This book touched my heart. It is filled with practical advice and hope for patients and healthcare providers. Very pertinent and encompassing, it is filled with pearls of wisdom. This book should be on the reading list of all who care for, live with, or know individuals with chronic suffering. His journey and acquired wisdom are a reminder that people can thrive despite a chronic disorder and that indeed ‘life is more than good health.’”

—*Charles E. Sanders, Jr., MD, FACP, FACR,
rheumatologist and former vice president of medical
education and research, Mount Carmel Health System*

When There Is No Cure

*How to Thrive While Living with the
Pain and Suffering of Chronic Illness*

Craig K. Svensson, PharmD, PhD

Important Note

This book provides general guidance for living with chronic illness. It is not intended to replace or subvert recommendations from a qualified healthcare provider nor discourage patients from seeking and following medical care. Healthcare decisions should be made in a collaborative manner between you and your healthcare provider. The author is not endorsing specific treatment plans and holds no liability for decisions patients make based on this book.

Patient names and minor details have been changed to protect their privacy.

When There Is No Cure: How to Thrive While Living with the Pain and Suffering of Chronic Illness

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In memory of my mother, Teresa Svensson,
whose example of living with chronic illness
taught me many valuable lessons.

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Introduction

A trio of pathological enemies work daily to disturb any sense of normalcy in my life. Pain rarely allows me to sleep more than two hours at a time. I have been reduced to a passive observer as my wife lifts or moves something heavy to prevent me from experiencing more intense back pain. My persistent standing when others are seated has stimulated remarkable comments—at times humorous, though more often rude or thoughtless. I could not count the many vacation options we have rejected over the years because they would require far more sitting than I could tolerate.

On too many occasions, I missed important events for our children because I was stuck in the bathroom with a flare of a chronic intestinal ailment. Responding to a dinner invitation at the home of others usually results in an embarrassing conversation for me or my wife. We must either provide them with a list of food ingredients to avoid or risk having me buckled over with intense abdominal pain shortly after dinner and then quickly

checking out their indoor plumbing. Either way, people understandably often regret extending an invitation.

Rounding out the trifecta of ailments, several of my body parts emit a persistent burning pain or tingling. Standing is best for my back, but the bottom of one foot feels like it has a bad sunburn, while the other feels like it is being pricked by a thousand little pinheads. Do I stand or sit? Which hurts worse at the moment? Sometimes all three diseases conspire with one another to launch a simultaneous assault on my plans for the day. On other occasions, they take turns increasing the discomfort in my life. While these chronic conditions could overtake my life, I am not willing to surrender to their rule.

I am just one of millions who live with chronic medical conditions bearing ominous labels like systemic lupus erythematosus, fibromyalgia, multiple sclerosis, rheumatoid arthritis, and ulcerative colitis—just to name a few. There is no cure for what ails us. Pain and persistent suffering are expected parts of our future. Often the degree of both is certain to worsen as the years progress. Our illnesses are commonly invisible. The grimace with certain movements or the avoidance of other activities may be the only outward sign something is amiss with our bodies. Nevertheless, underneath the façade is a daily challenge to press on despite the discomfort. This is a well-worn path for me, and I have written this book to help others on a similar road.

The suffering brought about by our chronic illnesses can lead to dramatic changes in our lives. Activities that once brought us joy may no longer be possible.

Simple movements long taken for granted are now painful or exhausting. Body parts we have never given much thought to begin to scream for attention. The future, once so promising, seems rather bleak. Hope crashed into the hard rock of reality when the doctor said, “There’s nothing more we can do.”

You can thrive in the face of suffering brought on by chronic illness. You can know joy when parts of your body constantly rebel against their normal function. You can restore a sense of balance when illness has overturned the priorities and plans once carefully laid. But how do you do so?

I have been on a nearly thirty-five-year journey accumulating several incurable ailments. Each additional malady has brought with it a host of unwanted alterations in how I live life. But this experience has also taught me that, yes, those of us living with chronic conditions can thrive in the face of our long-term suffering. Sadly, I have seen many who do not. Often their failure to live well is not due to the incurable ailment itself but rather to their response to this unwanted companion bringing havoc to their body. We cannot control the arrival of pathological invaders into our lives. What you can control is your response to these uninvited diseases. Your response is what will determine your ability to thrive in the face of a life-altering ailment.

In my professional and personal travels across the country, I visited many bookstores and posed a simple question to the booksellers: “What book would you

recommend to someone diagnosed with an incurable, but not fatal, illness?” The frequent response was a perplexed look, sometimes accompanied by scratching the head or chin. At best, they directed me to books focused on living a healthy lifestyle—often through a diet plan of unproven value. A few pointed to books focused on a very specific disease. These invariably dealt with an unconventional and poorly supported approach to treatment. But all the booksellers were at a loss for a book that addresses the many issues faced by those of us living with incurable ailments that lead to many years of an altered lifestyle, such as:

- How do we get physicians to take our health complaints seriously?
- Where do we turn when doctors acknowledge our ailment with upturned hands and confess they don't know how to help?
- How do we deal with the overwhelming sense of loss upon receiving an untreatable diagnosis—one sure to produce profound changes in our life?
- How do we address those whose reaction to our ailment increases our suffering?
- Can we live well with inescapable pain?
- How do we avoid living in a state of fear when facing an uncertain prognosis?

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- Should we try to keep our disease a secret from others?
- How do we choose between treatment options when each could cause harm?
- How do we tell if new symptoms are from our chronic disease or signs of some new ailment?
- How do we live with regret when an ailment is a result of choices we made?
- How can those who love us help?

I address these questions in the chapters ahead.

What qualifies me to write a book on living with the chronic suffering an incurable ailment brings? I trained as a clinical pharmacist, learning to manage drug therapy for patients with acute and chronic disease. Later, I earned a second doctorate with a focus on pharmaceutical research. My own research career focused on adverse reactions from drugs. Throughout my professional career, I have educated future nurses, pharmacists, physicians, and physician assistants on the fundamental principles of drug therapy—how drugs act in the body, how to select which drugs to use for what conditions, and how to deal with side effects and adverse reactions.

In addition to my formal training and clinical experience, education relevant to this book came from being a patient myself. In the mid-1980s, I developed a rare form of colitis for which there were, and remain, no proven treatments. In 1997, I experienced a back injury

leaving me with unremitting pain that remains to this day—though less intense than the first decade. Then, in 2005, symptoms of multiple sclerosis (MS) began to emerge. Repeated relapses have left me with a variety of persistent symptoms not responsive to treatment.

My personal experience has helped me better understand the experience voiced by others. I knew of people who grumbled about the difficulty of getting healthcare providers to take their complaints seriously. I sensed their frustration and felt sorry for them. But it was not until I walked the same road and experienced these frustrations that I actually *understood* what they were saying. I heard patients express a sense of helplessness in living with the diagnosis of an incurable ailment. After experiencing and needing to deal with those feelings through my own diagnoses, my eyes have opened in a manner only experience can accomplish.

Having lived most of my adult life on a journey through an unexplainable series of such ailments, I now better identify with the troubled existence of many of my fellow travelers. Without doubt, my own experience has made me more observant of how others respond when there is no cure. I have seen the heroic and the hopeless, the resilient and the restless, as well as the defiant and the despairing. As a pharmacist-scientist, I have also watched with dismay many patients taken advantage of by charlatans making a buck off the vulnerable among us who are on a desperate quest for relief.

As I have accumulated a progressive list of incurable diseases, I have visited an impressive array of medical

specialists who investigated and prescribed interventions for each ailment. All were well-qualified professionals devoted to their calling. Still, they never spoke about the myriad ways each ailment would change my life. None inquired about or gave advice on how my ailment would affect those I lived with. Perhaps it was not their role to do so. These were all things that took time and experience to learn. I cannot recapture the time nor relive the events I now wish I handled differently. I have written to help others on their journey so they are better prepared to deal with difficult issues not often discussed—or at times poorly addressed.

I hope this work will help fellow sufferers and those who care about and for them (professionally and personally) deal with issues most health professionals don't address. Years of experience taught me things that would have been helpful early in my journey. I have written this book to help those facing a life of chronic suffering think through key issues they will need to consider—regardless of their specific ailment. I open each chapter with a vignette of my personal journey, including elements of my medical experience known to very few in my life. Personal stories are used to introduce topics because of the power of story to communicate to both the heart and the head. These experiences have also provided a strong motivation for this book. I am convinced that thriving in the face of the suffering produced by an incurable or unexplainable chronic ailment is foremost a matter of the heart. I invite you to travel through these pages with me to see if you conclude likewise.

CHAPTER 1

Avoiding the Dangerous Ditches When Living with Chronic Illness

The clock's stroke marked a new day. It began the same as every other day for the preceding six months. As usual, sleep eluded me for most of the night, leaving unabated fatigue in its place. Pain always screams loudest when everything else goes quiet. With the room still cloaked in total darkness, a slap of my hand silenced the annoying alarm. The move from lying to sitting sent a shock of greater pain in my right lower back. Showering and dressing were less painful than walking on a bed of nails, but not by much. Then came the most dreaded part of the day—getting into a blasted gas-powered torture chamber with wheels. Nothing increased my pain with such intensity as sitting in this wonderful invention gifted to us by Henry Ford. The thirty-minute drive to my office each morning

provided a workout for my tear ducts. I began to better understand the agony of Job when he declared, “I am allotted months of emptiness, and nights of misery are apportioned to me.”

Despite the physical and emotional agony, the day offered a glimmer of hope. A midmorning appointment with a renowned spinal specialist provided an opportunity to find a route to escape this persistent pain clinging to my life like barnacles on the bottom of a boat. As the hours leading up to the appointment ticked by, my hope heightened. Perhaps this journey with pain was near its conclusion. Surely, today I would get the help I needed.

“I am headed out to see a specialist. I hope he’ll have ideas for getting relief from this back pain,” I told my colleagues when departing my office. At the appointed hour, I entered the spinal clinic, grateful this specialist was only a short drive away. The receptionist scrunched her face when I declined to take a seat to wait. My time seemed less treasured than the specialist’s, for I was the only one ready at the designated hour. After sufficient time for an unwanted level of anxiousness and annoyance to emerge, I followed a nurse down the hall to a sterile examination room. She confirmed my vital signs were stable enough to survive further waiting. The mild scent of some unknown disinfectant was all that remained as she left me in a silent chamber—providing time for me to meditate on the sad state my life had become since incessant pain parked in my back six months earlier. As I awaited the spinal specialist’s

assessment of the latest round of tests, and an answer as to why nothing relieved the pain, I longed for a path to escape the neurological intruder who upended my daily activities.

No aura accompanied the specialist's entrance into the exam room—just a file containing a portion of my medical records, a report from physical therapy, and images from an MRI. After bringing him up to date on how I was doing, he gave his expert opinion. Shredding hope to pieces, his words pierced like a knife into the deepest core of my being: “There is really nothing more we can do for you. You will just have to learn to live with it.” Feeling as though he had punched me in the gut, I became overwhelmed with the urge to leave. Whatever else he said went unheard. I ignored the expected stop at the receptionist's desk on the way out. An unnatural darkness surrounded me as I walked from the clinic to my car. Tears clouded my vision as I drove back to my office after this appointment. This time, however, the tears were more from emotional than physical pain.

“Live with it.” What would this mean for my life? I sat only when it was an absolute necessity. Other than driving, sitting was a foreign posture. It hurt too much. Typing on a keyboard balanced on top of the computer monitor—which enabled me to work standing—became a new skill. While everyone else sat, constant pain required me to remain standing at meetings. I crawled up a set of stairs on my hands and knees to our bedroom each day upon arriving home after work so I could lie down. Our children took

turns eating dinner at my bedside so they wouldn't forget their father's face. My contribution to the myriad chores around our home became marginal. We canceled a planned vacation to avoid the car ride. The out-of-town funeral of a beloved family member passed unattended. Professional opportunities went by the wayside to avoid travel. What would life be like if I "lived with it"? Would it really be life?

Many Live with the Suffering of Chronic Illness with No Cure

Millions across our globe suffer with incurable ailments. Symptoms whose cause is often unknown, and whose treatment eludes the best medical minds, alter their daily lives drastically. Many are silent sufferers, their persistent agony far from obvious to those with whom they work and live life. Some live with a ticking time bomb within—dreading the next body function to go awry. Each patient has a unique experience, but all share feelings of frustration and weariness from unwelcome pathological companions who have joined them in their life journey.

The increasing life span among the general population, and our ability to aid those with declining body functions, means more people than ever are living with chronic ailments of unknown origin and/or for which there is no cure. The numbers are staggering. In the United States, two hundred new cases of multiple sclerosis are diagnosed *each week*, with almost one million people

afflicted overall. Fibromyalgia, a disease leaving patients with chronic pain and fatigue, afflicts an estimated ten million people in the US, while sixty thousand people receive a diagnosis of Parkinson's disease each year. Various forms of inflammatory bowel disease affect over one and a half million Americans. Some patients manifest an incurable ailment at a young age and face a lifetime of debilitating and/or deteriorating symptoms (for example, juvenile arthritis afflicts approximately three hundred thousand in the US). Added to this are millions living with chronic pain from injuries or unknown causes. Some estimate 10 percent of the population suffers from a medical condition resulting in a disability invisible even to those who live with them. The goal of finding preventive measures and treatments will continue to be the focused effort of some of the brightest biomedical minds. Still, what are sufferers to do while they await a helpful discovery? How does one live with an ailment when there is no cure? Not just live, but also *thrive* while living with chronic illness? How do those who care about them best help?

Some incurable diseases do not produce chronic suffering. High blood pressure most often arises from unknown causes and cannot be cured. Medications for this disease reduce the risk of adverse consequences. Nevertheless, most patients with high blood pressure do not see themselves as chronic sufferers. In contrast, diseases like multiple sclerosis are incurable and marginally controlled with medications. Most patients with this disease suffer a lifetime of pain and other

symptoms, including interference with important life activities. The experience of these two patient populations is quite different. Patients would not declare their high blood pressure to be life altering. Most patients with multiple sclerosis would. They and many others must live with the chronic suffering illness brings.

It is also true some diseases that cause few or no symptoms in the early years after diagnosis (such as high blood pressure and diabetes) can result in long-term organ injury, altering a patient's life dramatically. Even in their silent phase (where no symptoms are evident), patients may live with the emotional stress of knowing there is a disease lurking within their body with the potential to alter their life. For some, this knowledge itself causes unbearable distress.

Some incurable diseases are life threatening in the near term. Many forms of cancer present with minimal odds of defeating the unchecked growth of cancer cells, with survival often measured in months. The challenge this diagnosis presents is profound but quite different from those of patients facing an ailment whose slow destruction of body functions leaves sufferers with decades of debilitating symptoms. Nevertheless, many battling cancer also have life-altering experiences like those suffering from chronic ailments. Just as important is the reality that the most promising medical advances on the horizon will convert cancer to a chronic but controllable disease rather than bring a cure. Consequently, the chronicity of suffering in cancer patients is likely to be more common.

Health Professionals Are Poorly Prepared to Deal with Suffering

The expanding number of patients who are chronic sufferers has profound implications for health professionals. Health professionals are not well prepared to deal with patient suffering. Yet that is what affects patients most—not the laboratory abnormalities clinicians often try so hard to correct. The failure to train health professionals in this area of human experience means your doctor is not well prepared to help patients diagnosed with an incurable ailment deal with the profound impact of chronic suffering.

I learned to better empathize with patients in a high blood pressure clinic where I trained as a clinical pharmacist by entering into their experience. After I stressed the need for them to adhere to a low-salt diet, patients sometimes asked, “Do you know how hard that is, Doc?” Well, no, I did not. So, I went on a low-salt diet to learn what it was like. It wasn’t easy. But it enabled me to engage patients with greater understanding of their plight and help them address challenges they faced to accomplish this goal since I learned to overcome some of these challenges through personal experience.

In contrast, I had no way to enter into the experience of the chronic suffering vocalized by diabetic patients with nerve pain. The first patient I cared for with this condition provided an intractable therapeutic dilemma. None of the drugs we tried relieved his pain. He told me I could not imagine what it was like to experience such a sensation in your foot all the time. He was right.

I did not know what it was like to feel a tingling pain in one of your extremities 24/7/365. Decades later, my own neuropathological companion joined me on life's journey—teaching me what it was like to experience such incessant nerve pain in an extremity. It feels like someone has inserted myriad little pins, points up, into the sole of my shoe. The worst part is that I can't make it go away. So, how do I live with it? How do I prevent it from becoming the driver of my life course? More importantly—can I thrive in the face of an added source of unremitting pain?

Every person with an incurable ailment experiences life in his or her own unique way. It would be foolhardy for anyone to write a book declaring this is what *you* should do in *your* unique circumstances. Nevertheless, I am confident there are common threads in the experience of chronic sufferers that enable me to help patients see issues they must navigate in order to thrive in the face of an incurable ailment. *How* one navigates these issues will need to be specific to their particular ailment, circumstances, and values. Nevertheless, as patients, face them we must.

The Key Challenge for Those Living with Chronic Suffering

The overarching question those of us living with chronic illnesses must face is this: How do we live with the chronic suffering of an incurable ailment without becoming obsessed with it or possessed by it?

To express it as a beneficial goal, how can we thrive despite the suffering chronic illness brings? I believe answering this question will enable us to live well. To do so means we must be intentional in our response to chronic suffering. We cannot just allow life to happen. We must think through our experience and responses to those experiences with care.

Those of us who live with an incurable ailment that alters our life course must recognize the ditches on the sides of our journey's path. Many have fallen into the ditch of obsession—becoming consumed with their ailment. For these individuals, their entire life centers on finding a solution to their suffering. In their obsessive pursuit to learn everything about their ailment and solutions for it, they often drive those most important to them to the periphery of their lives. Many seem unable to think about anything but their ailment. Their affliction defines them. They assess every minute element of their experience in terms of its potential effect on their health. The desire to avoid anything causing the slightest increase in their discomfort is the driver on their life journey. These individuals lose their joy in the simplest of activities. They view everything through the lens of their ailment and demand those around them do the same.

Others have fallen into the ditch of surrender—yielding their lives to suffering. They become hermits and withdraw from experiences that make life fulfilling and bring joy. They morph into fatalists who no longer wish to press themselves to overcome the barriers their physical ailment has produced. For them, hope has disappeared

over the horizon. They define their lives by the darkness that has descended on their life through suffering.

Both ditches are easy to fall into, but neither will serve us well on the journey we call life. Neither positions us to thrive in the presence of chronic suffering. Life is more than good health. The foolish—but oft repeated—mantra, “If you don’t have your health, you don’t have anything,” represents a depressing and narrow view of life. It also casts tens, if not hundreds, of millions who lack good health onto a path of despair. It is disheartening to encounter those with incurable ailments who have surrendered to a life of despair. The truth is, many who suffer from chronic illness have found their life journey to be fulfilling and marked by abundant joy. I am convinced this path is open to all who live with an incurable ailment that leads to chronic suffering. Yes, life is different from before chronic illness. Nevertheless, different can be fulfilling.

Managing a chronic ailment can be time consuming. Keeping track of multiple medications, making and attending various appointments with specialists, fitting innumerable lab tests into our busy schedules, and seeking as much information as possible about our disease and treatment options easily makes our head spin. It can all be quite exhausting. So much so that we can forget to manage the most important component of our lives: our hearts. Avoiding the ditches of obsessing over our illness or surrendering to suffering requires intentional management of our hearts. This is what will determine whether we thrive in the face of chronic illness.