The path you'd never choose can lead to the faith you've always wanted

LORI ANN WOOD



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For the family that made me:

For my parents who introduced me to faith, grace, and resilience;
For my siblings who share my stories;
For my children and grandchild,
who give my writing urgency and purpose;

Above all, for my husband who, even when we were living the story we didn't want, always believed God really was up to something.

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Foreword

ori Wood came to my clinic seven years ago for the first time with her husband pushing her in a wheelchair. I had a sinking feeling when I met her that she would not survive, despite all my years of training as a heart failure and transplant cardiologist.

She was frail, losing muscle mass, and had a big, baggy heart with a strength of just 6 percent. Most heart failure medications decrease blood pressure. Lori's blood pressure was already extremely low, even on the minimal doses she was taking, making me wonder how I could increase them enough to make any difference at all. I had a few options that rushed through my head: I could take her to surgery for a mechanical heart, place her on the heart transplant waiting list, or I could stick with medications. After examining her, I knew the output from her heart was somehow adequate since her hands were still warm. I also knew that although I could use advanced heart failure care options, there was a slight chance her heart could strengthen and her prognosis might be even better if I relied solely on medical therapy. Was this realistic given the enormous size of her heart? I had an impossible choice to make. Unsure if recovery was even realistic, I asked if they could return to Ohio since she lived in Arkansas and my medical practice was at the Cleveland Clinic. The answer was yes, and we began our long journey together.

Throughout the years I have treated Lori, I have been drawn in by her determination to face every dark, unknown path in front of her. She has always forged ahead, wherever it led. Medical prognosis was no

match for her will to face the daunting problems head-on. She seemed empowered and even strengthened by embracing the questions.

This is the story of a brave woman, a loving husband, and the amazing cooperation and trust between her local medical team and myself. But it is also the story of undeniable direction. I am still not sure how we all met. (Some might suspect it was the luck of the draw or perhaps they somehow knew my research focus was heart failure in women.) At so many steps, the story could have taken a very different turn. Lori's diagnosis was established after multiple visits to healthcare facilities for shortness of breath and failed treatment for infection with antibiotics. By the time she went to an emergency room she was in severe heart failure with respiratory distress and kidney failure. Once admitted to her local hospital, she was given life-saving inotrope support. This treatment caused a 35-beat run of ventricular tachycardia that could easily have been deadly. She was discharged with a life vest capable of shocking her heart from outside her body. A few days later, Lori and her husband traveled to my office that first time by plane. The flight was delayed and almost cancelled because she passed out after boarding. Paramedics treated her on the tarmac and advised her not to fly. The risky decision was made by her team of doctors to continue to Cleveland Clinic because her options and chances were limited otherwise.

Every three months Lori made her way to Cleveland and between visits had amazing care by her local cardiologist Dr. Christopher Simpson who gradually increased medications based on my recommendations. In retrospect, Dr. Simpson was incredibly brave because Lori's blood pressure remained low. With time and therapy, her heart function rose from 6 percent to 16 percent but did not further improve until she had a biventricular pacemaker implanted in 2016 for a left bundle branch block. Her heart strengthened and its size shrunk significantly.

The visits to Cleveland became fewer and our focus changed. Lori wanted to be an advocate for other women with heart disease. She requested I write a recommendation letter for her to become a member of WomenHeart, a national patient advocacy group that provides emotional support, education, and representation on Capitol Hill.

How odd, we both had joined the same group for the same purpose a few years apart. I joined the scientific advisory committee for Women-Heart when they were preparing a Congressional report, *The Top Ten Cardiovascular Questions for Women with Heart Disease*. Lori independently recognized the value of WomenHeart and is now a trained Champion who assists other women with heart disease.

We have made podcasts together and developed a strong relationship which has become a great friendship. I have had a front row seat to see Lori face a difficult diagnosis and dark days up close. Through it all, I knew she was a person of faith. It is my honor to introduce to you this amazing woman. For seven years I have wanted to know what else, besides world-class medical intervention, has kept her going. Now I know, and true to her spirit, she wants to help you along your unknown path, too.

The book you're holding is a testament to the will and faith of my patient and friend. It is the culmination of several years of treatment and questions. It is Lori's gift from her heart to yours.

Eileen Hsich, MD Medical Director Heart Transplant Cleveland Clinic

Introduction

very life experiences a moment when the story breaks into two pieces: pre-tragedy and post-tragedy. When there suddenly becomes a *before* and an *after*. When the carefully planned journey takes a decided detour. This was mine.

"If we're lucky, it's pneumonia."

Our beloved family physician's words hung like thick fog in the bright exam room. Taking the stethoscope out of his ears, he led us down the long hallway to the X-ray lab.

After a week with what I thought was the flu, I had finally made an appointment with my family doctor. My husband was with me. It was Black Friday and rather than go shopping with our daughters, he opted to drive me. We had expected it to be quick and rather routine, perhaps a steroid shot at worst. We had made a bet about how soon we'd be back home that day: *Would I miss the door busters altogether?*

It would be more than two weeks before I made it home, and I would be a different person when I finally did walk through that door. I was wounded, yet on the verge of an understanding of faith that I may never have experienced outside the tragedy that was unfolding. I crossed that familiar threshold disillusioned and frightened, begging for answers to the big life questions of worry, doubt, and control.

My primary care doctor would later describe that day in his office as

the worst day of his professional career. He couldn't believe he'd missed it all those years. Honestly, the subtle symptoms didn't alarm me, and I never reported the shortness of breath, fatigue, or inability to exercise. I attributed the symptoms to "getting older," and "being out of shape" compared to my marathon-running husband. So, my physician never knew about the warning signs.

This doctor was more like an old friend or family member I saw only a few times a year. He had burned pre-cancerous moles from my back, prescribed antibiotics for strep, and delivered my babies. He knew and remembered the health histories of both of my parents, though he'd never met them. He simply loved taking care of people.

That's why it hit him so hard when the chest X-ray showed something else. Something much worse. I was diagnosed with severe idiopathic dilated cardiomyopathy, a form of heart failure brought on by an unknown cause.

For lack of a more glaring suspect, doctors assume a virus had attacked my heart. My heart was functioning at just 6 percent the day I walked into my doctor's office. I spent fourteen days in the hospital, most of it in ICU, as doctors worked around the clock to save my life. All of this despite having no risk factors, no family history, low blood pressure, low cholesterol levels, and a recent life insurance evaluation declaring I had less than 3 percent chance of ever developing heart disease.

I was flown to the Cleveland Clinic where I became my cardiologist's most critical patient for a year and a half. Later I learned that I was the sickest patient she had treated in her sixteen years as Director of the Women's Heart Failure Clinic and as Associate Director for the Heart Transplant Program at the Cleveland Clinic, the top heart hospital in the nation. Not the badge I was hoping to earn. Eventually, I was implanted with a Biventricular CRT-D, a combination pacemaker/internal defibrillator.

Thousands of people prayed for me around the clock despite a grim prognosis and sympathetic tears from every doctor we encountered. Contrary to what the rational part of my brain wanted to do, I held on

tight and trusted. Miraculously, I survived. Against all medical odds, my heart function was temporarily restored sixteen months later.

But as heart failure goes, my condition has experienced ups and downs since then.

And as the Christian walk goes, so has my faith.

My story is not fully written. Since that remarkable reversal, my heart function has dropped twice and is now stable at a lower plateau. I am learning more every year about the unpredictability of this condition. Heart failure is a chronic, progressive disease. There is no cure. For most, medical science can manage the symptoms. For some, they can slow the progression. Doctors believe I will likely need a heart transplant in the future.

I still struggle with questions, almost daily. But rather than seeing them as a threat to my faith, I see them as a lifeline to keeping it.

The post-diagnosis years have taken me on a faith detour I never saw coming. As a longtime believer, I felt profoundly disappointed. I wanted answers, but more importantly, I needed permission to ask the questions.

This forty-day book is a result of my pursuit to embrace the questions and navigate the desert I've found myself in.

In Scripture, the number forty represents trial or testing. Moses fasted forty days in the wilderness, the Israelites wandered forty years in the desert, Noah survived forty days and nights in the flood, Elijah suffered forty days without food or water at Mount Horeb, the spies spent forty days scouting out the land of Canaan, Jonah warned that in forty days Nineveh was approaching doom.

Perhaps the most well-known forty-day period is the one Jesus endured in the desert before beginning his public ministry, described in Matthew 4:1–11:

Then Jesus was led by the Spirit into the wilderness to be tempted by the devil. After fasting forty days and forty nights, he was hungry. The tempter came to him and said, "If you are the Son of God, tell these stones to become bread."

Jesus answered, "It is written: 'Man shall not live on bread alone, but on every word that comes from the mouth of God."

Then the devil took him to the holy city and had him stand on the highest point of the temple. "If you are the Son of God," he said, "throw yourself down. For it is written: "He will command his angels concerning you, and they will lift you up in their hands, so that you will not strike your foot against a stone."

Jesus answered him, "It is also written: 'Do not put the Lord your God to the test."

Again, the devil took him to a very high mountain and showed him all the kingdoms of the world and their splendor. "All this I will give you," he said, "if you will bow down and worship me."

Jesus said to him, "Away from me, Satan! For it is written: 'Worship the Lord your God, and serve him only."

Then the devil left him, and angels came and attended him. (NIV)

Satan's whispers during that foray into the desert were meant for more than just a good Bible story. Those whispers continue to echo through the deserts every believer will face in this life. And they manifest in deep faith questions.

My story involves a testing period as well. I have spent some time in that desert. But I have also had my hand directly in the hand of Jesus during these days, as One who knows the territory personally. In fact, as I live and learn through my chronic illness, my journey has been surprisingly parallel to the questions Jesus wrestled with during his forty days in the desert. I suspect yours has as well, regardless of which detour you have trekked.

When the Enemy tempted Jesus to turn the stones into bread to satisfy his physical hunger, he was whispering something to Jesus that he often whispers to us in our physical suffering: Survival is most important. Do whatever it takes to make sure you are comfortable in this life. Nothing else is guaranteed but what you can see and feel and taste here.

Our immediate concerns matter most. As believers, we are left with a Question of Worry. Question #1: Is this life all there is?

Then Satan tried the second whisper, bending down to Jesus's ear and to ours: Jump and see if God will suspend natural laws to save you. God will catch you if He loves you. He won't let you get hurt. A good God won't let His child suffer. If He does, He must not care. We struggle with the Question of Doubt. Question #2: Is God always good?

Finally, Satan asked Jesus to worship him instead of God in exchange for wealth in this life. The Enemy has whispered that lie to many of us. Your life plan is at least as good as God's, probably better. Besides, you don't have to be all-in with God. You can still run your part of the show. We come face to face with a Question of Control, especially when we end up in the desert. Question #3: Is God's plan enough?

These whispers of the Enemy can hound us in our tedium, or they can haunt us in our trials. Either way, these three questions must eventually be addressed. Just as the Spirit led Jesus into that dark desert to be tested, it is part of the plan for us to be tested as well. It is a faith-building gift God allows in every Christian: the opportunity to question, to engage our belief, and to choose Him again and again.

This book contains forty essays to spur your own encounter with these three life questions.

Though my journey through the desert is not yet complete, the detour is now the expected route. My everyday faith is tempered by knowing that He doesn't always behave like I want Him to. However, God's abundant grace encourages my questions along the way. And more importantly, His Spirit never stops pursuing my inquisitive heart.

Forty is trial, but God never leaves us in our trials. Forty also indicates deep transformation is coming. Forty signifies God's environment for change. Forty represents a new set of instructions for a new phase in life. Forty is testing, but it is also fulfillment, of plans and promises, long-suffered and hard-fought, that have come to reality. The most celebrated end to a forty-day period happened forty days after the resurrection. The restored Jesus ascended as hundreds, maybe thousands, of new believers celebrated His earthly existence, a job

well done, and an eternal homecoming. The same Jesus who faced the forty days in the desert encountered Glory on the other side of another forty-day period.

This is our God. The God who comes full circle from testing to triumph, never leaving us with a story unfinished. While these forty essays represent forty days, they don't have to be forty consecutive days. Take whatever forty "days" you want, over whatever period feels right. Each of us will wrestle with these questions at a different pace. I pray these forty days, however you choose to encounter them, will help you confront the three life questions and move you toward your own triumph, on a journey deeper into the heart of our amazing God.

A NOTE ABOUT FORMAT

The book you are holding is not a chronological memoir of my heart failure journey.

Instead, you will find forty stand-alone story-driven essays, organized among the three life questions. Jesus used stories to deliver His most important lessons. Jesus knew we figure out life in short bursts, in single scenes, in sound bites, rather than in novel form. He knew that's how we encounter faith as well.

As you read through these essays, you will find different parts of my story (and related journal entries) sprinkled among the three questions. These story fragments will not necessarily appear in the order they occurred. This is by design.

While life is lived on a linear timeline, faith is not developed in the same way. It's not how I've grasped hold of belief, and I'm guessing it's not the way you have, either. In this book you will find the Question of Worry may include events relating to my early diagnosis, my eventual device, my sudden improvement, my subsequent downturn, and my lower plateau. The same with the other questions, Doubt and Con-

trol—I confronted each question in all parts of my journey. I never want to give the impression that a question is resolved and tabled, and that we move on to other "higher level" questions. Instead, as believers we face the same three questions throughout life. We tackle Worry only to question it again and again.

To be honest, it seemed at first logical and tidy to detail the events in order and label the sections with the alliteration, *Diagnosis*, *Device*, and *Downturn*. Then I realized this book has always been more about developing your faith than about detailing my medical events. I hope this format speaks to you and gives you permission to continue questioning, in all three areas, wherever you are along your own divine detour.

Take hold of your uncertainties. Let's step out together in inquisitive faith. I'm with you on this journey.

A Question of Worry

Days 1-13

Jesus's Desert Dilemma

"The tempter came to him and said, 'If you are the Son of God, tell these stones to become bread" (Matthew 4:3 NIV).

What We Hear

My top priority is my immediate physical need.

Life Question

Is this life all there is?

A Season of Grief and Gratitude

My older sibling laid the harsh words on me early one Christmas break. I was a little unclear about what I had done, but I knew it was bad, and this faux pas had created a big loss. We could no longer be friends. Ever again.

Crushed, I did the only thing my five-year-old self knew to do, the only thing that was in my control at the time.

I ran away from home.

I packed my Holly Hobbie suitcase with a handful of saltines, two pieces of leftover Halloween candy, and three carrots to balance it out. Then, grabbing my coat, I headed to the most desolate and private place in my known universe: the pasture next to the house.

As I walked deeper into the dry landscape, I noticed a structure in the distance and hatched an idea. I climbed the cold metal steps to the top of an oil storage tank that sat in the middle of the pasture. Pretending it was my own house, I unpacked my suitcase and set up my kitchen. I felt self-sufficient.

Aside from a few Angus steers, I was totally alone. Or so I thought. As I turned to glance back nostalgically at my not-so-distant child-hood home, a truck barreled toward me in a whirlwind of dust.

I imagined it was Dad, coming to rescue me or beg me to reconsider.

It wasn't.

Instead, an oil field worker arrived, unwelcome, at my new residence. He scolded me, warned me of certain injury or possible death, and threatened to tell my parents. In deep fear and a tinge of humiliation, I packed up and headed home.

Even in the glow of the freshly decorated Christmas tree, I felt the scowl of the offended sibling across the table that evening. Grateful to be back with my family, out of danger (and out of trouble), I was still feeling the grief that took me there in the first place. I struggled with that mix of feelings the entire holiday. It was a difficult place to be.

GRIEF MIXED WITH GRATITUDE

Following that runaway incident, I lived in the tension between grief and gratitude. Many live in this tight space, holding both in equal measure. Sometimes the whole world has felt too heavy. At least mine has:

Grief for the loss of both parents within four months.

Grief for the loss of a quarantined year that seemed to evaporate from my certainly shortened life.

Grief for graduations, gatherings, hugs, that should have been.

But alongside my grief sits a corresponding helping of gratefulness:

Gratitude for extended family and understanding friends, for feeling alive at the far end of a harsh prognosis.

Gratitude for the existential push to start pursuing a delayed dream. Gratitude for God-given medical expertise.

I am perplexed to feel both emotions so strongly; it seems almost hypocritical. But I am also struck that the things I am most grateful for reflect what I am grieving deepest. Just like that attempted move to the pasture.

Francis Weller says it is possible and even beneficial to experience both grief and gratitude, "The work of the mature person is to carry grief in one hand and gratitude in the other and to be stretched large by them."

Grief and gratitude are not an either/or proposition. We can be grateful and still be grieving. One was never meant to negate or supersede the other.

GRATITUDE NEEDS GRIEF

Grief and gratitude can coexist, and maybe they have to. Maybe we can never appreciate fullness without loss. Maybe they are actually partners in bringing the realization of God's mercy into our hearts.

"Grief and gratitude are kindred souls, each pointing to the beauty of what is transient and given to us by grace." —Patricia Campbell Carlson

It's the human condition. Songs have been sung about it, poems have been penned about it, and hearts have been hurt by it. You don't know what you've got until it's gone. Health, family, grand plans. As I get older, I am increasingly grateful for all those things that go missing because their absence reminds me of how blessed I am to have had them at all.

"It is the gift of grief, the price we have to pay for relationships and the deep love for those we have lost, that makes it possible to be grateful." —Adam Rabinovitch

My journal entry while I was first in ICU:

After the dust settled on the immediate life-saving measures, I learned that, by medical opinion, I likely will not live five years. Statistics say 50 percent of people with any type of heart failure die within five years. For those with a BNP at the drastic level of mine, only 50 percent survive ninety days after being released from their initial hospital stay. Ninety percent of those die within a year. It's as if I'm standing outside the window of my own life, and it's not a pretty scene. My numbers are so bad and my chances look even worse.

The future is still not any clearer than it was that day in ICU. It's not how I hoped it would be, but I'm thankful for what it is. And acknowledging that never discounts the grief for the way I wish things could be.

One year represents 20 percent of the life expectancy I'd been given. Woven into one twelve-month segment were the perfect opportunities to talk deeply with my dad as I sat at his hospice bed, and with my mother, my siblings, and my children, as we planned then processed funerals. Without the losses that were part of that year, none of that would have happened.

FEELING SEEN IN OUR GRIEF

So much of our lives can be summarized by a statement Jesus made. "You do not realize now what I am doing, but later you will understand" (John 13:7 NIV).

Jesus's own mother must have felt this too.

Young, unwed Mary expecting the Savior of the world was surely grieving the loss of her planned life and guarded reputation. "How can this be?" (Luke 1:34 NKJV).

For all of us managing our expectations, grief comes in the confusing, challenging, "not realizing" phase. And it can be a lonely place to be.

If we feel alone and unseen, grief can become polluted with self-focused guilt and regret. (I secretly wanted *someone* to notice I was missing from the house that half-hour I was in the pasture. Otherwise, what would be the point?)

But if we feel seen, grief can be felt and processed in light of a bigger picture. And gratitude can emerge from that dark place. Even when we're living the story we didn't want.

Mary felt seen by her cousin Elizabeth and wrote a song of praise and thanksgiving, "The Magnificat," just weeks after the shock of the angel's baby announcement. "My soul glorifies the Lord, and my spirit rejoices in God my Savior, for he has been mindful of the humble state of his servant" (Luke 1:46–48a NIV).

These post-diagnosis years, difficult as they've been, I have felt seen. By my family, my friends, professionals in the medical field. But most importantly, by *El Roi*, the God Who Sees. And it has made all the difference in how my grief has held space for soul-soothing gratitude.

Author Kelly Buckley writes about grieving with gratitude. "Gratitude does not change the pain of the loss. But it does alleviate some of the suffering." Indeed, with the help of community, it has.

Running away to the pasture, it was easy to get back. But so much of that was pretend, and most of what we're now living is not. Still, that grief we are carrying into a new season, or trying to escape as we head into a new year, can be the truest springboard to gratitude.

And it all starts by being seen in our grief. Maybe first by a fellow sufferer online or a quarrelsome family member, or even a stranger in an oil truck.

But ultimately, by our good and gratitude-worthy God.

Soft Endings

he summer after second grade, I wanted two things more than I wanted to breathe: to finally attend overnight 4-H camp like my older siblings, and to own a miniature dachshund. In the '70s, they both cost about \$35, which was a chunk of change. I knew it, and my dad knew it, so he said I could have my choice.

Of course, I chose the dog.

She was perfect. Tiny, tan, smooth, and wiggly. Missy and I had the best summer together. But inevitably, summer ends and third grade calls. About a week into the new school year, I was running late. I usually played with Missy for about fifteen minutes each morning before I left. I still didn't have my routine down of feeding Missy, feeding myself, and catching the 7:10 a.m. bus. Feeling rushed, I knocked Missy down with my shoe when she wanted to play. I grabbed my jacket and headed out the door, ignoring her sweet, pleading eyes.

That afternoon a message came from the office into my third-grade world via the intercom box above the classroom flag. The secretary's garbled voice relayed to my teacher that my dad was there to pick me up. I knew that was not a good sign. We lived seventeen miles from town, and Dad didn't casually drop by my school in the middle of the day. Immediately, my mind went to the worst thing I could imagine. I walked toward the office. *God, please don't let this be about Missy.* I crawled into Dad's pickup and squeezed the worn vinyl seat. *God, please don't let this be about Missy.*

But it was. She had been hit by a car while I was at school.

UNEXPECTED LASTS

My nine-year-old soul was crushed.

I regretted that our final encounter wasn't a happy one. Mostly, I remember being sad that I didn't know it was the last time I would see her.

That was my first taste of the reality James described as a fog that appears for a brief time and then evaporates. "Why, you do not even know what will happen tomorrow. What is your life? You are a mist that appears for a little while and then vanishes" (James 4:14, NIV).

Moments evaporate, without fanfare, without warning.

So much of life just slips away from us.

I didn't know the last time I rocked a child to sleep, the last time I received a colored picture from one of my children, the last time my son said he wanted to marry me, the last time I heard a child sing on stage, the last time I saw a daughter's softball pitch, the last time I saw my mother's smile. They all slipped away quietly, unassumingly, with me never suspecting the gravity of the moment. I also never knew my last mission trip to Mexico, the last time I sprinted or ate restaurant food without fear of sodium overload. And I never knew the last time I'd wake up carefree and not think instantly about my heart.

These soft endings were not endings until they were deemed so by future events.

Other endings are more expected. Your child's high school graduation is a door you see coming for eighteen years. Retirement, moving from a house, a daughter's wedding, my dad's last days battling cancer, all bittersweet moments that come at you with warning. These hard endings may be more difficult in the moment, but more easily accepted in the long run.

The soft endings, the unexpected ones, the ones that were not endings until the time had long past to appreciate them as such, are the tough ones for me. Life itself can be a soft ending. But like at an auction, I thought I'd hear "fair warning" before the gavel fell. Now I realize you usually can't count on that.

REMOVING REGRET

Our good God designed much of our existence as soft endings. He didn't want us obsessing over these very beautiful, but very human lasts. We can live captive to hard endings, which will always leave us bound to regret on the soft ones.

And regret can be a powerful force.

From my journal:

Heard some hard news today from doctors: My heart function is "abysmal," even for someone with heart failure. But that's not the worst part. Apparently, the heart is the only muscle that can't heal. It is one of the least renewable tissues in the body. Though meds and certain devices can help, the heart can't repair itself. So apparently, this is forever.

I have mountains of regret for not going to the doctor years ago when my husband first suspected something was wrong. Caught in its early stages, heart failure has a much better outcome. He urged me for years to get evaluated. I didn't want to be labeled a "hypochondriac." Now I felt more like the poster child for "Don't Be An Idiot."

I feel like I've failed my children and my family. I'd do anything for a do-over.

I had to move past that. And grace was my only way forward.

Early on, I learned that regret and grace can't be roommates.

My overdue diagnosis has taught me that grace is a big deal. Grace is the root of Christianity—if we can't embrace grace, we can't live in faith. For far too long, I wanted to believe in Him, and yet not accept that I needed His grace. Turns out, I was missing something big. As John Piper says, "Grace isn't just pardon, it's power."

Grace is God's perfect plan to bring all of His children home. But fully internalized, it is also a way of living this life until we get there.

Grace allows us to take risks with our faith and invest fully in imperfect people. And, perhaps most miraculously, it urges us past regret by extending God's costly pardon to ourselves.

We can't foresee soft endings. Eventually, everything we have here will disappear like morning fog, gone before your lunch hour. Mean-

while, we can only live as fully as this broken life allows. And rest in grace for the times we miss it.

Even when soft endings catch us off guard.

Especially when a sick heart (or a perfect dachshund puppy) is involved.