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HOPE AND ENCOURAGEMENT FOR

THOSE JOURNEYING THROUGH CANCER

GOD

meets us in our

Suffering

ROLF A. JACOBSON

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Diagnosis

Dealing with the Disorienting News of Cancer

When I was well, I said to myself,
"It won't happen to me."
By your grace, O LORD,
you made me as healthy as a hill.
Then you hid your face;
I was terrified.
—Psalm 30:6–7 (our translation)

ROLF (1980)

I was just coming out of what I was hoping was the worst part of my life—junior high. If you ever hope that you might experience reincarnation, just remember those two words—"junior high"—and realize that God doesn't reincarnate us

because God is good. Our family had moved just before I started junior high, and those years weren't the greatest. But as I started tenth grade, I felt like I was finally getting established in the town of Northfield, Minnesota.

The previous summer, my sister Anne and I had biked on a four-day trip. Day 1: Northfield to Hudson, Wisconsin (about 60 miles, the way we went). Day 2: Hudson to Amery (about 45 miles). Day 3: Amery to River Falls (about 45 miles). Day 4: River Falls to Northfield (about 45 miles). We were supposed to make Northfield, anyway. But about 15 miles from home, I couldn't go any farther. My right leg hurt, and my stamina was gone.

A couple of weeks later, I went to tennis camp. The tennis part of the camp went pretty well. I played well, my game developed a great deal, and I was even awarded the Most Improved Player trophy. (In the words of Bill Murray's character in the movie *Stripes*, "Who could develop more than me? Talk about massive potential for growth!") In the mornings at camp, the students could go on a run with one of the counselors. I had never been fast, but I always had stamina. But I couldn't keep up with the other kids. By the end of the run, I was half a block behind. My stamina was gone.

End-of-summer chores around the house left me tired and in pain. My siblings thought I was lazy and a quitter, but the pain was real enough that I went to see our family doctor, Dr. Halvorson. Twice—once in August and again a month later. It turns out sarcoma—the type of cancer that was developing in my leg—is rare enough that most family physicians will never encounter a patient with it in their careers. And, as it turns out, it would have been impossible to detect even via a CT or bone scan at that point, even though I had symptoms.

Our doctor prescribed exercise. I was neither lazy nor a quitter, so I applied myself to exercise for over two months.

On Sunday, October 26, along with over thirty fellow tenth graders, I stood at the front of the sanctuary of St. John's Lutheran Church and confirmed my Christian faith. The Lutheran church teaches that God says yes to us in baptism. At confirmation, we say yes to God's yes. I still have a note that my godfather, Jim Limburg, wrote to me at my confirmation: "You've made a fine start on your life—we wish for you God's blessing in the years to come."

On Sunday, November 16, I was tossing the football in our front yard at halftime of the Vikings game. It was a peak-beautiful, fall day in Minnesota (you can look it up). The air was warm but dry. Dr. Halvorson lived next door and was gardening in his yard. My dad called him over to look at my leg, which was still bothering me. He took one look at my femur, which now had significant swelling, and said with alarm, "It didn't look like this before. Come see me again tomorrow." After the game, my parents went out for dinner. The Vikings beat Tampa Bay 38–30 (you can look it up).

I was home alone when Dr. Halvorson knocked on our door a couple of hours later, asking for my parents. I told him they were out for dinner in the Twin Cities with my aunts and an uncle. He said, "Get in my car. We are going to the hospital. I want to get an X-ray of your leg."

It was a different world in 1980. Parents would let a nineteen-year-old girl and her fifteen-year-old brother go on a four-day bike trip by themselves. Doctors could have a kid X-rayed without the consent of either his parents or the insurance company—as I remember, Dr. Halvorson operated the X-ray by himself.

My parents returned home around midnight. Dr. Halvorson had been watching for them and was knocking on our door before they even sat down. My parents got me out of bed. Holding up an X-ray over a living room lamp, Dr. Halvorson explained that I might have a tumor in my leg. He had called the Mayo Clinic in Rochester, Minnesota. They were expecting us first thing in the morning.

By the end of a day of medical tests on Monday, I was exhausted. My stamina was gone to the point that I could barely stand in the elevator. Late in the afternoon, I met Dr. Frank Sim for the first time. He walked into the little consulting room on the fourteenth floor of Mayo, followed by a small army of medical students, residents, and visiting surgeons from around the world. After making introductions, he jammed an X-ray into the light screen and pointed. I'll never forget his words. "We have a problem. This is cancer. Tomorrow, we will check him into the hospital. First thing Wednesday morning, we will amputate his leg and this boy will live a normal life." I can still hear the ringing silence that ensued. (He clearly didn't know me; if he did, he would never have said that I would live a normal life.)

More discussion followed, led by my dad. My dad will tell you that I hated it a little bit when he asked doctors questions. He is wrong. I *hated it a lot* when he asked doctors questions, even if they were good questions. What kind of cancer do you think it is? *Osteosarcoma (bone cancer)*. Why amputate, why not just cut the tumor out? *It doesn't work*. What caused this cancer? *We don't know.* And so on.

We were sent to see the oncologists next. Oncologists—aka, doctors with feelings. They explained that surgeons weren't always right. There was a chance that it wasn't cancer.

Even if it was cancer, there was some good news. There was no sign of cancer anywhere else in my body, especially in my lungs, which is where osteosarcoma spreads. So there was no need for chemotherapy at the moment. (Spoiler alert: The cancer had already spread to my lungs. The dozens of tiny tumors in each lung simply weren't large enough for a Jimmy Carter–era CT scan to detect yet.) They sent in the social worker next—Carol.

On Wednesday, November 19, they amputated my right leg above the knee. The last thing I remember of that day was lying on a gurney, waiting to be wheeled into surgery, visiting with a fellow who was also awaiting surgery. When they came to get me, he said, "May God bless you."

And you know what? God has indeed blessed me. The whirlwind diagnosis and amputation were a staggering blow. The discovery the following April that the cancer had spread to my lungs was a further blow (more on that in a later chapter). But the innumerable blessings that flowed my way through so many people in the months and years since then have been mind-blowing. Those blessings have come through so many people. My immediate family and my (almost) innumerable extended family. Our church—especially the members of American Lutheran Church Women of St. John's Lutheran Church. My teachers and coaches. My musical mates. My friends and my friends' parents. (Shortly before my mom died, someone asked me what was the key to winning my war with cancer. My mom piped up, "Great friends!") Our neighbors and the wonderful love of many townsfolk in Northfield, Minnesota.

MIKE (2022)

On Friday, January 14, 2022, I was doing what every pastor I've ever known absolutely *loves* doing: a high school youth lock-in. Not surprisingly, over the course of that evening I experienced some stomach discomfort—who wouldn't experience some "stomach discomfort" after an evening of pizza, chips, pop, and other youth favorites?! So, I paid it no mind.

As the evening wound down, I retired to my pallet rolled out in a corner of the church's fellowship hall, knowing that, whether the kids slept or not, I was in for a long night. For the past two weeks, since my wife Kari and I and our young adult children had spent the Christmas holiday with her family at her folks' lake place outside Aitkin, Minnesota, I had been experiencing some lower-back pain. But I had dismissed that pain. I attributed it to sleeping on a middling mattress, rather than the lovely mattress we have at home. So, *both* the stomach and back discomfort that evening at the church were not promising factors for a good night's sleep, never mind whatever hijinks the youth had up their sleeves. But again, I paid that back pain no mind. (Detecting a pattern here?)

The next morning, I cooked breakfast for the youth to wrap up the event, helped with cleanup, and spent a couple of hours in my office to prepare for the next day's Sunday service, before heading home. By the time I returned home, the night's stomach discomfort had morphed into occasional waves of sharp pain. Darn kids and their junk food. But as the evening wore on, the pain increased, and each wave increasingly sharpened, enough that by supper time I had to admit to Kari: "I think I'm going to have to have you get me to the emergency room." As we headed to the car, I experienced a

wave of abdominal pain like I had never encountered before. It dropped me to my knees and took my breath away. There was no room for not paying any mind to this.

After I checked in at the ER, a bout of diarrhea seemed to relieve the pain—darn kids and their junk food. But, since we were there, at Kari's insistence (I was ready to go home) "we" decided it was best to get this checked out. The ER doctor began to examine me for what he thought could be possible culprits: gallbladder, appendix, kidney stones. Nothing in my blood or urine labs indicated any of these. And, since the pain had subsided, I was discharged with the advice to check back in with our primary care provider.

Which was fortuitous. Unbeknownst to Kari, I had already scheduled an appointment for later that week. Since around Thanksgiving, I had noticed a small lump on the right side of my neck. I had been battling cold symptoms (but not COVID-19) off and on throughout the fall. I thought the lump must just be an inflamed lymph node like anyone might have when one's body is battling an illness. Little did I know I was only partially right. But with the Advent and Christmas seasons looming, I paid that little lump no mind. (Yeah, definitely a pattern.) But since the lump never went away and seemed also to grow some, I thought it best, without saying anything to my spouse, to make an appointment to have it checked.

On Thursday, January 20, 2022, I went in for that appointment. Our physician's assistant felt my neck. She pressed on my abdomen and back. Looking at my blood and urine labs, she had some pointed questions about family health history, with one question in particular bringing me up short: Any occurrence of lymphoma or other blood-related cancers? My

sister Kristen is a Hodgkin's lymphoma survivor. (Turns out, there is no family-history correlation at all between Hodgkin's and non-Hodgkin's lymphoma—I was simply about to "win the lottery.") But in my health-care provider's mind, the things to which I had paid no mind were all related. So, an ultrasound was scheduled for that very day for both my abdomen and neck, with a follow-up appointment scheduled for Friday to read the results. The ultrasound revealed enlarged lymph nodes in my neck, chest, and abdomen. The latter, being in very close proximity with my right kidney, were the likely culprit of what I was reporting as "back pain."

The next-day follow-up with our physician's assistant led to a recommendation for a CT scan with contrast dye just to find out the extent of these swollen lymph nodes. That appointment came the following Monday, January 24—we were fully a week into this sudden and strange ordeal.

Beginning with that CT scan, I had to learn to deal with the embarrassment that was part and parcel of some of the procedures. I had to learn to either laugh or cry—so I did my best to laugh. The CT tech told me that when the dye was administered, I would begin to feel an "unusual warmth" that would begin at my shoulders and progress through the rest of my body, ending in my "groin and behind area." What the tech didn't tell me is that there were two *very specific* areas in my groin and behind—a little nugget of knowledge over which Karl and I were later able to share a laugh!

Before I had even returned home, I had the results of that scan on my handheld device that doubles as a phone, results not wrapped in medical speak: "suspected lymphoma" located (or "diffused") throughout my neck, chest, and lower abdomen. The next procedure would be an ultrasound-guided

needle biopsy to tap into one of the swollen nodes, which would tell us much more about what we were dealing with.

With all this news, information, and questions swirling, I was given an opportunity from two of my most trusted friends and confidants, Karl and Rolf, to join them and their dad, Del, for a couple of days of good food and drink at Del's cabin on Mule Lake near Longville, Minnesota. The needle biopsy had not been scheduled yet, and there was a good chance the call could come while I was at the cabin. After a couple of days with my pals, sure enough, the call came: biopsy scheduled for Thursday, January 27. The biopsy revealed, indeed, stage 3, diffuse large B-cell non-Hodgkin's lymphoma.

The only other wrinkle in this part of the saga was, it turns out, there is no such thing as "just" non-Hodgkin's lymphoma. The next step was to determine the genetic labeling of my lymphoma, not only to determine its particular flavor, but more importantly to figure out what treatment offered the best response. That was when I met Dr. Hani Alkhatib, an oncologist with CentraCare based out of St. Cloud, Minnesota: "We will be treating you not just for remission—which is our first goal—but for a cure." That was on Monday, February 7. "It takes us a while to do that genetic tagging," he concluded.

Unfortunately, or fortunately—I'm not even sure if either of those words is appropriate—on Wednesday, February 9, I encountered another bout of that abdominal/lower-back pain that first put me on this journey, this time worse than before! A second of what would become numerous trips to the ER ensued. It was suspected that my swollen lymph nodes were even more swollen, pressing on things not normally pressed,

and causing me all this pain. A bed space was procured at the St. Cloud hospital, and without the genetic tagging in hand, Dr. Alkhatib, thankfully, ordered the start of my first round of chemotherapy, a cocktail called R-CHOP: rituximab, Cytoxan, hydroxydaunomycin (doxorubicin hydrochloride or Adriamycin, affectionately called "the red devil"), Oncovin (vincristine), and super-high doses of prednisone. Dr. Alkhatib was confident this initial round of chemo would immediately shrink my lymph nodes and bring relief, and once the genetic tagging came back, we would know if we needed to change cocktails. He was right. On Friday, February 11, I was discharged from my first round of chemo pain free and with the lump in my neck almost gone.

On Thursday, February 17, I returned to the Coborn Cancer Clinic for a follow-up with Dr. Alkhatib. The genetic tagging indicated my flavor of lymphoma required a more targeted version of chemo going forward, a cocktail called R-EPOCH—same as R-CHOP but with an additional drug in the cocktail, plus a chaser called methotrexate, which crosses into one's spinal cord to make sure there aren't any rogue cancer cells camped out there. Recurrence, if/when it occurs, often shows up in the spinal cord or brain.

Thus began what would become five five-day in-hospital R-EPOCH treatments and three more three-day in-hospital treatments of methotrexate (interrupted once by a weeklong COVID bout, just for fun).

Through it all, I encountered—even in my suffering, or perhaps because I was suffering—the presence of God through Christ Jesus. Martin Luther used to say that in Holy Communion the body of Jesus Christ is mysteriously present "in, with, and under" the bread and the wine.[1] At the lowest

point of my cancer and chemotherapy, I experienced Christ as present in, with, and under the suffering—I *encountered Jesus* there. This encounter occurred through the efforts, well-wishes, cards, meals, phone calls, and visits from my family. Through the congregation I was serving at the time, Trinity Lutheran Church in Princeton, Minnesota. Through my friends. Through the medical staff associated with the CentraCare system. God promises to meet us in the cross, in suffering. Because of my experience of Christ's presence in the very part of my life when it felt like God was not going to be present, but was, this has meant for me an expansion of my faith's imagination to be apprehended by and met by God, through faith, in these other ways by my family, my friends, and more.

KARL (2022)

To paraphrase our mutual friend Hans, "2022 can go straight to hell." It was Wednesday, February 16, 2022—three weeks after Mike's biopsy. When we'd been together at my dad's lake place and I'd complained about some back pain of my own, Mike's unspoken thought at the time was, "Oh no, he's got it too."

I'd been having back and chest pain for a while. I'd had one virtual visit with a doctor, which ruled out heart issues (this entailed lots of going up and down stairs at home, getting the heart rate up, and so on, which my dog loved supervising). I had a follow-up appointment scheduled for an in-person visit on Thursday afternoon. That Wednesday night I had the worst night of sleep I'd ever had: pain, shaking, and vomiting

(due, my doctor later told me, to the pain in my back). My wife, Angela, was on sabbatical at a remote mountain retreat in the Cascade Mountains of Washington, and I had our three daughters at home. Thursday morning, I asked my stepdaughter Nora (the only other driver in the house) to get her sister Claire and her stepsister Lucy to school so that I could go to urgent care right away. I said that I'd see them later in the afternoon. I didn't get home for a month.

After some blood work at the urgent care, they sent me to the ER at Regions Hospital in St. Paul but told me that I couldn't drive myself, since I apparently had neither blood pressure nor white blood cells. I called my brother Rolf, who lived and worked nearby, and he drove me to the ER. By noon, I'd had a bone marrow biopsy, and I'd received an initial diagnosis of leukemia. They said, "We suspect you have leukemia." I asked, looking for clarification, "So, you're going to test for leukemia?" Rolf answered for the doctor (Rolf will answer for anybody), "Karl, they're telling you that you have leukemia."

Toward the end of the day, Rolf asked a doctor, "Is Karl staying here tonight?" The doctor replied, "He isn't leaving here for a month!"

The general diagnosis was expanded to B-cell acute lymphoblastic leukemia (ALL), with the added bonus of being positive for the Philadelphia chromosome—a genetic mutation due to which parts of two chromosomes (numbers 9 and 22) break off and switch places, before reattaching. Philadelphia "positive." Right. "City of brotherly love." Uh-huh. I'm still not over the Vikings versus Eagles 2018 NFC title game. Words like "Philadelphia" and "positive" could go the way of 2022.

The goal was to treat to "first remission," killing as much of the leukemia as possible, after which a bone marrow transplant (BMT) would be the only path to a cure. A transplant is not done unless the cancer count is less than 5 percent of one's blood cells. As my doctor said, "You gotta be below five. Four would be okay. Three would be better. One would be better still. What we'd really like is zero, 'cause zero is best." (Zero percent cancer is better than 5 percent? Really?! Shocking what medical school will teach you.) So, treatment was chemotherapy, which included spinal taps (now more often called "lumbar punctures," because that's less scary, and less B movie) to introduce chemo medication into the spinal fluid prophylactically in order to prevent the leukemia from settling in the spine and brain. All of this took place over the course of three months, some inpatient, some outpatient.

After the first round of treatment, I was in line for a clinical trial, something called CAR-T treatment, which is an immunotherapy that teaches one's T cells (lymphocytic cells that fight infections/disease) to bind to cancer cells and kill them. This would reduce my "residual disease" to as close to absolute zero as possible, in preparation for the BMT.

But blood work in preparation for the trial showed that the flavor of leukemia I had wasn't actually ALL, but CML—chronic myeloid leukemia. How could that be? Was it a secondary cancer? Was it a misdiagnosis? No, as it turns out, it was a change. As it happens, ALL can, sometimes, in very rare cases, transform into CML. This happens in about 1 percent of all ALL cases, which made me, as one of my nurses said, "A real unicorn." She had never seen this in more than twenty years at the BMT clinic.

While I remained in the first-remission stage, my cells were in what is called "lymphoid blast crisis"—basically meaning they were about to go turbo, which is usually fatal. So, we were back on board the transplant train, ASAP (lots of abbreviations are explained here, but you already know that one).

I've compared this experience to a roller coaster, while Angela has called it whiplash. (You can get whiplash on a roller coaster, by the way, so we're both right.) After further chemo treatments and four radiation treatments to kill my bone marrow and make room for new marrow, I was ready for the BMT. Both of my sisters were a match to be my donor, but the doctor chose firstborn sister Anne. Proving that it doesn't always pay to be older.

On June 14, 2022, I had a bone marrow transplant composed of five hundred million bone marrow cells. Five hundred million, which at the time reminded me of comedian Mitch Hedberg's joke about rice: "Rice is great when you're hungry, and you want two thousand of something." Five hundred million bone marrow cells, which meant a chance at second remission, and potentially a cure.

But the reality is that there were and are more statistics. There is 20–25 percent mortality rate because of the transplant procedure alone. This is then followed by the risk of what is called "graft versus host disease." Every kind of transplant—organ, tissue, and so on—runs the risk of rejection. Typically, it is the body that rejects the new organ or graft, but when it comes to bone marrow, the risk is for the graft bone marrow to reject the host body. It's kind of like when you throw a party when your parents are out of town, and some of your rowdy friends who come to the kegger go, "Hey, wait a minute, this isn't our house, let's trash the place."

I spent thirty days in the hospital, followed by seventy more days at home, during which I couldn't be left alone and had to be within thirty minutes of the clinic, in case I experienced graft versus host disease. I survived the transplant and, like FDR (here I'm talking about the president; all these abbreviations are great, aren't they?), my first one hundred days were a success.

One year later, in June of 2023, a bone marrow biopsy showed no sign of disease—of either cancer or genetic mutation. My physical recovery was slow. I still have fatigue, weakness, and days where I have no energy at all, and from what I gather, I will likely never be at 100 percent again. All along there have been troubling numbers, statistics, and odds that have been in front of me. One of five BMT patients does not survive; three in five recover with significant limitations. There is something like a 40–45 percent recurrence rate even after transplant. But, as the great Han Solo said in *The Empire Strikes Back*, "Never tell me the odds!"

What got me to this point, through a difficult passage and ready to face what might come next, is that I was strangely well prepared for all of this. I had a family of origin shaped by faith. I watched my parents navigate my brother's cancer, how they dealt with what it all meant for our whole family. I've had my brother as an example of how to face cancer and life after cancer with courage and humor. I have phenomenal friends, generous members of the congregation I was pastoring at the time, supportive family members, and a partner in my wife Angela, who was (and is) remarkable. And, being able to walk with Mike, "side by side" through cancer, as we've said from the beginning, has made all the difference in the world. (Although as Mike's

wife Kari said, "You guys need to find something better to do 'side by side.'")

But Mike and I have been using the language of "side by side" for a good while now, because our diagnoses were so close together, and we've been doing things side by side for almost thirty years—from our time as classmates at Luther Seminary, to marriages, children, callings, continuing education, and more. And for each of us, at numerous times in our lives, and indeed all along, there have been others who stood by our side. This is, we firmly believe, the key to facing anything, everything, that life might throw at us—the bad and the good—sticking side by side, by side, by side, by side. In other words, faithfulness.

And, of course, according to Psalm 23, when facing any crisis—cancer, illness, divorce, unemployment, aging, death—God is the faithful Good Shepherd who walks side by side with those who enter the valley of the shadow of death. As the King James Version puts it, "Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art with me." And according to Psalm 23 and the other psalms of trust,[2] God is present with sufferers not merely in an intellectual or emotional sense. Rather, God is with sufferers in spiritually powerful ways. Psalm 23 describes God's presence as similar to a shepherd's rod and staff: "Your rod and your staff comfort me." The rod and staff were the shepherd's tools to fend off predators and also to keep the sheep in line. God is similarly present with sufferers in powerful ways—bringing sufferers through crisis and into a new day.

The Immediate Aftermath of a Shattering Diagnosis or Disastrous News

A cancer diagnosis can be a shock—especially when it comes out of nowhere to punch a seemingly healthy person right in the face. It can be shattering. This can be true of any significant, sudden trauma: a heart attack, the sudden death of a loved one, a major accident, the unexpected loss of a job, being the victim of a crime, and so on. One day, Rolf was a fairly typical tenth grader. A couple of days later he only had one leg. What do you do with a closet full of tennis, ski, and marching band gear? One morning, Karl was rebuilding his life with a new wife and a new job. By the end of that day, he was confined to a cancer ward for a month. How do you respond when the wind is taken out of your sails so suddenly? One month, Mike was doing his best to fight through chronic pain in order to lead a congregation and father a family. Then, suddenly, he was forced to focus his energy on his own body . . . which was trying to kill him. What next?

Being diagnosed with a severe illness can be shattering. So can other disastrous news, such as the sudden death of a loved one, being fired from a wonderful job, being told by one's spouse that they are divorcing you, and the like. We simply want to acknowledge how devastating bad news can be. As individuals, the three of us have received such shocking news more than a few times. Many more times, as pastors, we have journeyed with others who have been greeted with similarly crushing news; the examples are too numerous and painful to list.

The very first challenge is simply to absorb the news. Bad news can be like a winter gust of twenty-degree-below-zero

blizzard. You're just overwhelmed. You literally struggle to understand the words. Someone says, "You have cancer." Or, "I regret to inform you that your spouse is dead." And you think, "What? Can you say that again? I don't understand." Sometimes, when you immerse a really large, old sponge in water, it takes a while for the sponge to absorb the water—it isn't instantaneous. And you can't rush the process. The first challenge is to give yourself *and your loved ones* the space to absorb the news. In September 2020, Rolf was awakened one morning by a text from our friend Hans's wife saying that Hans had had a stroke. Rolf had to read the text three times before it could make sense. Then he had to wake his wife Amy and read it to her three times before she could wrap her brain around it. Some thinkers embrace the old "cycle of grief" model, which describes the process as including things such as denial, anger, bargaining, depression, and acceptance. (Our friend Hans jokingly proposes other stages such as "procrastination," "doom scrolling," and "fully body itch.") Not everyone goes through each of these stages, but the stages do help to name the difficulty of letting the crushing news soak in. In the Bible, after Job lost all of his property, all of his kids, and then his health, he is pictured as sitting in the ashen ruins of his life. Eugene Peterson offers a gut-wrenching paraphrase of the scene: "Job was ulcers and scabs from head to foot. They itched and oozed so badly that he took a piece of broken pottery to scrape himself, then went and sat on a trash heap, among the ashes" (Job 2:7–8 The Message). Though the scene is heartrending, it does offer a poignant image of what it is like to receive devasting news.

So what do you do when you suddenly find yourself sitting in the ashes of your shattered life? As we've already said, the

first step is to let the news soak in. And don't rush that part. And, of course, as pastors we encourage everyone to seek God as best you (or your faith community) are able to do so. Call a pastor! Even if you haven't been to church in forty years, call a pastor. More on seeking God later in this book. As we reflect on the beginnings of our battles with cancer, we offer three other thoughts in this chapter: (1) the power of denial and learning *to pay attention* to one's body; (2) the *importance of slowing down to care for your health* and admitting that you can't do everything yourself; and (3) the reality that medical care can dehumanize a person, so one must *tend what is human* in a person.

The Power of Denial and Learning to Pay Attention to One's Body

For reasons that are both similar and dissimilar, Mike and Rolf waited too long to get the proper medical attention and diagnosis. Here is a truth about human nature: We are not good at receiving bad news. When we get bad news or even think bad news might be coming, we often choose to ignore it, and at times some people actively choose to believe something other than reality. This fact about human nature is so true that even when there is overwhelming evidence that something is not right, we still often choose not to face it head-on. It's called *denial*. Denial is not just for those struggling with chemical dependency who aren't ready to face reality. Denial can be a reaction to any life-altering news, such as the signs of or diagnosis of a disease.

There is another problematic aspect of human nature that, when combined with denial, can multiply one's problems.

One might call this pride, fear of embarrassment, aversion to asking for help, or other names. In 1980, Rolf experienced enough pain and exhaustion that he went to the doctor twice. After the second visit, he didn't want to go back a third time because of fear of embarrassment. Rolf was afraid the doctor and others would think he was the boy who cried wolf (which is kind of funny, because the name Rolf means "wolf"). Twice the doctor had examined him and prescribed exercise. In the two months that followed, the tumor grew slowly, but it grew to the point that the swelling was noticeable. Rolf should have returned to the doctor, but pride and fear of embarrassment kept him away. Only the fortuitous fact that his family physician lived next door allowed the cancer to be diagnosed when it was. Mike's story is similar—he ignored symptoms such as a lump on his neck, pain in his back, stomach discomfort, drop-you-to-your-knees abdominal pain, and finally diarrhea. Even at the ER, once the diarrhea relieved this stomach pain, he was ready to return home. Only the fortuitous wisdom of his wife, Kari, kept him there long enough to get examined. Why? Oh, let's guess—pride, denial, fear of embarrassment. And for both Rolf and Mike, the inconvenient truth that our society tells men that bearing pain is manly. "Don't worry, I can handle the pain. Just throw me that bottle of aspirin."

The power of denial, pride, and fear of embarrassment is not just a psychological or emotional problem; *it is a spiritual problem*. And spiritual problems demand spiritual responses. The book of Proverbs says, "Before a disaster, there is pride; and before a fall, there is a haughty spirit" (16:18; our translation). Pride and fear of embarrassment can stem from overconfidence ("I can handle it" or "I can bear the pain") or

insecurity ("I might be embarrassed" or "They might think I'm weak").

The Importance of Slowing Down to Care for Your Health

Another major factor in human nature that often prevents people from getting timely diagnosis and treatment is busyness. People who are too busy—or who are too focused on all of the tasks in front of them—often fail to attend to basic life matters, such as health or helping someone. In his book *The Tipping Point*, Malcolm Gladwell made famous the results of an experiment that two Princeton University researchers, by the name of Darley and Batson, conducted in 1973 with some Princeton Theological Seminary students. The experiment was inspired by a parable of Jesus, in which a man was beaten, robbed, and left for dead on a road (Luke 10:29–37). In Jesus's parable, a Levite and a priest pass by the man and don't help him; but a third traveler—a Samaritan—helps the man. Gladwell writes that the seminary students were asked to prepare a short speech—a sermon—on this parable. Then they were sent to another building to deliver the speech. Some students were told they needed to hurry, because they were late. Other students were told that they could take their time. Along the way to the next building, the researchers had placed a man slumped in an alley, as if beaten and robbed. The researchers wondered which of these aspiring ministers—having just prepared a message about three men who encountered a beaten-and-robbed man—would stop to help. The answer? About 10 percent of the students who were told that they were late stopped to help. But over 60

percent of those who were told that they had plenty of time to get to the next building stopped to offer help. Gladwell concluded, "The words 'Oh, you're late' had the effect of making someone who was ordinarily compassionate into someone who was indifferent to suffering—of turning someone, in that particular moment, into a different person."[3] For our purposes in this book, the point is that those who are too busy are more likely to fail to care for themselves and for others. When we are consumed with all of the *things* we need to get done, we are less likely to care for *people—including ourselves*.

There is again a spiritual element to the problem of being overly busy. There is a temptation to think, "If I don't do it, nobody will do it, or worse—they will do it wrong." Or, "If I don't show up, maybe people will realize that they don't need me." Or, "If I don't get this deal, I won't have enough—enough money, enough success, or enough influence." At the heart of this focus on the next meeting or task is the sin of putting ourselves at the center of our own universe. We become the star of our own drama and the narrator of our own story. It is a form of idolatry—worshiping something other than the one, true God. Placing something other than God at the center of our lives. God is the center of existence—the creator of all, the savior of all, the Lord who loves and guides all.

In Martin Luther's Large Catechism, in his explanation of the first commandment—"You shall have no other gods before me"—he wrote, "A god is that to which we look for all good and in which we find refuge in every time of need."[4] When we become workaholics—or get so busy that we cannot tend to our health—we are functionally becoming our own gods. We become the thing we worship; we become our

own false gods. The thing about worshiping a false god rather than the true God is that false gods don't keep promises. False gods are not capable of bearing the weight of our worship. They are not able to rescue us from distress or crisis.

God's answer to our broken tendency to place ourselves at the center of our own drama and to get lost in busyness is the Sabbath. The word "sabbath" (Hebrew *shabbat*) literally means "stop." Stop working so hard. Your body and your spirit need rest. Taking a full day off from work won't make you go broke—you will have enough. And taking a day off will give your mind time to attend to the things that you are neglecting when you lose yourself in your busyness. A farmer we know refused to work on Sundays. He said, "If I can't make this farm profitable working six days a week, something is wrong!" He was right—and not just about himself, but about all of us.

In the Bible, the sabbath isn't just one day a week—it is also a general principle that calls for regular rest. The sabbath principle calls for people to rest one day in seven, for the land to rest one year in seven, for debts to be forgiven one year in seven, for slaves to go free after seven years, and for all land to be returned to the original family owners one year in every forty-nine (seven times seven years). The sabbath principle extends logically to worship—worship the Lord every seventh day, but also worship the Lord for major festivals three times a year. Logically, it also implies time with God every day and a period of rest and quiet every day.

Such regular periods of resting and stopping all the busyness—on a daily basis, on a weekly basis, on an annual basis, on an every-seven-years basis—allow a person to listen to God and to listen to their own body. Or, in Mike's case, to

listen to one's wife, so that one can get the medical treatment that is needed.

Such stopping, listening, and obeying one's wife requires humility. It means asking for help. It means admitting that one's presence or activity is not as indispensable as one had thought. Humility is really hard. Asking for and receiving help is really hard. But sometimes a little humility—even if it is hard—can save your life. Humility is essential when battling illness or any trauma.

Here is an urgent word of advice for newly diagnosed people (or their caregivers). *Be your own advocate!* One piece of advice that we give to everyone who is diagnosed with cancer is *to be your own most assertive advocate*. Medical systems can be slow. (If time were raindrops, Mike could fill up many a rain barrel with the hours he spent trying to get various treatments authorized by his insurance provider.) As a patient or a caregiver, with as much humility and urgency as you can gather, press for the care that you want. Do not be afraid to tell your providers how you are feeling and what you think you need. And that includes God. As an old gospel tune says, "Call him up, call him up, *tell him what you want*."

Medical Care Dehumanizes, So Tend What Is Human in a Person

Earlier Mike mentioned his encounter with the CT scan tech's polite, genteel description of the warm feeling from the contrast dye in his "groin and behind area." The reality of that experience was a not-so-unpleasant feeling, specifically in his penis (Can we write "penis" in a book like this?!) and anus (Can we write "anus" in a book like this?!), like an ever

so tender "poof." That realization was cathartically humorous enough, literally eliciting a little giggle right there on the CT scan bed. But later, when Mike found out Karl, too, would be having a CT scan, Mike told Karl: "Okay. They're likely going to tell you about the warm feeling starting with your shoulders and ending in your groin and behind area. It's waaaaay more specific than that!" It wasn't just funny to share that with Karl then. It continued to be funny when Karl later confirmed, "So *that's* what you meant!"

One of the things to know about severe illness is that medical care can dehumanize a person. Medical care can diminish a person's humanity, either by making a person feel less human or by literally taking away a part of their humanity. A friend of mine reminded me of a poignant line from Jason Isbell's song "Elephant," sung from the perspective of "Andy," whose lover is dying of cancer. "One thing that's real clear to me: no one dies with dignity. We just try to ignore the elephant somehow." The "elephant" is both death and the dehumanizing way cancer kills. At the most basic level, this dehumanizing can occur when medical professionals treat the disease rather than care for the person with the disease. Almost all medical professionals know this and make extreme goodwill efforts to care for the person with the disease, rather than just fight the disease. But it is almost inevitable that when a person has a long-term fight with a disease, they will at some point feel like the physicians are treating the disease more than the person.

This potentially dehumanizing aspect of medical care starts with low-grade interactions. The patient is poked, prodded, and palpitated. The patient is stabbed with needles, scanned with X-rays, and penetrated in other uncomfortable ways. The

patient is required to strip naked in front of strangers. The patient may be cut with scalpels, burned with radiation, or poisoned with chemotherapy. (One of Rolf's oncologists said, "We only know three ways to treat this disease: cut, burn, and poison.") In Rolf's case, part of his humanity was cut off: his legs. In Karl's case, part of his humanity was killed by chemotherapy and radiation: his bone marrow. In Mike's case, he never had a human soul, so there was nothing to dehumanize.

In Karl's case . . . yeah, his case was super special. He mentioned four radiation treatments. Actually, there were six: the four full-body treatments and two extra-special, targeted treatments. Leukemia isn't like other cancers, in that there aren't "stages." Leukemia doesn't start as a tumor and then metastasize, spreading to other parts of the body, as was the case with Rolf's cancer, or with Mike's diagnosis of "diffuse" (i.e., spread) large B-cell non-Hodgkin's lymphoma. Leukemia is already running all through you. It can, however, "hide." And where does it hide? Two places. One is the brain, so his fifth radiation treatment targeted his brain—which, after they found his brain, went smoothly enough. The second place leukemia can hide is . . . um . . . well, may we leave it at "lower"? Further south? Is this making you, dear reader, as uncomfortable as it is me? Okay, out with it, using the technical medical term: the testicles. And let us tell you, that process wasn't nearly as smooth as the brain blast. It took three University of Minnesota medical residents to set it up (two young women and one young man, all three half Karl's age). Here, we will let Karl speak for himself:

> There I was, lying on my back, while they taped my penis
> (We agreed we would use technical medical terms, right?)

> to my stomach, and put a half-inch-thick lead plate between my testicles, and radiated my testicles for fifteen minutes from each side. I've never felt so exposed, so vulnerable, and so humiliatingly on display in all my life. And as I lay there, my mind racing with embarrassed, nerve-racking energy, I kept saying to myself, "I am as God made me! I am as God made me!" To add insult to injury, after it was over the doctor informed me that the radiation treatment would "eliminate any possibility of impregnation." So, I guess all that money I spent on that vasectomy was wasted.

If medical care can be dehumanizing, what is the answer? *You tend what is human in the patient.* Tend what is human! According to Genesis 1:26–28, every human is created in the image of God. You tend what is human in a person by cultivating and nurturing that divine image in a person—their creativity, their growth and development, their hopes and dreams, their passions, their ability to love and be loved, their sense of humor. This is what Jerry Seinfeld meant when he said, "Humor is the most powerful, most survival-essential quality you will ever have or need to navigate through the human experience."[5] For "humor," in that sentence, one might substitute music, art, literature, sports, food, games, adventure, friendship, and many other worthy aspects of the human experience. This can, of course, be a problem if the disease or accident takes away a person's passion, as it did with Rolf. Rolf had loved playing tennis and being in the marching band. Those were taken away suddenly. So other passions needed to be nurtured in their place—guitar, reading, puzzles, friendship. A different and new part of humanity sometimes has to be nurtured.

If you are the patient, tend what is human in yourself. Reread a favorite book. Listen to your favorite music. Take time on nice days to sit outside and literally smell the flowers. Go hunting, fishing, or bird-watching. Call a long-lost friend. Get a massage. Go out for dinner and order a Grand Marnier. Get another massage. You are human; tend what is human in yourself.

If you are a caregiver, tend what is human in the one you love or care for. If they're confined to bed, wash their hair or hold their hand. Bring a book of pictures from their childhood and ask questions about the photos. Let them win at *Settlers of Catan*. Watch a baseball game or a favorite movie. They are human; tend what is human in them.

Also, if you are a caregiver, tend what is human in yourself. And care for your own health. Oh, and slow down. Caregivers often take on too much and experience a decline in their own health and sense of well-being. So apply all of these things to yourself, if you're a caregiver. Tend what is human in yourself.

If you are a friend, walk with the patient side by side, as we have done. Or rather, side by side by side. And if you are a dog, well, you are probably the best tender of humanity that a patient can have, so be yourself. Because who knows how to tend what is human in a human better than a dog? I suppose you want a treat now.