Before

My wife, Julie, says that among the many reasons she fell in love with me was my work ethic. I'd grown up on a Kansas dairy farm where there was always work to do. My siblings and I had several hours of chores beginning early in the morning. We'd feed calves and milk cows before and after school. I also developed a love of hunting as a boy. Any spare time we could find, my brother Ron and I went hunting for pheasants, prairie dogs, and jackrabbits. To this day, my brother Ron, who also now lives in northern Indiana, and I still spend a lot of time deer hunting together.

Working and spending time outdoors in general connects me to the earth. Physical labor invigorates me, and I still keep a hobby farm. The sweat of felling trees, cutting logs and cleaning up the tops is exactly how I love to spend an afternoon.

Julie and I married in 1975. We met at Hesston College in central Kansas where she received her degree in nursing. After I graduated from Wichita State with a degree in Social Work, we decided to volunteer three years with Mennonite Central Committee, a relief and community development agency of our church denomination. From 1980 through 1983, we loved working alongside our Brazilian neighbors in a brutal subtropical environment in the northeast state of Pernambuco. Julie taught health classes and worked with a local agency in training rural health workers. I helped communities hand dig around 50 wells. The wells we dug were up to 30 feet deep, using shovels and picks to dig through clay and stone until water was found. We'd lower concrete rings three feet high and three feet across, into the hand dug wells. Once completed with a concrete lid and hand pump, many families in each community would have clean, healthy water. This is the kind of hard physical labor I find incredibly rewarding.

After our return from South America, I worked on a construction crew: framing, roofing and finishing homes. Our daughter Lindsy was born in Brazil, and after moving back to the United States, we added two sons, Eric and Casey. In the mid 1980s I became co-owner of a construction business, and shortly thereafter, began studies to become a pastor. I attended Associated Mennonite Biblical Seminaries receiving my Master of Divinity degree. These were busy years.

During seminary studies from 1990 to 1994, I was a full-time stay-at-home dad in the summer months while Julie worked as a nurse. I loved being an active dad. I coached little league soccer teams for many years while our children participated, and was also active in 4-H, helping each of our children in showing beef, poultry, rabbits or sheep at the fair.

By the time Lindsy was 16, Eric 14, and Casey 12, Julie was campus nurse at a local college, and I was living my calling as a Pastor of a large thriving congregation. Pastoring brought on a new form of physical stress and emotional work, but I loved being a pastor. I took on the long hours and different job situations with the same stamina as I'd dug wells in Brazil years earlier.

One afternoon I visited an elderly woman in our congregation who was dying and sat with her family. From there I went to the hospital to visit a young couple who was celebrating the birth of their second child. I treasure a job where you get to be involved in the lives of people from birth to death. Pastoral care brings me great fulfillment. Even as early as high school I felt a calling to church ministry.

We kept a small farm with cattle to satisfy the farmer in me, and I was enjoying life to its fullest. Julie and I planned to build a new home on our dream location, a property we'd purchased well off the road and in a wooded area with a swamp we could dig out for a pond. I spent the summer of 1999 clearing a spot for us to build, relishing the joy-filled challenge of cutting over 40 large hickory trees and cleaning up countless smaller trees and brush. Smells, sights, and sounds of the woods bring me peace.

We moved into our new home in January 2000, and it was that winter that I started running a low-grade fever that didn't go away for four months. At age 46, I developed flu-like symptoms and fatigue that I just couldn't shake. This was the beginning of a devastating blow to my sense of self.

I made several visits to our family doctor who could find no good explanation for the fever or fatigue. Fatigue reshaped my life for the first time. I would go home occasionally in the middle of the day to rest, something that was totally out of character for me. I pushed through, but I was always tired. And the fatigue lasted. One summer when I traveled with our church's youth group to a convention, I couldn't keep up with the group and marveled at how fast they walked without tiring. More frustrating yet was my inability to keep up with the other adult leaders.

One afternoon I attended a seminar for sponsors put on by a nationally known youth ministry speaker. What I really wanted to do was go to my room and crash, but I didn't let myself. The speaker was entertaining, funny, and thought provoking, but it wasn't long until I had fallen asleep. I woke up close to the end of his speech. He had talked about the story from Luke 7 of the woman who anointed Jesus' feet in the home of the Pharisee Simon. He told us to turn to another person and tell them which character in the story we related to the most. I turned to my sister, Marlene, who was also attending as a sponsor from her church, and said "I'm the broken jar. I just feel empty." I had no idea what was going on with me, nor that I would continue to feel this way for years.

Julie and I agree that we try to live as equal partners. But during the years before we knew what was wrong, and when I was too tired to move, that sense of equality was sometimes very difficult to find. I lost connection to many of the activities that made me whole. It became very difficult to enjoy hard work, take care of the farm, keep up with the kids, and all physical outlets that had kept me in touch with the earth and with myself. I was doing what I needed and wanted to, but without the enjoyment. We were losing the life we knew, and couldn't figure out why.

from Julie:

Our children still remember their childhood years with fondness when Terry was at home full-time during the summer. Our daughter, Lindsy, remembers doing fun things like going bowling. Terry told the kids if their scores totaled more than his that he would take them to Dairy Queen. If their scores didn't beat his, they would go to Dairy Queen anyway. A lot of time was spent outdoors and in the barnyard with animals. It seemed as if Terry and the kids ganged up weekly and brought yet another animal onto the farm. Animals included donkeys, angora goats, geese, chickens, a nest of baby skunks that were trapped at a friend's home, bottle fed baby raccoons, a pony with a cart, and the cows with baby calves. Inside animals included hamsters, a white rat, a turtle, lovebirds, a cat and others. Our farm really became more like a zoo.

Terry was energized and enjoyed his years in Seminary. Some of our friends during college informed me that Terry would someday become a pastor, so I wasn't at all surprised when that's what he ended up doing. We went into our marriage open to whatever God might call us to do, whether in a church setting or elsewhere. And we've always been supportive of one another's work as parents and as professionals.

I enjoyed watching Terry's ministry evolve. His strength in pastoral care and counseling was evident and we could see the usefulness of his Social Work degree. We soon grew to love the people of Clinton Frame Church as they encouraged and embraced Terry in his various roles on the pastoral team. Eventually he would become lead pastor. During these years, we felt we were right where God meant for us to be. Little did we know at the time what a gift God gave us by placing us into this faithful community that would pray and care for us through the many difficult years ahead.

During the first years of Terry's fatigue I talked him into going to an endocrinologist who could find nothing. Even though I had training as a nurse in the medical field, I was raised in a home that practiced alternative modes of health care, so I also talked him into going to a chiropractor and at one point to an Iridologist—a practitioner that studies the color patterns and characteristics of the iris—to gather information about a person's systemic health. She told us that Terry's liver was in serious trouble and had him do a liver cleanse. We never returned to her, and many years later, we would learn that she was absolutely correct.

At times, I talked Terry into taking Vitamins or some natural supplement. Later on, Terry would do infra-red sauna treatments, IVs for detoxification, lymph massage, detox foot baths and lots of herbals.

As a nurse I wanted to talk about his fatigue and try and figure out what the underlying problem might be. At times this caused tension between us. Terry likely didn't know how to talk about his *health, or even how to understand or name how he felt. At times he became defensive and irritable, saying that I was being critical of him. So mostly I quit talking about my concerns, and the issue of fatigue remained unspoken. Preserving our relationship mattered more than addressing the fatigue.*

Terry mastered the art of denial during the early years of his fatigue. His work schedule included many evening meetings and very long work days. He managed to do what he had to. He pushed himself through the long days. Then he made it to the kids' sporting and other events, cut wood for our wood burning stove, and kept up with work around the farm, but just barely. I would look into Terry's eyes at the end of the day and see 'an empty man.' Most evenings he would sink into the recliner and barely move a muscle until he forced himself to go to bed. He was not himself.

Beginning

It would be another twelve years before we had a firm diagnosis, but I believe it was probably while I was felling and cutting up trees to clear space for our dream home that I contacted Lyme disease through a tick bite. We cannot know for sure since we had also traveled to Wisconsin and the northeast, areas known for Lyme disease, over the previous years. At any rate, it was the winter of 2000 that my first symptoms of Lyme occurred.

At the insistence of Julie and myself, my family doctor agreed to put me on antibiotics a couple of times. We have wondered if the early treatment of these antibiotics may have been one of the reasons the more critical symptoms were delayed.

With good intentions, our family doctor also prescribed an antidepressant, which thankfully I didn't take since we later learned that individuals with Lyme disease often experience devastating complications from the medication. Almost all Lyme patients are diagnosed as depressed at some point, when their doctor has no other explanation. Often the anti-depressants have horrible side effects and the patient ends up being admitted for inpatient treatment. Others end up committing suicide. It is hard to overstate the desperateness of feeling horrible and being told it is just in your head or that you are depressed, the desperation that can come from wanting to feel better but after many doctor visits still finding no improvement and no hope. This psychological war within one's mind is certainly part of the suffering of many persons with Lyme. Julie and I both knew that depression was not the cause of my problem, which is why I chose not to take the medication.

After several months my fevers went away, and I believe the Lyme bacteria slowly began to infiltrate my body. My main symptom continued to be fatigue. I lacked energy, but I learned I could push through. I worked long hours, but would occasionally hit a wall and crash for a day. Later I became very familiar with that wall, when I simply could not keep going. During these years, I was often frustrated by what I thought was a weakness as I could not keep up with the energy level of others. One morning on a youth service trip to Toronto, Julie insisted that I sleep in, and I felt tremendous guilt and frustration in not being able to do my job.

One symptom of Lyme disease is brain fog, and the years of 2004-2011 are somewhat of a blur to me. I was also doing everything in my power to cover up and deny how I was feeling. I continued to work the long hours for the church, and to work on my farm because I was determined not to let tiredness dictate how I lived. I wanted to be my old energetic strong self. In my heart, I knew something was happening to my body that I could not explain, and that no one else could explain either. As best I could, I fought overwhelming frustration by throwing myself into the busyness of being the father to three rapidly growing kids and working in a job that I loved. While I felt weak and inadequate, I tried not to give in to those feelings.

Once I began having one major health issue after another, I began to take my health very serious, and tried to take as much responsibility as I could. It could have been easy to let Julie take over and communicate in medical jargon with doctors and other nurses. But since I was the patient, she tried very hard to allow me and insisted I have the conversations with the doctor or practitioner. She'd chime in only if I asked or if it seemed I needed backup. Before many appointments, however, Julie coached me how to be brutally honest and detailed about my health. According to her, I tend to minimize or downplay my symptoms. I sometimes tired of these rehearsals, but I did learn to talk medically and clearly communicate my problems and needs.

Going from one specialist to the next, I am thankful Julie was with me to help decipher the medical language. Among the doctors we visited included a neurologist, urologist, endocrinologist, cardiologist, electrophysiologist, retinologist, general surgeon, on top of primary care physicians. Years later when we finally had our first appointment with a Lyme disease specialist, the admission form listed thirteen specialists, and we can recall at least three more physicians we did not put on the list.

from Julie:

I believe the severe symptoms of Lyme disease began with Terry's retinal bleed in 2008. Next came the first episode of Brachial Plexitis in 2009. He also had four major surgeries in ten months. He had a Nephrectomy (removal of a kidney due to cancer), repair of the nephrectomy incision, which opened three days later, hernia repair and removal of his gallbladder. At this time especially, his immune system hit rock bottom. Early in 2011, a slow, irregular heart rate began which Terry lived with for over a year, at times struggling with a heart rate in the low 40s. Eventually he had two ablations. Terry also lived with neuropathy (pain and numbness) of both feet for seven years, and *had frequent headaches and constant pain in his neck and shoulders. His fatigue was ever-increasing.*

Terry often became discouraged, and even angered, as we became used to hearing the words, "there is no reason why this should have happened, you are healthy otherwise." Terry would tell me this, "when you are told often enough that there is nothing wrong with you, you start believing that it must be in your head." I knew without a doubt that it was not in his head and that something was desperately wrong, but we had no medical evidence to back us up. Terry's personality is such that he suffered quietly with very little complaining, even through the many years of treatment when he was at his worst.

Considering the massive amount of medical language involved in blood tests, scans, ultrasounds, MRI's, you name it. Terry had a lot to learn. Considering his lack of energy and time, he did an amazing job at learning as much as he could. Often I would find articles on the Internet to explain an upcoming test, new medication or a new diagnosis, and he would gladly read these to become more informed. I marveled at how compliant he was to any orders, whether it was testing or taking medications. Only once in a while Terry would say that he is done and wasn't going to do something, but I think it was his way of asserting his independence to see what kind of reaction he would get from me. Dependence on me—even temporarily—was sometimes hard to accept. Terry's compliance and determination to learn all he could about his health has made me love and respect him all the more.

During these years, I was having my own battles with menopausal symptoms and serious hormone imbalance. As a result, I had many years of severe insomnia, often sleeping only two to four hours at night. I have shared this with very few persons, but have resolved that there was purpose for this time in my life. As I lay awake for hours beside Terry, wondering what to do next, I started praying. I prayed hours in desperation, not only for sleep to come, but how to get needed help *for Terry. I often believed that he was slowly dying right in front of my eyes and beside me in bed. It was during the long nights that I noticed how shallow and irregular his breathing had become and that he had involuntary jerking of his legs and arms while he slept. I could not believe or accept that the medical world was failing us, and that there were no answers. So I turned to God for long talks at night. I often thought of something to research or a person I could talk with, so I guess my talks with God helped us both.*

A Blur

By the summer of 2011, I realized I was in trouble even though I was determined to try to save the life I loved. I had a health crisis in early July of that year which was a total mystery to me at that time. It was a hot summer day and we had a baptism service at our pond for the morning worship service. Julie and I had spent all week fixing our place up for the around 500 guests we would have that morning. For some reason, we felt like our property needed to look like a well-maintained park for the baptismal service. That Sunday morning my balance was off, and I knew I was not doing well. I was shaky doing the baptisms, but I didn't think anyone noticed. After the service two people asked me how I was feeling, and one said they weren't sure I would make it out of the water. My head ached, and I had overall weakness. That morning for the first time I felt my words were a bit slurred when I preached and led the service. I don't think those listening could have noticed.

After the meal was over and everything was cleaned up, I left on my motorcycle to ride six hours to Pittsburgh for a denominational assembly. Against Julie's wishes, I headed out. She always knew when I was struggling, but she could not talk me out of leaving. I have a stubborn side, a wall I sometimes put up when she is saying something I do not want to hear. She would say it was my male ego that makes me do things like this. I wasn't healthy enough to do it, but I did it anyway. Really, getting on a motorcycle when one's balance is off is not smart. I suffered through that ride, and about halfway to Pittsburgh I admitted to myself that this was pure craziness. But, I didn't stop and that evening finally arrived at the hotel in Pittsburgh.

In the hotel lobby I saw a pastor friend, and we talked briefly. He wanted to talk about how I was feeling, but all I would say was that I was doing fine. Two days later I saw him again and he pushed me hard on how I was doing. Finally, he told me how worried he had been after seeing me two nights earlier. He said he kept thinking about how terrible I looked. I told him that I was really tired that day, but that I had recovered and was doing great. It was so much easier to say that than to try to explain how I really felt. I didn't even understand how I felt myself. The truth was I felt horrible, and I took off every afternoon from the delegate sessions to sleep in my hotel room. I was weak and not able to do what I considered to be just normal activity.

Fatigue is so much of the journey of a person living with Lyme disease. January 2000 is when my fatigue moved in, and it would only get worse during the treatment phase. I recently read an article by Jennifer Crystal in *Lyme Times* (July 2016) entitled "The Debilitating Experience of Fatigue" that voices some of what I understand about fatigue. Every person's journey with Lyme disease is different, but Jennifer's explanation of fatigue hits home for me:

> *Fatigue can mean a lot of things. Muscle soreness after a bike ride. Feeling drained after a long day at work. Droopy eyes, the desire to take a nap, the need for an extra cup of coffee. All of these fit into the category of normal tired. What makes them normal is the base level underlying them. If a person is otherwise healthy, they are able to push through normal fatigue because their adrenals are working properly and their bodies are*

not worn down from fighting infection.

Sick tired is another story. The fatigue of the tick-borne diseases is not a general malaise that can be fixed with a nap or a cup of coffee. It is a crippling flu-like exhaustion, one that leaves muscles not sore but literally unable to function; one that makes the body feel shackled to the bed. It is hard for someone who has never been that sick to understand what a person with chronic tick-borne illness means by saying, "I'm so tired today." I have had well-meaning friends say, "I'm tired a lot too" but in the next sentence they tell me that they're going to the gym or planning a party.

This is especially unfair to patients with chronic fatigue syndrome—a nebulous umbrella under which many people with Lyme disease fall. "Fatigue" is hardly a strong enough word to cover what it feels like when your adrenals are shot, your nervous system has gone haywire and your body refuses to function. Even as a writer, it's hard to articulate exactly what I mean when I use the word exhausted.

It took years of medication, alternative therapies, and hard work to get out of the rut of "sick tired" and battle my tick-borne disease into remission. However, I still have to be very careful about pacing myself, or my "normal tired" can quickly slip into "sick tired." So I take a nap every afternoon. If I don't, I hit a physical, mental and emotional wall, melting down like a small child. Napping for me is a necessity, not a luxury.

My feelings of fatigue have been a bit different, but I resonate with much of what Jennifer Crystal says. What was worst for me was that in the midst of the fatigue, I had a nagging feeling of being weak and frail. I so struggled, not understanding and not wanting to accept the reality of what my body was saying to me.

There were many questions in my mind that I could not resolve. How can a middle-aged man admit that he was too tired to get out of bed in the morning? How could a middle-aged male accept the reality that he could not function and live life like his peers? How can a person feel so awful but all medical tests come back normal? How many times can a doctor not have an answer? What does a middle-aged man do when he fears his physical weakness is just in his mind? How does one admit that? This was a constant battle in my mind, with my emotions, with my own body. Julie would tell me that I needed to listen to what my body was saying, but my mind and will could not accept that. How does a middle-aged man listen to his body?

The other difficulty is that the sense of overall weakness and failing health is impossible to describe to people who genuinely care. I know that many persons battling cancer and chemo therapy experience this dilemma. At one church function, I went over and sat with a dear sister in the church who I knew was losing her battle with cancer. I asked her how she was doing and she said, "I'm doing okay." I told her I simply wanted to know how she was really feeling on this particular day. I genuinely wanted to know. She said, "I will tell you since I know you'll understand. I just feel awful but I don't know how to explain it. I really don't have a fever or a headache today. It is just an overwhelming feeling of weakness that I can't put words to. I feel drained of emotion and motivation. I can't explain it, I feel just awful all over." She went on to say how frustrating it is to try to explain something that she herself does not understand. My heart went out to her, and yes, even though my journey was very different, I knew exactly what she meant. When one is not able to describe the sickness, it is easier to say, "I'm doing fine."

I remember reading a comment written by a person who had suffered from Lyme for many years that has stuck with me. This young woman described living with Lyme as the walking dead. On the outside, she seemed normal and people could not see by looking at her that she was sick, but inside she felt like she was dying.

Now as I look back I can admit that for years I knew something was horribly wrong with me. However, doctors could not find a good reason for how I felt, and at times I questioned if they believed me. It was easy for me to just resolve that it was just in my head which made me question my mental stability. This uncertainty and frustration of feeling weak is a very difficult part of living with the Lyme bacteria that is secretly attacking your health in so many ways. The Lyme bacteria goes into an undercover mode and begins to attack any soft tissue in the body.

It would be another four years before I had the firm diagnosis, but the first obvious result of the Lyme disease I now know was the loss of sight in my right eye in the summer of 2008. Years earlier I had done Lasik surgery on both eyes. As a result, I had monovision. My right eye was used for seeing distance and my left eye for reading. I noticed that my vision was bad when driving but did not discover what was wrong until preaching a funeral sermon.

As I looked to the congregation, people's faces were blurry. Wondering what was wrong, I closed my right eye but the blur remained. When I closed my left eye, the sanctuary went black dark, and I realized that I could see nothing with my right eye. Immediately after the burial I called my optometrist and told him that I had lost sight in my right eye. He saw me the next day and found that I had a retinal bleed which resulted in a pool of blood behind my eye. On Monday I returned to his office for laser surgery which stopped the bleeding. He said there was no way to know how much of my sight would come back, but he'd be surprised if 50% of it returned. This was my first miracle. In a few months I had total sight back in that eye.

I was referred to a retinal specialist in Chicago for further treatment. He told me there were only three possible reasons for a retinal bleed: heart disease, diabetes, or high blood pressure. I did not have any of those illnesses so once again I was told, "Yes, it's true this has happened. We just have no explanation as to why." I would hear those same words from many doctors over the next few years. In her study of the retinal bleed, Julie read that this condition can be caused by Lyme disease. This makes sense since Lyme often attacks the eyes and some people go blind.

Julie, with her ever-present intelligence and research impulse, asked the retinal specialist if my loss of sight could be related to Lyme. He immediately said, “Oh, no, that is impossible.” He was the first doctor to essentially deny the existence of Lyme disease. He may not have said it outright, as some doctors would, but it was not at all a serious consideration for him.

I give total credit for the return of sight in my right eye to prayer. I am blessed to be a part of a praying congregation, a congregation that believes in the power of prayer and practices prayer on a daily basis. The power of prayer would be an integral part of my journey through the years ahead as I experienced many “God moments” and blessings in the midst of pain and health crises.