Part 1

My son Joe, age twenty-four, is resting in his bed, unresponsive, as he has been for the better part of two days. It is late afternoon and I am sitting with him, his several guitars and his bass in their stands behind me; gray acoustic soundproofing panels line the corner of his bedroom where he records his music.

My husband Jeff and my two adult daughters, Jamie and Anna, are there, too. The four of us sing our traditional Thanksgiving hymns: “For the Beauty of the Earth” and “Now Thank We All Our God”, in four-part harmony, because it is Thanksgiving Day and that is what we always do. I don’t feel like singing, but it somehow seems right to do so. We miss Joe’s baritone voice, but hope he is enjoying the music. The final lines of the hymn hang in the air: *The one eternal God, whom earth and heaven adore; For thus it was, is now, and shall be evermore.*

Then we are silent, just being present with Joe.

I hear him exhale, and I know he is gone.

I can’t breathe. My heart is slowly torn in two, unnamed emotions threatening to erupt, but I do not cry. I am stunned. I have had three and a half years to prepare, but can anything prepare a mother to lose her only son? I am not prepared.

I said goodbye to him the day before, quietly thanked him for being a wonderful son, told him he could let go whenever he was ready. But still I am not prepared.

1

First Symptoms

Behold, children are a gift from the L*ORD . . .*
—Psalm 127:3

In June of 2014 I was just back from a lovely ten days in England with my youngest daughter Anna, age sixteen.

We enjoyed London for several days, then rented a car, and I gamely faced the challenge of driving a stick-shift car on the “wrong” side of the road.

“You’ll have to be the navigator,” I told her. “I have to focus on driving!”

“I’ll try…” She was less than enthusiastic about this responsibility, and I understood. I too am somewhat directionally-challenged, easily lost. We would have to treat this trip as an adventure, and be flexible and gracious with each other.

We drove to Oxford, where we walked the college grounds where C. S. Lewis taught, attended a Sunday service in the beautiful Magdalen campus chapel, and visited Lewis’ church, his home, and his gravesite. We have always been big fans of *The Chronicles of Narnia* and other works of Lewis, so this was a meaningful and long-anticipated visit. We continued on to the Cotswolds, relishing our country walks amongst the sheep and attending a piano concert at the small but ornate St. James church (built 1627). We even took a day trip to Cardiff, Wales so Anna could visit the Dr. Who Experience.

In the process she became an expert navigator after all; we always ended up right where we wanted to be.

She'd recently had her hair cut short, which suited her petite stature and accentuated her green-gray eyes. Artistic from an early age, Anna could often be found producing handicrafts such as greeting cards she made with flowers she pressed herself, or making jewelry with beads. Sometime she even made her own beads. She learned to knit and crochet and made lovely hats and scarves.

She often put together unique yet fashionable outfits from items she found at thrift stores. Her carefully-curated song playlists often became quite popular once posted online.

My older daughter Jamie had graduated from college the year before and was the assistant manager at our large public library, putting her administrative skills to good use. On Sundays Jamie frequently sang on the worship team at our church. Her long hair often up in a cute messy bun, she had always been both capable and fun-loving, During her pre-teen years in children's theatre, she instinctively knew everyone's lines and cues and would whisper helpful reminders when others in the cast forgot what to say or do. When she was a young teen her ballet instructor often put her in charge of the class when the instructor needed a break.

As a child, Jamie seemed to relish her role as big sister, directing the plays and variety shows the kids performed for us, reading to her siblings, and generally providing a happy leadership for her younger brother and sister. Where Jamie went, fun usually followed.

My son Joe, the middle kid, exemplified the saying, "Still waters run deep." Intellectual, witty, and quiet, his peers admired him and his sisters adored him.

He wasn't interested in sports, especially team sports. As a young boy he told me he didn't want to have to depend on anyone else in order to succeed. I suppose we could have pushed him into baseball or soccer, but to what end? He had friends and got along well with others. He was physically active and fit. He was happy going to the archery range and shooting at targets, riding his bike, swimming. He did take a basketball class at the local YMCA when he was around eleven or twelve and was actually pretty good at this, despite his short stature. But it wasn't a passion.

One evening as he and I were walking down the hall of the Y after his basketball class, we saw through a window a kids' martial arts class in progress. Joe stopped to watch, captivated. He seldom asked for anything, so I prompted him, "Do you want to try martial arts?"

Still staring through the window, he replied, "Yeah, I might like that."

When his basketball class ended I signed him up for John Bishop's Kajukenbo class, and he never looked back. He had found his thing. He spent the next eight or so years pushing himself to the limits of his physical endurance in Kajukenbo, and he loved it.

He had high standards of behavior for himself and others, to the point where as teens Jamie and Anna teased him by naming an imaginary podcast, "Moral Adventures with Joe". Jamie assumed her best British accent as she introduced the show: "Welcome to Moral Adventuhs with Joe. In this episode, Joe reminds us one should not poke one's sister with a pencil."

Joe had decided after one semester that college was not for him, so he was working hard in order to pay rent, save money, and figure out what path to pursue. A talented musician and songwriter, he spent much of his limited free time writing and recording music in his bedroom studio.

At twenty years old Joe was working three part-time jobs: he was a courier for an escrow company, he did construction work for a family friend, and he was the worship music leader at a small church in a nearby town.

Coming in from work one afternoon he stopped to chat with me.

"Hi Mom."

I looked up from loading the dishwasher. "Hi Honey. How was your day?"

"It was okay. It's weird though—I'm having some trouble with my hand."

"What do you mean?"

"It's like my fingers are half numb or something."

"Hm, you mean your hand fell asleep?"

"It kind of feels like that, but it's been that way off and on for a few days. It's been hard to play the guitar. . ."

I massaged his right hand and asked if that made a difference.

"Not really. . ."

"Well, let me know if it doesn't improve in a day or two."

A few days later he mentioned having the same sensation in his right foot. "I'm not sure I should be driving; today on the way home I couldn't tell whether my foot was on the gas or the brake. I couldn't feel it."

I agreed with him about not driving, and advised him to make an appointment with our family doctor. "Maybe you have a pinched nerve or something. You may need an x-ray."

Our doctor wasn't available right away, but Joe was able to see his Physician's Assistant, Christina, the next day. Joe told her about the numbness in his right hand and foot. He mentioned that he had noticed some peripheral vision loss as well as double vision. She asked him some clarifying questions and performed a few basic neurological tests.

She then ordered an MRI scan of his head, scheduled for the following Monday.

Joe didn't feel well for the next two days and called in sick to work. He had a migraine and was nauseated.

He slept a lot over the weekend and tried to eat now and then, but nothing stayed down. He seemed to be declining since his doctor visit.

Joe was still queasy and weak the day of the MRI and didn't want to go, but I convinced him we needed to find out what was going on. He somehow made it through the ordeal and back into the car for the twenty-minute ride home, fighting nausea the whole time. He stumbled into the house and collapsed on the sofa. Crawling upstairs to his bedroom was too much to consider.

I spent the next two or three hours emptying his bowl and giving him sips of water. Finally I called our family doctor.

"Dr. Allen, Joe was in to see Christina the other day and had his MRI brain scan today. He's been really weak and nauseated and hasn't kept anything down for over twenty-four hours, even water."

Concern in his voice, Dr. Allen told me, "Take him to your nearest emergency room so he can have an IV of fluids. We don't want him to get dehydrated. I'll let you know when I receive the results of his scan."

I'm not easily rattled, but I was beginning to feel uneasy…

I called my husband Jeff at work to update him, then drove Joe to our local community hospital.

In the ER, Joe was given an intravenous line which supplied both fluids and medication to control his nausea. He was asked about his other symptoms, then admitted as a patient and taken away for further scans while I waited anxiously, prayed, and updated Jeff and the girls.

The next day I decided to let our friends know what was going on, so they could support us in prayer.

Wednesday, 6/25/14

Facebook post: Lori

For those of you who know Joe (my son, age 20), I wanted to let you know that he has been admitted to the hospital. He has had issues with partial numbness on his right side for a couple of weeks, in addition to frequent headaches/nausea and some limitations in his peripheral vision. He has had 3 MRIs so far and they show lesions on the left side of his brain. He also had a lumbar puncture last night and is scheduled to undergo several more tests today and tomorrow. The doctors don't have a diagnosis yet, but we will keep you posted. We will start a Facebook page just for updates for those who want to follow his progress.

I stayed at the hospital overnight and will be heading back there for the remainder of today. He is very weak and tired and has asked that we hold off on visitors for the time being.

This is a stressful time for all of us and we very much appreciate your prayers for Joe's health, as well as for peace, courage and wisdom.

The word "lesions" meant nothing to me, but the hospital doctors were obviously concerned and performed and repeated many scans and tests on Joe at all hours. While Joe was undergoing these tests, I called Jeff and the girls to keep them informed of all that I knew.

I spent the next few days and nights in Joe's hospital room. My smart, strong, muscular son was weak and nauseated and needed me to be there with him. I found myself in the new role of advocate: asking questions of the doctors and nurses, taking copious notes, fetching food and drink when Joe was able to eat.

I was exhausted but didn't want to leave. I wanted to be near him. I did eventually go home at night once or twice that week to sleep, but I constantly wondered what was happening with Joe at the hospital, and I returned first thing in the morning in case he needed me.

Around the fourth day I asked Joe, “Would you rather be alone for a while? I know you like solitude and I don’t want to crowd you.”

“No, it’s comforting having you here. Also it’s easier for me if you listen to the doctors and ask them questions. I’m too tired to talk to them much, and I might forget things. I appreciate you taking notes to help us remember stuff…” His voice trailed off as he closed his eyes to rest.

The doctors—specialists of all types—came and went and performed their tests all week. They ruled out Multiple Sclerosis, stroke, meningitis, parasite, Guillain-Barré, and several other ailments.

Finally they admitted, “We’re baffled.”

At the end of the week we were still at our small local hospital with no diagnosis. Julie and Maria, two of my friends who happen to be nurses in two different states, each began gently but firmly telling me Joe needed to be transferred to a larger, better-equipped hospital.

With Maria’s help I began the process to have him transferred to a large university hospital about forty minutes from our home. I later found out that several events had to line up in order for this transfer to take place as quickly as it did: a bed had to be available in the right unit in this busy hospital, case managers and doctors had to agree to the transfer, etc. I’m pretty sure Maria had to call in professional favors to make it all happen.

The doctors at our local hospital were very supportive and signed off on the transfer. The head neurologist met me at the nurse’s station as I was filling out discharge forms. He handed me his business card. “Would you mind letting me know when you have a diagnosis? I am very interested in Joe’s case. I have a son his age…”

I agreed to inform him when we had answers.

By late afternoon Friday Joe was settled into his new room at the University of California in Irvine Medical Center Hospital, where he would spend the next five days.