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# Spirituality and Chronic Illness: A Personal Narrative

SHEILA BOST

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*Editor's note: Sheila Bost became ill with a mysterious neuromuscular disease in the winter of 1990. For two years, she experienced her body deteriorating as she searched for a diagnosis and treatment. After much suffering, she did find healing and now lives a functional and productive life, the disease controlled by on-going treatment. Below are thematic excerpts of her personal perspective from a paper for a graduate class entitled "Ministry in Times of Crisis."*

## **REGARDING THE CHURCH**

The Sunday it was announced that I had a mysterious disease and would begin tests remains riveted in my memory. I wanted so much to be tearless, to appear calm, confident, a faithful servant ready to accept God's commission for my life. At the heartfelt prayers and the outpouring of support, my emotional state catapulted. I could utter few words without evidencing my grief. One friend aptly described me as having "feelings of helplessness, detachment, isolation."

Telling fellow friends and Christians of my heart's hurt challenged my being. Our family had definitely relied upon the prayers of the church family before—my son, Luke almost died at birth. God had answered our prayers with a resounding *yes* by sparing Luke's life, and what a joy he has been.

Memorial Day weekend, 1991, we attended a family retreat in the mountains with our congregation. This weekend is significant for several reasons. First, I did not want to attend because I was extremely uneasy with my newly discovered illness and with my lack of sleep. I was so tired. But this annual trip meant so much to Tom and the children, so I consented. Plus, it was becoming increasingly frightening for me to be alone. Second, after morning worship, a special prayer service was held for me; the first, I think, of three. I could not comfortably attend these. The experience was personally too emotional, but I was ever so thankful for the intercession of these saints. I found the situation painful because every part of me was so public. Last, at this retreat, several Christians understood I was in true crisis. I recall one particular meal where my hands fatigued so badly that by the end of the meal, I could no longer bring my fork up to my mouth. A friend stared and mumbled downward in disbelief.

## **REGARDING AWKWARD SILENCES**

At an earlier time in life, Luke's hospitalization had shaken me. My self-esteem was at its lowest ebb because I was physically and emotionally incapable of doing what I thought I always did best, mothering. When I was at the hospital watching Luke rest, I completely let down my guard to a minister. I bombarded him with questions about evil and suffering. Silence. He smiled and changed the subject. Being shunned and avoided is worse than being subject to uncomfortable conversation.<sup>1</sup> Talk means hope.

## **REGARDING MASKS**

After the neurologist suggested the possible diagnoses, I sat silent, overwrought, and desperate to think of an intelligent but unemotional response. I did not want to lose control. Somehow after these forty-five years of living, I automatically responded, made my future appointment, and exited without losing com-

posure. I stumbled to the car. At that point I allowed myself to begin the deluge. On the drive home, sobbing and talking to myself, I reasoned that even if I were to die right now, I was blessed. Crying became an uncontrollable voluntary response month after month after month, until I no longer could force a tear from my ducts.

I surprised myself. At times I could not share my experiences with my best friends. I tried to wear the mask that says “all is well.”

Our regular women’s small group Bible study hosted a guest speaker from Texas who had been told of my situation. Her study focused on the problem of evil and the ultimate Job question: why some are chosen to experience the storms and others seem to live with gentle rain. She noted that my situation was similar to that of her sister who was experiencing acute marital problems. Her belief was that God knew that her sister and I were strong, faithful women who could handle the Job-like storms, whereas she could not. The young speaker presented me with a Band-Aid marked Romans 8:28 which I stuck in the front of my Bible. Outwardly, I smiled and graciously tried to acknowledge her wish to fix my pain and to simplify the complex theological questions. Inwardly, my voice shouted that I was no superhuman! I wondered if my faith would see me through to the “good” that she promised me God would work.

### REGARDING CONTROL

I had always pictured myself as an essential doer and giver—a Martha at Culver Palms Church of Christ. I questioned how I was going to learn to *be* and not *do*. I had been relieved through study to recognize that Martha had a magnificent faith which she had declared at Lazarus’ rising: “Yes, Lord, I believe that you are the Messiah, the Son of God, the one coming into the world” (John 11:27). Discovering this truth helped me to rationalize my fierce independence, my self-control, and my very stubborn will. With this new challenge, I began to relinquish control and ask for help. “Asking for help is, first off, an admission of helplessness. People of less individualistic cultures may be less unnerved by the prospect of dependence, but it certainly seems un-American. Our language reflects our values. Words like independent, autonomous, and all those compounds of ‘self’: self-reliant, self-sufficient, self-confident, carry the imprint of virtue. When illness reduces the self to helplessness, self-esteem is diminished.”<sup>2</sup>

### REGARDING PHYSICIANS

Selecting the doctor to be in charge of my treatment consumed our thinking. We wanted nothing more than a knowledgeable, compassionate, devoted physician who came with an automatic guarantee to make me well.

Finding Dr. McElroy was a blessing from God. He was a rare commodity. He listened compassionately and actively to the details of my lurid tale. Deep down I thought he might think I was irrational and crazy. Soon I learned that McElroy excelled as a diagnostician. Immediately, he tried to contact my original neurologist. Dr. Drake refused to return phone calls and remained uncooperative and secretive about the failures of invasive treatments. Not to be daunted by the egocentricity of a man and the difficulty of dealing with an academic institution, McElroy charged ahead, bringing in his own team of experts. Until McElroy entered the picture, I had begun to lose all hope in the medical profession and all hope of healing. “Surrendering confidence in the medical profession is risky business. If doctors have no capacity to heal, what hope remains?”<sup>3</sup> No doubt Drake was a skilled doctor; but I needed more than a scientist in whose eyes I was merely a rat, a statistic in his research agenda. McElroy’s primary goal was to make Sheila Bost well. Drake’s goal was to make thousands well.

### REGARDING FEAR

My initial physician mentioned ALS (Lou Gehrig’s Disease) and caused neurons to fire frantically in my brain. I could remember twenty years before when we visited one of our dear friends, an elder in the church,

whose life was rapidly terminated by ALS. The specter of his memory haunted me. Death from ALS usually occurs relatively swiftly, with much suffering, in two to five years.

### REGARDING IDENTITY (OR LACK THEREOF)

Tom and I decided, in the interest of time, I would have a recommended electro-diagnostic evaluation that very afternoon. The five-page report of findings does no justice in representing the all-afternoon experience whereby Dr. Pape, after each painful probe, discussed his technique and findings with an eager young medical student. I became a nonentity; very rarely was anything said to me, and nothing was ever explained. I chose not to complain; rather, I sought to be the good patient with each doctor's visit. From my limited understanding of the Christian spirit, I was trying to be a good patient; my attitude toward medical tests and personnel was the one and only thing I could possibly control about this illness. I pursued an "A" on attitude. Medical reports described me as "lovely, pleasant." Perhaps I was, as Bernie Siegel describes, actually afraid of asking a lot of questions for fear of angering powerful physicians who were to make me well.<sup>4</sup> In the beginning of my illness, because of my attitude and probably because of denial, I remained passive. Later I read Siegel's work in which he states, "The so-called *problem patient* is also the rapid healer, the long-term survivor, and the one with the active immune system."<sup>5</sup> In time, these key elements, knowledge, assertiveness, and acceptance, provoked a good patient like me to take charge of my case—a primary step in healing and survival.

### REGARDING THE EVIL INTRUDER

With each test came the realization that a terrible disease had invaded my body and was vying for control. With each writing task, I noticed that my script became illegible; my hand muscles fatigued. I could not deny the intruder's hold on me.

One evening after dinner, I witnessed a sinister five-second phenomenon. Suddenly, I experienced a warm, uncontrollable, foreign force invading the nerves and musculature of my left hand. Within seconds, it vanished, leaving my left thumb limp, completely flaccid. I shrieked in terror. This uninvited force was, without warning or invitation, taking control of my body. That night, in my own family room, I thought I was encountering an alien from the authentic Twilight Zone. As Register so effectively describes,

The thought that the force exists within you, is a part of your own body acting in defiance of your will, is very hard to take. I felt assaulted, victimized and panic stricken. Once again, I predicted that I must be crazy. My husband witnessed the effect of the brutal attack, but to me his view of my experience seemed cursory, analytical and brusque. I longed for him to take me in his arms and attack this vicious enemy that was attempting to destroy me, us, and our family in the process. Ever so slowly, I was learning that "each case of illness is unique and private and inaccessible to everyone but the person inside the stricken body. While others can express sympathy, no one can truly empathize. Suffering, the saying goes, must ultimately be borne alone."<sup>6</sup>

Up to this point, Tom and I had shared everything. I yearned for him to have an innate ability to comprehend what I was experiencing without his actually being stricken by the disease. I desired the impossible.

During this progressive demise of my body, evident from an external perspective, there was a neurological Star Wars of cataclysmic proportions erupting inside my body with never-ending twitches, tugs, cramps, electric-like shocks, jerks, twitches, tingling and prickling sensations, numbness, temporary paralysis, extremes in hot and cold, shakes, throbbing, twitches. This invader's attack, however, was invisible to the untrained eye. People asked me how I felt, and when I tried to explain, they looked at me with crazed horror. The conversation usually stopped. Sometimes I received strange unsolicited advice—colon therapy, high-powered vitamins that a family member sold, acupuncture, stress reduction therapy. I soon learned the

proper etiquette for the diseased was to choose carefully with whom one shared one's weird symptoms; even though secretly, I wished to shout to the world that I felt absolutely ghastly and was deeply afraid.

### **REGARDING CHAOS**

Another part of the nightmare was the tremendous gap that existed between what was happening to me physically—the loss of my independent living skills, the loss of control over my body as the result of neurological warfare, my loss of weight, and the insomnia—and my family's perception of me. Part of the problem was the insidious nature of this disease; my muscles fatigued and swiftly vanished on a daily basis. Evening dinner consisted of deliveries from fast food eateries. On my own during the day, I lost muscular strength. I was without means to open cans or prepare my lunch. My family and I communicated about aspects of my illness, but somehow, actual information about my swift transition to a state of dependence was nonexistent. I was declining daily and yet my family was oblivious to this fact. I still wonder why and how all of this happened. Perhaps through the stages of isolation and silent anger, I was incapable or lacked the energy to communicate this fact to my husband.<sup>7</sup> Or perhaps I did communicate my state, but, because of Tom's denial and his hope in the right medical treatment, my intelligent, analytical husband failed to comprehend my dire circumstances. One friend described our crisis situation with the following: "I felt she was dying right in front of us and there was nothing we could do—this was when she was taking the first treatment. I cannot imagine that she and her family did not feel just as helpless."

### **REGARDING DEPRESSION**

Depression. The word has a new meaning to me. Leonard Cammer describes a person suffering from depression as one who "wishes that he had never been born or could return to nonexistence."<sup>8</sup> When I was ten years old, my mother was hospitalized for a nervous breakdown and depression. My parents had shared little about her story, but I knew my mom experienced a tragic childhood, losing both parents before she entered adolescence. Mom died in her early sixties as the result of a heart attack, complicated by obesity and diabetes. I assumed that I resembled my tall, lean, stable dad. However, after more than a year of living with this invader inside my body and taking high dosages of steroids, full-grown depression controlled my very personhood, soul, and spirit. I was powerless, incapacitated by depression. In the beginning stages, I was unable to concentrate; I was irritable, sad, and utterly hopeless. With time, I even became paralyzed, unable to make even the simplest decision, and had an irrational panic of being left alone.

I envisioned myself as swirling into a deep, black hole, completely unable to emerge—always feeling isolation, paralysis, fear, gloom, dread, and hopelessness. I was convinced that my husband of twenty-five years was going to leave me, and that it would be better for all concerned if I simply disappeared. Self-pity reigned. Previously, the children knew me as an encouraging mom on whom they could count. Tom recalled that my pessimism in this illness was the most fundamental change in our relationship—a huge change. Tom said there was "a time when Sheila couldn't give anything."

All day I would anxiously watch the clock's minutes slowly tick by and wait for Tom's arrival. I yearned to be smothered by his attention. He remembered the time that he asked the psychotherapist about my pessimism. I always saw the cup half empty; he saw the cup half full. We had both heard stories about people who would visit sick people; the ill person had such a positive disposition that the visitor left feeling better than before the visit. I was not a cheerful sufferer. Tom wondered when my attitude was going to change.

### **REGARDING GLIMMERS OF HOPE**

At Yosemite, soon after hearing the possible diagnoses, I decided to prove to myself that things were not that bad. While some people skied, I went on a vigorous, long hike by myself on the valley floor. Under Yosemite's mighty fortress, I walked hand in hand with God, meditating, contemplating, praying and bargaining.

Worship took on a new meaning. The songs “Peace Perfect Peace”, “It Is Well with My Soul”, and “O Lord Take My Hand” touched my raw spirit. The prayers, the communion, the fellowship, the scriptures all were experienced with a fresh, new significance—significance I would never forsake.

### **REGARDING AGAPE LOVE**

During this period, two other blessings were paramount. On a moment’s notice, my very special mother-in-law would respond to our cries of panic and spend a couple of weeks bringing nurture and order to our home’s disarray. Also, the Culver Palms Church of Christ, recognizing our needs, began to bring us dinner at least twice a week—a practice that continued for almost a year. Our neighbors also organized meals. All of my children related that they were amazed at the church’s response and would never forget it. I was reminded of Paul’s words in Galatians 4:14: “Even though my illness was a trial to you, you did not treat me with contempt or scorn. Instead, you welcomed me as if I were angel of God, as if I were Christ Jesus himself.”<sup>9</sup> Prayers from around the world, hundreds of cards, thoughtful, unique acts of mercy, and weekly meals made my illness bearable for my family. Tom and I will be forever grateful for the powerful witness of God’s people to us personally.

### **REGARDING MIRACLES**

After six weeks of being severely sleep-deprived from steroids—similar to having twelve cups of coffee running through your veins on a daily basis—Dr. John Scott, a Christian psychotherapist, personally recorded two cassette tapes on which he related the twenty-third Psalm to speak to my sleep-deprived spirit. He also brought me in contact with a healer, Dr. Donald Blake, a counselor who specialized in working with people experiencing catastrophic disease. Tom and I became true believers in the helpfulness of the therapeutic process. In time, with increased trust, he used my images of Jesus as the light and the rock to heal my weary body and spirit.

Tom invested himself in lifting me out of the grips of my despair. He left me notes with references to verses in the Psalms. He rented and borrowed funny movies. Every three months he took me on a weekend trip to give me a change of scenery. I was like a sponge—the more Tom gave to me, the more time I demanded. My fear of having a nervous breakdown like my mother had intensified; yet I staunchly refused to take any more medicine. Finally, through a trusted friend’s persuasion, I started taking anti-depressant medication that brought me out of the pit. Once again, I grasped hold of hope. My life changed dramatically. I remember the first time I laughed again because Emily remarked with surprise, “Mom, you’re laughing. You haven’t laughed in a year.” I had been on the new anti-depressant drug for approximately three weeks. Thanks be to God.

My trust in my new physicians and the glimmer of hope I felt for a possible treatment challenged me to move from my invalid state and attempt some normal activities again. The progress was slow, but in fourteen months, I saw an incredible difference. For the present, the Force had lost the battle. To me hope in the Lord was the essential ingredient. “Without hope we cease to try. Without hope we become mired in our problems. Without hope we despair. We always look to evidence for our hope. The prime evidence in counseling is a change in our behavior, or a change in our feelings. Hope is not a vacuum.”<sup>10</sup> “We also boast in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope” (Rom 5:3–4). I had read these scriptures for the last two years perplexed as to their meaning. Only now was I even beginning to comprehend.

### **REGARDING THE SEARCH FOR MEANING**

Emily seized on the idea: “If you didn’t have a spiritual relationship with God, our family probably wouldn’t have survived it . . . if Dad hadn’t wanted to help . . . if Mom hadn’t had a reason to live, she wouldn’t have fought hard . . . we had prayers from all over the country.”

I think my oldest son, Luke, who lives daily with epilepsy and knows first hand how difficult it is for your body to be out of control, states it best. He explains, “Crises, they are a part of life. There are going to be struggles on earth—we can’t complain because Jesus went through a lot more than we did. I will always have faith in God. When Papa died, my faith was jarred. God has a reason for everything. [We] don’t understand everything, but we understand enough that we’re able to trust God.” Thanks be to God!

As far as what I have learned, I agree with Mark Peachey, a minister who died after a bout with cancer. Peachey called illness “God’s megaphone”—a time for listening.<sup>11</sup> I have learned and heard things from God during this period that I had never heard before. But honestly, neither Tom nor I would ever choose to go through this experience again, although we probably will. We no longer have a romantic view of pain, illness, or crisis. My vulnerability, my “humanness,” and my feeble faith remain painful reminders of God’s grace, sovereignty, and power. Post illness I view myself as more compassionate and more realistic. Life is bittersweet. Daily I determine to find joy, to frequently laugh, and to pray for a balanced outlook.

### REGARDING VICTORY

I feel that during this siege, I came face to face with the essence of evil—Satan and his spiritual hosts—but I also came face to face with the grace of the Lord God Almighty. Intellectually, I know my God is far superior, but I will never forget the utter darkness of evil. Having confronted these two eternal superpowers and periodically struggling with loss of muscular strength and mobility, my life continues to face challenges. Thankfully, God continues to transform my life on a daily basis. My God, the Lord God Almighty, has worked before my illness, in my illness, through my illness, and after my illness. Thanks be to God, the power who turns darkness into light.

#### SHEILA BOST

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#### ENDNOTES

- 1 Virgil Fry, *Disrupted: Finding God in Illness and Loss*, Nashville: 21st Century Christian, 1999), 15.
- 2 Cheri Register, *Living with Chronic Illness* (N.Y.: Bantam Books, 1987), 73.
- 3 *Ibid.*, 7.
- 4 Bernie Siegel, *Love, Medicine, and Miracles* (N.Y.: Harper & Row, 1990), 172.
- 5 *Ibid.*, p. 172.
- 6 Register, 23.
- 7 Elisabeth Kubler-Ross, *On Death and Dying* (N.Y.: Collier Books, 1993), 34.
- 8 Leonard Cammer, *Up From Depression* (N.Y.: Simon and Schuster, 1969), 18.
- 9 Taken from Mark Peachey, *Facing Terminal Illness* (Scottsdale: Herald Press, 1978), 28.
- 10 Rebecca L. Propost, *Psychotherapy in a Religious Framework* (N.Y.: Human Sciences Press, 1988), 47.
- 11 Peachey, 22.

