

## Making Sense of Suffering

*Marilyn Damron White*

MY TALE BEGINS IN 1983—the year I turned thirty years old. It was definitely prime time. I had (and still do have) an incredibly fulfilling marriage with my husband, Lee. Our poverty-stricken years in graduate school with very small children were dimming, our three girls were getting settled into day care and school routines, and I was starting a part-time but seemingly glamorous and progressive job-share situation with my sister in the financial department of Huntsman Chemical Corporation.

But our 1984 Christmas letter was a catalogue of disasters. Our usually stalwart Subaru threw a rod and needed a rebuilt engine, new carburetor, and alternator. Total bill—over \$2,000. Lee had a positive job interview with the American Red Cross. However, after keeping us dangling for three months, their final answer was, “We’re hiring someone else.” After nine months, my boss told me he needed more continuity and fired me. And I spent my thirty-first birthday enduring three days of Demerol-induced hallucinations in the hospital before doctors finally operated and discovered that my appendix had been ruptured for those days. However, the real upheaval came in December of 1983 when the right half of my face became numb. When the pins-and-needles feeling hadn’t subsided by the fifth day, I pulled out the household medical dictionary, compared symptoms with a friend who had had Bell’s Palsy, and went to a neurologist. In brief, Dr. Michael Goldstein told me, “No, if you had Bell’s Palsy, the muscles in your face would be drooping. You may have one of four things: a

---

*MARILYN DAMRON WHITE is editorial assistant for DIALOGUE. She is currently a stake Primary music leader—the second-best calling in the Church, next to ward Primary music leader. A version of this essay was delivered at the August 1991 Sunstone Symposium, Salt Lake City, Utah.*

brain tumor, an aneurism, multiple sclerosis, or something undefinable. But my guess is that you have MS. You should hope for MS. It's better than the alternatives. Your symptoms will get worse before they get better, but they will eventually get better. You may have a series of diagnostic tests that will cost between \$800 and \$900, or you may go home and do nothing until you experience another symptom—maybe years from now."

I placed a shaky phone call to Lee, and we decided to have the tests. A CAT scan was done immediately. After a short wait while a few doctors conferred, Dr. Goldstein told me they were going to do it over again because of "irregularities" in the read-out. This I assumed was a euphemism for "brain tumor," which made CAT number two emotionally wrenching.

Fortunately, the CAT scan ruled out a brain tumor or aneurism, but the neurologist's original suspicion of MS seemed more likely. I knew little about MS—except I surmised its victims would likely end up in a wheelchair like a woman I'd met in childhood who ultimately was unable to care for herself. Those prospects scared me more than a brain tumor, which I thought could just be removed, so I was baffled that MS would be more desirable on a list of "Top Ten Diseases You'd Most Prefer If the Choices Were Limited."

Lee had excused himself from his weekly meeting as second counselor in the bishopric to be home when I arrived after the scan, but he immediately suggested we go over to the ward and have the bishopric join him in giving me a priesthood blessing. I admit some minor trepidation in receiving a priesthood blessing. A few years of feminist consciousness-raising had left some pent-up anxiety regarding exactly what the priesthood was, how it differed from basic faith, but, more important, how I as a woman interacted with priesthood. But anxiety over probable MS far outweighed priesthood anxiety, and I wanted a miracle—not MS. If I just had enough faith to be healed, my next doctor visit would reveal no symptoms and the doctor would shake his head in amazement. I was sure I could muster enough faith. Hadn't I glued minuscule mustard seeds on 3 X 5 cards for Primary classes with the verse from Matthew 17:20 typed neatly below, telling the children with firm conviction that if they just had enough faith, nothing was impossible to the Lord? I envisioned retelling my own miracle countless times before spellbound audiences.

Soon after the blessing, I recorded in my journal feelings and even words that came into my mind during the blessing. Those words have alternately aggravated and sustained me. Essentially Lee said that I was ill, but the doctors would not be able to diagnose what I had. I remember that the thought, hope, impression kept repeating itself in

my mind, "You don't have MS. You don't have MS." In retrospect I can see how easy it was to make this leap in logic—if doctors couldn't diagnose what I had, it must not be MS. Thus, I felt assured what I had was on the doctor's "undefinable" list. But I was nagged by the words that came into my mind during the blessing—"Even though you do not have MS, *if you do have it* or any other chronic illness in your lifetime, it will not destroy the essence of who you are, and the Lord will always provide comfort and peace—whatever the circumstances." I was very reassured though somewhat baffled by the phrasing, "if you do have it." I *knew* from that very blessing I didn't have it! Looking back I realize I mixed a heavy dose of wishful thinking with the deep whisperings of my faith.

The numbness on the right side of my face and head did, indeed, get much worse and more unpleasant, as the doctor predicted. And, as Lee predicted, doctors were unable at the time to pinpoint a diagnosis. The ordeal was definitely frightening, especially when I had a few days of nauseating double vision and dizziness. But at the height of the sickness, when I couldn't even navigate by myself down a hallway to the diagnostic area, I tested out normally on an audio-visual test for MS called "Evoked Potential." I will never forget sitting with Lee, waiting for the test results. My head was spinning so rapidly that I could only squint at Dr. Goldstein as he strode in wearing his white coat to announce rather loudly to a room full of people and with unabashed frustration, "You have passed the Evoked Potential test. I don't know what the hell is wrong with you." It struck me as morbidly funny—black humor in action. And it was the first time in my life I understood that doctors were mere mortals—that they couldn't always make everything better and were just as frustrated as I was.

Completely baffled that I passed the test, Dr. Goldstein still wanted to do a spinal tap for more definitive results. Because I was so sure a spinal tap would be unnecessary torture when the Spirit had already told me that I didn't have MS, I declined the procedure. I have since discovered that even the spinal tap may not have been conclusive. Dr. Goldstein's last comments, after assuring me the symptoms would diminish, were, "What you don't know won't hurt you. But if you ever experience similar symptoms, you should come back for the spinal tap."

With some faint, residual numbness on the right side of my face which has lasted to this day, my life gradually returned to some semblance of normalcy. In fact, I went right from employment at Huntsman Chemical to my "job-ette" (as Lee dubbed it) for about three years as the six-hour-a-day executive secretary for Jim Kimball and Bob Guymon at Kimball Travel Consultants. The salary was good and the unequalled travel perks—to Washington, D.C., California,

Vancouver, the Carribean, London, and Switzerland — are now etched in my memory. However, mostly because of deregulation of the airlines, the days of specialized travel agencies were fast drawing to a close. Jim merged his agency with one that has since merged again. I was lost in the shuffle but kind of happy to be home with my family more.

It doesn't take long for financial realities to catch up, though, and Linda Newell (for whom I had typed the *Mormon Enigma* manuscript) took me under her wing again for part-time employment during Linda and Jack's editorship of DIALOGUE. It also seemed like a good time to have one more child. And, even though I was six months pregnant during the summer of 1987, Jack Newell offered me temporary full-time employment at the Liberal Education department at the University of Utah.

After David's birth in September, I set up shop again at home. I replaced my electronic typewriter with an IBM computer and a laser jet printer. A new baby and freelance word processing for attorneys, engineers, students, and, of course, DIALOGUE kept life at its usual frenetic pace. However, the most serious crisis of my faith was looming, when, at the end of January 1988, when David was four months old, I began to lose feeling in my right leg from the knee down. I went into an emotional tailspin. If Lee and I had known that I had MS, we would not have considered another pregnancy. (Within three to six months after a birth the likelihood of an MS attack or exacerbation increases, while during pregnancy most women improve.)

This time, medical technology had a new diagnostic tool, Magnetic Resonance Imaging. The MRI scan confirmed MS on February 5, my second daughter Shannon's eleventh birthday. Lee and I sat on the bleachers at the Cottonwood Complex, watching her ice skate with her friends and reading brochures about MS. We knew that our lives would be dramatically altered. While there is controversy about the cause, MS is a disease of the central nervous system where the fatty coating of insulation around a nerve cell (the myelin sheath) is gradually destroyed—causing paralysis, numbness, and/or impaired sight, speech, hearing, and balance. A demyelinated nerve fiber cannot carry impulses to and from the brain. Every week in the United States an average of two hundred people are newly diagnosed with MS.

According to the literature and my current neurologist, Jack H. Petajan, patients face one of three futures: (1) about one-third experience exacerbations but recover completely and retain a high level of function, (2) about one-third do not recover completely from exacerbations and acquire neurological deficits over time, and (3) in about one-third, the disease progresses slowly without remission and may

increase in severity as well. Also, exacerbations decrease over time: two to three episodes per year during the first one to three years and less than one per year by the fifth year. The long-term course of the disease is established by three to five years in most people, and a young female has the best prognosis for recovery even though twice as many women as men contract MS. In males the disease is more likely to be progressive. Despite some lingering neurological deficits, it appears I am in lucky group number one, but at the time I was unaware of my ultimate providence.

For the next five months, I cycled through the symptoms. Most of them lasted about six weeks, a new one emerging just as another was subsiding. Here are some excerpts from a brief medical history my mother encouraged me to record as soon as I felt well enough. Since manifestations of this disease are never the same, I don't list these symptoms as a guide or as a comparison to anyone else but simply to provide a sense of what transpired in my case:

February 6-7—Major bout with dizziness and vision distortions—most comfortable on floor (as opposed to water bed); even slightest movement of eyes nauseating. Overwhelming fatigue—sleeping 10-14 hours per day.

Feb. 11—Still trying to complete an Honors Fine Arts Liberal Education class this quarter. Went to *Giselle* with Shannon for extra credit, but holding onto handrail and very dizzy and weak. Stupid thing to do. Did not drive after that night for three months. Feeling guilt about inactivity as Young Women's first counselor, but unable to let calling go just yet.

Feb. 18—Left ear starts ringing. By the 28th both ears ringing loudly during the day at a constant high pitch. Fatigue is so overwhelming, though, can usually block the ringing enough to sleep.

Feb. 25—Called an ear, nose, throat physician who informed me coldly over the phone, "MS patients can go deaf." First time I realized I was probably losing a portion of my hearing. Handwriting shaky and hands trembling at computer.

March 15—Went with Lee to see *Death of a Salesman* [that Lib Ed credit was hard to give up] but left after first act because of hearing distortions. Shooting pains down back, arms, and legs. Lee leaves town for three days. Assured him I'd do OK and call relatives for help if needed but spent scary nights as equilibrium still poor and David still nursing but not sleeping real well.

April 1—Mom comes from California. Must hold onto people to move.

April 8—Slurred speech begins. Now in addition to referring to me as "Sidewinder," we laugh through our tears as family mimics the unintelligible syllables.

I gradually improved over the summer, and even though I haven't had any major exacerbations in the last four years, I constantly have what I've dubbed "gentle reminders" (and one not so gentle) that the illness still lurks. And, I've lost a slight percentage of normal capacity in specific areas that were affected in 1988—vision, hearing, walking

(I drag my right leg after about twenty minutes of walking or light exercise). I also have poor balance and general klutziness.

This disease is particularly insidious, though, because it looms like a coiled snake biding its time before striking. One of the most poignant descriptions of MS I've ever read was written by an unidentified woman in Bernie Siegel's book, *Peace, Love and Healing*. She compares MS to "an inactive volcano. . . . At first it sits there blowing just enough smoke to be irritating. And I feel safe during these times. When the main eruption begins, I want to flee and get off the island. [But] there is no place to escape to" (1989, 54). I know that fear, that frustration, that terrifying helplessness of not knowing what damage will be done or how long it will last.

Two episodes have affected what sense I can thus far make of what happened. The first was a comforting experience with prayer, which came the day after the diagnosis was confirmed—when I was still asking, "Why me?" instead of "Why not me?" Not only was my right leg completely numb, but the dizziness and loss of equilibrium had begun. I was alone at the kitchen table—confused, depressed, and ill. I prayed that I would be able to cope with whatever came but wanted some relief, too—or at least an indication that the Lord had not abandoned or betrayed me. When I finished the prayer, an unusual sensation filled my body, and I felt the symptoms lift. My leg felt whole, and the dizziness stopped. I walked around the room normally for a moment. While I was marveling that this had happened, an even stronger impression consumed me. I sat back down. Somehow, intuitively but inexplicably, I knew that this absence of symptoms would only last for a few minutes, that it was strictly a gift to let me know the Comforter was near. I felt a caution, too, that almost bordered on rebuke, that I should not ask inappropriately. When we agreed to come into mortality, we accepted that conditions would not always be easy. I wept and silently said another prayer of gratitude for the knowledge that the Lord was with me no matter what I experienced in this life. In only about five minutes the symptoms returned.

I have analyzed—perhaps even overanalyzed—this experience. Was I part of the "wicked and adulterous generation" that seeks for a sign? Was my motive pure? Was I seeking for a sign or just some comfort? Besides, can we really ask "inappropriately" for relief? Aren't we supposed to "ask and it shall be given," or are there some things in life we should just accept as gracefully as possible even though life is not fair or easy? How do we know when we're asking for too much? Should we know God's will *before* we ask? I have no answers, only more speculation and more questions. I do know that I received a sign and witness of God's love, a very personal and sacred experience for me. I hesitate

sharing it publically since I can't adequately explain the impressions, but I've finally stopped trying to scrutinize. I just gratefully accept that specific communication to me as a gift.

The second incident happened the very next day on Sunday, 7 February 1988. The incongruities make this incident especially ironic, instructive, and poignant for me. I was lying on my bathroom floor, so dizzy and weak that I could not stand. Even shifting my eyes triggered nausea. But I was mentally composing yet another letter to my stake president, who was being released that morning after ten years of service. This president and I agreed on very few issues. But we had developed a tolerant, and even friendly, relationship over the years—especially after I learned years before to save time by addressing letters to him with copies to Gordon B. Hinckley and Thomas S. Monson because letters to them would just be channeled back to him anyway. That way he wasn't caught off guard quite so dramatically.

Lee and I had been to see him just before David was born to discuss a letter I had written, asking permission to stand in the blessing circle when Lee named and blessed our child. President Z, as I will call him, read to us a letter signed by Ezra Taft Benson, Gordon B. Hinckley, and Thomas S. Monson telling him to instruct me that I was not to participate in any way in my son's blessing and explicitly stating that he was to *read* the letter to me; under no circumstances was I to have either the letter or a copy of it.

President Z then defended the Church's point of view, which was also his own. He believed the Church should never have allowed nonmember or inactive fathers to participate in blessing circles and hoped the policy would shift back to allow only Melchizedek priesthood holders. He further hoped I would not worry about women and the priesthood and added that the most important thing to worry about was having a healthy baby. Despite my disappointment, I, as usual, felt his sincerity, guileless nature, and deep love for the members of our stake. He never seemed contrived or manipulative. Invariably when bearing his testimony at stake conferences, he would choke up with emotion and conviction. Before being called as stake president, he had been our stake patriarch—a calling which carried a lot of spiritual clout for me.

At the end of our discussion, to emphasize life's fragility and to help me see that a healthy child was more important than the form of a blessing, he shared a personal story. With tears flowing, he told how his own son, a star of Highland High's football team, died of a blood clot during his senior year. President Z had felt no sense of urgency when he went to the hospital to bless him and had no idea his son would be dead within a couple of hours. Just a couple of months ear-

lier, President Z had healed another boy of rheumatic fever after the doctors had indicated there was no hope. Surely the Lord would indicate when there was trouble in his own family.

Lee and I left this interview frustrated, as usual, but, also as usual, not bitter. I was thinking about President Z's son as I lay on the bathroom floor and composed my letter. When I could sit straight, I typed it out. I related the details of my first blessing from Lee four years earlier and then asked how he reconciled his blessing of his son with his death. A few days later, in response to my letter, President Z telephoned, then came to see me. He asked if he could give me a blessing. I said yes. He blessed me that the disease would not seriously debilitate me, that I would "have the desires of my heart granted" and "live to raise my children." At that part, I began crying, yet I had never seriously thought MS would kill me early. My patriarchal blessing promises, "You shall not die before your time." I had always laughed about this line. When your "time" comes, don't you go—whether you're young or old? Yet in my illness and at the time of that blessing, I interpreted it to mean I would have a long, full life.

In conversation, President Z speculated that the reason the MS could not be diagnosed in 1983 was that the Lord wanted to send us David. Even though that explanation is a comforting one, I think it's too easy. The God I believe in would not deceive me about an illness to ensure I would get pregnant later because he's assigned us one more spirit. The misunderstanding was my error, not God's deception.

So where am I now? Do I feel blessings don't work? Let me say that my understanding of blessings has changed, but my faith in them has not diminished. I had two more blessings from my husband during 1988 when I became so depressed I contemplated suicide. Those blessings unquestionably calmed me. I now feel blessings are basically intended to console and comfort. Occasionally we might experience a healing miracle—but we should accept it as that—a miracle. You can hope for a miracle, but you can't make one happen. And you're not a failure if a complete healing isn't forthcoming. Harold Kushner in his book *Who Needs God* thinks that miracles also come in other forms when death and other devastating events occur:

The miracle is that the faith of the community survives, that they are able to go on believing in the world and the value of prayer, even when they have learned that this is a world where innocent children die. . . . I have seen weak people become strong, timid people become brave, selfish people become generous. I have seen people care for their elderly parents, for brain-damaged children, for wives in wheelchairs, for years, even decades, and I have asked myself, Where do people get the strength to keep doing that for so long? (1989, 137)

Kushner concluded that strength comes by turning to God. I wholeheartedly agree and would add that strength and miracles also come from long discussions with caring, supportive people—whether it be friends, relatives, or medical professionals. Once, when I felt I just couldn't hang on any longer because of the continuous ringing in my ears, Lee encouraged me to “dig deeper” than I ever had before to find the resources to deal with physical and emotional pain. That conversation, probably as much or more than the blessings, helped me cope.

I also discovered that there are some facets of my illness I can control and some I can't. I can strive for peace of mind even though I am panicked. I can choose to be loving instead of embittered. But I have less or no control over what the disease does to my body. Special diets, primrose oil, and visualization didn't work well for me. I couldn't stop my ears from ringing or my head from spinning. And I came to the realization that more faith, more family home evenings, daily scripture reading, or more dedicated visiting teaching wouldn't have made any difference to the progress of the disease. Those are good things to have and do, and I want to be diligent. But I don't believe there's a direct link between a checklist and a conduit to heaven.

I'm also getting more comfortable with the notion that I will never completely make sense of the suffering I see in the world. Life is not fair, and there are myriad shades of gray. The pressing question becomes, can I accept the ambiguity and vulnerability of this life without needing absolute, comprehensive answers? Since I'm not a very patient person, it is hard for me to accept the waiting and uncertainty which this position imposes. But I also cannot accept the converse, dogmatic position that Mormons have the answers to all of life's complexities and a monopoly on truth. Can we as thoughtful, believing Mormons be content with *not* having answers to everything? I hope so.

I have emerged from this ordeal convinced that God does not grant us life with a full script from start to finish. We need to define the meaning of our lives according to our individual experiences. We not only experience life differently; we interpret our life experiences differently. But it is that interpretation which strengthens our individuality and defines our very being.

Gilda Radner, during her struggle with cancer, wrote:

I wanted a perfect ending, so I sat down to write the book with the ending in place before there even *was* an ending. Now I've learned, the hard way, that some poems don't rhyme, and some stories don't have a clear beginning, middle and end. Like my life, this book has ambiguity. Like my life, this book is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. Delicious ambiguity. (p. 268)

That quote accurately sums up my feelings. I don't think I'll ever make complete sense of suffering or comprehend the intricacies of priesthood blessings—and I desperately want to make sense of those things. I want tidy answers to theological paradoxes. I relish spirited religious debate and feel compelled to write letters to authority figures when I perceive injustices in my Church. However, no longer do I think criticism of Church leaders (constructive though it may be) or vociferous opposition to them will ultimately effect changes. What I have learned dealing with multiple sclerosis convinces me that I must learn to truly accept and even celebrate life's delicious ambiguities, injustices, and inponderables.

I feel with Kushner that looking for answers means looking at what we mean by "answers":

If we mean "is there an explanation which will make sense of it all?"— why is there cancer in the world? Why did my father get cancer? Why did the plane crash? Why did my child die?—then there is probably no satisfying answer. We can offer learned explanations, but in the end, when we have covered all the squares on the game board and are feeling very proud of our cleverness, the pain and the anguish and the sense of unfairness will still be there.

But the word "answer" can mean "response" as well as "explanation," and in that sense, there may well be a satisfying answer to the tragedies in our lives. The response would be . . . to forgive the world for not being perfect, to forgive God for not making a better world, to reach out to the people around us, and to go on living despite it all. . . . I think of . . . all that . . . life taught me, and I realize how much I have lost and how much I have gained. Yesterday seems less painful, and I am not afraid of tomorrow. (1981, 147-48)

My hope and prayer and blessing for all of you is that you can look ahead with optimism, forgiveness, and love. And I bless you that, difficult as it may be at times, you can savor the ambiguity that life holds in store.

#### BIBLIOGRAPHY

- Kushner, Harold S. *When Bad Things Happen to Good People*. New York: Avon Books, 1981.
- . *Who Needs God*. New York: Summit Books, 1989.
- Radner, Gilda. *It's Always Something*. New York: Simon & Schuster, 1989.
- Siegel, Bernie. *Peace, Love, and Healing*. New York: Harper & Row, 1989.