STILL MAKING SENSE OF SUFFERING: RUMINATIONS ON THIRTY-FIVE YEARS WITH MULTIPLE SCLEROSIS

Marilyn D. White

My article "Making Sense of Suffering" was published in *Dialogue*'s Summer 1992 issue. It detailed my journey of coping with multiple sclerosis. At the time of its publication, I was working for *Dialogue* as an editorial assistant, back when Ross and Kay Peterson were at its helm. As I reflect back on that experience, the thing that stands out most clearly is a profound answer to a prayer the day after the MS diagnosis was confirmed in 1988—although I had been experiencing symptoms as early as 1983 before MRI machines were used for diagnostic purposes. MS is a very complicated illness because, although they share many things in common, every sufferer has a unique manifestation. My 1992 essay explained it this way:

> 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.[1]

Above all else, I am still here! While the disease has forced me to adapt to painful losses, I have survived and argue that I am stronger because of experiences with MS. MS is considered to be an autoimmune illness

1. Marilyn D. White, "Making Sense of Suffering," *Dialogue: A Journal of Mormon Thought* 25, no. 2 (Summer 1992): 110.

where a body's own immune system attacks itself. The National MS Society website clarifies further. Here is a snippet:

> An exacerbation of MS (also known as a relapse, attack, or flare-up) causes new symptoms or the worsening of old symptoms. It can be very mild, or severe enough to interfere with a person's ability to function. No two exacerbations are alike. . . . In the most common disease course in MS—called relapsing-remitting MS—clearly defined acute exacerbations are followed by remissions as the inflammatory process comes to an end.[2]

In 1988, I was just beginning a very severe exacerbation that started with balance problems, but over the next several months would cause vision problems, loud ringing in both ears, dizziness, and slurred speech. The confirmation of my diagnosis came to us by phone on February 5, 1988, my daughter Shannon's eleventh birthday. The next day I was alone for a short while in the kitchen. Quoting again from my essay:

> 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

2. "Managing Relapses," National Multiple Sclerosis Society, https://www.nationalmssociety.org/Treating-MS/Managing-Relapses.

> 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.[3]The knowledge and comfort received from this supplication has shaped my faith ever since. I believed that God had not abandoned me and He knew the desires of my heart. The optimism and faith conveyed in that 1992 article is still valid, but much has gone on in the twenty-five ensuing years to keep me pondering and reevaluating. I have constantly had to be flexible and adapt at each level of decline. For many years, I was considered to be in the exacerbating/remitting category. Now I am in a wheelchair—although it will be comforting to others with MS to know that only 25% of people with MS end up in a wheelchair. Now with disease-modifying drugs, I am hopeful that percentage will be much less.

It was fortuitous that my husband, Lee, was transferred by his employer AARP to Seattle, Washington in 1995. The Pacific Northwest is an ideal location for MS sufferers. It has an extremely high percentage of MS patients and some of the best physicians and therapeutic regimens in the country. My daughters were aged twenty, eighteen, fifteen, and my son was seven. I was still walking with just a slight limp. If someone didn't know me well, I could keep my diagnosis hidden. Not so anymore.

I was still driving, but had switched my frequent form of working-out from bicycling to snorkeling at a pool three minutes from home in a picturesque state park. We also surmised that the exercise provided in

3. Ibid, 112.

the five-level home we purchased would be good for me. My mother-in-law was more prescient when she toured the house later and said to her son, "What the hell were you thinking?" By March of 1996, I bought my first manual wheelchair for long distances only, and the house soon got two chair lifts to access three levels of the house.

For my life with MS, 1997 proved to be a pivotal year. My coordination sharply slipped and I crashed the car from the garage into the family room level and spent a night in the hospital. At that point, I started using car modifications and learned how to drive with hand controls. I drove four different modified cars until, fortunately for others, I gave up my license in May 2003.

Before the end of 1997, I had three major exacerbations and had three hospitalizations getting infusions of prednisone each time. The swift decline was terrifying, but the FDA had given approval for three disease-modifying drugs known as the ABC drugs—Avonex, Betaseron, and Copaxone. (Now there are fourteen.) For three years, I gave myself weekly injections of the $24,000 per year Avonex. After all that time and needle-pricked thighs, my doctor and I discerned no easing of symptoms. We can only guess at what the drug might have prevented.

I was getting desperate when I heard about an exciting clinical trial and embarked on one of the most significant ordeals of my life. I was in a group of about twenty-five people accepted in one of the first experimental stem cell transplants for MS in the world. The doctors knew a reversal of neurological deficits already incurred was impossible, but the hope was to stop further disease progression. My physiatrist (a doctor of rehabilitation medicine), Dr. George H. Kraft at the University of Washington, was on the cutting edge of this clinical trial.

On a ten-point disability scale, a patient could not be worse than an eight to be allowed to participate. In the year 2000, when I got to a seven, then to seven and a half, I persuaded Dr. Kraft that I fit the criteria for eligibility. He finally relented. The first step was to get funding for the $150,000 procedure. "Go Fund Me" was not in

existence then and bake sales would not bring in enough money fast enough. AARP had a self-funded health insurance plan with Cigna, and I had a remarkable Medical Case Manager named Teresa Wachs. She knew the procedure would be denied but said, "I'll help with the appeals process every step of the way." Teresa was good to her word. I wrote an appeal statement, which Teresa expertly edited to persuade the insurance company to bankroll my request. Dr. Richard Nash, with Fred Hutchinson Cancer Research Center, also contributed his justifications. We were on a conference call with about fifty doctors and nurses in attendance from California on Cigna's Appeals Board. We each had ten minutes to separately make our pitch.

Teresa called me later to tell me they hadn't been able to reach an agreement and were sending it to three outside expert reviewers. A few weeks later, I saw her coming up to my house with helium balloons! Apparently, one reviewer had said "No," another "Yes," and the third, "It shows promise." So, they allowed AARP's executive team to make the final decision that turned out to be in my favor.

My prayer was answered, but the next step was, of course, the most grueling. Since Lee traveled extensively, my daughter, Aimee, postponed a quarter of college to be my chauffeur and support for the many weeks of testing prior to the chemotherapy and total body irradiation to come. It was an autologous transplant (meaning the doctors used stem cells harvested from my blood) to prevent problems that generally come when an outside "host" is used. A Hickman catheter was implanted near the heart for ease of blood work to facilitate the process of spinning out exactly the cells they wanted. Each day several of us were lined up in open cubicles to have our blood drawn and analyzed. It reminded me of cows coming for their daily milking.

After they harvested the right quantity of stem cells, they destroyed my dysfunctional immune system through chemotherapy and total body irradiation. I then spent three weeks in quarantine in a gigantic room on an upper floor of Swedish Hospital. I was in the middle of downtown

Seattle skyscrapers overlooking Elliot Bay, watching all varieties of birds fly by at eye level. In those days before smart phones, computers had been donated in the room of each transplant patient.

The chemo caused nausea and painful mouth sores, but the radiation was more tolerable to me. One morning however, I woke up after radiation with brittle hair all over my pillow and an itchy scalp. Aimee took an amazed look, calmly walked to my bedside, and pulled out a huge handful of hair. Another daughter, Shannon, teared up, but Lee, Aimee, and I burst into laughter as we all grabbed and yanked. A nurse stood by with an electric shaver to remove the rest. It felt wonderful to get all the dead hair off.

On May 8, 2000, a man in a business suit came striding into my room with a suitcase containing a vial of my new baby stem cells ready for infusion. He and the nurses called it my "New Birthday," and wrote May 8 prominently on a dry-erase board. After my release from the hospital and experimenting with head coverings, I started the slow process of regaining strength and growing new hair. In spite of it all, there was decline. Dr. Kraft was disappointed. On one visit, he put his arm around me and said, "I'm sorry it wasn't as successful for you as it has been for my younger participants. I'm not accepting anyone over fifty anymore." I said, "But I'm only forty-eight," to which he retorted, "You're almost fifty."

Lee and I are not so sure that the transplant hasn't been successful, and time has confirmed our conclusion. My MRIs have shown no active brain lesions since the transplant. I have not had any major MS exacerbations, even though I have experienced grief from the many losses, indignities, and pain associated with permanently landing in a motorized wheelchair in April 2002. My eleven grandchildren (ages seventeen and under) know me as "Grandma Wheels." I get great joy putting them to sleep as infants while riding them on my lap—or giving them raucous wheelchair rides at five mph when they get older. The disease has taken its toll on me and done permanent brain damage that

no therapeutic regimen can fix. I believe all symptoms and problems I have experienced since the transplant can be attributed to damage done by the MS prior to the procedure.

For instance, in June of 2004 I spent two weeks at the University of Washington Medical Center Rehabilitation Department. Function in my left hand had diminished, and I was trained to use voice-activated software. My years of secretarial typing jobs and piano playing came to an end. I was also preparing to see if I could tolerate the liquid Baclofen that would be injected directly into the spinal column through the implantation into my abdomen of a Medtronic drug pump. Baclofen is a powerful drug that relaxes my skeletal muscles so I can bend my knees. Doctors have now allowed morphine and bupivicane (the numbing drug used for epidural blocks in childbirth) to be added. So I have a cocktail of drugs in the little one-pound metal canister that makes my pain and stiffness much more bearable.

Also making life easier for me (and especially Lee or paid caregivers who *always* needed to be available to transfer me on and off the toilet) was the operation to install a suprapubic catheter. I now have a large urine drainage bag, or a small one hooked up and hidden under my swimsuit for those almost-daily swims. Looking back, I should have had this procedure done years earlier to save many caregivers thousands of transfers.

Something this major is not without its mishaps, however. After some initial glitches in the November 2007 installation, I did have a major scare in April 2013. After my third bladder Botox injection (usually done every six months to calm my spastic bladder), I had a major bladder hemorrhage. It's never good when you see your blood dripping down your wheelchair in the hospital waiting room, pooling on the exam room floor, and hear the ER nurse shout "Stay with me, Marilyn!" before being rushed to an operating room. It was later determined that my regular doctor probably should have used latex

rather than the stiffer silicone tubing when putting in the Botox the day before. The next day she apologized.

Life in a wheelchair made me sedentary and therefore more susceptible to blood clots. Mine came in February of 2009. I happened to be at my pain doctor. When I showed him my severely swollen leg, he said it had nothing to do with my drug pump. He immediately sent me to a clinic for a CAT scan. I started to feel faint as I sat in the waiting room until Lee arrived. I fearfully said a prayer in my mind, but a calm feeling washed over me. I had a sense that at least I wouldn't be dying on *that* particular day. However, it triggered a two-night stay in the hospital after the clot traveled to the lung causing a pulmonary embolism. I now require blood-thinning medication with clinical checks that range from every few days up to every month.

When devastating illness or accidents come along, caregivers are the unsung heroes. Lee is the embodiment of a perfect caregiver. He was able to take an early retirement to help with the household demands and be a very engaged grandpa. He does all the cooking. His patience, compassion, and humor make my situation tolerable. He allowed me to feel part of the wider community when I expressed interest in serving on my city's Library Advisory Board. For four years, he was my ride to and from the library for the quarterly evening meetings. Many paid caregivers through the years have also eased my way. They perform all sorts of ADLs (Activities of Daily Living) and chauffeur me to the swimming pool four days a week. Lee takes the fifth day.

Lee was recently diagnosed with a rare neurological condition called orthostatic tremors, which limits his ability to stand still without shaking. He can instantly diffuse it by moving or leaning against something stable. He waited five years before telling anyone in the family about his symptoms or seeing a neurologist.

It makes us take stock once again of the vicissitudes of life. He said he feels the Lord has given him extra strength to still be able to help with my transfers and anything else I need. But if you think of your life as

a three-act play, at ages sixty-five and sixty-seven, we are both in ACT III—facing all the realities of aging. While Lee spent his career working in the field of aging, we often feel as though we are approaching our later years ill-equipped to meet the myriad of surprises we experience. As most of us realize, life has no guarantees.

My earlier article quoted from Gilda Radner's book *It's Always Something* where she wrote about facing cancer and said, "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."[4]

I have thought about this profound choice of words many times through the years—as it applies to all of us. We live surrounded by paradoxes. The emotional and financial toll in dealing with MS has been challenging, yet we know others are in worse situations. I am blessed that I have adequate health insurance and retirement income.

I value the community and comfort zone I feel in the LDS Church. The hymns we sing give me great solace and often bring me to tears. I worked for Jack and Linda Newell for over a decade in various capacities. They were *Dialogue*'s editors from the last two issues in 1982–1988. The bulk of those years I worked for Linda King Newell as her typist for the book, *Mormon Enigma* (with Valeen Tippets Avery). It gave me a great opportunity to intensely study Mormon history. Therefore, strains of the fourth verse of "Come, Come Ye Saints" that starts, "And should we die before our journey's through, Happy day! All is well!" have intense meaning for me. I consider myself a basically happy person, but sometimes struggle to find joy. I receive loving service from family and church members. Through the miracles of modern medicine, I am allowed to remain alive and a part of my community. I am delighted that stem cell transplants for MS are more common now because I believe it was pivotal to a more positive future for me.

4. Gilda Radner, *It's Always Something* (New York: Simon & Shuster, 1989), 268.

We all make sense of the suffering in our life in various ways. Resignation in the face of adversity helps me embrace and cope with the MS that is so much a part of my outward appearance. The inner me intends to thrive instead of just survive. Through God's tender mercies, the grace of Christ, and the loving service of family and friends, I retain a hope of promising days to come and a firm conviction of what a resurrected body means for me.