
ESSAY/PERSONAL REFLECTIONS

Living with Multiple Sclerosis: A spiritual journey of loss

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I have been living with Multiple Sclerosis (MS) for 20 years. For 20 years I have gone to sleep with MS, awakened with MS, worked with MS, fell in love with MS, got married with MS, went through five miscarriages with MS, gave birth to a beautiful son with MS, raised a son whose life would be marked by the MS of a parent, and most importantly, I will go on living with MS for as long as fate allows. My wife Rachel has MS.

Rachel and I are fortunate. Rachel has a remitting relapsing form of MS that has been mercifully kind to us. Rachel first developed signs of MS when she was 26 years old, but was not diagnosed until age 28 when she developed severe weakness in her right leg and could barely walk. She also developed a neurogenic bladder and has to self-catheterize. I met Rachel at Memorial Sloan-Kettering Cancer Center a year after her diagnosis. She worked there as a social worker. I met her shortly after she stopped needing to use a cane to walk. When people meet my wife they are initially struck with her physical beauty. Soon after, they are overwhelmed by her spiritual beauty and warmth. Rachel's physical beauty did not escape my notice when we first met. I pursued her and soon discovered that she possessed two other miraculous attributes. She was very funny, and she understood that only love was infinite and everlasting.

I remember the night I learned she had MS. I could not tell that Rachel had MS when I first met her. It is not obvious unless one knows. I was searching for a way to tell Rachel about my history of thyroid cancer, fearful that she would be fright-

ened and reject me. She quietly struggled with the same problem; fear of being rejected in love because of MS. After our third date I asked her if she had ever had to deal with a serious illness. She said "yes." I didn't probe further, until the end of the evening when we revealed our "imperfections" to each other. I was relieved, and so was she. I was a bit frightened by the MS. She was a bit frightened by the thyroid cancer. We were "even." I tactfully explained to Rachel that she need not be concerned that I would reject her because of the MS. I told her I was an expert at finding reasons to reject women; the way one walked, the way one kissed, the way one laughed. I explained that rejecting her for having MS was not fair, but that I was confident that, given enough time, I could find some trivial reason to reject her. I never did.

Our courtship years were marked by two episodes of exacerbation of Rachel's MS. They were frightening, and caused great anguish, but they made our love stronger somehow. I was transformed by those experiences and, for the first time, was able to transcend my own personal concerns and truly join with Rachel in a life journey. I married Rachel with the full knowledge that she might one day be wheelchair bound. I had reached the realization that life with Rachel in a wheelchair would be preferable to a life without Rachel in it. From the moment, in 1986, when I placed a diamond engagement ring on her finger, Rachel has not had another serious exacerbation of her MS. Some call it "diamond therapy." I have occasionally attributed our good fortune to the healing effects of love. But I am very aware of the fact that there are so many other families struggling with MS who have just as much love in their homes but are not as fortunate as we have been. I know one thing. No family can live with MS without the healing power of love. The love and caring of family, friends, health

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care providers and others is vital to sustaining families like mine who live everyday with MS.

We were told not to have children by a misguided doctor who exaggerated the potential for pregnancy and delivery to exacerbate MS. Tens of thousands of women with MS become pregnant and deliver without exacerbations of their MS, under proper medical care. After several miscarriages our son Samuel was born.

What a miracle! He was born one month prematurely, but healthy. I will not lie. I worry about whether Samuel will grow up and develop MS. Rachel's cousin has MS and is wheelchair bound. MS has a genetic component that we do not fully understand yet. Likely, it is a genetic predisposition to develop antibodies to myelin on nerves after a specific viral infection. When Samuel is older we will discuss these issues with him. But when Samuel was 5 years old he started to ask, "Why can't Mommy run with me?" Rachel cannot run. She will reluctantly also admit to you that one of her saddest losses to MS is her inability to wear shoes with high heels, or open back sandals. The MS symptoms that are persistent include difficulty with balance, clumsiness of her fine motor abilities, fatigue, a neurogenic bladder, peripheral neuropathy, and weakness in her right leg and foot that becomes more pronounced when she is tired. We explained all of this to Sam when he was 5 years old, and revisited it each year since. Now at 13, Samuel still treats his mother as if she were an indestructible cleaning and cooking machine. Yet he also is tender and attentive when Rachel is walking down steep stairs or getting out of a car.

We have been spared many of the challenges of MS. Those challenges can be extraordinarily diffi-

cult. Sexual intimacy between couples can become a serious problem and challenge to overcome. Being wheelchair bound and other consequences of progressive MS can lead to severe physical incapacity, depression, and other mental disturbances, which can challenge even the most loving of relationships. The nature of marital and familial relationships can change dramatically as spouses and children start to take on a nursing or caregiver role rather than the role of a wife, husband, or child. This can lead to the challenges of alienation and isolation. Some marriages will not endure. Some families will grieve.

But many families, like mine, will continue to live with MS. We have a normal life, living with MS. Along the way, we have collected several more chronic diseases that our family also now lives with. Sam has diabetes, and I have Gaucher's Disease. But we have learned that life is a spiritual journey. Life is a series of challenges and adjustments to losses. Loss of perfection, loss of youth, loss of invulnerability, loss of immortality, loss of parents, loss of health. A spiritual journey of loss. And it is only through these challenges and losses that we can learn what is true and real and valuable in life. It is through these challenges that we can transform and transcend ourselves and return home, to the source of all that is infinite. Home, to our families, to the love that we share.

Life with Multiple Sclerosis can be a good life, a life worth living, a life filled with meaning and purpose and love. MS is a family affair. I know, I have been living with MS for 20 years, and I could not have done it without my family.