Explaining MS to Our Loved Ones

by DEBRA ROBERT

Explaining MS to Family and Friends

It was almost a year ago to the day when I first saw the neurologist’s report, my name suddenly and irrevocably attached to a diagnosis of multiple sclerosis (MS). Now, I thought, I get to tell my small, slightly neurotic, anxious family the news I did not want to share.

Driving back from the office, I had my husband pull to the side of the road. I was frozen in my thoughts. I did not want to move. It felt like if we went no further, maybe everything would go back to the hour just prior, with no label. No MS.

I recall every minute of that afternoon as I sit here now, looking out the window of my local coffee shop. I type these words, my trusty bling-encrusted cane at my side, returning to that moment on the side of the road, forever etched in my psyche.

We soon resumed our drive home, knowing it would be a matter of minutes before the phone started ringing. I did not want to answer these calls.

I didn’t want to further burden my family and friends. I didn’t want to hear myself say, “I have MS.” I had no idea how to respond to what I knew would millions of well-meaning but impossible questions.

How Do We Respond to It All?

We are all familiar with the difficult stage of revealing our MS to others in one form or other. We walk an emotional tightrope, appeasing others as we try to come to terms with our own, very new and frightening, twists of fate.

A week into my diagnosis, I was notified by my rather excited mom that her friend-from-Mahjohng’s-sister’s-nephew’s-cousin had MS and he was doing fine. I heard from my hope-filled brother, relating how he was “searching the internet for cures.”

How do we endure these kind acts along with the bevvy of well-meaning “instant cure” offerings whenever our MS is revealed? Trying to explain to anyone and everyone what is going on has become something of a well-intentioned Zen exercise. It becomes a practice in answering what comes down to extreme invasions of privacy.

A year in and I am still not always prepared for this. I want to be polite, yet my inside voice sometimes screams, “Please just stop talking, please shut up” as I smile and say, “Oh yes thank you, so very helpful.”

Stuck in Limbo

A couple months after my diagnosis I was hospitalized. This led to a re-visitation of explaining and answering a constant stream of even more impossible questions. My husband and I were trying to make sense of a scary and threatening situation while flailing to keep all others in the loop informed and at peace.

A few days later, my family had a major conference across my hospital bed, going over every subtle detail and moment in time that led up to my admittance. My dad, trying to find some voice of reason, asked anyone in uniform who entered the room extremely in-depth questions as to the nature of my malady.

My mind flew back to diagnosis week, when I must have replied “I don’t know” to innumerable questions. I realized, lying there with tubes in my arm, this was now my life and at any time I could be trapped in this very frustrating place.

I was unable to rest, unable to respond — and even if I could, what might I say? I remember thinking, “How on earth am I going to get through visiting hours, let alone a lifetime of change and uncertainty?”

My mom is a very doting person, but she is also an expert in the art of worry and suffering. I dreaded her barrage of tears and pining over me in that cold and drab hospital room. I did not want to see her that way and I was not up for responding in kind.

Permission Slip

This is where my usual nervous-talker, metabolism of a hummingbird, frantic mom quietly and calmly put an end to my woes.

My mother, tears in her eyes, stepped up to my bed, her massive purse on her shoulder. For as long as I can remember, that ever-present bag contained half a drug store’s worth of emergency items. She reached into her bag and pulled out a rather large tattered piece of cardboard.

She handed it to me, and I read what was scribbled on it in slightly shaky all-familiar mom handwriting. It read simply, in large print, “I Don’t Know.”

This simple act was like throwing a life preserver to a drowning swimmer. I relaxed, my shoulders dropped. I now had the means to answer every question without duress. I could simply hold up my sign.

The I Don’t Know sign: a permission slip to not be in charge. It was my safety net when I was not up for speaking or trying to explain what I could not grasp myself. If anyone asked when the feeding tube was due to be removed, I held up my sign. If anyone asked how long I would be in the hospital, I held up my sign.

I was in that bed for a few more days. The sign was never out of hand’s reach. To this day, that torn up brown piece of packaging remains a strong talisman for me.

Through all the unknowns, all the new symptoms and for all the questions I ask myself, I’ve got my sign. For all the fears and queries and hours of internet surfing to find answers, I’ve got my sign.

Coming to Terms

We don’t always want to talk about our MS. We don’t always want to try and sound as if we have all the answers. Sometimes, we just want to release ourselves from the constant reminders and just “be.”

We all go through our own process. We start down the road of acceptance with the fact that we have no idea where this road will lead. None of us has true control over MS and all it entails.

None of us has control over the actions and reactions of others. What we can control however, is how we react to others and how we absorb and face all the change.