Facing Mortality, Complications, and Fears

by DEBRA ROBERT

Addressing the Scariest Question: Is Multiple Sclerosis Fatal?

We all face multiple sclerosis (MS). Some of us, literally, in the face.

When I was a kid, I remember my brothers sitting in the back of the car, making silly faces at each other. My granddad would tell us jokingly, “If you make that face too often, you’re going to get stuck that way.”

Not yet savvy to the concept of dry sarcasm, I believed him. I’d look in the mirror, searching for signs of permanent distortions, afraid to move any muscle in a bad direction that might lead to permanent weirdness.

It Got Stuck That Way

Forty years later, my face inexplicably scrunched up into itself and remained that way. For two days, I waited for the ugly and extremely uncomfortable mess of the right side of my face to relax back to normal. It did not.

Wanting to rule out a stroke, my GP sent me to the ER. I nonchalantly drove myself to the hospital, thinking there was little more wrong than perhaps TMJ or a severe muscle spasm.

Three hours later, after a precautionary MRI and a few other tests, I was confident I’d be released as soon as the doctor returned. My husband and I figured I would be given a prescription for a muscle relaxer or something similar.

Life Stood Still

As the words from the attending doctor took hold, thoughts of my own mortality went from the shunned and distant shadows of my psyche to being shockingly thrust onto center stage.

I had a large lesion on my brain. The doctor could not be sure, but one of his suspicions was that it could be MS.

The stunned look on my husband’s face was too much to bear. We were newlyweds.

My first thought was “please no, don’t do this to him.” Randy’s mom had died from MS just before our wedding.

She had battled the worst case of MS that can possibly afflict a person. For 27 agonizing years, MS stole her ability to move, feed herself or communicate any more than ‘indicating’ with her beautiful eyes.

The second and last time I got to see her was in hospice on her final day. Now I looked into my husband’s eyes, terrified over what could well be my own agonizing death sentence.

For the most part, MS is not known as a ‘fatal’ disease. The thing is, we all know it is possible.

We have all heard stories or have known someone who has died from MS complications. This is an all too real part of coping with MS and all it entails.

We Didn’t Ask for This Information

No one knows how or when they are going to die, but for those of us with diseases such as MS, we have inescapable factors that may well determine how our lives might end.

This knowledge, I believe, puts us on bit of a different plane than your average healthy person. We have actual statistics on what exactly might lead to our eventual demise. Indeed, MS complications are harsh realities linked to our own mortalities and we somehow have to learn to live with them.

People Die *With* MS, Not *From* It

The National Multiple Sclerosis Society (NMSS) indicates that most people are listed as having died from accompanying illnesses. MS is rarely indicated as a primary or even secondary cause of death.

So, what does dying of MS complications actually mean?

People with a more severe course of MS may die from:

- **Pulmonary involvement.** Just as muscles in the arms and legs can continue to increase in weakness as MS progresses, so can ventilator muscles in advanced MS. Respiratory insufficiency from weakened diaphragm and accessory muscles that support respiration can be the cause of death in MS.
- **Sepsis.** A deadly bacterial infection of the whole body brought on by bacteria entering through recurrent or severe infections, such as bedsores, urinary tract infections and pneumonia.
- **Aspiration pneumonia.** Swallowing problems, or dysphagia, can deposit food or liquid into the lungs. The body will fight off these deposits resulting in inflammation and fluid accumulation. This can be fatal.
- **Depression.** Though treatable, depression is considerably more common and dangerous for MSers than for those with other chronic illnesses. NMSS states, “one study found that the risk of suicide was 7.5 times higher among persons with MS than the general population.”

NOTE: If you are having thoughts about harming yourself or feel you are at risk of hurting yourself or someone else, call the National Crisis Hotline at 1-800-273-TALK (8255) or text "ANSWER" to 839863.

Knowledge, However Unpleasant, Is Power

Fear of the unknown, as in what MS might do to me, is frightening. Facing the unknown and learning about what exactly it is I am afraid of certainly justifies those fears.

At least now my runaway imagination can no longer fuel my psyche with frantic, unrealistic scenarios. The realities are harsh, but my projections as to what may become my fate, are at least now anchored in reality.

Worry Is a Waste of Imagination

We have no idea and no control over where the roulette wheel of this blasted disease will rest. What we can control is being truly present in the moment.

We must live for what is right now. If we strive to live our lives as fully and unabashedly as we are able, any fear of the future will have less room to invade our imagination.

The Good China

A bit of fear can be a catalyst for living a richer life. I think this is similar to what my mom says is one of the brighter sides of her getting older.

She instinctively is living for today much more in her 70s than she ever did when she was younger. She is throwing a bit of her life's rulebook out the window and she's literally giggling over it.

For the first time in decades, momma is using the good china on a daily basis. She loves the way it looks on the table and enjoys daily dinners more than she has in years.

She wonders why, for all these years, it was that she simply knew it was forbidden to use these lovely plates for anything but a special occasion. In my 49 years, I don't remember us ever having that special occasion.

My mom has discovered that breaking the special occasion rule does not mean the good-china police will, at any minute, break down her door. Incidentally, the same goes for her diamond earrings — she now wears them whenever she wants.

My mom enjoys these little shifts she has chosen to make in her life. They make her days just a bit richer. I could not be more proud of my rule-busting mom.

We can all take on our own form of a rule-busting attitude toward the things our playful spirits (or inner child, if you will) are begging us to try. We can ask ourselves when we doubt, "What is the worst that can happen?"

With all the things we have to contend with as MSers, we deserve to give our souls a break. We can find those small things that make our days just a little better, any day of the week, no matter how our MS is doing. They in turn, start to add up and life and quite possibly our outlook towards it, becomes more rewarding.

Next page: Debra shares more of her wisdom regarding complications and fears.

Too Much of a Good Thing

When it comes to mortality and living for today, the idea of a bucket lists is never too far behind. As much as I like the idea of completing all the things I'd give anything to do before I die, I don't need the undue pressure.

We deal with enough as MSers as it is — just getting through what is already on our plate is enough of a trick. Let's treat the bucket list as a lighthearted wish book, not as some kind of must-do pressure cooker.

I dream of traveling to Africa to see elephants in the wild. This may not ever be in the cards for me. Regardless, I don't have to leave this life without experiencing as much as I can, with at least the tools and abilities I have in front of me, right here and right now.

What Simple Thing Have You Never Done?

I now entertain the things I used to always put on the backburner or label as silly, though I was curious about them.

I go out in the rain for absolutely no reason other than the realization that I want to know what it feels like. I have told a few people about this — some totally get it, and others have looked at me as though I am crazy.

No matter, I know now what it is to be out in the rain. I experienced the smells, the sounds, and the feel of drops on my skin without a care in the world. I went against the instinctual drive to seek shelter.

I have lived a tiny little dream and my heart opened up to it. I smile every time I think about it.

Anything you can do to raise your spirits, no matter how ridiculous you think it may be, could be exactly what you need to feed your soul.

Sleep on the opposite side of the bed for a night, empty out the junk drawer, or wear mismatched socks for the hell of it. These are all small things that prove to us that we have some fun control over our sometimes, not so fun situations.

Throw a Curveball Once in a While

When we throw curveballs into our daily routines, we find there is less time to dwell in the fear of an end result. We are too busy considering all the fun little options that might feed our souls, and raise our spirits, even through the pain and frustration of MS.

We deserve these mental breaks and they can be joyfully habit forming.

As I mentioned before, one of the easiest meters to use when allowing your spirit to take the wheel is to simply ask, “What is the worst that can happen?”

I can always dye my hair back to brown if my dream of being a blond was not what I thought it might be. I am allowed to just stop reading the book I always wanted to read, now that I realize I hate it. I can look forward to taking the scenic route home from work on occasion instead of sitting monotonously each day on the freeway.

By checking in with your intuitive self you can choose things that simply feel good.

Is This It?

I find the times that are hardest to listen to my own advice are through relapses and symptomatic periods. The fears of mortality and all the complications take a fairly firm hold of my thoughts — I suppose I could say I feel a bit closer to death at these times.

I begin to wonder, “Is this it?” I become anxious, wondering where it is all going to lead.

“Am I stuck like this now or is this a short relapse?” “Is this the point of no return?” I become more and more stressed as highly symptomatic days wear on.

Comedy Is Not Pretty

Of course we are told that stress and emotional upheaval can exacerbate our symptoms. This is an ironic conundrum that would almost be funny if it were not so cruel.

I hear my inner voice saying, “OK, so your legs are so numb, you cannot walk. The important thing is not to worry about it.”

I have not yet found a true remedy to quell my fears in these periods. Feeling sympathy for myself while being terrified of losing control over my own body is what makes me human.

I cherish what I have and do not want to lose it. Relapses remind me there is no going back with MS and I see them as glimpses of what my future may hold.

Reaching out, Going In

There are times when I turn to the MS community for a boost. I hit social media and reach out on forums. There are so many of us who ‘get it.’

The fact that we are not alone — that even at our worst, we can be our best — is a testament to living well in spite of the odds.

In my more isolated, contemplative times, I begin to come around. I tell myself again and again that I’m still me. MS can take a heck of a lot, but it cannot steal my soul.

I am who I am no matter what, and I intend to fight in whatever capacity I can to get the most out of this spin around the globe.

There Is More to Life

I have taken a hard look at what it means to truly live lately. MS led me to wanting — needing — to seek a deeper meaning and purpose to my life, so I became a volunteer. I spend many hours per week helping others get through some hard times and difficult situations.

Volunteering my time and attention gets me out of my own head and allows me to practice what I preach. As bad as things get for me, there are always others who could use help from another, who has just a bit more to give. Volunteering feeds my soul and I am grateful to have given it a try.

Looking Back in the Mirror

I think back to when I was that little kid looking in the mirror, hoping I would not see the silly face I made at my brother staring back at me. I tried to think of what I could do to never let that happen.

I know now there is only one thing you can do: you can refuse to dwell on it.

Out of all the things we cannot control, we do have things we can control. We can choose to live as fully as possible with what we have right now.

We can love a little deeper, play a little harder, work with a bit more purpose and maybe, with a little prodding from our inner child, we can use the good china.