Talking About MS – Putting on a Brave Face

by LIBBY SELINSKY

Talking About MS

You all have heard it. I know you have. Those words that sound kind and reverential on the surface. However, underneath, they are loaded with an unwitting obligation and judgment.

“She has MS, but she *never* complains or talks about it.”

Men, I am sure you have heard this too. Of course, you have, we all hear it.

For some reason, that statement is meant as a compliment. It is meant with the best intentions, for that I am sure, but the foundation of that statement is one that comes from a society that idolizes a false narrative of our very human experience of enduring disease.

What Is This About?

Every human knows one thing for certain. Our bodies are not eternal.

Each of us lives with the knowledge that every day we spend on this earth is taking us one day closer to our last, and that is a scary thought. I am sure that this fear is where it all begins.

Seeing other people struggle with a disease of any kind will lead us to reflect upon ourselves, our own mortalities. Encountering the messiness of a body that doesn’t work as it should is an uncomfortable thing for most people.

I have to admit; even I still have a hard time being around people who are further progressed with their multiple sclerosis than I am. I do not enjoy seeing what is possible for my future with this disease.

"I Think About This Issue A Lot."

The experience of going to a place where I run into a lot of other people with MS is emotionally difficult. These are great people, but my narcissistic mortality can feel crushed and overwhelmed by being around them.

I think about this issue a lot. I think about who I was before I got sick. Then, I didn’t see it as a burden to revel in the sick hero who braved their disease with nobility till the bitter end. Those stories are made into movies, time and again. Our culture loves them.

Is it because that is who we hope to be whenever, however, our inevitable time comes? Do people need to believe grace is tied to disease in order to feel secure about their own prospects?

I would like to believe that people don’t need this type of simplicity. But maybe, at least sometimes, people do. Unfortunately for my family and friends, I was never the noble type. I was loud, angry, scared, and needy.

Honestly, I still am each of these things from time to time. Not as much as I was ten years and four months ago, but I have my moments. These times never go away completely; they have just become less frequent.

When a Person Keeps Quiet, I Worry…

I don’t believe in being noble for the sake of others. People need to see weakness from time to time. When a person keeps quiet, I worry about them. I worry that they have not been given the support they need to be real, to be free, to be honest.

It is not possible for a person to live with a disease that is capable of stripping away everything they enjoy about life, at any time, and that person does not have deeply messed up emotions about living with it.

To say anything different is to live a lie. Or to not have anything that you love enough that it pains you to lose it. Since I don’t believe that the latter is possible, I must circle back to the person living a lie.

Society Romanticizing The Brave Fighter

I believe that is the thing that concerns me the most about our society romanticizing the "brave fighter."

Sure, we don’t want to live out every day, complaining about our plight in life. What kind of life would that be?

However, we should never feel obligated to fit into an empty image of serenity in the face of pain, to be loved and admired by those around us. Shouldn’t they already feel that way about us because of our human connections beyond our disease?

Look, any disease is a burden. It will be a burden upon those who live with the physical repercussions, and it will sometimes be a burden to those that we know and love, and that is OK.

We are human and being human is a painful burden sometimes. Should we let it take us over and drag us down? Of course not. But it is important to be true to ourselves and others.

Being real about our disease does push the comfort level of those around us, but is that so bad? I feel like a new narrative must be embraced. What if we looked at it as a favor to others to teach them about the reality of living with a disease?

Living Simple, Organized Lives

We have a society that is built around being and living a clean, simple, organized life. From the lines of our contemporary furniture to our modern architecture and even into our effortless consumerism. Modern life has embraced the images and ideals of flawlessness and simplicity.

This image is not our true reality though. Life is messy. Living with a disease is messy, but that is alright. That is a lesson our society sorely misses.

It is a problem having the clean simple narrative because eventually everyone learns that it is a lie. We are not passing down the true expectations or survival skills that are necessary for people to navigate and thrive when they are actually dealing with their own form of physical struggle.

Coping With This New Reality

When I was diagnosed with MS, my hardest struggle was the mental challenges of understanding how this new reality would define me. I felt like I was completely out of control of who I would become.

I felt a responsibility to become the picture perfect patient that I was incapable of understanding. The idea of sitting quietly and serenely to myself felt and still feels obscene. It takes a capacity of spirit that I still have yet to find within myself.

I have many days now, where I take stock of my life, and I am grateful for my family, my health, and my life.

"MS Is Hard."

Honestly, though, MS is hard and I would have enjoyed a world without it. However, I cannot choose a clean, simple and orderly life. The universe decided to do what it wanted with me and the results have been unpredictable and messy. The best I can do is learn to let go sometimes and allow whatever is to be.

I don’t aim for calm anymore – I aim for flexibility. I cannot float through this world, but I can learn resilience in the face of the storm.

Hopefully, it will happen many years from now, but when I die, I don’t want a single person to say that I had stayed silent in my struggle. I want to know that I made a difference – I want to know that I helped others to fight. I hope to have built hope.

I hope for that for us all.