MS and Sex: Embracing Love and Your Body

by LIBBY SELINSKY

Sexuality and the New Me

When I was diagnosed with multiple sclerosis (MS), sex was not something that even crossed my mind for at least the first couple of days. Life was upturned and my body was alien to me. I had been too engrossed in the whole experience of physical pain, along with anxiety and depression, to be in the mood. Sex was not on my mind.

My first symptoms were peripheral neuropathy and the dreaded MS hug. I was not capable of feeling anything below my shoulders on either side of my body. I also had the feeling of an incredibly tight corset around my rib cage. Breathing was difficult — scary even — and my skin felt like either incredibly painful pins and needles or alien skin, with no sensation of touch at all.

I was apoplectic about my diagnosis; I needed some sense of comfort. Life as I know it was gone and I needed to feel again.

You see, MS has its own brand of torture that it mixes up for each of us. We all have our own paths, phobias, weaknesses and stubbornness that MS is deeply proficient in tuning into and creating our own, one of a kind, brand of this disease.

After my initial shock and grief, I began looking for my most deep sense of comfort. I needed to make love to my husband. I wanted to be close. I wanted to feel safe. I wanted to recharge and to find my solace, my home, in my husband's arms.

For those of you out there that share this disease, if you have experienced my symptoms, then you will know what happened. I made love to my husband and I felt nothing. I knew it was going to be this way — after all, I hadn't felt myself pee in days. It was the reality of it all that hit home when I actually tried having sex that settled in and tore out my heart.

Who Am I?

It is a seemingly fortunate thing, being a woman. Men have to deal with all of the same symptoms as us, and additionally, their equipment can run amuck. Sorry, I know, I am not being very graceful in my description. I am trying for some brevity.

In the end though, we all struggle sexually. It isn't easy finding solace inside a body that disobeys us.

Making love to my husband that first time after my symptoms began was heartbreaking. I will admit it, I cried. Right there, in the middle of everything, I started bawling. I was so close I could kiss him, I could taste his lips, but there was just a vast emptiness everywhere else.

My place of respite and solace had been stolen from me.

I was terrified, I felt so alone. I thought that the world had just ripped away the very last shred of beauty that I had once carried. How cruel the world can be, to give us such beauty, such pleasure, only to strip it away arbitrarily.

What kind of woman was I now? How can I live like this? Is this going to last forever?

I get it, this article is sounding really depressing. I really am not one who enjoys wallowing in the depths, so let's just say MS sucks and sex does not suck, somehow those two points need to reconcile harmoniously or my life will get dragged down into the suck along with it all, and I am not going to let that happen.

I am still here. I am still me. I will still make love to my husband. I will find my way through. I will enjoy it.

Next page: embracing love, your body, and your sexuality

What Happens Now?

The answer is, I don't know. There are many different variables and situations that are wrapped up into sexuality and MS.

Physically, your body is going to do what it is going to do. It is important to remain actively engaged with your health and wellbeing in all regards now. You can seek out medical assistance through your doctor, if you are shy, try to remember that the benefit of speaking up outweighs the risk, so be brave! Physical therapy and medications can help. Also, your body will often go back to normal once a relapse has subsided.

My initial relapse left my body without feeling for three months. Once my body began to feel again, I had additional three months pass before I regained feeling in my hands.

I had a very long time pass. I often believed that this was my permanent condition. I spent those months learning how to enjoy the world again.

Finding More

My sensation of touch changed. I learned that by caressing my husband with my face, I could extrapolate the idea of that touch throughout my body. I converted my remaining sensations to a larger place in my mind.

It is amazing how much we can learn to forget through sheer convenience and limitless access. How often do we hold our lovers and breathe them in? The smell of their hair, their neck, their breath, the way those smells change throughout the moments of our intimacy.

What about sound? Do you listen to the timbre of your partner's voice while you are together?

I know that these things were not strangers in my bed, but I came to realize how little credence I had given to them in the past.

Today though, I realize that the moments are about everything. Taste, touch, sound, smell, pressure, friction — all of it.

Embracing the Skin We're In

We do not get to decide what the world will take from us. We do get to choose to live a life that is full. It is our choice to fill our experiences with all the beauty and joy that we can find. We all have a paradigm of capabilities in our tool belt.

People with MS have to become very resourceful with the tools that we have at our disposal.

The world may strip away something, but that does not mean that you are left with a void. You have to learn how to make the most out of what you do have, every day.

Sexuality is so deeply personal and important. The loss of something sexually can feel harsher than our normal MS symptoms, but we are not less because of it all.

We are never less of a person because of this disease, no matter how much MS would love for us to believe so. Our love for our partners and our ability to express our love may have to be different. I feel though that it is very worthwhile to put in that time and effort — learning how to love and be loved in the bodies we are given.

Live a Life of Love and Pleasure

MS can change how you feel pleasure; it is not allowed to steal your pleasure from you. You are beautiful people and you deserve to love and to be loved for the rest of your lives. This is how we wander through this crazy, unpredictable, amazing world we live in.