Finding Purpose and Meaning Through Life With MS: Part 2

by DEBRA ROBERT

The Key to Living a Good Life With MS

Debra searches for deeper meaning in life with MS. Don't forget to read part one of her journey to finding purpose as a newly-diagnosed MSer.

I received my drivers' license on my sixteenth birthday. I excitedly took to the road and never looked back. For 30 years, I savored both the independence and the sense of accomplishment I garnered from handling more and more highly tuned performance vehicles.

A couple years back, this all changed. Highway traffic rapidly became a confusing and unpredictable monster. My response times and motion-to-distance perceptions were becoming alarmingly inaccurate.

On more than one occasion, I found myself on the side of the road, gripping the wheel with tears flowing and my heart in my throat.

Multiple sclerosis (MS) had slowly stolen away the cognitive abilities I needed in order to keep up with daily driving. It devastated me to do it, but I turned in my keys.

I now ride the county disability bus anywhere I need to go. For the most part, I have to say, I enjoy it.

Identity Theft

At first, I resented the disability bus and all it represented. I had always been a fiercely independent person and free spirit.

Unable to come to terms with losing yet another source of pride, I'd take a window seat, twisting quietly away from all that the bus represented, including other passengers.

I spent my time on the ride in anguish. I enviously looked down at all the 'perfectly healthy people' zooming around in their cars, going about their business.

It felt unreal to me to not be down there, driving as they did. I felt angry and would not allow myself to believe I might be stuck, forever as a dependent passenger.

I did not belong here. This had to be a mistake.

A Funny Thing Happened on the Way to My Gastro

One particular morning the bus was completely full. For a full two hours, I had to sit in a dreaded aisle seat.

Having no window to disappear through, my attentions were forcibly turned to the space and fellow passengers around me.

What I listened to was laughter and friendly hellos. Mile after mile, I tuned into encouraging attitudes and supportive conversations.

No one seemed to care one bit about what was happening outside the bus (no one but me). I was taken by the fact that though many folks had disability issues far more complex than mine might ever be, they held incredible, almost enviable outlooks on life.

I started to realize that in the large scheme of things, we on the bus were no different than the drivers in cars racing around us. We were all, in one way or another, simply getting on with our lives.

My fellow riders taught me what it was I had been missing. With a purposeful spirit they entered and exited the bus, going to and from community centers, rehab clinics and career training facilities.

I needed to open my eyes enough to my present state, or I would always be stuck in a past that no longer fit with who I was in the moment. I needed to live in tandem with MS and all that it threw at me, both in present and future.

I would always be the person I've always been. The difference was, I had to be that person living in open and honest acceptance of the hurdles MS placed before me.

I had been down many dark roads before and had always eventually found the light. I knew what it was I had to do to get there this time around.

So There It Was

MS was not holding me back from living a life of purpose — my attitude and outlook were simply focused on the wrong things. I was trying to live with the tools of my past instead of making allowances in my psyche for the tools I'd need to live with, with MS.

I slowly began to get more open and honest with myself about where I was, right then and there, MS and all. I began to take inventory of what I could not (or could no longer) do as a result of MS and what I could do and/or wanted to continue doing.

My inventory came in the form of journaling; writing down my daily thoughts and ideas. I took out my frustrations and heralded my daily triumphs, all in my journal.

I carried it with me always and writing in it became a new ritual. Already, I had taken on a new method of coping and I'd barely scratched the surface.

It's Not MS, It's My Attitude With MS

I also began to look around and reason that plenty of people, who are quite well, are still completely miserable. From my humble beginnings on the bus and from the honesty I read back from journaling, I was beginning to get it.

My health was not the key to all things — it was my daily outlook, working with what I had, that would steer my ship and determine my fate.

Next page: cleaning house and changing focus.

Cleaning House

Taking a gentle but firm look at the reality of where we are at can be a rewarding exercise. Weeding through the things we no longer need or may never use again can be liberating.

For an MSer like me, both these actions become lifelines to the me I knew I could be.

Getting rid of clutter, though sometimes an arduous task, refreshes and energizes both the mind and the spirit. So, having already taken a bit of personal inventory, I then turned my attention to my home and the things that were in it.

I went through everything, seeking to clear space and no longer feel bogged down with material goods. I sold or gave away quite a bit, from old textbooks I'd never read again to my ski gear that took up tons of space in my closet.

The ski gear was a tough give. I loved the adventures and the memories it represented. Funny thing though, I realized I really couldn't stand to see it each day, knowing skiing was not likely to be a part of my new life plan.

I came to recognize that the space I was making would never take away the exciting, fun memories I had with my ski gear. I was simply making room for new and different adventures, yet to be discovered.

I can't say this process was easy or that it felt great all the time. What I can say is that the more I cleared, the more honest and realistic I became with myself.

I liked this feeling of unbridled honesty with my true self all that surrounded me. I knew I was on to something.

Time to Change Focus

With clearing the cupboards well under way, I began to work on ways to open up to new directions and ideas in my mind. I made it a point to take little breaks whenever I could each day.

In order to rethink my situation and find some sense of purpose, I sought time for myself in nature or in simple quiet, wherever I'd find myself. I sat out in my yard or I sat in my bedroom or on the bus, taking 10 deep, deliberate breaths with the intention and purpose of simply giving myself a break.

I knew through all this, answers would not instantly appear — far from it. However, it's a proven fact that letting go and not thinking about things can be a much faster and more authentic way to find solutions.

The more I continued with these breath breaks or tiny meditations, the more new ideas and new opportunities seemed to appear from out of the blue. This is the beauty of making space and taking some time to give oneself some kind of a break.

The Real You

Through all the big and little changes MS brings with it, we need to know that we are the same person we've always been.

Perhaps though, if you look deeply, your wants needs and goals may have shifted a bit. Be open and treat yourself to new experiences, perhaps try different types of music, or new kinds of foods.

The idea is to do something new and also do some of the things you always promised yourself you would get to someday, like going to a park or reading a certain book.

I bought myself a new brand of toothbrush and started folding my towels differently. Sure, these are small things, but they help break our daily routines and patterns in subtle ways.

Like little restart buttons, tiny changes recharge the soul. All these little allowances and minor but deliberate alterations will help you open to new thought patterns and interests. This is all on course with finding true purpose.

Through large and small adjustments to finding present day authenticity, we can find joy. Through joy we start to open up to new possibilities. Through possibilities we find the path to new or revised purpose that fits with our now and is more adaptable to future challenges.

Act, Don't React

I found the next step in seeking purpose with MS was to alter my standard of expectation.

There was always this responsibility I put on myself to just continue and keep pace as I always did. Even when I knew this was impossible, I still for some reason responded and acted as though I could.

I now think before I respond. Yes, I am still impulsive, but I set realistic expectations for myself and for others.

I give myself extra time to prepare or get ready for things in most cases. I also leave myself a 'last minute out' when I commit to certain occasions. I can say that taking those moments to sit and breathe sure helped me get to this place.

How Do You Do It?

All the soul-searching, inventory, cleaning house and taking small moments for myself have paved the way for two final subjects: kindness and volunteering. It does not take much of either before you begin to find a solid path to a real sense of purpose and joy, living with MS.

Random Acts

When we put our focus on something outside of ourselves, we instantly boost our sense of self-worth and reason for being. Start by intending to uplift someone's day, every day.

Next page: volunteering, and more ways to find bigger meaning in life.

How Do You Do It?

Random acts of kindness are easy to do and can be quite a quick pick-me-up when we get too tied up in our own miseries. Compliment someone's shirt, or pay a cup of coffee forward for the next person in line. How you do it does not matter — it is the intention that counts.

Often, giving doesn't have to cost us a thing. When I speak with a pleasant customer service agent on the phone, I make a point of asking for their manager.

I praise their good work and how I'll remain a loyal customer because of their service-oriented demeanor. This just improved your day and the two people you connected with, all on a routine call.

Volunteering Is Essential

One of the greatest and most proven avenues to finding a sense of purpose is through volunteering. Consider what you are able to do, be it from home or someplace close by, a few hours a week.

Become a pen pal to a soldier overseas, read to children at a hospital, train to become a responder on a crisis hotline, or volunteer at your local MS chapter.

Volunteering can sometimes seem to be a bit much to handle with our busy lives. Regardless, give it a try — even if it is something simple you do for a friend or immediate family.

There is no doubt that volunteering in ay capacity is uplifting and purposeful. Once you clear your mind and spirit of clutter, you may be surprised how easy it is to find the room for something that tugs at your heartstrings.

The virtue of giving time to those less fortunate or to worthy causes is a selfless act. It does absolute wonders for our sense of purpose and overall wellbeing.

No Matter What

Dismal outlook aside, there is one thing we all have. We have our ‘now’ in all its messy glory. The trick is to find ways to feel good about yourself every single day, no matter what.

There have been times in conversation when people ask me how I can have such a great attitude with ‘all I go through’ with MS. I have a simple answer to this: I choose to have a great attitude.

I think about the ways that I am a good person and I focus on bringing a little lightness and a smile to those around me, no matter what.

Catch Yourself — Change Your Focus

Sometimes I have to fake it ‘til I make it, before I can well up any kind of joy in my heart.

Certainly too, there are always going to be times where feeling down or simply being miserable fits the moment. The idea is to create a fulfilling enough life to not to get sucked into a vortex you cannot get out of.

Finding purpose will help you to rise up and out when you get stuck in a depressed place.

When I feel down or my mind spins into the depths of MS despair, I go back to my MS journal and breathing. Sometimes even in spite of myself, I work on checking my attitude and I change my focus, thinking of things that feel good to me.

I recognize that I am able to choose how I react and how I feel, I can decide to remain miserable or I can choose to push through and step up and out.

Back on the Bus

Some days I laugh to myself as I sit on the bus overlooking the people in cars all around. I realize my life is different now, and from that, I have the opportunity to use my time on the road in any way I choose.

My focus is on what I have now, in lieu of what I don’t have. This is my time and I — and only I — decide how to feel about it.

So, I choose to focus on either listening to my beloved lectures, disappearing into a meditation or I take on a random act of kindness.

I engage with others on the bus. As we sit amongst one another, we learn about each other’s lives, pass the time lifting each other up or just quietly support each other with knowing grins. No matter what I choose for my ride, I am a full passenger now.

My keys to living a good, purposeful life have changed — both figuratively and literally. In both cases, I am right where I want to be.