

Sense of self



MS may challenge you to redefine who you are and what you want out of life.

by Vicky Uhland

Multiple sclerosis is not like other diseases. The lack of a cure, the numerous and varying symptoms, and the uncertainty of exacerbations can affect you on every level-physically, emotionally, mentally and spiritually.

“In essence, your sense of self can be challenged by MS,” says Kevin Alschuler, PhD, a psychologist with the University of Washington Medicine Multiple Sclerosis Center.

MS can refocus who you are in relation to your family and friends, your vocations and avocations, and the world around you. At its deepest level, this disease can make you rethink your life’s values.

“Most of us don’t slow down enough to really take a hard look in the mirror,” Alschuler says. “I have patients who say while they would rather not have MS, it has created an opportunity to recognize who they are and what they want to focus on in life.”

Alschuler says both nature and nurture can affect how people with MS build and keep a sense of self. The age you’re diagnosed, the course of your disease, how tolerant you are of uncertainty, whether you tend to fix or flee distressing challenges in your life-all of these factors and more help shape how you live with MS.

Just as no two MS disease trajectories are the same, no two approaches to defining your

sense of self are the same. Here's how six different people with MS answer the question: "Who am I now?"



Elizabeth Jameson, formerly a social justice lawyer, continues her impact through her newfound artistic talent. Her colorful MRI projects are exhibited by nonprofits, researchers and physicians. Photo courtesy of Elizabeth Jameson

Elizabeth Jameson, 65, California

In 1991, Jameson was in a park pushing her two young sons on a swing set when she suddenly lost the ability to speak. Doctors suspected a stroke or a brain tumor-until they gave her an MRI and found lesions in her brain.

Jameson was 39, and she had just been diagnosed with MS.

"I felt like my life was over," she recalls. "I had to totally redefine who I was as a wife and mother, and in the work I loved. I learned that MS is the good, the bad and the ugly. It's everything."

Jameson's new life with MS was complicated by frequent exacerbations. "Each one made me feel smaller and smaller psychically, like I was a lesser person," she says. Eventually, she was diagnosed with primary progressive MS, and is now quadriplegic.

"In a way, it's much easier because I don't have the ups and downs in my disease anymore," she says. "For me, the hardest thing about relapsing-remitting MS was you're constantly redefining your identity after each exacerbation."

That also includes the identity of her 34-year marriage. "My husband and I were absolute equals when we married, but now I don't always feel equal to him because I'm so disabled," she says. "And I no longer make money, so I feel less powerful sometimes in the

relationship.”

Before her diagnosis, Jameson was a social justice lawyer, advocating for children’s rights in federal court. But the exacerbation in the park left her unable to talk for a month. When her speech returned, her voice was altered and she had problems remembering words.

“My job was based on my oral skills, and it was too traumatic and embarrassing for me to talk in court anymore,” she says. So she made the difficult decision to quit the vocation that she felt defined her.

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But she still wanted to make an impact through her work. The solution presented itself in an unlikely way: Her neighbor persuaded her to take an art class. Jameson had never drawn or held a paintbrush before. But the first day of class was a revelation. She adored the texture and patterns of painting. She loved the opportunity to play with colors. “One neurologist thinks my MS lesions woke up a part of my brain I had never used before,” she says.

Jameson’s MS informs her art in other ways as well. One day, when she came across a stack of her MRIs, she realized she had never really looked at them because the black-and-white images seemed so frightening.

“Going into an MRI machine is profound, life-defining, traumatic. You’re never quite the same emotionally afterward,” she says. “I realized my calling is to transform brain scans—one of the symbols of MS—into images that would invoke conversations with ourselves and our medical providers. I decided I wanted to be a public-interest artist to do as an artist what I did as a lawyer.”

Jameson uses Solarplate etching to create her colorful MRI art. Her work is exhibited by nonprofits, universities, researchers, physicians and other people with MS. She’s also working on art projects designed for health care waiting rooms to encourage people with MS and their caregivers to communicate with each other.

“I want to break the silence of the waiting room—the one area where you can be with your tribe,” Jameson says. “It’s hard to feel powerful when you can’t speak to one another in a safe space.”



Angel Muniz Jr. focused on building a stronger mind and body after he began experiencing MS exacerbations. As an athlete, he continues to exercise regularly and does CrossFit. Photo courtesy of Angel Muniz

Angel Muniz Jr., 38, Connecticut

Muniz was living his dream life when he was diagnosed with MS in 2002, at age 21. He traveled across the United States, competing in martial arts competitions with his father. His day job as a loan originator financed a carefree lifestyle without any fears or concerns.

For the first few years after he was diagnosed, Muniz says, he was in denial about his disease—helped by the fact that he was virtually symptom-free. He continued working and playing hard, got married, and accumulated property and investments. But in 2008, his marriage ended. Within a year, Muniz’s father died from pancreatic cancer.

And Muniz began experiencing MS exacerbations. “Things started changing dramatically with my disease,” he says. “I didn’t know at that time that stress plays a huge role in MS. I was having trouble walking, and I was getting more fatigued.”

No longer able to work, Muniz applied for Social Security Disability Insurance and moved in with his mother. “I went from being 100 percent self-sufficient to living in my mom’s basement,” he says.

And then, in 2013, Muniz says his body “shut down.”

“I couldn’t walk. I couldn’t feel my legs for a whole week,” Muniz says. After the exacerbation ended, he began using crutches. “It took me a year just to feel confident enough to go out with my crutches in public,” he says. “I used to be able to go out anywhere and feel at ease meeting new people all the time, but I didn’t have the confidence to do that with my crutches. Being Puerto Rican, we have a lot of family and social events. I didn’t feel comfortable going for a while because of how hard it had gotten for me to walk.”

But as an athlete, Muniz has always lived by the credo that “anything the mind can see, the body can achieve.” About a year ago, he saw a video of a person in a wheelchair doing pullups. “That was my ‘aha’ moment,” he says. “I realized I can only depend on [myself] to make me stronger in body and mind.”

So he started a CrossFit program and began working with a personal trainer.

“Working out, going to the gym has boosted my confidence physically,” Muniz says. “But I also didn’t realize it would give me the confidence to not let my crutches affect me emotionally and mentally. That’s not to say I don’t want to cry, don’t want to scream every day. But the world’s not going to feel pity for me. I have to get up, have to move.”

That acceptance of his disease has finally allowed Muniz to think about who he wants to be for the rest of his life.

“Before MS, I was so materialistic. I allowed objects to define who I was. I had everything, but I was never happy,” he says. “MS has made me so much more humble. It’s made me be the man I should be.”



Stacey Dorton takes a practical approach to life with MS. She sets attainable goals that help her live her life and leads a Facebook group called “Fight Club,” where members discuss tough topics about MS. Photo by Elizabeth Jameson

Stacey Dorton, 44, California

For Dorton, who was first diagnosed with MS in 1994 at age 21, the adage “I have MS but MS doesn’t have me” sometimes makes her want to scream.

“Phrases like that really chap my hide because I feel my life has continually fluctuated because of my MS,” she says. “There are patches in my life where I do great for a few years,

but then I lose my job because I can't get time off after an exacerbation, and I have to start over.

And that means I have to think about things like how will I pay rent or buy groceries? Should I sign up for long-term or short-term disability? Do I have people I can count on to look for me if I'm not around for a few days?"

It's "100 percent true" that MS defines many aspects of her life, Dorton says. "I don't see that as a negative or a positive-it just is what it is."

Dorton walks with a cane, and she also has fatigue, heat sensitivity, vision issues, and bladder and bowel problems. She believes her realistic approach to her disease helps prepare her for a future of uncertainty.

"I know something bad is going to happen, so I need to be ready for it. That way I don't get bothered by flare-ups," she says. "This doesn't make me unhappy. It actually prompts me to move forward in life because I need to do all I can to make sure I can deal with this disease."

For instance, Dorton, who works in administrative jobs, doesn't hesitate to ask for raises. Not only does she believe she deserves the extra pay, but she's motivated by the need to save money in case she can no longer work because of her MS.

Dorton's practicality also extends to her goals in life. "I don't have lofty dreams and ideas," she says. "I have very realistic, attainable goals that help me live my life."

This includes helping other people with MS figure out the day-to-day aspects of dealing with their disease. Dorton administers a closed Facebook group called Fight Club, where, twice a month, members discuss a specific topic related to their MS. And she gives talks on living with disabilities to public health classes at the University of California, Berkeley.

She doesn't shy away from the tough topics in these chats. "I talk about how MS messes with relationships, and how I think a lot of the MS-related depression comes from pushing people to be positive. We don't let people grieve for the life they thought they'd be living before they were diagnosed."

The bottom line, Dorton believes, is to acknowledge that sometimes MS does have you. "Don't pretend it doesn't, but get back up. It can have you, but don't let it keep you."



When MS made it difficult to work as a school teacher, Grace Ragland switched gears. Today she sets her own schedule as a seamstress and mountain bike instructor. Photo courtesy of Grace Ragland

Grace Ragland, 56, Alabama

Ragland believes she had her first MS symptom at age 10. During her teenage years, she experienced numbness, fatigue, balance issues, headaches and heat sensitivity. And then when she was 18 and a freshman in college, she lost the vision in her right eye.

That was in 1979, before MRIs and other means of reliably diagnosing MS were common. But Ragland's doctor suspected she had MS. He told her mother, who then had to deliver the bad news to her daughter.

"The way my mother told me about my disease really set the precedent for the rest of my life with MS," Ragland remembers. "She handed me some MS brochures, told me to read them and then throw them away, because MS is not going to define me. She told me, 'You're going to live your life, live your dream.'"

Ragland says she only had two questions for her mother: Is MS hereditary, and could she have children?

Reassured on both counts, Ragland went back to college and basically forgot about her diagnosis. She was used to her symptoms, after all, having lived most of her life with them.

In 1988, Ragland gave birth to a son. Four months later, she experienced major fatigue and weakness in her limbs, and was left with permanent numbness in her hands. "That's when I started to think this disease is for real," she says.

Realizing she had to take control of her own care, Ragland started an exercise, diet and sleep regimen she still practices today. And she adjusted her vocation to accommodate her MS. Although her dream was to be a home economics teacher, her neurologist said a school

environment wouldn't be a good fit because of her compromised immune system (from the disease-modifying medication that keep relapses and progression at bay).

And her cognitive problems wouldn't allow her to have a "typical, punch-the-clock job." So today, Ragland works as a seamstress and a mountain bike instructor-despite finger numbness that means she can't differentiate between velvet and corduroy, and a right leg that wobbles so much she calls it her "Elvis leg."

She also became an MS advocate for a pharmaceutical company. "I used to cover up my disease because I didn't want anybody to feel sorry for me," she says. "But now, I realize I'm a living example of MS, and I feel like I have a responsibility in life to inspire as many people as I can."

Despite having major disease exacerbations in her 40s, Ragland says she doesn't worry that more are on their way. "I can't predict them, so I refuse to live in fear. I figure I'll deal with it if it happens." But she did panic when she had a mountain bike accident in 2017 that necessitated knee surgery. "I was so scared because exercise clears and stimulates my brain and fights depression. I was afraid that without it, my MS would consume me and take over."

But her knee healed, Ragland got back on her bike and outraced her MS. "When you're riding a bicycle, you have to have momentum to keep your balance, and I transfer that over to life," she says. "You just have to keep moving."

Mike, 30, Texas

In early 2013, Mike, who asked that his real name not be used to protect his privacy, was lying on an exam table with a needle in his back. The doctor who was performing the spinal tap to confirm Mike's MS diagnosis asked him if he had health insurance.

Mike had just turned 25 and could no longer be covered by his parents' insurance. And he had recently started his own bankruptcy law business, so didn't have insurance through an employer. The doctor's response: Go home and get health insurance. Pronto.

The Affordable Care Act hadn't kicked in yet, and now Mike had a preexisting condition. Every insurance provider he contacted either turned him down or quoted unaffordable premiums. Panicked, he decided he needed to give up his dream of being an entrepreneur and get a job that provided health insurance. MS-related fatigue meant he couldn't withstand the long hours he'd need to work at a law firm. So he took a job as a high school teacher, even though constant pain in his legs and back make standing in the classroom difficult.

"I'm working this job because I have to," he says. "I feel like my life is literally in my employer's hands."

Five years after his diagnosis, Mike says, "80 percent of my mind still goes to thinking about health care. I rarely think about what I could do to make this disease better through exercise, diet, things like that."

The other part of his mind obsesses about his future. Mike, who admits he uses “humor, coffee and wine” as a way to make himself and others feel better about his MS, is uncharacteristically serious when he says, “When I’m alone with my thoughts, I worry about how I’m going to die young, broke and in a wheelchair. If I didn’t have my wife to talk to about this, I don’t know what I’d do.”

Mike also worries about how his MS affects his wife and young daughter. “I think I’m ruining everything for them, because my MS takes so much energy, time and money that could be spent on other things,” he says. “If I didn’t have MS, we could go on more vacations, have a nicer house, newer cars-you know, the American dream.”

He feels like every decision he makes now is influenced by his disease. “It’s almost like I died and was reborn the day I was diagnosed with MS,” he says.

But he does see some positives. “If I fight my MS hard and do it with a smile, that can be an example for my daughter,” he says. And knowing what it’s like to be in pain and struggling makes him want to help others in the same situation. “If I tell my story and one person feels better for 10 minutes, I feel like my MS is worth it.”

Mona Sen, 52, Schenevus, New York

As the daughter of an academic from India, Sen lived on three continents during her childhood. She grew up without a sense of home or identity. And then, in 1987, at the age of 20, she was diagnosed with MS-which further complicated her search for self.



Mona Sen describes in her memoir growing up in many places, including India, and moving to the United States, which held more challenges for her identity as she attempted to chart out a career while managing her MS. Photo courtesy of Mona Sen

Sen felt like things that traditionally define people in their 20s were out of her reach. “While

my friends were having children and starting their careers, I was dealing with my medication's side effects and college deferment because of optic neuritis," she says. "I spent a lot of time comparing myself to others and feeling like a failure."

After her diagnosis, Sen moved in with her parents and worked a series of unfulfilling jobs. By age 35, she felt like the only thing defining her life was MS. In an effort to change that narrative, she went to graduate school to study occupational therapy. But her cognitive issues made school difficult. Although she eventually graduated, her MS symptoms made it impossible for her to complete the occupational therapy licensing exam.

"I felt like my life had truly ended," she says. "I felt fragile, weak and like I had no direction."

In her early 40s, Sen began seeing a therapist. After two years, she felt stronger. "I realized I needed to start focusing on something besides my need to be something," she says. "I started looking at the world and saw so many people in worse predicaments than me."

Around this time, she moved in with her partner David, who gave her stability, and she began receiving disability insurance. She was also diagnosed with secondary progressive MS. "Now I'm just in a slow decline," she says. "It made me realize I need to make every day work as well as it can."

Sen became very active in her local National MS Society support group, and she began writing. In 2016, she published a memoir, "The Shifting Creek." Shortly afterwards, she began blogging for a health website. Today, she feels like she's defined by her writing rather than by her MS.

"Life is very different now. Not like a miraculous transformation, because it took a number of years to get here, but it feels like a cloud has been lifted," Sen says.

"Once in a while I sit back and realize I've lived more than half my life with MS. But now, finally, it's not staring me in the mirror anymore. I truly believe each of us has a spirit within us-whatever it may be-that gives us the strength to make living with this disease work for us."

Vicky Uhland is a freelance writer and editor in Lafayette, Colorado.

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