

Write to the point



An online class helps people with MS find creative ways to express themselves.

By Robert Lerosé

When members of the Finding Your Voice writing group turned in their first assignments, the instructors saw a disaster: run-on paragraphs, poor grammar, incorrect verb tenses. But they also saw enthusiasm and, six months later, an astonishing transformation.

“We were shocked that the quality of the stories just went off the charts,” says instructor Richard Arvey.

Launched via Zoom in March 2020, Finding Your Voice is a writing class sponsored by the Swedish MS Center of Seattle as part of its mission to “help people with MS live to their fullest.” The center’s newsletter carried a notice about the class, and multiple sclerosis support groups in the area were alerted that writers of all levels were welcome to join.

The class is led by the husband-and-wife team of Richard Arvey, a longtime college instructor who lives with MS, and Evelyn Arvey, a published author. The six class members get assignments every month. One assignment, for example, involved writing a one-page scene between two people from one character’s point of view, then writing the scene from the other character’s perspective. Another assignment instructed the class to write a paragraph based on a prompt during each Zoom session. The group then discussed the revised manuscripts in a subsequent 60-minute class.

Stories are posted on the center’s blog, and a collection titled “Stories from Our Center: Lives

Challenged by MS” is scheduled to be published on Amazon in early 2022.

Here, three class members share their experiences.

Unlocking the words

Katie Yusuf was enrolled in pharmacy school at the University of Kentucky when she began to lose vision in her left eye. After an MRI and a lumbar puncture test, her doctor confirmed an MS diagnosis in 2003. Upon graduation, Yusuf worked for three years before going on disability in 2009.

Yusuf has trouble walking and balancing and tires easily physically and mentally — but the writing class has opened a doorway to her inner feelings. “It gives me a chance to get words out on paper when I can’t get them out of my mouth. I can take as much time as I need to find the right words and put them in the right order,” Yusuf says.



Katie Yusuf

A lifelong reader, Yusuf, 42, began to write after she quit her job as a response to her new circumstances. In 2018, she published “Grandma’s Precious Memories,” a children’s book meant to help parents explain a grandparent’s dementia to a small child. Her nephew inspired the book. “It provided a way to reassure him that grandma had not forgotten him,” she says. Drawing on her personal experiences and expressing deeply felt sensations is a vital part of her pieces for Finding Your Voice.

“Conquering Hoh” is a first-person account of the obstacles she faced in tackling a tough walk in the Hoh Rain Forest in the Olympic National Park in Washington state. She then wrote a version from her husband’s perspective. “Face Behind the Numbers” described her nightmarish ordeal of taking part in a clinical drug trial, while “Before and After” recounts the callous way a doctor informed her of her MS diagnosis without offering any compassion or

support.

“Writing gives me a chance to get out pent-up emotions and frustration because of all the things you want to say about MS that you can’t necessarily express except in words,” Yusuf says.

The class has also become a safe space, populated by people dealing with the same condition, where members feel free to say things, positive or negative, without worrying about being judged or misunderstood. “It’s been very cathartic for all of us, being able to share and help each other advance with our writing,” Yusuf says.

Being himself

In “Help,” then-55-year-old Al Tietjen summed up his reaction to a fellow parent assisting him in navigating a rocky path at his son’s summer camp: “There goes my independent spirit — a lifetime to cultivate, a week to lose.”

Sharp, frank observations like this pepper Tietjen’s writing. A self-employed graphic designer since 1979, he was surprised when his vision turned blurry, and he would get sick to his stomach driving. An MRI revealed MS in 1993, but he continued working until 2014.



Al Tietjen

Tietjen has written throughout his life, and during retirement, he’s been tutoring elementary school children in writing.

He joined Finding Your Voice when a nurse practitioner at the center mentioned it.

“I wanted to improve my skill, my art. This was also a chance to write about adult things and get a little more rigor in my writing,” Tietjen says. After six months, he was ready to quit

because it felt like a “writing 101 class” and took time away from a memoir he had started. The Arveys persuaded him to stay and focus on memoir writing and things that happened in his life.

Tietjen doesn't think MS informs his writing, except when an assignment is specifically about the condition. Otherwise, “If you don't have to write about it, then you

don't have to think about it. You get to remember the life you had before MS,” he says.

In “Reunion Relationship,” Tietjen wrote about hearing from a high school girlfriend about their upcoming 50-year reunion. It restarted a long-dormant relationship, and now they communicate regularly. Putting down his thoughts helped him make sense of the patterns in his life — and about “a relationship that was very important and meaningful to both of us in a lot of ways, and still is.”

Through class discussions, he learned how distinctive his voice is. “When I'm writing, I have a strong sense of what I'm trying to say and how I say it. I don't think I was consciously aware of it. I was expressing myself the only way that I should, which is who I am.”

Scaling new heights

Lucinda Hauser has had a lifelong love of the outdoors: skiing, hiking and rock climbing. She even met her husband on a hike in preparation for a climb up Mount Rainier. Over the years, her legs would suddenly quit working. She lost vision in her left eye twice, and she had three transient ischemic attacks (TIAs) in a single day before getting an MS diagnosis in 1997.



Lucinda Hauser

Hauser, 60, spent her whole career as an educator, primarily working with high school students, many of whom had various learning challenges. After starting disability in 2017,

she joined different activities at the center until she enrolled in the writing class.

“My family is rich with stories from both sides. [My husband’s] parents grew up in the United States during the Depression, and my folks grew up in Europe during the war. I thought it would be great to write down the family memoirs for my kids, but I had no idea how to,” she says.

Hauser tries to infuse her writing with a positive angle, even when writing about her MS. While she can’t pursue outdoor activities the way she used to, she has found ways around it. In “Not an Option,” her family and friends organized a kayaking trip and insisted that she participate. She worried about accommodations for her MS but heartily embraced the adventure and looked forward to their next trip together.

MS affects every other part of her life, but her writing assignments are almost an oasis from her constant concerns. “I do think about the writing during the day to get more topics and clarity. It’s an escape from the anxiety and stress and questioning and effort you must put in with MS. There’s none of that with the writing.”

The class critiques have helped Hauser hone her editing skills, but perhaps the camaraderie is even more valuable. “Being in a group with people who are going through a lot of the same struggles — there’s an extra sensitivity and respect for the amount of time and energy it takes to get these things down.

Robert Leroise is a Long Island, New York-based writer.