

January 2021 Newsletter



Intention Tremor: A Visit With Author Tamara Sellman

According to the [National Institute of Neurological Disorders and Stroke](#), an intention tremor occurs when a person moves purposefully toward something. The shaking typically gets worse as they get closer to their target. For example, a person with an intention tremor may reach for a cup of coffee, only to find their hand beginning to shake when they grasp the cup's handle. When Tamara Sellman embarked on her career in journalism, little did she know intention tremor would come to mean so much more.



Tamara's life changed when she was 47 years old. A writer by trade, she'd gone back to school to study sleep technology. While preparing for finals in March 2013, she discovered she could see, but she could no longer read. In her words, "I could see just fine, but I could look all day at letters, words and sentences and it would be like trying to read a foreign language. That was really scary." As discussed in our [March 2019 newsletter](#), up to 65 percent of people with MS struggle with thought processes like information processing, attention and concentration at some point in the course of their

disease. Many also experience fatigue that has the potential to cause these cognitive issues. Three months later Tamara was diagnosed with relapsing remitting MS. When asked how she felt upon learning of her diagnosis, Tamara states, “It was a relief. I could finally do something about this problem. I wasn’t scared, I think, because two of my good friends had already been diagnosed, and they were working and living their best lives even with cases of MS that were far worse than mine.”

Once on MS treatment, Sellman finished the sleep technology program and worked the overnight shift directly with patients in the sleep lab for two years. When the resulting fatigue became too much of a problem, she returned to her roots in journalism and now



works as a science journalist, healthcare columnist, and online community advocate. Her award-winning [short works](#) (essays, poems, stories, and articles) have been published widely and internationally. They have also been featured on postcards, calendars and inside city buses across King County, WA.

Tamara’s most challenging MS symptom currently is the MS hug. She shares, “It usually arrives at around 4:30 in the morning, and while it can just be along the rib cage, often it is the diaphragm itself. Fatigue is less of a problem these days unless I’m working a lot, then my wordfinding and reading skills and general vision and speech slow down. That is more frustrating than painful. I occasionally have tremors and paresthesias, too, and digestive problems when stress hits.”

When asked how MS has affected her life, Tamara states, “Initially, it made me very angry. I’m not sure I was ever sad, just angry. I was completing an aggressive educational program toward a new career path when I was diagnosed. I’ve always loved working and saw the diagnosis as a roadblock.” However, her time in the sleep lab taught her exactly what sleep disorder patients experience. With this insight, she now writes two columns about sleep health. She also creates educational modules for her peers in the sleep field and uses her Certification in Clinical Sleep Health (CCSH) credentials to teach the general public (patients and their families in particular) about the risks of living with untreated sleep disorders. In her words, “This has been such a blessing. I can choose my hours, work from home, have creative control, and earn money doing



something I love. It's far lower stress, and if I'm having a bad day (pain, fatigue, digestive issues), I can just tend to it and get back to work when I'm feeling better... I very much loved the patient interaction, and do miss it so much, but feel like my new pathway as a sleep educator and healthcare writer means I can help many patients at once with my articles and columns."

MS has also affected Tamara's personal life. She has to adjust outside activities, depending on the temperature and humidity levels. Traveling is now difficult and she finds being in a crowd to be overwhelming. She shares, "My family was helpful from the get-go, but it was a challenge for them, as most of my symptoms are invisible... Friendships have changed. Some people faded into the background, while others emerged to be supportive." Through it all, she says, "Having these limitations placed on me is not necessarily bad. Now I know to read my body's signals when I've overdone something. I've learned how important it is to get outside as much as possible, as nature is a healing place for me."



Tamara is an enthusiastic member of iConquerMS. In her words, "I love the direct connection between communities: patient and researcher. I believe we need to amplify the voices of patients in the research world. There's a saying from years ago: 'Nothing about us without us.' Patient voices and experiences and interaction and engagement should be front and center with doctors, scientists, social workers, politicians, etc. iConquerMS provides an extraordinary linkage."

Sellman's recently published book, [*Intention Tremor*](#), is a collection of prose and poetry that chronicles her life as she adjusted to her new MS diagnosis. In her words, "I often turn to poetry and short prose to wrestle with personal issues... I think that the arts are a major pathway to understanding the human experience of life with chronic illness." The title was inspired by her MS symptoms. In her words, "I love the play on words and multiple meanings it implies."

Tamara wrote most of the pieces in the book next to a campfire or inside a travel trailer at Fort Worden State Park in Port Townsend, WA. She shares, "I've been a camper my whole life. I truly feel most in my element either camping or gardening. Around 2010 I started going on silent writing retreats in order to have uninterrupted time to write and

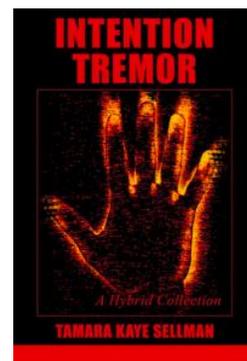
read and clear my head. It was one way I could maintain a writing life while being a working mom...I love tending campfires, there's something very meditative in that activity that supports my creative brain. The fresh air and access to beaches, trails, trees, and wildlife is also restorative. There's a term for it: forest bathing ([shinrin-yoku](#)). I make this an absolutely essential part of my MS treatment."



When asked what the take-away message from her book is, Sellman states, "I can't say that this will be what MS looks like for everyone, because it can vary so widely in how it presents and disables. But I do hope that they (readers) will see and understand that people with chronic illness (not just MS) struggle partly because the world is not built for them. I hope that people who don't have MS will read it and understand a little bit more about invisible illness and find a clearer path toward more empathy. Finally, I hope that people will read this and see that MS doesn't have to be a "death sentence" or a reason to not strive to live your best life, but rather be inspired to find workarounds to the limitations that such a disease imposes, and just keep reaching for your dreams. It may mean reassessing what those dreams are and going about these efforts in ways that are slower, but if we still get where we want to go, the pace doesn't need to matter so much."

Intention Tremor can be purchased on [Amazon](#) or directly from the publisher, [MoonPath Press](#). In Tamara's words, "I always encourage people to support the small press: without them, I might never have seen this book into being." Signed copies can be ordered on Tamara's [website](#). Because of the pandemic, there won't be a public "live" book launch at this time. She shares, "I'm hoping to put together one or more virtual readings in 2021. When the world becomes a safer place, there will be 'live' launches at booksellers, private parties, and other events."

Tamara is generously donating all of her proceeds from the sale of *Intention Tremor* to ACP. In her words, "I feel like this book really isn't just about me, it's about helping others who are new to the journey or who are caregivers or friends or family members trying to help their loved ones. I didn't write it to become famous or to make a living, I'd much rather take my earnings and give them to research efforts, especially in a pandemic world where research funding is drying up. ACP can do more with the proceeds of my book than I think I can."



For those interested, Tamara is teaching a [Kahini+](#) workshop on “Writing Illness” in 2021. Details can be found on Tamara’s [website](#), or by [contacting](#) her directly. In her words, “I recommend it to folks who want to write their own stories...It used to be that writing or speaking about concerns of the body was taboo. I think, especially now, with a pandemic impacting literally everyone on Earth, that people need tools for writing about their health challenges. It’s not only okay, but it’s necessary for our individual and collective mental health, to chronicle things like pain, guilt, loss, grief, and more. Writing can be instructive, illustrative, and practical, but it can also inspire, raise awareness, and serve an important therapeutic role. My goal is to empower and help launch new practices for beginning writers or uplift and energize established writers who have been previously discouraged by the old rules. It’s a new world now, let’s use our voices to shine a light!”



Kahini

Other Good Reads

As featured in our [August 2017 newsletter](#), Freda Spector Warrington’s life was touched by MS when her daughter was diagnosed while a college student. She’s published three books in her LISTEN TO THE LIGHT series. [LISTEN TO THE LIGHT: Stories of Interruptions, Intersections and Insights](#) is a collection of short stories about the unexpected experiences of everyday life and the wonder/deeper meaning behind them. [LISTEN TO THE LIGHT, The Daughter’s a Farmer](#) is a true story that describes the journey of a mother and a daughter moving gradually toward mutual understanding and respect for each other’s world perspectives and life choices, including lessons learned and insights gained that surprised them both. [LISTEN TO THE LIGHT: Courage in Recovery](#) adds a human face to the terrible disease of addiction. The author, who is trained in addictions counseling, describes her successes and failures with her patients in recovery. Warrington is generously donating profits from the sales of her books to ACP. Her donations are matched by the [HERO Fund](#) from Shell Oil Company.

Julie Stamm's recently published children's book, [Some Days We...](#), is a wonderful tool to help parents talk with their children about MS and/or any chronic illness. It's written from the perspective of a young child, Wyatt, as he navigates the unpredictable obstacles of MS with his mom, Anne. Each page is based on an actual moment lived by the author and her son. Julie takes the dark negative tone associated with chronic illness and turns it into uplifting empowerment for the reader.

