

My Marble Me Free Story

By S. Swan, August 22, 2022

12 years ago, I had a surgery that triggered the onset of a rare illness that ravaged my life. It was an ending, little did I know, it was a new beginning. This new life has made me an atypical expert on how to get up when life knocks you down.

Remarkably, serendipity came into my life for a whole week in 2021. It first showed up when I went to Zen Writing on Thursday, October 14th, when we found out that one of our members had been diagnosed with cancer. As we huddled around her with words of comfort and encouragement, I was asked, "How do you deal with your illness?" I shared how I continued to deal with it, hoping it would help her walk the difficult path ahead.

"Have you written a poem about that?" someone asked me. The question took me by surprise.

"No," I answered, thinking, "Why in the world would I want to write about that? I already know what I do. Why would I want to make it into a poem?"

"You should write that poem." The rest of them said, again to my surprise.

"No," I repeated.

The person I was trying to encourage told me, "If you write that poem, I would like to hear it."

This was the beginning of "Marble Me Free" and a turning point in my life.

I left not knowing what to do. I loved writing, but I did not want to write a poem about how I dealt with my illness. I felt very conflicted. I wrote to escape the hold Complex Regional Pain Syndrome (CRPS) had on my body and mind. To write the poem, I would have to concentrate on my physical and emotional pain; the trauma of being diagnosed with a terrifying illness and how it shattered my life. How I had to pick up the pieces. Writing about CRPS...not being able to hide from it...I did not want to focus on the trauma. I had already lived it.

CRPS showed me the paroxysm of pain. I woke from the surgery feeling I was being burnt alive, engulfed in flames that did not exist. The pain too real. The inextinguishable flames of pain still lick my body twelve years later without relief. It took two years of misery to get a diagnosis. Pain medications did not work. The doctor said, "There is no cure, no treatment. You need to get used to it. It's only going to get worse."

The only thing left in me was hopelessness. This is where I found God resides. What brought me back from the edge of suicide was the realization there was no cure and no treatment for this illness, not because it did not exist, but because it has not been discovered. My faith kept me alive and gave me the means to start chipping away at my marble block.

The poetess from Zen Writing had cancer, and I wanted to be supportive. The least I could do was to consider writing the poem. It was only Thursday, I had a whole week before our next meeting.

I had not made up my mind on Friday, nor Saturday, but serendipity stopped by in the form of an email to give me a nudge. Peggy, another friend from Zen Writing, sent me a link for Sunday, October 17th to a healing poetry workshop, “In the Time of Pandemic: Poetry Therapy, Creativity and the Practice of Mindfulness,” by John Fox, PPM and hosted by Diane Kaufman, MD, founder of The Arts and Healing Resiliency Center. Learning how to use poetry for healing was an interesting notion. I found it enticing, and in line with why I started going to Zen Writing. I was learning to meditate to help me deal with the pain from CRPS. The writing was an extra bonus. I wrote poetry because I must write, but I never thought poetry could be used as a path to healing.

On October 17th, I attended the online workshop. I learned about John Fox, and his work in Poetic Medicine. I did not know Poetic Medicine existed. I was glad to see a different way of addressing pain. Not trying to numb it with pills. Instead, providing us with tools to confront our fears in a safe, nontoxic manner, offering a safe place to express those fears. To create. A way to use words, metaphors, and similes to let the pain out without destroying yourself in the process. In fact, becoming aware, you are stronger than you realized. Because once you let your fears...your pain out, the world did not end. You are still whole. That is when you know—you can do this. You can face this demon, this pain, this marble block. Confronting it did not destroy you. This process is a way to safely let the pain out, little by little like water from a faucet. You are in control of how much you let out. You can let it drip or open the faucet and just let it flow. Instead

of bottling it in until the pipes cannot hold it back anymore, and the pain bursts out, destroying everything in its path.

The poems written in that workshop were beautifully profound, filled with both strong and delicate emotions. The workshop came to an end, Diane and John were saying goodbye. It was now or never. I cut in, speaking in a rushed manner, “I have Complex Regional Pain Syndrome. An illness considered the most painful one in the world. It's nicknamed the Suicide Illness. For CRPS there are no protocols for suicide prevention. Is there something you could do?” I said so much in so few words I felt there were no safety nets where I wish there were, since I kept falling through the cracks. I feared when the Zoom call ended, I wouldn't see Dr. Diane Kaufman again. A person that might be able to help prevent suicide in the CRPS community.

She answered me. “I never heard of that illness. I would like to speak with you some more. Is it ok if we meet this week?”

“Yes,” I said wholeheartedly. I didn't know when I would hear back from her. This was a busy person with a life and a career, but she contacted me right away. We set up a meeting for Thursday, October 21st, right before Zen Writing. I was so excited. Finally, I would have the chance to speak with somebody knowledgeable on suicide prevention and greatly qualified. I was very happy, but I still had the poem in the back of my mind. I still had not decided what to do.

On Wednesday, October 20th, I made up my mind. Writing the poem was my way of supporting a poetry friend in her fight. That was good enough reason for me to do it, so I wrote the “Marble Block.” The world did not end. I was whole.

The next day, I finally met with Dr. Diane Kaufman on Zoom. She had a welcoming smile, a gentle voice, and inquisitive blue eyes. She asked me, “How do you deal with your illness?” The question was a flashback to my moment of serendipity.

Little did I know then that Diane and I were two phoenixes that came back to life after life crumbled us to ash.

“I just wrote a poem about it.” I felt awkward. I don’t even know why I said that. I even surprised myself some more because I kept talking, and I found myself saying, “If you’d like...I can read it to you.” I don’t know what was going through my mind. Why in the world would I be offering to read this poem when I’m here for a completely different reason? I could have given her the same answer I gave in Zen Writing, but no, I went ahead, and I read her the “Marble Block.”

She listened, all the way to the end. “I can see this poem as a powerful animation, would you be okay with making it into an animation? I know somebody.” Her words stunned me.

I specialized in saying no, but I had been working, for a very long time, on learning to say yes. Not too long ago, I had made a commitment to myself. I vowed to say yes to whatever opportunities would open to me. And sure enough, this happens. Serendipity? I was blown away by her suggestion. I went with it. “Yes, sure.”

It was a very cool thing to hear somebody say, “Hey! Would you like something that you have written to be made into a film?”

“Yes, sure.” That is what dreams were made of. Dreams, they do not materialize for me. That was my reality.

My life had taught me over and over again that when I wanted to do something important to me, something I cared about, something I fought for—when I was almost there, when I could almost touch it—something out of my control would happen and I could never get to the goal. Honestly, I was thrilled, but...

As soon as the meeting ended, I googled her because I didn’t know with whom I was speaking. I knew that she was a doctor. A child and adolescent psychiatrist who specializes in preventing suicide in minors. I knew about her healing poetry workshop. I assumed she was a caring doctor with a creative healing approach. Hosting the workshop was one way for her to reach out in a time of pandemic when we cannot go anywhere, but we still need to feel part of a community. That was my perception of her, but I didn’t know her. When I googled her—oh my goodness gracious—she was all that and much more.

Dr. Diane Kaufman was in fact and foremost an artist, using her art to think outside the box to extend a healing hand. She has written books and award-winning lyrics. One of her children’s books was made into an opera of all things, with Danny Glover as the narrator.

I was blown away. Many of her songs and poems have been made into beautiful heartwarming videos. No wonder she knew somebody! The person she had been working with, creating those meaningful internationally acclaimed videos. Maybe just maybe, for once in my life, my dreams could become a reality.

We kept meeting through Zoom, and I met Lucía Martínez Rojas, the person Diane knew. Lucía became the sole animator for “Marble Me Free.” Seeing her outstanding work surpassed anything I could have imagined, and I have a big imagination.

Diane, Lucía, and I were a team of three. Diane called our meetings Creative Collaboration, and it was true. I was given the opportunity to stay and be a part of the evolving film-making process to bringing this poem to life. Diane’s vision and insight guided the whole project. That’s how “The Marble Block” became “Marble Me Free.”

Lucía’s artistry...the way she used images for storytelling...were so impactful and so well done. Diane and I couldn’t make up our minds when she showed us different styles. We wanted them all. We couldn’t give up on anything she had drawn. That’s how the marble block became an entity in itself. Lucía’s idea of bringing in influences from Picasso and Frida made the images tell a more in-depth story that creates a sensibility that goes straight into your heart.

Once the animation was done, Jean-Marc became a part of this project and with his exquisite sensibility wrote a score for this film. He even adjusted it to not cause me any pain. It was not only incredibly beautiful, but also soothed my pain like balm.

CRPS is a cruel illness that can turn sounds into torture. I used to love listening to music, now I have to be very cautious. It was horrible to find that something I love so much, that brought me so much joy, that was such a big part of my life, had become something I needed to avoid. I was so determined to still have music in my life, that one day patiently, painfully, I went through the different music channels, not stopping until I found music that wouldn't cause me pain. Before, I could listen to all types of music, now I am restricted. Once in a while, a song played that not only did not hurt me, but soothed me. Music was again not only part of my life, but part of what helped me. An ally against pain. My playlist is not made of my favorite songs, but those that relieve me from pain.

“Marble Me Free” started as a small poem. Through every step of the project, I felt heard. The respect with which everyone involved approached my poem...They did not change my point of view, nor my voice. They enhanced it through the music, through the images, through the vision. The project, the dream that was becoming a reality, became larger, became something more.

In this Collaborative Creative project, I have had the privilege to work with other artists to grow my poem into a film. A film we hope will resonate with and empower those who see it. The project has inspired us, and it is still growing because we are not going to stop with just a film. We are going to offer connection, support, and skills through workshops and presentations. We will raise awareness about CRPS and advocate research towards finding not only a treatment, but a cure. Already, through the

Marble Me Free website's many resources (<https://www.marblemefree.com/>) we are helping to prevent suicide. The Marble Me Free vision keeps growing.

Emotional or physical pain can unravel our lives, our bodies, our minds. It can ravage, our minds, our bodies, our lives, yet we can evolve to be more than we were before the pain. We don't know our own strength until we are faced with our own marble block. Don't be afraid to hope for better. When we do, we can chip at it until we are Marble Me Free.