

El Milagro [The Miracle]

Editor's note: The author of this article is a quadriplegic who is severely dysarthric as a result of multiple sclerosis; she lives alone at home with the assistance of three helpers. She previously wrote a successful and interesting newspaper column on disability, which has been collected into a book (see review page 92). She was asked to write this article to help physicians understand how patients feel in such dire circumstances and how our involvement, or lack thereof, is perceived.

—Vincent J Felitti, MD

*“What is life? It is the flash of a firefly in the night.
It is the breath of a buffalo in the wintertime.
It is the little shadow which runs across
the grass and loses itself in the sunset.”*

— Crowfoot, Blackfoot warrior and orator

In the medical profession, dealing with someone mortally ill leaves little time for the surrounding medical staff to consider how the patient feels emotionally, what medical treatment is to be taken, what family members are experiencing, and the mysticism and magic involved in healing.

Less than two months ago, I stopped breathing.

I live with a chronic condition: Multiple Sclerosis (MS) has been part of my life for over 15 years. Now in the chronic-progressive phase, I use a wheelchair. I have always eaten well and avoid alcohol, cigarettes, and drugs. Other than MS, I have been ill very little.

What happened?

I got pneumonia in the beginning of November. My friends Peter and Julia were visiting from England and this is their account:

“Our visit to New Mexico was a great joy for us both as we had not seen Karen for seven years and we were looking forward to catching up with news and seeing where she lived. Our visit came just after the first bout of pneumonia and although Karen seemed to be better she was in fact valiantly fighting against the infection. We all longed to be able to talk nonstop and to do things together but she was not really well enough. However, we did manage to have many wonderful chats and laughs, often in the evening between the shifts of

the care staff when we were ‘in charge.’ Positioning her in her wheelchair always produced great giggles due to our incompetence. It was a very emotional leave-taking; Karen was not well enough to come to the Amtrak station with us and parting was difficult, as we did not know when or if we would see each other again.”

Though I felt better, a week after their departure the pneumonia came back with a vengeance. I had a temperature of 104 degrees. Cold, wet rags were added to help lower the fever, and the home hospice nurse gave me morphine to ease the pain. I then told my helper, Angela, I was sleepy and I wanted to “chill.”

This is where the amazing saga begins. For some reason, I asked Angela, to sit with me—something I never do—while I rested. It was then that I stopped breathing due to the respiratory depressive affect of the morphine. Angela shook me, slapped me, and basically got me back to breathing, none of which I felt nor remembered.

What I do recall is her looking at me intensely and saying, “Don’t leave me now!” About that event, Angela says, “Karen had a bad reaction to the morphine. It was an experience that I will never forget. I found myself literally fighting for her consciousness. I felt in my heart that if I gave in to her unconsciousness, I would lose her.”

That evening, two people stayed with me as I slept in the chair, the upright position helping me to breathe better. A friend, Paula Thaidigsmann, a retired Nutritional Therapist says the following:

“Angela and I had agreed it might be safer and less stressful to allow Karen to spend the night in her chair. For several hours she slept peacefully while I sat close by, watching her to be sure that she was still breathing, I found myself struggling with my own feelings and perceptions. I felt then that it was necessary for me to let go of any concerns about what the outcome would be, to just be present to what was happening.”

The next morning, I woke up really sick, in much pain, my chest gurgling with each breath, my face ghastly white, and blood coming out of my mouth, possibly due to the large amount of Ibuprofen I was taking—and it wasn’t even Halloween! That morning, I was getting 83% oxygen saturation on my own, and was given oxygen to ease the struggle.



Karen G Stone
Columnist and
Disability Activist

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Then, more amazing things happened: Unaware of what happened the day before, but feeling *extremely* tired, I turned to Angela, and said, “Call my family.” And proceeded to go downhill.

Because of the excessive amount of phlegm, and the severity of my illness, double pneumonia was suspected. A stream of people started to come ... and the phone began ringing nonstop. A golden thread that was part of the tapestry included my physician. Though I had prior contact with her, it was this event that revealed to me her true nature. If I had to use one word to describe her, it would be “grace.”

During this whole episode, my physician dealt with friends, family, assistants. She exuded calmness, intelligence, compassion, and thoughtfulness. Part of her approach to healing is teamwork. Decisions were always reached by consensus. I was never left out of the loop.

I felt she respected how the situation would play itself out. She allowed the mysticism and magic to be a part. Without being dominant, she listened sans judgment, gently made suggestions, and rolled her sleeves up to do whatever was needed. I did not find out for three days after I took the morphine what had happened ...

Because the doctor was telling my family that I had a 50/50 chance of surviving with the proper antibiotics—otherwise it was 20/80—and because many people were saying good-bye to me at this juncture, I realized this was no ordinary cold. However, the thought that I was dying never occurred to me.

I consider myself a very spiritual person and have reflected on my feelings of death. I have spent years meditating on the aspect of letting go. Part of this search has made me a long-time admirer of Stephen Levine and his partner/wife, Ondrea. (See sidebar.)

Following in the footsteps of Elisabeth Kubler-Ross, author of *On Death and Dying*, they write in an open and poetic manner about death and dying issues. As a result, my feelings about death have been greatly enlightened and comforted by their words. My fear of death does not exist. And because I have lived such a good life, I hold dear Stephen Levine’s words, “We die as we live.”

I still refused to go to the hospital. Being surrounded by my plants, animals, and the familiar was a more appealing option. So to paraphrase Mark Twain, I’m glad the rumor of my death was precisely that: a rumor. Due to fantastic support of friends, family, and doctors, I am still here.

I felt surrounded and very cradled by love. After finishing all the drugs, I was quite unprepared for my emotional fallout, a common phenomenon that occurs frequently among patients that have survived a medical crisis. Though I experienced a great deal of amnesia during the crisis, I truly realized just how close to death I had been and was reeling from that as well. The fear of death did not bother me, but the flurry involving the details of my final affairs overwhelmed me. In brief, this experience was an excellent dress rehearsal.

I am now taking probiotics, acidophilus, and other good stuff like protein powder drinks—I am trying my best to gain weight and rest a lot. A select few have received a phone call from me. Mark Twain said, “Be good, and you will be lonely.” I am not lonely, but I am being good and avoiding crowds.

As a professional photographer in my earlier days, two images used as wallpaper on my computer came to mind during this crisis. The first image I posted shortly after my initial bout with pneumonia. Though this photograph was taken in broad daylight, the overall hue was dark, albeit colorful. As a close-up, the image involved a small creek deep in the woods. Taken in Oregon during the autumn, the creek was surrounded by moss-covered rocks, dotted with brilliant, fallen leaves. It is an introspective image. The second image, posted during the recovery days, reveals how my health was lifting. Taken from an airplane, the photograph of snow-covered mountaintops radiating in the early morning sunlight included a very blue sky. What a place.

When looking at this image, I cannot help thinking about Edna St Vincent Millay’s poem, *God’s World*:

O world, I cannot hold thee close enough!
Thy winds, thy wide grey skies!
Thy mists, that roll and rise!
Thy woods, this autumn day, that ache and sag
And all but cry with colour! That gaunt crag
To crush! To lift the lean of that black bluff!
World, World, I cannot get thee close enough!

It is now five and a half months later. I am full of “piss and vinegar.” Having faced death so closely, I have had the opportunity to test any residue of fear. It does not exist.

Vietnamese Buddhist monk, Thich Nhat Hanh, aptly describes very well my life as of present, “You become aware of the fact you are alive. You are still alive and you are walking on this beautiful planet ... The greatest of all miracles is to be alive.” ♦

Stephen and Ondrea Levine Reading List

- Living Into Life and Death
- A Year To Live: How to Live this Year as If It Were Your Last
- Who Dies? An Investigation of Conscious Living and Conscious Dying
- Unattended Sorrow: Recovering from Loss and Reviving the Heart
- A Gradual Awakening
- Guided Meditation