

“How Do You Do It?”

by Elizabeth Aquino



I am defined by my daughter. I hate to say it, but the fact is that I am. After almost fifteen years of dealing with her profound disabilities, watching tens of thousands of seizures and running ferociously toward any prospect of help, I am changed. Changed, though, from whom? I know that were I to extricate myself from Sophie, the neurologists, the alternative practitioners, the drugs, the treatments, I might have to build someone new. As a woman, I am told by the culture that I should “know myself” and “love myself” before I can give properly to another. As a married woman, I am told by the culture that marriage and its health supersedes even the relationship one has with one’s children. As women, we are told, often, that our identity should not be wrapped up in our children. While these admonitions and guides toward a healthy identity resonate for me, to be honest, I have found them exceedingly difficult if not impossible to follow.

When I gave birth to my beautiful daughter on March 8, 1995, I naturally had no idea what the future would bring. A new mother, my expectations were like those of millions before me. I would love this child and with my husband bring her up happy, well-adjusted, educated and, hopefully, tolerant and kind to others. My values were simple, my hopes pure, and my faith in the natural order of things profound. Three months later, when Sophie was diagnosed with infantile spasms, these expectations were quite abruptly upended. The particulars of that time—the abrupt and cruel diagnosis while nursing my baby seated on a metal folding chair, being sent home after one week in the hospital to administer intra-muscular shots of high-dosage steroids that rendered my tiny baby hoarse from screaming, covered in thrush and blown up like the moon—are crystal clear to this day, but only much later was I able to articulate the stunning loss I felt. It seemed that day that the child I had

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given birth to had been taken from me and replaced with someone new. It seemed that I would have to redefine my expectations, redefine Sophie, and redefine myself. And unlike those expectations that I had before, those of a normal life with a normal baby and family, what I expected, really, was nothing. I had lost all control or what I thought of as control over what life was supposed to be about.



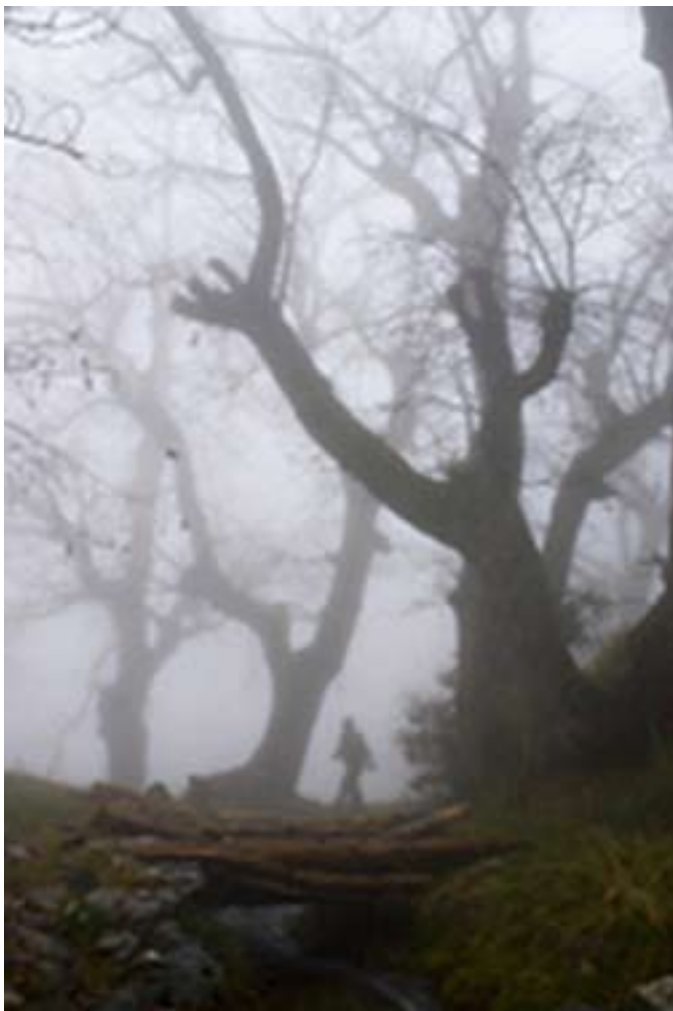
Sophie turned fifteen years old this March, and during all of those years, save her first three months, she has endured multiple seizures every day. We have yet to find out why, and her imperviousness to traditional antiepileptic medicines has stumped all of the doctors we have consulted. The western medical world has a way to describe Sophie's particular type of epilepsy, a definition that in essence reveals absolutely nothing.

Sophie's diagnosis is "refractory seizures of unknown origin." It seems that Sophie's brain is incredibly dysfunctional for no apparent reason and will not respond appropriately to any kind of customary intervention.

I often tell people who ask, "How do you do it?" that if someone had told me fifteen years ago that I would still be comforting my now five-foot tall adolescent daughter as she seizes on her bed, that I would still be feeding her because she can't feed herself, that she must be bathed and dressed and kept clean because she can't do these things, or that she could walk only with assistance and has never uttered a word—well, I might have felt like jumping out of the fourth story window of the tiny apartment where I lived, that baby in my arms. Fifteen years ago *this* place, *this* time, *this* person that I am and *this* young lady for whom I have been given the honor of caring were enveloped in fog, buried in deep moss, sheltered by thick trees, invisible to any presentiment or even reflection. I met women who were traveling the same path or had been down it before and they, above all else, were my guides and my support. They could do it and so could I. I found that despite the darkest days, I had been graced with a deep and often morbid sense of humor that

sustained me, perhaps even more than faith itself. I saw my husband grieve and mourn and then accept our situation, and his gentle acceptance taught me to slow down when I became frantic. I took a deep breath and had two other children whose development was not just typical, but miraculous and taught me perspective.

Despite the near-constant struggle, I look at my Sophie now and am filled with love for her. Despite her lifetime of seizures, her silence and her extraordinary difficulties, her eyes are deep and filled with expression. I know that it is more *that* expression



that moves those who encounter her than the disability itself. I marvel at her grace, while wishing for her ease and gather my other two children, my strong boys, and my husband into my gaze. I feel the presence of my family—my mother, my father, my sisters and brothers-in-law—around me, and then my friends, those who share much of my life quite literally, and those who are far away but with me in spirit or likeness. I have learned that my identity is very much defined by my daughter and supported by my relationships to these other people and that I am the better for it. I don't really know who I might have been without her but that doesn't really matter, anyway.

And it is good.

That is what I tell the person who asks, "How do you do it?" That is what I tell myself when the enveloping fog, the deep moss and the thick trees loom ahead, when the path is obscured and I think *How will I do it?* I know that I will find myself, fifteen years hence, *doing it*, and it too, will be good.

Elizabeth Aquino is a writer living in Los Angeles with her husband and three children. She is currently working on a memoir about raising her daughter who has a severe seizure disorder of unknown origin. Her work has been published in several magazines and newspapers, and she posts regularly at www.elizabethaquino.blogspot.com