



"DEAF-BLIND"

# BLIND IN THE FACE OF ADVERSITY

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Fear controlled her life. She subjected herself to his daily abuse in the form of hair pulling, pushing, slapping and finger crushing, which left no physical evidence. One evening, he helped her bathe, dress in her pajamas and crawl into bed. She asked for a snack, and hours later he brought it, riddled with anger because she shuffled her position while sleeping. He threw the banana at her, hitting her nose. He dragged her to the bed's edge by the ankles and threw himself on top of her. He harshly wrote letters on her cheek with his finger. "I put you where I wanted you." He degraded her into feeling like an animal by repeatedly demanding her to stay. She cried herself to sleep. She endured years of pain until Joseph, her 5-year-old son, said, "Daddy is bad because he hurts you."

Her son's simple, honest statement brought Angie Orlando to a life-altering decision. But she feared a judge would never reward custody of a child to a deaf-blind mother.

More than four years have passed since Angie sought freedom from domestic violence. Despite her disabilities, after years of legal battle, she won custody of her son, which she claims to be the most thrilling moment of her life. Angie and Joseph currently live in Kent with Angie's parents in the home where she spent her childhood. Her parents give ease to the whirlwind of being a single mother; Angie still faces numerous obstacles.

When Angie was 13, she started to lose her hearing. When she was 16, she started to lose her peripheral vision and had night blindness. About nine years ago, while still married, she suffered "the illness," as she calls it. "What we think is that my body was too stressed with something and my cells started stealing energy from nerves and muscles," Angie says. Within about two weeks of first becoming ill, she lost all feeling in her hands, and she couldn't walk. She also lost what little hearing and remaining vision she had.

"The last thing I saw was my son — his face was about seven months old, and he was creeping around, crying out, worming his way around the living room wearing a red sweatshirt. He looked up at me and smiled. The image was really fuzzy, but I could see his blue eyes and his mouth and the red shirt. That's the last thing I ever saw. The next day I woke up, and I couldn't see anything," Angie says, signing along to her own words. "Joseph says it's weird that his mother doesn't even know what he looks like."

Like most mothers, her main concern is for the well being of her son, but in this case, the concern is brought to the forefront because doctors can't actually figure out the definite cause of Angie's problems. The doctors think it may be the genetic disorder mitochondrial myopathy. One of her symptoms is polyneuropathy — a condition that causes nerve damage in multiple body parts.

"I'd like to move on with my life, but the medical stuff keeps dragging me back and slowing me down," Angie says. "I just have to wait."

The mother passes down Mitochondrial disorders, and her biggest fear in life is Joseph inheriting her disability, but he isn't showing any traces or signs.

But he *can* sign. He communicates to Angie by signing directly into her hands. Angie's mother, Lois, only knows a few words in sign, but she can spell out letters with her fingers to talk to her daughter. Angie's father communicates by sending text messages to her Braille reader, which is Bluetooth capable, so she can also email, read and surf the Web.

Angie recently took advantage of another technology: a new cochlear implant. With 25 years difference between it and the first one she had placed, the results are evident. In her blog, Angie writes about her struggles, encounters and experiences as a deaf and blind single mother. The new implant opened her ears to a new level of sound.

"More noise is turning to identifiable sound. I love just sitting and listening... trying to pick up something new. I always feel so rewarded when I do," Angie writes. With the old implant, she could only hear environmental sounds. Now she can hear minor dialogue, but it's difficult to comprehend it. Because she's showing improvement, she wants Joseph and her parents to verbally speak to her, as opposed to signing.

Angie blogged about practicing with her mother: "I asked my mother to name fruits that she likes to eat. I almost got them all. I distinctly heard her say strawberry, apple, grapes and cantaloupe. Then she decided to be cute. She said 'snozzberry.' I picked up on the 'S' sound but couldn't figure out the rest."

Although Angie likes the advantages of technology, especially when communicating with her Braille reader, she said it's always nice to rely on sign language as a backup. Last semester, her Introduction to Creative Writing class allowed her to practice her signing. An interpreter narrated the class lesson and dialogue into Angie's palms. It is somewhat difficult for her to



Angie uses her Braille reader to communicate, update her blog and surf the Internet. Angie's blog can be read at <http://www.dotbug3.blogspot.com>.

keep up because the class moves quickly; it is also physically straining.

Her elbows are exhausted from overuse. Pain radiates through her arm every time she feels her conversations, reads Braille or moves them.

"You never really think of how much work an elbow does until it begins to hurt. Every movement of the fingers, hands and wrists go back to the elbow," Angie blogs. "There's no way around an angry elbow. You just have to deal with it."

It seems as though Angie deals with everything in stride — because she does. Even simple frustrations don't faze her. One day last October, her computer wasn't communicating with her cell phone properly, which cut off communication. It wouldn't be out of the ordinary for someone in today's world to lash out against technology, seethe with frustration and curse, but Angie is extraordinary. Instead of throwing her hands up in irritation or cursing out all computers, she simply says, "I don't understand it. I charged it last night." And took steps toward solving the problem. Patience is vital in Angie's life, especially when trying to cope with pain — whether it is physical or emotional. She writes: "Patience. I will get over all of this soon enough. I just try to concentrate on how great it will be to have a healthy and pain-free arm again. I think in the end, it will all be worth it."

Along with being a deaf-blind single mom, student and patient, Angie is also adding the task of co-founding an organization to her list of roles. Currently, Angie is in the process of forming the Northeast Ohio Deaf-Blind Association.

"The main goal is a way for people who are deaf-blind to go out, socialize, have fun," Angie says. "It's purely a social group."

Regardless of whatever title someone can give Angie or her story, the root of everything is a mother's love for her son. Throughout all the struggles, pain and complications, Angie says Joseph is the most important part of her life.

"He gives me my strength and power. He's the reason I go on living." **B**



Angie's son is able to communicate with her by signing into her palms.