

# Blindness Can't Stop Me from Living the Life I Want to Live

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By Peg Rosen

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If all goes as planned, Las Vegas mom Terri

will cross the finish line of her first marathon in November with LED lights braided into her hair and her family cheering her on. It will be a remarkable accomplishment, but not for the usual reasons. Terri, 35, literally can't see where her feet are taking her.

"Running is my Zen," says Terri, who trains and races while tethered to the wrist of a buddy from the support group Achilles Las Vegas. "It lets me push my limits. It shows me and my kids that my blindness doesn't stop me from living the life I want to live."

rupp family photo

"We work so well as a family unit," says Terri, here with husband Aaron, daughter Marley and son Jackson on a hike. AARON RUPP, PHOTOGRAPHER AND OTHER BLOGGER IN THE FAMILY. WWW.THESEEDPROJECT.NET

Diagnosed at around age 5 with optic nerve atrophy, an incurable and often progressive disease that damages the nerve connecting the eyes to the brain, Terri doesn't just defy conventional images of blindness. She smashes them to smithereens.

She's the married mom of two grade-schoolers, president of the National Federation of the Blind of Nevada and a dedicated camper who navigates the woods with a long white cane. "I can do just about anything except drive," she says. "And there's Uber for that."

Terri makes it all seem easy, although her journey has been anything but. In fact, her experience — struggling for years to "pass" with what little vision she had and frustrated by the world's low expectations for her — drives her to help empower others like her.

"Disability doesn't define us," she says. "What defines us is how we live our lives."

Blindness is more feared than the loss of memory, speech, hearing or a limb, research shows, but it is also misunderstood. Only a small percentage of the estimated 1 million people in the U.S. identified as blind have no vision whatsoever, according to the National Federation of the Blind (NFB). Instead, most live a fuzzy middle, a gradual mash of blurs and contrasts, that Terri inhabits.

"I can see shades of dark and light, vague shapes, and I can tell if something is moving. But there's no detail," says Terri. She can sense the roundness of her daughter Marley's face, for instance, but can't make out her dainty features; can perceive the brightness of a favorite running top, but not its color. Over the years, Terri has developed ingenious work-arounds.

"When Marley started to walk, she would get into hard-to-find places," says Terri. The solution: "She wore bells or squeakers on her shoes." Terri also pinned tops and bottoms together before washing so she knew her daughter's clothes would match.

But even though she has a tiny degree of vision, Terri is comfortable identifying herself as blind. "Saying I have low vision or I'm vision impaired implies that somehow I'm 'less than' or 'insufficient,'" she says.

Only a small percentage of the estimated 1 million people in the U.S. identified as blind have no vision whatsoever. Terri's life today is a far cry from her childhood in an enclave of Cambodian refugees near Stockton, CA. "Disability was a stigma in our culture," says Terri. She didn't even know her disease had a name until she was in high school. "When people asked about me, my parents would say, 'Terri? She just doesn't see very well.'"

By the time she was diagnosed, Terri was in kindergarten and her sight was slipping. As is often the case with children like her, her school focused on enhancing the vision she had instead of providing alternatives to it, most crucially by teaching Braille.

"Many parents see Braille as a surrender," says Terri. And why bother with it anyway, in this age of audiobooks and smartphone apps that can read everything from a wine label to a school worksheet? "You can't learn syntax, spelling or punctuation just from listening," says Stacy Cervenka, chair of the NFB's Blind Parents Group. "If your writing is a mess, if you're basically illiterate, it's going to be very tough getting a job." The sad proof: Seventy percent of blind Americans are unemployed — but of those who do work, 85% are Braille-literate, according to the NFB. Currently, a paltry 8.5% of the 60,400 blind students in the U.S. are Braille readers.

"I never felt I was good enough, fast enough, smart enough," she says. "I struggle constantly with self-worth because of what I went through."

In school, she could barely read the worksheets teachers blew up into ever-larger print. "I filled in the blanks with random words because I didn't want to seem ungrateful," she says. She wept behind Coke-bottle-thick glasses because they did little to help. "A boy asked me why I read with my face right up in my books," she recalls. "I started holding them farther away and not really reading."

Faking it became Terri's secret strategy as she battled her way through high school and college. She brought schoolwork back to the apartment she shared with her sister, enlarging it on a special closed-circuit TV and working all night to complete it. But by her junior year, Terri was quietly failing all her classes but one.

She downplayed her disability socially too, even with the man who became her husband. Aaron, 36, met Terri while he was studying to be a paramedic. He knew she couldn't see well and thought it was sweet that she held on to him while they walked together. She didn't drive, but that wasn't unusual in their city. Then one day he opened Terri's bedroom closet and discovered something shocking: a folding white cane she had secretly started using while traveling to campus on her own.

"I fell in love with her before I knew she was blind," says Aaron. Terri wasn't ready to talk about it, but he was okay with waiting — they both knew the relationship was serious.

In January 2005, Terri left school and took an important step toward accepting her blindness, working as a receptionist at the Society for the Blind in Sacramento. There she found confident officemates openly navigating the world with white canes that were light-years beyond hers: feather-weight and exquisitely sensitive slivers of aluminum, carbon fiber or fiberglass that sent a constant flow of information as they swept the ground. These canes warned of toys on the floor, curbs and the slightest dip or rise. The metal tips also helped their users echolocate, telegraphing with a subtly changing "tap tap tap" the size of a room or the closeness of a wall. Bright white, often with a red tip, they sent a clear message: "Make way for me. I am blind!"

"There I was, still using this heavy, awkward cane, literally folding up my blindness and hiding it," says Terri.

She found her answer a few months later at an NFB convention. There she was blown away when she encountered hundreds of blind people "living their lives the way they wanted to," she says. She marveled at how they sized up souvenirs by smell and touch and asked waiters to read menus aloud. "I had no idea I was entitled to do that," says Terri. "Finally, I wasn't limited to asking for a Caesar salad."

Many people she met there had attended the Louisiana Center for the Blind in Ruston, LA, a preeminent training center. Its nine-month bootcamp requires students to wear eyeshades that block all vision, so there is no choice but to navigate by alternative means. Classes immerse them in positive blindness philosophy, and they learn cane travel with the intensity of fighter pilots. Braille and accessible phone and computer tech become second nature. They must even pass wood shop, complete with table saws and electric drills, to graduate.

By the time Terri arrived home from the convention, she'd made up her mind. "I've shoved a part of myself aside for too long," she told her parents and Aaron. Three months later, she was on a plane to Louisiana. Terri graduated from the program in 2006, moved in with Aaron, reenrolled in college and relaunched her life.

We knew she'd be okay. Because I'm blind and I'm okay.

Today she oversees her kids' homework, marches them to the park, whips up dinner and manages NFB business from home. But Terri accepts support when she needs it. From her parents, who moved nearby two years ago after selling their donut shop. From Aaron, who reads cooking instructions and fills out forms. From her son, Jackson, 7, who tracks down missing flip-flops. Even from the sales staff at Old Navy, whom she'll ask, "Do these shorts make my butt look fat?"

Above all, she is locked soul-to-soul with Marley, who was diagnosed at age 4 with the same form of blindness Terri has. (Jackson is fully sighted.) For years, Terri had suspected the truth, despite doctors' assurances. "When they told us, I cried with relief," says Terri. "Finally, no more false hopes. Marley would be blind. But we knew she'd be okay. Because I'm blind and I'm okay."

Now age 8, Marley is a blossoming Braille reader, a fearless self-advocate and, yes, a runner too. "Running makes me feel free, like I can fly," says Marley. And with Terri as her mom, there's no doubt she will