

A Tale of Two Parents

Parenting is never easy, but CMT adds even greater challenges. In this issue we bring you stories from the perspectives of a parent with a child who has CMT and of a parent with CMT.

Parenting a Child with CMT

By Abby Havermann

It was a day like any other when I hustled Jaden along the sidewalk on the way to second grade. My mothering mind ran on autopilot: Brush your teeth! Get your shoes on! Did you pack a water bottle? How hard is it to be on time? Suddenly, time slowed as I watched Jaden, now 11, fall over.

I didn't run back to hoist him up, I didn't dust him off. I stood watching him. As he climbed to his feet, I saw an image in my brain: Jaden loping next to me. Loping, loping, always loping to keep up.

That's when we began to pay attention to how he walked. I remembered how hard it was to teach him to ride a bike. It registered how often he complained of growing pains.

On bad days, when I reflect on the stress of my pregnancy, I'm sure that Jaden's CMT is my fault. On mediocre days, it's not that I know why this has happened, it's just that I know it's teaching me something. I wish he didn't have to suffer for whatever the lessons may be. On good days, I know that his soul chose me and mine him and the why doesn't matter.

No matter the emotions I wake up with, however, the choice of whether I live

out a bad, mediocre or good day is entirely up to me. I decide what thoughts I allow myself to indulge.

First, I must identify what horrible stories I'm telling myself about Jaden's future. I must become conscious of all the ways I'm beating myself up for not being better, not doing better, for not knowing what to do.

Then I must pour different information into my brain as if guzzling orange juice and a raw egg to treat a hang-over. Maybe it's an uplifting podcast, maybe it's an article on mindset, maybe it's an AI-Anon meeting, a webinar on gratitude or maybe it's just blasting dance tunes. I might have to go on a bike ride or meditate or practice a breathing tool, or all the above.

Most often these days, I can turn it around in short order if I'm paying attention. But there are times when it can take the better part of a day to turn myself right side up again. That is part of raising a child with a disability.

The biggest danger I face is when I go unconscious, the times I'm not paying attention to how I'm thinking and feeling and acting. That is when things turn ugly, not just for myself, but for whoever lives under my roof.

I'm not ashamed to crawl into bed for a day, but even that must be done with awareness. It's an act of self-love, an attempt to rejuvenate. It is not a self-in-

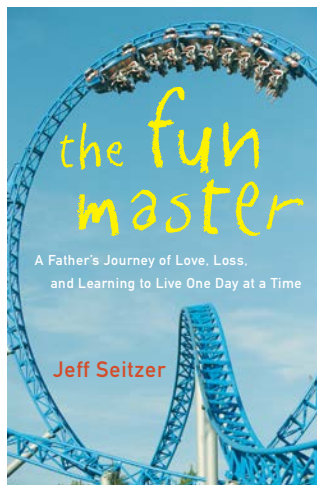


Abby and her son Jaden

dulgent pity party, and it is certainly not an excuse to self-flagellate for being a sloth. Neither of those things are loving to me, and if there is one thing my kid doesn't need, it's a self-loathing mom whose energy is sucked by her own guilt and shame and victimhood.

My goal is no longer to understand why Jaden was dealt his hand. My goal is to be the best version of myself I can be. Otherwise, how can I ask the same of Jaden when he has so many more mountains to climb than me? It is not whether we win or lose the battle on any given day, but the willful intention we bring to each one.

Abby lives in Colorado where she is a speaker, author and transformational coach.



Jeff Seitzer was a self-admitted self-involved academic struggling to cope with CMTX and the residual effects of encephalitis when he took over the care of his son Ethan, who was born in fragile health. Ethan thrived despite multiple surgeries, hospitalizations, serious breathing and swallowing problems, hearing loss, and a challenging social environment. His instinct for fun proved the perfect complement to Jeff's determination to live life fully. Ethan drowned in August 2010 at age 9, though not before he, his sister Penelope and their mother Janet taught Jeff that the true path to happiness was putting other people's needs before his own—and living in the moment rather than trying to control it. This is an excerpt from Jeff's forthcoming memoir, *The Fun Master: A Father's Journey of Love, Loss, and Learning to Live One Day at a Time* (SparkPress August 2022).

When the Parent Has CMT

By Jeff Seitzer

Early on a cold February morning, I stirred my coffee while Ted, the owner of my local café, told me about the plumbing problems that had caused him to close for a few days. Ethan and I had spent a lot of time in his establishment, reading books and chatting with the regulars. It was kind of a community center for us. I was relieved he had reopened that morning.

“Hope to see Ethan with you again soon,” Ted said, as I turned to leave.

“Later today if I have anything to say about it.”

I pushed the heavy door open with my shoulder and stepped out into a school of hurried commuters. I sipped my coffee while they weaved their way around me, then quickly crossed the street and entered the pharmacy.

“Back again so soon?” the pharmacist said. “That boy needs a lot of medication. How is he?”

“He’s great, thanks,” I said over my shoulder, as I hustled out. As always, crackling with nervous energy, I was anxious to get a walk in before having to return home. I had learned my lesson the day before—12 hours of unrelenting baby care without stepping a foot outside. I adjusted my scarf against the strong breeze, thinking longingly of a baby-care version of the famous Marxist formula. Instead of working a lathe in the morning, fishing in the afternoon, and doing literary criticism at night, one does baby care in the morning, exercises and reads in the afternoon, and socializes at night.

I rounded the corner by the library and stopped at the alley for a standing car. It merged into traffic, and it was like a curtain in a play had been raised, revealing a different winter scene. Most of the sidewalks I had traversed that

morning had been well-shoveled. The long block before me had not been cleared and appeared to be completely trampled. Small, hard-packed mounds of snow caused my ankles to buckle; deep ruts with hardened edges often caught and held the ball of my foot. Fearing a sprained ankle or perhaps a fall, I reversed course and went to the next block.

Even on the smooth pavement, my feet twisted and turned with each step, particularly my right foot, which was weaker and more deformed than its companion. I inherited CMT from my mom and my symptoms were comparatively mild, according to a long list of experts. The pain in my feet suggested otherwise and reminded me of how much I missed my exercise talisman—lap swimming—because it reduced the high-voltage electric current that coursed through me, without taxing my legs.

I hadn’t been near a pool since Ethan was born. There wasn’t enough time in the day. We spent every spare minute caring for him, and the complexity of his treatments and risk of infection kept us from hiring babysitters. Stretching helped counteract the effects of the disease by forcing bones, tendons and muscles into their proper position. But it was hard to find time even for that recently. My feet got worse and worse.

At the corner of our block, a black lab added some color to the feet of

a snowman some neighborhood kids and I had built.

“Hey!” I yelled to the owner, hurrying toward him. “Can’t you find a tree or something?”

“Oh, sorry,” he said, wide-eyed before yanking on the dog’s collar, too late to prevent our canine visitor from leaving a yellow trail across the snowman’s feet.

Farther down the block, a neighbor tried to pull her car out of the deep snow. I pushed from behind as she rocked back and forth, spraying sludge-covered snow all over my pants and boots. Suddenly, the vehicle jumped the rut, then lurched backward, knocking me back into a parked car before it sped forward and careened into the street at an angle.

“Thanks a million,” she said through the open passenger window. “I’m sorry to hear that Janet has gone back to work. We could all use more time with our kids.”

“Indeed we could,” I responded, waving as she drove down the street.

Walking toward our house, I recalled Uncle Maury asking me after I got my first teaching job if it bothered me that Janet made more money than I did. “Not nearly as badly than if she made less,” I countered.

That was before we had Ethan. It mattered a lot more now. If I taught full-time, Janet would still have to work at least part-time or probably even full-time to make ends meet. So, we were stuck in this difficult position, with her having too much career and me having too little.

As I trudged slowly up our front steps, I saw Janet inside gathering up her things to go to work. “The countdown begins,” I said under my breath.

“Good luck today,” she said as she zipped her backpack. “I hope you guys will be okay.”

“Like Ozzie and Harriett,” I said with a sigh as I watched her drive down the alley before reading Ethan’s care regimen for the day.

Jeff teaches at Roosevelt University and has published in Adoptive Families Magazine, The Omaha World Herald, Brevity Nonfiction Blog, Hippocampus, and elsewhere. Read more at www.jeffreyseitzer.com

