

Kelly L.

My story:

I was a driven, positive, mother, wife and management consultant, Chair of the Board of a biotech, and strategy consultant for developing businesses. I was strong, healthy, happy and focused. I had a socially engaged, smart, exuberant girl of 11 who did Ninja Warrior, gymnastics, soccer, circus classes, swimming, leadership group, knitting club, “little buddies” with younger kids, and was said by all teachers and coaches to be kind, positive, tough, and a real leader. My daughter and I canoed, camped, did art projects and ropes courses together, and climbed trees. Our mother/daughter saying was “push it – always push it,” and we loved it.

Then ME hit us.

We all (my daughter, my husband and I) caught a nasty virus on December 27, 2019 and my daughter never recovered. She lost the infection, the sore throat and the fever, but she never regained her energy. She would get exhausted with the smallest amount of physical or mental effort. She was calling to be picked up from school after an hour every day and we finally had to just keep her home. She missed almost all of her final year in elementary school and could not keep up with the work. Her friends started to drift away.

Our GP was insulting and accused her of being lazy. I was told to push her back to school and activities. We tried a pediatrician who accused me of being a bad mother and told me it must be a mental problem. Why, I asked? Do you see anything in her that suggests that? “No, but all the “real” tests came back negative, so it’s obvious she is just not opening up to me and she simply needs a psychiatrist and pressure to get back to school.” We were dismissed. And hurt. And angry. And alone. And we both knew they were wrong. Dead, dangerously wrong.

We still do not have any support from the medical community – there are few to no resources for children (or anyone!) with ME.

My daughter can rarely leave the house and will not be able to enter high school with her friends. We work together to keep positive and see the light and life in small things. But the pain, fear, loss, mourning, lack of contact with other kids, nausea, body spasms, sometimes difficulty breathing and thinking straight is exhausting and hard to handle for us both.

I have lost much of my career, a lot of my joy, and my vision for my daughter’s future. My daughter has lost almost everything.

This is ME.