

I'm a Disabled Parent. It Took a Pandemic to Let Me Join the P.T.A.

My chronic illness made it hard to volunteer at my kids' school. Now I can serve on the executive board of the P.T.A. without leaving my bed.

By Heather Osterman-Davis

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In a year of intense isolation, I've never felt more connection to my children's school.

I have a chronic illness that has kept me from volunteering in the highly engaged P.T.A. at my children's New York City public school. In a strange paradox, for many chronically ill parents like me, the pandemic has brought new opportunities to become substantially involved in our children's lives and schools.

With a background in teaching and educational reform, I'd spent most of my life in classrooms. I'd always assumed I'd be an active participant in my two children's learning. Initially, I was — when my first child was 2, I created a cooperative playgroup and later joined a more established group, where I served on the admissions committee. Then, when my older child entered pre-K, I got sick.

I went from a vibrant, engaged woman to a person who clung to her home, and often her bed, as if it were a life raft. Some mornings, despite 10 hours of sleep, I'd wake plagued by dizziness, feeling like I'd been hit by a truck. Eventually I was diagnosed with myalgic encephalomyelitis (M.E.), more commonly known as chronic fatigue syndrome, a disease that impacts between 836,000 and 2.5 million Americans, with women being afflicted at four times the rate of men, leaving the most severely ill completely bed-bound.

The first few years of my illness were the most challenging. On good days, I could muddle through short family events in my children's classrooms, but on bad days it took everything in me to drag myself one block to after-school pickup, timing the trek so I'd have to wait a minimal time at the gate. Volunteering was out of the question.

In addition to frequent meetings, the P.T.A. at my kids' school holds numerous social and fund-raising events. I couldn't even muster the energy to attend these as a participant, let alone assist in organizing. The annual P.T.A. board elections were a difficult reminder that though I had much to contribute, my illness kept me from getting involved.

Last spring, when the world went online in the pandemic, my children's school, like so many, did its best to pivot. But even with the commitment and energy of the school community, I'd be hard pressed to say it thrived. I knew the P.T.A. was going to be heavily involved in plans for the fall, so I reached out to see if I could help. There were conversations about everything from the flipped classroom model to improving the feedback loop between frustrated parents and overwhelmed teachers. Brainstorming solutions lit me up.

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In the fall, the P.T.A. presidents asked if I'd consider joining the executive board as co-vice president of publicity and communications, teaming up with another parent I liked and respected. The P.T.A. leaders told me they had a new vision for the organization. In addition to the ubiquitous fund-raising, they wanted a major push toward improving communications and building community in a landscape that made both challenging. The new mission, the role and working with the other parent appealed to me. Still, I wavered.

One of the cardinal symptoms of M.E. is post-exertional malaise, where physical and cognitive effort leads to a flare-up. Pacing, or monitoring energy expenditure, is a critical part of symptom management. While the severity of my illness had decreased through a combination of treatment, pacing and luck (that summer I'd even been swimming with my kids and on a few short hikes), I worried that overcommitting could catapult me back. But because I could do everything virtually from my house, even from my bed if need be, I took a chance and said yes.

Since October my co-vice president and I have collaborated on our school newsletter, planned a social-justice movie night, and after the chat in one P.T.A. meeting became problematic, helped develop procedures for more effective communication during virtual meetings. In addition, we're serving as liaisons between a parent-led advocacy group, school administration, and an external group that will be providing training to teachers and parents on how to more effectively address issues of race and racism both at home and at school.

I am not alone in appreciating this unexpected silver lining of the pandemic. In an online group for parents with M.E., run by the #ME Action Network, I encountered several other parents who also credit Zoom for allowing them access to their children's school in a new way. For Holly Latham,

from Jackson, Tenn., who self-describes as “barely hanging on by my fingernails,” it was as basic as being able to attend a meeting virtually to discuss an individualized education program, or I.E.P., for her child, instead of struggling to get there physically.

Before the pandemic, Marthe Schmitt, a 51-year-old mother of one from St. Louis, Mo., wished to be more involved in her 8-year-old daughter’s school, but couldn’t: “I was always hesitant to commit to something and then not be able to physically show up.” This year though, she dove in, serving as social-media coordinator and working with her husband to update the school’s bylaws and make them more inclusive. “M.E.’s a very isolating disease, but being on the board has made me feel more connected and less disenfranchised,” Ms. Schmitt said.

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Elin Daniel, a 42-year-old mother of one from Bothell, Wash., has moderately severe M.E. and is able to leave the house only a few times a week. “When school was in-person, just getting ready to attend an event would exhaust me and I’d always have a flare-up a day or two after,” she said. But since her children’s school went virtual, she’s joined her P.T.A. board as fund-raising chair, which has improved her mood and self-esteem. “I so rarely feel useful,” Ms. Daniel said. “It feels nice to contribute to the community and set an example for my daughter.”

For parents with chronic illnesses, the ability to be involved in our children’s lives isn’t something we take for granted. Mary Wu, a 41-year-old former teacher from Los Angeles and mother of three, only recently became ill but feels this deeply. Before her diagnosis, she and her 15-year-old

daughter had been involved with National Charity League, an organization dedicated to leadership development and philanthropic work such as volunteering at food banks, cleaning up beaches and providing healthy snacks to underfunded schools.

“It was a great way to spend time with my daughter while teaching her to give back,” Ms. Wu said. “But after the onset of my illness, there’s no way I could have done it in person anymore.” Luckily, the charity league’s pivot to online meetings and virtual service has allowed the Wus to continue, fulfilling some of their service hours by sewing face masks for a local organization dedicated to helping women with breast cancer.

“I want something positive to come from all this,” Ms. Wu said. “I hope in the future, organizations still provide access to parents that can’t be there physically.”

Heather Osterman-Davis is a writer, filmmaker and mother of two in New York City.