

Hope to Ease the Journey



"You're enabling your daughter to be ill," the child psychiatrist told me.

He pointed a finger of blame and dismissed the hard work of our two-year journey from specialist to specialist to learn what was wrong with my then 14-year-old. His words threatened to make the credibility of Trisha's recent diagnosis disappear. "Chronic fatigue syndrome (CFS) isn't real," he said.

Although CFS was defined by the Centers for Disease Control and Prevention in 1988, many health care providers find it difficult to wrap their arms around this baffling illness. My daughter's struggle for diagnosis and treatment is a testament to the problems of finding a knowledgeable, compassionate clinician.

Trisha's grueling journey began after she came home from two-weeks at summer camp complaining of flulike symptoms — sore throat, headache, muscle ache, and the bone-crushing fatigue that any amount of sleep couldn't touch. She dragged around the house until September and managed to begin school, but "crashed" with the first hint of Fall weather.

The pediatrician thought she had mono. After a few weeks of prescribed rest, she resumed classes, but fatigue returned with a vengeance. "I can't talk to my friends on the phone now," she'd say as she lay in bed. "I'm just too tired."

The infectious disease specialist ran a battery of blood tests but came up empty. "I'll send a note to the pediatrician," she said, then turned and walked away.

Next the rheumatologist said he had good news and bad news. "We have a name for what you have — fibromyalgia and maybe chronic fatigue syndrome," he said.

"Fibromyalgia is my area of expertise, so I'm sure about that — not so sure about CFS."

Then, he cautioned, "The bad news is that we don't know what to do for you. And he proved his caveat in subsequent visits; so we continued our search for care.

That was the year the pediatrician's associate took over her partner's practice. During the first physical exam she queried Trisha, "Chronic fatigue syndrome ... hmmm ... you're not over that yet?"

We rolled our eyes and wondered what part of the word "chronic" did she not understand?

It took years of pounding the pavement, reading the latest information, and attending CFS conferences, to discover why many don't accept CFS as real. Tough enough for them to treat illnesses that have specific diagnostic tests, known causes, and cures. CFS has none of these, causing physicians to rely on patients' subjective symptoms — so they falter. "Our doctor just wouldn't believe the pain I was in — or the fatigue I felt," people with CFS told us at conferences. "When I didn't seem to improve after a few months, my doctor seemed annoyed — as if I were doing something wrong."

Ideally, health care is a partnership where providers work with patients, helping them manage their care. Trisha's struggle showed us that in many cases health care hasn't matured to this point. We've been forced to take advocacy into our own hands — to educate ourselves about CFS and ask or make a case for the treatment she needs when different symptoms manifest themselves. We attempt to create partnerships with health care providers where we can or move on.

At 23, Trisha is old enough now to advocate for herself, and does so very well. She volunteers as a board member for the NJ CFS Association, speaks at CFS conferences, and validates others who are struggling with the label for their set of symptoms. "You're not crazy. It's not all in your head. Even if your health care provider rebuffs you, you have a genuine illness and what you are feeling is real," she tells them.

Until the cause, diagnostic test, and subsequent cure are found that will confirm CFS in the minds of health care providers, Trisha hopes for the future and continues to tell others about CFS, to legitimize it (and them) in the here and now.

Last month — almost 10 years after Trisha's journey to diagnosis — the CDC launched "Get Information. Get Diagnosed. Get Help." This national public education campaign is designed to increase CFS awareness among clinicians and the public of whom the CCD estimates 80% of the one million Americans with the illness remain undiagnosed. In its press release, CDC Director Dr. Julie Gerberding said, "The CDC considers CFS to be a significant public health concern, and we are committed to research that will lead to earlier diagnosis and better treatment of the illness."

We share the CDC's hopes for earlier diagnosis and better treatment of the illness — and that the campaign will help ease the journeys of other patients and families along the way.

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