

Testimony

Lori Chapo-Kroger

My name is Lori Chapo-Kroger, the founder of CFS Solutions of West Michigan. I would like to share with you the story of three of my friends.

Molly was a registered nurse and worked for the Michigan Department of Health. Molly's husband awoke one morning and found her dead next to him in bed. She died unexpectedly from ME/CFS.

Evert was a social worker until he got sick with ME/CFS. He spent the last several years of his life bedbound before dying of complications from ME/CFS. He died 3 days before Thanksgiving.

Jill took her own life last July because she was in so much pain. I'm not sure if she could no longer stand the pain caused by ME/CFS or if it was from the emotional pain of disbelief from her doctors, friends and family. Maybe it was a little of both.

Could their early deaths been avoided if they received proper medical care? Probably. Could their lives have been more bearable? Definitely! I was an ICU nurse and worked with the severely ill but nothing compares to the suffering and abuse ME/CFS patients endure.

We are the walking dead. Some of us are so close to death that it's like lying in a grave that has already been dug, desperately holding onto one strand of grass. Each time a doctor says there is nothing they can do, a shovel full of dirt is thrown on us. Disbelief. Another shovel. Told to exercise. Another shovel. We are being buried alive!

When in a crisis, we are afraid to go to the emergency department and often don't go. ME/CFS is not listed in THE emergency room book. If your illness or disease isn't in the THE book, then your condition does not exist. If you mention ME/CFS or fibromyalgia, you're automatically looked upon as psychotic and a drug seeker. You are dismissed without treatment, just verbal and emotional abuse.

Getting medical help should not be the hard part!

Healthcare providers are at a loss because ME/CFS is not taught in medical schools or nursing schools. There is no toolkit or protocol for chronic fatigue syndrome. Sadly, the only source of knowledge is from the misinformation on the CDC website.

For 30 years, patients have been misunderstood, undertreated and left to care for themselves. Often it's the patients who support and take care of each other; the sick taking care of the sick. There is something very wrong with that picture!

We need to change the lack of knowledge and the stigma around ME/CFS so I ask you to answer these 4 questions:

- What can you do as the panel of advisors for ME/CFS to get information about this disease into the medical and nursing school curricula?
- How can you get ME/CFS into the Merck Manual, THE emergency room book?
- Can the Medscape CME online course mentioned on the IACFS website be updated and reactivated?
- Can you put up a website with correct information or work with the CDC to ensure that their site is not filled with misinformation?

Please do whatever you can to make this happen. This won't take much money but can make a huge difference in patients' lives today.

Thank you.

Lori Chapo-Kroger, RN