

Jana S.

Her story:

My name is Jana and I am the sole caregiver to my husband who is currently bedbound with ME. He was first diagnosed about 15 years ago after experiencing symptoms that ranged from shortness of breath to extreme exhaustion to body pain. The first few years he was sick, he was still able to work and live almost normally. Then one day, a couple of years after he was first diagnosed, he felt better, back to normal. He likens it to a switch being flipped and we both forgot all about ME.

Then, three years ago, at the beginning of 2018, he was feeling tired, achy, dizzy and nauseous all the time. He went to the doctor and she gave him very strong anti-nausea medication. It didn't do anything. He was experiencing abdominal pain so he went back to the doctor and she didn't have any explanation so she ordered some tests. They all came back negative. The dizziness continued so she sent him to an ENT doctor. He finally got to see an internal medicine specialist and had even more tests that came back negative.

While still undergoing tests with the specialist, he was still experiencing seemingly unrelated symptoms and his primary care doctor was not helping. In fact, she began to cancel his appointments and he was basically left without a doctor. This actually turned out to be a good thing since I was able to get him into a new doctor who knew a little about ME and suggested it might be a resurgence.

By the end of 2018, my formerly active husband was housebound and increasingly bedbound. His official diagnosis came after countless blood tests, CT scans and an MRI ruled out diseases like Addison's and MS and his (new) doctor and two specialists said that the only remaining diagnosis was ME. The diagnosis took more than a year to get but we consider this fast. Many ME patients suffer for years without a proper diagnosis.

He now lives in bed. Thankfully he can still feed and bathe himself and he doesn't need my help going to the bathroom although he does sometimes need to use a walker to steady himself. But he can't do simple daily tasks like cooking or going to check the mail or even reading and watching TV. He used to write (he's published two books) but the brain fog and cognitive impairment makes that almost impossible these days. Although I have to act as his advocate and caregiver, we are thankful that he has a doctor who believes in ME and spent some of his own time to research the disease and how to try to help my husband. But he, and the thousands of other people suffering with ME in BC, need much more support.