



# Chronic fatigue syndrome hard to diagnose

Del. family dealing with hardships associated with insidious disease

By Jamie-Leigh Bissett

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HOCKESSIN — When someone is diagnosed with chronic fatigue syndrome (CFS), the name can be quite misleading.

“When I was diagnosed, I had never heard of it before. The name sounds like you’re just tired, but I knew there was more to it than being tired,” said Sue Jackson of Hockessin, a CFS sufferer for eight years.



Preeti Gupta

“Research shows that people with CFS are as disabled as those with multiple sclerosis, people undergoing chemotherapy for cancer, and battling late-stage AIDS.”

According to the Chronic Fatigue and Immune Dysfunction Syndrome Association of America, CFS is a debilitating illness with no known cause, diagnostic test or universally effective treatment.

Dr. Preeti Gupta, a family medicine doctor at Bayhealth Medical Center, said in her year and a half at Bayhealth, she has had four or five patients who have been diagnosed with CFS.

“Diagnosis is rare, but the syndrome is not rare,” she said.

Dr. Gupta said the reason diagnosis is rare is because symptoms can be similar to other medical conditions, which ultimately need to be ruled out first.

“First you must rule out other causes of fatigue such as infections or psychological causes,” she said. “It can be complicated. When a patient comes in with symptoms,



Submitted photo

**From left, Sue Jackson of Hockessin and her two sons, Jamie, 15, and Craig, 12, have been living with chronic fatigue syndrome for several years. Also pictured is Mrs. Jackson’s husband, Ken.**

we start with blood work, perform a psychiatric evaluation of the patient and do other neurological tests. There are so many steps before it can be diagnosed.”

Dr. Gupta said symptoms of CFS include fatigue, loss of memory and concentration, unexplained pain in muscles, joint pain, headaches and restless sleep, all of which last for more than 24 hours.

“Those who have chronic fatigue syndrome, when they wake up from sleep, they don’t feel like they’ve slept at all.”

Dr. Gupta said when patients exhibit this

particular sign, many doctors will perform a sleep study to rule out sleep apnea, a condition in which breathing repeatedly stops and starts during sleep.

Mrs. Jackson said based on the research she has done, and her own experience, one main reason CFS sufferers don’t feel rested is because they can’t fall into the deeper stages of sleep.

“You feel like you’re half awake all night,” she said.

Mrs. Jackson said in order to combat this particular CFS symptom, her doctor has prescribed medicines that increase serotonin and dopamine levels, which have “worked well for me.”

She said because there is not a cure-all for CFS, doctors and patients must treat CFS symptoms individually.

“Unfortunately the only effective treatment, because there isn’t really one effective treatment, is to deal with the symptoms,” Mrs. Jackson said. “Some people have joint and muscle pain or deal with severe headaches, so they take something for the pain. If you can find some underlying infections, you can be treated with antivirals and antibiotics.”

Dr. Gupta said treatment for CFS often requires a lifestyle modification, including cognitive behavior therapy.

“Those who have the syndrome can get depressed and feel socially isolated, which is why they might need the help of a psychotherapist,” she said.

Mrs. Jackson said she, like many CFS sufferers, did feel depressed in the beginning, which is why it can be common for a misdiagnosis.

“Unfortunately in the past, there has been a problem with doctors who don’t understand the physiology of the disease and think it is all in your head so they’ll send you to psychotherapy instead of treating you,” she said. “There have been hundreds of studies proving that depression is

different than CFS. This is a real, physical illness.”

Mrs. Jackson was diagnosed with CFS on March 2, 2002.

“On March 1, I felt fine. Then on March 2, I woke up with a sore throat and was achy all over. I thought I had just caught a bug, but three weeks later I was still sick,” she said.

Mrs. Jackson said she spent an entire year going from doctor to doctor, and specialist to specialist, to find out what was wrong with her.

“Just by luck, I was looking for a new doctor and found a family practice in Hockessin. Right from the first visit, my new doctor recognized what was going on with me,” she said. “I consider myself fortunate to have found (Dr. Kathleen Willey). I know people who went 10 to 15 years without being diagnosed because so few doctors understand this disease and keep up with the research.”

Mrs. Jackson said one of the hardest parts about living with CFS is the disease’s limitations on physical activity.

“Exercise makes us sicker. That is probably the worst part about this illness and the hardest to live with. And that doesn’t just mean running, it’s any kind of exertion. I could go to the grocery store and then be on my back for days. We have to be very careful,” she said.

Another toll CFS has taken on Mrs. Jackson’s life was the diagnosis of her two sons, now 11 and 15, a few years after she was diagnosed.

“There is a higher incidence of CFS for those who are blood related and those who live in the same household (with a CFS sufferer) even if they are not blood related,” she said. “My sons were probably exposed to the same infections, whatever it was.”

Mrs. Jackson said her boys have been fortunate, however, responding well to

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