

Chronic fatigue, fibromyalgia cause 'bone-crushing fatigue,' pain for many

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By **Wendy Leonard**, Deseret News

SALT LAKE CITY — The days are dotted with medications and supplements. To keep her awake. To keep her asleep. To keep her comfortable.

It is a constant struggle to maintain even a sliver of normalcy.

"I've had to spend almost all my time either in bed or in the bathtub," said 57-year-old Laurel Wright.

If it isn't fatigue, it's pain and the constant baths have led to eczema. Lying down all the time has given in to gastric reflux, causing chronic laryngitis and even asthma, and light-headedness when she stands too long and her brain is in an endless fog. But it wasn't always that way.

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Jeffrey D. Allred, Deseret News

Chronic Fatigue Syndrome sufferer Laurel Wright has placed her bed in her front room so that she can look out of the window in Salt Lake City May 13, 2011. She spends the majority of her day in bed.

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Less than 20 years ago, Wright was a hard-working, fun-loving, ambitious mother of two with hopes and dreams that included finishing college, international travel, establishing a career and devouring the great outdoors.

Now, with chronic fatigue syndrome, a good day includes little more than a handful of naps and a couple of hour-long baths to relieve the pain that medication can't touch, intermingled with an occasional PBS special or a crossword puzzle.

Dr. Lucinda Bateman, who has devoted the facilities of her local clinic and a [non-profit education organization](#) to helping people with chronic fatigue syndrome and fibromyalgia, said Wright is one of her more afflicted patients, one who "can barely make it to the appointment to see me."

The growing number of patients Bateman sees spans a wide spectrum of abilities and troubles. But she is there to provide meticulous care and the necessary pep-talk to those who can't find it elsewhere because of their often extensive medical histories.

"The majority of people are just normal people who are dealing with something very difficult. Not all of us can be very disciplined and perfect and control everything in real life. It's an easy thing to judge another person and yet, it's a lot harder to do it, especially when you feel horrible," Bateman said.

For many years, the public and doctors alike, refused to recognize the two ailments, which consequently greatly impact the life of those diagnosed. Bateman said it was because of a lack of understanding and education, something that drug companies are now helping to invert.

"When the FDA approves a drug for a disorder, it sort of makes it more difficult for people to wish it away," she said.

In the last five years, three drugs have been approved specifically for the treatment of fibromyalgia, or what is known as a chronic disorder, manifest by widespread musculoskeletal pain and tenderness in localized areas. It is commonly understood as the amplification of pain signaling in the brain and the drugs work like neurotransmitters to

Now, with increased understanding of the condition, Bateman said people are coming out of the woodwork. But it's OK, as more doctors, even locally, know how to address it and how to help those who need it.

There are still those who think it would be nice to be able to take a nap every day, but Wright said that rationale is "unbelievable" to her.

"We are victimized by the illness, and victimized all over again by people's disbelief in the reality and legitimacy of our illness," she said in an email interview, as holding the phone and talking for long periods

"We oftentimes don't look sick, so people don't believe that we are. It's like comparing a snapshot to a video — I might look OK in the moment, but if you were to follow me around for a couple of hours, it would give a much better picture of what my life is like," Wright said. The name of the condition she suffers, a syndrome, she said, "is far from giving a complete and accurate picture of reality."

"It feels like getting the worst flu you've ever had that never leaves. At the same time, it feels like I just ran a marathon, every day," she said, adding that the level of tiredness fluctuates from normal exhaustion to "bone-crushing fatigue."

"One of the cosmic injustices of chronic fatigue syndrome is that I'm so exhausted but I have a lot of trouble sleeping," Wright confessed. Laying in bed most of the day, she closes her eyes, but rarely ever really sleeps.

A person's resources often dictate the kind of care they receive, and while some can barely function, others, like fibromyalgia patient Kathleen Shumway, have the means to relax a little more.

About 15 years ago, the high-energy and intensely friendly personality that had come to define Shumway began to fade. She had muscle aches where she didn't know she had muscles and started compensating slight memory loss with excessive note-taking.

Internet searches and a distant relationship led her to Bateman's clinic, where she makes the trek from Pleasant View three to four times a year just to keep on top of her progress since being diagnosed.

"In spite of what I had read, I learned skills that really made coping much better," she said of the continuing therapy she receives from Bateman's office. But even she admits that she has the "perfect life for having to deal with something like this."

She can take time to rest herself after a busy day and plans for at least two to three days of down-time each week, which she can get under her circumstances.

Occasionally, her rose-colored glasses lose their tint, yet Shumway still finds it in her to embrace the black circles under her eyes and relish wearing her comfortable pants and curling up to read a good book

The otherwise healthy 52-year-old has a hard time being still, but really appreciates her diagnosis because it has taught her to carefully consider how she spends her time.

"It has affected my life," she said. "Your heart wants to take on the whole world every day but your body won't keep up or just can't sustain it."

For the most part, Bateman prescribes medications or various therapies and helps provide a source of motivation to patients so they can do what they need to do. She keeps up on the latest procedures and treatments and contributes her own research to the medical doctrine.

The frustration, she said, is that "lots and lots of different things can make people have pain and fatigue and have trouble sleeping." And while diagnosis is simple, treatment is a different animal. Symptoms vary greatly and can be a combination of genetic and behavioral components, which are hard to address.

"There are many factors that determine how well a person can improve from their symptoms and some of it relates to motivation and discipline and some of it relates to fate and their disease state and how long they've had it and how severe it is," Bateman said. "A lot of people think the fat, lazy ones don't get better and the motivated ones do, and I really don't think that's true."

And that is where further research is needed.

"Every bit of research out there shows that this disorder responds somewhat to cognitive behavioral therapy and exercise," Bateman said. "Somewhat means you can improve symptoms a little, doesn't mean you have cured the disease."

For now, they do what they can. But both Shumway and Wright long for the days not far gone, when they were a visible part of their communities and could live the lives they were made for, enjoying pastimes that have since passed.

"The ability to go and do something every day, and have energy, is really something I just don't have," Shumway said. "And it is not like I want something I never had. It is something that was me. I could go on very little sleep and accomplish a lot."

Wright can't do her own shopping and needs help with housework and other chores, and while she can cook her own meals, "some days I end up eating a lot of toast."