

Many autoimmune disease patients struggle with diagnosis, costs, inattentive care

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After years of debilitating bouts of fatigue, Beth VanOrden finally thought she had an answer to her problems in 2016 when she was diagnosed with Hashimoto's disease, an autoimmune disorder.

For her and millions of other Americans, that's the most common cause of hypothyroidism, a condition in which the thyroid, a butterfly-shaped gland in the neck, doesn't produce enough of the hormones needed for the body to regulate metabolism.

There's no cure for Hashimoto's or hypothyroidism. But VanOrden, who lives in Athens, Texas, started taking levothyroxine, a much-prescribed synthetic thyroid hormone used to treat common symptoms, like fatigue, weight gain, hair loss, and sensitivity to cold.

Most patients do well on levothyroxine and their symptoms resolve. Yet for others, like VanOrden, the drug is not as effective.

For her, that meant floating from doctor to doctor, test to test, and treatment to treatment, spending about \$5,000 a year.

"I look and act like a pretty energetic person," said VanOrden, 38, explaining that her symptoms are not visible. "But there is a hole in my gas tank," she said. And "stress makes the hole bigger."

Autoimmune diseases occur when the immune system mistakenly attacks and damages healthy cells and tissues. Other common examples include rheumatoid arthritis, lupus, celiac disease, and inflammatory bowel disease. There are more than 80 such diseases, affecting up to an estimated 50 million Americans, disproportionately women. Overall, the cost of treating [autoimmune diseases](#) is estimated at more than \$100 billion annually in the U.S.

Despite their frequency, finding help for many autoimmune diseases can prove frustrating and expensive. Getting diagnosed can be a major hurdle because the range of symptoms looks a lot like those of other [medical conditions](#), and there are often no definitive identifying tests, said Sam Lim, clinical director of the Division of Rheumatology at

Emory University School of Medicine in Atlanta. In addition, some patients feel they have to fight to be believed, even by a clinician. And after a diagnosis, many autoimmune patients rack up big bills as they explore treatment options.

"They're often upset. Patients feel dismissed," Elizabeth McAninch, an endocrinologist and thyroid expert at Stanford University, said of some patients who come to her for help.

Insufficient medical education and lack of investment in new research are two factors that hinder overall understanding of hypothyroidism, according to Antonio Bianco, a University of Chicago endocrinologist and leading expert on the condition.

Some patients become angry when their symptoms don't respond to standard treatments, either levothyroxine or that drug in combination with another hormone, said Douglas Ross, an endocrinologist at Massachusetts General Hospital in Boston. "We will have to remain open to the possibility that we're missing something here," he said.

Jennifer Ryan, 42, said she has spent "thousands of dollars out-of-pocket" looking for answers. Doctors did not recommend thyroid hormone medication for the Huntsville, Alabama, resident—diagnosed with Hashimoto's after years of fatigue and weight gain—because her levels appeared normal. She recently switched doctors and hopes for the best.

"You don't walk around hurting all day long and have nothing wrong," Ryan said.

And health insurers typically deny coverage of novel hypothyroidism treatments, said Brittany Henderson, an endocrinologist and founder of the Charleston Thyroid Center in South Carolina, which sees patients

from all 50 states. "Insurance companies want you to use the generics even though many patients don't do well with these treatments," she said.

Meanwhile, the extent of Americans' thyroid problems can be seen in drug sales. Levothyroxine is among the five most prescribed medications in the U.S. every year. Yet research points to some overprescribing of the drug for those with mild hypothyroidism.

A recent study, paid for by AbbVie—maker of Synthroid, a brand-name version of levothyroxine—said a medical and pharmacy claims database showed that the prevalence of hypothyroidism, including milder forms, rose from 9.5% of Americans in 2012 to 11.7% in 2019.

The number of people diagnosed will rise as the population ages, said McAninch. Endocrine disruptors—natural or synthetic chemicals that can affect hormones—could account for some of that increase, she said.

In their search for answers, patients sometimes connect on social media, where they ask questions and describe their thyroid hormone levels, drug regimens, and symptoms. Some [online platforms](#) offer information that's dubious at best, but overall, [social media](#) outlets have increased patients' understanding of hard-to-resolve symptoms, Bianco said.

They also offer one another encouragement.

VanOrden, who has been active on Reddit, has this advice for other patients. "Don't give up. Continue to advocate for yourself. Somewhere out there is a doctor who will listen to you." She has started an alternative treatment—desiccated thyroid medication, an option not approved by the FDA—plus a low dose of the addiction drug naltrexone, though the data is limited. She's feeling better now.

Research of autoimmune thyroid disease gets little funding, so the

underlying causes of immune dysfunction are not well studied, Henderson said. The [medical establishment](#) hasn't fully recognized hard-to-treat hypothyroid patients, but increased acknowledgment of them and their symptoms would help fund research, Bianco said.

"I would like a very clear, solid acknowledgment that these patients exist," he said. "These people are real."

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