

MIS diag nosed

It took 15 years before Joyce Dixon finally learned what was really wrong with her | BY VICTORIA SPENCER

FOR YEARS, no matter what diet she tried, Joyce Dixon just seemed to gain weight. In 1996 the five-foot-three mother of two weighed more than 200 pounds. But her self-esteem was the least of her problems. Her legs were so swollen and weak that she could barely climb the stairs in her own

When Joyce Dixon was ill (in snapshot from 1996) old friends didn't recognize her.



house. Her hair was falling out, her eyesight was blurry, and her skin was red and blotchy. She was often up all night, unable to sleep, and her mood swings were dramatic—sometimes manic, sometimes raging, often depressed.

Worst of all, she didn't know why. Doctors blamed her litany of problems on "obesity," a diagnosis that 55-year-old Joyce had heard so often she'd accepted it herself. But in the back of her mind, she knew there was more to it.

Though she says she was never super-skinny, Joyce had been a cute, active cheerleader in college. "Back then," she remembers, "if my girlfriends and I gained ten pounds, we'd diet and lose the weight. I never felt I couldn't control my weight."

But that started to change. In 1975, Joyce married Al Dixon, and gave up smoking two years later. Soon she gained 30 pounds and just couldn't seem to get rid of it. So when she heard about a radical no-carb diet that had been successful for one of Al's co-workers at IBM, she decided to try it.

The diet was designed to induce ketosis, which causes the body to burn stored fat for energy. Joyce did lose weight, but she felt lethargic. Her doctor thought she had an underactive

thyroid and prescribed medication to regulate the problem. In 1982 she and Al had a baby boy. They named him Albert. (She also had another son, Mark, 16, from her previous marriage.)

Joyce's weight continued to fluctuate. Human nature being what it is, she found ways of being in denial about the situation. "I never saw myself as fat," she says. "But I would walk down the street and happen to catch my reflection in a department store window and think, Oh yeah, that's right. I'm heavy."

Her weight, though, was not an issue at home. As her son Albert recalls, "My mother was always big, but I never thought about her being fat. That was just her normal size to me." He also thought it usual to have a refrigerator filled with diet foods.

Joyce showed great willpower with her dieting and even attended regular aerobic dance classes. "I would stay with the diet but just gained weight. That should have been a clue that there was something wrong. The doctors never believed I was sticking to the diet. It didn't make sense to them."

When Joyce and her family moved to San Francisco in 1984, she was referred to a renal doctor, who monitored her thyroid condition and medication. Her weight later bal-

Her legs began to swell, she bruised for no reason and her hair fell out. "I was just so sick," she says.

looned to 190 pounds. With her doctor's approval, she enrolled in the Obesity and Risk Factor Program of San Francisco.

On a low-calorie liquid diet she lost 40 pounds at first, but then began to gain again. The medical staff questioned whether she was following the program, and she wasn't: She was eating even *less* than the plan called for, but still gaining weight. Then her legs began to swell, her fingernails became brittle and her hair fell out so much that she had to wear a wig. She bruised for no apparent reason, her skin became jaundiced and she experienced severe memory loss. "I wasn't worried that I had to wear a wig or what I looked like," she recalls. "I was just so sick, I really couldn't cope."

She couldn't ignore or explain away her symptoms any longer. She was referred to a highly regarded endocrinologist to have her thyroid checked yet again. But the office manager would not set up an appointment when Al wanted to meet with the doctor. Medical records from the time imply that Joyce's husband was overly attentive, and both Joyce and Al think that doctors suspected him of abusing her and causing Joyce's bruising. No doubt it was an attempt to make sense of her symptoms, which seemed otherwise unexplainable. "She kept a cheery face, but I knew she was hurting," Al says of that terrible time.

Eventually the doctors concluded that Joyce's restrictive diet had caused the jaundice and took her off the program. They pronounced her thyroid



"I was so happy to feel like a normal person again," says Joyce, with her husband, Al, in 2005.

fine, reflecting that she could have been misdiagnosed as hypothyroid eight years earlier because her no-carb diet probably affected her test results. "They said that almost every one of my symptoms was something women just have at my age," Joyce says. "But I knew that there was something else. I didn't know what, though, so I had to believe what the physicians were saying: that I just needed to lose weight."

In 1994 Joyce, Al and Albert, now 12 years old, moved from San Francisco to Dayton, Ohio, when Al took a new job. Joyce was no longer seeing specialists but still struggled with her weight. "I was following a low-fat, low-

calorie diet of 1,000 calories a day," she says. For example, a typical day might include oatmeal or low-calorie cereal with skim milk for breakfast, a salad for lunch and meat and veggies for dinner. No snacks and almost no sweets. She really stuck to the plan, she says, "but my weight continued to be out of control."

In May 1995 she and her mother made a 15-hour drive to the Mayo Clinic for an evaluation. The diagnosis was all too familiar: obesity. Then, the following year, Joyce's health problems began to accelerate again, even though she wasn't on any diet. Al was working a lot, and Albert did not like his new school, but Joyce was feeling too weak and ill to deal with the teachers or find another school. "I couldn't remember things, and feared I might be getting Alzheimer's," she says. She was having so much difficulty remembering dates, numbers and appointments that she wrote down everything she had to do in a notebook. "I used to panic about losing that notebook. It was my life."

At 70 pounds overweight, she was almost unrecognizable to old friends in Ohio, where she grew up. "People I'd known for years didn't realize it was me," she says, "and then they

would be so embarrassed, they didn't know what to say."

Joyce's general practitioner in Dayton, Carrol Estep, MD, saw her struggling to lose weight and tried to pinpoint the cause of her health problems, sending her for various tests. In December 1996 Joyce was referred to a gastroenterologist after one of the tests revealed an abnormality on her liver. But it turned out to be nothing more than a cluster of blood vessels, another dead end.

When Joyce went to yet another specialist the next month, she felt that she couldn't deal with it anymore. She kept her appointment but was thinking, This is the last time. Just one more.

Joyce vividly remembers walking into the office of Susan Galbraith, MD, an endocrinologist who had recently finished a fellowship at Yale Medi-

cal School and begun a practice in Dayton, and realizing this time it would be different: "She didn't just look at me and say, 'You're fat. Start losing weight.'"

After more than 15 years and numerous doctors, Joyce was finally diagnosed: It was Cushing's syndrome, a rare hormonal disorder affecting an estimated 10 to 15 out of every million people. Dr. Galbraith told her later that she recognized the symptoms the

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minute Joyce walked into her office. Blood tests confirmed Cushing's disease, the most common form of the syndrome. Even though it had taken years to put a name to her symptoms, Joyce was overjoyed: "I was just so happy that I wasn't nuts all this time—that it was actually *something*."

The symptoms of Cushing's are caused by prolonged exposure to high levels of cortisol, a hormone that helps the body respond to stress. The disease is difficult to diagnose because the symptoms develop slowly and are non-specific, such as weight gain, high blood pressure and depression. Patients go undiagnosed or misdiagnosed for an average of seven to eight years. For Joyce it was even longer: more than 15 years. Her disease stemmed from a tumor on her pituitary gland, which stimulated her body to produce dangerously high levels of cortisol.

Joyce's happiness at finding a diagnosis turned to fear when she learned about the treatment: brain surgery. Al took his research skills to the Internet, soon learning that the success in curing a patient of Cushing's disease is directly related to how experienced the neurosurgeon is. So he set about narrowing the field to those who did hundreds of pituitary tumor removals

a year, ultimately choosing endocrinologist Beverly Biller, MD, and neurosurgeon Brooke Swearingen, MD, at one of the country's leading pituitary units at Massachusetts General Hospital in Boston.

Dr. Swearingen removed the tiny pituitary tumor through the sphenoid sinus, a facial air space behind the nose. A cut, only about half an inch, is made in the back wall of the nasal cavity and through it the surgeon can enter the sinus.

Joyce's happiness at finding a diagnosis turned to fear when she learned the treatment.

Joyce's surgery went without a hitch. "I didn't have postoperative problems," she says. "I think I was just lucky." While many patients with Cushing's live in fear of a recurrence in the first few years after their surgery and find that it takes up to a year to lose the excess weight, Joyce's recovery was swift. The pounds dropped off and stayed

off, the bruising and swelling on her legs disappeared, and she was able to wear skirts again. Her hair grew back, and her bad skin cleared up. Best of all, she says, "I was so happy that my memory was coming back and I could feel like a normal person."

One of her biggest regrets is how her mood swings must have affected her son Albert when he was growing up. "The only mother he knew was fueled by cortisol," Joyce says. "I was

so weirded out, so compulsive, so short with him. A lot of my Cushing's friends, who I've met through the Cushing's Support and Research Foundation, are divorced, so I thank God that I have my husband."

"I guess it proves that I love her," her husband says. "Sometimes she was difficult to deal with. But we always had hope."

Perhaps because she is a naturally bright and positive person, Joyce does not hold anyone responsible for her suffering and misdiagnosis, although she does question why none of the doctors ever put her symptoms together earlier and tested her for Cushing's. Instead, she was regarded as an obese woman who should lose weight.

To prevent others from suffering for so long with a misdiagnosis like hers, Joyce now volunteers with the Cushing's Foundation at medical conferences, working to increase aware-

ness of the disease among the medical community. But she also believes it is important for the public to be aware of Cushing's. "An ordinary person might recognize or notice a friend who is obese and say, 'You know, I read about Cushing's disease, and I think you should get tested.' That could make all the difference."

When she had the disease, Joyce recalls, she "wore long pants and tent shirts with long sleeves all the time. I had to be camouflaged." When she was well again, she threw out boxes and boxes of size 16 and 18 clothes. "Now I can wear shorts. I'm so happy to be able to wear something stylish again." She is a different person now—and it shows.

For more information on Cushing's syndrome, contact the Cushing's Support and Research Foundation, csrf.net.

rd.com For more on diseases doctors commonly miss, go to rd.com/misdiagnosed.