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Anorexia misdiagnosed

A dozen doctors assumed Laura Daly was suffering from an eating disorder, but her symptoms led one physician to correctly conclude that she suffered from another ailment that would have been fatal untreated.

By Kathleen O'Dell
News-Leader

This is not a story about a girl who starved herself to be thin.

She never skipped meals. She never binged on a favorite food or made herself throw up to purge the calories.

That was not the trouble with Laura Daly.

She knew it, and her parents, Marilyn and Steve Daly, knew it.

Still, it was hard for some to believe otherwise. Classmates, neighbors and co-workers watched her weight fluctuate through college and her first job, until her 5-foot-1-inch frame weighed only 78 pounds.

Only after a Pennsylvania surgeon discovered her underlying medical problem last year — a sick gallbladder — did Laura have her gallbladder removed and begin gaining weight.

"If I had waited any longer," she said, "I'd be dead by now."

Back to 101 pounds now after a 2,700-calorie-a-day diet, the 25-year-old

Enlarge

Once spectrally thin, Laura Daly has since recovered from her illness and is in the process of writing a book about being misdiagnosed.

AMBER ARNOLD / NEWS-LEADER

Enlarge

Missouri State University graduate is living at home, working as an interior decorator and writing a book about her ordeal.

Her working title: "Anorexia Misdiagnosed."

"I hope to publish it to help other girls in the same labeled situation I am to see if they have a bad gallbladder instead of being mislabeled," she said.

A MEDICAL EXPLANATION

In recent years more than a dozen doctors tested her for pregnancy, gallstones, cancer, anemia and intestinal candida, searching for some medical reason for Laura's weight loss.

In the end they usually concluded she had "anorexia nervosa" — an eating disorder of people obsessed with being thin and terrified of gaining weight. Experts say they use food and weight to deal with emotional issues.

One after another they told her, "It's all in your head," and advised her to see a psychologist. She didn't.

Laura grew more scared, as the recommended high-protein, good carb regimen failed to add pounds.

"There were nights I'd go to bed and worry I wouldn't wake up in the morning," she said.

In March 2005, her mother found the Internet site of a Pennsylvania surgeon who has successfully treated 90 patients with the same list of symptoms and diagnosis as her daughter.

"Laura fit every symptom," her mother said.

Dr. William P. Smedley, a board-certified general surgeon in Kingston, Pa., said all individuals had the same underlying, physical cause of their severe weight loss and related symptoms.

Many of them travel across the country in a last-ditch effort to find help. Between 5 percent and 20 percent of patients with anorexia nervosa die from its complications, Smedley said.

"I only get the desperate cases," he said in a telephone interview with the News-Leader. "The parents are absolutely devastated, and they've gone to all the eating disorder places."

No physician in their hometowns found the source using routine diagnostic tests. Smedley uncovered it after his patients underwent an additional ultrasound test while sitting up instead of the usual prone position.

If other diagnostic tests are negative, the patient should have a CCK Stimulation Test, Smedley said.

A patient is injected with CCK, or Cholecystokinin, a synthetic hormone that stimulates the gallbladder to contract as it would in response to fatty foods.

If the X-ray shows the gallbladder isn't contracting enough to do its job while the patient is in an upright position, or it shows the gallbladder flops over and creates a kink in the connecting bile duct — Smedley feels he's found the medical source of their problem.

At that point Smedley does a laparoscopic gallbladder removal, pulling it through a one-inch abdominal incision. The patient usually goes home the next day.

Springfield surgeon Dr. Jose Dominguez said CCK tests are common but he has not heard of doing them while the patient is upright and doesn't have an opinion about whether that's valuable.

Smedley said he plans to publish a paper about his work with the patients after he treats his 100th one.

But Dominguez added, "If a person's got information on that, he ought to publish it."

He agrees with the ultimate solution: Take out the gallbladder if it's not working. "The majority get better," Dominguez said.

LITTLE ORGAN, BIG TROUBLE

The gallbladder, about the size of a deflated balloon, is located in the upper right side of the abdomen, just below the liver, and aids in digestion.

Enlarge

Its purpose is to store bile — a bitter, alkaline yellow or greenish liquid secreted by the liver that aids in breaking down fatty foods for absorption and digestion.

When fat is eaten, that triggers the gallbladder to contract and squirt its stored bile into the bile duct and on its way to the small intestine.

Potential problems: If the bile duct is too small or kinks, bile can back up and stagnate, causing chemical irritation of the gallbladder walls — chronic cholecystitis.

Symptoms range from chronic indigestion to vague abdominal pain, nausea, belching, constipation or diarrhea. Patients report that fatty foods make them sick, so that they don't want to eat or avoid more and more foods that cause discomfort. Weight loss and depression are common.

Laura Daly's problem also stemmed from a birth defect, which Smedley discovered in surgery. The bile duct was kinked and not connected to her liver. An artery also had grown into the bile duct and was hammering against her liver, she said.

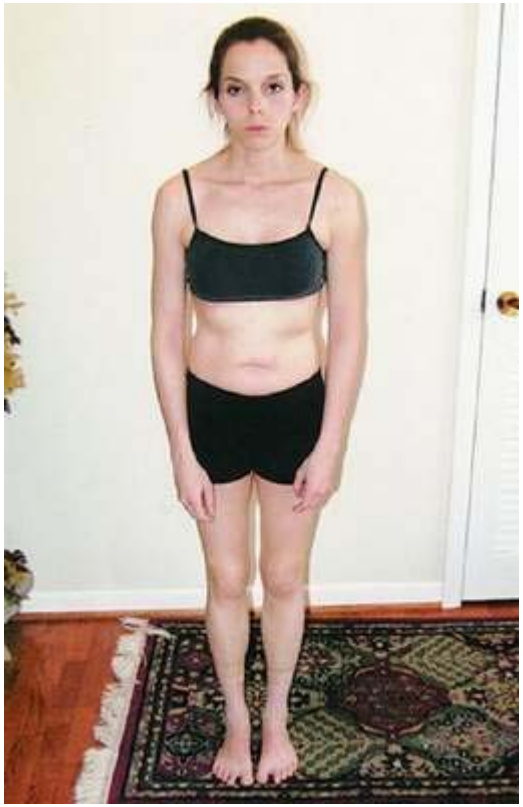
"I was ready for something because I was just at the end," Laura said. She had already been released from her job at an interior decorating company after she asked for a 30-day medical leave on the advice of her doctor. Her employer didn't feel it could leave her job open that long, despite her 30-plus days of vacation and sick time, she said.

Laura was tired of disapproving looks and comments from physicians and busybodies. One health care provider suggested, "If you shave her head nobody will look twice — they'll think she's a cancer patient."

A few months before her surgery, a stranger confronted Laura in a grocery store: "Don't tell me — you're anorexic." Marilyn Daly stepped in to shoo him away, but he persisted: "She is. She is one of those anorexics. I've read about it."

Her mother shakes her head. "This has been a long, tough road coming back ... for any of these girls."

THE GALLBLADDER LINK



These photos show Laura Daly when the effects of her illness were at their height (above), at the onset of the illness (top right) and Daly since her recovery (right).

DALY FAMILY

MORE ABOUT THIS STORY

To learn more

Dr. William P. Smedley discusses his treatment on a Web site, www. docsmed.com. He can be reached at docsmed@aol.com.

He has also written two books: "Mom, Do I Look Fat? The Alternative Look at Eating Disorders," (2001) and "The Fat Book," (2000), both self-published.

Surgeon stresses final diagnostic test for disorders Second stage First stage

Pennsylvania surgeon Dr. William P. Smedley says there are 11 million diagnosed anorexic or bulimic individuals in the United States.

But no one should accept the diagnosis before undergoing one final diagnostic test to rule out an underlying medical

Given the problems food can cause with those individuals, Smedley isn't surprised that some men and women wind up becoming anorexic or bulimic.

The latter is when individuals gorge on food and then throw up or use laxatives to prevent gaining weight.

If the symptoms are chronic, Smedley explains, the patient may not be aware anything is wrong and simply adapts to the condition.

Meanwhile their weight continues to plummet, and any effort to gain weight only aggravates their system — and their state of mind. By then so many professionals have told them it's psychological, they accept it, Smedley explains.

Some women are diagnosed with eating disorders in their 40s, he added. While some are obsessed with being thin, others may have adapted all those years to chronic gallbladder problems until their bodies could no longer cope, Smedley said.

Springfield psychologist Michael Murrell treats eating disorders as part of his practice, but has never heard of a possible connection between gallbladder disease and anorexia nervosa or bulimia.

After hearing about Laura's ordeal despite her efforts to gain weight, he added, "A good gastrointestinal doctor would have figured out she wasn't anorexic because that's not the behavior of an anorexic.

"Anorexia is diagnosed on behavior and refusing to eat, or eating and throwing up — observable behaviors," Murrell said.

Today, Laura says she feels great. Yes, she says, it's hard to look at the old photographs of herself, taken so Smedley could chronicle her progress.

"But I think it helps remind me of what I've been through, how far I've come," Laura said.

"And to know I didn't do it to myself."

condition, he said.

He said he has found the same gallbladder problem in 90 patients so far who earlier were diagnosed as anorexic and referred to mental health counseling.

The test, conducted in a diagnostic lab, is the "CCK Stimulation Test." It's a common diagnostic tool, but Smedley says it should be done while the patient is upright instead of lying down. That's the only way X-rays will show the true gallbladder problem, he said.

The test involves injecting a patient with CCK, or Cholecystokinin, a synthetic hormone that stimulates the gallbladder to contract as it would in response to fatty foods.

The X-rays show whether the gallbladder contracts enough to push out stored bile to help break down fats in the system, Smedley said.

The patient's upright position also shows whether the gallbladder tends to flop over and kinks the connecting duct, causing a backup of bile and resulting pain.

If that test shows the gallbladder is functioning properly, then it's time for the patient to seek mental health counseling.

But if the gallbladder is not contracting properly, or if the contraction causes abdominal pain, the test is positive and the simple solution is to remove the gallbladder, Smedley said.

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