

## Treatment challenge posed by 'diabulimia'

Type 1 diabetics lose weight by not taking insulin, but that brings a host of problems.

By Marie McCullough  
INQUIRER STAFF WRITER

Like other overweight teens, Erin M. Akers longed to be slender.

Unlike other girls, she discovered that she possessed a powerful weight-loss gimmick, a secret reward for being diagnosed at age 10 with her detested disease, type 1 diabetes.

"When I was 14, I realized that by not taking my insulin, I could eat anything I wanted and lose weight," recalls Akers, now 21, of Seattle. "For an overweight kid, that's like a dream come true. I lost 55 pounds that summer. I thought I was a genius. I thought no one else knew about this."

Akers spent the next six years in and out of hospitals, recovering from the life-threatening complications of skipping her insulin shots, before confronting the fact that she had an eating disorder. In 2008, she underwent intensive therapy, then set up an online non-profit group to help women like her.

She is part of a recent wave of

attention, activism, and research focused on type 1 diabetics who restrict their insulin for weight control.

The ranks of these complex patients are growing, according to eating-disorders treatment programs such as the Renfrew Center of Philadelphia. Yet recognition and understanding of their pathological pursuit of thinness remain sketchy.

In fact, there was no formal name for the dual diagnosis until three years ago, when an international group recommended "Eating Disorders-Diabetes Mellitus Type 1."

Patients and the media have embraced a catchier label: *diabulimia*.

"Clinicians have qualms about using that term because it's a media invention," said Ann Goebel-Fabbri, a clinical psychologist and eating-disorders specialist at the Joslin Diabetes Center, a Harvard Medical School affiliate.

"But it has given voice to a lot of women who are struggling with this, and now realize they aren't alone."

Type 1 diabetics, typically diagnosed in childhood or adolescence, can't make insulin, the hormone that cells need to convert sugar from carbohydrate foods into energy.

Without insulin, the body effectively goes into a state of speeded-up starvation, dumping unused sugar into the urine and breaking down muscle, fat, and liver cells for fuel. This process produces acids called ketones, which build up in the blood, leading to a metabolic crisis called diabetic ketoacidosis.

An infection such as the flu or an injury can accidentally set ketoacidosis. But diabulimics try to skate on the edge of it, strategically omitting insulin to purge calories and suppress appetite — and enduring the resulting thirst, frequent urination, dehydration, weakness, fatigue, racing heart, nausea, and vomiting.

Cumulatively, bouts of ketoacidosis can permanently damage the kidneys, liver, stomach, arteries, and nerves — especially nerves in the feet and eyes.

Like the well-known eating disorders anorexia (self-starvation) and bulimia (bingeing and purging by vomiting or laxative abuse), diabulimia involves a cycle of low self-esteem, struggle for control, fear, depression, shame, secrecy, deception, and guilt.

Yet doctors and parents may not recognize the psychological complexity, assuming instead that the diabetic is being "noncompliant" — neglecting or defying onerous

dietary, blood-sugar monitoring, and insulin regimens. In fact, after reports of weight loss induced by insulin restriction first appeared in medical journals in the 1980s, diabetes experts disagreed about the implications.

"There was a huge debate: Is this an eating disorder or not?" recalled Goebel-Fabbri at the Joslin Center.

Since then, she and other researchers have found that young women with type 1 diabetes are more than twice as likely to develop an eating disorder as their nondiabetic peers. One study found 10 percent of teenage diabetic girls had eating disorders, compared with 4 percent of same-age girls without diabetes. (Researchers have found no clear association between type 2 diabetes and eating disorders, probably because disturbed eating behaviors usually begin many years before the onset of type 2 diabetes, which is linked to obesity.)

Anecdotally, the number of diabulimics is growing.

The Renfrew Center's residential treatment program on Spring Lane, for example, now admits a few dozen diabetics a year.

"When I started working at Renfrew seven years ago, we had maybe one diabetic a year. It was rare," said Julie Dorfman, director of nutrition. "Now, we've created a special menu for them with the carbohydrates already counted."

Medical director Susan Ice said diabetics were also a big factor behind an increase in the number of newly admitted Renfrew patients who had to be transferred to a hospital because they were critically ill.

(continued on back)



Erin M. Akers works as a nanny for Kaitlyn and Rashann Olsen. She seeks to help other diabetics who have an eating disorder.



# How to treat 'diabulimia'

"Twenty percent who come in for admission, we send to the ER right away or during the course of treatment," she said. "Two years ago, just five percent" required such care.

Akers, a plump, candy-loving preteen when her diabetes was diagnosed, did not understand her life-transforming disease, and neither her doctors nor her parents adequately explained the risks of uncontrolled blood sugar.

"It was all very vague," Akers recalled. "No one said, 'If you don't keep tight control now, when you're 40, you're going to lose your eyesight and your kidneys will shut down.'"

Initially, Akers stopped her insulin out of recalcitrance. quately explained the risks of uncontrolled blood sugar.

"It was all very vague," Akers recalled. "No one said, 'If you don't keep tight control now, when you're 40, you're going to lose your eyesight and your kidneys will shut down.'"

Initially, Akers stopped her insulin out of recalcitrance.

"I had no idea you could lose weight. Through basic teenage rebellion, I just decided: I don't want to be a diabetic anymore," she said.

But as the pounds melted away that summer before her freshman year of high school, her self-esteem rose. She was a normal weight for the first time in her life — 150 pounds on a 5-foot, 5-inch frame — and peers, parents, even physicians expressed approval.

"All of a sudden, I was getting positive attention," she said. "Staying thin meant being popular and being 'healthy' to my doctors."

It also meant endless lying.

"Almost right away, I got so sick that I had to go to the ER. I couldn't stop throwing up," Akers said, recalling the first of 20 hospital sojourns that almost prevented her graduation from high school. "The first three or four times, I was able to convince my parents that I had gotten the flu and lost [blood sugar] control. Then I convinced them I had a weak immune system."

A series of doctors dropped her as a patient, recognizing that she was deliberately restricting insulin.

Yet no one, not even Akers, saw it as an eating disorder.

"I knew what anorexia was, and what bulimia was, and I didn't have that," she said. "But I didn't know any other way [than omitting insulin] to handle weight, or food, or stress."

In 2007, an infection spread to her spine and almost killed her at age 18, partly because her cover story — a weak immune system — had become a reality. That is when Akers' mother decided to find an inpatient treatment center.

It was not easy. Unlike Renfrew, which has treated diabetics since the facility opened 25 years ago, many programs are reluctant or unequipped to deal with the dual diagnosis.

Official guidelines for inpatient and outpatient care of diabulimics did not even exist until 2009, when an international group including Goebel-Fabbri published their consensus.

Basically, the treatment team takes control of diabetes and food management until the patient, with the help of psychotherapy, is able and willing to resume self-control.

Akers wound up at a Florida facility, where she spent three months and \$30,000 — only a third of it covered by health insurance.

"I'm lucky my parents had the resources," she said.

Diabulimia has left her with permanent numbness in both feet, digestive problems, an ongoing struggle against relapse, and one good thing — a mission. Through her nonprofit, diabulimiahelpline.org., and its Facebook page, she works to improve recognition and prevention of the double illness.

"Every day, I respond to girls all over the country and all over the world. It is such a moving thing," she said. "They've helped me tenfold more than I've helped them."

Contact staff writer Marie McCullough at 215-854-2720 or [mmcullough@phillynews.com](mailto:mmcullough@phillynews.com).