Diabetes FORECAST The Healthy Living Magazine
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Diagnosis: Diabulimia

This eating disorder affects people with diabetes, but there's hope for healing

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March 2020

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Asha Brown had been living with type 1 diabetes since age 5, but it wasn't until middle school that she began to feel limited by the disease. A vibrant redhead who worked as a dancer and actress during her teens, Brown "lived to move." She'd get frustrated when diabetes forced her to take breaks to tend to her blood glucose or treat a low.

At the same time, she became keenly aware of the importance of her appearance and what she perceived as a lack of control over her eating habits—and her own body. In an effort to keep her weight down, Brown started exercising even more than usual and restricting her food intake. When she was a sophomore in high school, however, she discovered an easier way to keep her weight down: She began bingeing on candy and skimping on insulin, behaviors that are indicative of what's known as diabulimia.

The condition isn't an official diagnosis (see "Types of Eating Disorders," below) but rather a colloquial term that's often used to describe an eating disorder specific to people with diabetes who use insulin. It shares some characteristics with bulimia nervosa: repeated episodes of extreme overeating followed by fasting, self-induced vomiting, or purging, often with the help of laxatives. People with diabulimia, on the other hand, deliberately binge eat and then skip or restrict insulin, so their body can't use the glucose for energy. Instead, the glucose gets excreted in the urine. From a weight perspective, it's as if they never consumed those carbs. That leads to weight loss—but it also keeps blood glucose levels dangerously high.

Throughout her teens and into her twenties, Brown's weight and blood glucose fluctuated dramatically as she cycled through periods in which she'd binge on sugary foods and take less insulin than she needed to manage her diabetes. "My **A1C** was over 14 and my weight was up and down. I was a size 2, an 8, then a 2 again," she says. "Yet no doctor ever asked me if I had an eating disorder."

Often on the brink of diabetic ketoacidosis (DKA), a serious condition that leads to a buildup of toxic ketones in the bloodstream, Brown was vomiting frequently and doubled over with stomach pain. Not surprisingly, she was losing jobs; as her career began to tank and she felt increasingly ill, she fell into a deep depression. "I was newly married, and instead of enjoying that time in my life, I was investigating methods of suicide," Brown says.

A Common Problem

Because diabulimia is not an official diagnosis, it's hard to know just how common it is. Research suggests that women with **type 1 diabetes** are twice as likely as those without diabetes to develop an eating disorder, and young women such as Brown are especially vulnerable: An estimated 31 to 40 percent of women with type 1 diabetes between the ages of 15 and 30 show signs of "disordered eating behavior," which includes diagnosable eating disorders such as anorexia and bulimia, as well as milder but still abnormal behaviors.

Men develop eating disorders, too, and so do older adults. In a study of adults with type 1 diabetes published in 2018 in the *Journal of Eating Disorders*, about 13 percent of men met the official diagnostic criteria for disordered eating behavior, as did 25 percent of women.

But people with type 1 aren't the only ones at risk for diabetes-related eating disorders. Research suggests that 6.5 to 9 percent of those with type 2 have a diagnosable eating disorder, though a larger number show some symptoms of disordered eating.

Amy Kimberlain, RD, LDN, CDE, a certified diabetes educator at Baptist Health South Florida and a spokesperson for the Academy of Nutrition and Dietetics, adds that many people with eating disorders (whether they have diabetes or not) don't fall into one specific category but rather experiment with a variety of unhealthy behaviors, such as flipping between bingeing and restricting.

Kimberlain believes borderline eating disorders are exceptionally common. Her former patients include a woman with type 1 diabetes who ate the same foods every day so she wouldn't have to calculate how much insulin to dose before meals and a teen who refused to rotate her pump site because she wanted to absorb less insulin in an effort to lose weight.

Whether you're talking about unhealthy behaviors that have the potential to turn serious or diagnosable eating disorders, the question remains the same: Why are people with diabetes at greater risk?

Risk Factors

There are many theories about why diabetes, especially type 1, seems to raise the risk for eating disorders. Diabetes burnout is one major factor, says Lindsay Friedman, RD, LDN, director of nutrition services at The Renfrew Center, which specializes in treating eating disorders. "You don't get a vacation from diabetes—ever," she says. "[If you have type 1] you always have to focus on food and insulin and the

impact that they have on your body." Constant attention to those details is key to keeping blood glucose in target range, but it can also backfire.

That focus on food can turn into a preoccupation, setting the stage for a disorder, says Claire Aarnio-Peterson, PhD, an assistant professor in behavioral medicine and clinical psychology at Cincinnati Children's Hospital Medical Center who has conducted research on eating disorders in people with diabetes. It's not unusual for teens with type 1 to lose some weight prior to getting diagnosed, she adds. "Then they start insulin and gain some weight, which can be really hard."

While there's no denying that the stress of developing or managing diabetes can take a toll, there may also be other reasons why eating disorders are more common among people with the disease. In 2017, researchers at the University of North Carolina at Chapel Hill conducted a genetic study and found that a specific spot on a chromosome was significantly associated with anorexia. Interestingly, previous research connected the same region with type 1 diabetes and other autoimmune disorders.

Aarnio-Peterson has also been delving into the possible physiological causes of eating disorders. In 2018, she and her colleagues published a study in the *Journal of Pediatric Psychology* that looked at diabulimia risk and found that hunger and satiety (satisfying fullness) clues were often disrupted in people with type 1 diabetes—even among those with well-managed glucose levels. "We may be seeing higher rates of disordered eating behavior because of disruptions to the hormones amylin and ghrelin," she says. Both hormones play a key role in how you perceive hunger and satiety.

For some people with **type 2 diabetes**, especially those who are obese, binge eating disorder may have predated their diabetes diagnosis. For others, the misbelief that they're responsible for their type 2 diabetes, and the shame that comes with it, may lead to the development of bulimia or anorexia, says Friedman.

Help With Healing

Eating disorders are dangerous for everyone—they have one of the highest mortality rates of any psychiatric disorder—but when you couple them with diabetes the stakes are even greater.

There's an imminent risk of death from DKA. And over the long term, high blood glucose levels, which result from underdosing insulin, damage blood vessels, leading to serious heart, kidney, nerve, and eye complications. Not surprisingly, research shows that women with type 1 diabetes and an eating disorder are more apt to be hospitalized, develop retinopathy and neuropathy, and die prematurely than those with type 1 who don't have an eating disorder.

Whether someone with an eating disorder has type 1 or type 2 diabetes, getting help requires a team-based approach that ideally includes an endocrinologist, certified diabetes educator, and mental health professional who specializes in disordered eating. "There is no evidence-based treatment for people with eating disorders who have diabetes," says Aarnio-Peterson. "What's happening now is that eating disorder treatments [for those without diabetes] are being adapted for people with diabetes."

What might treatment look like? "The initial goal is medical stabilization," says Friedman. For someone with type 1 diabetes who's been omitting insulin, the first step might be enrolling in an inpatient program so that a health care provider can make sure the person resumes regular insulin dosing.

Individual and/or group counseling is aimed at teaching people how to process negative emotions such as anger, shame, or burnout. Mental health professionals typically use some form of cognitive behavioral therapy (to show how thoughts influence behavior), including a type that focuses on learning to regulate emotions in order to overcome negative thought patterns.

Simultaneously, people with eating disorders have to reconnect with their internal hunger cues and figure out how to respond to them in a healthy way. "If [your blood glucose is] low, you have to eat or have some juice," says Kimberlain. That basic diabetes task is more stressful for people who are prone to bingeing or

anxious because they're more comfortable depriving themselves. "You may need to find a way to nudge your numbers up enough without feeling like you're excessively eating."

Some people, she adds, might say that eating isn't the problem; it's taking the insulin that's challenging. In that instance, a patient and health care provider may focus on delivering insulin for just one meal and work up from there.

How well do these approaches work? Reliable stats are hard to come by, in part because there's no standard definition of success, says Friedman. "Are we looking at minimization of behaviors? Mental status? Ability to eat?" she asks. "Plus, capturing that data is hard because you'd have to get responses from patients long after they've completed treatment. Recovery is possible—I've seen it personally—but I've also seen people who've struggled for years."

Brown, now 35, founded the nonprofit **We Are Diabetes** to provide support for people with type 1 who struggle with disordered eating. "It's really important for anyone feeling miserable and stuck in a cycle of disordered eating to know that recovery is also hard and uncomfortable, but if you're working toward recovery then there's a light at the end of that tunnel," she says. "If you're choosing fear, there is no promise of light."

Warning Signs

If you care for someone with diabetes, be aware of these signs of an eating disorder.

- An unexplained increase in A1C levels
- Repeated episodes of diabetic ketoacidosis (DKA)
- Extreme concerns about body shape and size
- Excessive exercise and related hypoglycemia
- Very-low-calorie meals or excessive consumption of carbs/sugar
- Menstrual irregularities

Types of Eating Disorders

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the tool mental health professionals use to diagnose people, defines five types of eating disorders:

Anorexia nervosa: Extreme calorie restriction, intense fear of gaining weight, disturbed self-image (for instance, thinking you look fat even though you are extremely underweight)

Binge eating disorder: Recurrent and extreme overconsumption of food in a short period and inability to control binge episodes

Bulimia nervosa: Recurrent and extreme overconsumption of food in a short period and inability to control binge episodes coupled with efforts to compensate for binges and avoid weight gain with intentional vomiting, excessive exercise, or misuse of laxatives or other medications. When insulin is the medication that's misused, this disorder is often referred to unofficially as "diabulimia." Medical professionals may refer to it as an "eating disorder with diabetes mellitus type 1."

Other specified feeding or eating disorder: If you meet some but not all of the criteria required for one of the other diagnoses

Unspecified feeding or eating disorder: If you suffer significant distress or impairment due to eating behavior, but a more specific diagnosis can't be made