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## WHAT YOUR PATIENT IS THINKING

### I live with “the world’s most dangerous” eating disorder

Having lived with the challenges of diabulimia and other eating disorders for years, our author describes how her experience might be helped by more official recognition of the disease and the education of healthcare professionals

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Diabulimia is the main reason I was urged to take a medical leave from my academic position. Coined “the world’s most dangerous eating disorder,”<sup>1</sup> diabulimia is a name used by the media and by some healthcare professionals to describe the omission of insulin to lose weight. Some academics use the term ED-DMT1 (eating disorders in diabetes mellitus type 1) to denote the spectrum of diabetes related eating disorders, such as diarexia. Unlike bulimia, anorexia, and binge eating disorder, diabetes related eating disorders are not yet officially classified in their own right.

#### Finding the holy grail of eating disorders

I have been struggling with diabulimia on and off since my diagnosis of type 1 diabetes in 2011, at age 30. I had just started a PhD and spent the first semester walking around campus with all the classic symptoms of type 1 diabetes: famished, dehydrated, constantly needing to urinate, and experiencing rapid weight loss. After my diabetes diagnosis, when I started injecting insulin, I gained the weight back—and then some. It didn’t take long to figure out that omitting insulin was not only an effective weight loss tool, compared with vomiting, it was a much less violent way to purge. Having a history of bulimia nervosa, I thought I had found the holy grail. I could eat what I wanted, not use insulin, and not gain weight.

Within months, my glycated haemoglobin (HbA1c) level crept back up to the dangerous range. I was fortunate to be connected to a diabetes team, but no one seemed to know about diabulimia, or ask me about my relationship with food and/or history of eating disorders. It was easy to keep my diabulimia secret—it was largely invisible. I was a “normal” weight. I didn’t look sick. I blamed my double digit HbA1c level on being someone with “brittle” or labile diabetes, meaning I am prone to large swings in blood sugar, which was true. I had figured out the right amount of insulin I needed to keep my weight down and avoid diabetic ketoacidosis. This behaviour carried on for eight years.

#### Every interaction with a healthcare provider counts

I hit rock bottom from diabulimia complications in the summer of 2019. I had travelled to New Zealand to present at a conference. What was supposed to be the trip of a lifetime left me in a pit of despair and loss of hope: my eating disorder had complete control

over me, and I could not stop omitting insulin. On one particularly dark day, suicidal thoughts prompted me to text my endocrinologist to say that I needed help. She texted me back right away and urged me to come to her clinic the next day. Recognising the seriousness and lethality of my condition, she recommended a minimum of a year off work to get my diabetes back on track and recover from my eating disorder. That was a hard pill to swallow for this workaholic, but I had run out of ideas, and decided it was time to put my health first.

Since being on leave, some of the most difficult days have involved interactions with healthcare providers. I had to convince one doctor that omitting insulin constituted a legitimate form of purging. Unconvinced, they said, “so you don’t really have bulimia,” followed by, “you’re just choosing to omit insulin? Don’t you know that will kill you?” I don’t believe these comments were meant to intentionally cause harm. They were made through ignorance. The healthcare providers were probably unaware of the prevalence of eating disorders—that women with type 1 diabetes are two and a half times more likely to develop an eating disorder, or that one in three women with the disease actively omits insulin to some degree. Regardless of intent, the impact is real. Every interaction with a healthcare provider counts. A better approach would be to use open ended questions to ask patients about their relationship with food, recognise how triggering and shaming discussions about numbers and the scale can be, and acknowledge the strong mental health component in diabetes.

If systemic change in the areas of formal recognition, screening, education, awareness, and a commitment to non-stigmatising language are not put into place, it is unlikely that diabulimia will ever lose its infamy as “the world’s most dangerous eating disorder.”

#### What you need to know

- Formally recognising diabulimia, such as including it in the sixth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, would provide a common language to start asking the questions necessary for screening and treatment
- Educating healthcare providers about diabulimia would help normalise experiences of people with diabulimia, which might encourage them to speak more openly about their eating disorder
- Ensure that each interaction with a patient is conducted sensitively (eg, consider whether it is

necessary to weigh the patient, or disclose their weight) and that no stigmatising or shaming language is used

#### Education into practice

- In this article, our author texted her endocrinologist to ask for help. How would you have responded to a similar text message?
- How could you learn about diabulimia? What information is available to you?
- How can you ensure that your interactions with patients are sensitive to eating disorders?

#### Support and resources

- Diabulimia support and resources [www.diabulimiahelpline.org/](http://www.diabulimiahelpline.org/)
- Support for people with type 1 diabetes [www.wearediabetes.org](http://www.wearediabetes.org)
- Diabetics with eating disorders [www.dwed.org.uk](http://www.dwed.org.uk)

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- 1 Torjesen I. Diabulimia: the world's most dangerous eating disorder. *BMJ* 2019;364:l982.