Diabulimia

Diabulimia is a media-coined term that refers to an eating disorder in a person with diabetes, typically type I diabetes, wherein the person purposefully restricts insulin in order to lose weight. Some medical professionals use the term ED-DMT1, Eating Disorder-Diabetes Mellitus Type 1, which is used to refer to any type of eating disorder comorbid with type 1 diabetes.

With the intense focus on food, labels, numbers (weight, blood glucose, A1c) and control, plus the many disruptions that occur in a person's metabolic system, we know that diabetes is a high risk factor for developing an eating disorder. Thus, a person may develop diabulimia or ED-DMT1 at any age and at any point after their diabetes diagnosis. Sometimes it begins with body image issues or a desire to lose weight, and sometimes it begins as diabetes burnout. Regardless of how it begins, treatment can be challenging as individuals with type 1 diabetes tend to show higher dropout rates and poorer treatment outcomes than other patients. Treatment regimens must address both the diabetes and eating disorder aspects of the disorder.

Diabulimia does not have a separate diagnostic code so a person's specific diagnosis will depend on their eating disorder behaviors. The diagnostic manual, DSM-5, classifies insulin omission as a purging behavior, therefore it may be coded as bulimia nervosa if the person is binging then restricting insulin. It may be diagnosed as purging disorder if the person is eating normally and restricting insulin or anorexia nervosa if the person is severely restricting both food and insulin. Diabulimia can also be diagnosed as Other Specified Feeding and Eating Disorder (OSFED).

WARNING SIGNS & SYMPTOMS OF DIABULIMIA

Emotional and behavioral

- Increasing neglect of diabetes management
- Secrecy about diabetes management
- Avoiding diabetes related appointments
- Fear of low blood sugars
- Fear that "insulin makes me fat"
- Extreme increase or decrease in diet
- Extreme anxiety about body image
- Restricting certain food or food groups to lower insulin dosages
- Avoids eating with family or in public
- Discomfort testing/injecting in front of others
- Overly strict food rules
- Preoccupation with food, weight and/or calories
- Excessive and/or rigid exercise
- Increase in sleep pattern

- Withdrawal from friends and/or family activities
- Depression and/or anxiety
- Infrequently filled prescriptions

Physical

- A1c of 9.0 or higher on a continuous basis
- A1c inconsistent with meter readings
- Unexplained weight loss
- Constant bouts of nausea and/or vomiting
- Persistent thirst and frequent urination
- Multiple DKA or near DKA episodes
- Low sodium and/or potassium
- Frequent bladder and/or yeast infections
- Irregular or lack of menstruation
- Deteriorating or blurry vision
- Fatigue or lethargy
- Dry hair and skin

HEALTH CONSEQUENCES OF DIABULIMIA

The human body is surprisingly resilient and people with diabulimia often manage to function with much higher blood sugars than should be possible. Thus, the major consequences of diabulimia or ED-DMT1 are usually related to prolonged elevated blood sugar. These complications can be severe and irreversible, so proper treatment and early detection are critical

Patients with weight related insulin restriction were 3.2 times more likely to die over an 11-year study period, and to die an average of 13 years younger than those who didn't restrict insulin. It is incredibly important to understand the many ways that eating disorders affect a person with diabetes.

Short-term consequences:

- Slow wound healing - high blood sugar causes poor circulation, decreases the function of red and white blood cells, and damages small blood vessels; all of which delay wound healing and can sometimes progress into an ulcer in a person with diabetes.
- Staph and other bacterial infections – high blood sugar causes the body to produce certain enzymes and hormones that negatively affect the immune system and reduce the body's defense against infection. This risk of infection plus slowed healing heighten a person's chance of developing gangrene, sepsis or a bone infection.
- Yeast infections – excess sugar allows the overgrowth of yeast, often in the vaginal area.
- Muscle atrophy – without insulin, the body cannot utilize food and cells begin to starve so the body begins to break down muscle for fuel.

- Menstrual disruption – without sufficient nutrition, a woman's estrogen levels fall which can keep menstruation from starting, or cause it to become irregular or stop completely; also when a woman's body senses starvation it will cease reproduction to conserve energy.
- Severe dehydration – insulin deficiency puts the body into a state of starvation causing it to break down tissues to create ketones to use as fuel; in an attempt to expel the ketones in the urine the body ends up dispelling too much fluid.
- Electrolyte imbalance – as the kidneys extract sugar and ketones to expel with urine, they also extract sodium and potassium which can lead to an extreme electrolyte balance, especially when combined with vomiting which often occurs with high ketone levels.
- Diabetic Ketoacidosis – people with type 1 diabetes will develop dangerous levels of ketones faster than others because the body needs insulin to transport ketones from the bloodstream into cells; without insulin, the ketones build up in the bloodstream faster than the kidneys can remove them causing the blood to become acidic. Not only does the acidic blood damage blood vessels, nerves and organs, but even a minor alteration in a person's blood pH can cause organ systems to shut down resulting in coma and sometimes death.

Long-term consequences:

High blood glucose causes blood to become like sandpaper scraping and damaging blood vessel walls. In addition, blood that is acidic from ketones can cause vessel damage. The consequences of this damage are often seen in the eyes where tiny vessels begin to leak into the eyeball.

- **Retinopathy** - small black spots or "floaters" disrupting a person's vision; the bleeding may be stopped with treatment, but persistent or recurrent retinopathy can eventually lead to blindness.
- **Macular Edema** – swelling of the eye ball from excess fluid; if untreated it can eventually cause permanent damage to the eye.

Nerve fibers are particularly vulnerable to prolonged periods of high blood sugar. Many factors can damage the small nerves in the body including reduction in oxygen supply; thick, sticky blood that has difficulty getting to the small capillaries that feed the nerves; and inflammation of the nerves.

- **Peripheral Neuropathy** – stabbing/burning/tingling pain, weakness or numbness in the hands, feet, legs and/or arms.
- Gastroparesis – slowed stomach emptying from damaged nerves preventing proper digestion and causing stomach pain, nausea and vomiting.
- **Vasovagal Syncope** – malfunction of the nervous system in response to stress or position change causing a sudden drop in blood pressure and heart rate and sometimes fainting.
- **Chronic diarrhea** or constipation – when nerves that control the intestines and colon are damaged, a person may experience abnormal fluid absorption or slowed motility.

Other organ damage.

- **Kidney disease** – High blood sugars make the kidneys work excessively hard causing damage to the kidneys filtering system. Kidneys begin leaking protein into urine and lose their ability to remove waste products and excess fluid allowing waste and fluid to build up in the body; it can eventually lead to kidney failure requiring frequent dialysis or kidney transplant.

- **Liver disease** – Although the specific mechanism is not well understood, we know that insulin deficiency results in non-alcoholic fatter liver - too much fat accumulated in the liver coupled with inflammation; in severe cases it can progress to cirrhosis and liver failure.
- **Heart disease** – hardening and narrowing of the arteries from high cholesterol.

Many of the above consequences can become fatal - sometimes over time such as kidney or heart disease and sometimes very quickly such as diabetic ketoacidosis.

- **Coma**
- **Stroke**
- **Death**

Without insulin, the body cannot utilize anything eaten putting the body into a state of malnutrition or starvation. As a result, in addition to the above complications a person with diabulimia can also incur the same consequences as someone with anorexia nervosa. And if a person engages in other forms of purging beyond insulin restriction, they can develop consequences associated with bulimia nervosa.

TREATMENT

- No matter where someone is at in their eating disorder or recovery, a multidisciplinary team is necessary to address the many entangled issues present with diabulimia or ED-DMT1. The best scenario for a patient is to see an endocrinologist, a dietician who has knowledge of both diabetes and eating disorders, and a mental health professional who specializes in eating disorders.
- Both healthcare professionals and patients need to remember that “good enough” diabetes management is the goal, not “perfect” control. The quest for perfection can lead to an increase in diabetes burnout and enhance all-or-nothing thinking which in turn can boost the eating disorder.
- Remaining in an outpatient setting should be contingent upon taking a minimum amount of insulin consistently, being able to eat enough food to maintain weight, and not engaging in degrees of purging that causes dangerous electrolyte imbalance.
- If the treatment team recommends a higher level of care, it’s important to choose a treatment center that has a specialty in diabulimia/ED-DMT1. Patients and healthcare providers can ask to review insulin reintroduction protocols, diabetes management and staff training in diabetes to determine a center’s true level of expertise, or reach out to Diabulimia Helpline which has a nationwide referral database for both centers and providers that have experience in both diabetes and eating disorders.
- Remember that diabulimia is a serious mental health disorder, thus it cannot be treated by simply reinforcing diabetes education or stressing the dangers of diabetes complications.

**These statistics have been taken from www.nationaleatingdisorder.org