The Dangers of Diabulimia

What Every Person With Type 1 Needs to Know

What is Type 1 Diabetes?

- An auto-immune disease in which the immune system attacks itself, destroying the insulin secreting beta cells of the pancreas until they produce little to no insulin
- Treatment requires a fine balance of 24/7 monitoring of blood glucose and insulin (plus carb counting and a million other things!)
- Less than one-third of people living with Type 1 in the U.S. achieve target blood glucose levels (1)
- There is no cure, just the lifeline of insulin
What Happens Without Insulin?

• DKA—diabetic ketoacidosis
  the body can’t use sugar for fuel so it turns
to alternative sources, like fat and muscle.

• As fat is broken down, acids called ketones
  begin building up in the blood and urine

• High enough levels of ketones are poisonous
  and if left untreated, can lead to coma
  or death

Does Insulin Cause Weight Gain?

• Myth “Insulin makes me fat”

• Excess energy intake causes weight gain

• Synthetic insulin is more efficient than
  natural insulin which means people with
  Type 1 tend to be heavier than their non-
diabetic peers by 4 to 13 lbs.
What Constitutes an Eating Disorder?

- **Anorexia Nervosa** – Sever restriction of energy intake leading to excessive weight loss; *fear of insulin* can cause a person to limit or reduce eating to avoid needing insulin.

- **Bulimia Nervosa** - Recurrent episodes of binge eating with inappropriate compensatory behavior such as vomiting, excessive exercise and *insulin omission*.

- **Binge Eating Disorder** - Recurrent episodes of binge eating; though less common some will *intentionally overdose insulin* to justify binge eating.

- **Purging Disorder** – Normal eating patterns with recurrent inappropriate compensatory behavior, including *insulin omission*.

Sarah MacLeod
d/x December 14, 2005
What’s the Secret?

• Studies show 30-40% of Type 1 young women engage in this life threatening behavior, as high as 50%.

• You may have innocently/accidentally discovered it for yourself and never recognized it for what it is.

• It can happen to anyone.

• It will kill you.

Diabulimia AKA ED-DMT1
Eating Disorder-Diabetes Mellitus Type 1

• Restricting insulin for weight loss.

• A complex eating disorder not currently listed in the bible of psychiatric disorders, DSM-5.

• Requires immediate medical attention and intervention.

• Rather than being a transient problem of type 1 youth, insulin restriction for weight loss is likely to persist and reoccur.
Possible Triggers

- Not checking your blood sugar, injecting or bolusing can make a person feel more “normal”
- Diabetes burnout
- Media influence to look or behave a certain way. “Thin is in” and “Lean is mean.”
- Peer influence
- Feeling “pressure” to impress: dating, friends, coworkers

Diabulimia: Contributing Factors

- Biology - genetics, metabolic disruption, neurochemical imbalance
- Psychology – depression, anxiety, low self-esteem, lack of control, perfectionism, anger at diabetes, attitude towards insulin, co-morbid mental health disorders
- Social – trauma, social pressure, troubled relationships, media, diabetes history and education
Insulin and Attitude

I Increased attention to numbers: Carb counting, blood glucose levels
N Not following dietitian, CDE or physician recommendations
S Satiety cues compromised
U Understanding hunger cues
L Label reading, menu planning, feeling deprived
I Insulin attitude
N Not doing the right thing! Judgment from health care professionals

People With Type 1 Diabetes Are at Higher Risk For Developing an Eating Disorder

• Women with Type 1 diabetes are 2.4 times more likely to develop an eating disorder than their non-diabetic peers

• 2.4-3.5 times more prone to complication and hospitalization
Ask the Right Questions

• Do you have rules about food that you follow rigorously?
• Do you eat on a timetable instead of when you’re hungry?
• Have you binged and felt like you couldn’t stop? (outside of a low BS)
• Do you feel guilty after eating?
• Do you exercise strenuously to control your weight?
• Do you give too much time and thought to food?
• Do you feel like food controls your life?

Recognizing Signs in a Loved One

• Not wanting to eat out or not wanting to eat with the family.
• Eating in secrecy - finding empty bottles, wrappers, containers stashed or thrown away
• Noticeable change in how much a person is eating
• Eating a lot of junk food or food high in sugar
• Increased or new secrecy around their diabetes management
• Increased or new concern over their body size, shape or weight
• Excessive exercising, severe anxiety/panic if they cannot exercise
• Increased moodiness/depression
Recognizing Signs in a Loved One

- Diabetes supplies are lasting too long/finding hidden unused supplies, especially insulin
- Increase in A1c since the last appointment or steady increase in A1c over several appointments
- Discrepancy between meter log/download and A1c
- Multiple missed doctor appointments
- Forgetting to bring their meter, especially twice in a row
- Missing data on the meter or pump without a good explanation
- Multiple infections – Urinary tract infection, yeast, skin
- Dry, brittle hair; flaky skin

Diabulimia Recovery

- It takes a village — endocrinologist, registered nurse, registered dietitian — nutritionist, certified diabetes educator with eating disorder/diabetes training, and a psychologist or social worker
- The treatment team must be non-judgmental and willing to set small, incremental goals
- Anticipate hurdles and problem solve ahead of time — new or worsening complications, hypoglycemia (real and false)
- Bring down average blood sugars slowly
Assessment Tools

T  Talk less, listen more. No judgment!
O  Only food related? Insulin related? Both?
O  One form to another- changes in eating disorders
L  Look into metabolic testing
S  Standard Eating Disorder Assessment Tool: Diabetes Eating Problem Survey

Dietitian’s Role

• Listening to a person’s diabetes story is as important as the rest of their medical and nutrition history.

• Clients may come to you wanting to recover from diabulimia, but not gain any weight – Recovery must come first.

• An eating disorder meal plan and diabetes meal plan are often contradictory. Your job is to find the happy in-between.

• Even people with diabetes can reach intuitive eating.
Unlike Typical Eating Disorder Recovery

• You still have to read labels to count carbs
• FACT: while you’re in eating disorder recovery, you still have diabetes
• Recovery with diabulimia means becoming "abnormal" again
  – testing your blood sugar, injecting insulin, etc.
• While eating disorder providers talk about how wonderful your body is, with Type 1, your body IS broken and you may feel betrayed by it
• Your body does still do a lot of other wonderful things, but providers need to acknowledge the physical and emotional challenges of living with a 24/7 chronic illness

Help and Support

• Providing Help
  – It's hard regulating blood sugars and maintaining good eating habits, especially on top of trying to recover from an eating disorder
• Inpatient/Residential
  – May be essential for nursing staff to take over diabetes management- both for medical stability and to allow the patient to focus on mental health aspects
• Outpatient
  – in extreme cases, a family member may temporarily take over diabetes management to ease anxiety and stress
  – For less extreme cases, having a trusted friend or family member available for support during times of daily insulin management.
Don’t Fear The Gear!

- Let technology help— it's hard being your own pancreas 24/7!
- Insulin pump therapy has been shown to help people recovering from an eating disorder
- CGM’s can help with roller coaster blood sugars
  - check your blood glucose regularly instead of spending time worrying

QUESTIONS & ANSWERS
Diabulimia Helpline Services

- 3 on-line Support Groups
- 24 Hour hotline
- Treatment referrals
  - Local outpatient providers
  - PHP and IOP programs
  - Inpatient and Residential centers
- Individualized insurance help
- Client Meet-ups and Workshops
- Healthcare Professionals Education Program
  - Seminars, Staff Training, Lunch-and-Learn
- Friends & Family Support

Resources

- Diabulimia Helpline
  - http://www.diabulimiahelpline.org
- We Are Diabetes
  - http://www.wearediabetes.org
- National Eating Disorder Association
  - http://www.nationaleatingdisorders.org
- Susan Weiner Nutrition
  - http://susanweinernutrition.com
- Diabetics With Eating Disorders
  - http://www.dwed.org.uk
- Behavioral Diabetes Institute
  - http://behavioraldiabetes.org
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