Research to Recovery: What We Know & Still Need to Know

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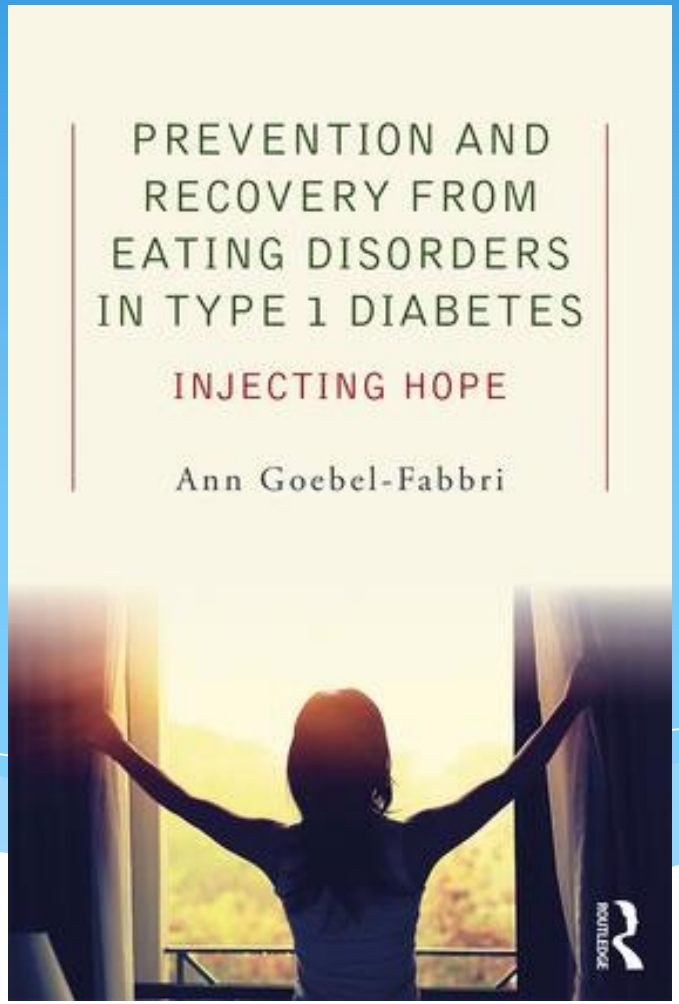
Nothing to disclose.



Overview

- “Diabulimia,” insulin restriction, and eating disorders in type 1 diabetes (T1D)
- Connections between T1D and eating disorders
- Review of the research: prevalence, medical risks, screening
- Treatment recommendations
- Learning from the experts

"Diabulimia" or ED-DMT1

The pros and cons of a name

- Pro:
  - A name indicates that others struggle with it.
  - Decreases shame and isolation.
  - Raises awareness.
  - Creates a way to talk about it.
  - Provides a community.
- Con:
  - *This* name risks conveying that it's exclusively bulimia.
  - Associated solely with insulin restriction.
  - Runs risk of over-simplifying a connection between two complex diseases.

Insulin Restriction

- Why is it a purge symptom?
  - Without or with too little insulin, body can't absorb glucose from blood, can't use or store calories.
  - As blood glucose increases, body attempts to regulate glucose by urinating as much glucose as it can.
  - Cells are starving, break down fat and muscle for energy.
  - Acidic ketone bodies form in blood, pH balance changes.
  - Diabetic ketoacidosis (DKA) is a medical crisis, requiring ICU treatment and can be fatal.

Peters & Laffel (Eds.), 2013. *Type 1 Diabetes Sourcebook*. American Diabetes Assoc/JDRF

Symptoms Associated with Insulin Restriction

* Elevated glucose levels
* Thirst, frequent urination
* Increased hunger
* Physical exhaustion
* Mood changes
* Difficulty concentrating
* Difficulty with memory
* Medical Crisis = DKA
* Nausea, vomiting
* Intense muscle pain
* Rapid breathing
* Delirium or loss of consciousness
* Can be fatal

Anorexia Nervosa and Type 1 Diabetes

- Calorie restriction leading to less than minimally normal body weight.
- Intense fear of weight gain, despite being underweight.
- Disturbance in perception of body weight/shape, or undue influence of weight/shape on self-esteem.
- Co-morbid w. T1D, low BG values and A1c "mask" ED until BMI dangerously low. Insulin underdosing in AN not mentioned in DSM-5. What about Binge/Purge type?

Diagnostic and Statistical Manual of Mental Disorders – 5th Ed. (2013). American Psychiatric Publishing.

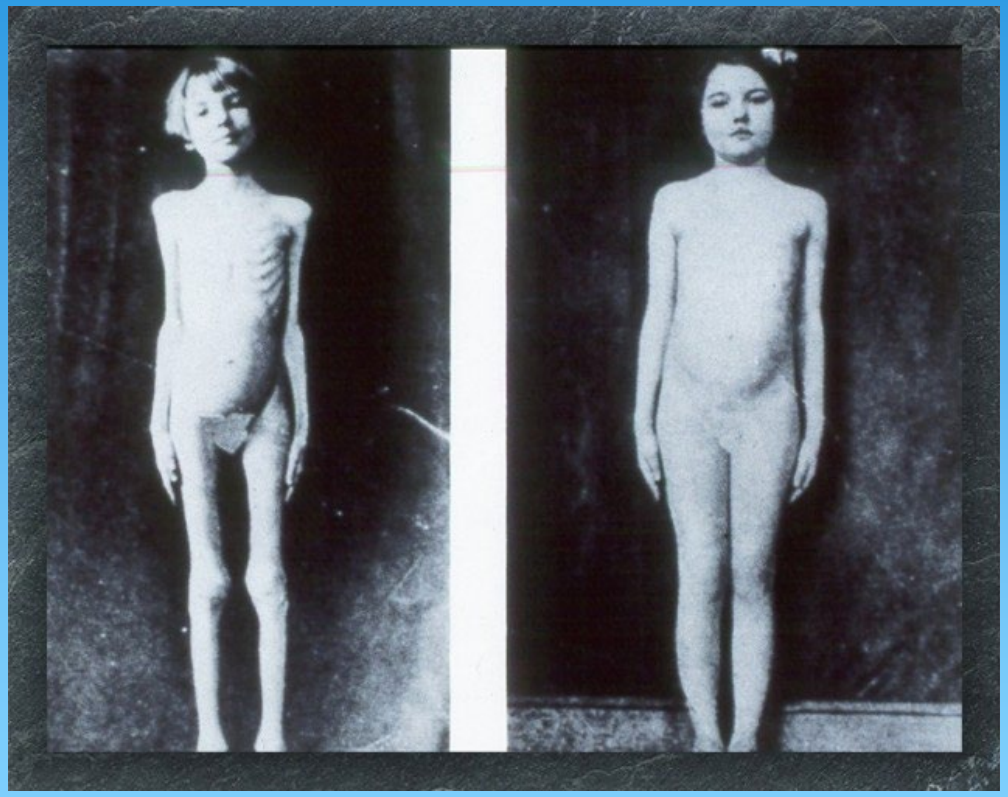
Bulimia Nervosa in Type 1 Diabetes

- Recurrent episodes of binge eating:
  - Larger amount of food than peers would eat under similar circumstances.
  - Sense of loss of control over eating.
- Recurrent purging to prevent weight gain:
  - Self-induced vomiting.
  - Misuse of laxatives, diuretics, enemas, or other medications. LIKE INSULIN
  - Fasting, Excessive exercise.
- Self-esteem unduly influenced by shape and weight.

Other Specified Feeding or Eating Disorder (OSFED)

- All criteria for AN except significant weight loss.
- All criteria for BN except bingeing and purging occurs less than once weekly.
- Recurrent insulin restriction without calorie restriction or bingeing also not mentioned in DSM-5.

Before & After Insulin Treatment (Discovered in 1922)



Weight loss prior to diabetes diagnosis and weight restoration after treatment

Eating Disorders & Type 1 Diabetes – some theorized connections

- Puberty is a dx peak for both T1D and eating disorders.
- T1D presents with initial weight loss. Once BG's regulated, weight is restored. What is learned? "Insulin makes me fat."
- T1D tx involves attention to meal content, portion size, exercise, and weight (can mirror the eating disorder mindset)
  - Old messages: Good and bad foods. Concepts of restriction and cheating.
  - New messages: Carbohydrate counting & all foods fit. Depends on how it's taught.
- DCCT intensive group gained 10.5 lbs more than conventional group.

Goebel-Fabbri et al. (2002). *Treatments in Endocrinology*, 1 (3): 155-162.

T1D disrupts more than insulin production (gratefully adapted from Dawn Lee Akers)

- Loss of hunger cues. Booth DA (2008). Appetite 51:433-441.
- Absence of Amylin decreases satiety and increases gastric emptying. Paspala I, et al. (2012). Cardiovasc Med J 6:147-155.
- Lack of Leptin disrupts appetite. Ahima RS (2008) J Clinical Invest 118:2380-83.
- Reduced Dopamine turnover reduces reward/pleasure. Kleinriddersa A et al. (2015). Proceedings Natl Acad Science 112:3463-68.

Eating Disorders & Type 1 Diabetes

- 2.4 times the risk than women without T1D.

  Jones et al. (2000). British Medical Journal 320:1563-1566.

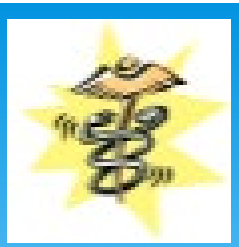
- 31% of 341 female Joslin patients (ages 13-60 years) omitted insulin for weight loss. Polonsky et al. (1994). Diabetes Care 17:1178-1185.

- Strong relationship to microvascular complications of diabetes. Rydall et al. (1997). New England Jrnl of Medicine. 336:1849-1854.

- Insulin restriction conveyed a three-fold increased risk of mortality during 11 yr follow-up. Goebel-Fabbri et al. (2008). Diabetes Care 31:415-419.

- AN 2.5%, T1D 6.5%, Combo 34.8% over 10 yrs. Nielsen et al. (2002). Diabetes Care 25:309-312

The Good News



- Diabetes Control and Complications Trial (DCCT), a multi-center, longitudinal study of type 1 diabetes.

- Demonstrated that treatments aimed at achieving “near normal” blood sugars (A1c </= 7%) reduced the medical risks of diabetes by 60% or more.

The Diabetes Control and Complications Trial Research Group. (1993). New England Jnl of Medicine 329:977-986.

Should screening tools be T1D specific?

* Non-T1D-specific tools may over-estimate disordered eating in T1D due to standard treatment strategies.
  * Ex: 50% of EDE & 6.6% of EDI-3 items could be influenced by T1D.

* To address this, some widely used tools have inserted T1D-related questions (EDE, EDE-Q & YEDE-Q, EDI-3).

Powers et al. (2015). Eating Disorders: The Journal of Treatment and Prevention

D'Emden et al. (2012. Acta Paediatrica 101:973-978.

Diabetes Eating Problem Survey – Revised (DEPS-R)

* Assesses for general eating disorder behaviors and T1D specific ones – including insulin restriction- but not the full range of symptoms.
* Widely used in research by teams around the world.
* 16 items, 6 point Likert scale.
* Clinical concern >/= 20.
* Takes < 10 minutes to complete.

Markowitz et al. (2010). Diabetes Care 33:495-500.

Screen for Early Eating Disorder Signs (SEEDS)

* Concerned that some T1D screening tools could inadvertently teaching the symptom of insulin restriction.
* Asks no T1D-related questions.
* 20 items, 7 point Likert, no questions about T1D.
* Three subscales: Body image, Feelings, Quality of life
* Generates risk scores: Low, Moderate, High

Powers et al. (2015). Eating Disorders: The Journal of Treatment and Prevention

mSCOFF

* Widely used general ED screen world-wide.
* Only 5 questions: realistic for a busy clinical practice.
* 2+ items are a positive screen.
* Modified for T1D by replacing final question.
  * Do you make yourself Sick because you feel uncomfortably full?
  * Do you worry you have lost Control over how much you eat?
  * Have you recently lost > 14 lbs (One stone) in a 3 month period?
  * Do you believe yourself to be Fat when others say you are too thin?
  * Would you say that Food dominates your life? REPLACED with Do you ever take less insulin than you should?

Zuijdwijk et al. (2014). Diabetes Care 37:e26-e27.

Open-ended discussion **No leading questions**

* Have you ever been overweight? (83% sensitive screen) Markowitz et al. (2010). Diabetes Care 33:495-500.
* Do you take less insulin than you should?
* Why do you think you do that?
  * People have many different reasons: burnout, fear of hypos, family conflict/rebellion, poor insurance coverage/financial issues, etc.
* Do you ever take less insulin because you want to change your body size in any way?

Questions:

1) How do we try to prevent eating disorders in T1D?
2) What are the most effective treatments?
3) How do people recover?

Answer:

Little is known so far

What is known about treatment?

- 4 treatment outcome studies - used CBT, were small (N<40), not all had comparison groups, only 1 with FU, 2 outpt, 1 residential, 1 inpt (mean 4 mos).

Takii et al. (2003). Journal of Psychosomatic Research, 55:349-356.
Custal et al. (2014). BMC Psychiatry, 14:140.
Dickens et al. (2015). Eating Disorders, 23(2):134-143.
Colton et al. (2015). European Eating Disorders Review, 23:312-317.

- Lower than expected recovery rates, increased risk of treatment dropout, lower motivation.

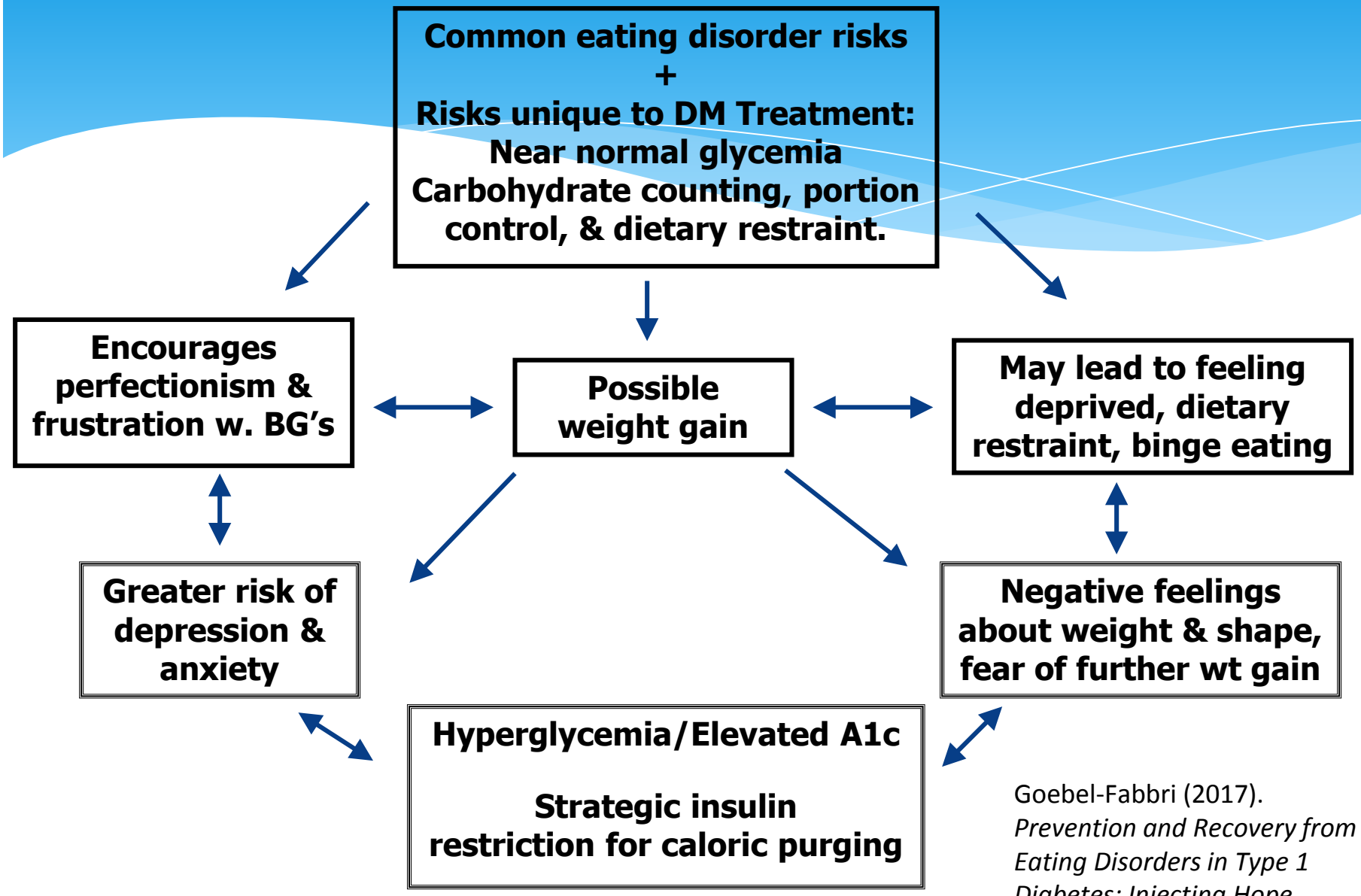
What else is known about treatment?

- Consensus guideline papers:

  1) Screening
  2) Inpatient treatment
  3) Outpatient treatment
  4) Role of diabetes educator

Diabetes Spectrum, 22(3), 2009.

Treatment Targets



Goebel-Fabbri (2017). *Prevention and Recovery from Eating Disorders in Type 1 Diabetes: Injecting Hope*.

Treatment Strategies for ED-DMT1

- Treatment requires a multi-disciplinary team.
  - Weekly therapy if outpatient, or begin with specialty inpatient treatment.
  - MD prescribing psychopharm as needed.
  - Monthly medical, nurse educator, nutrition appts.
  - Regular lab and weight checks.
  - Close communication between team members.

Treatment Strategies for ED-DMT1

- Early detection is critical: Best prognosis comes with shortest duration of eating disorders or at sub-clinical symptom levels.

- First focus on safety
  - Emphasize seriousness of DKA – can be fatal.
  - Teach signs of DKA – to help pts know when to go to ER.
  - Discuss risk of long-term complications, but this is less critical as patients typically know this information.

- For outpt tx, daily basal insulin and DKA prevention must occur *at a minimum* or inpt tx is required.

Treatment Strategies for ED-DMT1

- Address perfectionism directly.
  - (the patient's and your own).
  - Realistic BG goals.
  - Realistic self-care goals.
- Treat co-morbid depression/anxiety.
  - Psychopharmacology and therapy.
  - Medications chosen should be weight neutral.
- Develop FLEXIBLE routine for meals/snacks. Mindful eating with T1D limits.
- Affect regulation skills instead of ED behaviors (DBT) – hyperglycemia can produce affective numbing.

Incremental Goals

- Insulin edema can be decreased w. gradual lowering of A1c. Low dose, limited duration diuretic may also help.
- Gradual lowering of A1c also decreases risk of new or worsening retinopathy and neuropathy (Treatment-induced complications).

Gibbons & Goebel-Fabbri. (2017). Current Diabetes Reports, 17:48.

- Ex: 14% to 12% A1c, 400 BG's to 200 BG's in 1st 1-2 months).
- Gradual decrease in A1c also builds trust, decreases risk of tx drop-out, models realistic/non-perfectionistic goal.

Learning from the experts

- Interviewed 25 recovered women (over age 18)
- Recruited mainly from FB page "Diabulimia Awareness"
- T1D min 1 yr, ED min 1 yr, Recovered min 1 yr
- All received healthcare in the US

Defining Recovery:

1) Consistently taking appropriate insulin
2) Not engaging in rigid dieting or over-exercise
3) Not intentionally running BG's high
4) Eating flexibly most of the time
5) Not acting on ED thoughts or feelings

Topics Discussed

Ideas on Prevention

What Helped and Didn't Help –
from loved ones and healthcare teams

Finding Motivation

Treatment

Challenges/Gifts of Recovery

What You'd Like Others to Know

Ideas on Prevention

Be mindful when "educating" patients

My doctor at the time told me, "…You need to understand that if you don't take insulin, you'll begin to lose weight like this." Am I going to gain weight back, because I go on insulin? … I never had a normal relationship with insulin from the day I was diagnosed." Carrie

Prepare patients and explain weight gain carefully

If someone had said, "Your body has torn itself down, you didn't really lose fat, you lost all your muscle, you're going to gain some weight back, but it's your body repairing." It could have been different if it was presented to me like that. Carrie

Ideas on Prevention

Avoid perfectionism, blame, and judgment

I think a huge thing would actually be to have them explicitly say, "High blood sugars happen, not bad blood sugars … It's going to happen to you no matter what you do" … and also … keep the focus on feeling good, that you're going to feel better when your blood sugars are in a certain range. Caroline

Finding motivation

Robbed of energy

I remember being in the subway in [name of city removed] and going up 2 flights of stairs and thinking, "Oh my god, I can't do this." It was exhausting, just to move my own body around. Caroline

Damaged relationships

My husband was just like, "I'm not raising my child with a person who's like this. All you do is sleep, you eat, and you attempt to go to work ...You already lost school, you'll lose everything to this." And the end of our marriage was when I sought recovery. Because I just couldn't lose anything else. Carrie

Finding motivation

Feeling frozen in time

I was too sick in high school and most of college to even really think about dating … I didn't go away to college or live in a dorm ... I grew up thinking that everyone got married by 25 and had their first baby at 26, just like my mom. I'm almost 30 and those things are far down the road for me, if ever. Madeline

Fear

I could already foresee the future. I was like, "I'm going to be 32 one day ... and I'll want to have kids, but I'm not going to be able to have kids. I'm not going to have legs. I'll be blind because of what I'm doing right now. Anna

Treatment

Team Communication

I think having a comprehensive care team who could talk to each other was really important … Everyone sort of knew what was going on … I couldn't manipulate … Those sorts of things were really helpful. Julia

The Importance of "Diabetes-informed" Treatment

I couldn't get away with anything because they knew absolutely everything … I feel like this eating disorder is particularly isolating, because people don't understand it. Talking with someone who understands exactly what you've gone through is … it was priceless. Julia

Treatment

Non-diabetes-specific Treatments (CBT, DBT, ACT)

DBT and CBT groups were helpful for me especially when trying to deal with my perfectionist tendencies … learning how to deal with those traits in ways that did not lead to me spiraling into these negative behaviors. Tracy

Developing an identity other than that … Who are you outside of this? … Because it [the eating disorder] becomes your identity. Molly

Treatment

Gradual Improvements

They were gradually bringing my blood sugar down over time, so that I would be safe … But as soon as I was left to my own devices, I would keep my blood sugar in the low 100's or under 100 … That was a terrible idea, but I didn't know … Everything hurt … extreme pain and muscle fatigue … I finally go and get healthy, finally, and then my body is rebelling against me for doing the one thing that I hadn't been doing in the past. Abby

Achieving Small Goals

Every single meal if you eat what you're supposed to eat and you give yourself your insulin, that's a mini triumph in itself … and soon the little steps will turn into bigger steps. Megan

Challenges to Recovery

Fear of Feelings

I had no idea how to have feelings anymore … When I did have feelings, I would binge and then get really high and pass out … I didn't know how to feel anxious. I didn't know how to feel sad … I had no tolerance. Rachel

Fear of Fat

The weight gain … feeling like your skin is literally stretching to accommodate the water. I mean it's awful … Sitting in my closet … and nothing fit, closing myself in, and screaming my lungs out ... Every woman who has a weight issue … it's their worst nightmare. Julia

Challenges to Recovery

Finding the Right Treatment

Figuring out what the heck kind of help I needed [was hard] … Because you can't just Google diabulimia [therapists] to help you. There's nothing. Sophia

Nobody understands type 1 diabetes … I tried person after person after person. I went to this big, huge eating disorder center nearby … they didn't know anything about type 1 diabetes, and it just made me feel worse. Janine

Gifts of Recovery

Increased Health and Vigor

You don't know how tired you are until you're not that tired anymore. Abby

It has made me healthier, stronger … I can feel tired at the end of the day, but it's what I call "normal person" tired after a long day at work. Madeline

Friends and Family

I have an amazing family, I have a son … I have friends. I would never have those things. I would never be able to have a healthy pregnancy, ever … I don't even know if I'd be alive if I hadn't recovered. Caroline

Gifts of Recovery

Healthy, Functioning Brains

I was able to go back to college at the university I got suspended from, and graduated magna cum laude. Tracy

Personalities and Interests

I have a giant Scotch collection and 2 dogs. I go hiking on the weekends … I've been taking my time and figuring out what I like to do … It's a completely different process than when you really are firmly convinced you're not going to live past 30. Julia

Gifts of Recovery

Changed Relationship with Food

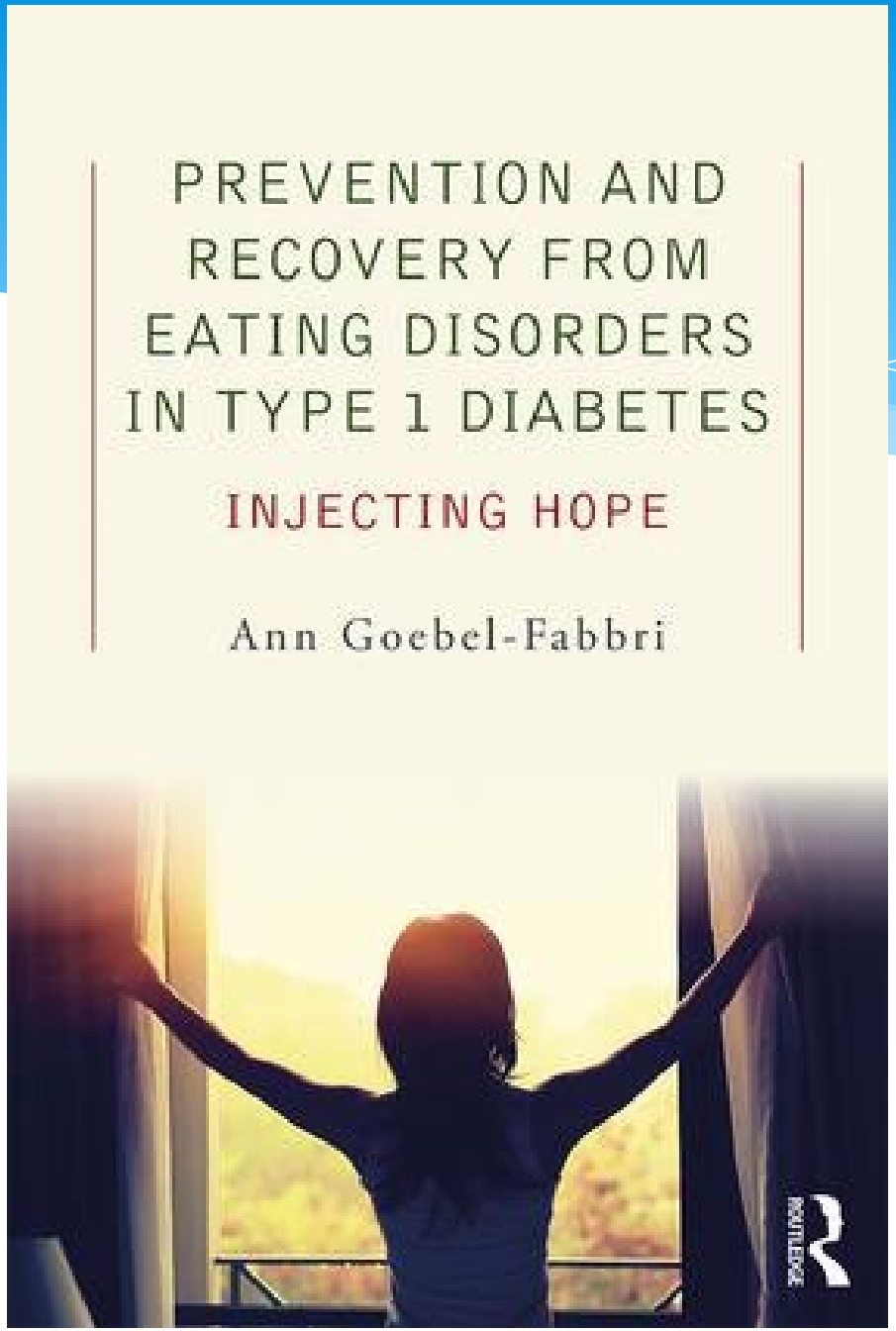
If I've wanted to eat something that's high in carbs, it's not going to ruin my day … I can still have a day and have a bagel. Grace

Changed Relationship with Diabetes

My relationship with diabetes has become much less resentful … I have definitely been more accepting of this as a part of my life and that some days are going to be better than others (blood sugar-wise), and that's okay because it's the nature of the beast. Alex

Injecting Hope

There are people that have gone through this and come out on the other side, and they're not amazing people. They're not shiny, happy people. They're just regular people who never felt like they could do it but did.
Caroline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