

Interview with Dr Ann Goebel – Fabbri: Author of the new book “Prevention and Recovery from Eating Disorders in Type 1 Diabetes – Injecting Hope”

Ann, at DWED we've been long time admirers of your academic work (you were our first rock star!), your research has informed much of our policy and continues to do so, how did you decide to shift into producing something for a more general audience and why now?

I thought about writing something like this for many years but was juggling too many other projects when I was still at Joslin Diabetes Center. I loved doing my research and direct patient care, and I wanted something that would blend the two experiences together. When my own patients recover, they often tell me that what helped was just “getting sick of being sick.”

The idea for the book began with my own curiosity about that statement. How could I take that concept and try to help move my other patients own level of readiness? I wanted to understand on a deeper level. By taking a qualitative research approach - collecting recovered women’s perspectives and finding common themes – helps to create a richer understanding of what puts people at risk initially, what the eating disorder costs them, and what some of the essential elements are that help with recovery. I also wanted to know what they wanted medical teams, mental health professionals, and loved ones to understand.

Most importantly, I knew they would have real-life lessons to share with women who were still caught in the cycle of their eating disorder. I truly believe that the women I interviewed are the real experts.

What do you think about the nomenclature 'Diabulimia'

I have mixed feelings about it. I believe it's very helpful for people to have a name; something to call what they are experiencing. If something has a name, then it must be “a real thing” and influence other people's lives. That can help end the feeling of isolation and perhaps even diminish shame and guilt. It's provided people with a way

to talk about their eating disorder with healthcare teams, loved ones, and others struggling with the same thing. It's created a vehicle for organizations like DWED to raise awareness, lobby for appropriate access to care, offer support, and even more. However, I also see a few problems with the term. It's important to highlight that it is not a formal diagnosis but a name used by laypeople and the media. Because it sounds like 'Bulimia' it can give the misimpression that eating disorders in type 1 diabetes are only characterized by binge eating and insulin restriction for calorie purging. Women with type 1 diabetes have 2.5 times the risk of developing an eating disorder than women without diabetes – this mean any type of eating disorder and not just Bulimia with insulin restriction. It concerns me that healthcare teams may miss eating disorders that could be just as harmful to women with type 1 diabetes but do not involve insulin restriction.

More than any book I've seen on any kind of Eating Disorders you feature patient voices prominently, why do you think that's so important?

The women I interviewed were incredibly generous with their time and the details of their experiences. People really wanted to help raise understanding of this complex problem. Within just the first 3 days of recruiting on Facebook, I already had 15 volunteers! From our conversations, I got the sense that many of them had not had the chance to discuss their experiences in detail – especially with their diabetes treatment teams.

I expected to learn their ideas about what kinds of treatment had been the most effective in helping them regain their health. But, they also had much to say about what they liked and didn't like about how they were treated by healthcare professionals. They shared the good and the bad and ideas about prevention as well. I wanted to share their voices and their own words, because I think hearing it from them has more power to influence change and teach us about best treatment practices. They have that knowledge as insiders.

From your many years of clinical practice as one of the few clinicians specialising in this area - what would be your key advice to other HCPs think about following you into specialisation?

Firstly, learn to 'speak the language' of type 1 diabetes. The patient is already burdened by diabetes and should not have the responsibility to teach this to you. Understand the complexity and sophistication of the disease itself, how a pancreas works, and what the multiple tools are (types of insulin, other medications, pumps, CGM, blood glucose meters) that are currently used to help in managing the disease. Know what low and high glucose feel like and how to identify the symptoms of DKA. Understand why treatment goals are what they are. Be able to identify the various complications and how they are treated.

Second, Develop a team that can help work with you and the patient – physician, therapist, nurse educator, dietician, possibly psychiatrist for medications. All team

members should be willing to learn from each other and should regularly update each other about the patient. Eating disorders in type 1 diabetes should not and cannot be managed alone.

And what about those working more generally in eating disorders or Diabetes?

I think there are several important factors to consider:

You should understand the very early challenges of treatment and educate the patient about them. Be sure to build trust and rapport and to have a consistently nonjudgmental stance. Establish realistic treatment goals that are consistent among all team members. Help the patient anticipate and cope with edema (fluid retention associated with lowering blood glucose). Aim to gradually improve blood glucose ranges – slowly and carefully – to avoid treatment induced complications.

Just as you must know diabetes like an expert, you must be knowledgeable about research-supported treatments for eating disorders. These are not diabetes-specific and will most likely need to be tailored to meet the patients' individual problems with diabetes management.

You must work to moderate your own perfectionism as well as that of your patient. Diabetes management does not and cannot go perfectly. It follows general rules of thumb that may work more often than not (on a good day!).

You have to work at your ability to do this work without becoming alarmist or overly anxious. Patients need reliable responses and stability. Crises certainly happen, but they have to be identified and managed appropriately. This is another critical function of the team – you are not doing it alone.

What is the most profound thing a patient has said to you in regards to recovering from diabulimia?

It's not any one thing in particular that comes to mind. For me, the most moving thing is hearing from people long after our work together has ended and having them update me on their lives. I find it simply remarkable how they rebuild parts of their lives that their eating disorder robbed them of and reach goals they never thought they would reach. I always try to make the point with my patients that the main goal is to create a life that is worth getting better for, and it's very profound when I actually get to hear about the details of that life.

What do you plan to do next?

I'm not really sure. I've had several academic book chapters and a journal article to write recently. It's been pretty hectic. I'm ready to leave writing aside for a bit.

Right now, I'm focused on my practice and trying to get the word out about the book. But, it's time to focus on other things as well. For example, I just got back from skiing with my family for a few days up in VT. I think I'll be focusing on those sorts of things for a while.

Thank you so much for your time Ann!