

WHAT DO  
THE  
PATIENTS  
SAY?

## FOR HEALTH CARE AND RELATED PROFESSIONALS

Most of the Health Care and Related Professionals (HCRPs) I have been lucky enough to come across in my 10 years as director of DWED have been incredibly dedicated to their patients often even in the face of fierce opposition, splitting and outright aggression. This having been said I have made some observations regarding what the attitudinal issues may be regarding the DWED population. Please bear in mind that this is a mass generalisation and not based on any academic evidence, rather what I have seen in not only interacting with those who have Type 1 Eating Disorders (T1EDs) but also the HCRPs who support them.

## WHAT IS THE CRUX OF THE PROBLEM

The issue is twofold:

- Type 1 specialist medical clinicians are being utilised in a psychological capacity. This means one of 2 things; that they are horribly out of their depth and therefore say the wrong thing thus triggering the patient or they are so afraid of that situation that they would rather say nothing and hope that at least the patient will come back. This is incredibly damaging for the patient who either feels misunderstood or uncared for.
- Clinicians working in Mental Health and Eating Disorders do not have even remotely enough knowledge regarding Type 1 Diabetes to effectively treat anyone. They often have little appreciation for exactly how desperate the situation is and are no where near versed in how just having Type 1 has massive implications for ED treatment. This is also incredibly damaging for the patient who often will have very high hopes for any intervention offered. Failure at this stage often leads to total disengagement.

I would like to make it clear at this point that no individual clinician is to blame here, we have all been put in an impossible situation. I also work within the NHS and I know firsthand how frustrating it can be to put in the boundary when someone is so desperate for help as is often the case in the Diabetes clinic or as I like to call it the first line of defense. Similarly, in the EDUs I know that essentially these patients are Zebras, you may come across only a tiny percentage in your entire career, so it may seem a bit much to develop a new protocol for such a rarity. It is essential however that both the EDU and the DClinic have a protocol for these patients, if you don't then take my word for it, they will die.

Diabetics  
with  
Eating  
Disorders

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## THE DIABULIMICS ARE COMING TO A SERVICE NEAR YOU !!!

Diabulimia is becoming more and more known and soon it will have be more formally recognised than it is now. So, we asked some patients questions regarding their T1D and MH/ED teams so you can be better prepared.

### WHAT IS THE QUESTION YOU WISH YOUR DIABETES HCP HAD ASKED YOU WHEN YOU WERE OMITTING INSULIN?

Patient A: Are you omitting insulin? They never noticed

Patient B: Are you omitting? How do you think I can help?

Patient C: How can I help you?

Patient D: This is an area that is new to me but tell me about it, let me learn and help you in the best possible way.

Patient E: What can I do to help you? Explain how are things?

Patient F: ok so you're struggling do you want to be admitted overnight to avoid a relapse

### WHAT WAS THE LEAST HELPFUL THING A DIABETES HCP HAS EVER SAID TO YOU IN CLINIC?

Patient A: Going on about weight or crap control.

Patient B: You just need to comply and you'll be fine.

Patient C: You're clearly just not working hard enough.

Patient D: My DSN literally losing it with me when she discovered I'd been faking my blood sugar readings and hiding what I was doing. Also, when I was told by my consultant as a young teen that I needed to be careful with my weight as I was the 'high end of normal' so i went away and lost a load, then at my next clinic apt was congratulated by him.

Patient E: You are too overweight to have an Eating Disorder.

Patient F: A nurse wanted to weigh me and I did not want to be weighed but she said it was essential so I said ok but I'm standing on it backwards so I can't see the number. She then read it out very loudly in front of 4 other patients. Cue relapse

#### IF YOU HAVE SEEN AN ED HCP WHAT DO YOU WISH THEY'D KNOWN ABOUT T1?

Patient A: I saw many. I wish they understood that our bodies don't work the same as other Eating Disorders. So to deny me water whilst I was dehydrated was cruel.

Patient C: Just how shitty you feel when your sugars are that high - that it is two illnesses you are dealing with.

Patient D: I wish they'd understand that me having to take my insulin and even ask the nurses for it when I was in inpatient and day-patient, was just as much of a struggle as Eating is for say someone with anorexia (which I also had/have.) That just because T1ED isn't widely recognised as 'official' it doesn't mean it simply doesn't exist! & if they need educating then they should do so and should also acknowledge I have more expertise on it that they do, far more.

Patient F: That EDs in T1D are fundamentally different from those in the general population, everything is turned on its head and if you don't deal with T1 treatment is useless

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WHAT WAS THE LEAST HELPFUL THING AN ED HCP HAS EVERY SAID TO YOU?

Patient A: Just take insulin

Patient C: You don't look like someone who has an Eating Disorder

Patient D: Doctor when I was inpatient simply refusing to believe that insulin omission was an Eating Disorder. Was told at my last clinic appointment 'not to start starving myself again' just because I'd gained a tiny bit of weight and hba1c was down - just seeing it as silliness.

Patient F: that if following his plan I put on XX amount of weight (as I predicted) in a week, he'd eat his hat. I went back the next week having put on even more than I'd feared, promptly relapsed after 3 months in recovery, completely disengaged and vowed never to see another ED specialist again.

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WHAT WAS THE MOST HELPFUL THING ANY HCP HAS SAID, AND WHICH HCP SAID IT?

Patient A: Eating is normal, you don't have to hide it. Taking insulin is normal, you don't have to hide that either. I used this the other week whilst eating in a restaurant myself. Something I have always avoided. It was the Eating Disorder nurse. Very helpful

Patient B: it's okay to find it hard sometimes, a children's Diabetes nurse specialist

Patient C: We will just take this one day at a time, a Diabetes nurse

Patient D: My GP actually has always been fantastic, he's patient with me, he listens and makes me feel like a person not just a patient. He doesn't scold me and actually told me that he was proud of how far I'd come since hospital which meant a lot to me as I feel like a failure so much. One DSN also fought for me to get the pump, she said it was discriminatory for me not to be allowed one just because my eating and insulin regime wasn't usual, and that instead of them saying well no you need to be eating and bolusing properly before you can have one they should work with me to improve my control and quality of life while appreciating that the ED won't just go away, but that it can still be beneficial to me and I deserved the chance, and honestly the pump did make a difference although an outsider might still see my situation as a disaster

Patient E: I've not heard anything positive particularly, especially since been struggling.

Patient F: That someone like me doesn't need a perfect hba1c and that aiming for one may do me more harm than good – Diabetes Consultant