**Inpatient treatment for people with type-1- diabetes and eating disorders: what needs to change?**

 Part 2

Here we continue our exploration into the issues found by people being treated at an inpatient level that have type 1 diabetes and eating disorders within eating disorder hospital units throughout the United Kingdom and Ireland (and of course beyond, but at DWED our primary concern is practiced nationally). Discussion points set out in these papers derive from my own personal experiences as well as from hearing the stories and struggles of many of our DWED members. This has uncovered a number of common themes and furthermore, serious risk factors that crop up in relation to eating disorder services being offered to those of us trying to live with and manage T1ED. Part 1, including services that market themselves as having specialist insight and understanding of what t1ED is and how it needs to be approached as a physical and emotionally intertwined illness. The most pressing and commonplace as well as multifaceted complaint stands out, with pertinence to the unfair weight of responsibility and expectations so often being put onto the shoulder of patients by health care professionals. But, there are more to points that need to be raised (and perhaps some degree of ranting to be had!) as well as some recommended do’s and don’ts which may be beneficial for health-care professionals to have awareness of.

In-patient hospitalisation is usually a last resort option offered when urgent stabilisation and supervision is seen as necessary in order to keep a person safe. This is usually a decision made by doctors that may enforce treatment or simply strongly suggest it, or it can be a self-motivated decision. The overall goal of inpatient should be to gain physical stability and in turn mental clarity alongside access to essential psychological and tailored therapeutic support. This should in time give patients the chance to practice self-monitoring, and enable them to be able to find strength and the confidence needed to aim towards a kind of recovery, whatever that may entail for any given individual. All of these guidelines are especially pertinent when these wards are promoted through press and their nursing and doctoral staff alike as adequately skilled in the area T1ED and/or Diabulimia, often going so far as claiming to provide a tailored program that specialises in the treatment of T1ED alongside more ‘typical’ eating disorders, most largely anorexia.

***\*breathes\* And so I return to the agenda. What should the parameters be and what should be expected of these facilities? What is best, acceptable practice? And on the flipside what is negligent and ergo potentially incident reporting practice?***

Scolding any episodes of insulin manipulation or omission with the impression that the patient is ‘acting up’ or being non-compliant

The nursing and physical team looking after someone with T1ED should be compassionate and patient in trying to help them. This means that they must be able to see T1ED as a legitimate eating disorder just like anorexia for example, despite the fact that it is yet to become an official diagnostic term. In order to ensure they provide the right support they need to be able to see insulin omission behaviours and the fear of insulin to be just as legitimate and real as the fear someone with solely anorexia may have of eating. This centres around the understanding of capacity and in turn being mindful of how someone with T1ED and/or ‘Diabulimia’ may have a resentment to increased insulin doses and may even try to restrict or misuse their insulin. Such behaviours don’t mean that they are just playing up and not complying with the rules of treatment, but rather that they are struggling with an entire inner monologue that we cannot hear, just like any other person that has an eating disorder without diabetes. Rather than being told off or patronising; staff should listen and try to support the patient.

Taking complete control of the administration of insulin and regular blood sugar testing during a patients entire admission from the start to the week or even last day of discharge

This should always be gradual and routinely reviewed with thorough care planning and discussions with the patient concerned, otherwise they are at risk of falling back into old unhealthy habits quickly as they have not have any experience with taking control of their type 1 diabetes on their own and without being ‘reassured’ or given permission to take insulin or test bloods regularly. It is paramount that towards the end of an admission a patient with T1ED be given that control back in stages so that they are prepared for discharge and not at risk of a relapse that may require another hospital admission. It is my belief, from what I have seen and know of through hearing the experiences of other people, that eating disorder units can overlook the importance of such a process. This will again be down to lack of training and confidence treating a patient with diabetes in the first place, while also being unfamiliar with just what that transition should look like.

Unhelpful and insensitive comments from staff that are ignorant about T1ED and type 1 diabetes

Again, this is about being aware of what exactly T1ED or Diabulimia is and doing the best to gain further knowledge about it, as well as the dynamics of type 1 diabetes itself. T1ED must be seen just as much of a legitimate eating disorder and just as in need of treatment as the widely known diagnostically labelled ones. Staff should be very careful with their choice of words and know the basics; the difference between type 1 and 2, the psychological impact of living with type 1 diabetes and the reasons as to how it so often can leave someone vulnerable to developing an eating disorder. This one ultimately comes down to respectfulness. Over the past year there has been much talk within the diabetic online community of how ‘language matters’ when a health professional talks to someone with type 1 diabetes. There has been a lot of advocacy and awareness raised to stress the need for health providers to be careful with their choice of words, in particular how certain terms should be avoided during conversations with the patient. Plenty of information about this is available online.

A generally conceived attitude that the severity of a patients eating disorder is primarily determined by their weight

Beliefs that a person needs to be at a certain dangerous BMI level to be in need of urgent care is something that is too often held within the treatment of eating disorders in general. This is of particular importance due to the way in which the practice of insulin omission or restriction in itself can be hugely damaging and potentially lethal regardless of what weight you are. People struggling with ‘Diabulimia’ as just a stand alone eating disorder are often of normal weight or even overweight but Diabulimia can kill you within hours and so someone with anorexia at a low but stable and maintained weight may be much more safe than a person with Diabulimia that has not taken their insulin for a sustained period. The fluid loss from a body that is starved of insulin is dramatic. However, the result by way of a state called ketoacidosis is either death or treatment, and so at some point the administration of some insulin is crucial in order for a person to stay alive. This can then cause water retention, meaning someone may be in a state of limbo as they crash down and rise up in weight on a frequent basis, yet they may well still remain above what is deemed a healthy weight. Eating disorder units need to be clued up on this and know that someone with T1ED may not need any kind of ‘refeeding’ diet plan, as providing a standard menu which is focused on weight restoration can be hugely distressing for someone with Diabulimia that is already dealing with the rehydration process as they tolerate the first stage of following an insulin regime that may cause a peak in weight that will surely settle after some time.

Insight on how physically harmful T1ED can be…

…as well as even just type 1 diabetes on it’s own. This means that nurses and doctors providing care to a person with T1ED may need to make certain allowances. For example, they should permit a patient to attend essential medical appointments and make sure they are also following the ‘15 care essentials’ suggested by Diabetes UK for anyone with type 1 diabetes. Sadly a number of health concerns will often develop in the long term from manipulating blood sugars including loss of vision, nerve damage, kidney disease and problems with digestion of (gastroparesis).

Can you think of anything I’ve missed? Please do let me know by commenting on this story, we always want to hear your views! I really do hope reading this may be of help to people, even just one bank nurse staff member or patient desperately needing recognition from their treatment team would be worth the efforts of typing with very impaired vision!