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

Part 1

*I’m waiting on a bed for an inpatient facility and not yet sure where I might end up. I feel confident in that my current treatment team will place me somewhere with adequate insight and training into type 1 diabetes when intertwined with an eating disorder. I’ve never felt this way before and I’ve been previously hospitalised in eating disorder unit on 3 occasions, the first in an adolescent ward at 16 and the last around 5 years ago. Each of those 3 admissions were shambles in terms of sufficient management of and care for diabetes. My most recent experience was so awful that I still feel traumatised by the memories I have of it. That hospital’s failings led to my diabetic nurse acting as a whistle-blower and issuing a complaint which led to me being safe-guarded as a vulnerable adult. The following are just a snapshot insight into a catalogue of errors that occurred:*

* *Firstly, I was told pre-admission that the staff would be sufficiently able to deal with my diabetes control while I was on the ward. Yet on the day I arrived they seemed dumbfounded when I brought up my diabetes, and completely panicked. They then did not have any insulin or needles on the ward and were later shocked to find my sugar levels were off the scale.*
* *Proceeding my admission date came a bank holiday weekend. I was automatically placed on a tube feed on arrival despite being adamant that I was willing to eat. I sense this was because my consultant didn’t want to deal with the hassle of figuring out my insulin requirements to fit the meals and snacks, while so eager to enjoy his time off. Nurses proceeded to follow his instructions which were to give a long acting dose of insulin each day and yet nothing else -no short acting whatsoever to remedy the tube feed boluses which were high in carbohydrates and sugar.*

*I pleaded with the nursing staff to deviate from what the doctor had told them to do (incredibly difficult for me to of o which I shall go into later) and instead at on my worsening physical state but they refused to listen. As a result, I ended up in ketoacidosis and had to be rushed to the nearby accident and emergency.*

* *Denial of the importance of allowing me access to extra hydration when my blood sugars were running high. The ward protocol was to restrict the amount of water given to patients as extra fluid could be used to manipulate the scales during the twice weekly weigh-ins. I explained that if I had high blood sugars than the water would not be retained and instead ped straight out but there was no comprehension of this. On numerous occasions I was desperately dehydrated and in need of hydration. On one occasion my mum went to the bathroom tap to get me a drink as I was so parched and in distress.*
* *Shocking protocol for treating hypos. They’d only give me Lucozade if I went below a magic set number even if I was clearly display signs of hypoglycaemia. At other times they would forget they needed to give me some Lucozade and I’d be left in a prolonged hypoglycaemia state, I remember laying on the bed wanting the world to swallow me up because everything felt so out of control a nobody was taking any notice. They also would expect me to go into meals during a hypo and eat after giving me my set insulin, so I had to struggle through shaking and in tears. See why I said I was traumatised? I still have nightmares about it. It is so horrible to feel unsafe in a place that’s supposed to be taking care of you.*

*I have never expected any of the units I’ve stayed in to be completely clued up on type 1 diabetes, especially not years back when T1ED and the practice of insulin omission were pretty much unheard of. But I have needed them to try and meet me halfway, to learn, to educate themselves, and listen to me as a way to understand as much as possible. That’s never been the case, I’ve just been treated as an someone with anorexia (which yes, I do have) that simply has a side diagnosis of type 1 diabetes that creates further problems. Never has my diabetes and eating disorder been regarded as one issue that needs to be tackled as such. I’ve been told T1ED doesn’t exist by consultants and been lectured when I’ve tried to provide knowledge because of course the professionals always know best, even when they really don’t*

*From my own experiences and also from speaking with DWED members I have picked up common failings that often occur within specialist eating disorder inpatient units. The following are the main ones. (If there’s any health professionals reading this then please do take note):*

**Responsibility being put onto the patient**

I’ve put this first one in bold as to me, it has been the biggest struggle I have faced during my hospital stays and underlines points that are to follow. It’s a widespread issue that spills over many aspects of the treatment process and very much relates to the approach and attitude of nurses and doctors within those services.

I’ve had to grapple with the concept of nurses regularly forgetting my insulin and blood tests. The sneaky thoughts that I should take the chance to omit insulin was my eating disorder trying to find a way in, and I should not have to deal with that choice], Such oversights became such a frequent occurrence that I almost became passive and couldn’t even be bothered to keep prompting them. *If they didn’t care about my heath then why should I?*

They were out of their depth, and they never could quite understand how hard it was for me to speak up, to use my voice. Yet they’d be horrified if they accidentally forgot to order the lunches in, because of course inpatient facilities mostly treat anorexia nervosa, and so Thais what they are most familiar with. The concept of how taking insulin could feel terrifying for a type one diabetic also having to deal with eating in that kind of situation just never really got through to the staff, no matter how many times and how hard I tried to tell them.

This should never happen. It shouldn’t have happened to me and I dread the thought of others going through the same - but I know my story is not a unique one. The fact is that if it has been necessary for a person with T1ED and/or diabulimia to be admitted to hospital typically indicates that they have been deemed unable to care for themselves without risk and so the period after admission the period after admission need to be focused on rest and coming to terms with their surroundings,, Additionally and crucially management of their medical needs should be taken to of their hands While trying to accept insulin and food when it is given, the patient should not also have to contemplate extra guilt and shame for actually having to assert themselves.

All of the above examples display the same urgent need for sufficiently trained staff members that have expertise in diabetes when treating a patient with T1ED on an eating disorder ward. This means they can feel confident in undertaking medical care, and be able to display this to the patient who can have confidence in them and be made to feel at ease and safe in their care. It is also just as important for them to be able to truly understand that it can be a very emotionally charged disease as well as a physically exhausting one.

Inaccurate diagnosis

Treating someone with T1ED as having anorexia or bulimia with just an added ‘complication’ of diabetes is simply unacceptable and can be hugely damaging. This especially in scenarios whereby insulin omission is the sole disordered behaviour. If the patient does not frequently engage in purging via any method aside from withholding insulin, and they are not restricting their food then they do not have anorexia or bulimia.

Nonetheless, I can count more than the fingers on both hands for the number of people I have met through DWED that have had the label anorexia or bulimia nervosa recorded in their notes. This means they then get treated under the guidelines suggested for people that have aa more ‘typical’ eating disorder and they may be fearful of deviating from what they know The effort needs to be made to understand and truly accept that T1ED and insulin omission, deemed under whatever terminology, is a seriously dangerous illness that needs to be acknowledged. The fact that it is not listed in the DSM under its own category is a part of this and should be addressed. But in the meantime, the health professionals need to stop going by what they read in manuals and outdated treatment frameworks, and instead listen, educate themselves on what they do not know.

Not accepting expertise of the patient – ‘I am a doctor and I know best.’

As an extension to the above, I know that a clinician can often have trouble accepting their own failings when they are not dealing with something, they are an expert on. This means they can try to ignore what the patient is telling them and trying to educate them about. Instead they may believe that because they have lots of post-graduate qualifications from medical schools that they know best and that any knowledge passed on to them from the patient should not be trusted because they are mentally unstable and perhaps manipulative I have seen first-hand, with witnesses that could prove it was not in my head, that this unease can be a front for a doctor that is majorly out of their depth and attempting to treat a condition they do not have the knowledge or skills to approach.

Serious incidents of malpractice and negligence

Staff forgetting insulin administration and not monitoring the patient as they need to can easily cause medical emergencies. This can also be caused by expected changes in the meal plan whereby insulin needs to be adjusted but staff refuse to do so. – for example, If the kitchen Is out of bananas for snack so provide a pear instead, or the portion size of a sugary dessert is larger or smaller than usual This can typically lead to uneasy with changing a prescribed die as set by the doctor, or even a diabetic specialist working with the team. Even after nurses have been told that a meal plan can only be a framework when diabetes is involved, they understandably can feel they should not change something if they are not completely sure that it needs to be. Yet as a result of this the person with T1ED may then experience episodes of hypo and hyperglycaemia, which again the staff do not grasp the urgency of acting quickly and providing appropriate treatment. Leaving a type 1 diabetic in prolonged hypoglycaemic state can be distressful for them and even lead to a prolonged feeling of trauma.

Not being able to trust one relies on the people that are caring for you can quite naturally lead to a sense of bitterness and resentment from the patient towards the hospital staffing team. This can undoubtedly ruin the belief that recovery may be possible that they may be desperately trying to hold on to. The patient sees again and again a belief that they are ‘untreatable’ as they have complex needs. No, it is not the person with T1ED that is complex, it is the health professional that is not doing their job properly. T1ED is treatable just like anorexia or bulimia is, people do improve and get better and everyone deserves the chance to try to do that with the right support in place.

*With several points still to go through and not wishing to overwhelm blog readers I am going to make this blog part one of two. The second part will be posted here shortly.*

So, to be continued…