

“Why Wait?”

Beat, the UK’s eating disorder charity which calls itself “a champion, guide and friend to anyone affected by eating disorders,” set the subject to be highlighted during this year’s Eating Disorder Awareness Week (EDAW) as “Why wait?” This related to the wait that someone with an eating disorder will endure from the start of their illness to the time of which they pursue treatment and recovery. It also served to underline the problem of waiting lists for sufficient eating disorder treatment. For our latest members content resources we decided to explore this subject in relation to people with ED-DMT1/T1ED and/or Diabulimia. We spoke to a number of individuals with their own stories which revealed many common themes.

The EDAW focus topic followed a report released by Beat in November 2017 titled “Delaying For Years, Denied For Months.” This report raised some extremely valid points of concern, all of which apply to those with eating disorders alongside type 1 diabetes. The following are guidelines it recommends in conclusion of findings from a series of surveys and widespread investigations.

- *Specialist treatment must be available for all, with particular focus given to ensuring adults are not treated in general mental health services, since these do not have the expertise to treat eating disorders.*

- *It is vital that medical professionals are familiar with, and follow, the NICE guideline on eating disorders. We particularly highlight its guidance that single measures such as BMI or duration of illness should not be used to determine whether to offer treatment.*

- *All children and adolescents with eating disorders should be offered intensive community care when appropriate, and research should be commissioned to investigate the effectiveness of intensive community care in adults, moving to rapid implementation if warranted by the evidence.* •

All funding for eating disorder treatment (including inpatient) should be held locally by the same budget holder to create incentives to develop improved community treatment and reduce costly inpatient care.

- *All patients should receive written information about their assessment and care plan, and be directed to other sources of support available.” Pg. 14.*

But what about us?

What about when the waiting lists don’t even exist?

When there is no clinical pathway, diagnostic criteria or waiting lists to be added to?

We spoke to people with T1ED about their experiences of making the decision to undertake treatment and their struggles to obtain appropriate NHS services. This is what we learnt:

- The fact that there's no official diagnostic criterion for T1ED has caused them to be overlooked by health professionals. They were often regarded as not having a problem and just being non-compliant.
- In turn this fed in to eating disordered thoughts such as 'I am not sick', 'I don't need or deserve help' etc and put them off pursuing treatment.
- There is little information available on T1ED and so it can be easy to feel like they are the only ones with this problem. This can mean you keep it to yourself for longer. There is nowhere to go for advice or any resources that make you feel understood (apart from DWED!)
- Many said they were often diagnosed incorrectly with anorexia or bulimia. Their diabetes was seen as separate and just an added issue they had to deal with.
- Negative and negligent inpatient admissions are common and as a result of inadequate training and lack of T1ED awareness.

Beat's report stated that "Anorexia nervosa has the highest mortality rate of any mental illness severe long-term physical health consequences sufferers can be left with." This may be true, but only because ED-DMT1 or T1ED is not officially recognised as an eating disorder. We believe the mortality rate of people with T1ED to be higher. This could be lessened significantly with timely treatment for the condition and its complications. Referrals need to be made by GP's in line with NICE guidelines that state the urgency of T1ED cases. WE NEED IT TO HAVE A NAME!