DIABETES
All Party Parliamentary Group

# Meeting

## Diabulimia

Wednesday, 16th October 2019

Houses of Parliament

5:15 – 7pm

Diabetes is not just a physical condition. It can have an emotional impact too, and can affect the psychological wellbeing of those who live with it. 7 in 10 people living with diabetes who spoke to Diabetes UK have said they have felt overwhelmed by the demands of the condition. Of these, three quarters said it affects how they manage their diabetes, putting them at risk of complications.

Changing the way we support people with diabetes can help prevent mental health problems, improve diabetes self-management and help people feel better.

Diabulimia is a type of disordered eating behaviour in which a person with diabetes reduce or omit insulin in order to lose weight. Diabulimia is dangerous. By making blood sugars high for long periods of time people are at risk of life-threatening complications. Overall, two in five people with Type 1 diabetes and one in four people with Type 2 diabetes have experienced some type of disordered eating behaviour.

Early intervention and referral is crucial. However, standard treatments for eating disorders are underequipped to care for people with diabulimia. Treatment for diabulimia is complex and will require a comprehensive understanding of diabetes, but the integrated physical and mental health support that people with diabulimia need is not yet available across the country.

- We need diabetes services to be supported by specialist mental health professionals. What are NHS England's plans to scale-up the diabulimia pilots in London and the South Coast and ensure access to diabulimia services across England?
- We need mental health professionals caring for people affected by diabetes to have knowledge of condition. How can IAPT services ensure IAPT practitioners working with people affected by diabetes understand diabetes and diabulimia? How can Commissioners ensure Community Mental Health teams have training to understand diabetes and diabulimia?

The meeting was introduced by **The Rt Hon Keith Vaz MP**, Chair of the APPG for Diabetes, and chaired by **The Rt Hon George Howarth MP**, Officer for the APPG for Diabetes. **Liz McInnes MP** was also in attendance.

**George Howarth MP** stated by welcoming everyone to the House of Commons. He highlighted how important was to discuss a topic so close to his heart. He thanked and introduced the distinguished panel of speakers and highlighted some of their work for the past decade. "It might seem like a long time to make any progress, but we're making progress."

### Prof Jonathan Valabhji, National Clinical Director for Obesity and Diabetes at NHS England

Professor Jonathan Valabhji defined diabulimia as a condition in a person with Type 1 diabetes characterised by insulin omission (to varying degrees), due to a fear that insulin will cause weight gain.

He explained that having undertaken his original research in Type 1 diabetes in the 1990s, he has run a Type 1 diabetes clinic once weekly for the most part since then. He explained that many specialist that run Type 1 diabetes clinics will have a small number of patients with severe manifestations of diabulimia, and that there are real worries that harm will come to these people due to insulin omission – both harm related to the long term complications of diabetes, and harm in terms of realising the higher mortality associated with this condition. More recently it has become appreciated that insulin omission related to fear of weight gain to some extent, is much more common – estimated in up to 40% of women and 10% of men with Type 1 diabetes between the ages of 15 and 30. It is appreciated that other age groups are affected as well.

While multidisciplinary team working has been long established in the field of diabetes – over many years he has run for example clinics with his vascular surgeons to effectively treat diabetic foot disease, and clinics with his paediatricians to treat young people transitioning from paediatric to adult services – it has proved much more difficult to establish multidisciplinary team working with colleagues delivering mental health care. This has been partly attributable nationally to the geographical separation of mental health and physical health care Trusts, but also in the years prior to 2013, due to the lack of parity of esteem between mental and physical health care.

The London Clinical Network (and what was the London NHS England Strategic Clinical Network), under the leadership of Paul Trevatt and Stephen Thomas, have put emphasis on diabulimia since around 2013, and in 2014/15 organised a workshop/symposium on diabulimia, one of the first of its kind, at which three members of today's panel gave keynote speeches – Dr Jacqueline Allen, Sir George Howarth, and Professor Valabhji himself.

Since publication of the NHS England strategy document in 2014, The Five Year Forward View, and through the more recent publication in January this year of the NHS Long Term Plan, there has been a significantly greater focus on diabetes – both on the treatment and care of all forms of diabetes, and on the prevention of Type 2 diabetes. In this context, a case was successfully made for investment in two diabulimia pilots, with an aim, in the absence of good published evidence of what works, to demonstrate which interventions might carry benefit. One of the pilot sites is Kings College Hospital, which will be focussing on those at the severe end of the spectrum of diabulimia. The other pilot is on the South Coast, centred at the Royal Bournemouth Hospital, Wessex, and will focus on the greater number of people with milder, perhaps subclinical, forms. A formal evaluation has also been commissioned of both pilot, in order that clinical effectiveness of the interventions can be assessed, so that if successful, a case can be made for scaling up and rolling out across other areas.

### Prof Khalida Ismail, King's College London

Prof Ismail started her speech by dedicating it in memory of Meghan Davidson, whose parents were in attendance. She read what Meghan wrote before she passed away, as a consequence of her diabulimia.

Prof Ismail continued by explained the work of King's College London Diabulimia clinic. You can read it in full here.

### Emma Curran, Patient Voice

Hi everyone. My name is Emma and I have Type 1 Diabetes. I was diagnosed 23 years ago when I was 11. In April 2013 I began missing injections, something which is known as Diabulimia today. I wrote something when I began my recovery in September 2014, which I would like to read to you.

“I came out of hospital 5 weeks ago yesterday. I went into hospital because i had been skipping injections for almost a year and i no longer felt like i was in my own body. I had just come back from a weeks holiday in Croatia. I had no energy whilst i was away, I couldn’t even walk for 5 minutes without drinking 5 coffees. My hair was falling out at such a rate that the plugholes would fill up with hair after a shower (I also lost most of my eyebrows/eyelashes/leg hair). My legs had become numb, almost hollow and my feet would swell up so much i could barely fit my fit into my shoes. I couldn’t concentrate at work (my work colleagues had no idea what was going on) and I felt so stupid when I couldn’t remember what i was doing or what someone had asked me to do as my mind was so foggy and the song “I can see clearly now” was on a loop in my head. In hospital the doctors asked if I had taken an overdose of battery acid as my body was so acidic. I had cut out all of my friends as it seemed easier to do this as then i didn’t have to face up to what i was doing to my body. My mind was taken over by food. “What was i going to eat next? how was i going to cope if i put on a bit of weight? I could see all of my friends moving on around me and i felt trapped. I guess the reason I went into hospital was because I had forgotten what it was like to live”

Since writing that 5 years ago I have been on Radio 4 to raise awareness about Diabulimia and the lack of psychological support for people living with long term health conditions.  I have gone on to have a baby, who is now 2. I worked for Diabetes UK for 4.5 years. I am back at college doing a higher education access course in combined science so I can go back to university to study Nutrition and Dietetics. These are all things I thought would never be possible. I am still suffering (although I don’t like to use that word) from the effects of the damage I did to my body, I had a major eye operation last Friday to try to save the sight in my right eye and my hair is mostly extensions as it never really grew back properly.

I have been questioning over the last few weeks, where was my support from Health Care professionals? I went to the doctors numerous times when I was in the midst of diabulimia. I told them of my hair loss, my numb legs. I had a ketone test done at a GP surgery and I had a level of 6 ketones in my blood only to be sent me away with hair loss cream. I saw my diabetic nurse when my HBA1C was 14, only to be told I looked really depressed and asked if I would like some antidepressants? I never ordered any test strips as I never tested. How is it that people are still questioned by doctors for ordering too many test strips (which is something that I compare to oxygen now), but never questioned for NOT ordering any? I tried to access local psychological services when I came out of hospital but the ITALK service in my area at the time were so baffled by the fact I had a complex issue (not injecting and also over eating) that they told me they would try and find someone to help me, but never called me back. I remember clearly I was not offered an appointment with a psychologist upon leaving hospital, instead I was made to feel like I was a burden on the NHS, and forever made to feel like I had always felt in my diabetic appointments, a feeling of shame. Shame because I wasn’t doing a good enough job. There were exceptions and I did manage to have a diabetic nurse who was lovely when I left the hospital. She called me every day for two weeks when I left but when I moved to a different borough in London I had to start all over again and move to a different hospital (the travel time was 2 hours from where I was based).

But on reflection, what really saved me was working for Diabetes UK for 4.5 years  and having access and knowledge about services. Receiving peer support, as I was working with and surrounded by other people working for Diabetes UK. My favourite job that I did in those 5 years was in events as I worked with children, young people and families with Type 1. I was able to talk about what did and didn’t work for others. I gained so much confidence, that I was and still am able to have proper conversations with my health care professionals about what I need and what I want when it comes to managing my diabetes. If all Health Care professionals were just able to signpost Type 1 patients to the Diabetes UK helpline then that would be a massive step in the right direction. It is really unfortunate that there are huge waiting lists for psychological services when help is often needed immediately.

**Jacqueline Allen, Diabetics with Eating Disorders (DWED)**

I am Doctor Jacqueline Anne Allan and I am a type 1 Diabetic. 10 years ago I set up a charity to deal with the issue of Type 1 Diabetes Related Eating Disorders (T1ED) and/ or Diabulimia called DWED or Diabetics with Eating Disorders and since then I have been a patient advocate, completed a PhD in the subject and commenced clinical psychology training

Firstly I would like to thank the following people without whom I would not be here to explain why despite recent innovations, T1ED is still woefully under researched, under treated, under recognised and misunderstood

DWED as a charity would have been unable to function without the generosity of Stuart Wright our accountant, John Allan my father and Claire Kearns my right hand woman. Also the endorsement of our trustees has opened many doors so I would also like  to thank them and the countless number of volunteers that have given up their time and energy to promote our agenda. Furthermore I would like congratulate Sir George Howarth, on his recent Knighthood, and to thank him for always giving a small charity a big voice.

As I said there have been recent advancements in the Field of Type 1 Related Eating Disorders; updated NICE guidelines, new research projects and Media events have all helped consolidate DWEDs vision. And it’s a simple one, whereby a patient suffering with Diabulimia/ T1ED can be diagnosed with an illness they actually have, treated in a timely fashion, with specialised treatment and perhaps most importantly with the respect and dignity that they deserve.

When the charity started this seemed like an impossibly optimistic dream, it was 2008 and one of my friends had just died on an inpatient eating disorder ward, surrounded by doctors who didn’t know what they were looking at. I was angry and I couldn’t bear to witness one more senseless death without knowing that I was at least trying to do something about it.  At first it was a real fight, trying to explain that this wasn’t AN or BN or Binge Eating but actually a mental illness within its own right, with Type 1 Diabetes specific etiological factors, accompanied by very specific and more frustratingly obvious behaviours which in any other circumstance would have proved a differential diagnoses.

We were dying and I had to convince HCPs that this was not something that was ‘made up on the internet’, we were dying and I had to convince HCPs to focus on fear of insulin instead of food, we were dying and I had to convince HCPs that the extolled measurement of bmi was pretty much irrelevant to us. We were dying and I had to convince the NHS and many other bodies that should have known better, that this was a crisis, no a scandal.

And so we clawed our way to where we are now, but many had to die for this issue to be taken seriously. They were causalities in a war against ignorance, and it is my deepest regret that among them were DWED volunteers who unfortunately will not be able to benefit from the very changes that they fought for.

So of course I welcome, the recognition of NHS England in the form of funded pilot projects. Although I’m not entirely familiar with the team at Bournemouth, I couldn’t think of another service which will squeeze every penny out of the funding better than Kings. That is mostly due to the dedication of the staff who have gone above and beyond to provide a service that is illness specific. Thank you, as with any service, nothing is perfect, but the fact you even exist is validating and hopeful for so many sufferers.

But squeeze every penny they will need to.

I had a client who within one year was admitted to A & E 90 times, was sectioned and detained on an inpatient mental health ward and the sent to a ‘specialist’ private treatment center that claimed, I would argue, falsely, that they had expertise dealing with this issue at a charge (to the NHS) of nearly £1000 per day. They did not. She was turfed out and left to fend for herself after less than a week. This is not an uncommon occurrence. We estimated this specific patients costs to the NHS over 12 months as being around £250K.

One Patient, One year and that was without retinopathy or nephropathy or any of the myriad of expensive complications that usually blight us.

And yet the pilot got less than 300K in running costs

Or 2 patients being paid for by the NHS for less than 6 months in private beds being treated for an illness that they don't have leading to inevitable relapse and a waste of everyone's time and the NHS's money.It's not nearly enough and it is absolutely not reflective of the catastrophic cost of this illness. Yes to me it's personal, it's my dead friends and the reason I have got out of bed every morning for the last decade, but also it just doesn't make any kind of financial sense. We all know how much trouble the NHS is in so why are we allowing this to continue. As a trainee clinical psychologist this is boggling me, trust me when you're paying nearly a grand a day for 1 patient to be treated, we are CHEAP, 10 of us are cheap. 100 of us are cheap. In this situation, even specialist psychiatrists are cheap.

And there are some easy wins here, please let me outline what I think the main 3 are

- Define a new taxonomy for Eating Disorders in Type 1 Diabetes that reflect diabetes specific aetiology and diabetes specific behaviours such as insulin omission and separate them from standard eating disorders. We don't know what the death rate is, we don't even know what the true prevalence is because the instruments that are used were not created with us in mind. And as much as there is debate currently surrounding the stigma attached to diagnoses, try moving through the world without one, you can't treat what you can't diagnose. At this stage I don't care what we call it but it is not AN, BN or Binge Eating Disorder.
- Specialist services must be supported and by supported I mean funded, we are literally dying on waiting lists.
- Research which heavily includes service users must be prioritised. The reasons that there are so many misconceptions about us is that we were excluded from research about.

## Discussion

**Julia Tyson** raised the issue of healthcare professionals not knowing if a patient has diabulimia. "The patient itself might not know. I took several years to realise I had diabulimia". She suggested more action towards educating healthcare professionals. **Jonathan Valabhji** highlighted how challenging it can be to educate healthcare professionals. "We have advanced within the diabetes clinic, but we're ensure if it has reached generalists yet. It needs to be more bottom up."

**Lesley Davidson** shared the story of her daughter, who passed away recently as a consequence of diabulimia. "There is a lot of money to treat DKA, but it's not worth it. All they are doing is sending people away to see them right back in. Just because you don't monitor what you're doing wrong, it doesn't mean you're not spending money on it". She shared how her daughter's blood levels were never in range, about the appointments she missed, the specialists she was referred to and the insulin that was wasted. "How can the NHS not afford to put these clinics in place? They are spending so much money just sending these people around with no help". **George Howarth MP** thanked Lesley's strength to share this message. "This is about better coordination and use of resources. The NHS doesn't look at the cost of not doing something". **Jonathan Valabhji** thanked Lesley for sharing her powerful experience and spoke about the need to build evidence on how we can successfully help people with diabulimia. "If we can prove it, then we add the piece of the jigsaw that we need to make the case for funding."

**Neil Davidson** complemented Lesley's argument of cost and highlighted the need of a more integrated physical and mental health service for people with diabetes. "Living with diabetes is hard enough. Adding to that an eating disorder, all pressures of young life, and then asking them to attend multiple appointments at different locations – it's unrealistic. It's too hard to navigate the system, and they vary from county to county. There should be a clear pathway to implement those services". **Prof Khalida Ismail** agreed with the points raised and highlighted the need for solutions at policy level. "It's about bringing a psychologist to the diabetes team. The work we're doing it's not that hard, nor expensive. So what can policy teams and politicians do?"

**George Howarth MP** shared his insight on the political scenario involving diabetes and diabulimia. He explained how it would be helpful to have health ministers for longer than one year, and how there is little knowledge of these topics outside the APPG. “I actually thought we were going to make more progress by having Theresa May MP as a Prime Minister, considering she has type 1 diabetes. I hope she can use her influence from the backbench. The reality is that I need support in this. I’m this lone voice in parliament. I get a sympathetic ear from the Minister, but not much else”.

Other topics raised were diabulimia pilots and services for under 18s; how diabulimia can be coded within the NHS; where information can be found for those with multiple conditions; the increase of diabulimia amongst men; how to improve diabetes education and raise awareness of diabulimia.

**George Howarth MP** closed the meeting with a commitment to further action from the APPG. “I think we should have an inquiry on diabetes services across the country. I will discuss this further with the APPG and Diabetes UK.”