

## Sugar and spice: Diabetes and eating disorders T1ED challenges

11 November 2014

### Event summary

The 11 November event, *Sugar and spice: Type 1 diabetes and eating disorders | Meeting T1ED challenges*, hosted by three London Strategic Clinical Networks (Diabetes, Mental Health and Children and Young People) recognised the importance of the issue with 100 delegates attending from across paediatric diabetes, adult diabetes, dietetics, psychological services and eating disorders teams.

People with type 1 diabetes were also present, plus charity organisations DWED (Diabetics with Eating Disorders), Diabetes UK, Young Minds and MIND. A panel session was chaired by Nicola Kingston, Patient Voice representative with the London Clinical Senate and mother to a son with type 1 diabetes.

The meeting heard evidence that **people with type 1 diabetes double their risk of developing an eating disorder such as anorexia or bulimia** and **40 per cent of 15 to 30 year old women with diabetes regularly omit insulin** ("diabulimia") over concerns about eating and weight.

People who experience these issues are associated with worse glucose control and a two- to four-fold increase in the risk of devastating complications, such as kidney disease, eye disease and even death. They frequently surface as recurrent emergency admissions and very poor glycaemic control.

However, **these issues are frequently unrecognised and individuals can suffer with these problems for many years** before the problems surface.

### Why does it matter?

Morbidity and mortality increase dramatically in those with type 1 diabetes and eating disorders or regular insulin omission for body image reasons. The impact on quality of life and indeed life expectancy is paralleled by an increase in healthcare costs dealing with increased rates of hospital admissions and increased costs dealing with the complications of diabetes.

### Patient perspective

*"I have to say that it was one of the most amazing, reassuring and inspiring meetings I've attended on T1 as it's a topic that has been ignored for decades. I'm thrilled that it's now reached the consciousness of healthcare professionals at long last! As I said at the meeting, it took over 40 years for me to get appropriate help via the NHS and I'm only fairly recently able to be at peace with food. I hope that other young people won't have to go through this life-long struggle for recognition of their difficulties with diabetes and food."*

-- Lis Warren

London  
Strategic Clinical Networks



*"There can be few scenarios that are more challenging, both for the affected individual and for the clinicians that try to support them, than the co-existence of type 1 diabetes and an eating disorder."*



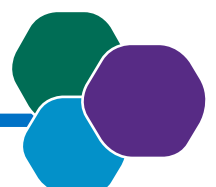
*While we in diabetes care have often led the way in delivery of multidisciplinary team approaches, we have not yet done well to bring together mental health care skills and diabetes expertise in the same multidisciplinary team for the benefit of this particular group. This is what we must look to do if we are to both increase the appreciation that disordered eating behavior is more common than we think in type 1 diabetes, and if we are to improve the care and outcomes for people in this situation.*

*The meeting supported by the London Strategic Clinical Network on 11 November was a great first step to bring together those committed to realising such improvement."*

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

### Links

- » Slides - <http://bit.ly/t1ed-slides>
- » Bios - <http://bit.ly/t1ed-bios>



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## What does good look like? *Integration*

The ethos of the diabetes clinic should be:

- » Psychological mindedness as a core component of treatment
- » Collaborative approach to development of self-management skills, and supportive skills training for families/carers

Simply relying on the appointment of a psychologist to the team to deliver this care fails to create integration. Education and skills training is needed for the whole multidisciplinary team. Discussions and expert insight during the meeting identified the need for greater identification by all people working in diabetes to understand the pressures and be able to support a young person with type 1 diabetes in order to reduce the risk of the development of these disorders, particularly around the time of diagnosis. Speakers felt that training is required for those who care for people with diabetes to support self-management of this severe and complex disorder, rather than stigmatising these as 'special' psychological problems that require mental health intervention.

Where these behaviours are established there is a need for diabetes teams to be supported in their care of these individuals and families by linking mental health and eating disorder teams with the diabetes team to transfer skills and training and, where necessary, jointly care for these individuals. It was strongly felt that integrating the approaches (rather than splitting care between diabetes teams and mental health/ED teams) was important, and this was particularly echoed by people with type 1 diabetes.

Skills from the mental health team need to be disseminated with families, carers and staff. These are highly valued as life skills. Interventions to disseminate these skills are delivered through workshops, books, peer support, telephone coaching and online resources. Diabetes services should:

- » **Deliver** training for staff alongside families/carers; aim for co-production
- » **Recruit and train** a small number of staff in higher level mental health / psychological therapy expertise
- » **Draft** informational materials for patients and families/carers
- » **Develop** partnerships with third sector organisations and expert patients and carers to deliver peer support through online and print materials
- » **Create** shared care pathways for the most severe and complex co-morbid type 1 diabetes and ED young people for integrated care from both diabetes and ED services

## Drivers for change

- » **Partnerships** between third sector organisations (eg DWED) and specialist services to seek **funding for development** of cost effective education and skills training.
- » **Research** is needed to further develop models for intervention, and to assess effectiveness and cost effectiveness. However, action should not be delayed whilst we await further evidence base.

"Parity of esteem" demands action now.



*"The Sugar and Spice event was an important step forward. All of the contributions acknowledged the need to improve the services provided to young people, particularly in terms of taking a more integrated and multi-disciplinary approach. I hope that the health professionals and campaigners can now build on the momentum and bring about these much-needed improvements."*

**Rt Hon George Howarth**  
MP for Knowsley



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Above: Word cloud of key themes tweeted throughout the event

### Sharing via social media

We used our Twitter account, @NHSLondonSCN, to generate interest and dialogue for the event. Twitter linked those in the room (attendees, the voluntary sector who had informational stands, speakers) with those outside the room -- and the the impact was clear.

With nearly 31,000 Twitter accounts reached and 186,000 impressions, it is evident that social media is a powerful channel to link up those passionate about this topic.

Networking in the virtual world will continue with participants as they tweet and retweet, sharing thoughts and ideas in future.

**30,883**

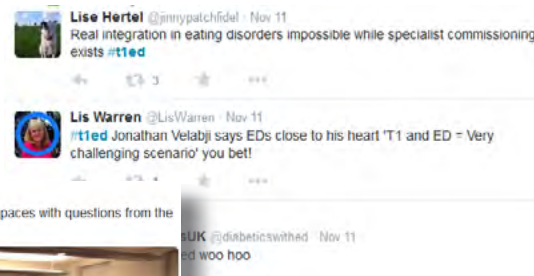
estimated Twitter accounts reached

**185,931**

impressions

**17**

hours of activity (pre, during, post event)



### In their own words

Participants rated the event quite positively, including:

- » **96 per cent** cited the overall event as excellent or good
- » **90 per cent** rated the effectiveness of the programme as *very effective* or *definitely effective* (with plans to modify practice whether in a major or minor way, respectively)
- » **93 per cent** said the quality of the presentations was excellent or good

### Comments included:

- » Thank you – very informative and inspiring
- » Really interesting and thought provoking
- » Good to know how to be more involved
- » I have clearly learned a great deal from discussions
- » Very personal, connected and empowering feel to the day
  - » Take it back to local practice and see how we can develop strategies to provide support
  - » Really useful networking

### Though there's still more to do...

- » It feels, despite everyone being in agreement about the need for psychology, we are still in need of funding to make this a reality.
- » Need to get the word out!
- » How do we raise awareness of this?

