Living with Type 1 diabetes - Finding an Eating Disorder

Sara Crowley
@Type1Hurdles
Nowhere in my medical notes will you find mention of an eating disorder.

Except in my HbA1c history, if someone looked beyond my numbers.

Therefore, I have never been able to access any formal help.

Because nobody saw beyond my numbers.
If I was missed, how many more people like me are not accounted for?

The scale of the problem is unknown, because it can’t always be measured. Or we simply get missed.
I’m lucky - I helped myself to recover.

Please note: Only one professional has ever asked if I have a history of an eating disorder. This came in 2017, from my dentist.

This talk isn’t to point fingers or throw blame at anyone.

But I hope it changes practice – because I believe there are varying degrees of insulin omission in every diabetes clinic, right in front of you.

And it can start subtly, rather than intentionally.
‘Rather than living with my condition, my condition lives with me and everything I want to do. I won’t let it stop me from attempting to live my life to its fullest.

It has given me reason to appreciate all aspects of my life, it’s been my greatest teacher and I believe I’m a better person for it, but pictures can often be deceiving….

Even with a positive attitude, I struggle.

And when I do, I don’t feel there is support in the way I need it. I understand how my pancreas should work, and what I should be doing but I don’t always understand my brain.’
Vulnerable points: High School through University
- Why I believe we have to better the way we support young adults.

My last school photograph. (17)

Visit home, first year of university. (19)

Signs of insulin manipulation from as early as year 8/9 (12-14 years old)

Which only worsened the older I became.

I couldn’t do what was expected of me.

I couldn’t ‘control’ my condition as my life stepped up a gear as a young adult.

But I could control …being uncontrolled.
This picture was taken within the first year or so of being under adult care. I never disengaged from services, I would not have been known to be a ‘frequent DNA-er’ as I was going to my clinic appointments, but I never found them particularly useful. It was more an afternoon of feeling like what they were asking of me was unrealistic and unachievable and I’d just go to not feel good enough.

Leave clinic and feel even worse.

This became a path of destruction and unknown unintentional self-harm.
It took a book written by someone in the United States, living with Type 1 diabetes who was also facing the same struggles as me to realise I was not alone.

Not one clinician ever explored my insulin intake or my behaviours around my condition, it was always all about the numbers, but with a HbA1c at almost 15 mmol/mol, the warning signs were there, but the support in the way I needed it wasn’t.

Again, I never felt good enough.

I travelled to Nashville on Aug 3rd 2017 to meet Amy and her family. I thanked her in person. She saved my life.
Missed signs or symptoms

Are you seeing these in your clinic?

- Constant high HbA1c \([9+ (74) \text{ is a sign, mine was almost 15 (140)]}\)
- Dishonesty and lies - made up numbers in log book, ‘forgot my meter’ etc.
- Unexplained weight loss & weight fluctuation (but BMI is useless!)
- Persistent thirst & frequent urination (multiple times through the night)
- Interrupted sleep, fatigue & lethargy - needing frequent naps
- 1 DKA & but hundreds of near DKA episodes (that aren’t accounted for anywhere)
- Frequent yeast infections – thrush
- No period for 6+ months
- Stock pile of unused insulin & prescriptions at home
- Face always looked gaunt – rosy cheeks, no colour
- Cuts not healing – scarring over body
- Self-harm - not in the way most consider ‘self-harm’ leading to addiction (bulimia)
Behind the numbers of HbA1c
- Underneath the surface

- Resentment towards my condition, turned to resentment towards myself
- Stopped checking my blood glucose for months
- Refused to take any diabetes related ‘stuff’ out with me
- Refused to talk about ‘my’ diabetes – pushed parents away
- Stopped taking basal insulin completely
- Reduced insulin to the minimum amount that kept me out of hospital
- ‘Inject’ in another room – usually my bedroom
- ‘Inject’ in front of people but the plunger wasn’t touching the insulin
- Limit the number of injections, conscious of my ‘lop-sided’ stomach
- Hated clinic: I was In the room, but I was disengaged
- Distrust with professionals – they were forever ‘tweaking’ my insulin, but obviously unable to ‘see’ I wasn’t taking in the first place.
I felt overwhelmingly controlled by food because of my diabetes regime.

Stigma — in particular with ‘obesity’ and society thinking ‘I did this to myself’

Restrict food to lose weight → hypo → guilt/failure → low self-esteem → binge → guilt → purge → repeat cycle.

Insulin omission, or ‘mis-matched insulin’ breaks this cycle.

The ‘worse’ the food, the higher my blood glucose = the more weight I lost.

It goes against everything society tells us about ‘dieting’

‘Diabulimia’ wasn’t recognised so nobody would question – lethal combo

Comments on my weight loss and my clothes hanging off me felt good

This, made me feel good – at a time I couldn’t feel good anywhere else

This spiralled out of control until I was also vomiting multiple times a day.
Other factors or potential triggers
That are too important to be overlooked

- Power imbalance between professionals and people living with diabetes
- How clinic made me feel about myself including being weighed so often and being asked how often I exercise when excessive exercise was one of my triggers
- I feel I’ve been conditioned to chase perfection – 4-7mmol/l
- I was coming to terms with sexuality, when LGBT+ wasn’t as accepted
- Unhealthy relationships that made me feel worthless
- Isolation (even though I always had friends/support around me)
- Lack of acknowledgement of the impact Type 1 diabetes on mental health
- Negative language – around diabetes, weight, food, complications, health
- Intense feeling of failure
- Body image & clothing including triggers like changing rooms
If someone is unhappy in their own skin or if they have low self-esteem, where do they find such strength, motivation and determination to look after something as intense as Type 1 diabetes, when the expectation is perfection and the reality of it is impossible?
Tips/Things that have helped me 😊

- I have found my own regimen of what individually works for me and my life
- I don’t avoid a single food group – everything in moderation
- Finding my voice – and developing the confidence to use it
- Being open with my current partner (she is amazing beyond words!)
- Diabetes tech – introduced when I was (mentally) ready to use it
- Trained myself to rethink numbers, and better still, the glucose line and arrows
- Setting my own expectations and knowing my limits
- Practicing and exploring different ways of self-care
- It’s hard, but I had to make friends with myself and learn to like myself
- I got rid of scales and full length mirrors in my house (re-introduced, not in view)
- I’ve learned when to challenge my thoughts and when to listen to them
- And when all else fails, there is nothing like being able to turn to peer support…
If you ‘don’t want to open a can of worms.’
- Eating disorders thrive on secrecy

We all need to understand mental health
and be able to support and talk about it.

Of the long list of ‘diabetes complications’ I was warned about, why wasn’t mental health one?

Not addressing this has certainly led to me to the physical complications they warned me about.
This picture is just one.

But, you can change this for others like me.
(Attitudes and language don’t require any funding!)
Breaking the stigma @Type1Hurdles

Diolch am wrando
Thank you for listening

‘My worth never was, never can and never will be measured in my HbA1c or weight.’ – Sara
The ComPASSION Project

Combined Pathway for Assessment and Support for the Syndrome of Insulin Omission – Type 1 diabetes

Wessex Pilot

Dr Helen Partridge
Consultant in Diabetes
Royal Bournemouth Hospital

Dr Carla Figueiredo
Consultant Psychiatrist
Dorset Eating Disorders Service
• Fear of hypoglycaemia
• Diabetes burn out
• Not getting insulin
• Lipohypertrophy
• Needle phobia
• Fear of weight gain
• Undiagnosed diabetes
• “Just can’t do it!”

Can’t dissociate physical and mental health in diabetes
Disordered eating

- Frequent dieting, anxiety associated with specific foods or meal skipping
- Chronic weight fluctuations
- Rigid rituals and routines surrounding food and exercise
- Feelings of guilt and shame associated with eating
- Preoccupation with food, weight and body image that negatively impacts quality of life
- A feeling of loss of control around food, including compulsive eating habits
- Using exercise, food restriction, fasting or purging to "make up for bad foods" consumed
Why is disordered eating common in T1D?

• having to carefully read food labels
• the focus on weight at clinic
• having to eat to treat hypos, which can cause weight gain and guilt
• being constantly aware of carbohydrates or calories in food
• feeling shame over how diabetes is managed
• a bad relationship with healthcare team
• difficulty keeping to a healthy weight.
• Significant weight loss at diagnosis
3 P’s of eating disorders

• **Predisposition** – genetic, environment, temperament

• **Precipitating** – Weight loss, trauma, chronic stress & negative affect, lifecycle transition, peer group, media, bullying

• **Perpetuating** – Malnutrition, social isolation, emotional responses, cognitive difficulties, body image disturbance, behaviours that maintain the problem
When disordered eating become an eating disorder? And what do we call it?

- Syndrome of Insulin Omission? T1DE?
- Criteria
  - Type 1 diabetes
  - Significant Diabetes Distress (>6 on DDS?)
  - Pervasive concern around weight gain and body image
  - Insulin omission to prevent weight gain

? Markers of severity
What are we trying to do?

Wessex Hub and Spoke model

• Joint working in MDT Bournemouth
  – Consultant diabetologist and consultant psychiatrist
  – Diabetes nurse specialist
  – Specialist dietician
  – Psychologist
  – Eating disorders specialist practitioner

• Spokes at Portsmouth, Poole and Dorchester
  – Consultant Diabetes
  – Eating disorders specialist practitioner
  – Specialist Diabetes nurse/dietician
So how are things going?

- Questionnaire to identify at risk/ screening tool for use in general type 1 diabetes clinic/ community
- Joint clinics with diabetes and eating disorder teams – shared care
- Weekly clinical MDT
- 3 monthly CPA
- Monthly joint calls with London Hub
- National Type 1 / Eating disorders conference
- Developing SOPs and protocols for clinical practice (joint with London)
- Developing Day Case provision
- Peer supervision
- Regular review of processes
- User involvement in service design and development
Education Program

• Language
• Awareness
• Communication skills
• Education

• Online Patient Partner Network
  – Peer to peer online support and mentorship?
  – Resource area for HCP
  – Support area for carers and family
Important things we have learnt!

• Diabetes teams need to learn about eating disorders
  • confidence in asking difficult questions
  • communication skills and MI techniques
• Eating disorders teams need to learn about diabetes
• Most other clinicians need to learn about both!
• Be open minded about phenotypes
  – Most people are of normal weight/ BMI initially
  – HbA1c may not be significantly elevated at first
  – May have comorbid psychopathologies
  – May have multiple behaviours
    • Insulin omission
    • Food/ carb restriction
    • Bingeing/ purging

Need to look like we know what we’re doing
Important things we have learnt!

• Single point of contact with team decision making and communication
• Give people time to assimilate emotions and concepts
• Take small steps and celebrate them
• Awareness that we may not cure everyone

• VERY emotional, difficult, frightening time
• Need to develop therapeutic relationship

“I started to move forwards once I really believed that you were all on my side”
Wessex Team

- Jacqueline Ryder – Diabetes Specialist Nurse
- Lindsey Rouse – Diabetes Psychologist
- Nicola Stacey – Diabetes Specialist Nurse
- Micki Bennet – Eating Disorder Specialist Practitioner
- Claire Pinder – Eating Disorder Specialist Dietician
- Caroline Cross – Project Manager

- Poole – Dr Adam Nicholls, Sarah Alicia
- Dorchester – Dr Fiona Wotherspoon, Kerri Hampton

- Portsmouth – Dr Eveleigh Nicholson, Lorraine Avery, Linda Gerrard-Longworth
T1DE Pan-London Collaborative

Diabetes Professional Conference
October 2019

Dr Sophie Harris
Overview

- Context
- KHP Definition of T1DE
- Hub & Partner model
- Model of care
- Example case load
Eating disorders in type 1 diabetes (T1D)

Disordered eating, diabulimia… increased awareness at patient, clinical and organisational levels of a serious life threatening mental-physical co-morbidity
The epidemiology of eating disorders in T1D

- **anorexia**
  - 0.3% vs 0.1% (T1D vs general population)

- **bulimia**
  - 1.7% vs 0.7% (T1D vs general population)

- **insulin restriction**
  - 30-70%

Geobel-Fabbri et al. Diabetes Care 2008;31:415-9
A theoretical pyramid model of severity of T1D and disordered eating

severe
~1-5%

moderate
~30%

Nil-mild ~60-70%

HbA1c >10% (107 mmol/mol) unscheduled care/inpatients*

HbA1c <10% (107 mmol/mol) outpatients

King’s Health Partners definition of type 1 diabetes and disordered eating

**Core criteria**

1. Type 1 diabetes
2. Pervasive fear of insulin as weight gaining
3. Omission of insulin to control weight

**Severity indicators**

- HbA1c ≥ 10% for at least the past 12 months
- Recurrent DKA defined as >1 admission for DKA in past 2 years
- Recurrent hypoglycaemia
- BMI ≤ 15 kg/m²
Map of Hub & Partner Sites across London

- The Royal Free NHS Foundation Trust
- Barnet, Enfield and Haringey NHS Mental Health Trust
- Barts Health NHS Trust
- North East London NHS Foundation Trust
- Guy’s and St Thomas’ NHS Foundation Trust
- Lewisham and Greenwich NHS Trust
- King’s College Hospital NHS Foundation Trust (HUB)
- South London & The Maudsley NHS Foundation Trust (HUB)
- Imperial College Healthcare NHS Trust
- Chelsea and Westminster Hospital NHS Foundation Trust
- Central and North West London NHS Foundation Trust
- St George’s University Hospitals NHS Foundation Trust
- South West London & St George’s Mental Health NHS Trust
- South West London & St George’s Mental Health NHS Trust (Spoke)
- Mental Health Trust (Spoke)
- Acute Care Trust (Spoke)
T1DE London Pilot Hub & Partner Members

Partner
Imperial College Healthcare
- Nick Oliver
- Divina Pillay

Partner
King’s College Hospital
- Fun Liu & Sophie Harris
  - Helen Cope
  - Jennie Brown
  - Diane Turner
  - Nikki Ottonaro
  - Clare Mudie
  - Bethan Parry

Partner
Guy’s & St Thomas’
- Dimitri Karyiawasam
  - Helen Cope

Partner
St George’s University Hospital
- Roni Jaha
  - Marcus Hughes (TBA)

Partner
Barts Health
- Chris Garrett
- Bobby Huda
- Sonya Freeman

Partner
The Royal Free
- Miranza Essedehal
- Nora Turkanski

Clinical Leads
- Khadla Ismail
- David Hopkins
  - Marietta Studier
At present no evidence for effective interventions for T1D for eating disorder to improve glycaemic control

Treatment effect size of intervention on HbA1c

Clery P et al. Diabetic Medicine 2017
Treatment Decision Flow Chart

- HbA1c ≥ 10%
  - Recurrent DKA (≥ 2 DKA in past 12 months)
  - Suspected or known eating disorder

  Joint psychiatric and diabetes assessment of 1, Diagnoses 2. Medical and psychiatric risk assessment

  Does patient need acute inpatient admission to stabilise medical status?

    NO

    Does patient need urgent psychiatric inpatient admission

      NO

      Is intensive integrated outpatient care indicated?

        NO

        Routine outpatient diabetes liaison or generic eating disorder care or return to local services

        YES

        YES. DELIVER INTEGRATED CARE PLAN

      YES

      Admit and initiate psychiatric care with diabetes input

    YES

    Admit and treat acute complications with psychiatric input
T1DE Pathway - first assessment

**Initial Assessment**
- Consultant Diabetologist
- Liaison/Eating Disorders Psychiatrist
- Diabetes CNS

**T1DE MDM**
- Patient-led Management Plan (discussed/agreed)
  - Patient +/- carer
  - Consultant Diabetologist
  - Liaison/Eating Disorders Psychiatrist
  - Diabetes CNS

**Management Plans can include one or more elements of care**
- Psychotherapy Sessions
  - Psychodynamic psychotherapy
  - Diabetes CNS led CBT
  - Carer work
  - Family work
  - Psychiatry
  - 50 mins per session

**Diabetes Focused**
- Diabetes Educator - DKA & Dietician
  - 50 mins per session

**Inpatient Admission (SLAM)**
- Psychiatrist
- Diabetes CNS
- Liaison/Eating Disorders Psychiatrist
- Consultant Diabetologist
- Inpatient stays can be up to 4 weeks / estimate approx 2 x inpatients at any given time

**Partnership Working**
Tailored to patient and local resources

**Important to note:**
This model is tailored to the individual needs of patients and they will interact with each component of care in different ways over the one year time frame.

**Detailed Breakdown of Initial Intensive Assessment**
- 20 minute handover from psychiatrist to diabetologist
- Medical management of acute hyperglycaemia
- 1.25 hour initial assessment with medical workup (supported by CNS)
- Consultant Diabetologist / Psychiatrist
- 45 min case planning session (MDM)
- Consultant Diabetologist / Psychiatrist
  - 30 min patient-led management plan discussion
  - 15 min discussion of crisis management plan
  - Treatment and therapy engagement terms and conditions

**Trigger**
- 1 hour post review of care
  - Psychologist / Diabetologist
Importantly to note:

This model is tailored to the individual needs of patients and they will interact with each component of care in different ways over the one year time frame.
Key components of King’s integrated model

- Referral criteria for severe T1D eating disorder
- Assessment: joint psychiatric and diabetes assessment
- Integrated psychiatric and diabetes report and care plan
- Interventions can include:
  - psychotropics
  - safer management of diabetes
  - graded titration of insulin dose
  - psychoanalytical psychotherapy
  - inpatient psychiatric unit to bring routine
  - cognitive behaviour therapy skills with diabetes care
  - medical investigations
  - family and carers
  - DNA management
  - Quarterly patient led care reviews +/- local teams
- Discharge: Feedback loop to referring team
## T1DE service 7/2018- 9/2019 severe spectrum service users with >6 months service use

<table>
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<tr>
<th>Hub</th>
<th>Age (diabetes duration)</th>
<th>DKA admissions /year at baseline</th>
<th>HbA1c first visit</th>
<th>diabetes late complications</th>
<th>Admission ED unit</th>
<th>Hba1c latest %</th>
<th>DKA admissions since T1DE clinic</th>
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</tr>
<tr>
<td>5</td>
<td>18 (6)</td>
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<td>12.0%</td>
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### Spoke- Diabetes

| 6   | 30 (17)                 | 0                                | 14.3              | Severe DRP, NP              | Aged 19          | 7.5%           | 0                             |
| 7 (RoyalFree) | 42 (32)                  | 1                                | 12.5              | Severe DRP, Nephropathy, Autonomic NP, MCI | 0                | 7.5%           | 4                             |
| 8 (RF) | 22 (6)                  | 1                                | 12.6              |                             | 0                | 7.5%           | 0                             |
| 9 (KCH) | 22 (16)                 | 0                                | 13.8              | Offered/refused             | 12.4             | 2              | 2                             |
| 10 (KCH) | 27 (6)                  | 5                                | 11.8              | considered                  | 2                |                | 2                             |

### Spoke- ED unit

| 11 (Bethlem) | 28 (1)                  | 0                                | 6.5%              | Severe hypoglycaemia, ED call outs | 2018/19          | 0              | 0                             |
| 12 (St George's) | 18 (11)                 | 0                                | 7.4%              | Anorexia nervosa               |                  |                | 0                             |
Research programme for mild to moderate Safe management of people with Type 1 diabetes and EAting Disorder studY (STEADY)

Barriers and facilitators in recovery (patient interviews)

Challenges and therapeutic strategies (Stakeholder focus groups)

Refining theoretical model

Multidisciplinary Co-design workshops

Modules safe graded insulin titration

Adapt/expand manual

CBT-enhanced diabetes educational intervention

STEADY research project is led by Dr Marietta Stadler
NIHR Clinician Scientist 5 year project, KCL 2018-23 £1.4m