University Hospitals Dorset
NHS Foundation Trust

Type 1 Diabetes and Disordered Eating (T1DE)

ComPASSION Project

A collaborative approach to a complex condition

Dr Helen Partridge, Consultant in Diabetes

Overview

Introduction to eating disorders

Introduction to T1DE

Principles of identification

Principles of management

Outcomes of pilot

Resources

Eating Disorders

- A group of serious psychiatric disorders -physical, psychological, social features.
- Disabling Deadly Costly
- 3 P's
- "Irrational"
- "Eating disorder brain" -evil, pernicious, "knows all your secrets and will use them against you"

Type 1 and Disordered Eating : T1DE

- 30% of people with T1 Diabetes report Insulin omission for fear of weight gain
- Insulin omission for fear of weight gain is associated with a three-fold increase in the risk of death and reduced quality of life
- 10% of people with T1DE are likely to develop advanced Diabetes complications within 5-10 years
- 12 yr follow up study mortality T1D 2.2 per 1000 person years, AN 7.3, T1DE 34.6

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
- Societal perceptions around diabetes

Why are Eating Disorders difficult to treat?

Patients with Anorexia/ Eating Disorders often don't want treatment

- Egosyntonic disorder; in harmony with their needs and goals so often deny they have a problem
- Becomes part of their identity, can't imagine life without anorexia
- Shame and secrecy, feel undeserving
- Often lack capacity to make informed decisions about their healthcare because can't appreciate how poorly they are

Why is T1DE difficult to identify

- Eating disorders are secretive
- No typical presentation (majority a normal weight)
- Not the only mental illness experienced by people with T1 Diabetes
- Diabetes professionals may feel they lack confidence raising sensitive matters
- Conventional screening tools have limitations : General ED Questionnaires are not sensitive to the influence of T1 Diabetes on eating patterns

Clinical presentations

Age	16 – 68y
Normal weight	94%
History of weight loss	100%
Fear of gaining weight	88%
Years since diabetes diagnosis	0-62
Body Image disturbance	88%
Dietary Restriction	94%
Excessive exercise	52%
Self-induced vomiting	35%
Insulin Omission	59%
Binge eating	41%
HbA1c	Mean 91mmol/mol (range 46-145)
KNOWN Co-morbid mental health diagnosis	29%
History of recurrent DKA	41%
Diabetes Distress Score	All over 6

Clinical phenotypes

- Food restriction –appropriate insulin dose
  - May struggle with hypoglycaemia
  - May struggle to treat hypoglycaemia
- Insulin restriction
  - Tend to have very high HbA1c
  - Run high ketones
  - High risk DKA
- Binge purge –with / without insulin

- Any combination of the above
- With additional behaviours

T1DE Working diagnosis

People with T1DM who present with all 3 criteria

1.Disturbance in the way in which one's body weight or shape is experienced or intense fear of gaining weight or of becoming overweight.

2.Recurrent inappropriate direct or indirect[1] restriction of insulin (and/or other compensatory behaviour*) in order to prevent weight gain.

***Self-induced vomiting, laxative use, dietary restriction, excessive exercise**

3.Person must present with a degree of insulin restriction, eating or compensatory behaviours that cause at least one of the following:

- **Harm to health**
- **Clinically significant diabetes distress**
- **Impairment in areas of functioning.**

Note:

[1]Indirect restriction of insulin refers to reduced insulin need/use due to dietary restriction.

Screening

providing the excellent care we would expect for our own families

The Royal Bournemouth and Christchurch Hospitals NHS
NHS Foundation Trust

Type 1 Diabetes Clinic Questionnaire

Name: _____

Date: _____

Today you will be seeing your consultant plus one of the team members either your nurse or dietitian. It can be difficult in the clinicroom to remember what you wanted to discuss or you may not have thought about it.

A. Is there anything in particular you would like to discuss today?

.....

.....

Would you like to discuss any of the subjects below?
Tick as many or as few as you would like!

Topic	
Travel, things such as: how to adjust insulin for long flights, eating in different countries, storing insulin when you are travelling	
I would like to learn about how alcohol affects diabetes	
I would like to talk about how I feel about my diabetes (frustrated, fed-up?)	
How do I work out eating out with friends	
I would like to learn more about Insulin pumps	
I feel I could learn more about Carbohydrate counting	
I am really unhappy with my body image	
What tricks and techniques are there around managing exercise	
I want to think about planning for having a baby	
I am struggling with hypos	
I feel I am constantly worried about my weight	
How do I deal with snacks	
I think I could do with talking about sex and contraception	
What do I need to think about when starting college or University/ moving house	
I really struggle with my diabetes whilst at work	

B. It is important for us to think about and measure hypoglycaemia –please could you fill in the 3 questions below by circling the answers that describe how things are for you. (We can explain this more clearly in clinic if you prefer)

1. Do you know when your hypos are starting?
(Circle **1** if you are **always** aware and **7** if you can **never** feel them starting or somewhere along the line depending on how you feel about your own awareness of them)

1 2 3 4 5 6 7

2. How often in the last month have you had readings less than 3.9mmol/L without symptoms?

Never 1 to 3 times 1 time/week 2 to 3 times/week 4 to 5 times/week Almost daily

3. At what level do you start to feel symptoms of hypoglycaemia/ low blood sugar?

Less than2.2mmol/L 2.2-3.3mmol/L 3.3-3.8 mmol/L 4-7 mmol/L 7-12mmol/L

C. Consider the degree to which each of the two items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number:

	Not a problem	A slight problem	A moderate problem	Somewhat serious problem	A serious problem	A very serious problem
1. Feeling overwhelmed by the demands of living with diabetes	1	2	3	4	5	6
2. Feeling that I am often failing with my diabetes routine	1	2	3	4	5	6

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Findings

Data between two sites were combined for greater sample size

1. Greater percentage of patients with T1DE want to talk about their weight/body image/both.

	Patients without T1DE	Patients with T1DE
Weight	19.6%	66.7%
Body image	13.4%	77.8%
Both	9.3%	66.7%

Assigned value (1) to weight and body image and calculated Total score

(DSS + Weight + Body Image)

3. Total scores showed statistical significant difference between the mean score of those with vs without T1DE (<0.01)

Total scores

	Patients without T1DE	Patients with T1DE
Mean	4.86	11.88

Statistical significance of <0.01 found using both
- Two tailed T test assuming unequal variance
- Mann-U-Whitney test using mean rank assuming data not normally distributed

4. Weight and body image showed statistical significant difference between the mean score of those with vs without T1DE (<0.01)

2. DDS scores showed statistical significant difference between the mean score of those with vs without T1DE (<0.01)

DDS scores

	Patients without T1DE	Patients with T1DE
Mean	4.53	10.44

Statistical significance of <0.01 found using both
- Two tailed T test assuming unequal variance
- Mann-U-Whitney test using mean rank assuming data not normally distributed

Score 12, HbA1c 117
What would you recommend?

1. Warn them of the consequences of long term diabetes complications

2. Attend structured education course

3. Low carb diet

4. Increased basal and/or bolus insulin

5. Something else

What emotions do people with T1DE report?

1. Fear

2. Embarrassment

3. Shame

4. Self loathing

5. All of the above

What is that something else?

Build engagement

Acknowledge the difficulties

Normalise the abnormal

Assess risk –nutritional, psychological, biochemical

Pick up phone to local Eating disorders team (Have MEED at the ready) -try and get joint appointment

Simplify treatment

Set reasonable goals

Celebrate the small wins

Organise regular follow up with the same person preferably

How do you open the conversation about your concerns?

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- I can see you have scored quite highly on the diabetes distress score –tell me about that? Tell me about your relationship with your diabetes?
- Is there anything about your diabetes or your diabetes treatment that might be contributing to your concerns around your weight or body image?
- Living with type 1 is really tough - Some people don't always manage to take all their insulin as required.....how many times a week do you manage to take your long acting insulin?
- How many times a day do you manage to take all your short acting insulin?

Key components of interventions

- Engagement

"I couldn't move forward until I knew they were on my side and I could trust them"

- Formulation –holistic psychological/ physical approach

"I was sectioned in an eating disorders unit before but they didn't understand diabetes"

- Psychoeducation
  - Enhancing self-efficacy and confidence around making changes
  - Cognitive restructuring
  - Developing compassion for oneself
  - Give people time to assimilate emotions and concepts

  - Building acceptance
  - Identifying and living in line with personal values –why they (not us) want to make change
  - Crisis management and relapse prevention plans

  "If I'd got sick I wouldn't have called you. I was never that poorly"

  - Supervised administration of insulin
  - Modified sick day rules

Insulin management

- Immediate focus on ideals of near normal glycaemic management are unreasonable and unsafe
- Emphasis on small incremental steps that are attainable
- Accept high blood glucose and ketone levels temporarily
- Gradually increase the regularity and amount of insulin dosing and monitoring, moving towards recommended targets.

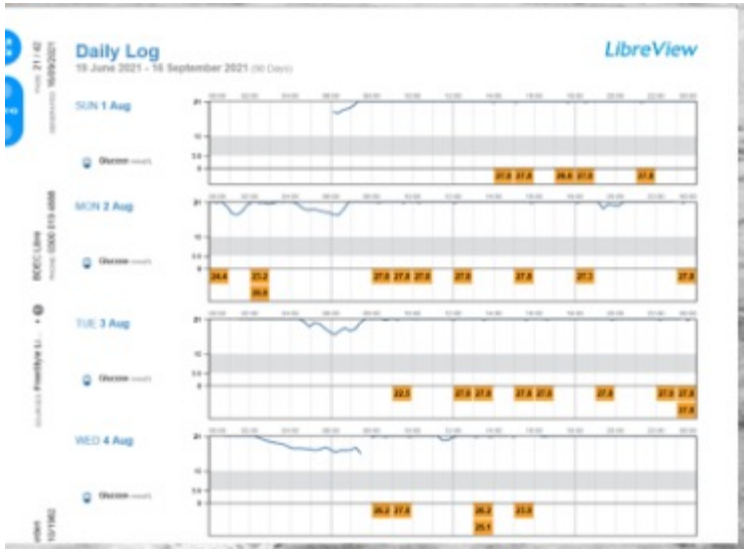
Nutrition

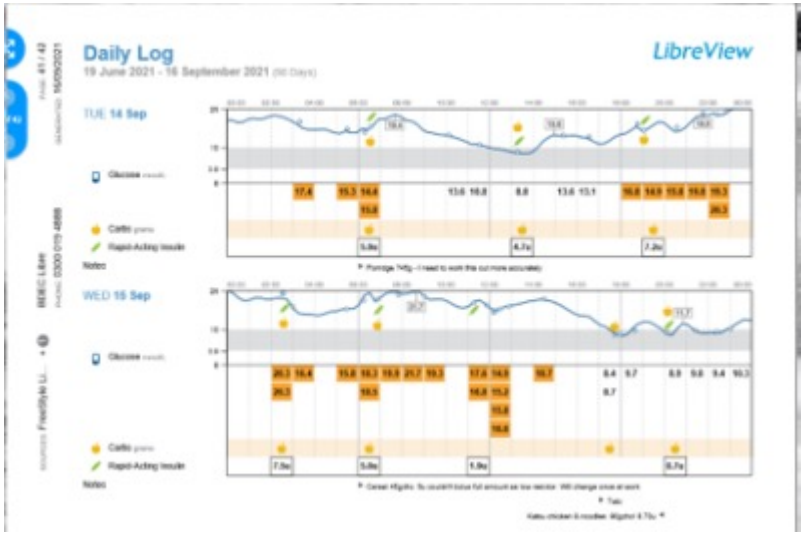
- Manage refeeding risk
- Gradual move towards a normalised pattern of balanced eating in line with mainstream nutrition recommendations for type 1
- Consider no carb counting temporarily, instead taking a more generalised dietary approach alongside fixed doses of insulin.
- Technology?

Risk management

- Physical health risks :
  - diabetes parameters (HbA1c, ketosis)
  - ?biochemical parameters with risk of Refeeding Syndrome
  - Pseudohypoglycaemia
  - ?sudden drop in glucose
- Mental health risks :
  - harm to self or others
  - self-neglect
  - vulnerability
  - disengagement from services.

Outcomes


Daily Log
LibreView
SUN 1 Aug
MON 2 Aug
TUE 3 Aug
WED 4 Aug


Daily Log
LibreView
TUE 14 Sep
WED 15 Sep

Admissions and DKA

Table ES1 Admissions with a primary diagnosis of DKA in the years before and after T1DE assessment, patients with at least 12 months of data following T1DE assessment, London (n = 44)

	Year before/after T1DE assessment			
	-3	-2	-1	1
Total admissions	10	12	31	13
Mean admissions	0.23	0.27	0.70	0.30
Maximum admissions per patient	4	5	7	2
Patients with at least 1 admission	6	5	11	9

HbA1c

Chart ES1 Mean baseline and follow-up HbA1c, patients with ≥12 months follow up, (n=11 Wessex, n=14 London)

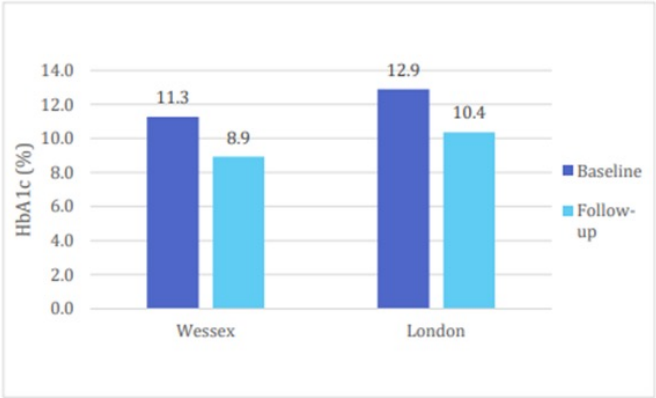
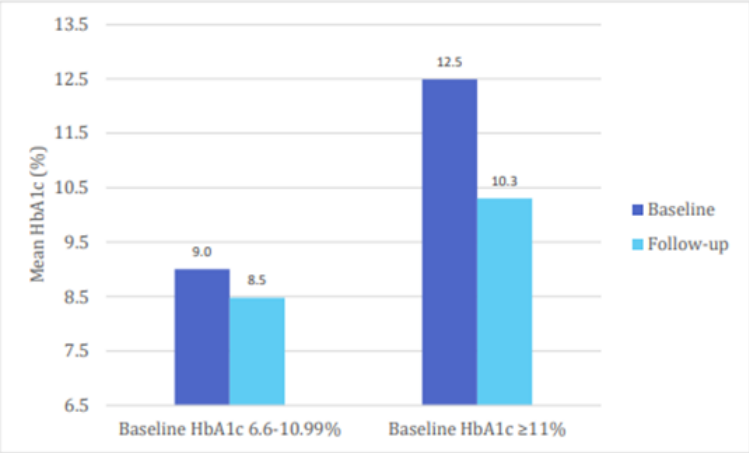


Chart 3.6 Mean HbA1c at baseline and follow-up, by baseline level, Wessex (n=19)



PROMs

Table 3.3 Health-related quality of life scores at initial assessment and at follow up, Wessex (n = 5-8)

	n	Mean score at baseline	Mean score at follow up	Mean change from baseline	Standard deviation of change
DEPS-R	6	32.83	29.33	-3.50	19.08
EDE-Q global	6	4.57	3.74	-0.83	0.80
EDQOL	5	2.24	1.54	-0.69	0.42
PAID	6	54.15	36.04	-18.11	19.37
GAD-7	8	14.88	12.38	-2.50	3.94
PHQ-9	8	18.38	12.25	-6.13	5.62
WSAS	4	18.50	16.00	-2.50	5.72

Resources

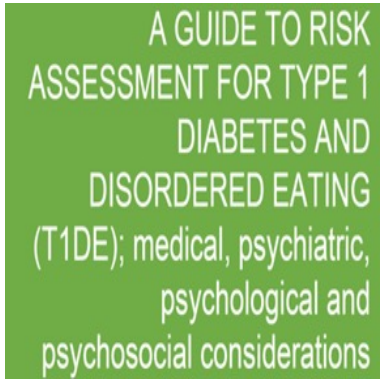
https://feed.podbean.com/thet1depodcast/feed.xml

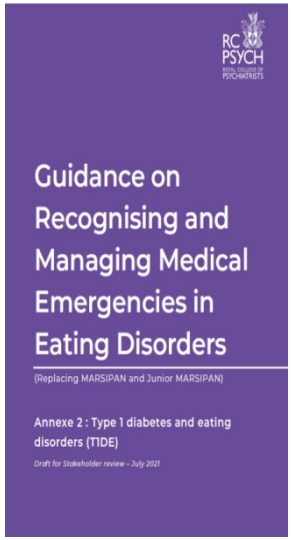
A GUIDE TO RISK ASSESSMENT FOR TYPE 1 DIABETES AND DISORDERED EATING (T1DE); medical, psychiatric, psychological and psychosocial considerations https://bit.ly/2WaeJQg

college-report-cr233---annexe-3.pdf (rcpsych.ac.uk)

https://www.jessgriffiths.co.uk/peersupportt1de/

www.beateatingdisorders.org.uk





Hi
I wanted to just say thanks to you all for supporting me to get where I am now. Around this time last year, I was sat on the beach, feeling pretty unwell. Carrying litres of water with me, constantly drinking and desperate for the loo. Planning my days only ever involved how much water I could take, if there was a shop nearby, was there access to toilets and could I get to a hospital if needed. I'm not sure there was room for anything else. I really felt dreadful, but would never really admit it.

Today I'm sat on the same beach, having eaten 2 meals (shock!) And not desperate for a drink. I can concentrate on just being here, with friends. I don't feel I'm about to collapse. I cant taste ketones. Im not worried of being sick. My legs are not painful or burning. I'm not worrying if I have enough ketones, but not too much. I'm not trying to decide if my next journey needs to be a&e or if I can make it through just the next few hours. I'm not dreading the night time, when no ones around. I'm not scared to sleep, wondering if it would be the final sleep.

Anyways, far too deep!

Thank you for all sticking by me, for not giving up on me. I'd given up so many times, but somehow, between you all, you helped pull me through.

I know I still have a long way to go, but jeez I feel so different already. Although, I also don't think I was that sick. Wasn't sure how I felt with hearing this earlier.

Thanks again! I know I said Claire is amazing, but you all are and I really appreciate everything.....remember this if it all goes tits up, I can be nice ;)