As complex as it gets!

Sophie first developed an ED around 11 years of age and requiring a 9-month inpatient admission St Elsewhere under section 3 aged 15 including NG tube feeding.

She remained well in the community, achieving a degree in law specializing in medico-legal work.She travelled extensively, moved to another area of the country with her partner, bought a flat on the beach and outwardly was functioning at a very high level.

She was diagnosed with Type 1 diabetes in August 2020 (aged 32) with classic symptoms admitted in DKA on holiday in Peru. HbA1c 105.

WIthin 3 months she had been taught carbohydrate counting, was on MDI, Libre 2 and HbA1c 52

At this point nothing in her medical notes locally about disordered eating

Question 1

Jan Reporting highs and lows particularly with exercise. Starting to affect her work and struggling to manage the stress levels around important cases. TIR 40%.

Referred for insulin pump at pt request. HbA1c 64

2x DKA Jan

Discharge summary

“No identified trigger for DKA however Sophie has a history of an eating disorder and when questioned reports regularly only eating one meal a day and will often make herself sick following a meal. Has a Libre sensor but hasn't had this on for the last week. Plan-will chase up insulin pump referral”

2x DKA Feb

Diabetes IP nurse

“Once you started insulin you gained weight and this concerned you and you acknowledge that you have not always bolused insulin for your meals even if they contain some carbohydrates”

Referred to T1DE team

2 x DKA March –self discharged against medical advice.

T1DE clinic BMI ?18 HbA1c 105

You describe that your current relationship with diabetes is "pretty awful".

You think that an episode in January when you went to clinic and were weighed sent you into a spin.

Question 2

T1DE MDT Plan

Weekly DSN contact for support

Regular dietitian input

Appointment with consultant psychiatrist

Formulation and plan for psychological therapies

Modified sick day rules

Daily "low dose" tresiba

Aim to keep ketones less than 3

Aim to minimise weight loss

Aim to minimise vomitting

Aim to minimise exercise

Consider additional stresses and risks –work, relationships, family, finances, driving

Crisis management

Education of diabetes IP team, A&E, ED re modified DKA and emotional support and MHA/MCA

Outpatient Work

Psychological therapies –trauma work, internal family systems and behavioural approach for habit reversal

Diabetes Acceptance work

Diabetes distress

CBTE

Screen for neurodivergence, personality disorder

Daily insulin administration in diabetes centre or by phone

Insulin administration by father or overseen by father

Daily telephone support.

Pharmacotherapy for anxiety and depression

Despite Sophie trying her best, daily DSN contact, supervised insulin, therapy as above –continued recurrent DKA, deterioration in mood, weight loss, purging

Always attended T1DE clinic but declined insulin, declined weighing, declined admission, declined A&E

Question 3

Voluntary admission to Secure Eating disorders unit August , however self-discharged after 1 week

?BMI HbA1c 130

Re-admitted voluntarily late August due to physical and psychological deterioration in community

?BMI TIR 0%

Detained under Section 3 of the MHA on September .

Discharged from Section 3 by a tribunal on November applied for by her father

With Sophie's legal background she would read up on MHA and her rights and the rules etc!

Continued deterioration and concern for her health and mental state further section 3 MHA January and remained an inpatient under section.

Introduction to father William.

Very close relationship with Sophie and has tried to support her since her initial diagnosis AN

Parents divorced. Mother not on the scene

Clearly a very strained relationship and clearly terrified for her and risk to life.

Practically and financially dependant on father –he would bail her out of many situations eg when she wanted to leave law school. Would run away from home and dad would drive around looking for her and bring her home.

Dad moved down into local rented accommodation when Sophie first detained

Sophie declined all consent for us to meet with her father independently or to share any information but frequently invited him to ward reviews therefore we were unsure of his knowledge of true situation.

He had no idea of the ideas we had tried, things suggested, options considered

“Can’t keep doing the same thing and expecting different results”

Family feeling “burnt out and want less responsibility as aware they are being influenced by ED and colluding with it”

William asked for his visits to be restricted to 1 hour per day BUT want it to appear it was a medical decision –not able to explain this to Sophie

Question 4

During SEDU admission-really traumatic torrid time

Sophie felt unable to manage plans –would agree and maintain for 3-4 days but then thoughts, feelings, behaviours returned –self harm on the ward, significant insulin overdose on weekend home leave

Frequent episode awol despite 3:1 observation

Adamant wouldn't have NG feeding –but couldn't eat

Required restraint for NG feed and insulin

Multiple admissions to the acute hospital for DKA/ ketones

Review by neurology and opthalmology and surgery for multiple additional concerns with CT/MRI etc

Real concern about mental health deterioration, physical health deterioration, breakdown in relationships

What did we try?

Multiple variable insulin patterns and goals

Basal only

Basal plus corrections

Basal plus intermediate acting

MDI –patient administered, nurse administered, under restraint?

Insulin pump

Meal plan –

¼ portions

Fresubin only

Bringing own food in

NG feed under restraint

Transfer to acute hospital under Gastroenterology for assistance with feeding

I think it is fair to say at this point there were many concerns within the whole team

Question 5

What else did we do/consider?

?Out of area including abroad –family approached multiple areas with offer to self fund –no bed available, no other team felt able to support

?Long term admission to general hospital for NG feeding –Sophie accepted all therapy whilst IP at DGH so discharged back to EDS (x3)

?ITU and sedation to feed

Discussion with other T1DE teams for advice/ second opinion

Discussion with other mental health teams for advice/ support/ second opinion

Formal second opinion

PICU bed?

Trust MHA lead re insulin under restraint

Trust complex case panel

DGH ethics panel re long term ITU feeding

Senior colleagues within trust

MARM

Court of Protection

Complete therapy and notes review and documentation

Discharge?

Question 6

- Is there anything else we should have considered?

Current situation.....

- After nearly 2 years as an in-patient under section 3