

Type 1 Diabetes with Disordered Eating Service

Introduction

This leaflet describes the pilot service for patients with **Type 1** diabetes and **Disordered Eating** (T1DE). T1DE is a clinical service that brings together diabetes and mental health care under one team. The aim of T1DE is to help patients with type 1 diabetes who have severe fears of weight gain on insulin to improve their confidence and ability to manage their diabetes, and at the same time improve their mental health. This is the first integrated service of its kind in the UK. We have received funding from NHS England (London Division) for a limited period.

Who is this service for?

Sometimes living with type 1 diabetes can be burdensome. When this happens, it can lead to feelings of anger, frustration, low mood and anxiety, which can at times be persistent and debilitating. With so much focus on the type and amount of food eaten for healthy blood glucose levels, some people develop fears that insulin leads to weight gain. This can lead to disordered eating and reducing the dose of insulin given, which can cause serious complications.

This service is for people who meet the King's criteria for severe disordered eating and related insulin omission. The criteria are as follows:

1. Diagnosis of type 1 diabetes
2. Fear that insulin causes weight gain
3. Deliberate omission of insulin
4. Serious effects on diabetes self-care, including **at least one** of the following:
 - recurrent diabetic ketoacidosis (more than one admission in the past two years)
 - HbA1c level 10% or greater in the past 12 months
 - recurrent severe hypoglycaemia
 - low body weight (body mass index 15 kg/m² or less) or significant weight loss

This service is for patients who live in one of the boroughs of London and are registered with a London GP surgery. As this is a pilot service, there may be other clinical presentations we may need to include or exclude

We understand that patients who may not meet the service criteria still need and want help. We will advise your referring team if there are any other local options where we can.

What do I need to prepare for my initial assessment?

Please bring your glucose meter, insulin pens, insulin pump, sensor and any other diabetes-related technology. It would also be helpful if you could bring your copies of recent clinical letters including:

- eye screening report
- diabetes clinic letter
- psychology or psychiatry letter (if applicable)
- blood results
- anything else you want to share with us.

What happens during my initial assessment?

You will meet several members of our multi-disciplinary team (MDT). We are diabetologists, liaison psychiatrists, diabetes nurse specialists, specialist dietitians and psychotherapists.

Firstly, we will need to check that you are clinically safe to have an assessment on the day. This will involve taking some blood, checking your ketones and an ECG (tracing of the heart).

Then we will ask you some questions about your physical and mental health to get a complete picture of your situation. If you would like us to, we would welcome the opportunity to talk to your loved ones either separately or with you. We will only do this with your permission.

We will also ask you to complete some questionnaires about your mood, anxiety, eating patterns and your quality of life. These will help us monitor your progress.

Finally, we bring together all the assessments and meet with you to share our findings. We will discuss the treatment options with you. Your own ideas about what might help you will be very important.

How long does the assessment take?

Please expect to spend at least four hours at the hospital. You can bring someone with you for support. Please also bring some food and drink.

What happens to my diabetes care while I am on this treatment?

Your diabetes care will continue to stay with your usual diabetes team at your local diabetes centre.

What are the treatment options?

We aim to help you set small, realistic goals towards better diabetes self-care. We believe that focusing on improving your diabetes care will make you safe and have a positive effect on your mental health. We are not expecting you to make sudden big changes overnight. Our service is informed from our previous work in this area and from the research we are conducting. You are the most important member of the team.

There are several treatment options which will be tailored to your individual needs. These take into account what is available, realistic and what you want to get from the treatment. These include:

- **Diabetes cognitive behaviour therapy.** This is delivered by a diabetes specialist nurse. This therapy aims to gradually encourage you to develop new ways of thinking and acting about diabetes and insulin.
- **Psychodynamic psychotherapy.** This aims to encourage you to think about the emotional relationship with your diabetes in the context of all your life experiences.
- **Carer support.** This involves offering family members guidance on how best to support you.
- **Optimising your diabetes care,** such as making the best use of diabetes technologies and supporting your diabetes self-care skills.
- **Medications review** for your diabetes and your mental health. This includes a discussion as to whether you could benefit from antidepressants.
- **Inpatient admission.** This will be either to a medical ward or an eating disorders unit. Patients are only admitted to an eating disorders unit if their condition puts them at high risk of developing dangerous complications or of death.

The frequency and location of consultations, and which health professionals you will see, will depend on your needs and wishes and where you live. We expect that your treatment will last for about 6 to 12 months, but it could be longer.

How do we monitor your progress?

Together with you, we will regularly check your mood, the balancing act of wanting better health versus your body image, any admissions, and whether you are getting hypoglycaemia.

About every 3 to 6 months, members of the MDT will meet with you (and your family, if you wish) to share feedback about what is going well and what can work better.

We will also repeat the questionnaires you completed at the initial assessment.

What happens at the end of treatment?

Again, this depends on your unique situation. There are a number of options. Some people may be well enough to return to their local teams. Others may be at different stages of recovery. As this is a pilot service with limited funding, we will be working very closely with your local services to ensure good communication channels.

Sharing your information

T1DE is based at King's College Hospital, Guys & St Thomas Hospital and the South London and Maudsley NHS Trusts which are part of King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care. In addition, we are obliged to work with your local diabetes and mental health teams in London (where these exist). Therefore, your relevant medical information may be shared, respecting patient confidentiality, with members of the multidisciplinary team involved in your care across these sites.

Research

King's Health Partners has one of the largest research programmes on diabetes and mental health. Therefore, we have many ongoing research studies. We may invite you to participate in research as a volunteer. Whether you decide to participate or not will not affect your care.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: **020 3299 3601**

Email: **kch-tr.palsdh@nhs.net**

You can also contact us by using our online form at **www.kch.nhs.uk/contact/pals**

If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.