Best & Worst Practices

Best Practice

- Ensuring that all professionals involved in the care of the patient are in regular communication
- Clearly understanding the difference between type 1 and type 2 diabetes and demonstrating that to the patient
- Respecting the patient's knowledge of their Type 1 diabetes.
- Ensuring that the patient has checks for other contributory issues particularly hypothyroidism, neuropathy and gastroparesis
- Drawing any meal plans in line with good diabetic practice and taking other conditions such as gastroparesis into consideration
- Ensuring that the patients medications are up to date and wont interfere with Type 1 Diabetes . Ensuring that pain medication is working
- Patient tailored treatment which takes diabetes aspects and eating disorder aspects into consideration.
- Not being afraid to ask questions about diabebetes, most people with Type 1 are expert patients and appreciate the interest
- Taking the development of complications into consideration and dropping blood sugar slowly long term
- Often it only takes one health professional who really 'get's it' to help the patient sustain recover. Don't be afraid to take charge
- If you don't know who to refer to. Please see www.dwed.org.uk and we will do our best to find a suitable service.
- If you need to know more then request training, it's what we are here for
- Understanding the mechanisms of Diabetic Ketoacidosis

Worst Practice

- ED-DMT1/ Diabulimia is not a phase, a fad, a denial of diabetes, a short—cut or stupid and to tell our members that it is will automatically ensure a major setback if not a complete disengagement with health services
- People with mental illness may miss appointments, please don't discharge them from a service that they desperately need on the back of one missed appointment
- Our members know more than most the consequences of high blood sugar, they know that they are at serious risk of death, please don't assume that they are engaging in this behaviour out of ignorance
- A good diabetes diet is often in direct contradiction with a standard ED treatment plan. Please do not put our members on a refeeding plan when they are normal weight and do not have anorexia.
- There is no point on feeding someone with Diabulimia and then watching for them being sick or stealing food, the disease operates via a lack of insulin and high blood sugar so the most important thing is to ensure that the insulin is administered properly and is matched to the carbohydrate consumed
- Many anorexia treatment plans involve not informing the patient of the composition of what they are eating. Type 1 Diabetics need this information to survive and to know exactly what to inject
- If therapy doesn't involve feelings and thoughts around injecting and diabetes it will fail.
- Weighing is very distressing for many of our members who may be normal/ overweight

Complex Care Plan for:

Name: ....

Email: ....

Phone Number: ....

Table of Contents: Page:

Section	Page
Type 1 Diabetes and Eating Disorders: Diabulimia, ED-DMT1 and Comorbid Anorexia/ Bulimia	1
Current Situation/ Main Issues/ Barriers to Recovery	2
Last Test Results	3
Health Professional Details & Emergency Contact Details	4
Current Diagnoses and Medication/ Investigation	5
Supporting Documents	6
Plan	7
Plan Progress	8
Training and Further Information	9
Signs and Symptoms	10
Best & Worst Practice	11

Date	Time	Appointment	Location

Signs and Symptoms of ED-DMT1/ Diabulimia

It is important to note that in Type 1 Diabetes, Anorexia and/ or Bulimia can develop as it would in a someone without T1. However an Eating Disorder can also develop independently and have Diabetes specific roots. It is for this reason that these signs and symptoms should be taken into consideration as well as those associated with Anorexia and Bulimia. Please also note that this list is informed by academic research and also input from our members:

- Recurrent episodes of DKA/ Hyperglycaemia
- Recurrent episodes of Hypoglycaemia
- High HbA1c
- Frequent hospitalisations for poor blood sugar control
- Delay in puberty or sexual maturation or irregular menses / amenorrhea
- Frequent trips to the Toilet
- Frequent episodes of thrush/ urine infections
- Nausea and Stomach Cramps
- Loss of appetite/ Eating More and Losing Weight
- Drinking an abnormal amount of fluids
- Hair loss
- Delayed Healing from infections/ bruises.
- Easy Bruising
- Dehydration – Dry Skin
- Dental Problems
- Blurred Vision
- Severe Fluctuations in weight/ Severe weight loss/Rapid weight Gain/Anorexic BMI
- Fractures/ Bone Weakness
- Anaemia and other deficiencies
- Early onset of Diabetic Complications particularly neuropathy, retinopathy, gastroperisis & nephropathy
- Co – occurrence of depression, anxiety or other psychological disturbance i.e. Borderline Personality Disorder.
- Anxiety/ distress over being weighed at appointments
- Frequent Requests to switch meal plans
- Fear of hypoglycaemia
- Fear of injecting/ Extreme distress at injecting
- Continually requesting new meters (for the b.s. Solution)
- Injecting in private
- Insisting on having injected out of view
- Avoidance of Diabetes Related Health Appointments
- Lack of BS testing /Reluctance to test
- Over/ under - treating Hypoglycaemic episodes
- A fundamental belief that insulin makes you fat
- Assigning moral qualities to food (i.e. good for sugars/ bad for sugars)
- An encyclopaedic knowledge of the carbohydrate content of foods
- Persistent requests for weight loss medications
- If T1 is concurrent with hypothyroidism – abuse of levothyroxine
- Metformin abuse

Training and Further Information

DWED is an Information, Advice , Support and Advocacy service. All of our 20 Volunteers are former sufferers and their experience along with that of the trustee board informs everything that we do. Our Trustee Board consists of Founder and Former Sufferer Jacqueline Allan, World Renowned Eating Disorder Specialist Prof Janet Treasure, Diabetic Specialist Nurse Nicola Allen, Former Carer and Parent Advocate Kymin Hackett and Solicitor John Allan. We have trained, The Royal College of Nurses, B-Eat, the Juvenile Diabetes Research Foundation numerous diabetes and Eating Disorders Units and Services and work closely with bodies such as the Institute of Psychiatry and the Royal College of Psychiatrists. We have represented our members, of which there are over 2000 in parliament and have appeared in the national press.

We deliver a dedicated training service to health professionals all over the uk. Training is tailored to your service and audience number whether it's a one on one meeting with you as a GP or a department of diabetic specialists. This training service is totally free although we do always appreciate a donation to help with travel expenses.

It may be that you feel a service that you are using would benefit from DWED training. All you need to do is fill in an advocacy request form from our website here: http://www.dwed.org.uk/Get-Help/ we will then get in touch with your service/ professional and offer them support and training

It may be that you want to pass this sheet on to someone so they can request training or have a look around the website for further information

Where can you find Diabetics with Eating Disorders?:

http://www.dwed.org.uk/

http://www.facebook.com/DiabeticswithEatingDisorders

http://www.facebook.com/groups/DiabulimiaSupport/ (peer support group)

https://twitter.com/diabeticswithed

http://dwed.tumblr.com/

http://www.youtube.com/user/DWEDinfo

http://www.tudiabetes.org/group/diabeticswitheatingdisorders

Where can you donate?

http://www.justgiving.com/diabeteswed/donate

Type 1 Diabetes and Eating Disorders: Diabulimia, ED-DMT1 and Comorbid Anorexia/ Bulimia

What does type 1 Diabetes have to do with Eating Disorders? Diabulimia

When a person with Type 1 Diabetes does not take enough insulin the level of (glucose) sugar in the blood increases. Lack of insulin leads to glucose being unable to convert to glycogen for energy. This glucose is then lost in the urine and the calories it contains are not used. As this goes untreated the body responds to the lack of energy by burning the body's fat stores, muscle and if left, tissue from major organs. This process creates by-products known as ketones which are acidic and dangerous to the body. When there is a certain level of ketones in the system the body develops Diabetic Ketoacidosis (DKA). DKA is always fatal if left untreated. 'Diabulimia' is the common term for when someone with Type 1 diabetes uses this process for weight control, and it will be included in the DSM V released in May 2013 While for some the use of insulin omission may be intermittent, there are more who are trapped in this behaviour long term. The Joslin Diabetes Centre estimates that 40% of Type 1 females aged 15—30 regularly omit insulin for weight control. Diabulimia is a serious, pervasive and complex psychiatric condition and should be treated as such, with understanding & compassion but also with urgency as per NICE guidelines.

ED-DMT1, Co-morbid Anorexia & Bulimia

ED-DMT1 (Eating Disorders in Diabetes Mellitus Type 1) is an umbrella term to describe a multitude of eating disturbances in Type 1 diabetes . Current research suggests that those with Type1 Diabetes are twice as likely to develop anorexia or bulimia. There are several suggestions as to why there may be Type 1 specific reasons for this eg. when there is too much insulin in the blood a person with Type 1 Diabetes experiences hypoglycemia (commonly known as 'a hypo'). Hypos are extremely distressing often leading to blackouts and if untreated a coma. To avoid over injecting many Type 1s cut back on their food and/or insulin intake which can lead to accidentally learning the hyperglycemic process, it can also foster anorexic behaviours. When in a hypo the body sends signals to the brain to consume sugar as quickly as possible. This can become problematic and lead to binge/purge cycles commonly associated with Bulimia. Type 1 Diabetes care has other aspects that contribute to eating disordered behaviour. To achieve good blood sugar control it is often necessary to follow a strict diet and exercise regime leading to moral judgments on foods and behaviours. This is often inadvertently encouraged by health teams and parents and can prove much to cope with at a time when most adolescents crave more control and independence.

Why have a Complex Care Plan?

If diabetes specific aspects are not attended to then psychological therapy will be ineffective. If diabetes professionals ignore emotions around food and body shape then diabetes education will be ineffective. We see many of our members being misdiagnosed and treated using methods that do not take into account the patient's issues as a whole. One of the main barriers to long lasting recovery and effective treatment is mis/non—communication between professionals. The idea behind this complex care plan is to ensure that all parties involved in the patient's recovery are providing consistent, compatible treatment. DWED has seen that only a multidisciplinary approach will be successful and this plan aims to make communication as simple as possible while keeping the patient at the centre of their own recovery.

Current Situation/ Main Barriers to recovery

What do you think are the main problems? Do you have any issues that are not being dealt with? Do you feel that you have been misdiagnosed or under diagnosed? Are you having an issue with a specific health care provider? We have provided space here for you to write a short note, but we suggest that you write this on a separate piece of paper so that you can update it periodically.

Latest Test Results

We have provided space here to record how you are progressing with standard Diabetic health checks. We understand that you may have other issues that you want to chart and so we have provided extra space for you to fill them in

	Date	Date	Date	Date
Renal Function				
Retinopathy				
Foot Check				
Hba1c				

Progress

It is a good idea to document here any issues you are having as you progress through recovery. If you can show these to your health professionals then they can help you overcome any problems you ma y feel are holding you back.

Plan as Agreed by Health Professionals

It takes a multidisciplinary team working together to ensure the safety and recovery of a person with Type1 and an Eating Disorder. It is vitally important that all parties involved are working towards the same goal so here we have provided a space for you to detail what your plan for recovery is and on the next page how you feel about how you are progressing

Health Professional Details

GP Details: DR

Address:

Telephone: Email

Diabetes Clinic: Consultant DR DSN

Address:

Telephone: Email

Eating Disorder Clinic: Consultant DR ED Nurse

Address:

Telephone: Email

Other :

Address:

Telephone: Email

Address:

Telephone: Email

Emergency Contact Details

Name Relationship:

Address:

Telephone: Email

Name Relationship:

Address:

Telephone: Email

Current Diagnoses and Medication

The purpose of this section is to keep all your health professionals up to date with what you are currently diagnosed with i.e. bulimia, neuropathy, gastroparesis, who by i.e GP, ophthalmologist, psychologist and what you have been prescribed to treat it. i.e flueoextine, domperidone, thyroxine.

Diagnosis	Diagnosed by	Date	Prescribed

Investigation

Many people who have suffered from a Diabetic Eating Disorder have avoided appointments or have been too afraid to get an issue investigated. This section here is for you to be honest about what issues you are currently facing and for your health professionals to help you get these investigated. I,e you may feel like you are having issues with your eyes or stomach that warrant specialist care from a gastroenterologist and an opthomologist. In this case you would report it to your GP and they would refer you to a specialist clinic who will give you an appointment.

Issue	Reported to	Date	Appointment date

Supporting Documents

We advise you to keep a copy of all communications sent to you/ between your health professionals so that everyone is upto date . Here you can also keep a record of what you have .

From	To	Date	Regarding