**POSITION STATEMENT**

**Diabulimia**

**KEY POINTS:**

- Diabulimia is not a recognised medical or psychiatric term but describes the practice of reducing or omitting insulin in order to lose weight.
- It has been suggested that 40% of women with Type 1 diabetes may omit or reduce insulin to lose weight and 11% of adolescent boys.
- Diabulimia is associated with increased morbidity and mortality.
- Awareness of the signs and consequences of diabulimia must be raised with friends and family of people with Type 1, and with healthcare professionals.
- Appropriate support and treatment must be available to people with diabulimia.

**Introduction**

Diabulimia is not a recognised medical or psychiatric condition but a term used to describe a ‘disordered eating behaviour’ in the practice of reducing or omitting insulin in order to lose weight. While not formally recognised as a mental health condition in its own right, the Diagnostic Statistical Manual of Mental Disorders (DSM-5) considers that insulin omission in order to lose weight is a clinical feature of anorexia and bulimia. Similarly, Diabulimia has also been recognised in the most recent NICE guidance for eating disorders (currently in press). Research has found diabulimia to be the term that people who reduce or omit insulin in this way like to use to describe the practice. Consequently, the term “diabulimia” will be used in this position statement.

There are a number of reasons why insulin may be reduced or omitted, such as fear of hypos or underestimating carbohydrate counting. However, when this is related to weight control and occurs over a long period of time, it is classed as diabulimia.

**Current situation**

It is difficult to estimate the number of people with diabulimia. Published prevalence data are inconsistent due to the different methodology used, and so findings should be used with caution. However, estimates of insulin omission have been reported in up to 40% of people with diabetes.

It is not just women that can be affected by diabulimia. Research also shows that men with Type 1 diabetes have a ‘higher drive for thinness’, a key driving factor in the development of an eating disorder, than their non-diabetic counterparts, making them more susceptible to diabulimia. A recent study from Germany suggests that 11.2% of boys between 11-19 omit insulin to lose weight.

The recommended management of Type 1 diabetes can make an individual more vulnerable to an eating disorder. The following have been...
listed as diabetes-specific contributory factors that can lead to eating disorders in people with Type 1 diabetes:

- Attention to food labels
- Attention to weight
- Bingeing following hypoglycaemia
- Constant awareness of numbers
- Parental attitude towards Type 1 diabetes
- Shame over management
- Negative relationships with healthcare professionals
- Difficulty losing weight due to insulin therapy

It is unlikely that any of these factors exist by themselves and diabulimia usually develops from a complex combination of biological, psychological and social difficulties.

**Consequences of diabulimia**

Diabulimia is associated with an increase in retinopathy, nephropathy and foot problems \(^7\-^9\), and the duration of severe insulin omission is the factor most closely associated with the development of retinopathy and nephropathy \(^8\).

**Diabetes UK calls to action**

Diabetes UK calls for the following action across the UK to improve recognition and management of diabulimia, and so improve patient outcomes.

- Psychological factors should always be considered, assessed and excluded in all episodes of DKA
- Sufficient time, resources and training must be in place to enable diabetes healthcare professionals to identify and support people with diabulimia effectively

**Healthcare professionals across the UK**

- Must be aware of the possible signs of diabulimia (see below)
- Must consider diabulimia as a potential reason for recurrent DKA
- Must refer people with diabulimia to appropriate specialist services without delay

- Must offer sensitive support to people with diabetes and avoid comments or procedures that may trigger insulin omission (eg unnecessary monitoring of weight), see [www.dwed.org.uk](http://www.dwed.org.uk).

In addition, there are specific calls to action in England and Wales:

**England**

- The Mental Health Taskforce recommendation to increase access to evidence-based psychological therapies for people who are living with long-term physical health conditions must be implemented. The choice of therapy offered should consider evidence for effectiveness and patient choice
- As part of this, NHS England and Health Education England must ensure that the right staff and services are available to identify, support and treat people with diabetes who are misusing insulin to control their weight within the multidisciplinary diabetes team.

**Wales**

The Welsh Government’s Together for Health: A Diabetes Delivery Plan\(^1\) states that:

‘It has been estimated that 41% of people with diabetes have poor psychological well-being, with eating disorders as well as depression and anxiety as presenting difficulties. Assessment of psychological difficulties that may pose a barrier to effective self-care and medical management of diabetes is essential. Health boards must ensure sufficient psychological input into the management of patients in line with national standards. All members of the care team should be supported to provide an element of psychological support, in line with the pyramid of psychological need, to target clinical psychologist support at those with the greatest need.’

Diabetes UK Cymru is working with Welsh Government and other stakeholders to monitor implementation of the plan.
This section sets out Diabetes UK’s recommendations in relation to diabulimia. These are around awareness and treatment of the condition.

**Awareness**

Healthcare professionals, family and friends of people with Type 1 diabetes should be aware of the signs that could indicate diabulimia. These can include \[^{11-12}\]:

- Weight loss/fluctuation in weight
- High HbA1c
- Recurrent DKA/admission to hospital for hyperglycaemia
- Regular symptoms of high blood glucose levels
- Early onset of diabetes complications
- Secrecy over or fear of injecting
- Reluctance to be weighed
- Not attending diabetes appointments
- Lack of blood glucose monitoring/reluctance to self monitor
- Depression, anxiety or other psychological disturbance
- Pubertal delay, amenorrhea or irregular menses
- Changes in appetite
- An encyclopaedic knowledge of nutritional composition of foods
- Fear of gaining weight
- Distorted body image
- Withdrawal from usual activities

It is important to note of course that there are other reasons for these signs or behaviours and they do not necessarily always indicate diabulimia. However, healthcare professionals, family and friends should be aware that diabulimia could be a cause.

**Treatment**

Standard treatments for eating disorders are not usually appropriate for cases of diabulimia. Treatment for eating disorders tend to involve removing the focus on food, which is of course contrary to recommended advice for management of Type 1 diabetes. Instead, better access is needed to diabetes specialist psychological services that can provide the integrated support that people with diabulimia need. Early intervention and referral is crucial. An example of good practice is the service at the South London and Maudsley NHS Foundation Trust. Professionals at the Trust state that treatment for diabulimia is complex and requires good physical and psychological care.

Psychological therapy relies on a brain which can learn and reflect so is less effective if brain function is compromised by poor diabetic control or a low BMI. Likewise if diabetes professionals do not consider emotions around food and body shape then diabetes education will be ineffective.

The Trust offer a service for people with diabulimia where psychiatrists and diabetes clinicians work in teams together - bridging the gap between physical and psychological care. The service provides inpatient, day patient and outpatient care and offers people with diabulimia an opportunity to explore their difficulties and gain control over their eating disorder through one-to-one, group and family care.

**Research**

Given the difficulties in establishing the number of people with diabulimia, there is a need for more research into effective screening instruments. This is applicable to both men and women, but is particularly pertinent to men, as numbers of men affected are very difficult to establish. There must also be further research into effective treatments.

**Conclusion**

Diabulimia is a serious condition which can result in increased and earlier complications of diabetes and reduce both life expectancy and quality of life. Currently there is a lack of awareness of the condition amongst family and friends of people with Type 1 diabetes, and also amongst healthcare professionals who do not necessarily consider it as a cause for recurrent DKA or persistent hyperglycaemia. Added to
this, there is extremely poor access to the specialist care that is vital to support people with diabulimia in the most appropriate way. Diabetes UK recommends that both awareness of the condition and access to appropriate treatment are improved as a matter of urgency in order to reduce the number of people who develop serious complications of diabetes and a severely reduced quality of life due to diabulimia.

Further information

- http://dwed.org.uk/
  www.deda.org.nz*

References

1. Diagnostic Statistical Manual of Mental Disorders 2013
   http://www.dsm5.org/psychiatrists/practice/dsm
2. NICE 2016
   https://www.nice.org.uk/guidance/GID-CGWAVE0703/documents/draft-guideline
3. Allen J.A. 2015
   https://www.researchgate.net/publication/274416053_UnderstandingPoorOutcomesinWomenWithType1DiabetesAndEatingDisorders
6. Hevelke L.K. et. al Prevalence of disturbed eating behaviour in children and adolescents with Type 1 diabetes: assessment and comparison to healthy peers – results of a multicentre questionnaire based study
   https://www.ncbi.nlm.nih.gov/pubmed/2

    http://gov.wales/topics/health/nhswales/plans/diabetes/?lang=en
11. Diabetics with Eating Disorders
    http://dwed.org.uk/
12. Expert opinion

*Diabetes and Eating Disorders Awareness is based in New Zealand so all information may not be applicable to the UK