



**DWED: OUR FEEDBACK ON
NICE GUIDELINES AND
QUALITY STANDARDS FOR
TYPE 1 DIABETES IN
ADULTS, CHILDREN &
YOUNG PEOPLE**

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The information provided to you in this fact-sheet should assist you in engaging with health practitioners regarding eating disorders in those with type 1 diabetes. DWED endeavours to help you in understanding your clinician’s responsibility to recognise ED-DMT1 (any kind of eating disorder present in someone with type 1 diabetes) and Diabulimia (deliberate insulin omission with the aim of weight-control), the result of which should be the referral to appropriate services as a priority. The following resource has been produced in response to the updated 2016 NICE Guidelines and Quality Standards in treating type 1 diabetes in both adults and children/ young people.

What is NICE?

The National Institute for Health and Clinical Excellence (NICE) is an organisation that was founded in 1999. Their aim is to be a valuable source for national guidance and advice in improving health and social care. This involves making public health recommendations with the intention of preventing ill health and promoting healthier lifestyles. NICE publish essential information for key groups including GPs, local government, public health professionals as well as members of the public.

Which NICE recommendations apply to me?

NICE have produced various documents that address recommendations for the treatment of diabetes. Both NICE Guidelines and Quality Standards include information that can be used to assist in advocating for appropriate care of someone experiencing diabetes and an eating disorder. If you are under the care of adult diabetes services

NG [NICE Guideline] 17 [August 2015, updated July 2016]

QS [Quality Standard] 6 [published 14 July 2016]

are applicable. If currently under the care of children and young people services, the relevant recommendations can be found in

NG [NICE Guideline] 18 [August 2015, updated July 2016]

[Quality Standard] QS125 [March 2011, updated August 2016]

This guide will breakdown these recommendations and give you DWED's interpretation of them in order to ensure that your Health Care Providers are providing you the appropriate support.

What is a NICE Clinical Guideline?

A NICE clinical guideline is a directive aimed at health professionals which focuses towards delivering 'best practice' care. Best practice means treatment that is tailored to an individual and addresses all possible needs that an adult with diabetes may have. The following explanation is taken from NICE Guideline 17

Patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution for England– all NICE guidance is written to reflect these. Treatment and care should take into account individual needs and preferences.

An independent advisory group referred to as 'the committee' develops the recommendations. Committee members include practitioners, care providers or commissioners, and others working in the area covered by the guideline. Additionally, at least 2 members of every Committee are people using services, their family members or carers, or members of the public and community or voluntary sector with relevant experience (lay members). Recommendations are compiled by the use of evidence, ranging from scientific research to testimony from practitioners, people using services and the views of stakeholders. This process usually takes between 12 and 27 months from the start of scoping to publication, depending on the size and complexity of the topic

What is a NICE Quality Standard?

A NICE Quality Standard is a specific rationale separated into areas of structure, process and outcome. Quality Standards are based on NICE guidance as well as other NICE-accredited sources. They are independently produced but in collaboration with health and social care professionals, practitioners and service users. Quality Standard 6 (diabetes care for adults) describe Quality Standards as a

concise set of prioritised statements designed to drive measurable improvements in the 3 dimensions of quality – safety, experience and effectiveness of care – for a particular area of health or care.

This involves listing statements to help improve quality of care and also offering procedures on how to measure progress against the statement.

NICE quality standards are written by an advisory committee, Standing members of a committee include commissioners, primary care professionals, experts in quality measurement, social care experts, local authority representatives, lay members, secondary care providers and public health practitioners. They are recruited in line with NICE policies and procedures for recruitment and selection to advisory bodies. Quality statements are then revised after input from stakeholders and then finally approved for publication by the NICE Guidance Executive. This entire process can take up to 40 weeks.

Are NICE recommendations mandatory?

The recommendations... represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take...guideline[s] fully into account, alongside the individual needs, preferences and values of their patients or service users. The application of the recommendations... are not mandatory and... [do] not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian. [Page 2, NICE Guideline17]

This means that although NICE expect their guidelines and quality standards to be carefully considered, every case is unique. Ultimately, NICE recommendations can be used to advocate for appropriate treatment for you or for your child or young person, but only in cases where they are relevant and useful.

Adding to this NG17 states that

treatment and care should take into account individual needs and preferences.

DWED believes that the behaviours of someone with diabetes and an eating disorder need to be specifically addressed and acknowledged in order to lead to the right treatment. In light of this it is important that NICE have stressed that their guidance is not wholly compulsory. In turn, tailored treatment should ensure that a patient is given the right kind of diagnosis and so deliver better outcomes for recovery. This should also improve relationships between health care providers and service users by establishing trust and confidence that the correct treatment is being offered.

Do NICE recommendations for Type 1 Diabetes specifically mention Eating Disorders?

Yes, crucially NG17 reads:

1.4.12 Modify nutritional recommendations to adults with type 1 diabetes to take account of associated features of diabetes, including:

Eating Disorders

1.4.13 Be aware of appropriate nutritional advice on common topics of concern and interest to adults living with type 1 diabetes, and be prepared to seek advice from colleagues with more specialised knowledge. Suggested common topics include:

- *comorbidities, including nephropathy and renal failure, coeliac disease, cystic fibrosis or eating disorders*

1.15.43 Members of diabetes professional teams should be alert to the possibility of

- *bulimia nervosa, anorexia nervosa and insulin dose manipulation in adults with type 1 diabetes with:*

- *over-concern with body shape and weight*
- *low BMI*
- *hypoglycaemia*
- *suboptimal overall blood glucose control.*

See also the NICE guideline on eating disorders. [2004, amended 2015]

1.15.44 The risk of morbidity from the complications of poor metabolic control suggests that consideration should be given to early, and occasionally urgent, referral of adults with type 1 diabetes to local eating disorder services. [2004]

These guidelines emphasise the importance that clinicians be aware and able to recognise the signs of an eating disorder as early as possible. If any such difficulties are suspected then early intervention is paramount and so if advice from colleagues with more expertise are required this should be arranged immediately. This we assume is because there is such a great risk of fatality from ED-DMT1 and insulin omission which can happen within days. Additionally, the recommendations imply that sensitivity around any nutritional advice should ideally involve an eating disorder specialist as well as a diabetes consultant.

Quality Standard 18 refers to recognising eating disorders for patients under children and young people's diabetes services:

1.2.107 Diabetes teams should be aware that children and young people with type 1 diabetes, in particular young women, have an increased risk of eating disorders. See also the NICE guideline on eating disorders. [2004, amended [2004, amended 2015] 2015]

1.2.108 Be aware that children and young people with type 1 diabetes who have eating disorders may have associated difficulties with:

- *suboptimal blood glucose control (both hyperglycaemia and hypoglycaemia)*
- *symptoms of gastroparesis.[2004, amended 2015]*

1.2.109 For children and young people with type1diabetes in whom eating disorders are identified, offer joint management involving their diabetes team and child mental health professionals.[2004, amended 2015]

This segment of the Quality Standard for the care of diabetes in young people (QS125) provides education on the high prevalence of diabetes related eating disorders and the issues that may occur as a result of such. It also enforces the need for patient centred, integrated care and further requirements for specialist services to be involved. This means that all service users should be given access to mental health professionals and if this is not the case then clinicians can be held to account for not adhering to the quality standards as they are expected to.

Quality Standard 6 recommends that children and young people with type 1 or type 2 diabetes are offered access to mental health professionals with an understanding of the illness. It says:

Psychological issues (such as anxiety, depression, behavioural problems, eating disorders, conduct disorders and family conflict) and psychosocial issues have a significant and adverse impact on the management of type 1 and type 2 diabetes, and on the general wellbeing of children and young people and their family members or carers. Children and young people with diabetes are at high risk of anxiety and depression, and it is important that they have early access to mental health professionals when they need it. Mental health professionals who have an understanding of diabetes and the particular problems it causes are essential for delivering psychological interventions and engaging with children, young people and their families.

In terms of implementing access to such arrangements QS6 suggests:

Multidisciplinary paediatric diabetes teams should include a psychologist, and provide access to them in an appropriate timeframe. Each child and young person with type 1 or type 2 diabetes should have an annual assessment by their multidisciplinary team to decide whether they need support from the psychologist.

[Adapted from Diabetes (type 1 and type 2) in children and young people: diagnosis and management (2015) NICE guideline NG18 (full guideline) and expert opinion]

Are there other points in the Guidelines and Quality Standards that relate to me?

Yes, for adult service users NICE Guideline 17 advises:

Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals...Healthcare professionals should follow the Department of Health's advice on consent. If someone does not have capacity to make decisions, healthcare professionals should follow the code of practice that accompanies the Mental Capacity Act and the supplementary code of practice on deprivation of liberty safeguards.

This part of NG17 is very important in treating someone with type 1 diabetes and an eating disorder, specifically in reference to the Department of Health's advice on consent. An eating disorder is a mental illness and so those with ED-DMT1 or diabulimia can lack the capacity to care for themselves appropriately and so need assistance with this. Decisions that would normally be a patient's own responsibility, for example the monitoring of blood glucose levels or insulin administration, may need to be assigned to a carer or if in day or inpatient services, an appropriate nurse or doctor. If it is suspected that a patient lack sufficient consent to undertake such tasks and they refuse to agreement that such responsibilities be assigned to somebody else, then a mental health act assessment for immediate care would be required.

NICE Guideline 17 sets out instructions relating to the stage of a diagnosis of type 1 diabetes:

"1.15.45 Make provision for high-quality professional team support at regular intervals with regard to counselling about lifestyle issues and particularly dietary behaviour for all adults with type 1 diabetes from the time of diagnosis (see sections 1.3 and 1.4). [2004]"

This directive is particularly important as a diagnosis can often be a trigger for eating disordered symptoms or lead to the development of unhealthy associations around food. This may result from fluctuations in weight after an insulin regime is introduced or the great focus on nutritional info and intake that is required to sustain blood glucose control. We hope that this guideline will lead to more sufficient emotional support being offered to patients from the time of diagnosis.

NICE Guideline 17 also indicates:

1.2.2 Advice to adults with type 1 diabetes should be provided by a range of professionals with skills in diabetes care working together in a coordinated approach. A common environment (diabetes centre) is an important resource in allowing a diabetes

multidisciplinary team to work and communicate efficiently while providing consistent advice. [2004]

1.2.7 The multidisciplinary team approach should be available to in-patients with type 1 diabetes, regardless of the reason for admission (see section 1.14). [2004]

This guidance accounts for current failure within the system in delivering fully incorporated care which is so important when mental illness is a conflicting issue. It is often the case that someone with ED-DMT1 and/or diabulimia is told what insulin doses they need to take by their diabetes team, what foods they should eat at such times and so on. Furthermore, they may be given dietetic and/or psychological based support by an eating disorder clinic that struggles to grasp the emotional toll type 1 diabetes can have. This can be hugely frustrating as someone with type 1 diabetes as there is a breakdown in communication between the two services. DWED is aware that many people with diabetes and eating distress are seen as too complex and simply referred to an eating disorder team that have great expertise in anorexia and bulimia but struggle to grasp difficulties involving insulin and weight in a diabetic patient. This can lead to the wrong treatment being delivered and leave the patient feeling isolated and open to the risk of insulin manipulation that will go unnoticed.

When blood glucose levels drop too quickly after a prolonged period of running high this can lead to the risk of complications such as retinopathy or neuropathy. General hospitals without any psychological training can often put a patient that has been omitting insulin straight onto a sliding scale which may reintroduce insulin too rapidly. The following NICE Guideline can be used to assert the need for insulin to be reintroduced at a rate that will reduce a patient's HbA1C at a gradual rate so to avoid lasting complications:

1.6.7 Agree an individualised HbA1c target with each adult with type 1 diabetes, taking into account factors such as the person's daily activities, aspirations, likelihood of complications, comorbidities, occupation and history of hypoglycaemia. [new 2015]

Metformin can help improve glutotoxicity (insulin resistance caused by high blood glucose levels) and so can be helpful for someone with Diabulimia. This is because it may enable them to accept lower insulin doses if they feel incapable of increasing during an acute hospital admission or the early stages of recovery. This has been reflected by the NICE Guideline:

1.7.14 Consider adding metformin[1] to insulin therapy if an adult with type 1 diabetes and a BMI of 25 kg/m² (23 kg/m² for people from South Asian and related minority ethnic groups) or above wants to improve their blood glucose control while minimising their effective insulin dose. [new 2015]

The following part of NG17 can be useful in accessing the appropriate action regarding incidents of ketoacidosis:

1.11.4 Professionals managing DKA in adults should be adequately trained, including regular updating, and be familiar with all aspects of its management which are associated with mortality and morbidity. These topics should include: precipitating causes

1.11.12 To reduce the risk of catastrophic outcomes in adults with DKA, ensure that monitoring is continuous and that review covers all aspects of clinical management at frequent intervals. [2004, amended 2015]

Unfortunately a common occurrence that eating disorder related diabetic is not identified as such. A type 1 diabetic presenting with DKA needs immediate medical treatment but this should be followed by psychological help if deliberate insulin omission is suspected. This would hopefully lead to less repeat admissions and less long term damage to the patient's health as they are emotionally supported in taking their prescribed insulin.

NICE Guideline 18 talks about the importance of psychological support and the understanding of social issues in children and young people with diabetes:

1.2.94 Diabetes teams should be aware that children and young people with type 1 diabetes have a greater risk of emotional and behavioural difficulties. [2004, amended 2015]

1.2.96 Assess the emotional and psychological wellbeing of young people with type 1 diabetes who present with frequent episodes of diabetic ketoacidosis (DKA). [2004, amended 2015]

1.2.97 Be aware that a lack of adequate psychosocial support has a negative effect on various outcomes, including blood glucose control in children and young people with type 1 diabetes, and that it can also reduce their self-esteem [2004, amended 2015]

NG18 also recommends that all diabetes teams have the expertise of mental health professionals to assist them in determining psychological distress:

1.2.100 Diabetes teams should have appropriate access to mental health professionals to support them in psychological assessment and the delivery of psychosocial support. [2004]

Best practice would mean that there is a psychological specialist on site at all diabetes clinics and as part of the team delivering inpatient care in a general medical setting for a type 1 diabetic. This is a point that has been raised in various focus groups centered around what NHS care for diabetes should involve and has been acknowledged as an obvious failing by many people with type 1 diabetes.

NG17 contains a section that focuses on inpatient admissions for patients with type 1 diabetes:

1.14.7 From the time of admission, the adult with type 1 diabetes and the team caring for him or her should receive, on a continuing basis, advice from a trained multidisciplinary team with expertise in diabetes. [2004]

1.14.8 Throughout the course of an inpatient admission, respect the personal expertise of adults with type 1 diabetes (in managing their own diabetes) and routinely integrate this into ward-based blood glucose monitoring and insulin delivery.[2004, amended 2015]

1.14.9 Throughout the course of an inpatient admission, the personal knowledge and needs of adults with type 1 diabetes regarding their dietary requirements should be a major

determinant of the food choices offered to them, except when illness or medical or surgical intervention significantly disturbs those requirements. [2004]

1.15.30 Reassure adults with type 1 diabetes that acute painful neuropathy resulting from rapid improvement of blood glucose control is a self-limiting condition that improves symptomatically over time. [new 2015]

1.15.31 Explain to adults with type 1 diabetes that the specific treatments for acute painful neuropathy resulting from rapid improvement of blood glucose control have the aim of making the symptoms tolerable until the condition resolves may not relieve pain immediately and may need to be taken regularly for several weeks to be effective. [new 2015]

These set of guidelines can be useful in alerting health professionals to the rapid onset of complications that can be applicable to someone with diabulimia or ED-DMT1. This can be particularly specific when blood glucose levels are being lowered in a medical setting.

The mention of personal dietary requirements can be helpful in asserting the need for health professionals to respect that an individual with type 1 diabetes and an eating disorder has particular fears of certain foods for example. A meal plan should be discussed with the patient and carefully considered with acknowledgement of what is safe but also manageable. Such recommendations also convey a sense that someone suffering from diabetes and an eating disorder should be treated with compassion and sensitivity which is important as of course their condition is not simply a consequence of ignorance or non-compliance, but the result of psychological disturbance.

Are there any points from the guidelines that are problematic?

Yes, DWED find the following sections from NG17 to be problematic:

1.14.6 Enable adults with type 1 diabetes who are hospital inpatients to self-administer subcutaneous insulin if they are willing and able and it is safe to do so. [new 2015]

The use of *"if they are willing and able and it is safe for them to do so"* in relation to self administration of insulin is crucial. This risk should be appropriately considered and assessed in patients presenting with type 1 diabetes and eating disorders. The following point is also relevant:

1.14.8 Throughout the course of an inpatient admission, respect the personal expertise of adults with type 1 diabetes (in managing their own diabetes) and routinely integrate this into ward-based blood glucose monitoring and insulin delivery.[2004, amended 2015]

Here the focus on ‘personal expertise’ is problematic as someone suffering from an eating disorder may not be able to rely on their own expertise which is compromised by their eating disorder. Extremely close supervision of blood sugar levels and insulin administration is a must if someone is very ill.

The entire section of NICE Guideline 18 giving dietary advice for treatment of those receiving care under children and young people’s services can easily conflict with the considerations required for someone with ED-DMT1 and/or diabulimia, This is because mental health difficulties and the emotional impact of diabetes management of food and weight is not sufficiently addressed, For example:

“1.2.42 Explain to children and young people with type 1 diabetes and their family members or carers (as appropriate) that a low glycaemic index diet may help to improve blood glucose control and reduce the risk of hyperglycaemic episodes. [new 2015]

1.2.43 Offer children and young people with type 1 diabetes and their family members or carers (as appropriate) advice and education to promote a low glycaemic index diet.[new 2015] “

What can I do if I feel my Teams are not following the Guidelines and Quality Standards?

If you are an adult or young person with type 1 diabetes experiencing an eating disorder or you are a carer or guardian for a child or young person in a similar situation, the NICE recommendations can be of use to you. You can urge clinicians to read the comprehensive NICE Guidelines and Quality Standards documents or instead simply provide them with all the eating disorder relevant information DWED have provided within this fact-sheet. Having a detailed dissemination of the 2016 NICE Guidance and Quality Standards should be of great assistance in facilitating care needs for yourself or for a child or young person. Although the NICE recommendations are not mandatory they are expected to be utilised by health professionals, If your health practitioners chose to ignore the advice available to them and continue to withhold access to appropriate treatment then DWED would suggest you make a formal complaint, first of all to NHS England, and then if not sufficiently addressed, the Health Ombudsmen. You can find out more about this process by visiting: www.NHSEngland/complaints-and-feedback/Pages/nhs-complaints.aspx