Clinical Excellence Queensland

# Disordered Eating and Eating Disorders in Children, Adolescents and Adults with Type 1 Diabetes















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### Disordered Eating (DE) and Eating Disorders (ED) in Children, Adolescents and Adults with Type 1 Diabetes (T1D)

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#### **Contents**

1	Intro	duction	5
	1.1	Defining DE and ED	6
	1.2	Prevalence and contributing factors	7
	1.3	Consequences of DE/ED in T1D	9
2	Preve	enting DE/ED in T1D	. 10
	3.1	Principles of 'healthful' eating	. 13
	3.2	Identification of DE, including signs and symptoms	. 13
	3.3	Routine psychosocial screening	. 15
	3.4	Clinical interview and assessment for DE/ED- including assessment of medical and psychological risk	. 17
4	Phys	ical indicators for hospital admission	. 21
	4.1	Questions and algorithm for asking about self-harm and suicidality risk	. 23
5	Interv	rention to Manage DE/ED in T1D	. 24
	5.1	Principles of treatment	
		Principle 1: Prompt response with sensitivity	
		Principle 2: A Multidisciplinary Team approach	
		Principle 4: Individualised care pathway	
		Principle 5: Concurrent Integration of diabetes knowledge, dietary and psychology interventions	
		Principle 6: Early collaboration with specialist eating disorder services/clinicians	
6		ested MDT Roles for Management of T1D with DE	
	6.1	Medical/endocrinologist/general practitioner	
	6.2	Dietitian (APD)	
	6.3	Credentialled diabetes educator (CDE)	
	6.4	Mental health practitioner/psychologist	
	6.5	Specialist services referrals	
		DSM-5 and ICD-10 criteria	
Appe	ndix 2	Diabetes Psychosocial Assessment Tool (DPAT)	. 32
Appe	ndix 3	Diabetes Eating Problem Survey – Revised Scale (DEPS-R Scale)	. 34
Appe	ndix 4	Specialist eating disorder services	. 35
Supp	lemen	t	. 41
Fig	jure	es e	
			07
Figur	e z Aiç	gorithm for asking about self-harm and suicidality risk. – age ≥ 16 years	. 37
Tal	bles		
Table	1 Pot	ential contributing factors to DE/ED in T1D	8
Table	2 Sig	ns of DE	. 14
		essment of DE/ED in T1D	
	•	rsical indicators for hospital admission – paediatric	
Table	5 Ind	cations for medical admission in people with both DE/ED and T1D (for age ≥ 16 years)	. 22

#### **Abbreviations**

AN	Anorexia nervosa
ARFID	Avoidant restrictive food intake disorder
BED	Binge eating disorder
ВМІ	Body mass index
BN	Bulimia nervosa
CGM	Continuous glucose monitor (monitoring)
CYMHS	Child and Youth Mental Health Service
DE	Disordered eating
DE/ED	Disordered eating or eating disorders
DEPS-R	Diabetes Eating Problem Survey – Revised Scale
DKA	Diabetic ketoacidosis
DPAT	Diabetes Psychosocial Assessment Tool
DSM-5	Diagnostic and Statistical Manual of Mental Disorders Edition 5
ECG	Electrocardiogram
ED	Eating disorders
HbA1c	Glycated haemoglobin
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision.
ICR	Insulin to carbohydrate ratio
ISF	Insulin sensitivity factor
LFT	Liver function tests
MDT	Multi-disciplinary team
NDSS	National Diabetes Services Scheme
OSFED	Other specified feeding and eating disorder
OzDAFNE	Dose adjustment for normal eating (Australian version)
T1D	Type 1 diabetes mellitus
mSCOFF	Screening tool: Modified Sick, Control, One, Fat, Food tool
UFED	Unspecified feeding or eating disorder

#### **Definitions**

Eating Disorders	Characterised by severe and persistent disturbances in eating behaviours with associated distressing thoughts and emotions. Eating disorders can be very serious conditions affecting the physical, psychological and social function. Types of eating disorders include Anorexia Nervosa (AN), Bulimia Nervosa (BN), Avoidant Restrictive Food Intake Disorder (ARFID), Binge Eating Disorder (BED), Other Specified Feeding or Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED). Refer to DSM-5 and ICD-10 for full diagnostic criteria.
Diabulimia	Insulin omission in T1D as a purging behaviour to achieve weight loss.
Disordered Eating	Spectrum of severity from mildly abnormal thoughts and behaviours regarding weight, shape and eating to more concerning thoughts and behaviours with medical and mental health consequences that do not meet formal ICD-10 or DSM-5 diagnostic criteria for an eating disorder.

#### 1 Introduction

In the past 30 years there has been an increased awareness of the higher prevalence of disordered eating (DE) and eating disorders (ED) in people with Type 1 Diabetes Mellitus (T1D) and associated risk factors. Consequences of DE/ED in people with T1D are serious with high levels of morbidity and mortality (1). Insulin omission is one DE/ED high-risk behaviour associated with life-threatening consequences. DE may persist at a subclinical level for prolonged periods impacting on physical and/or mental health outcomes or escalate to a clinical ED diagnosis.

Individual hospital-based protocols for management of comorbid DE/ED and T1D exist, but to date there are no evidence-based treatment protocols showing improvement in both DE and glycaemic outcomes published in peer reviewed journals (1). This poses considerable challenges, even to experienced health professionals. There is emerging evidence from trials examining brief interventions to reduce the risk of developing DE (2) or progression of DE in individuals with T1D (3), although more studies are also needed.

International Diabetes Management Guidelines (ADA, ISPAD, NICE) state that all young individuals with T1D should have access to specialised multidisciplinary diabetes services with T1D expertise (4, 5). Specialist diabetes MDT management is also considered to be of positive therapeutic value for adults with T1D.

Burden of chronic disease in T1D is well-accepted and regular psychosocial screening is part of specialist diabetes care. Specialised diabetes services should have psychologists/mental health professionals as integral team members who can provide client support at diagnosis and regularly thereafter (6). Clinical consensus suggests that all health professionals who care for those with T1D should be knowledgeable in identifying signs of DE and facilitating early intervention. Individuals with T1D are likely to benefit from access to a tertiary diabetes multidisciplinary team (MDT) with processes for regular psychosocial screening and increased awareness/screening for signs/symptoms of DE/ED.

Community-based teams/health professionals are encouraged to access advice and support from tertiary diabetes and specialist ED services/practitioners. Increased telemedicine services have improved access to tertiary diabetes teams for people living in rural and remote regions.

Early intervention is highly recommended if there are signs of DE/ED (7). A collaborative MDT approach is central to safe, individualised and targeted assessment and management of the dual diagnosis. The patient's general practitioner should remain involved to coordinate patient care, facilitate appropriate referrals and provide access to Medicare Benefits Schedule (MBS) reimbursable schemes (such as mental health care plan) where required.

Collaboration and bi-directional upskilling of diabetes and ED teams is recommended (7).

#### 1.1 Defining DE and ED

- DE encompasses abnormal thoughts relating to weight, shape and eating concerns, as well as a range of disordered behaviours which may include insulin omission.
- DE occurs on a spectrum of severity but does not meet formal diagnostic criteria for an ED.
- ED diagnosis is based on the DSM-5/ ICD-10 criteria and has been recently revised to include co-morbidities such as diabetes.
- Insulin omission is a unique DE behaviour used for weight control in those with T1D.
- The term 'Diabulimia' does not describe the range of DE/ED behaviours in those with T1D.

#### **Disordered Eating**

DE occurs on a spectrum of severity from mildly abnormal thoughts and behaviours regarding weight, shape and eating to more concerning thoughts and behaviours with medical and mental health consequences that do not meet formal DSM-5 or ICD-10 diagnostic criteria for an ED. DE thoughts include preoccupation with food, weight and shape, distortion in body image, over-evaluation of weight and shape in terms of self-esteem and fear of weight gain. DE behaviours include restrictive eating practices, food rules, erratic oral intake, excessive or compulsive eating/exercise, chronic energy restriction, binge eating, inappropriate hydration practices, and inappropriate use or manipulation of medication (e.g. insulin omission, laxatives, diuretics, thyroxine or Duramine) Females often strive for thinness, males may desire increased muscularity (8, 9). [Refer to Section 3.2 Signs of DE for full list].

#### **Eating Disorders**

ED are characterised by severe and persistent disturbances in eating behaviours with associated distressing thoughts and emotions. They can be very serious conditions affecting physical, psychological and social function. Types of eating disorders include Anorexia Nervosa (AN), Bulimia Nervosa (BN), Avoidant Restrictive Food Intake Disorder (ARFID), Binge Eating Disorder (BED), Other Specified Feeding or Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED). Further information and diagnostic criteria are available at:

- Inside out Institute: https://insideoutinstitute.org.au/assets/dsm-5%20criteria.pdf
- International Statistical Classification of Diseases and Related Health Problems: https://www.who.int/classifications/icd/en/bluebook.pdf

Recent revisions of the diagnostic DSM-5 now include comorbidities such as diabetes but are not comprehensive. Important biomedical markers such as diabetic ketoacidosis (DKA), hyperglycaemia and recurrent hypoglycaemia that are associated with ED are not included in the diagnostic criteria. Monitoring of outcome measures for both the ED and diabetes should occur to assess the effectiveness of treatments for each condition, and the potential impact they have on each other (10). Weight, growth (in paediatrics as measured on percentile charts), body mass index (BMI), BMI z-scores, glycated haemoglobin (HbA1c), blood glucose levels and patterns, insulin administration, menstrual cycle regularity, DKA episodes, cerebral oedema, diabetes complications, cardiovascular complications of malnutrition, and bone health should be monitored along with mental health. (Refer to Table 5 for full list). Categorizing DE/ED by type (restrictive dieting, bingeing, and/or intentional insulin omission) may help identify DE/ED and assist in identifying diagnosis-specific treatment options (11, 12).

#### Insulin Omission (IO) (MDI vs Pump)

Insulin omission (IO) is a unique weight control behaviour available to those with T1D. For those using multiple daily injections this may involve the omission of bolus and/or basal insulin, whilst those on insulin pump therapy this may be evidenced as missed boluses, frequent disconnections, over-rides and usage of temporary basals. Insulin, an anabolic hormone, is required to utilise carbohydrates as fuel and to build/retain muscle. Without insulin, blood glucose levels rise, resulting in an osmotic diuresis and dehydration. In addition, the body's fat and muscle stores are used as an alternative source of energy via ketone production resulting in weight loss. Insulin omission can result in life-threatening complications such as DKA, and accelerated vascular disease (11).

#### Diabulimia

'Diabulimia' is a media-coined term referring to IO in T1D as a purging behaviour to achieve weight loss. This term is recognised by many, including people with T1D who have developed peer support groups. 'Diabulimia' is

Disordered Eating and Eating Disorders in Children, Adolescents and Adults with Type 1 Diabetes – August 2022

misleading as it does not describe the range of EDs seen in people with T1D and may lead to underdiagnosis. Use of correct terminology assists in assessing prevalence rates to inform prevention and treatment programs (13).

#### 1.2 Prevalence and contributing factors

- Prevalence of DE in the T1D population may be as high as 40%.
- Young females with T1D are 2.4x more likely to meet diagnostic criteria for an ED.
- Weight loss or low BMI associated with DE/ED is not as evident in T1D.
- The increased prevalence of DE in T1D is related to both, diabetes-specific and psychosocial factors.

#### Prevalence of DE/ED

The prevalence of DE in adolescent girls with T1D may be as high as 40%, higher than their peers without diabetes (8, 14). In males with T1D, rates of 13-18% are reported (8, 14, 15). Clinical ED diagnosis in adolescent girls with T1D is ~7%, which is twice the rate of those without diabetes (14). DE behaviours can present at pre-adolescence and increase through to adulthood, with common age of onset being mid-late adolescence (16).

Reported prevalence rates of co-morbid DE in T1D vary due to methodological limitations (14, 17) such as differing sample characteristics, lack of consensus as to valid and reliable screening tools to compare people with without diabetes, and the definition of DE in T1D (11). Diagnosis of DE is currently based on the absence of fulfilling the DSM-5 and/or ICD-10 criteria for ED [refer to Appendix 1: DSM-5 and ICD-10 criteria].

Compared to their peers without diabetes, girls with T1D are 2.4 times more likely to have a clinical ED and 1.9 times more likely to engage in DE (18). Binge Eating Disorders, Other Specified Feeding and Eating Disorder (OSFED) and Bulimia Nervosa (BN) are twice as common in people with T1D compared to the general population; however, there is no difference in rates of Anorexia Nervosa (AN) co-morbid with T1D (19).

#### Contributing Factors to DE/ED in T1D (For full list, refer to Table 1)

People diagnosed with T1D during their adolescent years are at greater risk for DE and body image discontent. Adolescent females are at risk, partly due to normal pubertal body changes and societal pressures to be thin. Males can be driven to achieve increased muscularity (8, 20).

Body dissatisfaction is a strong determinant of DE, dieting practices and reductions in prescribed insulin dosing. Earlier diagnosis of T1DM (between 7-18 years), female gender and a history of overweight or obesity is associated with higher risk (21).

Contributing factors for all age groups include weight loss at diagnosis and subsequent weight regain with insulin commencement, the trend for a higher BMI on insulin therapy, daily focus on dietary management, carbohydrate counting and blood glucose levels. These factors can result in an unhealthy preoccupation with food and weight (20). Additionally, the prevalence of overweight and obesity in youth with T1D at diagnosis has increased, consistent with the general population (22). The first 12 months post diagnosis are crucial to preventing rapid weight gain and/or return to previous levels of overweight or obesity (23, 24).

Higher body weight and DE behaviours increase risk of further weight gain; both entities are associated risk factors for ED in T1D (25). Prevalence of T1DM and DE/ED's correlates with higher body weight and obesity (21). Significant weight loss and low BMIs normally associated with restrictive eating disorders are less common in the presence of T1D, where a normal or raised BMI may be maintained in the presence of significant ED behaviours (19).

Dysglycaemia (chronic hyperglycaemia, glycaemic variability, DKA and, to a lesser extent, severe hypoglycaemia), result in subtle neuropsychological changes. The effects vary according to the stage of neurodevelopment with those diagnosed early in life at greater risk. Deficits are seen across multiple cognitive domains including executive function and speed of information processing. Some evidence exists that this could affect psychological and mental

#### Table 1 Potential contributing factors to DE/ED in T1D.

Diabetes specific factors	Psychosocial factors			
<ul> <li>Weight loss pre-diagnosis due to insulinopaenia followed by rapid weight regain secondary to commencement of insulin can result in body dissatisfaction</li> <li>Focus on diet, carbohydrate counting and glycaemic control in T1D management</li> <li>Increased emphasis on maintaining healthy weight</li> <li>Being overweight/ obese</li> <li>Routine focus on weighing at clinic visits to assess insulin requirements and growth</li> <li>Episodes of recurrent hypoglycaemia can trigger bingeeating episodes and subsequent weight gain</li> <li>Restricting or omitting insulin, a unique, easy purging behaviour to achieve rapid weight loss without the need for significant food restriction</li> <li>Complex and burdensome healthcare, leading to frustrations, particularly in those with perfectionist traits</li> <li>Dysglycaemia (chronic hyperglycaemia, glycaemic variability, DKA and to a lesser extent severe hypoglycaemia) results in subtle neuropsychological changes.</li> </ul>	<ul> <li>Diabetes burden and related distress</li> <li>Depression and anxiety (more prevalent in people with T1D)</li> <li>Weight and body dissatisfaction</li> <li>Low self-esteem</li> <li>Family functioning and parental involvement in managing chronic condition including increasing autonomy with age concerning diabetes self-management</li> <li>Exposure to social media about 'ideal' body shape and positive appraisal of weight loss from parents, peers and health professionals</li> </ul>			

#### 1.3 Consequences of DE/ED in T1D

- DE in people with T1D is a serious problem with associated high levels of morbidity and mortality.
- DE can persist at a subclinical level for prolonged periods impacting on physical and/or mental health outcomes or escalate to a clinical ED diagnosis.
- Insulin omission is a high-risk behaviour associated with life-threatening consequences.

DE thoughts and behaviours occur along a continuum of severity and are associated with poorer glycaemic control. Consequences for those with T1D are very serious, more so when insulin omission is present (11). Early detection and management of DE may prevent escalation to diagnosable ED, medical consequences requiring hospitalisation, and reduced mortality (27).

DE can increase risk and earlier onset of complications including:

- Impaired growth in children and adolescents
- Diabetic microvascular complications: nephropathy, neuropathy and 5-fold risk of retinopathy
- Episodes of recurrent DKA
- Recurrent hypoglycaemia
- Impaired mental health (anxiety, depression, diabetes distress)
- Acute complications of malnutrition such as impaired cognition, electrolyte abnormalities, postural hypotension, bradycardia, tachycardia
- Consequences of hormonal abnormalities such as menstrual abnormalities and poor bone health.
- Other consequences impacting on quality of life include family conflict, fatigue and sleep disturbances, excessive hunger/thirst, dehydration, muscle atrophy, and digestive problems (11)
- Increased ten-year mortality rates: 35% in women with AN and comorbid T1D, compared to 6.5% for AN and 2.5% for T1D alone. (28)

#### 2 Preventing DE/ED in T1D

Treatment delivered by skilled MDTs with clear communication channels and consistent messages, goals and targets regarding T1D management achieve better psychological outcomes. Skilled teams employ the following general treatment strategies which may avoid triggering DE thoughts and behaviours in people with T1D:

- The person with T1D and their family/support people (including schools) are the central members of the care team.
- Health care teams must be capable of identifying the educational, behavioural, and psychosocial factors that impact on diabetes outcomes and work to overcome identified barriers or adjust the treatment goals where appropriate.
- At T1D diagnosis, care pathways acknowledge the support and education needed, and include support from a mental health professional.
- At T1D diagnosis, education is to be provided and includes:

insulin is vital for growth, and for the body to rebuild, heal and rehydrate.

Insulin initiation is likely to lead to weight restoration.

- Explain reasons for monitoring growth and weight, and regard individual weight or shape concerns seriously.
   Conversations about weight are a sensitive topic for many, especially those struggling with DE.
- Weight importance and dieting for weight control have been identified as predictors of development of DE/ED in
  young people. In younger people with T1D, excessive focus on child's weight by authority figures leads to body
  dissatisfaction, dieting, low self-esteem, and weight bias (29). Consider discussing growth instead of weight and
  utilising a 'weight neutral' Health at Every Size (HAES©) approach, with an emphasis on 'healthful' eating and
  exercise behaviours as opposed to weight control. For children and adolescents engage a family approach to
  lifestyle behaviours
- Prior to increasing insulin doses, conduct a dietary assessment and provide advice regarding dietary quality and
  quantity, plus encouragement to regularly participate in physical activities with goal of optimal insulin management
  and minimisation of excessive weight gain.
- Good quality sleep is an essential component of healthy development and is required for physical and mental health. Poor sleep is associated with food cravings, poorer quality diet and higher body weight (30)
- Language is important. Language has power and can persuade, change, or reinforce beliefs. Be mindful to discuss growth and healthy lifestyle behaviours, rather than weight per se. Use positive and motivational language (31)
- The multidisciplinary team need to be aware of the signs and symptoms of DE.
- Routine psychosocial screening is recommended for identification of early signs of DE.
- Consider referral (for those aged ≥ 17 years) to an evidenced-based structured education program such as OzDAFNE.

Access to specialised multidisciplinary diabetes services with T1D expertise is essential for young people with T1D and of positive therapeutic value for adults with T1D. (32, 33). The core MDT includes an endocrinologist, dietitian, credentialled diabetes educator, and psychologist with T1D expertise, along with the general practitioner. The MDT for youth with T1D should include specialists with training and expertise in paediatric, adolescent and young adult development.

The mental health professional in the MDT will assist the person with diabetes and support other team members to recognise and address coping, behavioural or mental health problems (34). Psychologists also provide psychoeducation on increased prevalence of DE/ED and other mental health issues in the diabetes population.

The following clinical approaches are suggested:

- From T1D diagnosis, it is most important the MDT provides a positive, motivational, and supportive approach. Clear consistent goals and communication around diabetes education and management plans lead to better psychological outcomes (5). The primary aim is to achieve glycaemic targets without compromising psychological wellbeing. The person with diabetes and their family/caregivers are the central members of the team (5, 35) and involved in decisions related to their care.
- At diagnosis, provide factual information about insulin initiation so individuals clearly understand that insulin is required for medical safety, growth, and to rebuild and heal which will result in weight restoration. A small percentage of individuals may experience temporary fluid retention {Goebel-Fabbri, 2017 #7
- Intensive insulin therapy is recommended; however, an insulin regimen is only effective if the individual is able to implement and maintain the regimen {Amer Diabet, 2020 #736}. The diabetes team must evaluate educational, behavioural, emotional, and psychosocial factors that could impact the implementation of the management plan. The team should work with the individual and family to overcome barriers and redefine goals as appropriate (6).

Ongoing support and education should include the following actions:

- Establish care pathways outlining the education plan and frequency of visits to MDT members at diagnosis and beyond (5).
- Introduce the psychologist/mental health professional in the team to assist in normalising emotional reactions to the diagnosis and in coping during this period of change.
- Provide dietary education in a staged manner according to their needs. Explain the food-centric principles
  of diabetes care is crucial including individual assessment and advice on meal plans and macronutrient
  distribution (4). Emphasise the need to avoid dietary restriction and that healthful eating involves a regular,
  flexible, and balanced approach to food selection and consumption to meet daily nutritional requirements.
- Explain reasons for monitoring weight, growth and blood glucose level for normal growth and development. Ensure concerns raised about weight, growth, muscle mass or shape are taken seriously and addressed (36). Proactive discussions around common problems such as insulin omission may decrease the likelihood of these problems occurring (6).
- Optimise insulin management and monitor diet quality and quantity for age appropriateness. Encourage physical activity to assist with expected growth and weight profiles. If glycaemic targets are not being met, assess and optimise diet and activity before increasing basal insulin rates.
- Ensure MDT clinicians are aware of the signs and symptoms of disordered eating (including indicators of insulin omission) and assist the individual at an early stage before DE thoughts and behaviours become entrenched.
- Carry out psychosocial screening as part of routine care in T1D, and screen for DE/ED for those identified as at risk (6, 37).
- Consider referral to the OzDAFNE structured education program for those aged 17 years and older in the
  year following diagnosis. OzDAFNE teachings increase flexibility with food choices, encourage selfefficacy, and reduces diabetes distress, severe hypoglycaemia and DKA admissions (38, 39). OzDAFNE
  assists with weight management by implementing physiological levels of basal insulin, carb counting and
  using of insulin to carb ratios, insulin dose adjustment for exercise, and lowering the amount of
  carbohydrate foods required to manage hypoglycaemia.
- Address sleep patterns. Short sleep duration, poor sleep quality, and late bedtimes are all associated with excess food intake, poor diet quality, and obesity in adolescents (40). Poor sleep also affects cognitive and psychomotor function including mood and is associated with negative outcomes such as depression, decreased school performance, quality of life, and risk-taking behaviours. To establish and maintain healthy sleep patterns, it is recommended to have consistent bedtime and wake-up times, avoid screen time 1 hour before sleep, and to keep screens out of the bedroom. Sleep recommendations include:
  - o children aged 5 to 13 years get 9 to 11 hours of uninterrupted sleep
  - young people aged 14 to 17 years get 8 to 10 hours of uninterrupted sleep (41)
  - o Adults to have approximately 7-9 hours of sleep: <a href="https://www.sleephealthfoundation.org.au/">https://www.sleephealthfoundation.org.au/</a>
- Consider additional psycho-educational programmes:
  - Useful resources addressing body image for individuals and clinics can be found on the Butterfly Organisation website which address body image for young people and parents as well as tips to support use of social media: <a href="https://butterfly.org.au/resources/">https://butterfly.org.au/resources/</a>

#### Emerging evidence:

- Online or face to face sessions directed at pre- and young adolescents enhance protective factors for eating disorders such as resilience, self-esteem, self-compassion and media literacy (7).
- A pilot study involving a six week virtual program for females aged 16-35 years resulted in meaningful reductions in ED risk factors and symptoms (2).
- A two week self-compassion intervention for adolescents comorbid DE also resulted in improved coping resources, increased mindfulness, and a greater awareness of not being alone with problems (3).
- A feasibility randomised controlled trial will assess a psycho-education intervention for parents of children aged 11-14 years with T1D to help prevent development of disordered eating and improve parental wellbeing (42).

## 3 Identification, screening and assessment of DE/ED in T1D (including assessment for hospital admission)

- Health professionals involved in provision of care to the T1D population should understand the principles
  of a 'healthful eating' and be aware of signs of DE [Refer to Table 2 Signs of DE].
- General psychosocial screening should be routine in T1D care and followed by specific screening for DE/ED where suspected (e.g. DEPS-R).
- Clinical interviews are required for assessment and confirmation of DE/ED for individuals at risk of DE.
- Once DE is identified promptly assess severity of medical/psychological risk (using Table 4 and Table 5; and Error! Reference source not found. and Figure 1) to determine need for escalation of care, referrals to specialist services, or if meets criteria for hospital admission.
- Be mindful of DE/ED in youths that are transitioning from paediatric to adult services, that assessments/interventions for DE/ED are well coordinated.

#### 3.1 Principles of 'healthful' eating

Identifying and addressing DE early can prevent thoughts and behaviours becoming entrenched with associated serious long-term health outcomes.

DE is best identified by comparison with 'normal' or 'healthful' eating behaviours. 'Healthy' eating practices include allowances for appetite fluctuations, supporting age-appropriate growth, stage and physical activity levels, minimising eating in response to emotional triggers, eating a wide variety of foods and social/cultural aspects of food.

Clinicians need to gauge when behaviours or attitudes to eating/food differ from normal expectations for T1D management e.g. behaviours encouraged for T1D self-management such as weighing food and carbohydrate counting are considered normal in diabetes management yet may be considered dysfunctional in the general population (43).

#### 3.2 Identification of DE, including signs and symptoms

MDT members should maintain vigilance for signs of DE, as early signs of DE/ED are often first observed by members or the multidisciplinary team and should be addressed. Potential DE signs in isolation may not be defined as DE, as DE behaviours are also accompanied by abnormal cognitions, associated with weight, shape, and self-worth. Growth charts, continuous glucose monitors (CGM) and insulin pump downloads can provide further evidence of disordered eating behaviours with diet, activity, or insulin dosing.

Transition from paediatric to adult services is a high-risk time of loss to follow up care and engagement with health professionals (44). Consider appropriate timing/arrangements for transition for those with T1D with DE/ED and/or other psychosocial concerns, to ensure appropriate assessment and treatment occurs.

#### Table 2 Signs of DE

- · Frequent weighing or reluctance to be weighed
- Body checking
- Excessive use of "body building" supplements
- · Restraint with/without excessive eating/binge
- · Insulin restriction or omission for rapid weight loss
- Restrictive patterns of eating e.g. restricting carbohydrate, intermittent fasting, gluten free without clinical indication, compulsive and excessive eating
- Binge eating i.e. consuming large amounts of food in an uncontrolled manner, with associated feelings of guilt/shame
- Change to whole-foods diet including vegetartian/vegan diet when this does not align with previous dietary choices or family intake
- · Excessive exercise
- Laxative/diuretic abuse (including herbal remedies/teas/supplements)
- · Vomiting, chewing and spitting behavior
- · Misuse of medications to cause weight loss e.g. Duramine, thyroxine

## **Psychosocial**

Behavioural

- Preoccupation and dissatisfaction with body weight (and shape), including positive appraisal of weight loss at diagnosis
- Rigid focus on food, unhelpful interpretation of food as good or bad, food rules and/or restrictive patterns of eating e.g. restricting carbohydrate, intermittent fasting, gluten free without clinical indication
- Impaired psychological wellbeing including negative affect, deterioration of interpersonal relationships, anxiety and/or diabetes distress. (NB in the general population, 55-98% of those with an ED have a concurrent mood/anxiety disorder).
- · Perfectionism, low self-esteem or other psychopathology
- Concern expressed by a third party (parent of partner)

# Diabetes and management related

- Frequent DKA admissions
- Acute changes in HbA1c (>1.5% in 3 month period) or chronic high HbA1c (>9%/75mmol/L) indicative of insufficient insulin
- Variable BGL (e.g. excessive food post hypoglycaemic episode
- Skipping meals/restrictive eating/secretive eating/not eating in front of others
- Excessive food/binge eating with inadequate insulin
- Frequent unprescribed changes of baseline insulin regimen
- Acute increase/decrease in weight, crossing or falling in centiles, significant weight fluctuation
- · Overweight and/or obesity
- · Stunted height on growth charts
- · Early development of microvascular complications
- Insulin pump and continuous glucose monitor (CGM) downloads indictive of skipped meals, restrictive eating, excessive or binge eating with/without bolus insulin,
- Missed basal and bolus doses.

## **Tedical**

- Cardiac symptoms:
  - Hypotension or Postural hypotension
  - Tachycardia or Postural tachycardia
  - Bradycardia
  - o ECG abnormalities/arrhythmia
  - Hypothermia
- · Pathology:
  - o Electrolyte abnormalities
  - Raised LFTs
  - Neutropaenia
  - o Hypoalbuminaemia
- Weight change

- Hormonal imbalance:
  - Menstrual abnormalities (e.g. amenorrhoea)
  - Lowered bone mineral density, osteoporotic fractures
  - Poor dentition, loss of enamel, sore gums, halitosis, calloused knuckles (secondary to vomiting)
  - Hair loss, lanugo, dry skin, brittle nails (secondary to nutritional deficiencies)
- Also refer to table: Physical Indications for Admission

#### Disordered Eating and Eating Disorders in Children, Adolescents and Adults with Type 1 Diabetes – August 2022

#### 3.3 Routine psychosocial screening

Routine comprehensive psychosocial screening is recommended to identify those struggling in any of the emotional domains; symptoms of depression, anxiety, diabetes distress and body dissatisfaction are associated with DE behaviours (45). Where DE/ED is suspected, a diabetes specific DE/ED screening tool is recommended. The DEPS-R has the most evidence to date as a screening tool for those with T1D (>10yrs age) (6).

#### **Step 1: General psychosocial screening in T1DM management**

#### Paediatric psychosocial screening

At diagnosis and during routine follow-up care, psychosocial issues and family stresses that could impact diabetes management should be assessed. Provide appropriate referrals to trained mental health professionals, who are ideally integral members of the MDT, or at least have paediatric diabetes experience (6).

Ensure within the family, there is timely transfer of diabetes tasks to children and adolescents, as premature transfer of diabetes care to the child can result in diabetes burnout, or hinder the ability of the adolescent to take on diabetes management tasks, and result in a deterioration in glycaemic control. Ideally, questions should be asked of peer relationships, social adjustment, and school performance to determine whether further intervention is needed (6).

From age 7-8 years, psychosocial and diabetes-related distress should be assessed. By age 12+ years, or when developmentally appropriate, and no later than one year prior to transition, offer adolescents time by themselves with members of the multidisciplinary team (6, 44).

There is no consensus in guidelines on which psychosocial screening tools to use. The Diabetes Psychosocial Assessment Tool (DPAT) [refer to Appendix 2: Diabetes Psychosocial Assessment Tool (DPAT)] is a suggested comprehensive psychosocial screening tool developed for routine use. There is a child version (age ≥ 12 years of age) and teen version (age 15-17 years). The DPAT incorporates three validated tools to assess diabetes distress (PAID), symptoms of depression and anxiety (PHQ-4), and general emotional well-being (WHO-5). It also includes questions on social support, finances, weight, shape and eating concerns as well as problems with hypoglycaemia (46).

Other pediatric measures include:

- Children's Depression Inventory (CDI): <a href="https://www.apa.org/obesity-guideline/depression-inventory.pdf">https://www.apa.org/obesity-guideline/depression-inventory.pdf</a>
- Center for Epidemiologic Studies Depression (CES-D) scale: https://www.brightfutures.org/mentalhealth/pdf/professionals/bridges/ces\_dc.pdf

These measures are self-reported questionnaires containing items on types of symptoms (e.g., sadness and low self-esteem) and functional areas (e.g., not having friends, schoolwork is not as good as it was before, and arguing with others). Suitable for those aged ≥ 7years (47).

Pediatric Quality of Life Inventory (PedsQL) generic, and type 1 diabetes modules. These measures offer a child self-report for youth ages 5 to 7 and for youth ages 8 to 18. There are also PedsQL parent proxy reports for children ages 2 to 18 (48, 49). <a href="https://www.pedsql.org">https://www.pedsql.org</a>

Diabetes-specific emotional distress can be assessed in children ages 8 to 11 and their parents using Problem Areas in Diabetes Survey-Children (PAID- C and P-PAID-C (50). Similarly, the PAID-Parent (PAID-PR) scale and the PAID-Peds scale can be used from age 8 for parents and youth, respectively (51)}

#### Adult psychosocial assessment (age 16 years and over)

The Diabetes Psychosocial Assessment Tool (DPAT) (refer to Appendix 2: Diabetes Psychosocial Assessment Tool (DPAT)) is a suggested comprehensive psychosocial screening tool developed for routine use in people with

Disordered Eating and Eating Disorders in Children, Adolescents and Adults with Type 1 Diabetes – August 2022

Refer to online version, destroy printed copies after use.

T1D (≥16 years). The DPAT incorporates three well-known, validated tools to assess diabetes distress (PAID), symptoms of depression and anxiety (PHQ-4), and general emotional well-being (WHO-5). It also includes questions on social support, finances, weight, shape and eating concerns as well as problems with hypoglycaemia (46). This tool is well accepted by young adults (18-25 years) with T1D (52).

The DPAT can be used as a conversational tool during routine consultation and provides a referral pathway to specific members of the MDT (46).

Address weight, shape or eating concerns with a clinical dietetic assessment, or a conversation initiated by an MDT member who has attained rapport with the person. Weight, shape and eating concerns could be as mild as wanting to "eat healthier", refresh carbohydrate counting, or lose/gain weight appropriately. However, the possibility of underlying DE or an ED should be considered in these assessments and conversations. The National Diabetes Subsidy Scheme (NDSS) 'Enhancing your Consultation Skills' resource (43) suggests the following approach to broaching the topic of DE:

- Promote open and honest communication
- Start with non-threatening questions
- Ask about weight and body image concerns
- Comment on the presence of a biological marker of DE e.g. elevated HbA1c
- · Ask directly about insulin omission

#### Step 2: DE/ED specific screening tools

Screening for eating disorders is recommended for all children from age 10-12 years. The Diabetes Eating Problems Survey-Revised (DEPS-R) is a reliable, valid, and brief screening tool for identifying disturbed eating behaviour [Refer to Appendix 3: Diabetes Eating Problem Survey – Revised Scale (DEPS-R Scale)]. For those with any indication of DE/ED risk, consider using a diabetes-specific DE/ED questionnaire or direct referral to qualified members of the MDT for clinical assessment of DE/ED.

Diabetes-specific ED/DE screening tools are recommended as insulin omission is a potential weight control behaviour unique to people with diabetes, and questions related to this compensatory behaviour should be included. Monitoring of carbohydrate intake, assessment of dietary restraint, and eating refined carbohydrates to treat hypoglycaemia, all need consideration in the context of T1D as affirmative answers could be attributed to diabetes management per se rather than DE behaviours and cognitions (43).

The Diabetes Eating Problem Survey-Revised (DEPS-R), suitable for those 10 years of age and over, has the most evidence to support its use to date (37, 53). It is helpful in clinics as it can be administered in 10 minutes. Scores greater than or equal to 20 indicate greater risk of DE behaviours requiring prompt clinical assessment to exclude ED. There are limitations to its use in males as it does not capture desire for muscularity or excessive exercise as a compensatory behaviour (8). The Modified Sick, Control, One, Fat, Food (mSCOFF) is a brief 5-item screening tool. The mSCOFF may not be sensitive enough to pick up early stages of DE (54). Also, the fifth item 'Do you ever take less insulin the you should', could overestimate DE, as there may be appropriate reasons to reduce insulin. A positive response on this item should be further explored to avoid misinterpretation.

Screening questionnaires are a useful first step in identifying DE. Responses may provide indications of potential DE and facilitate conversation. Clinicians should be aware of limitations of screening tools and that the client may not be ready to share their struggles with eating, weight and body image. Responses may not line up with clinical observations. A clinical interview by an experienced psychologist or mental health professional and/or dietitian will be needed to further explore presence, severity and specificity of DE.

## 3.4 Clinical interview and assessment for DE/ED- including assessment of medical and psychological risk

**Clinical interviews** should be carried out by the diabetes team psychologist and/or psychiatrist. In the absence of these team members, consider early referral to an eating disorder specialist service.

**Clinical assessments** can be conducted by various members of the treating team. These assessments should be discussed in the MDT case discussions to formulate an individualised management plan [refer to Table 3, Table 4, and Table 5]. At any point in the assessment process referrals can be made to eating disorder specialist services or clinicians for diagnostic clarification and management/treatment advice.

Table 3 Assessment of DE/ED in T1D

Aspect	Assessment
Diabetes	Insulin management:
	<ul> <li>Insulin omission or under-dosing for meals. Indications include:</li> </ul>
	overrides to decrease meal time bolus dose
	reducing the amount of carbs recorded at meal times
	lack of carbs recorded at meal times
	use of temp basals with pump therapy
	injecting insulin into parts of the body that make supervision difficult (e.g. upper thighs)
	actively avoiding supervision of insulin
	squeezing insulin out after injection
	reporting an allergy to insulin
	diluting blood glucose levels; water on fingers
	Type of insulin omitted (basal verse bolus)
	For meal insulin, how much e.g. 50% of required bolus and how frequently e.g. all meals, half of meals over a week, omitted for binge eating episodes or unhealthy foods, snack times
	How much long acting insulin taken e.g. number of days per week or % taken of required dose.  How many hours an insulin pump is disconnected
	Corrections taken; frequency, % taken, according to correction factor or guessed
	Triggers for insulin omission
	Blood glucose level monitoring and glycaemic control:
	Blood glucose level checking; frequency, method e.g.: flash glucose monitoring (FGM), coninous glucose monitoring (CGM), glucometer
	Flexibility and rigidity around blood glucose level management
	Fear of hypo or hyperglycaemia
	CGM/FGM time in target range / % time hyperglycaemic after meals and overnight
	Significant deterioration in glycaemic control e.g. HbA1c rise from 6.5% (48mmol/mol) to 8% (64mmol/mol, an acute change in HbA1c (>1.5% change within a 3 month period), or a HbA1c of > 9% (>75mmol/mol) (56)
	CGM/FGM indicates lack of regular meals with restrictive/binge cycles.
	Large correction doses of insulin after binge(s)
	Frequency of Diabetic Ketoacidosis and hospital admissions for diabetes
	History of Diabetes:
	Age of diagnosis, diabetes duration
	Self-management of diabetes:
	Attitudes towards carbohydrate counting, focus on blood glucose levels and insulin dosing
Cognitive-	History of dieting/disordered eating
Behavioural	Family history of DE/ED
	Frequency of weighing (including excessive avoidance)
	Satisfaction with body weight, shape, and appearance
	Body checking behaviours and frequency (including excessive avoidance)
	Other medication use for the purposes of weight management e.g. laxatives, diet pills,
	diuretics, sports supplements
	baking, eating at school, isolation or withdrawing etc
	Food and eating attitudes
	Current and past relationship with food
	Amount of time spent thinking about food, weight and body image
	<ul> <li>Body image, past and present (considering feelings about having diabetes technologies e.g. pump, CGM attached to body)</li> </ul>
	Wearing baggy, ill-fitted or layered clothing

Aspect	Assessment
Medical	Medical assessment of physical indicators for hospital admission [Refer to Section Physical indicators for hospital admission]
	<ul> <li>HbA1c not consistent with meter, pump, CGM/FGM downloads (e.g. dilution of blood, measuring milk instead of blood).</li> </ul>
	Non-insulin medication including contraception
	Menstrual history (including age of maternal menarche) and current menstrual pattern
	Review of biochemistry, haematological and hormonal profiles
	Bone health and consider bone density assessment
	<ul> <li>Diabetes Annual Cycle of Care screening including for peripheral neuropathy (feet), retinopathy (eyes), nephropathy, co-morbidities e.g. coeliac screen and TFT's for hypothyroidism</li> </ul>
	Gastrointestinal symptoms or concerns including gastroparesis, reflux and constipation
	<ul> <li>Physical features indicating disordered behaviours including calloused knuckles, fine hairs on face, dry skin, hair loss, bad breath, sore gums or loss of enamel on teeth</li> </ul>
	Exclude coeliac disease/hypothyroidism
Emotional	Emotional well-being including diabetes distress and DPAT scores
	<ul> <li>Mental health comorbidities (depression, anxiety, personality disorders, substance abuse, self- harm and suicidal ideation)</li> </ul>
	<ul> <li>Assess for perfectionism traits, interpersonal problems, family conflict, core low self-esteem, maladaptive coping strategies.</li> </ul>
Dietary	<ul> <li>Full diet history and fluid intake. Assessment of adequacy of dietary intake including overall energy intake compared with estimated requirements, macro and micronutrients. NB relative energy deficiency/ low energy availability (with associated negative consequences) may be present in a weight stable state</li> </ul>
	Dieting behaviours e.g. calorie counting, food group avoidance including meat, or low carbohydrate diet patterns and reasoning for such
	<ul> <li>Inconsistency between reported intake and CGM/FGM/pump reports (e.g. skipped meals, lack of carbohydrate)</li> </ul>
	Inconsistency between child/parent reported intake
	<ul> <li>Special diets followed e.g. low carbohydrate, lactose free or confirmed diagnosis e.g. gluten free for coeliac disease</li> </ul>
	<ul> <li>Meal and eating patterns e.g. skipping meals, late night eating, fasting behaviours, secretive eating, not eating in front of others</li> </ul>
	Carbohydrate counting methods and rigidity
	<ul> <li>Binge eating including frequency, time of day or week, triggers, location, and detail of content of a typical binge</li> </ul>
	Chronic, excessive food intake
	Purging/vomiting behaviours including frequency and timing
	Use of 'sugary' drinks or artificially sweetened drinks, chewing gum
	Caffeine consumption, including coffee, tea or energy drinks
	<ul> <li>Food rules, fears and beliefs e.g. "cut" or banned foods in diet, avoidance of foods, feared foods including particular consideration of carbohydrates</li> </ul>
	Flexibility or rigidity around food or nutrient intake
	Food allergies/intolerances
	Current and past vitamin, mineral or sports supplement use
	Alcohol intake and drug use including tobacco cigarettes and other substances
	Person's views on eating habits or difficulties and personal nutrition goals
Exercise	Type, frequency and duration
	Use for purposes of weight management
	<ul> <li>Consider if compulsion to exercise or as a compensation for eating e.g. after meals, or believes it essential to exercise daily</li> </ul>

Aspect	Assessment
Other	Previous counselling /treatment for DE /history of ED diagnosis
	Family history of dieting, ED, mental health issues, relationships with food
	Food security and access to food

Adapted from Australian Institute Sport (AIS)/National Eating Disorder Collaboration (NEDC) and Dietitians Australia (DA) Eating Disorder Assessment template (57)

#### 4 Physical indicators for hospital admission

Table 4 Physical indicators for hospital admission – paediatric

If ANY parameter is met at the time of assessment, inpatient treatment should be considered.

This list is not exhaustive, and any other medical concerns should be discussed with the treating medical practitioner/s. If unsure, seek specialist advice.

Aspect	Parameter	Indication for medical admission
Physical	Systolic blood pressure	less than 80 mmHg
observation	Postural blood pressure	Greater than 20mmHg drop with standing
	Heart rate	less than 50 bpm
	Postural Heart rate	postural tachycardia rise greater than 20 bpm
	Temp	less than 35.5C
	12-lead ECG	any arrhythmia including QTc prolongation greater than 450 ms
	Visual	Cold/blue extremities
		Oesophageal tears
Pathology	Electrolyte	<ul> <li>any electrolyte abnormality particularly Magnesium (Mg<sup>2+</sup>), Phosphate (PO<sub>4</sub><sup>3-</sup>) and Potassium (K<sup>+</sup>)</li> </ul>
	Hypoglycaemia	Blood glucose level below reference range less than 4 mmol/L
	Liver enzymes	Markedly elevated or rapidly rising (refer to age reference ranges)
Nutritional	High risk factors for Refeeding (58)	A child/adolescent is considered high risk for re-feeding syndrome if the child/adolescent has:
		One or more of:
		o Body Mass Index (BMI) less than 5th Centile
		<ul> <li>Weight loss of more than 15% within the previous 3–6 months</li> </ul>
		<ul> <li>Insufficient oral nutritional intake to sustain normal functioning for 10 days (use clinical judgment)</li> </ul>
		<ul> <li>Hypophosphataemia, hypomagnesaemia, hypocalcaemia or hypokalaemia prior to re-feeding.</li> </ul>
		Two or more of:
		o BMI between 5th and 10th Centile
		<ul> <li>Weight loss of more than 10% within previous 3–6 months</li> </ul>
		<ul> <li>Insufficient oral nutritional intake to sustain normal functioning for 5- 7 days (use clinical judgment)</li> </ul>
	Oral intake	Refusal of oral intake
		Dehydration, refusing fluid intake
		Uncontrolled/unmanageable vomiting or exercise.
Anthropometry	Weight loss	Rapid weight loss (i.e. 1 kg/week average over 6 weeks)
	Weight	Weight loss of greater than 15% of pre-morbid weight in the last 3–6 months
Diabetes	Blood Glucose Indicators	HbA1c greater than 9% mmol/mol, diabetic ketoacidosis, regular hypoglycaemia, episode of severe hypoglycaemia*
	Insulin	Insulin omission, restriction of insulin or suspicion of this behaviour that requires inpatient re-establishment or titration of insulin regimen.
	Ketones	Ketosis—Blood ketones greater than or equal to 1.5 mmol/L or urine ketones +++
Other		<ul> <li>Severe family stress and strain and/or behaviours relating to eating disorder impacting on child/adolescent and family functioning.</li> <li>Suicidality/self-harm unable to be managed in outpatient setting</li> </ul>
		Suicidality/self-narm unable to be managed in outpatient setting  Children, Adolescents and Adults with Type 1 Diabetes —

Adapted from 'QuEDS Guide to Admission and Inpatient Treatment'

#### Table 5 Indications for medical admission in people with both DE/ED and T1D (for age ≥ 16 years)

#### If ANY parameter is met at the time of assessment, inpatient treatment should be considered.

This list is not exhaustive, and any other medical concerns should be discussed with the treating medical practitioner/s. An admission for Type 1 diabetes with an eating disorder or disordered eating would be most appropriate in a medical setting for initial medical stabilisation and insulin titration. There may be some exceptions where a mental health admission is more appropriate.

more appropriate.		
Aspect	Parameter	Indication for medical admission
Physical	Systolic blood pressure	Less than 90mmHg (adolescent: less than 80 mmHg) ^
observation	Postural blood pressure#	greater than 20mmHg drop with standing
	Heart rate	Less than or equal to 50 bpm (adolescent: less than 50 bpm) or greater than 120 bpm
	Postural Heart rate#	postural tachycardia greater than 20bpm
	Temp	less than 36.0C (adolescent: less than 35.5C)
	12-lead ECG	Any arrhythmia including QTc prolongation, or non-specific ST or T-wave changes including inversion or biphasic waves
Pathology	Sodium	less than 125 mmol/L
	Potassium	less than 3.5 mmol/L
	Magnesium	Below normal range
	Phosphate	Below normal range
	eGFR	less than 60 or rapidly dropping (25% drop within a week)
	Albumin	less than 30 g/L
	Liver enzymes	Markedly elevated (AST or ALT greater than 500 U/L)
	Neutrophils	• less than 1.0 x 109/L
Nutritional	Oral intake	<ul> <li>One or more of:         <ul> <li>BMI less than 16 kg/m2</li> <li>Weight loss greater than 15% within the last 3–6 months</li> <li>Little or no nutritional intake for more than 10 days</li> <li>Low potassium, phosphate or magnesium prior to feeding, attributable to malnutrition</li> </ul> </li> <li>or; Two or more of the following:         <ul> <li>BMI less than 18.5 kg/m2</li> <li>Weight loss greater than 10% within the last 3–6 months</li> <li>Little or no nutritional intake for more than 5 days</li> <li>A history of alcohol dependence</li> </ul> </li> <li>Grossly inadequate nutritional/fluid intake (less than 1000 kCal / 4 MJ daily).</li> </ul>
Anthropometry	Weight loss	<ul> <li>Uncontrolled/unmanageable vomiting or exercise.</li> <li>Rapid weight loss (i.e. 1 kg/week over several weeks)</li> </ul>
, and a pointed y	Weight	
Diabetes	Blood Glucose Indicators	<ul> <li>Body Mass Index (BMI) less than 14kg/m²</li> <li>HbA1c greater than 10% (86 mmol/mol), diabetic ketoacidosis, episode of Severe hypoglycaemia*</li> </ul>
	Insulin	Insulin omission, restriction of insulin or suspicion of this behaviour that requires inpatient re-establishment or titration of insulin regimen.
Other		Not responding to outpatient treatment

## 4.1 Questions and algorithm for asking about self-harm and suicidality risk

A suicide risk assessment is essential if an individual is suspected of having an established ED as this is a major cause of mortality. This risk may be due to co-existent mood disorders or a consequence of the cognitive and psychological changes from malnourishment (59).

Asking the following questions and undertaking actions as indicated by the algorithm [Refer to Appendix 5] can help improve the safety of people with DE/ED and T1D:

- 1. Have you been feeling down or depressed? If 'no', no further action. If 'yes', ask:
- 2. Do you ever experience any thoughts of suicide or self-harm? If 'yes' ask:
- 3. If you were at risk of acting on these thoughts, would you feel able to call someone for help? (if patient doesn't volunteer a person, suggest Lifeline (131114), MHCALL (adults) or Kids Helpline). If no, clinician should seek urgent advice from MHCALL (1300 64 2255) Kids Helpline (1800 55 1800).

If patient/client answers 'yes' to any of above, referral to mental health clinician is recommended.

MHCALL (for people aged 16 and over) or Kids Helpline can assist with triage, prioritisation and follow-up.

#### 5 Intervention to Manage DE/ED in T1D

- · Respond promptly.
- Optimise communication with sensitive approach.
- Individualise the Care Pathway with increased frequency of appointments, supports and monitoring.
- Use an MDT approach with realistic, joint management plans. Utilise staff with most rapport.
- Consider early, shared care with specialist ED Teams or CYMHS.
- Address diabetes knowledge, diabetes management skills, dietary management, diabetes distress and other psychosocial concerns concurrently with DE/ED.
- Ensure regular MDT review of progress and management plan.
- Escalate support at any stage if risk increases or there is inadequate treatment progression.
- Be mindful of DE/ED in young people who are transitioning from paediatric to adult services, that assessments/interventions for DE/ED are well coordinated.

There is limited evidence of effective interventions to reduce DE as well as improve glycaemic control (11). The following plan represents the consensus of experienced professionals working in this field with clinical expertise in managing comorbid DE/ED and T1D.

#### 5.1 Principles of treatment

Clinical consensus recommends that the MDT apply certain core principles when treating DE in T1D. A prompt response is paramount. Communication style is important. Careful word choice can make a powerful and positive difference to the emotional well-being, self-care and health outcomes of people affected by diabetes. Conversely, careless or negative language can cause harm and demotivation. A position statement by Diabetes Australia serves as a guide for anyone communicating with and about people with diabetes (31).

An MDT using a person or family-centred approach is key. It is important that a decision is made at the outset of treatment whether family/carer support is needed and appropriate, as in the case of the paediatric population and in consenting adults.

Out-of-routine, individualised care is required to provide appropriate level of support and monitoring. Concurrent addressing of diabetes knowledge, insulin therapy, dietary management and psychological interventions is needed. To do this, early collaboration with specialized Eating Disorder Teams or Child and Youth Mental Health Services (CYMHS) is essential.

These principles are explored in detail below.

#### **Principle 1: Prompt response with sensitivity**

- Avoid complacency
- People with diabetes and their families/carers, need and deserve communication that is clear and accurate, respectful and inclusive, free from judgement and bias (31)
- Explain to person +/- family/carers that based on the clinical assessment the person displays signs of DE
- Explain that deviation from previous growth trajectory (when this is known) is concerning in the context of DE/ ED
- Elicit the person +/- family/carers awareness and concerns
- Acknowledge the focus on food and glycaemic control in diabetes management and potential challenges for the person +/- family/carers.
- Advise the person that their concerns with weight and shape are valid and will be addressed
- Explain the necessity of treatment, and that support is available
- Inform the person on the consequences of untreated DE, including insulin omission (if evident) on overall short-term, and long-term health (such as diabetes-specific complications, ED complications, fertility and poor bone health)
  - Give information factually and avoid instilling fear as this may lead to disengagement from treatment.
  - Verify with the person/family/carer that the information is clear
  - o Invite the person/family/carer to ask questions
- Seek collateral history with the person's consent when appropriate (e.g. parents, partners, other HCP)

#### **Principle 2: A Multidisciplinary Team approach**

- Persons with T1D and DE benefit from an MDT approach.
- Utilise the staff with whom the person +/- family/carer has developed a rapport to relay information
- The core MDT should include an endocrinologist, dietitian, credentialled diabetes nurse educator, psychologist, +/- psychiatrist with T1D expertise.
- The general practitioner should be involved in patient care, facilitate appropriate referrals, and provide access to MBS reimbursable schemes where available.
- Engage early with ED Services or CYMHS for guidance.
- Effective communication within the team and a collaborative approach is essential.
- Suggested MDT approach:
  - MDT case discussion at every post clinic meeting
  - o MDT based treatment decisions, goals and targets, in consultation with the person +/- family/carer
  - MDT to reassess treatment plans at least 3 monthly (more frequently, if the person's progress is deteriorating or treatment targets are not being met)
  - MDT to decide the timing of referral of the person +/- family/carer to ED Team, CYMHS or hospital admission

#### Principle 3: Family-centred or Person-centred approach

- Decide at the outset of treatment, whether family/carer support is needed and appropriate, as in the case of the paediatric population and in consenting adults.
- Shared decision-making
- Treatment decisions should be realistic, achievable, modifiable and flexible
- Align with the person's +/- family/carer's goals wherever possible
- Identify issues within family dynamic which may be contributing to risk factors or DE/ED behaviours
- Commence treatment where the person feels ready to focus, if safe and appropriate, as they are more likely to engage with treatment plan
- Be sensitive if the person prefers not to be weighed or know their weight
- Celebrate the small successes along the way
- If treatment goals are not achieved, explore the person's +/- family/carer's challenges and revise the treatment plan
- Identify and discuss the parameters and timeframes in which escalation of treatment for DE/ED will be required. [Refer to Principle 4: Individualised care pathway]

#### **Principle 4: Individualised care pathway**

- Individualise the person's care pathway outside of routine clinical care.
- Joint (person/family/carer and MDT) treatment goals and plans should consider the frequency of appointments, level of support and monitoring.
- Treatment plans should take consider the severity of DE along its spectrum, ranging from mild symptoms to diagnosed ED.
- Be mindful of DE/ED in young people who are transitioning from paediatric to adult services, that assessments/interventions for DE/ED are well coordinated.
- Recommendations for and referral to OzDAFNE in those 17+, should be individualised. OzDAFNE has
  been shown to reduce diabetes distress (39) (38) and may be useful in the prevention of DE as it promotes
  dietary freedom. However, there is no evidence for its efficacy in those with ED or moderate/ severe DE.
  As OzDAFNE training occurs in a group setting (group dosing and eating), involves the rapid tightening of
  glucose control and has a high focus on carbohydrates, it may be inappropriate for certain people.

#### Suggested treatment plan:

- Full involvement of MDT from the outset.
- Individualise the frequency of visits:
  - 2–4 weekly appointments, if thoughts and/or behaviours of DE (excluding insulin omission) and in the absence of the following: poor glycaemic control, failure to maintain growth and weight trajectory, diabetes-related complications, ED-related complications, poor QOL or other mental health diagnosis
  - 1–2 weekly appointments if thoughts and/or behaviours of DE including insulin omission or the
    presence of the following: poor glycaemic control, failure to maintain growth and weight trajectory,
    diabetes-related complications ED-related complications, poor QOL, other mental health diagnosis
  - Inpatient admission if there are acute clinical or metabolic complications of DE/ED [Refer to Table 4 and Table 5], risks of self-harm or suicidality [Refer to Error! Reference source not found. and Figure 1].
  - Inpatient admission should be offered at any stage if the person/family is unable to cope. It should also be considered if there is evidence of chronic symptoms/signs of DE that has not improved with outpatient management but concerning for the MDT.
  - Frequency of visits can be adjusted at any stage based on the person's current clinical assessment or general concerns.
- Individualise which members of the MDT require greater intensity of involvement.
  - E.g.. the individual with diabetes distress would benefit from consulting the CDE and social worker more often than other members of the MDT [Refer to Section 6 Suggested MDT Roles for Management of T1D with DE].
- Individualise the monitoring of specific health outcomes at each visit
  - Refer to Table 4 and Table 5 for comprehensive list.
  - Examples include HbA1c, growth velocity, BMI, psychopathology in addition to ED specific medical monitoring (12).

## Principle 5: Concurrent Integration of diabetes knowledge, dietary and psychology interventions

- Provide education on insulin management, including importance of basal insulin to prevent DKA
- Provide education on the signs and symptoms of DKA
- If possible, provide sick day management including checking for ketones
- Clinical consensus suggests that in person's with T1D and DE/ED, all medical and psychological aspects
  of care should be addressed concurrently.

A systematic review and meta-analysis in 2017 discussed six intervention studies based on psychotherapies that identified and challenged cognitions and affect about DE (1). Whilst there was some improvement in DE symptoms and a reduction in insulin omission was reported, none of the interventions showed improvement in HbA1c. The lack of improvement in glycaemic control could be attributed to the use of HbA1c instead of time in range (TIR) as an outcome measure, lack of diabetes integration into the DE treatment or may reflect a more relaxed approach to diabetes targets while the DE was addressed.

Family based therapy has been established as the strongest evidence-based treatment for adolescent anorexia nervosa (Jewell et al, 2016). There are few treatment outcome studies for the T1D plus ED subgroup that address the success of these therapies or recommended therapeutic adaptations. The agreed treatment principles (60) include a multidisciplinary approach with team members communicating frequently to maintain congruent treatment goals. Prior to outpatient treatment, the person may need inpatient care to ensure medical and psychiatric stability, particularly if there is a severe risk of DKA. The outpatient team must work collaboratively with person +/- family/ carer to establish small goals that are realistic and achievable.

In those children/adolescents with established ED, Family Based Therapy in Phase 1 is geared at empowering parents to coach the child to eat. The child is not invited to be part of conversations about their nutrition, meal planning or meal preparation. Parents may be required to assume a greater responsibility for nutritional restoration and closely supervise insulin injections when following this evidence-based treatment for ED.

Emerging evidence supports the use of CBT-E (cognitive behaviour therapy-enhanced) with adolescents if FBT is either unacceptable, contraindicated or ineffective. CBT-E is also the evidence-based treatment for adults with EDs and can be modified to incorporate insulin use/misuse as a treatment target.

## Principle 6: Early collaboration with specialist eating disorder services/clinicians

- Early involvement of local or statewide specialist Eating Disorder Services/clinicians or CYHMS for assessment and/or support with management is crucial.
- Rural and regional centres are encouraged to consider accessing Telehealth opportunities to gain access to Eating Disorder Teams or CYHMS.
- Consider shared care between specialist ED services/clinicians and the diabetes MDT.
- Frequent communication between both teams is paramount.
- It is essential for Diabetes teams to remain involved with care when a person is referred to an Eating Disorder Service/clinician or CYHMS.
- Teams should discuss and confirm who has the primary responsibility for monitoring the physical health of the patient. In most cases this management will remain with the diabetes team and GP.
- Bi-directional upskilling of Diabetes and ED Teams are required to integrate care.
- Diabetes teams should be aware of risk and normality of relapse for someone with DE/ED

## 6 Suggested MDT Roles for Management of T1D with DE

#### 6.1 Medical/endocrinologist/general practitioner

#### **Insulin Management**

- Explain the reasons why basal and bolus insulin doses are required and not negotiable.
- Both MDI (preferred) or pump therapy is acceptable.
- Support and supervision of insulin dosing is required for children/adolescents and should be considered in adults.
- For children/adolescents the school care plan should stipulate that children/adolescent should consume food and administer insulin in a supervised environment. This can be helpful in cases of insulin omission.
- Prevent hypoglycaemia which may cause associated fear and trigger binge eating behaviours.
- For adults with chronic hyperglycaemia, reduce the blood glucose levels slowly to standard targets by gradually increasing insulin doses.
  - This will reduce the risk of sudden worsening of existing retinopathy, inducing autonomic neuropathy, peripheral neuropathy and/or nephropathy (61).

#### Monitor for Insulin oedema with insulin re-initiation

• Insulin oedema following initiation, re-initiation or intensification of insulin is a rare phenomenon in paediatrics (62). It appears to be associated with DKA and children with chronic poor glycaemic control where there is significant long-term malnutrition. In adults (6, 44), the incidence is 3-3.5%. It can be mild or result in generalised oedema. It occurs 1-week post initiation and is usually self-limiting within 4 weeks of conservative management of fluid and salt restriction. Occasionally diuretic therapy is required. Oedema is more severe in those who are underweight with poor cardiac, renal or hepatic reserve (63, 64).

#### Monitor growth and weight

- Monitor growth and weight centiles for children/adolescents.
- Monitor weight and BMI for adults when appropriate.
- Be mindful that weight can be a sensitive topic. Consider use of HAES principles.

#### Monitor for diabetes-specific complications and ED complications

- Monitor and treat long-term complications secondary to T1D.
- Long-term complications secondary to T1D are not frequently seen in children and adolescents.
- Monitor pathology e.g. biochemistry, haematological, hormonal profiles
- Monitor for menstrual cycle irregularities and bone health
  - O Bone health has been shown to be worse in children with T1D compared to unaffected children. There is also an association between increased fracture risk and poor glycaemic control. Amenorrhoea is a well-recognised risk factor for poor bone health. Evaluation of bone health with a Bone Mineral Density is recommended in those with complications of amenorrhoea for more than 6 months duration (65). Children and adolescents require BMD z-scores using approved radiology software packages.
  - Complete nutritional restoration is required to reverse suppression of the neuro-endocrine axis and restore the natural menstrual cycle.
  - In adolescent females, there is insufficient evidence to recommend any specific hormonal therapies to restore the menstrual cycle or protect against bone loss other than weight restoration and ensuring adequate levels of calcium and vitamin D (66).
  - Encouragement of weight-bearing activities to improve bone health should be provided with awareness that exercise may be used inappropriately to manipulate weight.
  - In adult females, further consider supplementation of oestradiol to bone safe levels with progestin (67).
- Escalate care when required

#### 6.2 Dietitian (APD)

#### Principles for Children/Adolescents/Adults with T1D/DE

- Acknowledge individual's thought and feelings around eating.
- Aim for regular three meals with snacks between to normalise eating habits and moderate hunger and satiety levels.
- In children, address normal serve size of foods and adequate representation of food groups appropriate for the age and growth requirements. This changes with the age of the child, activity and growth.
- Consider clinical dietary requirements (e.g. coeliac disease, gastroparesis)
- Ensure adequate caloric intake for growth, development and maintenance of adequate nutritional status.
- May require weight gain and catch-up growth if tracking away from previous height and weight centiles.
- · Adjust carbohydrate amount and distribution to meet individual needs and prevent rapid weight gain
- Consider micronutrient supplementation to address deficiencies e.g. multivitamin, thiamine, vitamin D, calcium, phosphate, iron (68).
- A meal plan may be required for the person +/- family/carer.
- Address any 'fear' foods
- Address eating behaviours such as picking, timing and pace of eating.
- Encourage a safe, protected environment for eating e.g. the dining table with others, away from television or games and out of the bedroom. This enables insulin to be supervised.
- Consider supervised bathroom time after a meal for those that are purging.
- Explain the reasons why insulin doses must be administered, this is not negotiable.
- Consider changing focus of carbohydrate count to reduce the diabetes distress/anxiety of variable insulin
  doses and reduce the burden of carbohydrate counting. Remove the focus on "numbers". For example,
  give a carbohydrate range for meals and snacks, considering serve sizes and age-appropriate for growth
- Educate around the importance of daily activity and regular exercise (if medically safe) for maintaining physical health, regulating weight and beneficial effect on blood glucose levels.
- Address fears around exercise with diabetes. Education on strategies to maintain blood glucose levels with
  exercise is important to empower the person to manage exercise safely and confidently.
- Monitor frequency and duration of exercise as DE food behaviours decrease, exercise may increase.
- Address sleep patterns. To establish and maintain healthy sleep patterns, it is recommended to have
  consistent bedtime and wake-up times, avoid screen time 1 hour before sleep, and to keep screens out of
  the bedroom.

#### Additional Principles for Adults with TID/DE

- In adults, consider dietary education approaches such as HAES© (69), RAVES©(https://rdcu.be/chpYn) motivational interviewing, mindful eating etc. and consider dietetic alignment with concurrent evidence-based psychological therapies (e.g., CBT-E and MANTRA).
- Dietitians who are unfamiliar with these approaches should consider seeking professional supervision/support from an ED specialist dietitian. Dietitians within the MDT should consider being upskilled in these techniques.
- Adjust total glycaemic load and carbohydrate distribution to meet their individual needs and prevent rapid weight gain.
- In adults with concurrent diabetes distress, consider consistent carbohydrate exchanges at each meal to reduce the distress/anxiety of variable insulin doses and carbohydrate counting. Alternatively, if counting carbohydrate in grams is identified to contribute the DE/ED, consider teaching 10g carb portions or 15g carb exchanges.

#### 6.3 Credentialled diabetes educator (CDE)

- Review understanding of the pathophysiology of T1D
- Provide education around the action of insulin and the goals of management
- Review insulin administration
- Explore feelings associated with hypoglycaemia and hyperglycaemia
- Educate on the accurate treatment of hypoglycaemia
- Manage diabetes distress and consider referral to diabetes self-management and resilience building programs such as OzDAFNE
- Educate on the signs and symptoms of DKA, and insulin adjustment for sick days.
- Discuss diabetes technologies such as Flash Glucose Monitoring or Continuous Glucose Monitoring Systems which may assist with the burden of diabetes self-care
- Discuss the impact of exercise on diabetes and strategies to effectively manage blood glucose fluctuations around exercise
- Address reasons and details of insulin omission or restriction
- · Address other barriers to taking insulin including hypoglycaemia-related fears or needle phobia

#### 6.4 Mental health practitioner/psychologist

- When using the DPAT or other psychosocial questionnaires, start conversation around the persons responses in the questionnaire
- Explore adjustment process in managing diabetes (including diabetes distress, low self-confidence in diabetes management)
- Explore thoughts and feelings related to body image/weight and eating
- Explore underlying personality traits which may lead to unhelpful thoughts and feelings (e.g. perfectionism, obsessive thoughts)
- Focus on well-being and healthful eating rather than weight
- Focus on nutritional adequacy in children/adolescents, focus on nutritional adequacy to support growth along appropriate trajectory on centile charts
- Explore social support network (including family)
- Consider family involvement in treatment plan
- Although effective interventions are lacking, consider psychotherapy to address identified psychological problems specific to T1D and DE
- Address co-morbid psychopathology e.g. depression, anxiety

#### 6.5 Specialist services referrals

- Specialist Diabetes Service/Endocrinologist
- Specialist Eating Disorder Service/clinician/Child and Youth Mental Health Services
- Consultant Psychiatrist
- General Paediatrician
- Exercise Physiologist
- Consider referral to lifestyle management programs such as OzDAFNE (Dose Adjustment for Normal Eating). This may be more appropriate in prevention, early stages of Disordered Eating or in recovery stages
- Drug and Alcohol Service
- Escalation to Hospital Inpatient Admission

#### Appendix 1: DSM-5 and ICD-10 criteria

**DSM-5 Criteria:** American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.). Washington, DC: available <a href="https://www.psychiatry.org/psychiatrists/practice/dsm">https://www.psychiatry.org/psychiatrists/practice/dsm</a>

ICD-10 criteria: https://www.icd10data.com/ICD10CM/Codes/F01-F99/F50-F59/F50-/F50.9

## **Appendix 2: Diabetes Psychosocial Assessment Tool** (DPAT)

#### Diabetes Psychosocial Assessment Tool (DPAT) – 16-18 years

Access full example: <u>Diabetes Psychosocial Aseessment (Phase Three) | Queensland Health (clinicalexcellence.qld.gov.au)</u> | Follow local processes to access clinical form

h) 200 708 90 Heal	Queensland		(Af	fix identification	on label here	)				
d Health 3 096 7 ensland alth ald	Government	URN:								
ensland ABN 8 ed/Quee		Family name:								
nd (Que Limited se Limit so netwo	Diabetes Psychosocial	Given name(s):								
ueensla Icordiae ericordia diabete	Assessment (Phase Three)	Address:								
© State of Queensland (Queensland Health) Developed by Mater Miserinordiae Limited ABN 35 056 708 92 Revised by Mater Miserinordiae Limited ABN 30 408 708 92 Revised by Mater Miserinordiae Limited ABN 30 404 Contact statewise diabetes network@health oid ow.	Facility:	Date of birth:			Sex:	M	F 🗌 I			
© Sta by Mate d by Ma	Date: / /									
veloped Revise Con	Do you have any concerns or questions that you would like addressed today?									
Q	1									
	2.									
	Checklist:									
	Phase two assessments are completed  Young person has been in transition clinic and ready	for transfer to	adult servic	es						
	Young person is approximately 16–18 (dependent up			, I						
	Independent visits occurring between the young pers									
	Confidentiality explained to young person and strictly Written transition plan with regular revision of goals h	,	s appropria	te)						
	Problem Areas in Diabetes – Teen Vers		T\							
7	Instructions: Living with diabetes can sometimes be di			nere may be	many prob	lems and h	assles	1		
3GIN	with your diabetes. The problems may range from minor	r hassles to ma	ajor life diffic	culties. Liste	d below are	a variety o	of possible			
MAF	problem areas which people with diabetes may have. The bothered you <b>DURING THE PAST MONTH</b> and tick (🗸)			of the item	is below ma	ly nave ups	et or			
DO NOT WRITE IN THIS BINDING MARGIN	Please note that we are asking you how much each iter true for you. If you feel that an item is not a bother or a would tick "6".	n may be bothe problem for you	ering you in u, you would	your life, Noted tick "1". If	OT whether it is very bo	the item is othersome t	merely o you, you			
IS BI	During the past month I have been	I have been Not a problem Medium problem Big problem								
<b>4</b> E ⊠	Feeling sad when I think about having and living with diabetes.	h1	2	_3	_ 4	5	□ 6			
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Δ	Feeling "burned-out" by the constant effort to manage diabetes.	le 🗆 1	2	3	4	5	<u>6</u>			
	Feeling that I am not checking my blood sugars ofter enough.	n	2	3	4	5	<u></u> 6	) 옷		
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20	<ol> <li>Feeling that my friends or family act like "diabetes police" (e.g. nag about eating properly, checking bloosugars, not trying hard enough).</li> </ol>	od 1	2	3	4	5	<u> </u>	PSYCHOSOCIAL AS		
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v1.00 - 11) WINC Code	Missing or skipping blood sugar checks.	□1	2	3	4	5	<u></u> 6	NSS:		
=	The selling that I am often failing with my diabetes regimen.	1	2	3	4	5	<u>6</u>	IENT		
	Feeling like my parents blame me for blood sugar numbers they don't like.	1	2	3	4	5	<u>6</u>	SESSMENT (PHASE		
V4 068	12. Feeling that my friends or family don't understand ho difficult living with diabetes can be.	1	2	3	4	5	<u></u> 6	ASE		
890 WS	13. Worrying that diabetes gets in the way of having fun and being with my friends.	1	2	3	4	5	<u></u> 6	THREE		
	14. Feeling like my parents worry about complications to much.	DO 1	2	3	4	5	<u> </u>	] EE		
		Page 1 of 4								

## Diabetes Psychosocial Assessment Tool (DPAT) - Adults Access full example: Diabetes Psychosocial Assessment | Queensland Health (clinicalexcellence.qld.gov.au) |

Follow local processes to access clinical form

Queensland Government  Diabetes Psychosocial Assessment  Facility:  Date: / / //  Problem Areas in Diabetes (PAID) Questionnair		(Affix identification label here) URN:								
ok@pe	Family	Family name: Given name(s):								
Diabetes Psychosocial	Given									
Assessment	Addre	ss:								
Facility:	Date o	of birth:		Sex	:м	]F				
Date://										
Problem Areas in Diabetes (PAID) Questionnaire										
Tick (✓) the number that gives the best answer for you. Please provide an answer for each question. Please bring the completed form with you to your next consultation where it will form the basis for a dialogue.										
Which of the following diabetes issues are curren problem for you?	ntly a	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem				
Not having clear and concrete goals for your diab	etes care?	o	□1	2	3	4				
Feeling discouraged with your diabetes treatment	t plan?	О	1	2	3	4				
3. Feeling scared when you think about living with d	iabetes?	o	1	_2	3	4				
Uncomfortable social situations related to your dia (e.g. people telling you what to eat)?	abetes care	0	1	_2	3	4				
5. Feelings of deprivation regarding food and meals	?	o	1	<u></u> 2	3	4				
6. Feeling depressed when you think about living wi	th diabetes?	o	□1	_2	3	4				
Not knowing if your mood or feelings are related t diabetes?	to your	o	_1	_2	3	4				
8. Feeling overwhelmed by your diabetes?		0	1	2	3	4				
9. Worrying about low blood sugar reactions?		0	1	2	3	4				
10. Feeling angry when you think about living with dia	abetes?	0	1	2	3	4				
11. Feeling constantly concerned about food and eati	ing?	o	1	2	3	4				
12. Worrying about the future and the possibility of secomplications?	erious	o	1	2	3	4				
13. Feelings of guilt or anxiety when you get off track diabetes management?	with your	o	1	2	3	4				
14. Not "accepting" your diabetes?		o	1	2	3	4				
Not "accepting" your diabetes?  15. Feeling unsatisfied with your diabetes physician?		o	1	2	3	4				
16. Feeling that diabetes is taking up too much of you physical energy every day?	ur mental and	o	1	2	3	4				
17. Feeling alone with your diabetes?		o	1	2	3	4				
18. Feeling that your friends and family are not suppodiabetes management efforts?	ortive of your	o	1	2	3	4				
19. Coping with complications of diabetes?		o	1	_2	3	4				
20. Feeling "burned out" by the constant effort needed diabetes?	d to manage	o	1	2	3	4				

PAID - © Joslin Diabetes Center 1999

Page 1 of 4

## **Appendix 3: Diabetes Eating Problem Survey – Revised Scale (DEPS-R Scale)**

Diabetes Eating Problem Survey – revised Scale (DEPS-R Scale) (70)
Access full example: <u>diabetes-deps-r-scale.pdf</u> | Follow local processes to access clinical form

(2010 (2010 gov.a	Queensland		(Affix identification label here)					
'Queensland (Queensland Health) 2020 Diabetes Centre Inc., Boston, MA (2010) 1e_diabetes_network@health.qld.gov.au	Government		URN:					
eenslar nc., Bos rork@he	Eating Disorder Screening (DEPS-R Scale)		Family name:					
and (Qu Centre I es_netw			Given name(s):					
of Queensia Diabetes ( de_diabete			Address:					
State of C Joslin Di statewide	Facility:		Date of birth:		Se	ex: M	F I	
© S Developed by, Contact: st	Notes for clinician undertaking the screening:  • The 16-item DEPS-R Scale* From Markowitz et al (2010) <a href="https://www.diabetesonthenet.com/uploads/resources/dotn/">www.diabetesonthenet.com/uploads/resources/dotn/</a> master/3349/files/ <a href="https://master/3349/files/pdf/idn17-6-228-32.pdf">pdf/idn17-6-228-32.pdf</a> • Items are answered on a 6-point Likert scale: 0 = Never; 1 = Rarely; 2 = Sometimes; 3 = Often; 4 = Usually; 5 = Always. • Please see 'Scoring instructions' below on how to score the screening.							
	Do you take insulin? Yes No If No, do not complete this form.							
	Living with diabetes can sometimes be difficult, particularly regarding eating and diabetes management. Listed below are a variety of attitudes and behaviours regarding diabetes management. For each statement, tick ( ) the ONE answer that indicates how often this is true for you during the PAST MONTH.</th							
	How often this is true for you during the past month	Never	Rarely	Sometimes	Often	Usually	Always	
	Losing weight is an important goal to me	o	1	□ 2	3	4	5	
	I skip meals and/or snacks	o	1	2	3	4	_ 5	
	Other people have told me that my eating is out of control	o	□1	_2	Пз	<b>4</b>	5	
	When I overeat, I don't take enough insulin to cover the food	0	1	□2	_3	4	5	
	I eat more when I am alone than when I am with others	_ o	□1	_2	Пз	_ 4	5	
	I feel that it's difficult to lose weight and control my diabetes at the same time	0	1	_2	<u></u> 3	4	_ 5	
	I avoid checking my blood sugar when I feel like it is out of range	_ o		_2	3	4	5	
	I make myself vomit	o		_2	3	4	_ 5	
	I try to keep my blood sugar high so that I will lose weight	0		2	3	4	5	
	I eat in a way to get ketones	0	1	2	3	4	5	
	I feel fat when I take all of my insulin	o	□1	2	3	4	5	
	Other people tell me to take better care of my diabetes	0	1	2	3	4	5	
Code:	After I overeat, I skip my next insulin dose	o	1	2	3	4	5	
WINC Co	I feel that my eating is out of control	o	1	2	3	_ 4	5	
>	I alternate between eating very little and eating huge amounts	0	1	2	3	4	5	
	I would rather be thin than to have good control of my diabetes	o	1	2	3	4	5	
<b>≣</b> ¼	Sub-totals							
SW1064	Scoring instructions: . Calculate the mean of all non-missing items Multiply this value by 16. Ossible total score 0 to 80. A score >20 indicates more disordered eating behaviour and varrants in depth conversations/referrals.						/80	

Page 1 of 1

#### **Appendix 4: Specialist eating disorder services**

#### **Queensland Health - Adult services**

#### **Queensland Eating Disorder Service (QuEDS)**

(For health services outside Gold Coast, Sunshine Coast and North Queensland)

- Services provided: phone intake and advice, specialist consultation (assessment) clinic (based at RBWH), consultation and workforce development and training
- Individual and group treatment: Cognitive Behaviour Therapy-enhanced (CBTe), Specialist Supportive Clinical Management (SSCM) and a 12week intensive Day Program
- Access to RBWH specialist beds if inpatient treatment goals aren't met with QuEDS Consultation Service input

Contact: 07 3114 0809 or email: QuEDS@health.qld.gov.au

#### **Gold Coast Eating Disorder Program (GCHHS-AEDP)**

 Services provided: Consultation and assessment, workforce development and training, evidence-based individual outpatient treatment

Contact: 07 5635 6200 Referrals 1300 MHCALL

#### **Sunshine Coast Eating Disorder Program (EDS-SC)**

 Services provided: Consultation and assessment, workforce development and training, evidence-based individual outpatient treatment

Contact: (07) 5202 9500 or email: <a href="mailto:sc-MHAS-EDS@health.qld.gov.au">SC-MHAS-EDS@health.qld.gov.au</a> or Fax: 5202 9501

#### North Queensland Eating Disorder Service (N-QuEDS)

Services Provided: Consultation, Training, Evidence-based Outpatient Treatment

Contact: Cairns Hospital Centralised Intake Service (CIS) 1300-64-22-55

#### Services offered

- Assessment and treatment recommendations clinic
- Individual, time-limited, evidence-based therapy e.g. cognitive behaviour therapy-enhanced, specialist supportive clinical management
- Group programmes
- Day programmes
- Specialist eating disorder beds or facilitation of inpatient admission
- · Provision of consultation to inpatient and community teams
- Intake service
- Education of health professionals

#### Child Health Queensland - Paediatric/adolescent services

**CYMHS Eating Disorders Program** 

#### Non-Queensland Health services

Contact Butterfly Foundation for listing of private specialist eating disorder clinicians/services

Private eating disorder services may provide a similar range of services.

#### The Butterfly Foundation

https://butterfly.org.au

Services may include:

- Individual counselling in evidence-based therapies and supportive counselling
- Online support
- Group programmes
- Supportive meal therapy
- Residential programmes e.g. Butterfly, EndED Butterfly House.

#### **Eating Disorders Queensland (EDQ)**

https://eatingdisordersqueensland.org.au/

EDQ provides services for carers, including:

- Individualised coaching
- Family coaching
- Carer Peer Mentor Program
- Carer Connect Support Group
- Fostering Recovery workshops.

## Appendix 5: Algorithm for asking about self-harm and suicidality risk

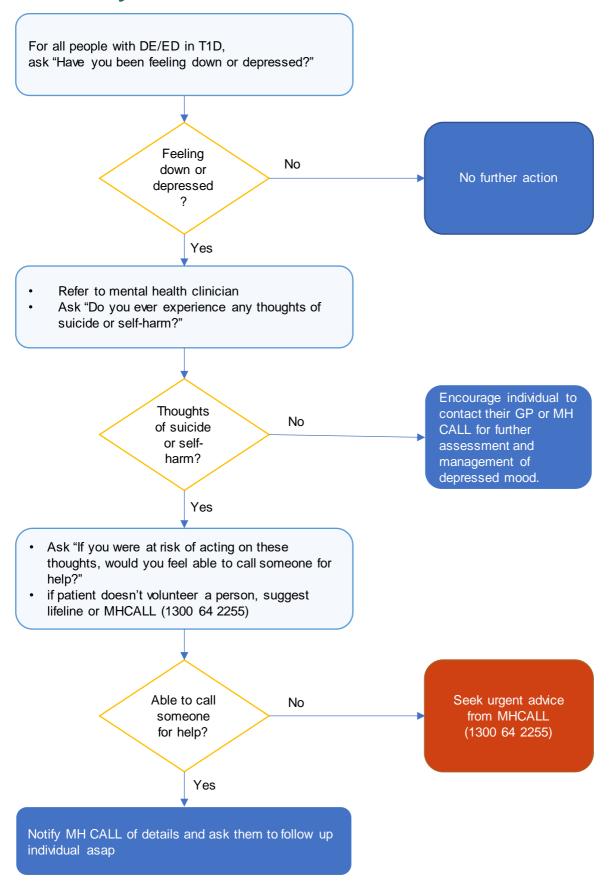


Figure 1 Algorithm for asking about self-harm and suicidality risk. – age ≥ 16 years

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#### **Supplement**

This document was developed by the Queensland Statewide Diabetes Clinical Network. It is based on the available evidence at the time of development and consensus of experienced diabetes and eating disorder professionals. All recommendations are based on clinical consensus unless otherwise stated.

#### **Funding**

Development of this guideline was supported by Diabetes Queensland and the Healthcare Improvement Unit (Queensland Health).

Consumer representatives were paid a standard fee. Other panel members participated on a voluntary basis.

#### **Expert panel members**

#### **Clinical leads**

Chair the panel, lead literature review and consensus building activities with panel members.

- Helen d'Emden Credentialled Diabetes Educator Diabetes Qld
- Dr. Neisha D'Silva Senior Staff Endocrinologist, Queensland Diabetes and Endocrine Centre, Mater Health

#### Panel members

Participate in literature review and consensus building activities.

- Amanda Davis Senior Dietitian, Queensland Eating Disorder Service (QuEDS)
- Nicole Ward Consultant Dietitian MacIntyre Health Queensland
- Dr. Christel Hendrieck, Associate Director Australian Centre for the Behavioural Research in Diabetes
- Dr. Warren Ward, Director Queensland Eating Disorder Service (QuEDS)
- Dr. Carmel Smart Senior Paediatric Dietitian and Clinical Research Fellow, John Hunter Hospital Newcastle
- Michelle Fuery Dietitian, Queensland Children's Hospital
- Dr. Michelle Boyd, General Paediatrician, Mater Health
- Dr. Tony Huynh Director Director of Endocrinology and Diabetes, Queensland Children's Hospital

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#### **Conflict of Interest**

Declarations of conflict of interest were sought from panel members. No conflict of interest was identified.

#### Consensus processes

Consensus was achieved using round table discussions

#### Review process and summary of changes

Release	Summary of changes				
V1 August 2021	First publication				
V2 March 2022	Expanded scope to include paediatric population				

#### Literature search strategy

The search strategy was conducted in the EMBASE, CINAHL and PsycInfo databases, using controlled vocabulary and free text search terms. Concepts were kept broad to enable wide coverage, focusing on type 1 diabetes and eating disorders/disordered eating. The final search was run in June 2021 and limited to English language papers published in the last 10 years. There was no restriction placed on study type.

#### Consultation

Stage 1 Disordered Eating and Eating Disorders in Adults with Type 1 Diabetes (aged 16 years and over)

Major consultative and development processes occurred in September 2019 to April 2021

- Expert panel members with significant clinical and research experience on this topic were invited.
- Initial development occurred between March 2020 and December 2021 by the expert panel. A statewide EOI process was also undertaken. These members reviewed the document at key stages, September 2020, December 2021 and April 2021.
- Consumer engagement was performed, with review of the document at key stages September 2020, December 2020, April 2021
- Statewide consultation was undertaken at key stages September 2021, December 2020, April 2021
- Expert panel reviewed final recommendations and formed consensus

Stage 2: Disordered Eating and Eating Disorders in Children, Adolescents and Adults with Type 1 Diabetes

Major consultative and development processes occurred in August 2021 to December 2021

- Panel members with significant paediatric clinical and research experience on this topic were invited to revise the guideline to include children and adolescents.
- The revised guideline "Disordered Eating and Eating Disorders in Children, Adolescents and Adults with Type 1 Diabetes" was forwarded to Australian Paediatric Endocrine Group (APEG) in March 2022 for further review and endorsement.

#### **Endorsement**

Stage 1: The guideline "Disordered Eating and Eating Disorders in Adults with Type 1 Diabetes (aged 16 years and over)" was endorsed by the Statewide (Queensland) Diabetes Clinical Network in July 2021 Statewide (Queensland) Diabetes Clinical Network in July 2021.

#### Stage 2:

#### Citation

The recommended citation of this guideline is:

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