Chapter 8

Eating Problems

Key Messages

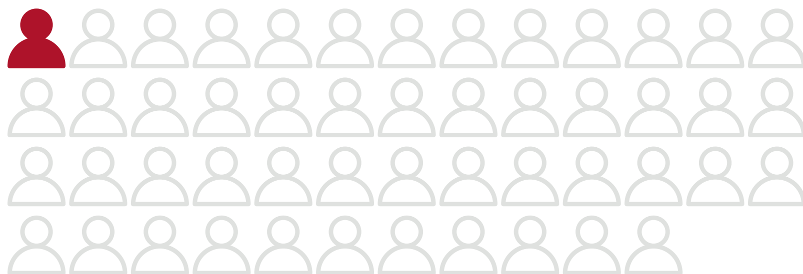
- The term "eating problems" encompasses both "sub-clinical" disordered eating behaviors and full syndrome eating disorders.
- Disordered eating behaviors include food restriction, compulsive and excessive eating, and weight management practices, which are not frequent or severe enough to meet the criteria for a full syndrome eating disorder.
- Eating disorders include several diagnosable conditions (e.g., anorexia nervosa, bulimia nervosa, and binge eating disorder), which are characterized by preoccupation with food and body weight, as well as disordered eating behavior, with or without compensatory weight control behaviors.
- Among people with diabetes, the full syndrome eating disorders are rare. The most common disordered eating behaviors are binge eating and insulin restriction/omission, but prevalence is not well established.
- Eating problems in people with diabetes are associated with suboptimal diabetes self-management and outcomes, overweight and obesity, and impaired psychological well-being. Eating disorders are associated with early onset of diabetes complications, and higher morbidity and mortality.
- A brief questionnaire, such as the modified SCOFF adapted for diabetes (mSCOFF), can be used as a first step screening questionnaire in clinical practice. A clinical interview is needed to confirm a full syndrome eating disorder.
- Effective management of eating problems requires a multidisciplinary team approach, addressing the eating problem and diabetes management in parallel.

Practice Points

- Ask the person directly, in a sensitive/non-judgmental way, about eating behaviors and attitudes towards food, insulin restriction/omission, and concerns about body weight/shape/size.
- Be aware not to positively reinforce weight loss or low A1C when eating problems are (likely) present.
- Be aware that acute changes in A1C and recurring diabetic ketoacidosis could indicate insulin omission and may be an alert to the presence of an eating disorder.

How Common Are Eating Problems?

Eating disorders (anorexia nervosa, bulimia nervosa, and binge eating disorder)



Type 1 diabetes[a,1–3]

Type 2 diabetes[2,4]

Disordered eating behaviors

Type 1 diabetes[5–8]

Type 2 diabetes[9–11]

WHAT ARE Eating Problems?

Eating Disorders

These comprise a group of diagnosable conditions, characterized by preoccupation with food, body weight, and shape, resulting in disturbed eating behaviors with or without disordered weight control behaviors (e.g., food restriction, excessive exercise, vomiting, and medication misuse).[2,3] They include:

- **Anorexia nervosa:** characterized by severe restriction of energy intake, resulting in abnormally low body weight for age, sex, developmental stage, and physical health; intensive fear of gaining weight or persistent behavior interfering with weight gain; and disturbance in self-perceived weight or shape. There are two subtypes:
  - restricting subtype, with severe restriction of energy intake
  - and binge eating/purging subtype, with restriction of food intake and occasional binge eating and/or purging (e.g., self-induced vomiting, misuse of laxatives, etc.).
- **Bulimia nervosa:** characterized by recurrent episodes of binge eating, at least once a week for three months, and compensatory weight control behaviors. Similar to anorexia nervosa, weight and shape play a central role in self-evaluation. In contrast to anorexia nervosa, weight is in the normal, overweight, or obese range.
- **Binge eating disorder:** characterized by recurrent episodes of binge eating, at least once a week for three months. People with a binge eating disorder do not engage in compensatory behaviors and are often overweight or obese.
- **Other specified or unspecified feeding or eating disorders:** characterized by symptoms of feeding or eating disorders causing clinically significant distress or impact on daily functioning, but that do not meet the diagnostic criteria for any of the disorders. Specified eating disorders are, for example, “purging disorder” in the absence of binge eating, and night-eating syndrome.

a Based on young women only.

The complete diagnostic criteria for the above-mentioned eating disorders can be found in the *International Statistical Classification of Diseases and Related Health Problems*, 11th revision (ICD-11)[12] and *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM-5).[13] The criteria for eating disorders were revised in the fifth edition of the DSM.[13]

Although eating disorders develop typically during adolescence, they can develop during childhood or develop/continue in adulthood; they occur in both sexes.[14] For example, binge eating disorders are more prevalent in middle-aged individuals than in youth and young adults, and there is no female preponderance.[15]

BOX 8.1 Prevalence of Eating Disorders and Disordered Eating in Adults with Diabetes Is Not Yet Well Established

Diabetes is likely associated with an increased risk of eating problems. However, published prevalence data are inconsistent, with some studies showing no difference in rates compared to a general population, and others reporting higher rates.[2]

The inconsistencies are largely due to the methodology used (e.g., measures and inclusion criteria), for example:

- Data are collected typically with general eating disorder questionnaires, and the findings are not necessarily confirmed with a clinical interview or examination.
  - These questionnaires tend to inflate the estimated prevalence of eating disorders and disordered eating behaviors in people with diabetes.[1,3,9] The focus on diet that could be considered problematic for people without diabetes may be a necessary aspect of self-care for people with type 1 diabetes. Thus, some of the items in general eating disorder questionnaires are not appropriate for people with diabetes.
  - Apart from overestimating prevalence, the questionnaires are not sensitive enough to identify diabetes-specific compensatory behaviors, such as insulin restriction/omission.[16]

In addition, most studies have included predominantly female adolescents or young adult women, and sample sizes are small.[17]

Due to such limitations, the evidence of eating problems in adults with diabetes is limited and findings should be interpreted and generalized with caution.

Though the current evidence base is limited, it has been established that:

- the prevalence of anorexia nervosa in female adolescents and young women with diabetes is low and not more prevalent than in the general population[18]
- and people with diabetes are more likely to present with periodic overeating, binge eating, and compensatory weight control behaviors,[19] with more frequent and severe behaviors likely to meet criteria for a full syndrome eating disorder such as bulimia nervosa or binge eating disorder.

Future studies about eating behaviors should include men, because, as is true in women, binge eating is more common in men with type 2 diabetes than it is in men without diabetes.[3,20]

Disordered Eating Behaviors

These are characterized by symptoms of eating disorders but do not meet criteria for a full syndrome eating disorder. For example, binge eating episodes occurring less frequently than specified for a diagnosis of bulimia nervosa or binge eating disorder. However, if left untreated, disordered eating behaviors can develop into a full syndrome eating disorder. The following disordered eating behaviors can present in isolation or as part of an eating disorder:[13]

- **Binge eating:** includes eating in a two-hour period an amount of food that most people would consider unusually large, plus a sense of loss of control when overeating. It is a symptom in all three main full syndrome eating disorders (binge eating/purging subtype of anorexia nervosa, bulimia nervosa, and binge eating disorder). It can occur in response to restrained eating (e.g., rule-based/restrictive eating), emotional cues (e.g., eating when distressed or bored), and external cues (e.g., eating in response to the sight, taste, or smell of food) (see Box 8.2).
- **Compensatory weight control behaviors:** include deliberate acts to compensate for weight gain following overeating or binge eating. For example, self-induced vomiting, excessive/driven exercise, medication misuse (e.g., laxatives or diuretics), omission or restriction of insulin (or other medication), fasting, or abstinence from/severe reduction in several or all food and beverages.

Intentional Insulin Restriction or Omission

- The restriction or omission of insulin for the purposes of weight loss is unique to people with diabetes and the most common form of compensatory weight control behavior.[17] Intentional insulin restriction or omission induces hyperglycemia and loss of glucose (and calories) in the urine, enabling a person to eat with reduced concerns about gaining weight.
- In individuals with type 1 diabetes and disordered eating behaviors, rates of insulin omission have been reported in up to 40% of people.[21] However, people omit or restrict insulin for other reasons than weight loss (e.g., fear of hypoglycemia, or rationing insulin for financial reasons).
- Not all people with diabetes and an eating disorder restrict or omit insulin for weight loss. They may restrict food/calories while taking insulin as recommended and they may also compensate for overeating with more typical eating disorder symptoms.[21]
- Both negative affect and diabetes distress substantially increase the odds of insulin restriction.[22]

BOX 8.2 Eating Styles

Certain eating styles are associated with difficulties in adjusting or maintaining healthy eating habits and weight; they may put people with diabetes at risk of developing an eating problem.[18] For example:[23]

- **Emotional eating** (in response to negative emotional states, such as anxiety, distress, and boredom) provides temporary comfort or relief from negative emotions, as a way of regulating mood. It is associated with weight gain in adults over time[24] and tends to be more common in people who are overweight or obese.[25]
- **External eating** (in response to food-related cues, such as the sight, smell, or taste of food) accounts for approximately 55% of episodes of snacking on high-fat or high-sugar foods in people who are overweight or obese.[26]

Emotional and external eating may increase the likelihood of snacking on high-fat or high-sugar foods,[26] higher energy intake,[27] overeating and binge eating,[28] and nighttime snacking.[29]

- **Restrained eating** (attempted restriction of food intake, similar to being on a diet, for the purpose of weight loss or maintenance) may be an adaptive strategy to manage diet and weight for people with diabetes, but there is evidence that it may be associated with suboptimal A1C.[30]

As a first step approach, a dietitian with experience in diabetes is best placed to support people with diabetes whose eating styles hinder maintaining a healthy diet and weight.

Eating Problems in People with Diabetes

There are indications that diabetes itself could be a risk factor for developing or exacerbating eating problems due to:

- **Behavioral changes:** the emphasis on dietary management (type, quantity, and quality of foods eaten, as well as timing of food intake), can lead to dietary restraint (restriction of food intake and adoption of dietary rules), which is associated with an increased risk of disordered eating and eating disorders.[31,32]
- **Physical changes:** people with type 1 diabetes commonly experience weight loss prior to diagnosis, and weight regain following insulin treatment,[17] while overweight and obesity is associated with the diagnosis of type 2 diabetes.[33] Increasing body weight is associated with body dissatisfaction and concerns about body shape,[17] which in turn increases the risk of developing disordered eating.[34]
- **Psychological changes:** the psychological burden of diabetes management can lead to low mood and psychological distress, which are associated with eating problems. Between 55–98% of people with an eating disorder report a concurrent mood or anxiety disorder.[35]
- **Physiological changes:** in type 1 diabetes, beta cells are destroyed and unable to secrete insulin and amylin,[17] while beta cell functioning declines and insulin resistance worsens over time in people with type 2 diabetes.[35] These changes in insulin secretion and insulin resistance lead to dysregulation of appetite and satiety and disruption of long-term weight regulation in people with diabetes.[17]

It may be difficult to distinguish disordered eating behaviors from self-care behaviors required for diabetes management, both include weighing foods, counting calories and carbohydrates, and avoiding certain foods. Signs of disordered eating behaviors may remain undetected if mistaken for “normal” diabetes management behaviors.[17,19]

Diabetes self-management behaviors may become disordered when they are:

- used inappropriately to achieve rapid weight loss (or to maintain an inappropriate goal weight)
- and carried to excess or impose rigid rules on the person’s lifestyle.

As a result, these inappropriate diabetes self-management behaviors can interfere with activities of daily living, pose a significant health risk, and impair the person’s emotional well-being.[17]

The combination of diabetes and an eating disorder adds to the complexity of the treatment. Therefore, early identification of the signs of disordered eating and body dissatisfaction is warranted to prevent full syndrome eating disorders. As evidence has shown,[3] eating disorders usually develop early in life, and as such, screening should start during adolescence.

Eating problems in people with type 1 diabetes are associated with:

- blood glucose levels above recommended targets[36]
- and other mental health problems.[36]

Eating disorders in people with type 1 diabetes, especially when insulin restriction/omission is involved, are associated with:

- earlier onset of[17] and increased risk of microvascular complications[7,37] (e.g., retinopathy or neuropathy)
- more frequent episodes of diabetic ketoacidosis and diabetes-related hospital admissions[5,38,39]
- and up to three times greater risk of mortality over a 6–10 year period.[16,40]

Eating problems in people with type 2 diabetes have not yet been widely investigated, but available research shows that they are associated with:

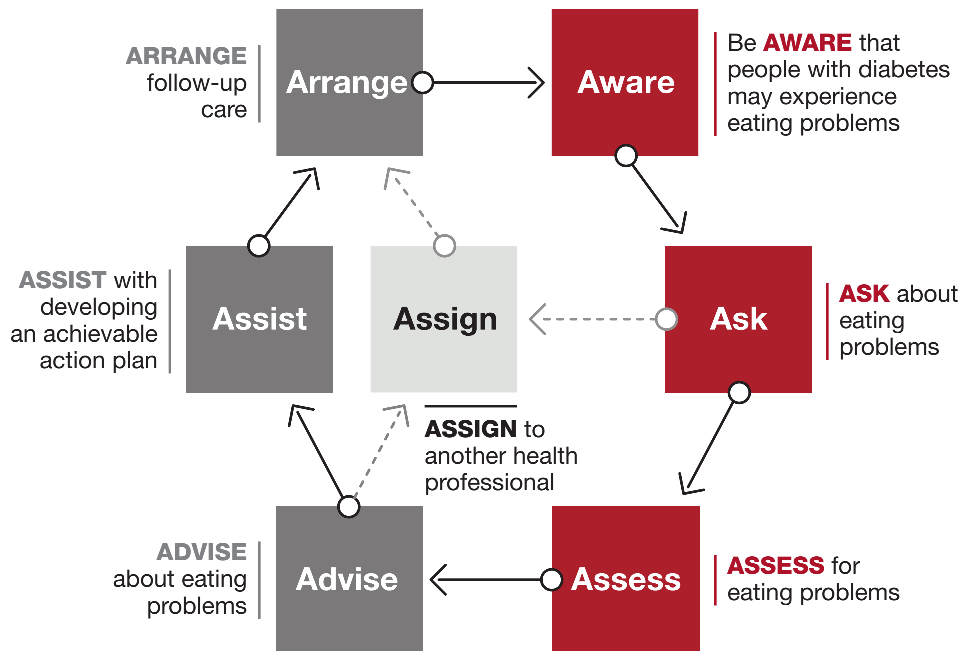
- overweight and obesity[41,42]
- lower self-efficacy for diet and exercise self-management[43]
- suboptimal dietary and glucose levels, but not A1C[44]
- not taking medications as recommended[45]
- and impaired mental health[46] and quality of life.[4,43,47]

7 A's Model: Eating Problems

This dynamic model describes a seven-step process that can be applied in clinical practice. The model consists of two phases:

- How can I identify eating problems?
- How can I support a person with an eating problems?

Apply the model flexibly as part of a person-centered approach to care.



HOW CAN I IDENTIFY Eating Problems?

Be AWARE

The following signs (general and diabetes-specific) may indicate a full syndrome eating disorder or be part of disordered eating behavior:[2,14,16,19]

- frequent and restrictive dieting and beliefs about food being "right" or "wrong," "good" or "bad"
- preoccupation and/or dissatisfaction with body shape, size, or weight (signs may include reluctance to having their weight taken or negative self-statements about weight and/or shape)
- unexplained weight loss or gain (disordered eating behavior can occur in low weight, average weight, and overweight people)
- suboptimal diabetes self-management, including less frequent or no blood glucose monitoring (i.e., not presenting blood glucose readings at consultation), frequent changes to insulin regimen, restriction/omission of insulin, overdosing of insulin (to compensate for binges), or missed clinical appointments
- suboptimal diabetes outcomes, including unexplained high or low A1C (which can be a sign of food restriction without insulin omission); acute change in A1C (a sign of the onset of an acute eating disorder, often with insulin omission); erratic fluctuating blood glucose levels; recurrent hypoglycemia (sometimes after attempts to dose

insulin after binge eating and self-induced vomiting); recurrent diabetic ketoacidosis and diabetes-related hospitalizations; and early development of microvascular complications

- distress, depression, and anxiety
- personality traits such as perfectionism and obsessiveness
- low self-esteem
- overall impaired psychosocial functioning (e.g., at school, work, or in relationships)
- concern expressed by a third party (e.g., partner or parent)
- dysfunctional family dynamic
- or physical signs as a consequence of an eating disorder (e.g., calluses on the hands, edema, or dental problems).

Not all of the above-mentioned signs automatically indicate an eating problem, as some may relate to other underlying psychosocial problems.

Two classification systems are commonly used for diagnosing eating disorders: DSM-5[13] and ICD-11.[12] Consult these for a full list of symptoms and the specific diagnostic criteria for each type of eating disorder.

Look for signs of eating problems in men, not only in women.

Disordered eating behaviors can be hidden, and the signs of eating problems can be subtle and difficult to determine from observation alone.

If any of the markers of eating problems are present, further inquiry is warranted (see **ASK**).

ASK

When you have noticed signs of eating problems (see **AWARE**) or the person raises a problem, ask directly, in an empathetic and non-judgmental way, about eating and weight management behaviors, as well as concerns about body weight/shape/size.

Option 1: Ask Open-Ended Questions

You may find it helpful to lead into questions with a comment about the focus of food and carbohydrate counting in diabetes management, which could cause concerns or anxiety about weight and food intake. For example:

- *"Women [men] with diabetes are sometimes concerned about their weight or shape. How do you feel about your weight or body shape?"*
- *"People sometimes feel that food and eating are a difficult part of managing diabetes. Do you find it hard to control what and how much you eat? Can you tell me a bit more about it? How often does this occur?"*

Explore the underlying reasons for disordered eating behaviors, for example:

- *"Could you tell me a bit more about the recent changes in your eating patterns?"*
- *"Have you noticed any changes in your life that could be the reason for the changes in your eating patterns?"*

Explore the person's beliefs, behaviors, and concerns about food, eating, body image, and weight. Enquire further to help identify the specific underlying causes of the problem. You will find that not all of the underlying causes relate to eating problems (e.g., social/family stress or other mental health issues may also contribute).

Explore any changes to their diabetes management plan or blood glucose levels, and difficulties encountered with diabetes management.

- *"Some people with diabetes find it difficult to keep up with their insulin injections/boluses. How is this going for you? Do you sometimes miss or skip your insulin?"*
    - If the answer is yes, *"Could you tell me about the reasons you miss [skip] insulin?"* Explore how often this occurs, and the person's beliefs and feelings about medication restriction/omission. Ask this more specific question if you do not get a clear answer to the broader question above. *"Do you ever adjust your insulin to influence your weight?"*
- *"Your A1C has been going up over the last couple of months and you mentioned you have gained/lost weight. How do you feel about this? Have you thought about what may be going on?"*

There is controversy about whether asking about insulin omission could unintentionally trigger inappropriate weight loss behaviors in people with type 1 or type 2 diabetes who use insulin therapy. Health professionals may feel uncomfortable asking about insulin omission/ restriction for the same reason. Whether or not this conversation can take place comes back to the respectful and non-judgmental relationship between the health professional and the person with diabetes, the way the questions are phrased and how the person with diabetes' responses are addressed during the conversation (see "Having a Conversation about Diabetes and Emotional Health" on page 6). Disordered eating behaviors, such as insulin omission, often go unrecognized for a long time, perhaps because this conversation is not taking place. The consequences of insulin omission are serious, for the physical and mental health of the person. Be aware that people with diabetes have other ways of learning about these behaviors (e.g., pro-eating disorder websites or social media). Not talking about it will not prevent people with diabetes from omitting insulin.

People may restrict/omit insulin for weight loss purposes after they have overtreated a hypoglycemic episode. You might like to use following questions[22] related to hypoglycemia:

- *"When you think your blood glucose is low (or when you have a hypo), do you eat foods that you do not normally allow yourself to have (e.g., chocolate, chips)?"*
- *"When you think your blood glucose is low, do you continue to eat until you feel better, rather than waiting 15 minutes or so between servings to see if your symptoms improve?"*
- *"Do you feel like you lose control over your eating when your blood glucose is low?"*

If the person with diabetes responds "yes" to any question, ask how often it occurs.

Some people with diabetes may feel relieved that you have asked about their eating behaviors/problems, for example, because they feel alone and hopeless about overcoming the problem. Other people may be reluctant to talk about their eating problem because they:

- have had a negative experience with a health professional
- feel ashamed or guilty about their eating habits or weight/body
- fear being judged
- find their current habits rewarding (e.g., they might have lost weight or received compliments from others about their appearance)
- or deny the seriousness of their symptoms and condition.

Therefore, creating a respectful, non-judgmental, empathetic relationship will create a safe environment for a person with an eating problem to open up and ask for support.

If the person is not ready to talk about their eating problem now, or with you, consider referring them to online or telephone support (see "Resources" on page 145).

When needed and if possible, speak to other people (e.g., their partner, family members, or other health professionals) to gain information about the person's eating behavior. Gain consent from the person with diabetes before having this conversation.

Option 2: Use a Brief Questionnaire

Currently, there are limited choices for eating problem questionnaires that are validated in people with diabetes.

The mSCOFF is a short screening questionnaire for eating disorders and adapted for people with diabetes. It was trialled with a small sample of adolescent girls with type 1 diabetes.[48,49]

The mSCOFF consists of five questions:

Question		
Do you make yourself sick (vomit) because you feel uncomfortably full?	☐ Yes	☐ No
Do you worry you have lost control over how much you eat?	☐ Yes	☐ No
Have you recently lost more than 14 pounds in a three-month period?[b]	☐ Yes	☐ No
Do you believe yourself to be fat when others say you are too thin?	☐ Yes	☐ No
Do you ever take less insulin than you should? (modified item)	☐ Yes	☐ No

© American Diabetes Association, 2014.[49]

For information about using questionnaires in clinical practice, see pages 10 and 11.

You might also consider The Diabetes Eating Problem Survey—Revised (DEPS-R), a 16-item diabetes-specific questionnaire, which has been validated in type 1 diabetes.[50,51]

Both the mSCOFF and DEPS-R have items about insulin. These are not suitable for people with type 2 diabetes who are not managing their diabetes with insulin

Instead of administering this as a questionnaire, you could integrate these questions into your conversation. Some questions to consider are as follows:

"How do you feel about your body size, shape, or weight?"

"Have you been trying to change how you eat? If so, in what ways?"

"Do you ever take less insulin than your diabetes team recommends? If so, could you tell me about it?"

If the person answers "yes" to one or more mSCOFF questions, further assessment for eating problems is warranted.

If the person answers "yes" to the last item, explore the reasons for taking less insulin as these may not necessarily be related to weight loss goals.

If disordered eating behaviors are identified through the conversation or the person's mSCOFF responses, further assessment is recommended to better understand the person's specific issues and severity of the eating problem (see "Next Steps: **ASSESS** or **ASSIGN**?" below). From a clinical perspective, any problematic eating behavior requires further attention, as it has a significant impact on the person's short- and long-term diabetes and health outcomes and can intensify over time. At this stage, it is advisable to ask whether they have a current diagnosis of an eating disorder and, if so, whether and how it is being treated.

NEXT STEPS: **ASSIST** OR **ASSIGN**?

If **AWARE** or **ASK** has indicated disordered eating, a comprehensive clinical assessment is required to diagnose the type and severity of the eating problem. This includes both a clinical interview and clinical examination (see **ASSESS**).

If a comprehensive clinical assessment is outside your expertise, you will need to refer the person to a health professional with expertise in eating disorders. These specialists are best placed to conduct comprehensive clinical assessments to diagnose disordered eating behaviors/eating disorders (see **ASSIGN**).

ASSESS

A comprehensive clinical assessment includes both a clinical interview and clinical examination. For a full description of how to diagnose anorexia nervosa, bulimia nervosa, and binge eating disorder consult the Academy for Eating Disorders' *Eating Disorders: A Guide to Medical Care*[14] and recommendations specifically for type 1 diabetes in Goebel-Fabbri.[52]

b We suggest changing the wording of this question to: "Have you recently lost/gained weight in a three-month period?" If the person has lost/gained weight, explore how much weight was lost/gained and why the weight change might have occurred (e.g., change of medication, diet, or physical activity levels).

Clinical Interview

A clinical interview assesses:

- any physical symptoms (e.g., gastrointestinal, cognitive, and sleep problems, or menstrual disturbances)
- the history of the current problem
- the history of any previous eating disorders (and treatment)
- eating habits and beliefs, or concerns about and importance of weight and shape
- personality traits (e.g., perfectionism or obsessiveness)
- any co-existing mental health issues (e.g., anxiety or depression)
- and current risk and previous attempts at self-harm and suicide (see Box 6.3).

Also see **AWARE** and the above-mentioned guidelines/recommendations for topics to cover in the interview.

Clinical Examination

A clinical examination checks the person's medical history and complications, current health status, general physical examination, and laboratory tests (e.g., A1C, ketones, potassium, and sodium).[14] The clinical examination is also able to exclude any other conditions that could cause changes in weight or appetite.[53]

A list of the required medical checks to assess for eating disorders can be found in the guidelines/recommendations mentioned above.

Laboratory tests and/or physical symptoms do not always confirm an eating disorder even when one is present.[53]

Consider whether there is an acute risk for the person (see ASSIGN).

Additional Considerations

- If there are no signs of disordered eating or an eating disorder, but you or the person with diabetes still have concerns about/dissatisfaction with their weight/shape/eating behaviors, consider assessing their eating styles (see Box 8.2) or body dissatisfaction. Referral to a dietitian and/or psychologist may be the best option.
- Consider whether there are co-existing mental health problems, for example, mood disorders and anxiety disorders (see Chapter 7), as these are associated with changes to appetite, physical activity, medication adherence, and self-esteem; these changes are also found in disordered eating behaviors and eating disorders. Depression (see Chapter 6) and disordered eating behaviors commonly occur together,[3] suggesting either a shared vulnerability to both or that experiencing one of these problems may increase the risk of developing the other.

HOW CAN I SUPPORT A PERSON with an Eating Problem?

ADVISE

Now that you have identified signs of an eating problem:

- Acknowledge the high focus on food in the management of diabetes and the difficulties it may cause for a person with diabetes.
- Explain that, based on your conversation or the mSCOFF scores (if used), they may have an eating problem, but that this needs to be confirmed with a clinical interview and clinical examination.
- Elicit feedback from the person about their mSCOFF scores or signs (i.e., whether they have considered they may have an eating problem).
- Describe the differences between disordered eating behaviors and eating disorders.
- Advise that untreated eating problems can impact negatively on their life overall, as well as on their diabetes management/outcomes and general health.
- In the event of insulin omission, advise them about the risk for early onset of long-term complications (e.g., retinopathy or neuropathy).
- Advise that support is available, that eating problems can be managed effectively, and that early intervention (before the eating problem is well established) is important to prevent long-term health problems.
- Recognize that identification and advice alone are not enough; explain that treatment will be necessary and can help to improve their life overall, as well as their diabetes management.
- Offer the person opportunities to ask questions.
- Check how the person is feeling before ending the appointment, as the information you have provided may have an emotional impact on the person.
- Make a joint plan about the "next steps" (e.g., what needs to be achieved to address the eating problem and who will support them).

To begin the conversation, you may say something like this:

- *"From what you have told me, it sounds like you are having some concerns about your [eating habits/weight/body image/insulin use]. These concerns are not uncommon in people with diabetes. If you are OK with this, perhaps we could talk a bit more about what is going on and see what is needed to reduce your concerns."*
- Continue: *"After listening to you and seeing your lab results, I wonder if you might be struggling with disordered eating or even an eating disorder. Has this crossed your mind? Has anyone else suggested they are concerned about your [health/eating habits/weight?]"*

NEXT STEPS: ASSIST OR **ASSIGN**?

Support and treatment for eating problems requires a collaborative care approach. The decision about which health professionals are a part of the multidisciplinary team will depend largely on the severity and type of the eating problem, and who has the relevant expertise to support the person.

Disordered eating (behaviors): The PCP involved in the person's diabetes management has a key role in the early detection of disordered eating behaviors and/or body dissatisfaction. If the person is experiencing disordered eating, PCPs are best placed to coordinate collaborative care with other health professionals, such as a dietitian and a psychologist. Because diabetes adds to the complexity of an eating problem, input/support from a diabetes health professional (e.g., endocrinologist or certified diabetes educator) for adjusting the diabetes management plan may also be required. Thus, if you are not the person's PCP, you will need to **ASSIGN** the person to their PCP, but you may also play a role in the **ASSIST** as a part of the multidisciplinary team.

Full syndrome eating disorder: Collaborative care integrating a multidisciplinary team with expertise in eating disorders (and including medical, dietetic, and psychological/psychiatric intervention) is the standard approach for support and treatment of eating disorders.[14]

(cont.)

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Inclusion of a specialist in diabetes in the team is also essential.[53] Therefore, you will need to collaborate with other specialists to **ASSIST** and **ASSIGN** the person to health professionals for specialist care outside of your expertise. Consider:

- Options for support and treatment vary accordingly to geography and include outpatient, day program, and inpatient treatment in severe cases.[14] Where to **ASSIGN** will depend on multiple factors (e.g., availability of services, type and severity of the eating disorder, and geography). Treatment in the least restrictive context is recommended utilizing a stepped care approach.
- The safety of the person is the first priority; therefore, inpatient treatment may be required depending on the severity of the eating disorder.
- Involuntary assessment and treatment may be required if the person has impaired decision-making capacity and cannot or will not consent to life-preserving intervention. However, most specialty eating disorder treatment centers in the U.S. are voluntary admission only.[14]

ASSIST

Evidence for the management of eating disorders in combination with diabetes is very limited.[54,55] Thus, in practice, general eating disorder treatments are applied to address the needs of people who are living with both conditions.

Once disordered eating behavior(s) or an eating disorder has been confirmed by a comprehensive clinical assessment, and if you believe that you can assist the person as a part of the multidisciplinary collaborative care team:

- Provide information about the specific eating problem that was identified during the comprehensive clinical assessment, and its likely impact on diabetes management/outcomes and general health.
- Explain and discuss treatment options with the person to enable them to make a well-informed decision. This will help them to engage with the treatment/therapy, which will likely be a combination of:
  - an adapted diabetes management and dietary plan: with more flexible and realistic blood glucose targets, and with less focus on weight loss or strict dietary plans
  - psychological therapies: for example, family-based therapy (if the person is still living with family), enhanced cognitive behavior therapy (CBT-E) or interpersonal therapy (IPT). These aim to address maladaptive thoughts, emotions, and behaviors (CBT-E) or problems in relationships (IPT)[56,57] and pharmacological treatments.[14]
  - Assist the person to identify and access appropriate support and treatment (e.g., if you are a PCP, establish a collaborative care team and write a treatment plan[58] and/or a referral to a relevant health professional who can provide psychotherapy).
  - Explain that a collaborative approach is needed, and which health professionals will be part of the team.
  - Agree on an action plan together and set achievable goals for managing their diabetes and eating problem.
  - Make sure the person is comfortable with this approach.
  - At the end of the conversation, consider giving them information to read at home or refer them to online resources. At the end of this chapter (see page 145), there are resources that may be helpful for a person with diabetes who is experiencing eating problems.

There may be a need to work with the family and to connect with schools and other agencies if the person with diabetes is still living at home or attending school.[14]

For a comprehensive guide to treating eating disorders such as anorexia nervosa, bulimia nervosa and binge eating disorder, consult *Eating Disorders: A Guide to Medical Care*.[14] Also, eating disorder treatment recommendations specific to type 1 diabetes can be found in Goebel-Fabbri.[52]

ASSIGN

If the person is at immediate risk, they will need to go to a hospital. For example, people with recurrent episodes of diabetic ketoacidosis, cardiac arrhythmias, hypothermia, hypotension, electrolyte abnormalities, or if the person has stopped taking insulin,[19,52] should be referred to specialist inpatient services or taken to the nearest hospital for treatment. For a comprehensive list of indicators for high medical risk, refer *Eating Disorders: A Guide to Medical Care*.[14]

To locate specialist eating disorder inpatient services in your state, visit the Academy for Eating Disorders expert directory at https://www.aedweb.org/expert-directory.

If the person is not at immediate risk: refer them to specialist eating disorder outpatient services or day programs. To check where these are available in your state, see https://www.aedweb.org/expert-directory.

It is likely that the staff of the specialist eating disorder in- or outpatient services do not have expertise in diabetes management or the unique aspects of eating disorders in diabetes. You will need to keep regular, close contact with the treatment team to help ensure that the person receives appropriate care.

ARRANGE

As an eating disorder requires a multidisciplinary approach, the follow-up plan will depend on the agreed-upon course of action for treatment:

- If you are part of the multidisciplinary team, continue to monitor the person's progress (e.g., laboratory assessments or diabetes complications). Medical treatments, nutrition plans, and diabetes self-management goals will need to be adjusted regularly throughout the treatment. The management of an eating disorder will require regular follow-up visits and/or extended consultations to evaluate progress and the action plans. Telephone/video conferencing may be a practical and useful way to provide support in addition to face-to-face appointments.
- If you are not part of the multidisciplinary team, enquire at each appointment about the person's progress (e.g., have they engaged with the agreed treatment?).

CASE STUDY

Sarah

59-year-old woman living alone

Type 2 diabetes, managed with diet and exercise; BMI=32

Health professional: Dr. Lydia Morris (PCP)

Be AWARE

When Sarah arrives for her routine check-up, Lydia notices that she has put on weight. When Lydia asks how she has been since she last saw her and how her diabetes management is going, Sarah informs Lydia that she:

- has been trying really hard to lose weight but her efforts do not pay off
- has gained 12 pounds over the past few months
- and feels down about her weight and embarrassed about her body.

ASK and ASSESS

Using open-ended questions, Lydia explores Sarah's feelings about her weight and her current eating patterns. Sarah confides that she:

- has always struggled with her weight and that she is currently at her highest weight ever
- eats little throughout the day and then overeats most nights
- and overeats when she's lonely or bored.

Lydia is concerned about Sarah's weight gain and overeating and the impact it might have on her diabetes in the long-term. Lydia informs Sarah that she would like to ask her some further questions about her eating, body image, and weight.

Lydia goes through the mSCOFF with Sarah. Sarah replies "yes" to two items: "Do you make yourself sick because you feel uncomfortably full?" and, "Do you worry you have lost control over how much you eat?" Sarah's responses suggest that she may be experiencing eating problems, most likely, disordered eating. Sarah confides that she feels distressed about her overeating and resulting weight gain, and has a tendency to restrict her food intake, but also to overeat at the end of the day and in response to negative emotions.

ADVISE

Lydia explains the mSCOFF results to Sarah and reassures Sarah that emotional eating can be successfully modified. Given Sarah's tendency to set rigid rules for her diet that she often breaks, resulting in her feeling "like a failure" and eating more to feel better, Lydia and Sarah agree that she needs to develop a more flexible approach to her diet and more effective ways of dealing with her negative emotions. As such, support from both a dietitian and a psychologist (who specializes in eating disorders) is the preferred approach.

ASSIGN

Lydia explains what Sarah can expect of each of the health professionals (e.g., psychologist to undertake further assessment and support Sarah with her negative emotions). Then, Lydia refers Sarah to a psychologist and a dietitian. Lydia suggests that Sarah makes appointments to see them as soon as possible.

ARRANGE

Despite her concerns, Lydia is satisfied that Sarah is not at immediate risk. She encourages Sarah to make a follow-up appointment in one month to update her on her progress with the dietitian and psychologist. She checks whether Sarah had any other agendas for this consultation and continues with the routine check-up.

CASE STUDY

Eliza

25-year-old woman, lives at home with her family

Type 1 diabetes (14 years), managed with insulin pump; BMI=19

Health professional: Dr. Mark Haddad (endocrinologist)

Be **AWARE**

Mark has been seeing Eliza in his practice since she was first diagnosed with type 1 diabetes at age 11. Eliza has been managing her diabetes very well until recently; in the past six months, she has been hospitalized twice for diabetic ketoacidosis. Additionally, her most recent A1C was 12.8%, while previously it ranged between 7% and 8%. Mark is concerned that Eliza is struggling to keep engaged with her diabetes management. He wonders what may have changed over the past six months for Eliza.

ASK

Mark informs Eliza about her most recent A1C result. He asks how she feels about this result, whether she expected it, and about her recent hospitalizations.

Mark notices that Eliza's appearance and demeaner seem different than usual, and that she:

- has lost weight since he last saw her
- appears uncomfortable and does not look at him much during the consultation
- seems "flat" and does not seem to have much energy
- and answers his questions with few words.

Mark asks Eliza what she thinks may be causing the higher A1C. First, she says she has "no idea," but then confides that she is "not eating well" and that she sometimes "forgets" to bolus. Based on what Mark has observed and Eliza's recent hospitalizations, Mark is concerned that Eliza might be at an early stage of an eating disorder and is omitting insulin for weight-loss purposes (she has missing data in her pump downloads).

Mark informs Eliza that people with diabetes sometimes struggle with their eating, and that it can have a negative impact on diabetes outcomes and general health. He asks Eliza if she will answer some questions to help him better understand her eating patterns. Eliza agrees and Marks uses the items in the mSCOFF to guide a conversation about Eliza's eating behavior and body image. Eliza indicates that she:

- has lost about 13 pounds in the past three months due to restricting what and how much she eats
- often feels unhappy with her weight and shape, despite her recent weight loss
- skips insulin when she feels like she has eaten too much
- started skipping insulin eight months ago, at first sporadically, but now on most days
- and is avoiding seeing her friends, as she feels unhappy with her weight.

Mark takes time to ask additional questions about what may have caused these changes.

ADVISE

Based on their conversation, Mark is concerned for Eliza. He explains to her that:

- the things she has described suggest she may have an eating problem possibly she is at an early stage of an eating disorder

- as she has already experienced, the eating problems and skipping insulin can have a negative impact on her diabetes management and outcomes (e.g., recent diabetic ketoacidosis episodes) and other areas of her life (e.g., not wanting to see friends, feeling "obsessed" with weight and eating)
- not taking all the required insulin puts her at risk of developing complications
- with treatment, eating problems can be resolved
- and that it is important to address eating problems as early as possible, to prevent them from evolving into an eating disorder.

Mark will continue to support her with her diabetes management (and to work with her in overcoming the insulin omission), but he also suggests seeing other health professionals for support with the eating problems.

ASSIST

Given Eliza's recent hospitalizations for diabetic ketoacidosis and her ongoing insulin omission, Mark suggests that Eliza attend a specialist outpatient clinic for eating disorders to see a psychologist and a dietitian. Although initially Eliza is hesitant to consult with other health professionals, she understands that her future health is at risk. She agrees for Mark to call the outpatient clinic to arrange for Eliza to visit the next day. Mark writes a referral for Eliza to take with her to the clinic.

ARRANGE

Mark and Eliza agree to see each other again in two weeks to follow-up on her visit to the specialist clinic. Eliza gives Mark permission to stay in contact with the specialists in the clinic (for collaborative care). At the next consultation, Mark and Eliza will discuss whether her diabetes management plan needs adapting while she is seeing the specialists in the outpatient clinic.

Resources

For Health Professionals

Peer-Reviewed Literature

› **Disordered eating behavior in individuals with diabetes: importance of context, evaluation, and classification**

Description: This review reports on the prevalence of disordered eating, available assessment measures, and the impact of insulin on weight.

Source: Young-Hyman D, Davis C. Diabetes Care. 2010;33:683-689.

› **Outpatient management of eating disorders in type 1 diabetes**

Description: This paper focuses on outpatient strategies for the management of eating disorders and lists treatment recommendations specifically for people with type 1 diabetes.

Source: Goebel-Fabbri AE, Uplinger N, et al. Diabetes Spectrum. 2009;22:147-152.

› **Comorbid diabetes and eating disorders in adult patients**

Description: This overview paper describes procedures for assessment and interventions for people with type 1 and type 2 diabetes, with focus on the role of diabetes educators in this process.

Source: Gagnon C, Aime A, et al. The Diabetes Educator. 2012;38:537-542.

Books

› ***Prevention and Recovery from Eating Disorders in Type 1 Diabetes: Injecting Hope***

Description: Based on interviews with women with type 1 diabetes who recovered from eating disorders and the author's expertise in the area (research and clinical), this book provides insights in the lived experiences the women and their views on support they found helpful for their recovery.

Source: Goebel-Fabbri AE. Abingdon, UK: Taylor & Francis; 2017.

Websites (not diabetes specific)

› **Academy for Eating Disorders (AED)**

Description: AED helps physicians, psychiatrists, psychologists, nutritionists, academic researchers, students, and experts connect and collaborate with each other and keep abreast of recent developments in eating disorders research.

URL: www.aedweb.org

› **National Eating Disorders Association (NEDA)**

Description: NEDA is the largest nonprofit organization dedicated to supporting individuals and families affected by eating disorders. Their helpline offers support, resources, and information via phone, online chat, or text.

URL: www.nationaleatingdisorders.org/help-support/contact-helpline

Phone/Text: (800) 931-2237[c]

For People with Diabetes

Support

› **American Diabetes Association (ADA)**

Description: The ADA website offers patient information on diabetes and eating disorders and ways to seek treatment.

URL: https://www.diabetes.org/healthy-living/mental-health/eating-disorders

› **We Are Diabetes**

Description: We Are Diabetes is a non-profit organization devoted to providing much needed support, education, guidance, and hope to individuals living with type 1 diabetes who struggle with disordered eating behaviors.

URL: http://www.wearediabetes.org

› **Diabulimia Helpline (DBH)**

Description: DBH is a non-profit organization dedicated to education, support, and advocacy for people with diabetes and eating disorders, and their loved ones. They offer a 24-hour hotline for emotional support and assistance with treatment referrals and insurance coverage.

URL: http://www.diabulimiahelpline.org

Phone: (425) 985-3635[c]

Information

› **Diabetes and Disordered Eating**

Description: A handout for people with diabetes about disordered eating created along with this practical guide.

c Call charges may apply.

Source: National Diabetes Services Scheme and the American Diabetes Association, 2021.

URL: https://professional.diabetes.org/meetings/mentalhealthworkbook

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“I wanted to ask for help, like a counsellor, but I didn’t want to do it directly, because in my mind there was a bit of a stigma and shame related to that. So, I dropped really big hints on how alone I was feeling and how I wasn’t coping very well, but every time, my health professional brushed them aside. I was left scrambling to find my own support, I was looking up different counsellors and psychologists, but it got so overwhelming that I stopped looking.

—Person with type 1 diabetes