Diabetes distress

7 As model

Be AWARE that people with diabetes may experience diabetes distress

- Diabetes distress is the emotional burden arising from living with and managing diabetes.
- Look for signs: sub-optimal HbA1c or unstable blood glucose levels, missed clinic appointments, reduced engagement in diabetes self-care tasks, ineffective coping strategies, multiple life stressors, chronic stress, impaired relationships (personal or with health professionals), appearing passive/aggressive during consultations.

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ASK about diabetes distress

- When to ask: routinely ask all people with diabetes.
- Use open-ended questions to explore the impact of diabetes on daily life and well-being, such as:
  - ‘What is the most difficult part of living with diabetes for you?’
  - ‘How is your diabetes getting in the way of other things in your life right now?’
- If diabetes-related concerns are raised, continue to ASSESS.

ASSESS for diabetes distress using a validated questionnaire

- When to assess:
  - annually, and
  - if AWARE or ASK indicates possible diabetes distress.
- Use a validated questionnaire, such as the Problem Areas In Diabetes (PAID) scale
  - an individual item score of 3 or more indicates a ‘problem area’ or concern
  - a PAID total score of 40 or more out of 100 indicates severe diabetes distress.
- If diabetes distress is not identified but a problem remains, consider whether another psychological problem is present (e.g. depression or anxiety).

ADVISE about diabetes distress

- Explain diabetes distress.
- Acknowledge that living with diabetes can be challenging; it is normal to have negative feelings about it, and to feel frustrated, anxious, distressed or overwhelmed by diabetes.
- Explain that learning about the signs and consequences of diabetes distress will help them to recognise and respond promptly.
- Make a joint plan about the ‘next steps’ (e.g. what needs to be achieved and who can help).

ASSIST with developing an achievable action plan

- Explore the individual’s source(s) of diabetes distress and the kind of support needed. For example, diabetes education, a review of their management plan, emotional/social/professional support, or a combination of these.
- Provide relevant information and support.
- Together, develop a plan for addressing their distress, prioritising their most important or burdensome issues.
- Consider the need for a referral if diabetes distress persists.

ASSIGN to another health professional

- People with diabetes tend to prefer their diabetes health professional to help them with the emotional impact of diabetes.
- As diabetes distress is common and intertwined with diabetes management, it is best addressed by the diabetes health professional.
- If you do not feel comfortable or equipped to do this, arrange referral to a relevant health professional to ASSIST.
- Maintain ongoing communication with the health professional to whom you made the referral.
ARRANGE follow-up care

- Arrange a follow-up appointment to:
  - ask about the person’s progress
  - assess the potential need for revising the action plan.
- If you used a questionnaire to ASSESS (e.g. PAID) consider using it again to reassess their level of diabetes distress. Agree on how often the reassessment would be helpful.
- Be prepared to offer more support (e.g. through telephone reviews or more/extended consultations) during this time.
Fear of hypoglycaemia

7 As model

Be **AWARE** that people with diabetes may experience extreme fear of hypoglycaemia

- Fear of hypoglycaemia is specific and extreme fear evoked by the risk and/or experience of hypoglycaemia.
- Look for signs: ‘over-compensatory behaviours’ (e.g. insulin dose reduction or over-eating), ‘avoidance behaviours’ (e.g. limiting exercise or social activities), an excessive number of daily blood glucose checks, acceptance of persistent high blood glucose levels, or not implementing ‘agreed’ treatment changes to lower glucose levels.
**ASK about experience and fear of hypoglycaemia**

- **When to ask:**
  - about experience of hypoglycaemia – at each consultation
  - about fear of hypoglycaemia – when you have noted signs (see AWARE).
- **Use open-ended questions to talk about hypoglycaemia and related fears, such as:**
  - ‘What has been your worst experience with hypos?’
  - ‘What concerns you the most about hypos?’
- **Ask directly about compensatory behaviours:**
  - ‘Some people take less insulin because they are worried about having a hypo. Do you ever reduce your insulin to avoid hypos?’
- **If the person indicates that they fear hypoglycaemia, continue to ASSESS.**

**ASSESS for fear of hypoglycaemia using a validated questionnaire**

- **When to assess:** if AWARE or ASK indicates possible fear of hypoglycaemia to further explore the specific concerns leading to fear.
- **Use a validated questionnaire such as the Hypoglycaemia Fear Survey-II Worry scale (HFS-II W)**
  - For item scores 3 or 4 invite the person to explore their concerns. For example, ‘I note here that you are concerned about [issue]. Can you tell me more about that?’ or, ‘You seem to have a few worries about hypoglycaemia. Which of these would you find most helpful to talk about today?’
- **Also assess whether the person purposefully keeps their blood glucose levels higher to reduce the risk of hypoglycaemia.**
- **If fear of hypoglycaemia is identified, continue to ADVISE.**
- **If fear of hypoglycaemia is not identified, but a problem remains, consider whether another psychological problem is present (e.g. diabetes distress or anxiety).**

**ADVISE about fear of hypoglycaemia**

- **Acknowledge the specific worries the person has raised under ASK or ASSESS.**
- **Acknowledge that it is common for people with diabetes to be concerned about hypoglycaemia.**
- **Explain that a certain level of concern is adaptive and can motivate a person to act appropriately to treat or avoid hypoglycaemia – but extreme fear needs attention.**
- **Advise that there are several ways to reduce fear of hypoglycaemia. For example:**
  - diabetes management strategies to reduce the frequency and severity of hypoglycaemia
  - psychological strategies that focus directly on extreme fear.
- **If the person is persistently keeping their blood glucose levels in a higher range to avoid hypoglycaemia, explain that this may have consequences for their long-term health.**
- **Make a joint plan about the ‘next steps’ (e.g. what needs to be achieved and who can help).**
**ARRANGE follow-up care**

- Arrange a follow-up appointment to:
  - ask about the person’s progress
  - assess the potential need for revising the action plan.
- If you used a questionnaire to **ASSESS** (e.g. HFS-II W) consider using it again to reassess their level of fear of hypoglycaemia. Agree on how often the reassessment would be helpful.
- Be prepared to offer more support (e.g. through telephone reviews or more/extended consultations) during this time.

**ASSIST with developing an achievable action plan**

- Through hypoglycaemia/diabetes management:
  - review the person’s knowledge about hypoglycaemia, how to treat, and barriers to treatment
  - review current diabetes management and discuss technologies (e.g. pump, continuous glucose monitor)
  - provide additional hypoglycaemia training and/or diabetes education
  - agree on an action plan to reduce hypoglycaemia.
- Through fear management:
  - provide accurate information on their personal risk of hypoglycaemia
  - provide support to change behaviours and unhelpful beliefs about hypoglycaemia
  - develop a stepwise plan to restore confidence and regain a sense of personal control.
- Consider the need for a referral if fear persists, or it is part of an anxiety disorder or the result of a traumatic hypoglycaemia experience.

**ASSIGN to another health professional**

- People with diabetes tend to prefer their diabetes health professional to help them with the emotional impact of diabetes.
- If you do not feel comfortable or equipped to do this, arrange referral to a relevant health professional to **ASSIST**.
- Maintain ongoing communication with the health professional to whom you made the referral.

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Diabetes and emotional health - A practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes
Psychological barriers to insulin use

7 As model

- **Arrange** follow-up care
- **Assist** with developing an achievable action plan
- **Advise** about psychological barriers to insulin use
- **Assign** to another health professional
- **Ask** about psychological barriers to insulin use
- **Assess** for psychological barriers to insulin using a validated questionnaire
- **Be AWARE** that people with type 2 diabetes may experience psychological barriers to insulin use

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**Psychological barriers to insulin are the negative thoughts and feelings that people with diabetes may have about starting, using or intensifying insulin.**

- Look for signs: avoidance of talking about insulin (e.g. changing the topic, missing appointments), expressing concerns (e.g. about possible side effects, injecting, effect on lifestyle, perceptions of self and others), insulin misuse (e.g. missing doses, smaller doses than recommended).
- Psychological barriers to insulin are experienced by people using insulin as well as those not yet using insulin.
**ASK** about psychological barriers to insulin use

- **When to ask:**
  - shortly after diagnosis of type 2 diabetes
  - when you notice signs of concerns or worries about insulin (see **AWARE**)
  - if the person has sub-optimal HbA1c despite being on (near) maximal oral agents.
- **Use open-ended questions to discuss insulin and explore concerns, such as:**
  - ‘How do you feel about going onto insulin [now or in the future]? Can you tell me more about that?’
  - ‘Some people have concerns or questions about insulin. Have you thought about insulin? Can you tell me more about that?’.
- If the person with type 2 diabetes indicates that they have questions or concerns about insulin, continue to **ASSESS**.

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**ASSESS** for psychological barriers to insulin using a validated questionnaire

- **When to assess:** if **ASK** indicates concerns or worries about insulin.
- **The Insulin Treatment Appraisal Scale (ITAS)** is a validated measure. Barriers to insulin use are indicated by:
  - scores of 2 or less on positive appraisal items (3, 8, 17, 19)
  - scores of 4 or more on negative appraisal items (the remaining items).
- **Invite the person to explore their concerns. For example,** ‘I note here that you are concerned about [issue]. Can you tell me more about that?’ or, ‘You seem to have a few worries about insulin. Which of these would you find most helpful to talk about today?’.
- If psychological barriers are raised, continue to **ADVISE**.

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**ADVISE** about psychological barriers to insulin use

- **Acknowledge the specific barriers the person has raised under ASK or ASSESS.**
- **Acknowledge that it is common to have questions and/or concerns.**
- **Reassure them that needing insulin does not indicate they have ‘failed’.**
- **Advise that many people need insulin as part of the natural progression of diabetes.**
- **Tell them that people who use insulin find it beneficial because it:**
  - is a powerful way to keep blood glucose within an optimal range to prevent long-term complications
  - allows for more flexibility in diet and planning of meals
  - improves energy levels.
- **Advise that insulin use may begin with just one or two injections per day.**
- **Make it clear that it is the individual’s decision whether or not to use insulin and you would like to assist them in making an informed choice.**
- **Make a joint plan about the ‘next steps’ (e.g. what needs to be achieved and who can help).**

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*Diabetes and emotional health - A practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes*
**ARRANGE** follow-up care

- Arrange a follow-up appointment to:
  - ask about the person’s progress
  - assess the potential need for revising the action plan.
- Be prepared to offer more support (e.g. through telephone reviews or more/extended consultations) during this time.

**ASSIST** with developing an achievable action plan

- Assist the person with:
  - overcoming identified barriers to insulin using appropriate strategies (e.g. motivational interviewing techniques, ‘insulin trial’)
  - making an informed choice about an action plan, including achievable and measurable goals for overcoming psychological barriers to insulin
  - identifying sources of advice and support (e.g. structured group education, peer support).

**ASSIGN** to another health professional

- People with diabetes tend to prefer their diabetes health professional to help them with the emotional impact of diabetes.
- If you do not feel comfortable or equipped to do this, arrange a referral to a relevant health professional to **ASSIST**.
- Maintain ongoing communication with the health professional to whom you made the referral.
Depression

7 As model

Be AWARE that people with diabetes may experience depressive symptoms

- Depression is a diagnosable mental condition characterised by a persistent state of low mood and lack of interest or pleasure in activities (for minimum two weeks).
- Look for signs: lowered mood (e.g. sadness, hopelessness, teariness), loss of interest or pleasure in usual activities, irritability, feelings of worthlessness or excessive/inappropriate guilt, difficulties concentrating, lack of energy, changes in weight and sleep patterns, psychomotor changes (e.g. moving or speaking more slowly than usual or being fidgety or restless), withdrawal from social and professional supports, reduced engagement in diabetes self-care tasks, recurrent thoughts about death or suicide.
**ASK about depressive symptoms**

- **When to ask:**
  - in line with clinical practice guidelines (e.g. on a routine or annual basis)
  - when the person reports symptoms or when you have noted signs (see AWARE)
  - in periods of significant diabetes-related challenge or adjustment (e.g. following diagnosis of diabetes or complications, hospitalisation, or significant changes to the treatment regimen)
  - during or after stressful life events
  - if the individual has a history of depression or other mental health problems.
- **Use open-ended questions or the Patient Health Questionnaire Two (PHQ-2):**
  - ‘Over the last two weeks, how often have you been bothered by having little interest or pleasure in doing things?’
  - ‘Over the last two weeks, how often have you been bothered by feeling down, depressed, or hopeless?’
  - Response options are scored: ‘Not at all’ (0), ‘Several days’ (1), ‘More than half the days’ (2), ‘Nearly every day’ (3). Sum the responses to form a total score.
- **If the PHQ-2 total score is:**
  - 3 or more – check whether the person has a current diagnosis of, or is currently receiving treatment for, depression; if neither, then further assessment is warranted (see ASSESS)
  - less than 3 but you suspect a problem – consider whether the person may be experiencing diabetes distress, elevated anxiety symptoms, or another psychological problem.

**ASSESS for depressive symptoms using a validated questionnaire**

- **When to assess:**
  - in line with clinical practice guidelines (e.g. on a routine or annual basis)
  - if AWARE or ASK indicates depressive symptoms.
- **Use a brief, validated questionnaire, such as the Patient Health Questionnaire Nine (PHQ-9).**
- **PHQ-9 total score 10 or more – moderate-to-severe depressive symptoms are indicated:**
  - enquire about any past history of depression and other mental health problems
  - consider the possibility of co-existing conditions (e.g. anxiety disorder)
  - explore physiological, psychological, and behavioural causes for the depressive symptoms (including diabetes-related factors)
  - continue to ADVISE.
- **PHQ-9 total score less than 10 – depressive symptoms are not indicated. Consider another psychological problem (e.g. diabetes distress, elevated anxiety symptoms).**

**NB:** A clinical interview must be conducted (e.g. by a GP or mental health professional) to diagnose major depression – see ASSIGN.

**NB:** It is essential that you conduct a suicide risk assessment if the person’s PHQ-9 total score is 10 or more, or they score 1 or more on Item 9 of the PHQ-9.
If mild or major depression has been confirmed by clinical interview, assist the person to:

- make an informed choice about a suitable treatment for depression – discuss the pros and cons for each option
- set measurable goals to reduce depressive symptoms and adapt their diabetes management plan if needed
- identify sources of advice and support
- start the preferred treatment (e.g. write a referral to a specialist for psychological support, or a prescription for medication).

If you do not feel comfortable or equipped to ASSESS or ASSIST, arrange a referral to a relevant health professional.

Maintain ongoing communication with the health professional to whom you made the referral.

ADVISE about depressive symptoms

- Explain that their questionnaire responses indicate they are experiencing depressive symptoms; they may have major depression, which will need to be confirmed with a clinical interview.
- Describe what depression is, and how it might impact on their life overall and their diabetes management.
- Advise that depression is common, treatable, and can be managed effectively.
- Advise that treating depression can help to improve their life overall and their diabetes management.
- Make a joint plan about the ‘next steps’ (e.g. what needs to be achieved and who can help).

ASSIST with developing an achievable action plan

- If mild or major depression has been confirmed by clinical interview, assist the person to:
  - make an informed choice about a suitable treatment for depression – discuss the pros and cons for each option
  - set measurable goals to reduce depressive symptoms and adapt their diabetes management plan if needed
  - identify sources of advice and support
  - start the preferred treatment (e.g. write a referral to a specialist for psychological support, or a prescription for medication).

ASSIGN to another health professional

- If you do not feel comfortable or equipped to ASSESS or ASSIST, arrange a referral to a relevant health professional.
- Maintain ongoing communication with the health professional to whom you made the referral.

ARRANGE follow-up care

- Arrange a follow-up appointment to:
  - ask about the person’s progress
  - assess the potential need for revising the action plan.
- Be prepared to offer more support (e.g. through telephone reviews or more/extended consultations) during this time.
Anxiety disorders

7 As model

- **Arranging** follow-up care
- **Assisting** with developing an achievable action plan
- **Assisting** with developing an achievable action plan
- **Assigning** to another health professional
- **Assessing** for elevated anxiety symptoms using a validated questionnaire
- **Asking** about elevated anxiety symptoms
- **Advise** about elevated anxiety symptoms
- **Assess** for elevated anxiety symptoms
- **Assign** to another health professional
- **Aware** that people with diabetes may experience elevated anxiety symptoms

**Be AWARE** that people with diabetes may experience elevated anxiety symptoms

- An anxiety disorder is a diagnosable mental condition characterised by frequent, intense and excessive anxiety symptoms (for minimum six months).
- Look for signs: frequent, intense, and excessive nervousness or worry, irritability, restlessness, trembling, dizziness, muscle tension, sleep disturbance, or panic attacks.
**ASK about elevated anxiety symptoms**

- **When to ask:**
  - when the person reports symptoms or when you have noted signs (see AWARE)
  - in periods of significant diabetes-related challenge or adjustment (e.g. following diagnosis of diabetes or complications, hospitalisation, or severe hypoglycaemia with loss of consciousness)
  - during or after stressful life events
  - if the individual has a history of anxiety disorder(s) or other mental health problems
  - in line with clinical practice guidelines.
- **Use open-ended questions or the Generalized Anxiety Disorder Two (GAD-2):**
  - 'Over the last two weeks, how often have you been bothered by feeling nervous, anxious or on edge?'
  - 'Over the last two weeks, how often have you been bothered by not being able to stop or control worrying?'
  - Response options are scored: ‘Not at all’ (0), ‘Several days’ (1), ‘More than half the days’ (2), ‘Nearly every day’ (3). Sum the responses to form a total score.
- **If the GAD-2 total score is:**
  - 3 or more – check whether the person has a current diagnosis of, or is currently receiving treatment for, an anxiety disorder. If neither, then further assessment is warranted (see ASSESS)
  - less than 3 but you suspect a problem – consider whether the person may be experiencing diabetes distress, depression, or another psychological problem.

**ASSESS for elevated anxiety symptoms using a validated questionnaire**

- **When to assess:**
  - in line with clinical practice guidelines
  - if AWARE or ASK indicates elevated anxiety symptoms.
- **Use a brief, validated questionnaire, such as the Generalized Anxiety Disorder Seven (GAD-7).**
- **GAD-7 total score 10 or more – moderate-to-severe anxiety symptoms are indicated:**
  - enquire about any past history of anxiety disorder(s) and other mental health problems
  - consider the possibility of co-existing conditions (e.g. depression)
  - explore physiological, psychological, and behavioural causes for the elevated anxiety symptoms (including diabetes-related factors)
  - continue to ADVISE.
- **GAD-7 total score less than 10 – elevated anxiety symptoms are not indicated. Consider another psychological problem (e.g. diabetes distress, diabetes-specific fears, depression).**

NB: A clinical interview must be conducted (e.g. by a GP or mental health professional) to diagnose an anxiety disorder – see ASSIGN.

NB: If you identify a person as having elevated anxiety symptoms, consider whether a suicide risk assessment is needed.
If an anxiety disorder has been confirmed by clinical interview, assist the person to:

- Make an informed choice about a suitable treatment for the anxiety disorder – discuss the pros and cons for each option.
- Set measurable goals to reduce anxiety symptoms and adapt their diabetes management plan if needed.
- Identify sources of advice and support.
- Start the preferred treatment (e.g. write a referral to a specialist for psychological support, or a prescription for medication).

If you do not feel comfortable or equipped to assess or assist, arrange a referral to a relevant health professional.

Maintain ongoing communication with the health professional to whom you made the referral.

Explain that their questionnaire responses indicate they are experiencing elevated anxiety symptoms; they may have an anxiety disorder, which will need to be confirmed with a clinical interview.

Describe what an anxiety disorder is, and how it might impact on their life overall and their diabetes management.

Advise that anxiety disorders are common, treatable, and can be managed effectively.

Advise that treating the anxiety disorder can help to improve their life overall and their diabetes management.

Make a joint plan about the ‘next steps’ (e.g. what needs to be achieved and who can help).

If an anxiety disorder has been confirmed by clinical interview, assist the person to:

- Make an informed choice about a suitable treatment for the anxiety disorder – discuss the pros and cons for each option.
- Set measurable goals to reduce anxiety symptoms and adapt their diabetes management plan if needed.
- Identify sources of advice and support.
- Start the preferred treatment (e.g. write a referral to a specialist for psychological support, or a prescription for medication).

Arrange a follow-up appointment to:

- Ask about the person’s progress.
- Assess the potential need for revising the action plan.

Be prepared to offer more support (e.g. through telephone reviews or more/extended consultations) during this time.
Eating problems occur on a continuum from full syndrome diagnosable eating disorders to disordered eating (behaviours).

Look for signs: frequent and restrictive dieting and problematic attitudes to food/eating, preoccupation and dissatisfaction with body weight/shape/size, unexplained weight gain or loss and other physical signs (e.g. calluses on hands, dental problems), less frequent (or no) self-monitoring of blood glucose, omission or restriction of insulin/medication, missed clinic appointments, recurrent diabetic ketoacidosis, erratic fluctuation of blood glucose levels, acute change of HbA1c (a sign of acute eating disorder onset and often insulin omission), very high or very low HbA1c (in the case of food restriction while still using insulin), and concerns expressed by another person.

Be **AWARE** that people with diabetes may have eating problems.
**ASK about eating patterns and body image**

- When to ask:
  - when the person raises a problem or concern, or when you have noted signs (see AWARE).
- Use open-ended questions to talk about eating habits, weight and body image, such as:
  - ‘Women [men] with diabetes are sometimes concerned about their weight or shape. How do you feel about your weight or shape?’
  - ‘Could you tell me a bit more about the recent changes in your eating patterns?’.
- Then, ask directly about insulin restriction/omission in a non-judgemental way:
  - ‘Some people with diabetes find it difficult to keep up with their insulin injections/boluses. How do you feel about it?’
  - ‘Some people miss or skip their insulin injections/boluses to manage their weight. Do you sometimes adjust your insulin to influence your weight?’ ‘How often does this happen?’.
- Or use the mSCOFF:
- If the person indicates a problem through open discussion, or responds ‘Yes’ to one or more mSCOFF items, further assessment is warranted (see ASSESS).

**ASSESS for eating problems**

- When to assess: if AWARE or ASK indicates a possible eating problem.
- 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. If this is outside of your expertise, you will need to refer the person to a health professional with expertise in eating disorders (see ASSIGN).

**ADVISE about eating problems**

- Explain that the earlier conversation (or their mSCOFF score) indicates a potential eating problem, and further assessment is needed with a clinical interview.
- Explain what disordered eating is and how this differs from an eating disorder.
- Advise that untreated eating problems can impact negatively on their life, but also on their diabetes management and outcomes now and in the future.
- Advise that eating problems are treatable, and can be managed effectively.
- Advise that treating eating problems can help to improve their life overall and their diabetes management.
Provide information about the specific eating problem identified.

Explain treatment/therapy options.

Assist the person to access support and treatment.

Explain that a collaborative approach is needed, and who will be part of this multidisciplinary team and their role.

Agree on an action plan and achievable goals.

Make sure the person feels comfortable with the approach.

If the person is at immediate risk: refer them to hospital.

If the person is not at immediate risk, refer them to specialist eating disorder services.

Maintain ongoing communication with the health professional/service to whom you made the referral.

If you are part of the multidisciplinary team: continue to monitor the person’s progress (e.g. laboratory assessments, diabetes complications). Medical treatments, nutrition plans, and diabetes self-management goals will need to be adjusted regularly throughout the treatment.

If you are not part of the multidisciplinary team: enquire at each consultation about the person’s progress (e.g. have they engaged with the agreed treatment?).

Be prepared to offer more support (e.g. through telephone reviews or more/extended consultations) during this time.