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## Chapter 4

# Fear of Hypoglycemia (and Other Diabetes-Specific Fears)



### Key Messages

- This chapter focuses mainly on fear of hypoglycemia. Other diabetes-specific fears (worries about complications, and fear of hyperglycemia and needles) are briefly described. “Fear of hypoglycemia” refers to extreme fear that affects quality of life and diabetes outcomes, which differs from an appropriate level of concern about hypoglycemia.
- Fear of hypoglycemia is a specific and extreme fear evoked by the risk and/or occurrence of low blood glucose levels.
- Fear of hypoglycemia affects one in seven people with type 1 diabetes or type 2 diabetes. These fears can also affect family members.
- Fear of hypoglycemia is associated with impaired quality of life and emotional well-being, suboptimal diabetes self-management and A1C, and more diabetes-related complications and symptoms.
- The Hypoglycemia Fear Survey-II Worry scale (HFS-II W) is useful for assessing fear of hypoglycemia and to guide conversations about fears.
- Psycho-educational interventions are effective for reducing fear of hypoglycemia.
- People with diabetes and their families often have limited knowledge about hypoglycemia beyond “survival skills,” which may lead to fear of hypoglycemia.
- People with diabetes may also experience other types of diabetes-specific fears, including fear of hyperglycemia, diabetes-related complications, and injections/needles.



### Practice Points

- Acknowledge that fear is a normal response to a threat (e.g., hypoglycemia) and that a certain level of fear is adaptive (e.g., keeping the person alert for symptoms or motivated for self-management), but also acknowledge that extreme fear may impair the person’s well-being, self-management, health, and quality of life.
- Be aware that a person may experience extreme fear of hypoglycemia in the absence of actual hypoglycemia and regardless of their A1C.
- Remain mindful that people may be reluctant to talk about their fear (or experience) of hypoglycemia with a health professional (e.g., embarrassment or fearing loss of driver license).

## How Common Is Fear of Hypoglycemia?



Type 1 diabetes<sup>a</sup>



Type 2 diabetes<sup>a</sup>

## WHAT IS Fear of Hypoglycemia?

Fear of hypoglycemia is a specific and extreme fear evoked by the risk and/or occurrence of hypoglycemia (low blood glucose).<sup>1</sup> Hypoglycemia is a side-effect of glucose-lowering medications (e.g., insulin and sulfonylureas), and caused by relative insulin excess in the absence of sufficient blood glucose.<sup>2</sup> If undetected and untreated, glucose continues to fall, resulting in severe hypoglycemia (a very low blood glucose level, requiring the assistance of another person to treat it). Also, hypoglycemia can lead to a “vicious cycle” of recurrent hypoglycemic episodes. Unsurprisingly, many people with diabetes worry about having hypoglycemia.<sup>3-5</sup> People fear losing consciousness in public, having an accident/injury, becoming emotionally upset or uncooperative, and embarrassing themselves. They also worry about the very worst (but rare) scenario, sudden death.

**In adults with type 1 diabetes**, fear of hypoglycemia is more pronounced in people with a history of severe hypoglycemia<sup>b</sup> (often complicated by loss of consciousness or hospitalization, or affecting work, or nocturnal),<sup>6-12</sup> or who have impaired awareness of hypoglycemia.<sup>7</sup>

**In adults with type 2 diabetes**, fear of hypoglycemia is greater in those using insulin compared to those using sulfonylureas,<sup>13</sup> which can also increase the risk of hypoglycemia. As the prevalence of severe hypoglycemia in adults with type 2 diabetes using insulin for more than five years<sup>c</sup> is very similar to adults with type 1 diabetes,<sup>14</sup> they may share the same concerns about hypoglycemia. In those using oral agents, anticipation of problematic hypoglycemia can be a psychological barrier to insulin initiation (see [Chapter 5](#)).

Being concerned about hypoglycemia is both rational and adaptive, as it keeps a person attentive and responsive to hypoglycemic symptoms to enable timely and adequate treatment.<sup>1</sup> However, if these concerns evolve into excessive fear, it may have a huge negative impact on the person’s quality of life and their ability to manage their diabetes.<sup>15,16</sup> It can also affect family members’ quality of life (e.g., with sleep disturbances or worrying about the person’s safety when alone).<sup>17</sup> The absence of concerns about hypoglycemia is discussed in [Box 4.1](#).



Although the focus of this chapter is on extreme fear of hypoglycemia, other diabetes-specific fears are discussed briefly: fear of needles, injections, and finger pricks (see [Box 4.2](#)); extreme concern about hyperglycemia (see [Box 4.3](#)); and worries about long-term complications (see [Box 4.4](#)).

Sometimes, the person’s level of fear is disproportionate to their actual risk of hypoglycemia. Striving to maintain A1C within target while avoiding hypoglycemia is challenging, and understandably may lead to high levels of fear of hypoglycemia.<sup>18</sup>

Fear of hypoglycemia may develop for many reasons:

- Limited understanding of hypoglycemia and skills in preventing, recognizing, and treating hypoglycemia can cause more frequent and severe hypoglycemia episodes, which can evoke fear of hypoglycemia.

a Fear of hypoglycemia is usually assessed with the Hypoglycemia Fear Survey-II, but there is not yet a clinically relevant cut-off point available. Data are based on mean +1SD (personal communication Linda Gonder-Frederick, 2015).

b Annual prevalence of severe hypoglycemia (requiring assistance from another person to treat) in adults with type 1 diabetes: 22% with diabetes duration <5 years; 46% with diabetes duration >15 years.<sup>2</sup>

c Annual prevalence of severe hypoglycemia in adults with type 2 diabetes: 25% who have been using insulin >5 years; 7% using oral medications.<sup>2,14</sup>

- › Awareness of hypoglycemic symptoms can decrease the longer a person lives with diabetes, making it more difficult for them to notice falling blood glucose levels and could lead to fear. Typically, their brain will already be lacking glucose before they recognize it. When it gets to this stage, the person’s ability to stop what they were doing and treat the low blood glucose (promptly and effectively) is severely impaired.
- › Previous experience of a traumatic hypoglycemic episode—especially one complicated by loss of consciousness, hospitalization, or happening while asleep—can make people fear another episode. One severe hypoglycemic event, as well as recurrent mild episodes, can trigger fear of hypoglycemia.<sup>19</sup>
- › Certain personality traits, for example neuroticism (type 1 diabetes),<sup>20</sup> high-trait anxiety, and general fear (type 1 and type 2 diabetes)<sup>9,10</sup> are associated with fear of hypoglycemia; this relationship is most likely bi-directional.<sup>6</sup> A person with trait anxiety may be distracted and miss out on recognizing hypoglycemic symptoms, increasing their risk of a low blood glucose level. Conversely, the experience of recurrent severe hypoglycemia may induce fear and anxiety in people who were not previously anxious.<sup>21</sup>
- › The autonomic symptoms of hypoglycemia (e.g., tremors, sweating, and palpitations) are similar to anxiety symptoms (see **Chapter 7**). This overlap can hinder interpretation and appropriate treatment of a falling blood glucose level.

There are various ways that adults with diabetes respond to their fear:

- › Some may use “compensatory behaviors” to avoid hypoglycemia and thus reduce their fear. The most common behavioral strategies include reducing insulin doses, omitting injections, or snacking continually to maintain higher blood glucose levels; this may lead to a higher A1C.<sup>19,21</sup> Over time these behaviors may evolve into a habit, which makes them more difficult to identify. Reducing insulin occasionally (e.g., when attending an important meeting or giving a presentation) will not have a major impact on diabetes outcomes but it becomes problematic if the strategy is used repeatedly.
- › Others cope with their fear by restricting their activities (e.g., exercise) or by avoiding being alone, which will have an impact on their independence, confidence, and spontaneity.

Fear of hypoglycemia is associated with:

- › impaired quality of life and emotional well-being<sup>21,22</sup>
- › reduced engagement with diabetes management<sup>22–24</sup>
- › and impaired diabetes outcomes.<sup>23,25</sup>

**BOX 4.1 An Absence of Fear Can Also Be a “Problem”**

People who have impaired awareness of hypoglycemic symptoms have a six-fold higher risk of severe hypoglycemic events.<sup>2</sup> Qualitative studies revealed that some of these people are not concerned about their loss of awareness and, therefore, do not appear to fear hypoglycemia.<sup>26,27</sup> Beliefs underlying this lack of concern include:

- › normalizing impaired awareness of hypoglycemia: loss of awareness and hypoglycemia are considered “normal” aspects of living with diabetes and not as a problem; indeed, some feel that regaining awareness of symptoms would be more of a problem
- › minimizing the consequences of impaired awareness of hypoglycemia: they believe they function well even when their glucose level is below 54 mg/dl
- › avoiding the “sick role”: not attracting attention, not making a “fuss” and “getting on with life” is perceived by the person with diabetes as being “in control of diabetes” and not allowing diabetes to “infringe” on their life
- › and overestimating the risk and impact of hyperglycemia: responses emphasize significant anxiety about developing long-term complications and extreme behavioral responses to high blood glucose levels.

These beliefs and attitudes are likely to prevent people with diabetes from being motivated to regain awareness or minimize severe hypoglycemic events.<sup>26</sup> They may be reluctant to take action to prevent, detect, and promptly treat low blood glucose. This attitude can cause a significant burden on their partner or family members who are often the first to notice signs of hypoglycemia and/or the ones who have to manage a severe hypoglycemic event.

**BOX 4.2 Fear of Needles, Injections, and Finger Pricks**

A diagnosis of type 1 diabetes may evoke anxiety and fear of needles, injections, and finger pricks. People with type 2 diabetes not using insulin may have these fears too, which can contribute to reluctance to begin using insulin (see [Chapter 5](#)). It is the fear of the unknown.

For most people, these fears lessen after they have participated in diabetes education, adjusted to the diagnosis, and acquired skills and confidence for injecting insulin and checking blood glucose. Modern insulin pens, finer needles, and lancets all help to minimize the pain of insulin injections and blood glucose checks.

Needle phobia is a more extreme and debilitating form of fear. For people with a needle phobia, the sight of a needle or blood evokes anxiety and an increased heart rate, followed by a drop in blood pressure, dizziness, fainting, sweating, and nausea.

Needle phobia is rare but, if it is present, it will complicate self-management.

Fear of needles, injections, or finger pricks can affect:<sup>28</sup>

- › diabetes management (e.g., by reducing the number of injections or blood glucose checks)
- › diabetes outcomes (e.g., elevated A1C and greater risk of long-term diabetes complications)
- › and emotional well-being (e.g., impaired general well-being and diabetes distress).

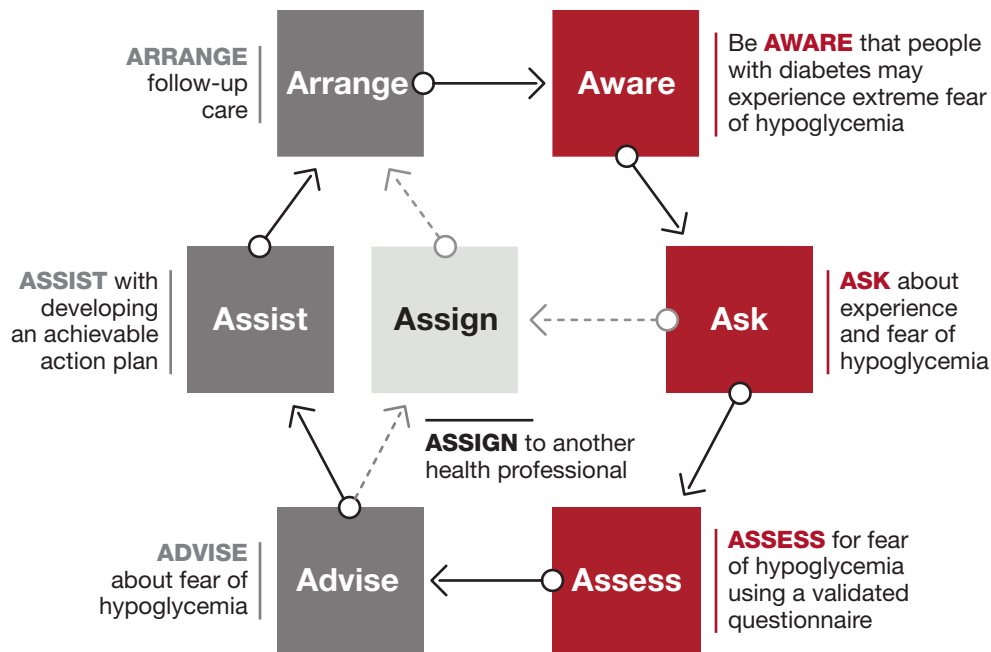
Explore the causes of the person’s fear—this will help to inform the action plan. Strategies to reduce the fear may include diabetes education, behavioral therapy, desensitization or distraction, and relaxation.

## 7 A's Model: Fear of Hypoglycemia

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 fear of hypoglycemia?
- How can I support a person who experiences fear of hypoglycemia?

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



## HOW CAN I IDENTIFY Fear of Hypoglycemia?

### ■ Be **AWARE**

Fear of hypoglycemia can present itself in many ways. Some common signs to look for include:

- › “over-compensatory behaviors” (e.g., taking less insulin than needed or frequent snacking)
- › “avoidance behaviors” (e.g., limiting physical or social activities, and avoiding being alone or in situations in which hypoglycemia may be more likely)
- › acceptance of persistently high blood glucose levels
- › excessive daily blood glucose checks
- › and not implementing “agreed” treatment changes to lower blood glucose levels.



Although a history of hypoglycemia is a well-established risk factor for fear of hypoglycemia, fear can occur in the absence of actual hypoglycemia. Perceived and actual risk of hypoglycemia are equally likely to cause fear.

## ■ ASK

Hypoglycemia is very common when diabetes is managed with glucose-lowering medications. Therefore, it is advisable that you ask people with diabetes using these medications about their experiences of hypoglycemia at every consultation. If this conversation reveals or the person exhibits signs that they fear hypoglycemia (see **AWARE**), explore this further with them.

As fear of hypoglycemia can have various causes, the following questions are examples of how to gain a better understanding of the underlying reasons.

**Ask about their experiences of hypoglycemia (hypos)**, to explore frequency and severity, how they manage a hypoglycemic episode, and their knowledge about low blood glucose.

- *“Have you had any hypos [in the last month/week/ since we last met]?”*
  - Explore the frequency, severity, time (night or day), and place (at home or elsewhere).
  - Did they need help from someone to treat the hypoglycemia?
  - Did they access health services (e.g., ambulance, emergency room, or hospital admission)?
- *“Could you describe the symptoms you had when your blood glucose was going low?”* or, *“What do you feel when your blood glucose goes low?”*
  - Explore what they define as hypoglycemia, and at what level they usually recognize symptoms.
  - Explore how they identified hypoglycemia (e.g., because of symptoms or by checking their blood glucose).
  - Ask about any additional symptoms, as this process will encourage them to reflect on what exactly happened.
- *“What do you think caused this hypo?”*
  - Explore whether they believe the cause to be due to external factors (e.g., an imbalance between food intake, insulin dose, and physical activity; or heat, illness, stress, or alcohol).
- *“How did you react to this hypo?”*
  - Explore both behavioral and emotional reactions.
  - Check for inappropriate self-treatment behaviors (e.g., delaying treatment or using ineffective foods/drinks as “hypoglycemia treatments”).
  - Check for psychological barriers (e.g., feeling embarrassed or criticized when taking a sugary food/drink in the presence of others or in public places).

- Ask whether they reduced their insulin to avoid future hypoglycemia.
- *“Is there a way you could avoid a similar episode in the future?”*
  - Explore the extent to which the person has reflected on the causes and considered how/what to learn from the experience.

If the person does not experience hypoglycemia, this does not necessarily mean that they have no fear of hypoglycemia. Ask the following questions regardless of the person’s responses above.

**Ask open-ended questions to explore the level of fear of hypoglycemia:**

- *“People with diabetes using [insulin/oral medications for type 2 diabetes] are sometimes concerned about their blood glucose going low. How do you feel about low blood glucose levels/hypos?”*
  - If the person has few or no concerns, verify whether this is consistent with their actual risk or experience of hypoglycemia.
  - If the person is highly concerned, explore whether it affects their diabetes management and/or quality of life, for example:
    - *“What has been your worst experience with hypos?”*
    - *“What concerns you the most about hypos?”*
    - *“How is your life affected by hypos?”*
    - *“Have you ever had a severe hypo in the past with unpleasant consequences for you or others? Tell me a bit more about what happened.”*
    - *“What is the lowest blood glucose level you feel comfortable with?”* and, *“What is the highest?”*
    - *“When you go out, what is the lowest blood glucose level you feel safe with?”*

**Ask directly about compensatory behaviors, in a sensitive and non-judgmental way:**

- *“Some people take less insulin because they are worried about having a hypo. Do you (ever) reduce your insulin to avoid hypos?”*
- *“Some people keep their blood glucose at a higher level to avoid hypos. Are there times you keep your blood glucose higher for this reason?”*



**Ask about how their family, friends, and colleagues react to hypoglycemia**, as it may be affecting their significant others, too (perhaps even more so). For example:

- › “Do other people around you worry about you having hypos? How do you respond to their concerns?”
- › “Does your [significant other] wake up during the night when you are low?”
- › “Do you think your [significant other] worries about you going low when you are out?”
- › “If your [significant other] asks you to check your blood glucose or drink juice because s/he suspects you are going low, how do you feel about that?”
- › “Does having a hypo—or being at risk of hypo—cause any conflicts between you and your partner [family/other]?”



People with diabetes may be reluctant to talk about their experiences of hypoglycemia because of:

- concerns about losing their driver’s license or their job
- the associated stigma—losing control as a result of a hypoglycemic event can be perceived by others as “being drunk,” which can cause feelings of embarrassment, shame, and guilt, and can sometimes lead to unnecessary emergency interventions
- concerns that a health professional would expect them to know how to avoid severe hypoglycemia (particularly if they have lived with diabetes for many years)
- or an unrealistic blood glucose target range they may have set for themselves.

If there is an indication that the person experiences fear of hypoglycemia, you may consider using a validated questionnaire (see **ASSESS**), which will help you both gain a better understanding of what worries them the most.

However, only use a questionnaire if there is time during the appointment to talk about the scores and discuss with the person what is needed to reduce their fear. For information about using questionnaires in clinical practice, see pages 10 and 11.

## ■ ASSESS

### Validated Questionnaire

The Hypoglycemia Fear Survey-Version II Worry scale (HFS-II W)<sup>29</sup> is an 18-item questionnaire for people with type 1 diabetes or those with type 2 diabetes using insulin. A copy is included on page 70. It is the most widely used questionnaire to assess fear of hypoglycemia. Adapted versions are also available for spouses/partners. Each item is measured on a five-point scale, from 0 (never) to 4 (almost always). The individual item scores can highlight the major concerns related to hypoglycemia. Based on a study of people with type 2 diabetes, a score of 3 or 4 on any item of the HFS-II W scale indicates fear of hypoglycemia and needs to be explored further.<sup>13</sup> This is also likely to be the case among people with type 1 diabetes, although there was no empirical evidence available at the time this guide went to print.

In addition to the HFS-II W, ask about compensatory behaviors the person may use to avoid hypoglycemia (e.g., keep blood glucose at a higher level). This provides insights into the person’s acceptance of hyperglycemia in order to cope with their fear of hypoglycemia.

### Additional Considerations

- › **Is the fear a sign of post-traumatic stress disorder?** If a person develops fear of hypoglycemia after a traumatic hypoglycemic experience (e.g., causing a car accident or injuries), it may be a sign of post-traumatic stress disorder. “Flashbacks”/ memories/dreams of the event; lack of enjoyment; avoidance of activities or situations related to the source of the trauma; and feelings of emotional “numbness” are common reactions in the first days or weeks after a trauma. However, if these symptoms worsen or do not reduce, referral to a mental health professional is recommended for further assessment and treatment.
- › **Is the fear part of a co-existing anxiety disorder?** If this is possible, you may consider using an anxiety questionnaire (see **Chapter 7**). Before doing so, check whether the person has been diagnosed with an anxiety disorder now or in the past, and whether they have received treatment.



## HOW CAN I SUPPORT A PERSON Who Experiences Fear of Hypoglycemia?

### ■ ADVISE

Now that you have identified that the person has fear of hypoglycemia, you can advise on the next steps and then, together, decide on an action plan. If the person has completed the HFS-II W, you could use their scores to guide the conversation. Explain the scores and talk about items with high scores.

- Acknowledge that it is common for people with diabetes to be concerned about hypoglycemia.
- Explain that “fear of hypoglycemia” is a normal response to a threat, and a certain amount of fear is okay—because it will help to keep them alert for hypoglycemic symptoms—but extreme or overwhelming fear is a problem because it can compromise their diabetes management. It can also impair their quality of life, and even the lives of their family members.
- Advise that there are ways to reduce their fears (e.g., strategies that directly focus on the fear, or strategies to prevent or reduce the frequency and severity of hypoglycemia).
- Explain:
  - that hypoglycemia is the result of an imbalance between insulin, carbohydrate intake (including alcohol), and physical activity
  - that not every person with diabetes will experience severe hypoglycemia (requiring assistance to treat)
  - that most severe episodes are experienced by a minority of people with diabetes, and many of these can be prevented through improving certain self-management techniques and treating mild hypoglycemia without delay
  - and the mechanisms underlying hypoglycemic symptoms (e.g., counter-regulation and neuroglycopenia), if it seems helpful for the person.
- Acknowledge that frequent mild (self-treated) hypoglycemic episodes may be as disruptive as one severe hypoglycemic episode.
- Indicate that you recognize that the person may choose to keep their blood glucose levels in a higher range to avoid hypoglycemia in general or in specific situations. However, if this behavior is frequent or persistent, it could have long-term health consequences.
- Offer the person opportunities to ask questions.

- Make a joint plan about the “next steps” (e.g., what needs to be achieved to reduce their fear and what support they may need).

### NEXT STEPS: ASSIST OR ASSIGN?

- People with diabetes who experience psychological problems often prefer to talk about this with their diabetes health professionals or their primary care provider (PCP) rather than with a mental health specialist.<sup>30</sup>
- As fear of hypoglycemia is intertwined with diabetes management, it is best addressed by a diabetes health professional or PCP (if they are the main health professional). If you have the skills and confidence, support the person yourself, as they have confided in you for a reason. A collaborative relationship with a trusted health professional and continuity of care are important in this process; it rarely requires a referral to a mental health specialist.<sup>18</sup>
- There will be occasions when it is more appropriate to refer to another health professional. This will depend on:
  - the needs and preferences of the person with diabetes
  - your qualifications, knowledge, skills, and confidence to address fear of hypoglycemia
  - the severity of the fear of hypoglycemia, and the specific worries identified
  - whether other psychological problems are also present (e.g., fear is part of an anxiety disorder [see [Chapter 7](#)] or post-traumatic stress disorder triggered by a traumatic hypoglycemic episode)
  - whether other life stressors co-occur
  - and your scope of practice, and whether you have the time and resources to offer an appropriate level of support.
- If you believe referral is needed:
  - explain your reasons (e.g., what the other health professional can offer that you cannot)
  - ask the person how they feel about your suggestion
  - and discuss what they want to gain from the referral, as this will influence to whom the referral will be made.



## ■ ASSIST

The two main aims when assisting a person with fear of hypoglycemia are for the person to restore their self-confidence in managing diabetes and to regain a sense of personal control over their glucose levels. For some people, improving their self-management knowledge/skills will reduce their risk of hypoglycemia and, in so doing, will increase their self-confidence and personal control. For others, fear is more entrenched and unrelated to their knowledge or skills. This will require a focus on fear management. Both approaches are discussed below.

### Focusing on Enhancing Knowledge/Skills in Hypoglycemia Management

- Effective and timely treatment of hypoglycemia is crucial because of the small window of opportunity to respond before awareness and judgement may be compromised.
  - Review the person's knowledge about recognizing the symptoms of hypoglycemia and how to treat it. Verify that they understand:
    - not to delay treatment, and to treat with appropriate food/drinks. Explore their barriers to hypoglycemic treatment<sup>31</sup> (e.g., feeling embarrassed when eating in front of others or dislike of recommended food) and talk about strategies to overcome these barriers.
    - the external cues (e.g., the interplay between insulin, food, physical activity, and other factors such as alcohol or stress).
    - how to recognize various internal symptoms: physical, cognitive, and emotional. Over the years people with diabetes often rely on one or two hypoglycemic symptoms, without taking notice of the full range of symptoms (e.g., changes in mood or difficulties in concentrating and performing tasks).
    - the symptoms related to the brain not getting enough glucose (e.g., confusion and cognitive impairment). Many people with diabetes and their families are not aware how lack of glucose (e.g., below 54 mg/dl) can affect the brain.
    - that reduced awareness of hypoglycemic symptoms can limit their ability to treat hypoglycemia.
    - that hypoglycemic episodes can be asymptomatic, and treatment should therefore be based on a blood glucose reading, not on perceived symptoms.
  - Provide additional education on hypoglycemia management to fill identified knowledge gaps, enhance skills, and restore confidence:
    - Suggest that they keep a record of their hypoglycemic episodes (e.g., glucose readings below 70 mg/dl) for two weeks noting:<sup>32</sup>
      - their blood glucose level and experienced symptoms (or lack thereof)
      - identified cues (e.g., delaying or missing a meal, or mismatch between insulin and carbohydrates, after unplanned or more vigorous physical activity, or alcohol consumption)
      - and the actions taken.
- Use the recorded information as a learning opportunity to review their personal reliable hypoglycemic symptoms and observed causes of it.
- Suggest that they reflect on symptoms that are unusual in the actual situation (e.g., sweating on a cold day or feeling cold on a hot day) or when their thinking/acting is slower or requires more effort/is more difficult than usual (e.g., difficulty opening a door with a key or tying a shoelace).
  - Agree on actions to prevent or reduce their risk of hypoglycemic episodes.
- Support the person to build confidence and assertiveness to respond/act immediately to low blood glucose or hypoglycemic symptoms.
  - Review their current diabetes management plan:
    - Review their diabetes medications (e.g., doses and type of insulin) to exclude the possibility of over-treatment or “insulin stacking.”
    - Review their self-management knowledge and skills in injection techniques, insulin dose adjustment, carbohydrate counting, blood glucose monitoring, and the impact of alcohol and physical activity on glucose levels (including delayed impact).
    - Discuss whether the person will consider using an insulin pump instead of injections and/or using a continuous glucose monitor. Explore the pros and cons for each option.
  - Encourage the involvement of another person (e.g., a partner, family member, friend, or colleague) to assist in hypoglycemic management at home/work/school. Identify a person who is well informed and skilled to provide help and administer glucagon (if needed) or is willing to be trained to assist in managing hypoglycemia.

- If the person's partner/family member worries excessively about hypoglycemia, suggest that they join the person with diabetes at the next appointment. At the appointment, talk with the partner/family member about the causes of their worry, and how they can support the person with diabetes (and vice versa).



Older people may have cognitive impairment, which makes them more vulnerable to not recognizing hypoglycemic symptoms. In older people, hypoglycemia symptoms become less specific (e.g., feeling unwell or dizzy) and some are similar to signs of dementia (e.g., agitation or confusion).<sup>33</sup> Furthermore, recurrent hypoglycemia in older people is associated with decline of physical and cognitive function, which can lead to frailness and disability. For example, older people also are more prone to falls, and if this happens during a hypoglycemic episode, they may be more likely to experience fractures.<sup>33</sup>

Guidelines for hypoglycemia management in older people can be found in “Special Considerations for Older Adults with Diabetes Residing in Skilled Nursing Facilities” (see “Resources” on page 72).



Enhancing self-management knowledge/skills is likely to be effective if the person's fear is at a moderate level, and if the person is motivated and skilled to “solve the problem.” Explore whether the person fears *hyperglycemia* (see Box 4.3) more than *hypoglycemia*, as this may be a barrier to making changes to avoid hypoglycemia.

### Focusing on Fear Management<sup>d</sup>

- Helping the person with diabetes to feel safe needs to be a key priority.
- Before considering any action plan, ask, “*What do you think is needed to reduce your fear?*” Explore:
  - what they could do, or are willing to do
  - and the kind of support they need from you or others.

- If the person lives alone and this is causing fear:
  - talk about prevention of hypoglycemia (e.g., frequent blood glucose checks and immediate treatment)
  - discuss whether the person would find it helpful to have someone check on them (e.g., neighbors or friends) on a regular basis
  - and inform them about the possibility of a personal medical alarm that may help them to feel safer when alone at home.
- Provide the person with accurate information about their actual risk of hypoglycemia and challenge their unhelpful ways of thinking about their perceived risk or beliefs of “disasters waiting to happen.”
- Develop a stepwise plan. Agree on:
  - a blood glucose target range that is both safe and comfortable for the person; this “individualized” target may be higher than the standard targets
  - when and by how much the target range can be reduced
  - and “experiments” to bring their blood glucose levels back, gradually, to the recommended targets (e.g., increase their insulin dose at a time/place that feels safe for them, such as when other people are nearby, or at home).
- It is best to “go slow” and have the person decide when they are ready to take the “next step” to lower their blood glucose levels (i.e., to minimize the risk of increasing their fear or reducing their feelings of safety/personal control).



It is very unlikely that having knowledge about the long-term consequences of hyperglycemia will motivate a person with fear of hypoglycemia to reduce their blood glucose levels. Fear of hypoglycemia is related to the “here and now,” not to long-term health risks. For points to consider when supporting someone with fear of hyperglycemia, see Box 4.3.

<sup>d</sup> For a comprehensive description of fear management skills and strategies, read the paper by Vallis and colleagues (2014) (see “Resources” page 72).

### BOX 4.3 Fear of Hyperglycemia

Little is known about fear of hyperglycemia (high blood glucose) and the underlying mechanisms.<sup>34</sup> It may be caused by:

- › worrying about the future and the possibility of diabetes complications
- › limited knowledge and skills to manage diabetes
- › experiencing unpleasant symptoms of high blood glucose levels (e.g., lacking energy or feeling lethargic)
- › fearing diabetic ketoacidosis
- › or perfectionistic tendencies.

A person may respond to their fear of hyperglycemia by keeping their blood glucose levels (too) low, resulting in an increased risk of recurrent mild or severe hypoglycemia. In turn, this will increase their likelihood of impaired awareness of hypoglycemic symptoms (due to recurrent hypoglycemia), and their risk of adverse consequences of undetected hypoglycemic episodes (e.g., while driving or at work).

Maintaining blood glucose levels within target while avoiding hypoglycemia and hyperglycemia is a challenging task and, fear of hypoglycemia/hyperglycemia can co-exist.<sup>34,35</sup> Micromanaging blood glucose levels (i.e., continually correcting levels with extra insulin or food) may be a sign of high fear of hypoglycemia/hyperglycemia.

Understanding the reason(s) for the person's underlying fear of hyperglycemia will help you to support them.

**If fear is due to worries about developing long-term complications, see Box 4.4.**

**If fear is due to limited diabetes self-management knowledge/skills, you may want to offer additional diabetes education.**

#### If fear is due to unpleasant symptoms:

- › Advise the person to track their blood glucose levels when they perceive symptoms.
- › Problem-solve with the person about how they can manage their perception of the unpleasant symptoms (e.g., have water and sugar-free chewing gum/mints available).
- › Assist the person to experiment with increasing their capacity to tolerate and build resilience to the perception of unpleasant symptoms using cognitive coping statements, for example: *“This feeling may be unpleasant, but I can manage it. I’ve survived other unpleasant feelings, such as ... [insert one or more personal examples, e.g., hunger, tiredness, a shaving or paper cut].”*

#### If the underlying reason is concern about diabetic ketoacidosis:

- › Provide education about how diabetic ketoacidosis occurs and how to avoid it.
- › Reassure the person that ketoacidosis does not happen by chance.
- › Explain that they can manage their risk with regular blood glucose checks and appropriate self-care if ketones are present.

#### If fear is due to perfectionistic tendencies:

- › Explain that “perfect” blood glucose levels do not exist, and that minor fluctuations will have little impact—it is the average blood glucose level that is known to be important in preventing long-term complications.
- › Talk about “coping strategies” to help them modify their perfectionist beliefs over time. For example, assist them to overcome “oversimplification” (black-and-white thinking), set realistic diabetes goals, and recognize that self-care is a process, not an outcome.<sup>36</sup>

### BOX 4.4 Worries about Long-Term Complications

Research has shown consistently that people with type 1 or type 2 diabetes are very concerned about developing serious complications.<sup>3,5</sup> Diabetes does, indeed, increase the risk of long-term complications, when glucose levels have been above target over a long period.

However, people with diabetes often overestimate their risk of complications,<sup>37,38</sup> which can result in unnecessarily high levels of fear. People who are very concerned about complications are also more likely to be emotionally distressed, anxious, and depressed.<sup>35,39</sup>

Diabetes education has a strong focus on the risk of long-term complications. This may trigger (unrealistic) severe concerns, especially in people who do not feel equipped to maintain their blood glucose levels within recommended targets. Compared to providing general risk information, discussing individualized risk is more effective in adjusting the person's risk perceptions and enhancing engagement in healthy self-care behaviors. Also, shifting the focus from "scary" messages about complications to strategies to maintain blood glucose in optimal ranges is more encouraging and more likely to be successful.

To address the person's worries about complications:

- › Ask the person about the diabetes complication(s) they are most worried about.
- › Gain a better understanding of their knowledge, beliefs about the seriousness of complications, their perceived risk of developing complications, and related feelings. For example, if they have family members with diabetes who have (had) diabetes complications, this can exaggerate the individual's perception of their own risk. This insight will enable you to provide individualized, relevant information about the person's actual risk.
- › Advise them that diabetes complications:
  - are avoidable and that not every person with diabetes develops complications
  - and do not develop "overnight" and that minor lapses/blood glucose levels occasionally "out of target" are not cause for concern; it is persistently elevated glucose levels (over long periods of time) that place a person at higher risk of developing complications.
- › Explain that:
  - keeping blood glucose levels within target will prevent "rebound" high blood glucose levels after hypoglycemia
  - and living with hypoglycemia does not guarantee that they will avoid long-term complications.
- › Reassure them that rates of complications have reduced considerably in recent years due to more effective, modern diabetes treatments and technologies.
- › Use the conversation to inform an action plan. For example, together, develop strategies for preventing complications/maintaining blood glucose levels within target.

## ■ ASSIGN

If a decision is made to refer, consider:

- **a certified diabetes nurse or educator**, for hypoglycemia management, general diabetes education (e.g., to review blood glucose monitoring and injection techniques/skills), and support
- **an endocrinologist** for a review of the current diabetes regimen
- **a structured type 1 diabetes education program** focusing on management of hypoglycemia
- **and a mental health professional** (e.g., a counsellor, psychologist, or psychiatrist, preferably with an understanding of diabetes) if the strategies in **ASSIST** do not reduce the person's fear of hypoglycemia or for post-traumatic stress disorder as a result of an "unprocessed" traumatic hypoglycemic experience in the past. The American Diabetes Association (ADA) Mental Health Provider Directory ([https://professional.diabetes.org/mhp\\_listing](https://professional.diabetes.org/mhp_listing)) provides a listing of mental health providers with expertise in diabetes.

Most of these professionals may be covered through insurance or through Medicare. A PCP can assist with the referral process.

See **Chapter 9** for guidance about preparing mental health referrals and what to say to the person with diabetes about why you are making the referral.



**If you refer the person to another health professional, it is important:**

- **that you continue to see them after they have been referred so they are assured that you remain interested in their ongoing care**
- **and to maintain ongoing communication with the health professional to ensure a coordinated approach.**

## ■ ARRANGE

Depending on the action plan and the need for additional support, it may be that extended appointments or more frequent follow-up visits (e.g., once a month) are required until the person feels less fearful about hypoglycemia and is confident in sustaining the behavioral changes. Encourage them to book a follow-up appointment with you within an agreed timeframe. Telephone/video conferencing may be a practical and useful way to provide support in addition to face-to-face appointments.

Special attention needs to be given to those who have recently experienced a traumatic hypoglycemic episode, to assess both their behavioral and emotional responses in the weeks following the episode.

At the follow-up appointment, use open-ended questions to enquire about the person's progress, for example:

- *"Last time we talked about your concerns about having hypos. How do you feel about it now?"*
- Explore their concerns, and whether they experienced any hypoglycemic episodes since you last saw them, and if so, explore the circumstances, perceived symptoms, causes, and their actions and feelings. Continue: *"We talked about making some changes to your diabetes management to reduce your hypos. How has this worked out for you?"* Explore what has/has not worked, including obstacles or concerns.
- *"Last time we talked about you seeing a psychologist to help you with your fear of hypos. How has this worked out for you?"* If this has not helped, enquire what else is needed. If the person has not yet seen the mental health provider, explore the reasons, address these barriers, and identify ways to help them make that connection if they are still interested.
- If you previously used a questionnaire (e.g., HFS-II W), you could consider using it again to reassess their level of fear of hypoglycemia.





## Irena

### CASE STUDY

32-year-old woman, moved from Greece to the United States with her husband several years ago

Type 1 diabetes (diagnosed 16 years ago), managed with four daily injections

Health professional: Dr. Anna Garvin (endocrinologist)

#### ■ Be AWARE

Irena has been seeing Anna on a quarterly basis. They have established a collaborative, trusting relationship. They have focused on optimizing Irena's diabetes management plan, as her daily blood glucose and A1C levels are above target. Irena is very motivated and open to Anna's advice to improve her diabetes outcomes. Irena has participated in a diabetes education course, which she found useful. She and Anna have discussed the pros and cons of insulin pumps, but Irena does not want to be attached to a device "24/7." Irena thinks she is "doing well" with her diabetes management since her work with a diabetes educator, so she is not concerned about long-term diabetes complications. Anna wonders whether the lack of improvement in Irena's blood glucose levels could be due to how Irena feels about her diabetes management.

#### ■ ASK

At the next visit, while Irena is waiting for her appointment, Anna invites her to complete the Problem Areas in Diabetes (PAID) questionnaire. She explains to Irena, *"Over the last few months, we have been focusing on your diabetes treatment, and you have put a lot of effort into improving your management. I thought it might be good to talk about how you are feeling about your diabetes. This questionnaire lists common problems that people with diabetes may experience on a daily basis. Would it be OK for you to answer these questions while you wait? Then, we can talk about it when you come in to see me."* Irena is happy to complete the questionnaire.

#### ■ ASSESS

Most of Irena's scores on the PAID are in the lower range (scores 1 or 2). She scores 3 (moderate problem) on three items:

- › "worrying about low blood glucose episodes"
- › "feelings of guilt and anxiety when off track with diabetes management"
- › and "feeling burned out."

Anna enquires about Irena's experience filling in the form. Irena says, *"It was OK,"* but she notices that Irena avoids eye contact and becomes restless. When Anna says, *"I may be wrong, but I get the feeling that these questions have upset you,"* Irena starts crying. Anna gives her some time to express her emotions, then continues: *"It look likes things have been tough. Would you like to talk about it?"* She pauses to give Irena time to consider and respond to the question.

Irena tells Anna about a severe hypo—and resulting accident—she had a few years ago when she was driving home from work. Irena was taken to the hospital. Her recovery went well and she was back at work after three months, but the accident has had ongoing effects. Irena:

- › regularly has bad dreams about causing an accident and hurting other people
- › continues to blame herself for not treating the impending low blood glucose in time
- › no longer drives a car, which affects her social life and independence
- › avoids going out alone
- › and is having marital problems as a result of her concerns.



At first, her husband was very supportive, but now he does not understand why Irena does not get on with her life. He is also unhappy that he has to drive her around.

Anna acknowledges the impact this severe hypo has had on Irena's life for so many years. She further explores whether Irena has reduced her insulin, which could explain her high blood glucose levels. *"Some people may take less insulin after they have been involved in such an accident. Have you reduced the amount of insulin to avoid another severe hypo?"* Irena replies that she has, indeed, been taking less insulin than required over a long period of time.

### ■ ADVISE

Anna thanks Irena for opening up about this experience and asks how she is feeling now. *"Every time I came to see you, I wanted to tell you about this accident. But I couldn't do it. I am really scared when I see these high numbers on my meter, but I'm also scared of having another accident."* Anna asks Irena if the timing is right to talk about the kind of support that is available to work through her traumatic experience.

### ■ ASSIST

Anna asks whether Irena has considered consulting a psychologist for help with processing the trauma and overcoming her fear of hypoglycemia. Irena has thought about it but doesn't know where to start. Anna suggests that she go to the ADA website to see if she can find a mental health professional with expertise in diabetes in her area.

### ■ ARRANGE

They agree on a time for the next visit. Anna explains that while Irena is seeing the psychologist, they will together work out a diabetes management plan that is both "safe" and achievable for Irena. In future visits, they will talk about how best to reduce these high readings without increasing Irena's risk of hypos. But overcoming the fear is the first priority because, if this remains unresolved, it will be a major barrier to making any changes to her diabetes care plan.



## CASE STUDY

## Aaron

25-year-old man, living with his wife, Hannah, and one-year-old daughter, Leila

Type 1 diabetes (diagnosed 20 years ago). Typically injects insulin four times per day and checks his blood glucose at least 10 times a day. His A1C ranges between 5.9 and 6.4%

Health professionals: Dr. Paul Asher (endocrinologist) and Steven Mazumdar (certified diabetes educator)

### ■ Be AWARE

Aaron is highly motivated and well-informed about diabetes. But Dr. Asher has concerns about Aaron's frequent hypoglycemic episodes (on average 10 episodes per week that he can self-treat). He is aware that Aaron does a lot of finger pricks per day and that he often injects extra insulin to bring his blood glucose level down. Last month, Aaron had a severe hypo while surfing with friends, and he had to be rescued by a lifesaver. Dr. Asher has referred Aaron to Steven, one of the certified diabetes educators in the team, to review his diabetes management plan and aim to reduce the frequency of hypoglycemia.

### ■ ASK

Steven welcomes Aaron and his wife Hannah to the appointment. He asks Aaron the purpose of his visit. Aaron replies, *"I don't know. Dr. Asher asked me to come and see you. But all is going well, my last A1C was 6.1%, and my tests were all fine."* Hannah, clearly unhappy with Aaron's reaction, tells Steven about Aaron's severe hypoglycemic episode whilst surfing and that he has at least one hypo every day. Aaron responds that, *"it's not a big deal, it's to be expected... don't worry, I know what I'm doing."*

Steven asks Aaron about his history of hypoglycemia and his recent severe episode. He learns that:

- The surfing incident was not Aaron's first severe hypo this year. Hannah treated his last severe hypo at home with glucagon.
- Aaron checked his blood glucose before leaving home; it was 67 mg/dl but he did not treat himself. He knows most people would consider this to be "too low."

- Aaron often surfs with low blood glucose. *"Usually, it is okay. I have carbs with me and as soon as I feel my sugar dropping I eat some."*
- This last time while surfing, Aaron did not respond when he felt his glucose levels dropping. *"I knew my blood sugar was getting low, but I couldn't be bothered getting out of the water for food.... It was stupid of me."*
- Aaron feels *"best when my sugar sits between 65 and 135 mg/dl."* He gets annoyed if his blood glucose gets higher than 140 mg/dl and will give himself *"a few units [of insulin] to bring it down."*

Steven also asks Hannah about her feelings. Hannah tells him that she:

- is very worried because Aaron has many "lows"
- is concerned that Aaron will have a hypoglycemic episode when he is alone with Leila and will be unable to take care of her or might even drop her
- knows that Aaron drives with low blood glucose levels (below 70 mg/dl) and is afraid that he will have an accident while Leila is in the car
- and is frustrated that Aaron does not appreciate how worried she feels.

Steven considers whether Aaron may be more anxious about hyperglycemia than about hypoglycemia and that maybe he is avoiding blood glucose levels above 140 mg/dl by taking more insulin than required.

Steven further explores Aaron's motivations for keeping his blood glucose levels within such narrow targets. *"Aaron, it sounds like keeping your blood glucose level below 140 is very important to you. Could you tell me a bit more about it?"*

Aaron says that he:

- › does not want his diabetes to stop him from surfing and building a successful career
- › will do anything to prevent long-term complications, as they will get in the way of his plans
- › is happy with how he is managing his diabetes right now and feels “in control”
- › has heard Hannah’s concerns today, but acknowledges that in the past he has avoided having that conversation with her
- › and wants Hannah to trust him to be able to look after their baby.

### ■ ADVISE

Steven acknowledges the effort that Aaron puts into his diabetes management and Hannah’s concerns about the well-being of her family. Although he understands that Aaron is well-informed about his diabetes, Steven reiterates to Aaron and Hannah:

- › how hypoglycemia could impair his brain and that it makes it hard to treat a low blood glucose level in a timely way
- › that Aaron’s actual risk of complications, based on his past A1C results and annual screenings, is relatively low
- › and the negative consequences of living “on the edge” of hypoglycemia.

### ■ ASSIST

Steven acknowledges that it has not been easy for them to have this conversation. But Aaron and Hannah are both glad that Steven took the time to ask these questions—they could not have had this conversation at home. Steven notices that Hannah’s words have had a big impact on Aaron.

Steven provides them with some strategies about how the couple could “meet in the middle” to reduce Aaron’s fear of hyperglycemia and Hannah’s fear of hypoglycemia. He also suggests that they individually write down the kind of support that would be helpful to them. Then, together, talk about and agree on a realistic plan for mutual support.

### ■ ARRANGE

Steven suggests that Aaron and Hannah take some time to think about what has been said today and that the three of them meet again in two weeks to see how things have been going. Aaron and Hannah agree.

## Questionnaire: The Hypoglycemia Fear Survey-II (HFS-II W)

**I. Behavior Instructions:** Below is a list of things people with diabetes sometimes do in order to avoid low blood sugar and its consequences. Circle one of the numbers to the right that best describes what you have done during the last 6 months in your daily routine to AVOID low blood sugar and its consequences. **(Please do not skip any!)**

To avoid low blood sugar and how it affects me, I...	Never	Rarely	Sometimes	Often	Almost always
1 Ate large snacks.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2 Tried to keep my blood sugar above 150.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3 Reduced my insulin when my blood sugar was low.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4 Measured my blood sugar six or more times a day.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5 Made sure I had someone with me when I went out.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6 Limited my out of town travel.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7 Limited my driving (car, truck, or bicycle).	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8 Avoided visiting friends.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9 Stayed at home more than I liked.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10 Limited my exercise/physical activity.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11 Made sure there were other people around.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12 Avoided sex.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13 Kept my blood sugar higher than usual in social situations.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14 Kept my blood sugar higher than usual when doing important tasks.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15 Had people check on me several times during the day or night.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

**II. Worry Instructions:** Below is a list of concerns people with diabetes sometimes have about low blood sugar. Please read each item carefully (do not skip any). Circle one of the numbers to the right that best describes how often in the last 6 months you WORRIED about each item because of low blood sugar.

Because my blood sugar could go low, I worried about...	Never	Rarely	Sometimes	Often	Almost always
16 Not recognizing/realizing I was having low blood sugar.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17 Not having food, fruit, or juice available.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18 Passing out in public.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19 Embarrassing myself or my friends in a social situation.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20 Having a hypoglycemic episode while alone.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
21 Appearing stupid or drunk.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
22 Losing control.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
23 No one being around to help me during a hypoglycemic episode.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

24	Having a hypoglycemic episode while driving.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
25	Making a mistake or having an accident.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
26	Getting a bad evaluation or being criticized.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
27	Difficulty thinking clearly when responsible for others.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
28	Feeling lightheaded or dizzy.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
29	Accidentally injuring myself or others.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
30	Permanent injury or damage to my health or body.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
31	Low blood sugar interfering with important things I was doing.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
32	Becoming hypoglycemic during sleep.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
33	Getting emotionally upset and difficult to deal with.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

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### Background

The Hypoglycemia Fear Survey-II is a 33-item questionnaire with a Behavior Subscale and a Worry Subscale.<sup>29</sup> It was developed to assess specific behaviors people with diabetes engage in to avoid hypoglycemia and its negative consequences and the concerns people with diabetes may have related to their risk of having hypoglycemia.

### How to Use the HFS-II Fear Survey in Clinical Practice

Respondents are asked to indicate how much they engaged in or worried about each item during the last six months. This timeframe can be adapted. Each item is measured on a five-point scale ranging from 0 (never) to 4 (almost always).

Take note of the higher scoring items (especially scores of 3 and 4) and use these to start a conversation about their worries about hypoglycemia.



For tips about using questionnaires, see “Using Questionnaires to Inform Appointments” (pages 10 and 11).

# Resources

## For Health Professionals

### Peer-Reviewed Literature

- › **Fear of hypoglycemia in adults with type 1 diabetes: impact of therapeutic advances and strategies for prevention—a review**

**Description:** This review summarizes the current state of science related to fear of hypoglycemia by examining the influence of current treatments, technology, and interventions and their implications for practice and research.

**Source:** Martyn-Nemeth P, Farabi SS, et al. *Journal of Diabetes and its Complications*. 2016;30:167-177

- › **Impact of severe hypoglycemia on psychological outcomes in adults with type 2 diabetes: a systematic review**

**Description:** This systematic review provides a synthesis of research findings, showing that severe hypoglycemia is associated with increased fear of hypoglycemia and decreased emotional well-being, health status, and diabetes-specific quality of life in adults with type 2 diabetes.

**Source:** Hendrieckx C, Ivory N, et al. *Diabetic Medicine*. 2019;36:1082-1091.

- › **Managing hypoglycemia in diabetes may be more fear management than glucose management: a practical guide for diabetes care providers**

**Description:** This paper describes strategies that can be integrated into routine diabetes care to support people with diabetes and fear of hypoglycemia.

**Source:** Vallis M, Jones A, et al. *Current Diabetes Reviews*. 2014;10:364-370.

- › **Impact of fear of insulin or fear of injection on treatment outcomes of patients with diabetes**

**Description:** This systematic review summarizes the findings of six research papers focusing on fear of insulin and fear of injections.

**Source:** Fu AZ, Qiu Y, et al. *Current Medical Research and Opinion*. 2009;25:1413-1420.

- › **How has psycho-behavioral research advanced our understanding of hypoglycemia in type 1 diabetes?**

**Description:** This paper describes how psycho-behavioral research of the past 25 years has yielded

new insights into emotional well-being, risk factors, and intervention strategies related to hypoglycemia in type 1 diabetes.

**Source:** Hendrieckx C, Gonder-Frederick L, et al. *Diabetic Medicine*. 2020;37:409-417.

- › **Evidence-informed clinical practice recommendations for treatment of type 1 diabetes complicated by problematic hypoglycaemia**

**Description:** This review paper summarises the current evidence and recommends strategies for problematic hypoglycaemia in people with type 1 diabetes.

**Source:** Choudhary P, Rickels MR, et al. *Diabetes Care*. 2015;38:1016-1029.

- › **Special considerations for older adults with diabetes residing in skilled nursing facilities**

**Description:** An overview of the needs for skilled nursing facility residents with diabetes and the special needs for this group related to nutrition, hydration, physical activity, and medical therapy.

**Source:** Haas LB. *Diabetes Spectrum*. 2014;27(1):37-43.

## For People with Diabetes



Select **one** or **two** resources that are most relevant and appropriate for the person. Providing the full list is more likely to overwhelm than to help.

### Support

- › **American Diabetes Association (ADA)**

**Description:** The ADA has a hotline that can provide information and resources. It can be reached at 1-800-DIABETES.

**URL:** [www.diabetes.org](http://www.diabetes.org)

- › **Juvenile Diabetes Research Foundation (JDRF)**

**Description:** This organization has an online diabetes support team who will respond to questions within 48 hours.

**URL:** [www.jdrf.org](http://www.jdrf.org)



## Information

### › *Diabetes Burnout: What to Do When You Can't Take It Anymore*

**Description:** Chapter 17 of this book focuses on “Worrying about hypoglycemia” and Chapter 10 on “Worrying about long-term complications.” The book provides easy-to-use strategies to overcome these concerns.

**Source:** Polonsky W. Virginia, U.S.; American Diabetes Association. 1999.

**URL:** [www.shopdiabetes.org/products/diabetes-burnout-what-to-do-when-you-cant-take-it-anymore](http://www.shopdiabetes.org/products/diabetes-burnout-what-to-do-when-you-cant-take-it-anymore)

### › *Fear of Hypoglycemia*

**Description:** A handout for people with diabetes about fear of hypoglycaemia that includes suggestions that the person may try in order to reduce their fear, and offers suggestions for support and additional information.

**Source:** Australia National Diabetes Services Scheme and American Diabetes Association. 2021

**URL:** <https://professional.diabetes.org/meetings/mentalhealthworkbook>

## References

- Gonder-Frederick L. Fear of hypoglycemia: a review. *Diabetic Hypoglycemia*. 2013;5(3):3-11.
- Graveling AJ, Frier BM. Hypoglycemia: an overview. *Primary Care Diabetes*. 2009;3(3):131-9.
- Snoek F, Pouwer F, et al. Diabetes-related emotional distress in Dutch and US diabetic patients: cross-cultural validity of the Problem Areas in Diabetes Scale. *Diabetes Care*. 2000;23(9):1305-9.
- Nicolucci A, Kovacs Burns K, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2™): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabetic Medicine*. 2013;30(7):767-77.5.
- Speight J, et al. Diabetes MILES – Australia 2011 Survey Report. Vic, Melbourne. Diabetes Australia. 2011.
- Anderbro T, Gonder-Frederick L, et al. Fear of hypoglycemia: relationship to hypoglycemic risk and psychological factors. *Acta Diabetologica*. 2014;52(3):581-9.
- Anderbro T, Amsberg S, et al. Fear of hypoglycaemia in adults with type 1 diabetes. *Diabetic Medicine*. 2010;27(10):1151-8.
- Gold AE, Macleod KM, et al. Frequency of severe hypoglycemia in patients with type 1 diabetes with impaired awareness of hypoglycemia. *Diabetes Care*. 1994;17(7):697-703.
- Polonsky WH, Davis CL, et al. Correlates of hypoglycemic fear in type 1 and type 2 diabetes mellitus. *Health Psychology*. 1992;11(3):199-202.
- Irvine AA, Cox D, et al. Fear of hypoglycemia: relationship to physical and psychological symptoms in patients with insulin-dependent diabetes mellitus. *Health Psychology*. 1992;11(2):135-8.
- Nixon R, Pickup JC. Fear of hypoglycemia in type 1 diabetes managed by continuous subcutaneous insulin infusion: is it associated with poor glycemic control? *Diabetes Technology & Therapeutics*. 2011;13(2):93-8.
- Tak-Ying Shiu A, Yee-Man Wong R. Fears and worries associated with hypoglycaemia and diabetes complications: perceptions and experience of Hong Kong Chinese clients. *Journal of Advanced Nursing*. 2002;39(2):155-63.
- Hajós TR, Polonsky WH, et al. Toward defining a cutoff score for elevated fear of hypoglycemia on the Hypoglycemia Fear Survey Worry subscale in patients with type 2 diabetes. *Diabetes Care*. 2014;37(1):102-8.
- UK Hypoglycemia Study Group, Risk of hypoglycemia in types 1 and 2 diabetes: effects of treatment modalities and their duration. *Diabetologia*. 2007;50(6):1140-7.
- Martyn-Nemeth P, Farabi SS, et al. Fear of hypoglycemia in adults with type 1 diabetes: impact of therapeutic advances and strategies for prevention—a review. *Journal of Diabetes and Its Complications*. 2016;30(1):167-77.
- Hendrieckx C, Ivory N, et al. Impact of severe hypoglycemia on psychological outcomes in adults with Type 2 diabetes: a systematic review. *Diabetic Medicine*. 2019;36(9):1082-91.
- Jørgensen HV, Pedersen-Bjergaard U, et al. The impact of severe hypoglycemia and impaired awareness of hypoglycemia on relatives of patients with type 1 diabetes. *Diabetes Care*. 2003;26(4):1106-9.
- Vallis M, Jones A, et al. Managing hypoglycemia in diabetes may be more fear management than glucose management: a practical guide for diabetes care providers. *Current Diabetes Reviews*. 2014;10(6):364-70.
- Leiter LA, Yale JF, et al. Assessment of the impact of fear of hypoglycemic episodes on glycemic and hypoglycemia management. *Canadian Journal of Diabetes*. 2005;29(3):186-92.
- Hepburn DA, Deary IJ, et al. Structural equation modeling of symptoms, awareness and fear of hypoglycemia, and personality in patients with insulin-treated diabetes. *Diabetes Care*. 1994;17(11):1273-80.
- Wild D, von Maltzahn R, et al. A critical review of the literature on fear of hypoglycemia in diabetes: implications for diabetes management and patient education. *Patient Education and Counseling*. 2007;68(1):10-5.
- Barendse S, Singh H, et al. The impact of hypoglycaemia on quality of life and related patient-

- reported outcomes in type 2 diabetes: a narrative review. *Diabetic Medicine*. 2012;29(3):293-302.
23. Cox DJ, Irvine A, et al. Fear of hypoglycemia: quantification, validation, and utilization. *Diabetes Care*. 1987;10(5):617-21.
  24. Böhme P, Bertin E, et al. Fear of hypoglycaemia in patients with type 1 diabetes: do patients and diabetologists feel the same way? *Diabetes and Metabolism*. 2012;39(1):63-70.
  25. Tak-Ying Shiu A, Yee-Man Wong R. Fear of hypoglycaemia among insulin-treated Hong Kong Chinese patients: implications for diabetes patient education. *Patient Education and Counseling*. 2000;41(3):251-61.
  26. Rogers HA, de Zoysa N, et al. Patient experience of hypoglycemia unawareness in Type 1 diabetes: are patients appropriately concerned? *Diabetic Medicine*. 2011;29(3):321-7.
  27. Speight J, Barendse SM, et al. Cognitive, behavioural and psychological barriers to the prevention of severe hypoglycaemia: A qualitative study of adults with type 1 diabetes. *SAGE Open Medicine*. 2014;2:1-10.
  28. Fu AZ, Qiu Y, et al. Impact of fear of insulin or fear of injection on treatment outcomes of patients with diabetes. *Current Medical Research and Opinion*. 2009;25(6):1413-20.
  29. Gonder-Frederick LA, Schmidt KM, et al. Psychometric properties of the Hypoglycemia Fear Survey-II for adults with type 1 diabetes. *Diabetes Care*. 2011;34(4):801-6.
  30. Davies M, Dempster M, et al. Do people with diabetes who need to talk want to talk? *Diabetic Medicine*. 2006;23(8):917-9.
  31. Lawton J, Rankin D, et al. Self-treating hypoglycaemia: a longitudinal qualitative investigation of the experiences and views of people with type 1 diabetes. *Diabetic Medicine*. 2013;30(2):209-15.
  32. Cox DJ, Gonder-Frederick L, et al. Blood glucose awareness training: what is it, where is it, and where is it going? *Diabetes Spectrum*. 2006;19(1):43-9.
  33. Abdelhafiz AH, Rodríguez-Mañas L, et al. Hypoglycemia in older people – a less well recognized risk factor for frailty. *Aging and Disease*. 2015;6(2):156.
  34. Singh H, Gonder-Frederick L, et al. Assessing hyperglycemia avoidance in people with type 1 diabetes. *Diabetes Management*. 2014;4(3):263-71.
  35. Olsen SE, Åsvold BO, et al. Hypoglycaemia symptoms and impaired awareness of hypoglycaemia in adults with type 1 diabetes: the association with diabetes duration. *Diabetic Medicine*. 2014;31(10):1210-7.
  36. Basco MR. Perfectionism and diabetes care. *Diabetes Spectrum*. 1998;11(1):263-271.
  37. Asimakopoulou KG, Fox C, et al. The impact of different time frames of risk communication on type 2 diabetes patients' understanding and memory for risk of coronary heart disease and stroke. *Diabetic Medicine*. 2008;25(7):811-7.
  38. Meltzer D, Egleston B. How patients with diabetes perceive their risk for major complications. *Effective Clinical Practice*. 2000;3(1):7-15.
  39. Hajos TRS, Polansky WH, et al. Do physicians understand Type 2 diabetes patients' perceptions of seriousness; the emotional impact and needs for care improvement? A cross-national survey. *Patient Education and Counseling*. 2011;85(2):258-63.