



Diabetes and Emotional Health

A Practical Guide for Health Professionals
Supporting Adults with Type 1 and Type 2 Diabetes



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Foreword

We are delighted to introduce *Diabetes and Emotional Health: A Practical Guide for Health Professionals Supporting Adults with Type 1 and Type 2 Diabetes*. This guide is a much-needed complement to the medical strategies offered by leading organizations worldwide, such as the *ADA Standards of Care*. Life with diabetes is complex and multi-faceted, and its management requires much more than medical treatment—it requires a whole-being approach.

As of the publication of this guide, there are over 34.2 million people living with diabetes in the United States, and 88 million more living with prediabetes. With those numbers growing, it is the commitment of the American Diabetes Association to create a life free of diabetes and all its burdens. While we aim to decrease the number of people developing diabetes, we are also committed to helping those living with diabetes thrive. Emotional health is a critical part of that commitment, since it is a contributing factor to both better diabetes clinical outcomes and overall quality of life. The scientific literature is clear regarding the negative predictive nature of poor emotional health, which is why we are thrilled that this valuable resource is available to professionals across the globe.

The toll associated with the consequences of diabetes affects more than just the person with diabetes. It is understandable that people, regardless of age and form of diabetes, often struggle to manage the ups and downs of blood glucose, personal advocacy, the financial cost of diabetes, emotions surrounding life with the disease, and overall quality of life. Connecting clinical and emotional care in diabetes is a necessary step in moving toward a more complete approach that focuses on the individual's journey with the condition and strives to help the person—and the family and caregivers surrounding them—thrive.

This guide has been developed from the *Diabetes and Emotional Health Handbook*, published by the National Diabetes Services Scheme in Australia and authored by a team of health professionals specializing in psychology and diabetes. It has been adapted for a U.S. audience by an equivalent expert group of U.S.-based clinicians and professionals. Throughout this guide you will find resources aimed at improving the overall knowledge of emotional health and strategies to best serve people with diabetes. We at the American Diabetes Association see this as a transformational moment in diabetes care. It is our hope that this book will become an indispensable tool for health professionals as they strive to help people with diabetes live their best life. The evidence is strong, and the need is great.

Dr. Robert Gabbay

Chief Medical and Scientific Officer,
American Diabetes Association

Dr. Nicole Johnson

Vice President, Operations in Science and Health Care,
American Diabetes Association

Author Biographies

Christel Hendrieckx, MSc, PhD

Christel is a Senior Research Fellow at The Australian Centre for Behavioural Research in Diabetes (ACBRD), a partnership for better health between Diabetes Victoria and Deakin University. She trained as a clinical psychologist at the Brussels Free University (Belgium). She has a PhD in psychology, awarded by Royal Holloway University of London, for her research on the psychological impact of screening for type 1 diabetes. Christel has been actively involved in both the clinical care of people with diabetes and research throughout her career, spanning over 30 years. Her key clinical and research interests focus on improving the emotional well-being of people with diabetes, on preventing severe hypoglycemia in people with type 1 diabetes, and evaluating the impact of new treatments and technologies on psychological outcomes.

Jennifer A. Halliday, BHlthSc (Hons)

Jennifer is an Associate Research Fellow at The Australian Centre for Behavioural Research in Diabetes. She has a Bachelor of Health Science with first class Honours from Deakin University. Her research focuses on the psychological well-being of adults with diabetes, as well as barriers and enablers to screening for emotional problems in routine diabetes care. Jennifer coordinated the National Diabetes Services Scheme Mental Health and Diabetes National Development Programme between 2013 and 2017.

Linda J. Beeney, PhD

Dr. Beeney is the Principal Investigator of the ReMinD Program (Researching Media in Diabetes) as a Senior Research Fellow with Sydney Medical School, The University of Sydney. She completed her undergraduate degree in psychology and her PhD in medicine at The University of Sydney. As an NHMRC Scholar, she was awarded an NHMRC Travelling Fellowship and completed a Post-doctoral Fellowship at Harvard Medical School. Dr. Beeney's current research is focused on experimental studies of diabetes language, analysis of media messages about diabetes and framing of complications risk communication, thanks to funding support from the ADEA Research Foundation, Medical Psychology Services, ACU and The University of the Sunshine Coast. Dr. Beeney has a thriving private practice as a Diabetes Psychologist and is the Director of Medical Psychology Services, a consultancy specializing in medical illness research and industry collaboration.

Jane Speight, PhD, CPsychol, AFBPsS

Jane is the Foundation Director of The Australian Centre for Behavioural Research in Diabetes, and holds the Chair in behavioral and social research in diabetes at Deakin University. She has a PhD in health psychology, awarded by Royal Holloway University of London, for her research on developing knowledge and quality of life measures for improving diabetes care. She is a chartered psychologist, awarded by the British Psychological Society (BPS), a Fellow of the BPS, and a Fellow of the Royal Society of Medicine (U.K.). Having specialized in the psychological aspects of diabetes for over 20 years, Jane leads a large and varied program of research in Australia, and maintains active collaborations in the UK and Denmark. Through her work, she aims to improve both the health and the quality of life of people with diabetes and encourage health professionals to better understand the impact of diabetes and its management from the individual's perspective. Since 2012, Jane has been the leader of the National Diabetes Services Scheme Mental Health and Diabetes National Priority Area (formerly National Development Programme).

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You can find the updated version of the Australian practical guide (2020), including the original Foreword, Acknowledgements, and Expert Reference Group at:

www.ndss.com.au/health-professionals-resources

Peer Reviewers

Name	Role and affiliation	Guide section reviewed
Martha Funnell	Associate Research Scientist in Department of Learning Health Science (University of Michigan Medical School) and Adjunct Lecturer of Nursing (University of Michigan)	Chapter 1
Jill Weissberg-Benchell	Pediatric Psychologist, The Pritzker Department of Psychiatry and Behavioral Health Professor of Psychiatry and Behavioral Sciences (Northwestern University Feinberg School of Medicine)	Chapter 2
Danielle Hessler	Associate Professor in the Department of Family and Community Medicine (University of California, San Francisco)	Chapter 3
Linda Gonder-Frederick	Clinical Director of the Behavioral Medicine Center, Licensed Psychologist, and Associate Professor, Department of Psychiatry and Neurobehavioral Sciences (University of Virginia Health System)	Chapter 4
William Polonsky	President of the Behavioral Diabetes Institute and Associate Clinical Professor in Psychiatry (University of California, San Diego)	Chapter 5
Mary de Groot	American Diabetes Association past President Health Care and Education, Associate Professor of Medicine and Acting Director of the Diabetes Translational Research Center (Indiana University)	Chapters 6 & 9
Ann Goebel-Fabbri	Assistant Professor of Psychiatry and Licensed Psychologist (Harvard Medical School)	Chapters 7 & 8
Douglas Tynan	Professor of Pediatrics, Sidney Kimmel Medical College (Thomas Jefferson University)	All materials

Acronyms and Abbreviations

7 A's	Aware, Ask, Assess, Advise, Assist, Assign, Arrange
A1C	Glycated Hemoglobin
ADA	American Diabetes Association
ADA MHPD	American Diabetes Association Mental Health Provider Directory
BMI	Body Mass Index
CAT	Crisis Assessment or Acute Treatment team
CBT	Cognitive Behavioral Therapy
CBT-E	Enhanced Cognitive Behavioral Therapy
DDS	Diabetes Distress Scale
DEPS-R	Diabetes Eating Problem Survey—Revised
DSMES	Diabetes Self-Management Education and Support
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
GAD-2	Generalized Anxiety Disorder (questionnaire); two-item version
GAD-7	Generalized Anxiety Disorder (questionnaire); seven-item version
HFS-II W	Hypoglycemia Fear Survey version two: Worry Scale
ICD-11	International Statistical Classification of Disease and Related Health Problems, tenth revision
ITAS	Insulin Treatment Appraisal Scale
IPT	Interpersonal Therapy
JDRF	Juvenile Diabetes Research Foundation
MHPN	Mental Health Professionals Network
MSCOFF	Modified SCOFF (questionnaire)
PAID	Problem Areas in Diabetes (scale)
PCP	Primary Care Provider
PHQ-2	Patient Health Questionnaire; two-item version
PHQ-9	Patient Health Questionnaire; nine-item version
SPIKES	Setting up, Perception, Invitation, Knowledge, Emotions, Strategy, and Summary
SSRIs	Selective Serotonin Re-uptake Inhibitors
WHO-5	World Health Organization Well-being Index Five (questionnaire)

“Diabetes clinic consultations often feel like a one-way street, it’s the professional telling you what you need to do and there’s not a lot of exploration of how difficult that may be for you or how worried you may be about it... they don’t necessarily explore with you how you are managing, within yourself. Being able to talk about these things makes you feel that the health professional is actually interested in you as a person and in your situation, it’s very empowering and validating... it makes you feel that it’s okay for you to have these concerns and anxieties and fears and feelings, that it’s actually normal and okay.”

—Person with type 1 diabetes

Introduction

Diabetes self-management is demanding and complex. Activities such as monitoring blood glucose, injecting insulin, taking oral medications, regular physical activity, and healthy eating all require a comprehensive understanding of diabetes, as well as healthy coping, and skills in problem-solving and risk reduction.¹ Diabetes is more than a physical health condition, it has behavioral, psychological, and social impacts, and demands high levels of self-efficacy, resilience, perceived control, and empowerment.² Thus, it is unsurprising that living with diabetes negatively affects the emotional well-being and quality of life of many people living with the condition.

Emotional and mental health problems (collectively referred to as “psychological problems” from here on), such as diabetes distress and depression, are common among adults with diabetes and are associated with suboptimal self-management, diabetes-related complications, reduced quality of life, and increased healthcare costs.³ As noted by Jones and colleagues: “maintaining or achieving good psychological well-being and quality of life is an important outcome of diabetes care in its own right.”⁴ This sentiment is shared by people with diabetes and health professionals, who recognize emotional health to be an important component of standard diabetes care.⁵⁻⁹

Why Is This Guide Needed?



We must move beyond the tendency to place an artificial divide between the emotional and the physical aspects of diabetes management that can lead to labeling the emotional aspects of diabetes a pathological condition. The two are so intertwined and interrelated that simply calling the emotional side a comorbidity is counterproductive.

—Lawrence Fisher, Jeffrey Gonzalez, and William Polonsky¹⁰

Given that separating psychological care from the context of diabetes self-management is rarely easy nor desirable, there is a strong argument that basic psychological care needs to be incorporated into diabetes care pathways, including assessment and treatment of the psychological problems frequently faced by people with diabetes.¹¹

American Diabetes Association and international guidelines reflect this view; recommending awareness and assessment of psychological problems in diabetes clinical practice (see **Box 1**).

Furthermore, mental health care for people with diabetes is recognized as a priority area in the “Psychosocial Care for People with Diabetes” position statement from the American Diabetes Association (**Appendix A**):

- › Psychosocial care should be integrated with collaborative, patient-centered medical care and provided to all people with diabetes, with the goals of optimizing health outcomes and health-related quality of life.
- › Providers should consider an assessment of symptoms of diabetes distress, depression, anxiety, and disordered eating and of cognitive capacities using patient-appropriate standardized/validated tools at the initial visit, at periodic intervals, and when there is a change in disease, treatment, or life circumstance.

—American Diabetes Association¹²

Despite the numerous guidelines, and recognition by health professionals and the American Diabetes Association, the emotional and mental health needs of people with diabetes are often undetected and unmet in clinical practice.^{13,14} Furthermore, there is little evidence to demonstrate significant progress in the implementation of such recommendations.^{15,16} Health professionals cite lack of skills, confidence, time, and limited access to practical resources as common barriers.¹⁷ While existing guidelines acknowledge the importance of psychological problems in diabetes and some make recommendations for assessing them, most fall short in providing guidance about how to incorporate this into the daily clinical practice setting. This guide is designed to complement and facilitate the implementation of existing guidelines (see **Box 1**).

The aim of this guide is to promote awareness of, and communication about, psychological problems affecting adults with diabetes. The objectives are to:

- › raise awareness among health professionals of the prevalence and consequences of psychological problems among adults with diabetes

- › provide a set of practice points for how to identify, communicate about, and address psychological problems with adults with diabetes in clinical practice
- › foster skills development among health professionals for communicating about psychological problems in diabetes care by providing examples of questions and responses, with case studies to demonstrate their implementation
- › and provide the practical tools (e.g., questionnaires, information leaflets, and other resources) to support health professionals in this endeavor.

What Does this Guide Offer?



I'm really excited... it's really important and if any health professional reads even any chapter of [the guide], I think they'll come away with a lot more depth and understanding of what it's like to live with diabetes.

— Person with diabetes^a

This guide is an evidence-based, clinically informed, practical resource to support health professionals in meeting the emotional and mental health needs of adults with diabetes. While the handbook is informed by evidence, it is not an evidence-based guideline. An early decision of the National Diabetes Services Scheme (NDSS) Mental Health and Diabetes National Development Program's Expert Reference Group in Australia, which first developed this guide, was that developing new guidelines would require several systematic reviews, which are time-consuming and resource intensive. Furthermore, as recommendations for routine monitoring of emotional well-being have existed in guidelines for more than 20 years,¹⁸ there is little evidence that producing yet another guideline would benefit people with diabetes.

This practical guide was originally authored by a team with expertise in psychology and diabetes (see page iii). Their work was overseen by a multidisciplinary Expert Reference Group. The guide was also peer-reviewed by academic and clinical experts with relevant expertise, and by end users (people with diabetes and health professionals). To adapt the guide for a local audience, the American Diabetes Association engaged a team of

reviewers to ensure the material was appropriate for the healthcare system, cultures, and values of the U.S. We acknowledge those involved on page iv.

Who Should Use This Guide?

This guide is expected to support health professionals working with adults with type 1 or type 2 diabetes.^b

Such health professionals include primary care providers (PCPs), certified diabetes educators, nurses, dietitians, endocrinologists, and other health professionals supporting adults with diabetes. Mental health professionals including psychologists, psychiatrists, mental health nurses, and social workers may also find this practical guide to be a useful resource.

Thus, this guide has been written in a general format that can be adapted to individual needs and circumstances, and it can be used in many ways, depending on your level of knowledge, expertise, setting, and available time.

Information about how to use this guide is included on pages xiii to xvii.

What Is the Scope of the Guide?

The practice points in this guide have been developed for use specifically with adults with type 1 or type 2 diabetes, and adapted for the context of the American healthcare setting.

The scope of this guide does not extend to:

- › Children and adolescents with type 1 or type 2 diabetes, as the advice may not be appropriate to their developmental stage.
- › Adults with other types of diabetes (e.g., gestational, MODY, LADA). It may be appropriate to apply parts of this guide, but we advise you to use your professional judgement before doing so.
- › People with language, cultural, cognitive, health literacy, or other barriers. It is beyond the scope of this guide to provide specific recommendations for each of these diverse groups, and for many groups the evidence base relating to mental health and diabetes is sparse. Where relevant resources exist for special populations, these are noted in the chapter. In the absence of evidence specific to particular groups, it may be reasonable to extrapolate from this guide and use your professional judgement.

a Participant of the stakeholder consultation for this guide during its development in 2015.

b In many instances it is appropriate to refer to type 1 and type 2 diabetes separately. However, for readability purposes, and because research studies often do not separate the two types, we refer to people with diabetes collectively in many parts of the guide. Where a research study has definitively specified the type of diabetes, we have also made the distinction.

BOX 1 What Do National and International Guidelines Say about Emotional and Mental Health?

Guidelines for both type 1 and type 2 diabetes clinical care

“Consider assessment for symptoms of diabetes distress, depression, anxiety, disordered eating, and cognitive capacities using patient-appropriate standardized and validated tools at the initial visit, at periodic intervals, and where there is a change in disease, treatment, or life circumstance.”

“Routinely monitor people with diabetes for diabetes distress, particularly when treatment targets are not met and/or at the onset of diabetes complications.”

“Psychosocial care should be integrated with a collaborative, patient-centered approach and provided to all people with diabetes, with the goals of optimizing health outcomes and health-related quality of life.”

—American Diabetes Association, 2019¹⁹

“Screening for depression should be performed routinely for adults with diabetes because untreated depression can have serious clinical implications for patients with diabetes.”

“Patients with depression should be referred to mental health professionals who are members of the diabetes care team.”

—American Association of Clinical Endocrinologists and American College of Endocrinology, 2015²⁰

“Individuals with diabetes should be regularly screened for subclinical psychological distress and psychiatric disorders (e.g., depressive and anxiety disorders) by interview or with a standardized questionnaire.”

“Psychosocial interventions should be integrated into diabetes care plans.”

—Canadian Diabetes Association, 2018²¹

“People with diabetes are checked for psychological problems (such as depression, anxiety, fear of low blood sugar, eating disorders, and problems coping with the diagnosis) and any problems identified are properly managed... Treatment and care should take into account a patient’s needs and preferences.”

—U.K. National Institute for Health and Care Excellence, 2011²²

“Regular assessment of a broad range of psychological and behavioral problems in... adults with type 1 diabetes is recommended... this should include anxiety, depression, and eating disorders.”

“...refer those with significant psychological problems to services or colleagues with expertise in this area.”

—Scottish Intercollegiate Guidelines Network, 2017²³

Guidelines for type 1 diabetes clinical care only

“Clinicians should be aware that the co-occurrence of psychological disorders in type 1 diabetes is common... Consider the co-occurrence of psychological disorders, including clinical and subthreshold eating disorders, when assessing people with type 1 diabetes and suboptimal glycemic control, insulin omission, disordered eating behaviors, unexplained weight loss, or recurrent admissions for diabetic ketoacidosis.”

“Diabetes care teams should have appropriate access to mental health professionals to support them in 1) the assessment of psychological functioning [and] 2) the delivery of psychological support.”

—Australian Pediatric Endocrine Group and Australian Diabetes Society, 2011²⁴

Guidelines for type 2 diabetes clinical care only

“Annually: patients with diabetes can be assessed for mental health issues, social isolation/networks, and family or work stress. Consider assessment of diabetes distress through the use of the PAID questionnaire and depression with the Patient Health Questionnaire-2 (PHQ-2). Enquire about possible diabetes complications as well as known comorbid conditions including psychological stress and/or depression.”

—Royal Australian College of General Practitioners, 2014²⁵

“Explore the social situation, attitudes, beliefs, and worries related to diabetes and self-care issues. Assess well-being (including mood and diabetes distress) periodically by questioning or validated measures (e.g., WHO-5). Discuss the outcomes and clinical implications with the person with diabetes and communicate findings to other team members where appropriate.”

“Counsel the person with diabetes in the context of ongoing diabetes education and care. Refer to a mental health-care professional with a knowledge of diabetes when indicated.”

—International Diabetes Federation, 2014²⁶

Guidelines for type 2 diabetes clinical care (of older adults only)

“Screening for and monitoring of depressive symptoms in older people with diabetes should be performed at diagnosis, be an integral part of standard diabetes care, and be part of the annual review.”

—International Diabetes Federation, 2013²⁷

Furthermore, we emphasize the importance of tailoring your approach to the needs of the person—this applies to all people with diabetes, not just those from diverse groups. Throughout this guide, we make suggestions for words you might say or strategies you might use to address psychological problems. Be guided by the suggestions but avoid using them as a checklist. Reflect upon how relevant the suggestion is for each individual, and tailor your approach to their priorities and preferences.

What Are the Expected Outcomes of the Guide?

The overall purpose of this guide (and related toolkit) is to enhance opportunities for people with diabetes to talk about their emotional well-being with their health professionals and, if problems are present, to identify and address these. This conversation informs a shared decision about appropriate management strategies. It is an important and positive step toward holistic healthcare. We expect the following outcomes:

- Health professionals will feel supported, confident, and skilled to:
 - “have the conversation” about emotional and mental health generally or, specifically, how diabetes is affecting the person’s emotional well-being
 - address psychological problems that are within their skillset and authority
 - and make referrals to specialist care providers, as needed.
- People with diabetes will appreciate that their health professionals ask how diabetes is affecting their emotional well-being, and that they are offered support to address identified psychological problems.
- Health professionals and health services will approach psychological problems in diabetes in a consistent and systematic way.
- Emotional and mental health will be integrated into routine diabetes consultations as part of “usual care.”
- People with diabetes will be active participants in a person-centered approach to care for their psychological problems.

Organizational Culture and Considerations

This guide focuses on the skills and resources of the individual health professional, but most work in teams

rather than in isolation. We recognize that the service, practice, or department you work in may influence your capacity to implement the practices recommended in this guide. However:



Change will not come if we wait for some other person or some other time. We are the ones we’ve been waiting for. We are the change that we seek.

—Barack Obama

You can be the agent of change in your healthcare setting by implementing the following actions to promote holistic care:

- Model the behaviors you would like to see in others; you can be an example to others in your service, practice, or department by demonstrating that psychological problems are at least as important as other aspects of diabetes care.
- Ensure all staff have a copy or access to this guide and related toolkit.
- Provide opportunities for all staff to enhance their communication skills using a person-centered approach.
- Arrange ongoing training for staff relating to psychological problems and diabetes.
- Actively support supervision and mentoring to build skills in addressing psychological problems in people with diabetes.
- Support junior staff to observe discussions about psychological problems and diabetes, and help them review and reflect on the care they provide.
- Consider having an appropriate member of your team join the American Diabetes Association Mental Health Provider Directory (ADA MHPD)^c—and identify specialists in that network who can support you in providing holistic care.
- Incorporate a holistic approach to diabetes care in:
 - staff position descriptions
 - staff induction programs
 - and staff performance reviews.

c The ADA MHPD brings together mental health professionals working in the diabetes care sectors to discuss how to better support people with co-existing diabetes and psychological problems. Virtual monthly meetings feature guest speaker presentations, case study discussions and networking opportunities. For more information, visit: https://professional.diabetes.org/mhp_listing

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How to Use this Guide

The Practical Guide

This guide includes information about emotional problems that may be experienced by adults with diabetes. Designed for health professionals working with people with diabetes, it offers strategies and tools for how to recognize and have conversations about emotional problems, as well as for providing appropriate support.

There are nine chapters:

- › **Chapter 1:** Communication and engagement
- › **Chapter 2:** Facing life with diabetes
- › **Chapters 3–8:** each focuses on an emotional problem experienced by adults with diabetes
- › **Chapter 9:** Referring to a mental health professional

There are four appendices:

- › **Appendix A:** American Diabetes Association’s position statement on psychosocial care
- › **Appendix B:** Peer support
- › **Appendix C:** Examples of strategies to address diabetes distress
- › **Appendix D:** Examples of strategies for overcoming psychological barriers to insulin use.

This guide has been written with a multidisciplinary audience in mind. Therefore, the format has been

developed for the reader to use according to their own needs, knowledge, expertise, setting, and available time. You may choose to:

- › read the guide from cover to cover, to gain an in-depth understanding
- › read the key messages and practice points, then read the relevant detailed sections in the guide as you need them
- › or dip in-and-out of the specific chapters on a need-to-know basis.

For further information about the guide, including the aims and objectives, scope, and expected outcomes, refer to the Introduction on page vii.

Structure of Chapters

Chapters 1 and 2 provide background information on communication and engagement, as well as on the experience of diagnosis and how the health professional can best support a person at this time.

As Chapters 3 to 8 focus on specific emotional problems, they are all presented in a similar structure to make it easier for you to navigate the content and find the information you need. This common format is explained on pages xiv–xvi.

Boxes and symbols are used throughout (see below).

Boxes and Symbols

Shaded boxes contain additional information that is relevant but not “key” to the topic.

Important information is highlighted by the use of symbols.

BOX 3.2 Taking a Safe Break from Diabetes

It is unrealistic to expect people with diabetes to monitor their health vigilantly 24 hours a day, seven days a week.








An “exclamation mark” symbol indicates a key practice point.



A “note” symbol draws attention to specific points not to be overlooked.



Quote

<p>Key Messages and Practice Points</p> <p>Each chapter begins with a summary of the core content of the chapter. This is accompanied by “practice points,” offering applied advice for health professionals to consider.</p>	<hr/>  Key Messages <hr/>  Practice Points
<p>How Common...?</p> <p>An estimate of how common the emotional health problem is among people with diabetes.</p> <p>The symbols indicate an approximate proportion of people with diabetes who might be expected to be experiencing the emotional problem (e.g., one in five adults with insulin-treated type 2 diabetes experience diabetes distress).</p> <p>Underneath the symbols are descriptions of the population to whom the statistic applies. Typically, this refers to three groups: people with type 1 diabetes, people with type 2 diabetes who use insulin, and people with type 2 diabetes who do not use insulin.</p> <p>These estimates are based on the best evidence available. Keep in mind that your own clinic population may vary from the study population in terms of demographic and clinical characteristics. This information is intended as a guide only.</p>	<hr/> <p>How Common Is Fear of Hypoglycemia?</p>  <p>Type 1 diabetes</p> <hr/>
<p>What Is...?</p> <p>Background information about the emotional health problem and its consequences.</p>	 WHAT IS Diabetes Distress?
<p>How Can I Identify...?</p> <p>These are the signs to look for, “open-ended questions” to ask, and information about how to use validated questionnaires as part of your routine clinical consultation.</p> <p>It describes the first three of the 7 A’s (see page xvi): Be AWARE, ASK, and ASSESS.</p>	 HOW CAN I IDENTIFY Diabetes Distress? <ul style="list-style-type: none"> ■ Be AWARE ■ ASK ■ ASSESS

How Can I Support...?

Strategies and actions to support people with diabetes who are experiencing emotional health problems and referral options.

It describes the final four of the 7 A's (see page xvi): **ADVISE**, **ASSIST**, **ASSIGN**, and **ARRANGE**.



HOW CAN I SUPPORT a person with Depression?

- **ADVISE**
- **ASSIST**
- **ASSIGN**
- **ARRANGE**

Case Studies

Examples of how the 7 A's model can be applied in clinical practice. Keep in mind that they are illustrative; they are not applicable to, nor representative of, every person or circumstance. In each case, the content is a snapshot of a conversation, for example, to demonstrate how to ask questions or introduce the use of a questionnaire.

The characters in the case studies are fictional, though the content of their stories have been inspired by clinical practice.



CASE STUDY

Anna

62-year-old woman, living with her husband
Type 2 diabetes for 10 years; overweight
Oral medications for diabetes, high blood pressure, and high cholesterol
Health professional: Dr. Andrew Sutter (PCP)

Questionnaires

If a validated questionnaire is described in the **ASSESS** section, it is provided with brief guidance for scoring and interpretation.

Questionnaire: Problem Areas In Diabetes (PAID) Scale

Instructions: Which of the following diabetes issues are **currently** a problem for you? Tick the box that gives the best answer for you. Please provide an answer for each question.

	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
1 Not having clear and concrete goals for your diabetes care	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2 Feeling discouraged with your diabetes treatment plan?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3 Feeling scared when you think about living with diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4 Uncomfortable social situations related to your diabetes care (e.g. people telling you what to eat)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5 Feelings of deprivation regarding food and meals?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6 Feeling depressed when you think about living with diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Resources

Lists of key resources are included for:

- > health professionals (e.g., books, peer-reviewed articles, and guidelines)
- > and people with diabetes (e.g., support services, websites, and information leaflets).

Resources

For Health Professionals

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.

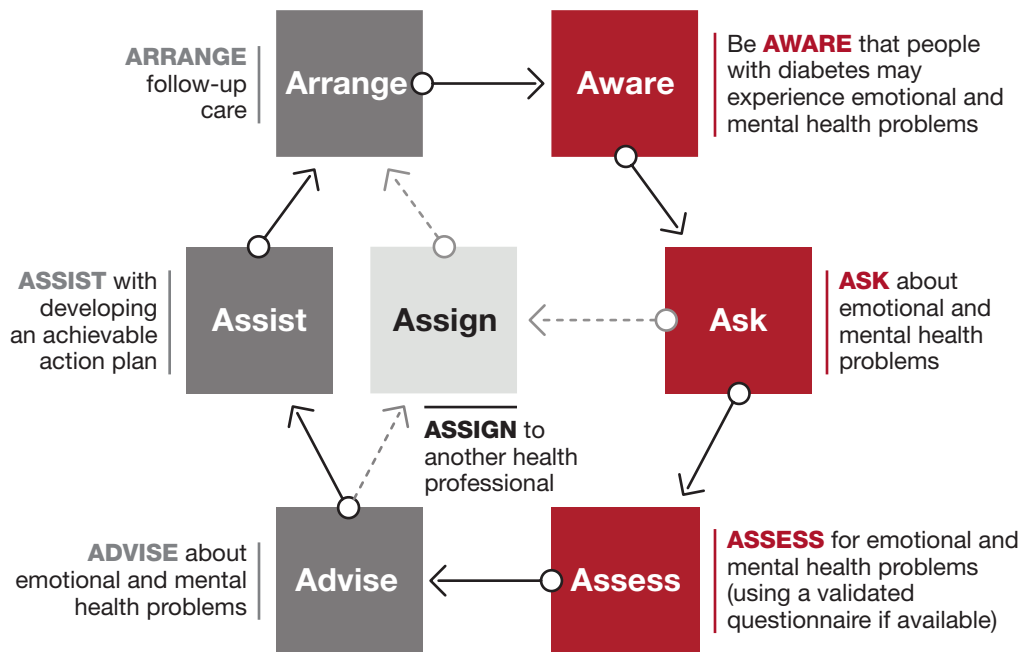
References

The reference list includes all evidence cited in each chapter.

References

1. American Association of Diabetes Educators. AADE7 self-care behaviors. *Diabetes Educator*. 2008;34(3):445-9.

7 A's Model



A key feature of the guide is a practical 7 A's model (see above). This dynamic model describes a seven-step process that can be applied in clinical practice as part of a person-centered approach. This model is adapted from the 5 A's model.^{1,2}

The original model included: "Ask," "Assess," "Advise," "Assist," and "Arrange." Our additions to the model, "be Aware" and "Assign," reflect the need for vigilance about emotional distress and the potential need for referrals to specialists.

The 7 A's model provides a consistent structure for Chapters 3 to 8. This part of the chapter starts with an image of the model, followed by two sections: "How can I identify...?" and "How can I support...?" (see below).

Within each section, the sub-headings refer to one step of the 7 A's (e.g., **Be AWARE**, **ASK**), providing guidance about how to apply each of the steps within a clinical setting. The steps have been color-coded to facilitate ease of use.

The model is designed to be flexible and dynamic. When applying the model in clinical practice, health professionals need to take into account their own characteristics (e.g., their role, qualifications, and skills) and the context (e.g., the needs and preferences of the person with diabetes, the severity of the problem, the setting, and resources).

The arrows around the perimeter of the circle show the path that a health professional can follow if they are the appropriate person to undertake all seven steps themselves.

The dotted arrows through the middle of the circle show places where the health professional may diverge from the main path, for example by **ASSIGNING** to another health professional because they do not have the necessary skills (or confidence) to undertake all of the step themselves.

The Practical Guide Toolkit

A toolkit has been developed to complement the guide and contains practical resources for health professionals to support people with diabetes. This material can be accessed at <https://professional.diabetes.org/meetings/mentalhealthworkbook>.

The 7 A's Model Summary Cards

“Quick reference” cards for easy access. Using the 7 A's model, each card provides a summary of an emotional health problem: how to recognize it and how to support the person experiencing it.

Information Handouts (for People with Diabetes)

Each handout focuses on a specific psychological problem, corresponding with the guide chapters. The handouts include tips and resources that people with diabetes may find helpful.

They can be used in various ways:

- keep copies in your clinic waiting room where people with diabetes can access them easily
- use a copy to facilitate a conversation about emotional health
- or give a copy to the person to take home with them after having a conversation about an emotional health problem.

Questionnaires

Master copies of the questionnaires referred to in the practical guide are provided so that you can reproduce them for use in your routine clinical practice.

References

1. Fiore M, Jaén C, et al. Treating tobacco use and dependence: 2008 update. Rockville (MD): 2008.
2. The Royal Australian College of General Practitioners (RACGP). Smoking, nutrition, alcohol and physical activity (SNAP): a population health guide to behavioural risk factors in general practice. South Melbourne, VIC, Australia: 2004

Chapter 1

Communication and Engagement



Key Messages

- People with diabetes want supportive health professionals with whom they can discuss any aspect of living with and managing the condition.
- An open, empathic communication style is important in enabling people with diabetes to talk about their emotional and mental health.
- The language that health professionals use can affect people’s willingness to talk about the challenges of living with diabetes, their motivation, self-confidence, self-management skills, and diabetes outcomes.
- As with any skill, communication skills can be acquired and improved with practice, and confidence increases over time.



Practice Points

- Seek to “meet the person” where they are in their life—rather than where you would like them to be, where you think they should be, or where you are.
- Active listening and open, empathic communication (verbal and nonverbal) improves the quality of the interaction and is essential for best clinical practice.
- Reflect on the proportion of the appointment time that you spend talking rather than listening. Is the balance right? Appointments are typically more effective when the person with diabetes talks more than the health professional.

Talking about Emotional Health Is an Essential Part of Diabetes Appointments



The great enemy of communication, we find, is the illusion of it.

—William H. Whyte¹

Arguably, the fundamental skills in any healthcare visit are communication and engagement. These are essential tools that health professionals use every day—to gather information, establish the problem/diagnosis, discuss options, and agree on an action plan. These skills are relevant no matter whether the issue is physical or emotional.

The most obvious reason for being attentive to emotions and mental health is to recognize the person's need for support. This is true in relation to general psychological distress, such as depression and anxiety, but also to the emotional impact of living with diabetes. Having a conversation about how diabetes affects the person's emotional health can help them feel that someone understands their perspective and is “on their side.” For example, they may no longer feel isolated by feelings of guilt and frustration about getting “off-track” with their diabetes management. This change can be very powerful because the way a person feels about their diabetes can have a significant impact on their motivation and ability to manage it.



Patients have their agenda... [and if that's] not dealt with they cannot move on. Anything I say or recommend will not be taken in if the patient's issues are not dealt with first.

—Practice nurse²

Health professionals can assist people with diabetes to develop or strengthen their skills and confidence for effective self-management—but first a conversation is needed to establish what challenges the person is facing, and how to assist the person to overcome them. However, this conversation is not (yet) part of routine practice.

Numerous studies demonstrate that people with diabetes want support with the psychosocial aspects of diabetes.³⁻⁷ Yet, distress related to living with diabetes is

not often acknowledged by health professionals.⁸ While half of health professionals report asking their patients with diabetes about emotional issues,⁹ only one quarter of people with diabetes report that a health professional has asked such questions of them.¹⁰ Why might this be the case?

Perhaps the person with diabetes is not expecting emotional issues to be discussed during that visit. Or, perhaps, health professionals are not asking the right questions, or not allowing time for the person to offer a considered response that actually reflects how they feel about living with diabetes.

Research shows that the person's agenda is elicited in just 36% of clinical encounters – more so in primary care (49%) than in specialist care (20%).¹¹ Health professionals interrupt the person within an average of just 11 seconds, typically with statements or ‘closed questions’ (see **Box 1.1**). This further reduces the opportunity to orient the clinical encounter towards the priorities of the person.¹¹

Seeking to understand the individual's priorities, preferences, and everyday challenges will enable you, together with the person, to establish a management plan that is achievable and reflects their life or well-being. Indeed, having the conversation may help you realize that the person needs more help than you can provide—for example, from a diabetes educator, endocrinologist, or a mental health professional.

To achieve this, using an open, empathic communication style (see **Box 1.1**) can create a safe and supportive environment, build rapport, and engage the person.



A systematic review found high continuity of care is associated with lower mortality rates.¹² The authors could only speculate about why this might be, but suggested that trust and open communication leads to greater disclosures and better tailoring of care to the person's needs, with a greater likelihood of optimal self-care and taking medications as recommended.

BOX 1.1 Open and Closed Communication Styles

People with diabetes seek out health professionals as much for their personal communication skills and interaction style (e.g., care and empathy) as for their clinical expertise.

As demonstrated in the table below, the immediate outcome of **open, empathic communication** is an honest exchange of ideas and challenges.¹³ Indeed, this may be the only tangible effect that the health professional is aware of—but it is likely to lead to other benefits.

In contrast, the immediate outcome of **closed, directive communication** is stereotypically brief, in which the person with diabetes leaves with a prescription, some pamphlets, or a referral. At face value, this may appear both effective and efficient. However, the person may have queries and concerns that affect their outcomes and matter to them, which they did not raise; they may leave the appointment with misunderstandings and mistrust. Importantly, they may also feel that they have not been “heard.”

Other potential consequences of these distinctly different communication styles are summarized below. In the longer term, these can translate into consequences for health (and healthcare costs), as well as quality and quantity of life.

Outcomes of open, empathic communication:	Outcomes of closed, directive communication:
› increased trust in the health professional	› mistrust and lack of confidence in the health professional; desire to change care provider
› increased knowledge, confidence/self-efficacy	› not seeking further care, lack of confidence
› increased engagement in decision-making/ collaborative decision-making/better decisions	› lack of engagement in decision-making (wasted efforts and opportunities)
› increase in coping skills to overcome daily challenges (proactive coping)	› increased reliance on health professional directives
› increased motivation	› decreased motivation
› personal care plan	› general care plans
› increased engagement with self-care activities (e.g., medication taking)	› at best, passive “compliance”; at worst, active disregard of health professional’s advice and recommendations
› increased satisfaction with the health professional/system	› increased complaints and negligence claims
› realistic expectations (for both parties)	› unrealistic expectations (by both parties)
› and reduced errors/mistakes (e.g., in prescribing or taking medication).	› and misunderstandings and misinterpretation of advice/ recommendations.

Enhancing Your Communication Skills



Communication is a skill that you can learn. It’s like riding a bicycle or typing. If you’re willing to work at it, you can rapidly improve the quality of every part of your life.

—Brian Tracy¹⁴

As a health professional, you bring considerable experience and a certain perspective to your interactions. So, too, does each person with diabetes—

they bring their life experience and their awareness of how diabetes does or doesn’t fit into their life.

Having a conversation about the emotional aspects of living with diabetes can be challenging. Many of the general techniques for effective communication (see **Box 1.2**) are applicable but, like any other skill, they are not necessarily intuitive. It takes time and practice to develop, and they can always be improved, but anyone can learn these skills and the community will notice the difference.^{15,16} Take this opportunity to reflect on how you incorporate these general techniques into your appointments.

BOX 1.2 The ABC's of Effective Communication

Active listening	<ul style="list-style-type: none"> ➤ Active listening is a fundamental communication technique that includes a range of verbal and nonverbal skills. ➤ Listen to what the person says AND how they say it (hesitations, timing, emotion, etc.). ➤ Demonstrate that you are paying attention by nodding your head, adopting a forward leaning posture, and using verbal facilitators, such as “<i>go on...</i>,” “<i>uh huh...</i>” ➤ Avoid interrupting too quickly—some health professionals worry that the person will keep talking for several minutes, but in reality, people tend to only talk for about two minutes (on average).
Body language	<ul style="list-style-type: none"> ➤ Look for signs that someone is not doing OK, despite what they may be saying verbally. ➤ Observe the person’s nonverbal communications (i.e., facial expressions, body language) and any inconsistencies between their verbal and nonverbal communications. ➤ Keep in mind cultural variations (e.g., eye contact is not appropriate in all cultures). What is their body language telling you? ➤ What is your body language saying about you? Maintain eye contact, if appropriate, and avoid being distracted by the computer or telephone. Be aware of crossed arms or legs (which can appear unwelcoming and even judgmental).
Clarify information and paraphrase	<ul style="list-style-type: none"> ➤ Reflecting and paraphrasing are important techniques to acknowledge that you have been listening to the person and to make sure you have understood. ➤ Repeating some of the person’s own words back to them (reflecting) as a question can help to prompt further detail. Doing this with a deliberate pause and invitation to say more can encourage them to continue their conversation. For example, “<i>You said it has been very hard to [...]?</i>” ➤ Paraphrasing means capturing the meaning in your own words: place the onus of understanding on yourself. For example, “<i>So I can be sure I’ve got this right, you are saying that [...]. Is that right?</i>” ➤ Similarly, encourage the person to ask you questions, and check their understanding by asking them to paraphrase what you have just said. For example, “<i>I want to check that I’ve explained this clearly, so can you please tell me in your own words</i>” If your message has not been understood, explain it again in a different way. ➤ Repeat key information (in different ways, if necessary).
Develop rapport	<ul style="list-style-type: none"> ➤ Most people with diabetes want someone on their side, someone who can help and support their self-management efforts, rather than someone who tells them what to do or criticizes them. ➤ Use motivational, collaborative language to appreciate the efforts the person makes and gain their confidence. For example, “<i>I can see how hard you have been working on your [blood glucose/activity levels/weight] since we last met.</i>” ➤ Keep a good balance to the conversation; ideally, the person with diabetes should be talking as much as (if not more than) you. ➤ Build trust through repeated appointments and interactions.

Explain clearly	<ul style="list-style-type: none"> › Use plain language—avoid jargon, acronyms, or shorthand without explanation. › Provide information in writing that is appropriate to the audience—use plain English, dot points, and short sentences, and consider readability design principles (e.g., large font size). › Use diagrams, pictures, or models, where appropriate. › Anecdotes and storytelling can be useful for explaining difficult concepts. Or, you may have visual aids or culturally appropriate or translated resources that you can use to improve the explanation.
Feedback	<ul style="list-style-type: none"> › Ensure the person has ample opportunity to tell you how they feel about your advice/ the action plan, and how realistic it is for them. For example, <i>“We talked about doing blood glucose checks before every meal. How do you feel about giving this a try in the next few weeks?”</i> › Also, ask for feedback about your service. This can be done routinely and anonymously. It will be enlightening.
Give clear signals	<ul style="list-style-type: none"> › Set up expectations at the start of the appointment (e.g., how much time is available, what will happen at the end, and what will happen next time). › Let the person know (by signposting) that you need to move onto another issue or to draw the appointment to a close. › It is important that the person does not feel dismissed or irrelevant. If the issue they are concerned with needs further discussion, arrange for them to return another day when there will be more time. › If you are referring the person to another health professional, let them know why you are doing this and make sure they feel comfortable with it.
Hear the sound of silence	<ul style="list-style-type: none"> › Don't feel obligated to fill every pause with questions or advice. › Silence allows the person time to gather their thoughts and express themselves. › If a pause becomes too long, ask what they are thinking about. › Remember that the person's body language will offer clues.
In conclusion	<ul style="list-style-type: none"> › Summarize the main issues at the end of the appointment, including action plans, to make sure there is mutual understanding of what has taken place and how to move forward. › Offer an early follow-up appointment to demonstrate that you are interested in continuing the conversation and finding out what happens when they try their action plan.

Having a Conversation about Diabetes and Emotional Health



I try to put patients at ease, be affirmative and responsive.... I hope to improve my skills for the areas where I don't feel comfortable.

—Practice nurse²

I'm confident and comfortable with bringing out the issues and giving the patient the space to discuss these, but I don't know what to do next.

—Diabetologist²

It is not always easy to know how to begin a conversation about emotions. Similarly, it can be difficult to know what to say when someone expresses their distress or shares that they are not coping well with their diabetes. You can help by asking **open-ended questions**, which enable the person to respond by describing their experience, thoughts, or feelings about a particular issue, rather than with simple “yes” or “no” answers. Creating an empathic and supportive environment will be conducive to having conversations about the emotional aspects of diabetes.^{11,17}

Start the Conversation

Begin the conversation with an opening comment to **build trust and rapport** (e.g., normalizing statement, or referring to a previous conversation/visit), such as:

- › *“Some people talk to me about how their diabetes affects how they feel, and that they don't always find it easy to live with this condition.”*
- › *“Over the past couple of months we have been working together to get your diabetes management on track. How has this been for you? Is there anything you've found particularly challenging that you'd like to talk about?”*

Ask **open-ended questions**, to show the person that you are interested in their experiences. Open-ended questions allow for longer responses and more detail, they require more than just a brief, one-word response (e.g., “yes,” “no,” or, “OK”). For example:

- › *“What brought you here today?”*
- › *“Tell me, how are you doing with [aspect of diabetes management]?”*
- › *“You've been [using medication] for about [a month now]. Tell me how that has been going.”*

- › *“You've had diabetes for [a year] now. What is going well for you? What is the most challenging for you?”*
- › *“What thoughts do you have about why that keeps happening?”*
- › *“How does that make you feel?”*

Normalize the issues raised by the person, by helping them to view their experience as common, “natural,” or “human.” For example:

- › *“That's understandable. You know, many people with diabetes feel that way, too.”*
- › *“This seems to be a normal reaction to struggling with this.”¹⁸*

Normalizing helps:

- › the person to disclose an experience, thought, or feeling that may be very sensitive for them
- › to see that they are not alone in experiencing certain feelings or thoughts, and this can enhance their sense of self-esteem
- › to reduce secondary emotional reactions, such as feeling anxious about revealing that they fear, for example, hypoglycemia, or that they feel guilty about not coping well with diabetes
- › and the person to feel they can confide in you.^{17,19}

Continue the Conversation

Afford the person time to share their experience (without interruption, question, or judgment). This makes it more likely that you will identify the issues of concern. You have earned their initial trust, but you have to retain it.

Be prepared for the response. How will you interpret the person's response and what actions will you take next? There are myriad questions you could ask, and there are many ways in which the person can respond. **Box 1.3** offers some examples of responses that you may want to consider. Attempts by you to redirect the questioning to elicit an honest response need to be handled sensitively. Refer above to “normalize the issues”—did you do enough to put the person at ease to share openly and honestly with you? The person may not be ready to discuss the matter with you now, so offer them the option to talk about it another time. Or, perhaps they do not feel comfortable discussing it with you (e.g., for personal or cultural reasons). In this case, offer the person an opportunity to discuss the matter with another health professional who may be more acceptable to them (e.g., someone they feel they can trust more or a person of the same sex or cultural background).

Be prepared for what to do next. What can or will you do if you discover, from open-ended questions or from a questionnaire, that the person is not OK? What resources are available to you and to the person with diabetes? First, you have this practical guide. Each chapter will guide you through the options relevant to the particular types of emotional or mental health issues you may identify. At the end of each chapter, there is a list of relevant resources and further reading (both for you and for you to recommend to the person with diabetes).

Accompanying this practical guide is a series of handouts, which cover the same topics as **Chapters 2–8** and **Appendix B**. You can give these handouts to the person with diabetes—they are designed to help them understand the issues they are facing and what help is available to them. These materials can be accessed at <https://professional.diabetes.org/meetings/mentalhealthworkbook>.

Close the Conversation

Finally, how you **close the conversation** is just as important as how you open it.

Acknowledge the confidence that the person has shared with you. For example, *“Thank you for sharing that with me today [I can see it has been difficult for you]. I hope it has helped you. Would it be a good idea to talk about this some more at your next visit?”*

A general closing might be to invite the person to consider what they would like to talk about next time, and agree to put it as the first item on the agenda of the next appointment. You could offer a list of possible topics, including emotional health issues for them to choose, if they want such a prompt.

BOX 1.3 Be Prepared for the Response

Here are some practical tips about what to do in various scenarios, for example, if the person:

- › **Does not reply immediately to a question.** We often feel awkward when conversation is not free flowing, and we feel a need to fill silences. However, it is OK to give the person an attentive look (not a stare) and allow some time for them to gather their thoughts. Then, acknowledge their reluctance and gently prompt with *“take your time.”* Ask if it is OK to ask another question or if they would like to ask you something instead.
- › **Responds with “no” or “nothing.”** Ask if they would like to add anything more. Acknowledge that the question may have been irrelevant. Ask, *“What would be useful for us to talk about?”*
- › **Stops talking.** Periods of silence are OK. They can help the person gather their thoughts and express their emotions. You may feel concerned that the silence will go on too long, but most people will break the silence within two minutes.
- › **Starts crying.** Let them see that you accept their emotions and tell them, *“It’s OK to feel this way,”* or *“I can see how upsetting this is for you.”* Do not try to reassure the person with words like *“It will be alright, you’ll see”*—this is not necessarily helpful or true.

- › **Becomes extremely distressed.** In times of extreme emotional distress, nonverbal support (e.g., sitting alongside someone and creating a calm environment) can often speak louder than words. Do you need to arrange an urgent referral to another health professional?

It is unlikely that the person will be able to take in or recall much of what you are saying because they are experiencing strong emotions. Could you provide some written information for them to take home? Would they like to bring a friend or family member to provide support and take notes at the next appointment?

- › **Seems to need more time than you have available in this appointment.** Proactively, you can set the time at the beginning. For example, *“We have about 15 minutes today to discuss these issues; what we don’t finish today, we can discuss next time.”* If time is becoming an issue during the appointment, acknowledge this. For example, *“Your feelings seem overwhelming at the moment, is that right? We have about [10] minutes left. What can we do in this time together that would help you most at the moment?”* This is a better strategy than moving onto something that you think will be quicker.

Overcoming Barriers to Talk about Emotional Health in Diabetes



[I was] uncertain of the correct advice to give—and worried in case the patient became aware of my own discomfort.

—Diabetes specialist nurse²

I feel less confident dealing with psychological problems... [I] want to pass them on as quickly as possible. I don't have the training to deal with them.

—Diabetes specialist nurse²

Even if I had the skills, I only have 20 minutes....

—Diabetes specialist nurse²

As these quotes show, health professionals face many challenges and barriers in providing adequate psychosocial support to people with diabetes.^{2,20} The health professional is required to make a shift from the role of “authoritarian” (i.e., someone with all the expertise who tells the person with diabetes what to do) to the role of a listener and collaborator.²⁰ While, at first, it may take more time to listen and gain insight into the person’s perspective, it will lead to establishing a trusting relationship with mutual respect. Some of the key barriers are described below, to enable you to reflect on which might apply to your appointments and what you can do to reduce those challenges.

➤ **Lack of time/fixed appointment times:** From a practical perspective, lack of time remains a perennial barrier to a more person-centered approach—but many health professionals do manage to overcome this. Listening to the person’s experiences and needs, and acknowledging their own way of experiencing their diabetes, is a vital component of person-centered care.²⁰ Ask yourself, is it ritual or rigid practice that limits your time? Do you think that if it does not concern diabetes directly it is not important? If you choose to interrupt at this point, you may lose the opportunity to elicit the person’s agenda or the concerns.^{REF11} One way to deal with time constraints is to agree with the person at the beginning of the appointment on the priority issues and manage their expectations about the time available. If there is more to be discussed, encourage the person to come back and book an extended

appointment time. Even if initial appointments take some time, there are long-term benefits to be gained. Remember that when the person is distressed, they may not be able to assimilate what you are saying about managing their diabetes better and may remain focused on managing their emotions. Furthermore, if emotional health is not addressed, the problem is likely to become worse. Ultimately, by building rapport, your subsequent interactions will be much more effective. People with diabetes are then more satisfied and feel more empowered.

- **Lack of confidence:** Many health professionals lack confidence in their own skills and report sticking to their own agenda as a mechanism for not having to adopt a person-centered approach. Confidence comes from within, and your skills will improve with practice. Health professionals may be fearful of what might be disclosed, or of issues that they cannot solve. Remember, you are not there to solve all of the person’s problems. Often, all the person with diabetes wants is to be heard, to have their feelings validated, and to know that “*someone is on my side.*”
- **Lack of skills or expertise:** Many health professionals perceive their skills or expertise to be limited when it comes to talking about emotions, but most have well-developed communication skills. If you feel you need training, working through this guide is the perfect first step. It is a learning process, so allow time and practice to improve your skills. For some psychological problems, a referral to a mental health professional will be necessary and it is important to acknowledge when this will be the case. For many other issues, you may find that emotional distress is related directly to the experience of dealing with diabetes on a daily basis. People with diabetes who experience psychological problems often prefer to talk about this with their diabetes health professionals or their primary care physician (PCP) rather than with a mental health specialist.³ For example, as diabetes distress (see **Chapter 3**) is so common and intertwined with diabetes management,²¹ it is best addressed by a diabetes health professional, or the PCP if they are the main health professional.
- **Lack of referral options:** Lack of psychological services (specifically those with expertise in both mental health and diabetes) is well documented. The American Diabetes Association (ADA) Mental Health Provider Education Program and the Mental Health Provider Directory^a are excellent resources, as are ADA

a The ADA Mental Health Provider Directory helps people with diabetes locate mental health professionals in their area that have expertise in diabetes care. To learn more about the directory or how to apply to be listed, visit https://professional.diabetes.org/mhp_listing.

Recognized Diabetes Self-Management Education and Support (DSMES) programs. You may be able to identify a mental health professional with an interest in diabetes through these networks. It is also important to realize that only a small number of people with diabetes may need a referral. People with diabetes may not need specialist services. Rather, they may need a diabetes health professional with whom they can talk about how distressing it is to live with diabetes (see **Chapter 3**). In the DAWN2 study, significant diabetes distress was reported by nearly half of the participants, but only 24% of them reported that their healthcare teams asked them how diabetes affected their lives.²² They may also benefit from the support of other people with diabetes (see **Appendix B**).

- › **Different agendas:** You and the person with diabetes may come to the appointment with different agendas. The best way to find out the individual's agenda is to ask. For example, “*Tell me why you're here today,*” “*How can I help you today?*” or “*What would you like to get from today's visit?*” People with diabetes may not be aware that they have the right to ask questions during appointments,²⁰ especially about psychosocial issues. Asking questions, giving them a voice and an opportunity to teach the health professional about what it is like to live with diabetes will establish trust, improve rapport, and assist in building a collaborative relationship.
- › **Costs:** Some health professionals may believe it is too time-consuming and expensive to integrate routine monitoring of emotional health into their appointments, or that offering psychological support adds a further financial burden (e.g., on the health system or on the person with diabetes). However, there is no doubt that people with diabetes who are distressed fare worse than those who are not. For instance, depression (see **Chapter 6**) increases the risk of long-term complications, healthcare costs, and mortality.^{23–25} So, psychological distress needs to be considered a cause—not merely a consequence—of complications, and reducing distress can be considered as a clinically meaningful way to reduce other diabetes-related complications.²⁶ This provides an economic rationale for improving communication about emotions and mental health.
- › **Health literacy, language barriers, and passiveness:** One of the key barriers to effective communication is understanding. Check the person's understanding—don't settle for the “smile and nod.”

Ask the person to explain their understanding of what you have told them in their own words. Do you know why they don't understand? Is there a language barrier or health literacy issue? Is your explanation too complex? If they don't understand, take the time to explain again in a different way.

- › **Stigma/myths about mental health and diabetes:** Fear of stigma and negative stereotyping can reduce the effectiveness of a visit. In extreme cases the relationship may become a sterile, ineffective exchange based on what the person thinks you want to hear and/or what the person is prepared to share with you. Experiences of stigma may discourage a person from engaging in self-care activities, attending future appointments, or seeking professional support.^{27–30} Health professionals may convey stigmatizing attitudes unintentionally in their language, actions, and reactions. Consider how your words and actions might inadvertently reflect negative attitudes about mental health³¹ and diabetes.³²

It is worth finding ways to overcome any of these barriers if you are experiencing them. The reality is that we work more effectively and efficiently when we seek to understand the person's feelings and their reasons for distress, particularly when these underpin their self-care behaviors. Clinical psychologist, Dr. Mark Davies, notes:

“Many diabetes professionals have highly developed communication skills and years of experience of dealing with people whose lives have been affected by diabetes. Whilst lack of time can frequently be an issue, it may well be that many... underestimate the skills they possess.”²⁶

Despite initial apprehensiveness, many health professionals report feeling positive about their handling of emotional health issues once they have tried engaging in such conversations. Furthermore, they realize that they had the skills to do so and that they applied them successfully during the appointment.²



At the end [of the psychosocial discussion] I felt pleased with the outcomes and the patient seemed more at ease.... I think I make patients feel comfortable and able to talk openly.

— Health professional²

What Else to Consider?

A Few Words about Language



Words are, in my not-so-humble opinion, our most inexhaustible source of magic. Capable of both inflicting injury and remedying.

—Albus Dumbledore in *Harry Potter and the Deathly Hallows*³³

A key element of communication is the use of language. Words can be incredibly powerful, so it is important to choose them carefully.

The ADA and Diabetes Australia have published guidance about the use of language in diabetes care,^{32 34} which highlights that:

- › **Words have impact.** Words can positively or negatively affect the person with diabetes. The language you use can affect the person’s willingness to confide in you; it can also have an impact on their motivation, confidence, and, ultimately, their diabetes outcomes.
- › **Words can label the person or perpetuate negative stereotypes.** For example, the label “*diabetic*” defines the person by their medical condition, and “*patient*” implies dependency on the health system. In contrast, referring to the “*person with diabetes*” acknowledges other facets of their identity/life/personality that are equally salient for them, and that they are functioning successfully in their own home/work environment.
- › **Words can be judgmental or demotivating.** Many people with diabetes report feeling criticized for not managing their diabetes well, yet they often feel they are doing the best they can. For example, criticism may be implied by phrases like “*poorly controlled*” or “*failing to manage*,” and can leave people with diabetes feeling demoralized and that their efforts are under-valued. The words you choose to use may stay with that person long after you have forgotten the appointment. It is important to acknowledge how challenging diabetes can be.
- › **Words can lead to missed opportunities—or create them.** Diabetes is a lifelong condition and people will, naturally, have times when diabetes is not their main priority, or when they are struggling with self-management. Labeling the person as “*non-compliant*,” “*poorly controlled*,” or “*uncooperative*”

can lead to missed opportunities to engage the person in a conversation about why things are not going well and how you can support them.

- › **Words can affect the relationship between the health professional and person with diabetes.** It is best to use words that neutralize any judgment about the outcome. Instead of referring to “*good control*” or “*poor control*,” refer to blood glucose levels being “*in target*” or “*above target*.” Rather than directing the person with phrases like “*you must...*” or “*you should...*,” choose words like “*you have some choices here...*,” and “*let’s discuss your options...*,” which respect the individual’s autonomy and indicate a collaborative relationship.

Using Questionnaires to Inform Appointments



I am just aware that I have a tendency to concentrate on my own agenda and feel I should improve my skill at focusing on the patient’s agenda.

—Diabetes specialist nurse²

Questionnaires can be very helpful for monitoring the emotional and mental health of people with diabetes. In particular, questionnaires about diabetes distress (see **Chapter 3**) can help to focus the agenda of the appointment on any challenges the person may be experiencing related to living with and managing diabetes.

Questionnaires can be used effectively in specialist care^{6,7} and primary care settings.³⁵ People with diabetes and health professionals alike value the assessment and discussion of outcomes, and generally express greater satisfaction with appointments in which this has taken place.^{6,36} Follow-up studies have shown that using questionnaires and discussing the outcomes, leads to reductions in diabetes distress and improvements in A1C.^{6, 37}

There are several well-validated, reliable, and easy-to-use questionnaires for assessing the emotional health of people living with diabetes. They are featured in relevant chapters of this guide (**Chapters 3 to 7**). Additionally, you may print copies from the PDF version of the guide, available at this website: <https://professional.diabetes.org/meetings/mentalhealthworkbook>

Before using questionnaires in your practice, here are some points worth noting:

- › **Have a good reason.** Be clear about why you are asking someone to complete a questionnaire. For example, it is appropriate to use a diabetes distress questionnaire on a routine basis because the issue is relevant to most people and because the person's responses can help you tailor the visit and plan to their needs. You can also monitor their distress over time. However, asking people to complete a large quantity of unnecessary questionnaires just so you have their "score" on record is a waste of their time and yours.
- › **Explain your reasons for asking the person to complete a questionnaire.** Explain why the questions are relevant to their individual situation. People will be more inclined to respond (and tell you how they really feel) if they realize you are trying to understand their experience of living with diabetes so you can be of greater help to them. Otherwise, they may perceive it as a waste of time and resources. Importantly, reassure them it is not a "test" and there are no right or wrong answers. Also, reassure them that the information will be treated as confidential and tell them what you intend to do with the completed questionnaire (e.g., will you keep the questionnaire in their medical notes?).
- › **Choose your method and timing wisely.** Select a method for administering the questionnaire that will be most suitable and convenient for the person with diabetes and yourself. Some people may prefer completing a questionnaire using their smartphone, a tablet computer, or via a website. Electronic versions may also be more convenient if they automatically calculate total scores and link with the person's electronic health records. However, some people may not feel comfortable with the technology and will prefer traditional pen and paper. Similarly, consider your timing—often people will be more willing to complete a questionnaire if they are asked to do so in the waiting room before an appointment, rather than at home or during the appointment.
- › **Questionnaires can save time and help you get to the heart of an issue.** Inviting the person to complete the questionnaire in the waiting room before they come in to see you can prepare them for the conversation to follow. You can then quickly skim their questionnaire responses to enable you to start a conversation about the issues of most relevance to them.
- › **Consider individual circumstances, needs, and capabilities.** Health literacy, language barriers,

disability, and other factors may affect a person's ability to understand and/or complete a questionnaire on their own. Differing cultural perceptions of health and mental health may impair the validity and interpretation of the questionnaire (see "**Cultural and Linguistic Diversity**" page 13). If you have concerns about the suitability of a questionnaire for the person, consider other options. For example, can you read the questions and response options out loud to them? Is there a suitable questionnaire in their first language or validated for their cultural group? Could you ask open-ended questions instead?

- › **Questionnaires may not always be the best way of gathering information.** Asking open-ended questions is a valid and practical alternative. Questions such as, "*What is it about living with diabetes that you find most difficult?*" and "*How does that make you feel?*" can help you gain some insight on these issues without using a questionnaire, and it makes the conversation more personal.
- › **Do something with the results.** Screening alone is not enough to improve health outcomes.³⁸ If you ask someone to complete a questionnaire, it is important that you always find a way to discuss and use the information. Ignoring it or just placing it "in the file" is unethical.²⁶

Creating an Enabling Environment



I don't mind discussing sensitive issues. The problem is finding enough privacy.

— Health professional²

The room setup is very important for enabling personal disclosure. Ideally, the room needs to be quiet and private. The furnishing and décor should create a welcome, safe, and supportive environment. Think about your environment and what you can do to improve it:

- › **Waiting room:** This is where the person gets their first impression. What messages do your posters, magazines, and brochures send to people? Are there campaign posters involving scare tactics, pictures of medical procedures and/or complications, or magazines focused on diets and body image? Perhaps it is better not to have these types of materials lying around—what is motivating to one person may fill another with guilt, despair, or irritation.
- › **Consultation room:** What do people see when they enter? Similar posters as in the waiting room? Is the

room set up as an exam room? Do you sit behind a desk or a computer? What do these things say about the power balance or your interest in having a conversation? Will the person feel comfortable raising sensitive issues with you in the space?

- › **Computer:** It is difficult to type and talk at the same time; it's even harder to type and listen at the same time. Give the person in front of you your full attention. Show that you are listening and, above all, that they matter to you.
- › **Lack of privacy or interruptions:** If you do not have a private room or are continually distracted by interruptions or noise, this can make the person with diabetes feel unimportant or that this is not necessarily a safe space to open up to you. Can interruptions be prevented? Can you put a sign on the door, close the blinds, and put your phone on silent?

Considering Social Determinants



*We do not see things as they are,
we see them as we are.*

—Anonymous³⁹

Social determinants of health are defined as the economic, environmental, political, and social conditions in which people live and are responsible for a major part of health inequality worldwide.^{40,41} The ADA now recommends that health professionals assess food insecurity, housing insecurity/homelessness, financial barriers, and social capital/social community support, and apply that information to treatment decisions.⁴² In this guide, we refer to people with diabetes from the general adult population but, of course, we live in a very diverse country and world. It is beyond the scope of this guide to consider the specific needs of every social and cultural group, or the specific approaches they may require. Guidelines and checklists are less important than “a reflective approach that avoids stereotypes and assumptions in providing care that is person-centered, culturally respectful, and aware.”⁴³

Social and cultural factors play an important role in determining:

- › why and when people attend healthcare appointments
- › the relationship between the health professional and the person with diabetes (“patient”)
- › beliefs about (emotional, mental, and physical) health and illness

- › attitudes to (emotional, mental, and physical) health and illness
- › the extent to which lifestyle can be modified to manage a chronic condition such as diabetes
- › people’s willingness to take medications
- › and people’s preferred communication styles.

Health professionals have a responsibility to develop appropriate communication strategies to meet the needs of all members of the community. The majority of this chapter advocates for an open, empathic communication style; however, keep in mind that this approach may not be suitable for every person—consider diversity and be reflective in your approach to communication.

Being aware of your own personal attitudes, assumptions, and stereotypes will help you to put these to one side and minimize their influence on the discussion. You can then focus on understanding the values and wishes of the individual as they discuss their health with you.

In certain situations, the individual may feel more comfortable if a family member, friend, advocate, community/spiritual leader, or other trusted person can attend the appointment. Make sure people know they are welcome to do this.

Health Literacy

Health literacy is more than basic literacy and numeracy skills; it includes a person’s ability to understand and apply health-related information and their ability to navigate the health system.⁴⁴ Low health literacy is very common—approximately 80 million adults in the U.S. are estimated to have limited or low health literacy⁴⁵ so be aware of the signs (see **Box 1.4**). Do not assume that people will tell you openly; many will not say anything for fear of judgment or embarrassment.⁴⁶ People with lower health literacy can be very reliant on the verbal information passed on to them by health professionals.

Think about what is required of a person with diabetes during a standard appointment—they need to provide information to their health professional, understand and make decisions based on the information that their health professional gives them, and remember to ask the right questions. When they go home, they need to remember everything that took place and was said during the visit and apply it. Imagine how challenging that might be for a person who has not clearly understood the message that their health professional has tried to convey to them, and how it might affect their self-care and health outcomes. Now, imagine having to do this not only for diabetes but

BOX 1.4 Signs That Someone May Have Low Health Literacy

Signs that the person is having difficulty understanding and applying health information include⁴⁶:

- › answering knowledge-based questions incorrectly (e.g., questions related to written information you have given them)
- › being nervous about, or avoiding, complex learning tasks
- › “forgetting” record books (e.g., blood glucose readings, food intake, or medication records)
- › making errors in calculations (e.g., carbohydrate counting or insulin dosage)
- › submitting incomplete forms
- › showing up at appointments seeming to have not “prepared” beforehand (e.g., not reading instructions you have given them previously) or missing appointments altogether where “preparation” is required
- › “forgetting” to bring their reading glasses
- › offering to complete a form “at home”
- › handing written documents to an accompanying person
- › or holding written documents close to their eyes and following the text with their fingers.

To check, you could ask the person “*How confident are you in filling in forms by yourself?*”⁴⁷ If you choose to do this, be sensitive and tactful in your approach.

for eye screening, foot care, and other aspects of health care relevant to diabetes.

Some of the strategies listed in **Box 1.2** will be particularly helpful for people with lower levels of health literacy. These tips include using plain language and anecdotes/storytelling/visual aids, encouraging questions, repeating key information, and checking understanding (yours and theirs).

Cultural and Linguistic Diversity

The U.S. is one of the most culturally diverse countries in the world. Some populations are more disproportionately affected by diabetes and in order to effectively provide

care and education, professionals need to be cognizant of social, cultural, and linguistic diversity.⁴⁵

“Culturally and linguistically diverse” is a broad term describing a wide range of people with regard to their country of origin, culture, religion, primary language, and other characteristics. Given this, it is impossible to provide specific advice to meet the needs of everyone, but here are some broad considerations on which to reflect:

› **Appreciate cultural differences.** Culture plays a large role in shaping values, beliefs, and practices. People from diverse backgrounds may have different beliefs, values, and practices from your own. It is ethical practice to reflect on your own cultural bias and to be aware of how this may influence your practice, and to be mindful of this in your communications and care.⁴⁸ For example, people may have varied:

- understandings of and beliefs about health (e.g., mental health and diabetes)^{49,50}
- communication styles (e.g., a preference for written, pictorial, or verbal communication, or a passive or assertive manner)^{49,51,52}
- and expectations and preferences for their healthcare (e.g., the expected role of the health professional,⁵² a preference for a same-sex health professional,⁵³ or a preference for traditional cultural remedies over modern medicines).⁵⁰

Ask questions to clarify their knowledge and point of view; don’t assume that you know this information.⁵⁴

- › **Recognize and adapt to language challenges.** While English is the primary spoken language in the U.S., at least 21% speak another language in their homes and may have limited or no English-language skills.⁵⁵ It is also important to be aware that being proficient in English does not mean someone is proficient in medical terminology. Language barriers can impede communication and affect the quality and uptake of care, and physical and mental health outcomes.^{56,57,58} Be willing to adapt the ways that you communicate and work to meet the needs of the person. It is also important to use an accredited interpreter rather than rely on family or friends.
- › **Cater to individuals’ needs and preferences.**^{43,58} A one-size-fits-all approach is not appropriate⁵³ and does not work.
- › **Seek advice and engage other experts.** Familiarize yourself with culturally appropriate services in your local area.⁵² With the agreement of the person with diabetes, consider contacting:

- Transcultural/multicultural health services in your area for advice regarding communicating with specific cultural groups and for help identifying appropriate services for referral.
 - Multi-lingual health workers to provide advocacy, support, counseling, and interpretation for the person with diabetes. They can also provide sociocultural insight for health professionals⁵⁹—some may specialize in diabetes or mental health.⁶⁰
 - Trained and accredited interpreters for help overcoming language barriers^{43,52,53,61} and preventing miscommunications and mistakes.^{58,62} It is advisable to consult guidelines for working with interpreters.
- › **Upskill.** Consider participating in accredited cultural awareness or cultural safety training.^{57,63}
 - › **Be cautious with questionnaires.** While several questionnaires have been translated into other languages, their cultural appropriateness may not be guaranteed. In a multicultural population, exercise caution when administering questionnaires originally developed and validated in English.⁶⁴

Disability

Finally, bear in mind that disabilities (e.g., physical, intellectual, or cognitive) may affect a person's emotional state, and their ability to communicate or understand. Making appropriate arrangements to help people with these challenges is also part of recognizing diversity.

Resources

For Health Professionals

Books

› ***The Art of Empowerment: Stories and Strategies for Diabetes Educators, 2nd edition***

Description: A unique and valuable resource for any health professional working with people with diabetes, with real life experiences, interactive techniques, and philosophical as well as practical approaches.

Source: Anderson R and Funnell M. *The Art of Empowerment*, 2nd ed. American Diabetes Association, Arlington, VA. 2005.

› ***Life with Diabetes, 6th edition***

Description: A complete curriculum to deliver high-quality diabetes self-management education and provide support, information, and tools with an emphasis on integrating psychosocial and behavioral strategies with self-management and clinical care.

Source: Funnell MM, Kloss KA, et al. *Life with Diabetes*, 6th ed. American Diabetes Association, Arlington, VA. 2020.

› ***1,000 Years of Diabetes Wisdom***

Description: A book of stories and lessons compiled by health professionals and what they learned from people with diabetes.

Source: Marrero DG, Anderson R, et al. *1,000 Years of Diabetes Wisdom*. American Diabetes Association, Arlington, VA. 2008.

› ***Approaches to Behavior***

Description: A toolbox for bringing thoughtful, empowering practices and strategies to the relationship between health professionals and people with diabetes.

Source: Roszler J, Rapaport WS. *Approaches to Behavior*. American Diabetes Association, Arlington, VA. 2014.

› ***Complete Nurse's Guide to Diabetes Care, 3rd edition***

Description: The comprehensive resource for all aspects of diabetes care and self-management for nurses who work with people with diabetes.

Source: Childs BP, Cypress M, et al. *Complete Nurse's Guide to Diabetes Care*. American Diabetes Association, Arlington, VA. 2017.

Book Chapters

› ***Tips and tricks on effective communication with people with diabetes: Helping people achieve their goals while achieving your own***

Description: A chapter providing advice and strategies on how to achieve person-centered appointments.

Source: Craddock S and Barnard KD in the book by Barnard KD and Lloyd CE, eds. *Psychology and Diabetes Care: A Practical Guide*. Springer, London. 2012.

› ***Theoretical and behavioral approaches to the self-management of health***

Description: A chapter comparing and contrasting behavioral and educational theories,

models, and approaches that support self-management and psychosocial health to help health professionals to use strategies to address the emotional, cultural, and health literacy issues that significantly influence self-management behaviors and quality of life.

Source: Piatt GA, Anderson RM, et al., in the book by Mensing C, Cornell C, et al., eds. *The Art and Science of Diabetes Self-Management Education*. American Association of Diabetes Educators, Chicago, IL. 2017.

Peer-Reviewed Literature

› **The use of language in diabetes care and education**

Description: Provides recommendations for person-centered language to be used by health professionals and others when discussing all aspects of diabetes and self-management.

Source: Dickinson JK, Guzman SJ, et al. *Diabetes Care*. 2017;40:1790-9.

› **Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators and the Academy of Nutrition and Dietetics.**

Description: Defines the four critical times to offer people with type 2 diabetes education and strategies to provide ongoing emotional and behavioral support.

Source: Bardsley J, Cypress M, et al. *Diabetes Care*. 2015;38:1372-82.

For People with Diabetes

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

Description: Addresses the emotional issues that can become barriers to optimal self-care.

Source: Polonsky WH. *Diabetes Burnout*. American Diabetes Association, Arlington, VA. 1999.

› ***How to Thrive: A Guide for Your Journey with Diabetes***

Description: This 40-page booklet contains the “need to know” information to manage and cope with about diabetes.

Source: American Diabetes Association, Arlington, VA.

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Chapter 2

Facing Life with Diabetes



Key Messages

- Living with diabetes involves acquiring new knowledge and developing skills to self-manage a lifelong condition.
- Responses to diagnosis can vary: some people experience a range of negative emotions (e.g., shock, grief, anger, distress, or self-blame), while for others, the diagnosis has little impact, or can bring a sense of relief after a period of uncertainty about unexplained symptoms.
- Responses are influenced by the type of diabetes diagnosed, and by the person's individual characteristics and experiences prior to diagnosis (e.g., symptoms and/or familiarity with the condition).
- The journey is different for everyone, but most people with diabetes will need support from their health professionals, families, and peers at some point.



Practice Points

- Reflect on how you might feel if you had to live with diabetes. Use your insights to support the person.
 - Be mindful that a new diagnosis can raise a range of emotions for a person.
 - Listen empathically, assist the person, and assure them that you can support them to live well with diabetes.
-

Experiencing the Diagnosis of Diabetes

The diagnosis of diabetes is the beginning of a new reality. Nobody chooses diabetes. The person is confronted with an incurable and potentially demanding condition. Life will not be the same as it was before diabetes. The person may feel that they will never return fully to their previous health state, or they may perceive they are losing their independence or control over their health.

For some people, the diagnosis of diabetes can be a shock.^{1,2} Their initial emotional reactions are disbelief, anger, self-blame, anxiety. For others, the diagnosis may be a relief after a period of uncertainty about symptoms and consequences of hyperglycemia.^{1,2}



I was just shocked, thinking, because I'm so healthy. And I thought, 'oh my, God, it's like the end of me,' kind of, you know, that shock.

—Person with type 2 diabetes³

[I was] jumping around from shock to denial to grief to tears to... I certainly went through that.... The reactions might go up and down for quite some time... for my first 12 months I went through lots of reactions.

—Person with type 1 diabetes

I don't think it's all that devastating. There are far worse incurable sorts of things.

—Person with diabetes⁴

I think it's quite good... that it's been sort of picked up.... If they hadn't done those tests... I could just have been sort of doing always what I've normally been doing... I could have been damaging myself even more.

—Person with type 2 diabetes¹

How a person responds to diabetes will differ according to individual characteristics, such as age, gender, social, and cultural background; their life stage; and experiences. Reactions are likely to vary also depending upon the type of diabetes diagnosed (see **Box 2.1**), and the person's beliefs about the condition, its trajectory, and how well it can be managed.



It was easy for me because my son had it, so I had the experience of it, I knew what it was already.

—Person with diabetes⁴

BOX 2.1 Reactions to a Diagnosis of Type 1 or Type 2 Diabetes

The onset of type 1 diabetes can be sudden and highly symptomatic (acute hyperglycemia). Sometimes, diagnosis follows a brief period of ill health and hospitalization due to diabetic ketoacidosis, which can be traumatic. Diagnosis of type 1 diabetes is almost exclusively considered devastating, despite the fact that people can live long, healthy, and happy lives with the condition. Thus, typical reactions can include both shock and relief.

Conversely, **the onset of type 2 diabetes** is rarely accompanied by such acute symptoms and can mistakenly be considered a “mild” condition, to be expected in older age. Typical reactions can include denial and apathy. The exception to this is when a diagnosis is made in the presence of complications (e.g., background retinopathy). In these exceptional cases, the potentially devastating consequences of diabetes are already obvious to the person and typical reactions can include anger, self-blame, and grief. A person's reaction may also depend on whether or not they expected the diagnosis. For example, someone who is experiencing symptoms that they suspect are related to diabetes or with a known family history of diabetes may feel more prepared for the diagnosis and may not be “shocked” by it. In comparison, a person who has been feeling unwell may feel relieved that the cause is now known and perhaps that the diagnosis is not something they perceive to be “worse.” The reaction of a person who is surprised by the diagnosis, for example because they were asymptomatic, may be more variable (e.g., “shocked” or “grateful” that it has been revealed).¹

It is crucial not to refer to type 2 diabetes as “mild” diabetes or “a touch of sugar”—these terms do not reassure the person and can do more harm than good. All forms of diabetes are serious and all can lead to complications if they are not managed well.

[Diabetes is]... the best thing that has happened to me for ages because it's brought around so many other changes and benefits.

—Person with type 2 diabetes¹

Some people believe that diabetes will not cause much disruption to their “normal” life—and this may be true. However, the perception that diabetes is affecting very little in their life can be a sign that the person has not grasped (yet) how serious diabetes is and what they need to change/do to manage it effectively. It may take them a few weeks, months, or years to fully realize how diabetes affects their life and future. Not acknowledging the need to adopt or change certain self-care behaviors can be a sign of low self-efficacy (i.e., that the person lacks confidence in their ability to make behavioral changes) or fear of failure. A lack of confidence and/or fear of failure is typically the experience of people who need to quit smoking or lose weight—repeated failed attempts lead to avoiding the need to continuing trying.



I don't let it worry me, nothing has been changed, even if I eat somewhat different now. Diabetes is something you can live with... or, am I wrong?

—Person with type 2 diabetes⁵

And to be honest I don't feel as if I've got diabetes... the only reason I know I've got diabetes is because the doctor told me I have... I don't feel as if I've got to do anything to correct it. Really I might as well carry on with my beer... if I... really took to mind that I'd got diabetes I'd do something more drastic about it.

—Person with type 2 diabetes⁶

I don't think I fully accept that [the diagnosis] happened... you have to, to continue getting on with life... I think you adjust to incorporating it or integrating it into your life.

—Person with type 1 diabetes

Not every person who has been told they have diabetes will immediately feel ready to deal with its consequences. This “avoidance” strategy can be an adaptive and effective coping mechanism. In the short-term it can serve a positive purpose, offering a way for people to adapt slowly and come to terms with change, without becoming overwhelmed.⁷ If it

continues for weeks, months, or even years, it may have negative consequences for emotional well-being, self-management, and health outcomes.



I think it was about two months later, if that, you know, and I think I still haven't got, sort of, you know, I haven't told myself that I have got it, you know, I'm still in denial... I still keep thinking 'they must have got it wrong.'

—Person with diabetes³

I've heard that diabetes can make you go blind, but I don't want to know. I just don't want to think about it.

—Person with diabetes⁸

Not engaging in diabetes self-management (e.g., not taking medication or not attending clinic appointments) may be a sign that the person has difficulties coping with the diagnosis or with self-care and, therefore, may need extra support.

Regardless of their initial reactions, for most people the adaptation process will have a natural course and they will find a way to incorporate diabetes and its management into their daily life and lifestyle.⁹ For some, it may continue to be a struggle and they may require support from a health professional.



Apart from emotional responses and beliefs, there are many other reasons why people with diabetes have difficulties incorporating the diabetes management demands in their lives. For example, health literacy, social and cultural consequences (e.g., fear of losing their job, being isolated in their community, or stigma), and limitations related to the healthcare system and access to care.

Often, during the weeks and months following diagnosis, a person can feel overwhelmed by “information overload” and the many complex management tasks they need to learn and apply. These initial overwhelming emotions can leave a person feeling unable to cope and may disrupt their memory and capacity to retain information.¹ If a person believes that they need to get everything right from the beginning, it puts extra pressure on them and adds to the emotional burden of diagnosis. You can help to reduce this pressure by assuring them that it will take time to learn what works best for them and by showing confidence that they will get there.



You feel a little like ‘Ahh, am I too high now [glucose level]? Should I take more [insulin] or not?’ Then I have to think, ‘Yes, I do that,’ or, ‘No, I don’t,’ so it takes a while to learn to know myself how I react.

—Person with diabetes¹⁰

Ask, at regular intervals during the first year after diagnosis, about how they are coping, and their beliefs and feelings about their diabetes, self-management, and its impact on their daily life (see **Box 2.2**). These conversations can help you identify, at an early stage, if the person is not adapting well and may need additional support.

Strategies to identify which aspect(s) of diabetes are causing coping problems (e.g., emotional, cognitive, or behavioral) and how to provide appropriate support are included in **Chapter 3** and **Appendix C**.

If you recognize that the person continues to struggle with feelings of denial, grief, self-blame, or anxiety associated with their diabetes several months after diagnosis, consider referring them to a mental health professional for specialist support. For information about making mental health referrals, see **Chapter 9**.



If there is a psychologist in your team, introduce them to the person with diabetes as early as possible. The best option is a face-to-face meeting so that they get to know each other from the start, which will lower the threshold to consult with the psychologist in the future and also “normalize” that asking for psychological support is not a sign of “weakness.”

In summary, there is no single way to respond to the diabetes diagnosis. Many factors play a role in the process of dealing with this condition. Understanding the person’s experiences prior to and since living with diabetes will help you to support the person effectively.

BOX 2.2 Asking How a Person Is Coping with the Diagnosis of Diabetes

Here are some examples of open-ended questions you might use to enquire about how the person is coping with the news that they have diabetes:

- › “How are you feeling at the moment about the news that you have diabetes?”
- › “How did you react when you were told you had diabetes?”
- › “How do you feel your diabetes may affect your [school/work/personal relationships/ family/ sport/hobbies, etc.]?”
- › “How do you feel about telling other people that you have diabetes?”
- › “How did your [close family members] react when you told them about the diagnosis?”
- › “How do you feel you are coping?”
 - “What do you expect will be the hardest part of fitting diabetes into your life?”
 - “What do you think will be easy for you to do/change?”
 - “What do you think may be more difficult?”

Acknowledging the daily challenges of living with diabetes and the efforts it takes to manage the condition can help people feel more comfortable about sharing their thoughts and feelings. You can do this by prefacing these open-ended questions. For example, “Many of the people that I see find living with diabetes challenging,” or, “Finding out you have diabetes can be a lot to take in.” Comments like these “normalize” the adjustment process and help the person to realize they are not alone in thinking or feeling this way.

Explain that incorporating diabetes into their life takes time. For example, “Living with and managing diabetes is a learning process, quite a bit can feel like ‘trial and error.’ Over time, you will become an expert in managing your diabetes.”

Diabetes Diagnosis: The Start of a Lifelong Relationship with Health Professionals

For many people, the diagnosis of diabetes is the start of a lifelong relationship with health professionals and the healthcare system.¹⁰ Although the time you will spend with the person is minimal, they will value your expertise and guidance when you show genuine respect and empathy¹¹ (see **Box 2.3**).

Remaining supportive will help the person with diabetes realize you are “on their side” rather than someone they are accountable to. In doing so, you will maintain the person’s trust and keep them motivated to take care of their diabetes and their overall health in the long term.

The blog reprinted in **Box 2.4** describes how a person with diabetes feels, what they would like their health professional to know, and importantly, how they would like their health professional to communicate.

It illustrates that it is important to use appropriate language and not to trivialize people’s diabetes management efforts and/or the challenges they face with ongoing self-care of this lifelong condition. A health professional’s communication style has a significant impact on how a person copes with and manages their diabetes (see **Chapter 1**).

BOX 2.3 What Is It Like to Live with Diabetes?

It is difficult to imagine what living with diabetes is like when you don’t have diabetes yourself. However, with the knowledge you have about the condition and the stories people with diabetes have shared with you, you may reflect on:

- › “How would I feel if I had diabetes?”¹²
- › The diabetes treatment regimen is just one aspect of managing diabetes. For most people, self-management is intensive and multi-faceted. Physical daily tasks include medication-taking, self-monitoring of blood glucose, dietary changes, physical activity, and foot care. Then, there are the regular health check-ups (e.g., A1C checks, blood pressure, and eye screening).¹³ However, effective self-management involves more than simply performing these tasks and attending appointments. It requires problem solving, decision making, healthy coping, and reducing risks.¹⁴ This means developing resilience to the everyday frustrations of living with diabetes, working out how to deal with other people’s reactions to their diabetes and their self-care choices, and being confident experts in their own condition.¹⁵
- › A person with type 1 diabetes:
 - who has lived with it for 40 years has done 58,400 finger pricks (average four per day) and has likely had over 4,000 mild hypoglycemic episodes and 40–60 severe hypoglycemic events.
 - typically makes over 100 diabetes-related decisions every day, feels tired of continually thinking about diabetes, and feels that their family is continually concerned about them and their diabetes.
- › A person with type 2 diabetes:
 - is typically asked to change the habits that have accrued over a lifetime; healthier eating, more exercise, and losing weight are not easy to achieve, especially when the rewards are not apparent in the short term.
 - has to make difficult and/or frustrating decisions at every meal (e.g., continually resisting their favorite foods, dealing with well-meaning family/friends who say things like “just one won’t hurt,” and being confused by healthy eating advice).
- › Many people with diabetes describe it as “more than a full-time” job.¹⁶ And so it is—but without any pay or holidays, and without assurance that your efforts will be rewarded.¹⁷ How would you feel if you were asked to keep doing your job 24/7 for a year, but without vacations and without the guarantee of being paid at the end of the year?

BOX 2.4 Dear Doctor: An Excerpt from the Diabetogenic Blog¹⁸

I frequently give talks about how to get the most out of our healthcare professionals [HCPs]. One of the things I talk about is making sure that we find the HCPs that work best with us. I talk about interviewing doctors—something that I did years ago when I was looking for the right endo. It's a two way street. One doctor told me that he didn't think that we would work well together. He was completely right and I walked out of that appointment rather quickly!

I also talk about being really clear and upfront about things—what we need from our HCP, what we expect. And then give them the opportunity to do the same thing.

This is pretty much what I want to say to every HCP when I meet them for the first time.

Dear Doctor

Hi. You and I are on the same side. My side. We are both championing for me to be the best I can be with the cards I've been dealt.

I thought that we would start out by me telling you what I need from you and I would love it if you did the same.

This is a relationship that works two ways. You need things from me, and I need things from you. Let's get all that out on the table from the beginning.

Mutual respect is really important. I come with mine ready to give to you. I won't, however, be quite so generous if you don't demonstrate the same thing.

Judgment is not welcome in our consultations. That message is actually for me as much as it is for you, because I am totally judging you. I expect you to be judgmental and not understand me or my condition. Show me that I'm wrong. And then don't judge me for being such a pain in the ass!

My health condition is one that you know a great deal about. That is why I am coming to see you. I want to know everything you know that is relevant. But I need you to remember that I have a unique expertise in the field of Renza's Diabetes. I am the world expert in this field and I will impart everything I have learned and continue to learn about it to you. If you could then help me make sense of that, I'd really, really appreciate it.

I am not stupid. I have a really good understanding of the health system of which I am, unfortunately, a user. I also know a lot about the technical sides of my condition. I totally get that you need to make sure that I am clear about what you are saying, but please don't dumb it down too much for me. I promise that I don't care about looking stupid. I'll ask if I don't understand.

I use humor a lot to try to deal with what is, at times, a really scary thing to live with. Sometimes you may think that my humor is not particularly appropriate. A lot of the time you won't find me funny (but for both of our sakes, please pretend; I promise to ignore your fake laugh). I don't make fun of the situation because I am making light of it. Or because I don't care. I always care a great deal. But sometimes, it's what I need to get me through.

I'm really not good at asking for help. But I am coming to see you because I need it. I may seem to be going the long way around getting to actually ask for what I need. Feel free to ask and prompt and even push a little.

I'll say it again. I care a great deal about my health. I want to be healthy and well and on top of everything. There will be times—and they may be extended times—where it seems that I don't care. The important word there is “seems.” I do care. Really. Sometimes, though, it is just overwhelming and exhausting. But I really, really do care.

I have a beautiful family and a great job and a shoe collection that may make you jealous and I really like to drink coffee. I bake a lot and love old black and white films. I have wonderful friends I spend time

with—frequently over a meal somewhere. Exercise and I are not mates. I read voraciously and should probably seek some sort of therapy for my inability to stop buying books. I have a thing for bright red lipstick and have too many handbags. I love Nutella. And bacon. And doughnuts. You may wonder why I am telling you this. It's because all of these things are part of my life. Just like diabetes. And it goes to explain why diabetes is not the most important thing in my life or the thing that I focus on all the time.

I'm terrified about my future. I am scared about diabetes complications, I lie awake at night worrying about the chance of my daughter getting diabetes and I fear becoming a burden on my loved ones. Diabetes is scary. It is not just a condition of numbers and lab results. It is (an unwelcome) part of my present and my future.

I solemnly swear that I will never, ever walk into your office asking you about some ridiculous cure I read about on the internet. Remember that bit about me not being stupid? But equally, the internet is where I get a lot of my support and information about living with diabetes. I have a support network of people living with diabetes from all around the globe. They build me up, tell me about new things, help me work through tough times. They are, to me, as important a part of my diabetes management as you are. Don't treat them with suspicion.

So, did you know that cinnamon can cure diabetes? I'm disconnecting my pump and eating cinnamon doughnuts and nothing more for a week to see how it goes. Just kidding. (Pretend laugh. Now.)

And finally. I want you to remember all the time that I am doing the best I can at that very moment. It may not be as much as you would like, but this isn't about you. It's probably not as much as I would like either. Acknowledging what I am doing makes me feel really great. And frequently then makes me want to do better.

Thanks for reading. I really do hope this is the beginning of a beautiful doctor-PWD [person with diabetes] friendship.

Best
Renza

Bringing Bad News

You may be the health professional who will tell a person that they have diabetes. Some health professionals may not feel skilled or confident in bringing bad news, as the response can be overwhelming. Bringing bad news is a crucial communication skill. The words used, the content, and the tone of the message can make a big difference for a “good” start to life with diabetes. It can impact on how a person responds to the diagnosis, their reactions now and in the future, and on their relationship with health professionals. Here is one approach for delivering bad news.

The SPIKES approach¹⁹ is a useful six-step protocol:

- › **Setting up:** prepare yourself for the conversation, including what you are going to say; create a private and quiet space; minimize interruptions; invite the person to bring a “significant other”; and establish rapport with the person.
- › **Perception:** determine what the person already knows about diabetes and their level of comprehension, including how much they appear to be assimilating or understand of what you are saying.
- › **Invitation:** ask about what level of detail the person would like to receive (brief or in-depth information) and offer the option to ask questions later.
- › **Knowledge:** provide the information they would like to receive in a language they understand. Take into account, for example, their educational level, socio-demographic background, and emotional state. Short sentences and pauses will help the person to process the information. Give facts about treatment options, prognosis, and costs.
- › **Emotions:** allow the person time to express their feelings and acknowledge their feelings, and respond empathically to the person's emotional response.
- › **Strategy and summary:** summarize what has been said; check whether the person has questions or needs clarification; develop a strategy based on the person's hopes, expectations, and specific concerns; and arrange a follow-up date and time.

First Principles and Philosophies for Moving Forward

As a health professional, you have expert knowledge about diabetes, its management, and potential consequences. It is important to acknowledge that only the person with diabetes has expertise about their own diabetes and their own life. It is your responsibility as a health professional to help the person with diabetes to explore their own expertise, to highlight how their diabetes fits into their lives, and where there is an obstacle that can prevent optimal management of diabetes. People are responsible for their own self-management. As a health professional, you can only ever have limited responsibility and influence over this.

You are responsible for providing the person with diabetes with accurate and clear information about diabetes and its treatment options. This is especially true in the short term following diagnosis. They need basic knowledge before they can learn how to manage the condition. Understanding the condition facilitates the coping process and will help them in making sense of the new reality.¹⁰ It is important for the person with diabetes to:

- › be well-informed about treatment options, the course of diabetes, and the seriousness of diabetes.
- › know that the condition can be managed effectively, and does not have to lead to complications—indeed, while “untreated diabetes is the leading cause of many complications, well-managed diabetes is the leading cause of nothing.”²⁰
- › and understand that they will experience “ups and downs” in the way they feel about living with diabetes.

Thus, as a health professional, you are responsible for providing up-to-date, evidence-based information ensuring people are aware of their risks, and then helping them to identify successful strategies for minimizing those risks. **Box 2.5** offers some guidance about how to support people in the development of their own strategies for preventing complications and living well with diabetes. However, in the real world, there are many barriers to optimal self-management that may hamper the individual’s efforts to achieve optimal outcomes or change their motivational focus. As a health professional, you need to acknowledge these barriers with empathy at all times. If in doubt, “over-celebrate,” “under-criticize,” and “honor effort as well as outcomes.”

BOX 2.5 Helping a Person Make Changes to Fit Diabetes into Their Life

- › When asking people to make significant changes to their lifestyle, it is important to convey a message of hope, empathy, and understanding, while being factual and informative.
- › It is important to refrain from using threat or fear-based persuasion,²¹ particularly if the person is not ready to face the reality and the consequences of diabetes for their future.
- › It is more constructive to understand why a person may not be making changes that would appear to be “good” for them.
- › Help the person to understand their own barriers in implementing optimal diabetes self-management and ways to overcome these.
- › Create a space where the person can reflect on where they are now, so they can realize their own priorities and preferences—what is it they like and don’t like about where they are now, and what they like and don’t like about where they see themselves in X years’ time if they don’t make some changes.
- › Acknowledge that other issues may have greater priority for them right now; explore the person’s own “roadblocks” and help them to identify how important these are to them or whether they can find ways to overcome them.
- › With all this in mind, explore what options they have for making changes that would benefit their health.
- › Enhance the person’s confidence to undertake specific behaviors. When someone is asking for help to achieve their goals, help them reflect on their options for changing and support them to make realistic steps. This makes it more likely that they will try and succeed.
- › Successful completion of one step (e.g., walking for 30 minutes once a week) increases a person’s confidence in undertaking the next step (e.g., walking for 30 minutes three times a week) and so on.
- › Work with the person to develop a realistic and individualized action plan, and to identify resources to aid change. Ensure that the actions you agree upon are relatively easy with few barriers.

Resources

For Health Professionals

Books

> The Journey of the Person with Diabetes

Description: This book chapter explains the unique journey that people with diabetes take during the course of the condition, including psychological, social, and other factors that may impact upon how they think and feel about living with diabetes.

Source: Speight J and Singh H. The journey of the person with diabetes, in the book by Dunning, ed., Diabetes Education: Art, Science and Evidence. Oxford, John Wiley & Sons. 2013.

URL: <https://onlinelibrary.wiley.com/doi/pdf/10.1002/9781118702666.ch2>

> The Skilled Helper

Description: Now in its 11th edition, this book provides training in how to have conversations to help people manage “problems” and identify opportunities using a three-stage model.

Source: Egan G. The Skilled Helper. US, Cengage Learning. 2018.

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: ADA offers resources through which people with diabetes and their family/friends can access diabetes information, education programs, and other events.

Phone: (800) 232-3472

URL: www.diabetes.org

> Juvenile Diabetes Research Foundation (JDRF)

Description: JDRF provides a number of resources for those living with type 1 diabetes, including educational material and in-person events related to resilience and distress. Sections include information on insurance, tool kits, and links to Type

One Nation, a social networking site for people living with type 1 diabetes.

Phone: (800) 533-2873

URL: www.jdrf.org

Information

> Learning About Diabetes

Description: Easy to understand teaching handouts in English, Spanish, and a variety of additional languages.

URL: <http://learningaboutdiabetes.org>

> National Diabetes Health Topics

Description: This section of the National Institute of Diabetes Digestive and Kidney Diseases (NIDDK) website contains much of the information originally found in the National Diabetes Education Program, which was discontinued in 2019. Topics include diabetes basics, statistics, and more.

URL: <https://www.niddk.nih.gov/health-information/diabetes>

> NIDDK School Guide

Description: A program of the NIDDK designed to help parents and school administrators optimize care for students managing diabetes in the school setting.

URL: <https://www.niddk.nih.gov/health-information/communication-programs/ndep/health-professionals/helping-student-diabetes-succeed-guide-school-personnel>

> Joslin Diabetes Education Library

Description: The education section of the website for the Joslin Diabetes Center has a wealth of information on a variety of topics of diabetes self-care, as well as access to in-person programs.

URL: <https://www.joslin.org/patient-care/diabetes-education-library>

> My Glu Website

Description: Mobile community for people with type 1 diabetes to connect with others with type 1, learn, and contribute to research.

URL: www.MyGlu.org

> Don't Freak Out: 10 Important Things to Know When You've Been Diagnosed with Type 2 Diabetes

Description: This pamphlet lists 10 important points that people with newly diagnosed diabetes should know. A PDF version can be downloaded

(‘previewed’) for free from the Behavioral Diabetes Institute website.

Source: Behavioral Diabetes Institute.

URL: www.behavioraldiabetes.org

Research

For those wishing to learn more about the scientific and research advances being made in diabetes, a number of sites provide information designed with a non-professional audience in mind.

URLs: www.diabetestrialnet.org, www.trials.jdrf.org, www.clinicaltrials.gov

Books

› *Bright Spots and Landmines: The Diabetes Guide I Wish Someone Had Handed Me*

Description: A person with diabetes shares the strategies for food, mindset, exercise, and sleep that have had the biggest positive impact on his diabetes. Along the way, he argues that the usual focus on problems and mistakes in diabetes—landmines—misses the bigger opportunity—bright spots.

Source: Brown A. *Bright Spots and Landmines: The Diabetes Guide I Wish Someone Had Handed Me*. US, The diaTribe Foundation. 2017.

› *Type 1 Diabetes in Children, Adolescents and Young Adults, 6th edition*

Description: A comprehensive guide to type 1 diabetes in children, enabling children and their parents to become experts in control of the child’s diabetes.

Source: Hanas R. *Type 1 Diabetes in Children, Adolescents and Young Adults*. Sweden, Class Health. 2019.

› *The Everything Parent’s Guide to Children with Juvenile Diabetes*

Description: *The Everything Parent’s Guide* helps readers cope with the challenges of helping their children live happy, healthy lives while controlling the disease.

Source: McCarthy M, Kushner J. *The Everything Parent’s Guide to Children with Juvenile Diabetes*. US, Adams Media. 2007.

› *Understanding Diabetes, 14th edition*

Description: A classic title from the Barbara Davis Diabetes Center in Denver, CO, now recently revised.

Covers a variety of topics, including diabetes basics, self-care, coping, and more.

Source: Chase HP, *Understanding Diabetes*. US, Children’s Diabetes Foundation. 2019.

› *KIDS FIRST Diabetes Second: Tips for Parenting a Child with Type 1 Diabetes*

Description: Based on the author’s “D-Mom” Blog, this resource shows parents how to automate tasks, navigate challenges, celebrate achievements, establish a support group, and relieve stress.

Source: Calentine L. *Kids First Diabetes Second*. US, Spry Publishing. 2012.

› *The Mindful Guide to Managing Diabetes*

Description: This guide helps those with diabetes manage stress, anxiety, and depression through mindful living.

Source: Napora J. *The Mindful guide to Managing Diabetes*. US, American Diabetes Association. 2019

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Chapter 3

Diabetes Distress



Key Messages

- Diabetes distress is the emotional distress that results from living with diabetes and the burden of relentless daily self-management.
- Severe diabetes distress affects one in five people.¹ In one of the largest cohort studies to date, severe diabetes distress was reported in one of four people with type 1 diabetes, one in five people with insulin-treated type 2 diabetes, and one in ten people with non-insulin treated type 2 diabetes (MILES-2 Study).²
- Greater diabetes distress is associated with suboptimal diabetes self-management, A1C, and impaired general emotional well-being.
- Diabetes distress is sometimes mistaken for, and is more common than, depression.
- The Problem Areas In Diabetes (PAID) scale and Diabetes Distress Scale (DDS) are used to identify diabetes distress and to guide conversations about diabetes distress.
- Diabetes distress is best managed within the context of diabetes care.
- Although greater diabetes distress tends to be associated with higher A1C, optimal A1C is not necessarily an indicator of low diabetes distress.



Practice Points

- As diabetes distress is relatively common and can also affect self-care, it is important that every healthcare appointment includes opportunities for the person to express how they are feeling about life with diabetes.
- Remain mindful that certain treatment options may increase the burden of diabetes self-management and increase the likelihood of diabetes distress.
- Collaboratively set an agenda for the appointment—talk about what each of your priorities are for today and agree about how much time to dedicate to each topic.

How Common Is Diabetes Distress?

Evidence from 50 studies across the world tells us that one in four people with type 1 and 2 diabetes have high levels of diabetes distress that is likely to be negatively affecting how they manage their diabetes.¹



Type 1 diabetes^{a,2}



Type 2 diabetes (insulin)^{a,2}



Type 2 diabetes (no insulin)^{a,2}



WHAT IS Diabetes Distress?

Diabetes distress (also known as “diabetes-specific distress” or “diabetes-related distress”) is the emotional response to living with diabetes, the burden of relentless daily self-management, and (the prospect of) its long-term complications.^{3–5} It can also arise from the social impact of diabetes (e.g., stigma, discrimination, or dealing with other people’s unhelpful reactions or their lack of understanding)^{6,7} and the financial implications (e.g., insurance and treatment costs) of the condition.^{3,8}

Diabetes distress occurs on a continuum defined by its content and severity.³ This emotional distress, to a greater or lesser degree, is part of having to live with and manage diabetes. It can fluctuate over time and may peak during challenging periods; for example, soon after diagnosis, during major changes in treatment regimen, or at diagnosis/worsening of long-term complications. It can also peak at times of heightened general stress, when the added burden of diabetes self-care becomes too much.⁹ The extent to which diabetes distress is stable or changes over time varies depending on the source of the distress.¹⁰ If left untreated, mild diabetes distress often persists¹¹ and may develop into severe diabetes distress and/or depression¹⁰ (see [Chapter 6](#)).

Living with diabetes is challenging. The most frequently reported problem areas among people with type 1 and type 2 diabetes are “worrying about the future and the possibility of serious complications” and “experiencing feelings of guilt and anxiety when diabetes management goes off track.”^{12,13} Although there are common stressors regardless of the type of diabetes, distress can differ by diabetes type (e.g., for type 1 diabetes more often related to insulin treatment and hyper/hypoglycemia;

for type 2 diabetes more often related to social consequences, food restriction, and obesity).¹⁴

The impact of these diabetes-related feelings should not be underestimated. Managing diabetes is a “24/7” activity, involving the continual need to make decisions, and take actions, with often unexpected and unsatisfactory outcomes. Doing everything “as recommended” is no guarantee of stable blood glucose levels—doing exactly the same things today as the day before can result in very different outcomes. The accumulation of these problems and frustrations may lead to “diabetes burnout” (see [Box 3.1](#)) and disengagement from diabetes care.

Diabetes distress involves emotional symptoms that overlap with several recognized mental health conditions, such as depression (see [Chapter 6](#) and [Box 6.2](#)).^{3,5} Despite their similarities, depression and diabetes distress are different constructs and require different assessment and management strategies. Unlike major depression, diabetes distress does not assume psychopathology—it is an expected reaction to diabetes, whereas depression refers to how people feel about their life in general.⁴

Greater diabetes distress is associated with adverse medical and psychological outcomes, including:

- › suboptimal self-management (e.g., reduced physical activity, less healthy eating, not taking medication as recommended, and less frequent self-monitoring of blood glucose)^{15–20}
- › elevated A1C^{19,21–26}
- › more frequent severe hypoglycemia^{15,27}
- › and impaired quality of life.^{16,28}

a 28%, 20%, and 11% had severe diabetes distress (PAID total score ≥ 40) respectively. Data based on the Diabetes MILES-2 report.²

BOX 3.1 Diabetes Burnout

Diabetes burnout is a state of physical or emotional exhaustion caused by the continuous distress of diabetes (and efforts to self-manage it).^{29,30} Typically, the individual feels that despite their best efforts, their blood glucose levels are unpredictable and disappointing. People with diabetes describe it as feeling “detached” from their diabetes care, combined with a sense of “powerlessness.”³¹

People with diabetes burnout “can’t be bothered” with the continual effort required to manage diabetes. This state of mind can be temporary, or it may be ongoing. These individuals are sometimes described by health professionals as being “difficult,” “non-compliant,” or “unmotivated,”^{32,33} while they are actually struggling with the relentlessness of managing a lifelong condition.

Signs of diabetes burnout include:

- › disengagement from self-care tasks (e.g., skipping insulin doses or not monitoring blood glucose)
- › unhealthy or uncontrolled eating
- › risk-taking behaviors
- › or non-attendance at clinic appointments.

People with diabetes burnout understand the importance of diabetes self-management for their future health but feel unable to engage with management of their diabetes. If and when someone with diabetes burnout attends their appointment, they are rarely open to any advice for change that you may offer: “*I’ve tried that before, but it didn’t work*”; “*I stopped doing finger-pricks because I know my blood sugar will be too high anyway.*” This disengagement from self-care can increase their fears of developing long-term complications and sense of powerlessness to take control. As clinical psychologist, Dr. William Polonsky, describes, “*they are at war with their diabetes—and they are losing it.*”^{29,*}

Diabetes burnout can co-occur with depression (see [Chapter 6](#)), anxiety (see [Chapter 7](#)), and negative mood. In contrast to diabetes distress, very little research has been conducted specifically about diabetes burnout.^{30,34}

The best way to prevent diabetes burnout is to regularly monitor for diabetes distress so that you can offer timely assistance to address concerns as they arise.

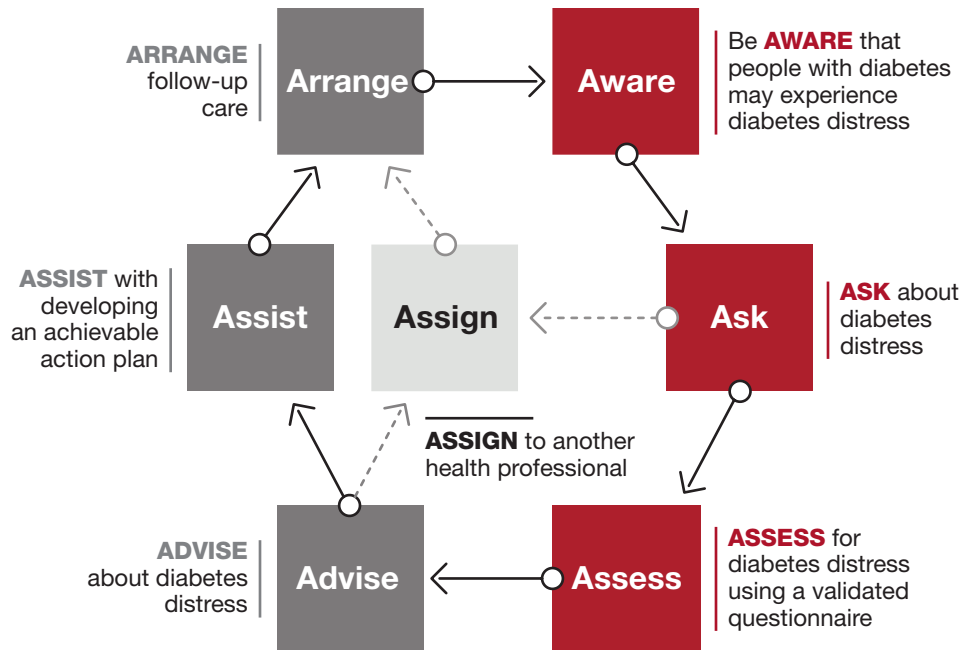
*Dr. Polonsky’s book, *Diabetes Burnout: What to Do When You Can’t Take It Anymore*, is a helpful resource for people with diabetes, but also for diabetes health professionals; it provides realistic and clear insight into what diabetes burnout is and how it can be treated.

7 A's Model: Diabetes Distress

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 diabetes distress?
- How can I support a person who experiences diabetes distress?

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



HOW CAN I IDENTIFY Diabetes Distress?

■ Be **AWARE**

Diabetes distress can present itself in many ways. Some common signs to look for include:

- › suboptimal A1C or unstable blood glucose levels
- › not attending clinic appointments
- › reduced engagement with diabetes self-care tasks (e.g., less frequent monitoring of blood glucose or skipping medication doses)
- › ineffective coping strategies for dealing with stress (e.g., emotional eating)
- › multiple negative life stressors or chronic stress distinct from diabetes (e.g., financial problems, unemployment, or homelessness)
- › impaired relationships with health professionals, partners, family, or friends
- › or appearing passive or aggressive during medical appointments.



Even if A1C or blood glucose levels are within target, this does not mean that the person is free of diabetes distress. Achieving these targets may require intensive efforts that are potentially affecting other areas of their life (e.g., social activities and quality of life) and are unsustainable. Remain mindful that recommending changes to diabetes self-management (e.g., recommending more frequent blood glucose monitoring) may increase the burden of diabetes and, thereby, has the potential to increase diabetes distress.

■ ASK

It is advisable that you ask about diabetes distress on a routine basis, as part of your person-centered medical appointments, to explore the impact of diabetes on the person's daily life and well-being.

Ask open-ended questions. You can preface these by acknowledging the expected daily challenges of living with diabetes, for example, *“Many people that I see feel that living with diabetes is quite challenging.”* This “normalizes” diabetes distress.

There are many ways you can ask about diabetes distress;⁸ choose an approach that you find most comfortable and one that best suits the person with diabetes. Here are some examples of open-ended questions you could use:

- › *“What is the most difficult part of living with diabetes for you?”*³⁵
- › *“What are your greatest concerns about your diabetes?”*³⁵
- › *“How is your diabetes getting in the way of other things in your life right now?”*

These questions offer the person an opportunity to:

- › raise any difficulties (emotional, behavioral, or social) that they are facing
- › and express how particular diabetes-related issues are causing them distress and interfering with their self-care and/or their life in general.

One example of how to follow up the conversation could be: *“It sounds like you’re having a difficult time with your diabetes. The problems you describe are quite common. And, as you also said, they often have a big impact on how you feel and how you take care of your diabetes. If you like, we could take some time to talk*

about what you and I can do to reduce your distress. What do you think?”

Additional Considerations

- › People may not expect to be asked about their emotions during a diabetes appointment. A distinct disconnect between you and the person with diabetes may be an indication of diabetes distress. For example, the person may not be listening to what you say or may reject your suggestions for changes to their diabetes management plan or lifestyle. Also, look out for people who regularly skip or do not attend their appointments.
- › People with diabetes may not be aware of diabetes distress and may interpret their experiences as depression.
- › Diabetes distress fluctuates over time. A person may not be experiencing diabetes distress today but they may be the next time you see them. Life circumstances can change quickly, and stressors (diabetes-related or not) may disrupt blood glucose levels or self-care behaviors and worsen diabetes distress. Therefore, at every appointment, it is always a good idea to ask the person how they are doing with their diabetes.

If the person indicates that they are experiencing concerns or distress about diabetes, you may want to explore this further (see **ASSESS**). Using a validated questionnaire will help you both get a better understanding of the specific problems the person is facing. Importantly, it will also give you a benchmark for tracking the person's distress over time.

However, only use a questionnaire if there is time during the appointment to talk about the scores and discuss with the person what needs to happen in order to address the identified “problems.” For information about using questionnaires in clinical practice, see pages 10 and 11.

■ ASSESS

Validated Questionnaires

The Problem Areas In Diabetes (PAID) is a 20-item questionnaire, widely used to assess diabetes distress.³⁶ A copy is included on page 44. Each item is measured on a five-point scale, from 0 (not a problem) to 4 (a serious problem). The scores for each item are summed, then multiplied by 1.25 to generate a

total score out of 100; with total scores of 40 or more indicating severe diabetes distress.¹³ Apart from the total score, an individual item score of 3 or more indicates a “problem area” or concern and should be further explored in the conversation.

Another widely used questionnaire for diabetes distress is the Diabetes Distress Scale (DDS), which has 17 items.⁶ A version of the DDS specifically designed for people with type 1 diabetes (T1-DDS) has also been validated in the U.S. and Canada.⁸ A copy of each scale is included on pages 46–48. Each item is measured on a six-point scale, from 1 (not a problem) to 6 (a very serious problem). Scores on individual items are averaged within subscales (sources of distress) and a total score; with scores of 2–2.9 indicating moderate distress, and scores of 3.0 or greater indicating severe diabetes distress.³⁷

To follow up on the completion of the PAID or DDS you may want to ask:

- *“How did you feel about answering these questions?”*
- *“When looking at your scores, does anything stand out for you?”*



Not all stressors that can lead to diabetes distress are addressed in the existing validated questionnaires, and therefore exploration through open-ended questions is recommended (see **ASK) to identify other causes of diabetes distress.**

Additional Considerations

No Diabetes Distress—What Else Might Be Happening?

- If the person’s responses to the questionnaire do not indicate the presence of diabetes distress, this may be because they are reluctant to open up about their distress or may feel uncomfortable disclosing to you that they are not “on top” of their diabetes.

Therefore, a very low score does not necessarily mean that the person is not experiencing diabetes distress. It may be that they are not yet ready to share that experience with you. It may take time for them to express their diabetes-related concerns and problems—or they may feel more comfortable talking about it with someone else. Acknowledging that many people experience difficulties and distress in managing their condition on a daily basis can be one way to show your support and openness to talk about their concerns; they may be ready to talk at future appointments.

- If not diabetes distress, consider other psychological problems, for example, depression (see **Chapter 6**), anxiety (see **Chapter 7**), or general psychological distress. Using a general psychological distress questionnaire (such as the Kessler-10)³⁸ could be informative in this instance, as the person may be experiencing other life stressors that are causing general distress and affecting their diabetes self-management and outcomes. Explaining and normalizing diabetes distress is the first step to addressing it (see **ADVISE**).



HOW CAN I SUPPORT A PERSON Who Experiences Diabetes Distress?

■ ADVISE

Now that you have identified what is causing the person's diabetes distress, you can advise them on the options for the next steps and then, together, decide on an action plan.

When using the PAID or DDS, the scores on the individual items are a useful first indication of the major problem(s) or concerns for the person and will guide the conversation.

Explain what diabetes distress is and that many people with diabetes experience it:

- Explain the signs and consequences of diabetes distress (e.g., the impact on their daily self-management and well-being).
- Acknowledge the significant daily efforts required to manage diabetes—this by itself may reduce the distress.
- “Normalize” negative emotions about diabetes.
- If a person is self-blaming (e.g., “*I am useless,*” or “*I can never get it right*”), explain that diabetes outcomes are not a reflection of who they are as a person; diabetes is not about being “good” or “bad” or “a failure.”^{32,33} Instead remind them that diabetes can be difficult to manage, so focusing on what they are doing well, despite less-than-ideal outcomes, is sometimes “good enough.”
- Offer the person opportunities to ask questions about what you just discussed.
- Make a joint plan about the “next steps” (e.g., what needs to be achieved to reduce diabetes distress and the 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.³⁹
- As diabetes distress is so common and intertwined with diabetes management, it is best addressed by a diabetes health professional (or the 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.³

- There will be occasions when you will need to refer the person to another health professional. This will depend on:
 - the needs and preferences of the person with diabetes
 - your knowledge, skills, and confidence to address the problem area(s)
 - the severity of the diabetes distress, and the specific problem(s) identified
 - whether it is combined with other significant life stressors
 - whether other psychological problems are also present, such as depression (see **Chapter 6**) or anxiety (see **Chapter 7**)
 - and your scope of practice, and whether you have the time and resources to offer an appropriate level of support.
- If you believe referral to another health professional 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

Explore the most appropriate support for the individual, for example, diabetes education or revising their management plan; advice on lifestyle changes; emotional or social support; or a combination of these.

Practical strategies for assisting a person with diabetes distress are detailed in **Appendix C**. The strategies are based on clinical experience, expertise, and evidence.^{9,40,41} Not all will suit everyone, so you will need to work with the person to tailor an action plan to meet their specific concerns, needs, and preferences. Discussing the individual's responses to the PAID or DDS (see **ASSESS**) is useful for this purpose. If multiple stressors are identified, prioritize their most important or burdensome issues.

You might ask questions to inform the action plan, such as:

- › *“It sounds like you are struggling with several aspects of your diabetes care. Which of these would you most like to talk about today?”*
- › *“You said you feel angry and guilty when you think about your diabetes. Could you tell me what exactly makes you feel this way?”* Explore whether it is the self-management tasks or the diabetes outcomes (e.g., high blood glucose levels) leading to these feelings, or whether it is related to how diabetes affects other aspects of their life (e.g., feelings of not being a “good” parent because of diabetes, or diabetes interfering with their work or social life).
- › *“You have indicated that you are concerned about developing complications. Could you tell me a bit more about your concerns?”* The person’s response will help you to identify unrealistic concerns so you can provide personalized information about their actual risk and preventative actions. It will give you a better understanding of the person’s specific concerns, for example, whether their concerns relate to the risk of vision impairment, problems with their feet, or other complications. Many people with diabetes overestimate their risk of complications and feel helpless to prevent them. This causes significant distress and can lead to disengagement with their self-care.
- › *“According to your responses, you feel supported in some aspects of your diabetes management but not in others, is that correct? Can you give me an example of this?”*
- › *“You feel that you are not getting support from your partner or family/friends. Is this your overall feeling?”*

Additional Considerations

- › **Reflect on aspects that are going well, to counterbalance “problems.”** Many of our conversations focus on problems and problem solving. However, it is just as crucial to explore what is going well; that is, in what aspect(s) of diabetes management does the person feel confident? This will highlight their strengths and skills, which could be applied to address their current problems.
- › **Agree on an agenda for the appointment.** Agree with the person about the time dedicated to talk about their concerns and the issues you both would like to address today. In practice, there is usually a big overlap between both agendas, but it is important not to assume this is the case. If there is insufficient time to cover everything, suggest a follow-up appointment

with you or someone else on your team who could provide the additional support.

- › **Stay open to the idea that people with diabetes can have safe, planned breaks from their usual diabetes management** (see [Box 3.2](#)).
- › **If the diabetes distress persists, a more intensive approach may be needed.** Although diabetes distress is best addressed during routine appointments, if the person shows no improvement it may be necessary to:
 - reconsider referring the person to a mental health professional
 - and assess whether there are additional or other underlying psychological problems, for example, depression (see [Chapter 6](#)) or anxiety (see [Chapter 7](#)).

BOX 3.2 Taking a Safe Break from Diabetes

It is unrealistic to expect people with diabetes to monitor their health vigilantly 24 hours a day, seven days a week. As this guide outlines, lack of motivation due to diabetes distress and/or depression can have serious negative consequences for a person’s health. People so inclined will take breaks from actively managing their diabetes with or without your support. Enabling them the freedom to take short breaks every now and then will increase their chances of maintaining motivation to take good care of their health in the long-term.

Where Do I Start?

Work with the person to meet their needs. Remember to put yourself in their shoes and think what it would be like for you to manage diabetes 24/7. For example, if they are struggling to check their blood glucose several times a day, consider reducing the number of checks required for a period of time. In the meantime, work with them on their concerns regarding this issue (e.g., through supportive counselling or goal setting). Regardless of the issue they are facing, it is important to remain supportive and encouraging. This will eliminate any feelings of guilt that the person may be experiencing for not managing their diabetes “perfectly.” Remind the person that you understand managing diabetes is a full-time job and appreciate that everyone needs a break now and then.

■ ASSIGN

If a decision is made to refer, consider:

- a certified diabetes educator or other diabetes health professional (e.g., endocrinologist) for difficulties with diabetes management and support
- a mental health professional (e.g., psychologist or psychiatrist, preferably with an understanding of diabetes) for stress management or if other emotional problems such as depression (see **Chapter 6**), anxiety (see **Chapter 7**), or more complex psychopathology are underlying the diabetes distress.



For some people, an intensive psychological intervention may be the best option to reduce severe diabetes distress. Cognitive behavioral therapy, motivational interviewing and brief solution-focused therapy have been successfully applied in diabetes.

These health professionals can be accessed in accordance with an individual's insurance coverage. A PCP or other diabetes-specific clinician can assist with this.

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 consultations or more frequent follow-up visits (e.g., once a month) are required until the person feels better skilled or stronger emotionally. 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.

Monitor people with identified diabetes distress closely, so that you can assess their level of distress and how it may change over time. The advantage of using a validated scale routinely (e.g., PAID or DDS) is that this systematic monitoring allows you to compare scores over time. Then you can be proactive in picking up early signs or a relapse.

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

- *“Last time we talked about you feeling overwhelmed with all the tasks you have to do in managing your diabetes. We agreed on making a couple of changes to your management and lifestyle. How has this worked out for you?”* For example, explore what has worked, obstacles, concerns, and whether any changes to the action plan are needed.
- *“Last time we talked about you seeing a diabetes educator to help you [get your blood glucose levels back on track]. You felt frustrated about [these high numbers].”* You could then ask the following questions:
 - *“Has this been helpful?”* If yes, *“How is this helpful for you?”* If no, *“What do you think needs to happen so that it will help?”*
 - *“What changes have you made?”*
 - *“Which changes were helpful/not helpful?”*
 - *“How do you feel now about [your blood glucose levels]?”*
 - *“Are you happy to continue with [these changes]?”* Explore response.
 - *“How do you feel about [these changes]?”*



CASE STUDY

Anna

62-year-old woman, living with her husband

Type 2 diabetes for 10 years; overweight

Oral medications for diabetes, high blood pressure, and high cholesterol

Health professional: Dr. Andrew Sutter (PCP)

■ Be AWARE

Andrew is aware that American Diabetes Association and international guidelines recommend assessment for diabetes distress in people with type 2 diabetes.⁴² He invites Anna to complete the PAID while she is waiting for her consultation.

■ ASK and ASSESS

When Anna hands over the completed questionnaire, Andrew notices immediately that 12 of 20 items have scores of 3 and 4. It is clear that Anna is feeling highly distressed about her diabetes. Andrew has known her for a long time and is aware that she has been having some difficulties managing her diabetes, but he did not realize she was struggling so much. Her medical results had been improving.

He thanks Anna for completing the questionnaire and asks, “How was it for you to answer all these questions?” Anna responds, “Well, it doesn’t look good, does it? I am really angry! But it feels good that I could say how I really feel about diabetes.” Andrew suggests that they first look at her questionnaire responses, before checking her blood pressure and looking over recent lab results, and Anna agrees.

The high PAID scores are mostly related to the emotional impact of living with diabetes and difficulties with diabetes management. Anna confirms that, yes, these are the most important problems she is experiencing at the moment. Andrew asks Anna to tell him a bit more about these difficulties. Anna responds, “It is so hard for me to control what I eat, to take all these medications every day, and to walk my dog in the morning. Most of the time I do all

these things, but it is a big effort! I am not sure how long I can keep doing this. Sometimes I wonder how I manage to get out of bed, eat, let the dog out, and go to work. At night I say to myself, ‘I made it through another day.’ I can’t keep my house clean. And that is really bad! I feel guilty when my house is a mess, but I am really too tired.”

■ ADVISE

Andrew reflects on the challenges Anna has been experiencing. “It sounds like you are overwhelmed by all the things you need to do every day, while not having much energy. But you still keep going.” He asks, “Is there anything at the moment that helps you to keep going?” Anna tells him that her husband and friends are very supportive, and that having her grandchildren around makes her feel better, too.

Andrew acknowledges Anna’s continuous efforts to take care of her health despite not feeling very well lately. He asks about the types of support that would help her to reduce the diabetes distress. She does not answer directly, instead she continues her story—her life has not been the same since she was diagnosed with diabetes. She feels like diabetes “controls” her life. Anna believes she got diabetes because she is overweight, and now she wants to make up for “not eating healthy” at the time she was diagnosed. But she feels like she “fails” constantly with her “diet.”

Andrew reassures Anna that it is not her fault that she developed diabetes—weight is only one of many reasons people get type 2 diabetes. Anna has other family members with type 2 diabetes, so there is probably a genetic factor involved, and no one can really say exactly how her diabetes came about. He

suggests that, rather than blaming herself for getting diabetes, the most important thing now is to focus on how best to manage it. Anna says she has not thought about it in that way, but that he is probably right. Andrew summarizes the different issues that Anna has described to him and he also mentions the support she gets from her husband. He checks with Anna regarding which of the difficulties she would like to address first. Anna tells him that her unhealthy eating is her major concern, and she would like to be a bit more active; having her husband join her may motivate her to go for longer walks. They talk about how she might raise this idea with her husband.

■ ASSIGN

Andrew explores whether Anna would like to talk to an accredited practicing dietitian or certified diabetes educator to help her find an eating pattern that is more achievable and sustainable—a healthy lifestyle change, rather than a “diet.” Anna agrees that she would like to try this approach and that Andrew may write her a referral to a dietitian.

■ ARRANGE

Anna feels understood by Andrew; the conversation has helped her to feel a bit less stressed about her diabetes. She feels positive about the plan they have made and looks forward to her appointment with the educator. Andrew suggests they meet again in one month to evaluate how she is doing with her walks and how the consultation with the dietitian went. He also asks if it would be OK to fill in the PAID at a future appointment to see if her diabetes distress has reduced. She tells him that she is happy to do so, but not too soon, because she would like to have enough time to make the changes they discussed first. They agree to revisit the PAID in a couple of months.

They continue the consultation; Andrew checks her blood pressure, and they talk about her recent A1C and cholesterol results.



CASE STUDY

John

31-year-old man, living with his partner and their daughter, and looking for employment

Type 1 diabetes for eight years, managed using an insulin pump for the past three years

Health professional: Sarah Jones (certified diabetes educator)

■ Be AWARE

The staff at the diabetes clinic that John attends are trialing diabetes distress monitoring as a part of their routine care. The receptionist is asking all people with type 1 diabetes to complete the type 1 version of the Diabetes Distress Scale (T1-DDS) while waiting for their appointment. She invites John to complete the questionnaire and explains that Sarah will go through his responses with him. She indicates that an explanation of the new protocol is included at the top of the questionnaire with the instructions. John agrees.

■ ASK

John hands Sarah the completed questionnaire, remarking, *“I hate my diabetes!”* Sarah is surprised by his outburst at first but invites him to tell her a bit more about what he hates most; his response will help her to understand how she can support him.

He tells her that he has always struggled. He had hoped that using a pump would take away his frustration, but at the moment he feels worse. *“My pump is a constant reminder that I have diabetes. And since I got it, I’m having more hypos. My diabetes ruins everything.”*

Sarah, who has known John since he was first diagnosed with diabetes, had not been aware of John’s difficulties until now. John has never mentioned a problem and, since he began using a pump, his A1C has always been on target. John tells Sarah that completing the questionnaire has given him a way to express his feelings about diabetes—something he has not been asked about before. John is aware that people think he is “on top of it,” as he keeps his stress to himself. He wants to be strong

for his family but, in reality, he is struggling. He has applied for a new job and is stressed that he may have a hypo during the interview. He doesn’t want to worry his partner or get other people involved. *“It’s my problem,”* he says. *“I have to deal with it.”*

■ ASSESS

Sarah casts her eye over John’s T1-DDS responses. He has scored most of the items a 1 or 2, indicating that they are not a problem or only a minor problem for him. Sarah notes that he has scored a few items with 4 or 5, indicating they are serious problems for him. Most of these problems were from a feeling of powerlessness or hypoglycemia-related sources of distress, including:

- › feeling that there is too much diabetes equipment and stuff I must always have with me
- › feeling that no matter how hard I try with my diabetes, it will never be good enough
- › feeling that I’ve got to be perfect with my diabetes management
- › feeling frightened that I could have a serious hypoglycemic event when I’m asleep
- › and feeling that I can’t ever be safe from the possibility of a serious hypoglycemic event.

These responses, in combination with John’s comments, give her a good understanding of how he is feeling. His averaged T1-DDS score indicates that he is just below the threshold for high diabetes distress (defined as ≥ 3.00). The T1-DDS total and subscale scores give Sarah a baseline level against which to compare future scores as they work to reduce his distress.

■ ADVISE

Sarah tells John that his questionnaire responses indicate he is experiencing diabetes distress, and she explains what this is. She reassures him that it is very common to have negative feelings about diabetes, and that the diabetes team is here to help. She tells him she would like to support him in reducing his diabetes distress, if he agrees, which he does.

■ ASSIST

Sarah checks whether John would like to keep using the pump. He is not sure about the long term but, for now, he would prefer not to change to injections. Sarah asks about his upcoming interview and his fear of having a hypo. They talk about practical strategies to avoid low blood glucose. John feels relieved now that he knows how to handle this. Sarah thinks John might benefit from seeking peer support, especially because he does not want to burden his partner with his distress. Sarah tells John about face-to-face and online peer support groups and asks him whether this is something he would be interested in joining. He says he will give it some thought. As there is no time to talk about the other problem areas identified in the T1-DDS that day, they will take this up in the next appointment.

■ ARRANGE

They agree to meet again in a month to follow up about John's distress and his experience applying the strategies they discussed today. They will also discuss how he feels about continuing with the pump. Sarah also makes a note to talk with John about not wanting to burden others with his worries, as there was no time to address this today.

Questionnaire: Problem Areas In Diabetes (PAID) Scale

Instructions: Which of the following diabetes issues are **currently** a problem for you? Tick the box that gives the best answer for you. Please provide an answer for each question.

	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
1 Not having clear and concrete goals for your diabetes care?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2 Feeling discouraged with your diabetes treatment plan?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3 Feeling scared when you think about living with diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4 Uncomfortable social situations related to your diabetes care (e.g. people telling you what to eat)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5 Feelings of deprivation regarding food and meals?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6 Feeling depressed when you think about living with diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7 Not knowing if your mood or feelings are related to your diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8 Feeling overwhelmed by your diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9 Worrying about low blood glucose reactions?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10 Feeling angry when you think about living with diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11 Feeling constantly concerned about food and eating?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12 Worrying about the future and the possibility of serious complications?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13 Feelings of guilt or anxiety when you get off track with your diabetes management?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14 Not accepting your diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15 Feeling unsatisfied with your diabetes physician?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16 Feeling that diabetes is taking up too much of your mental and physical energy every day?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17 Feeling alone with your diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18 Feeling that your friends and family are not supportive of your diabetes management efforts?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19 Coping with complications of diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20 Feeling burned out by the constant effort needed to manage diabetes?	<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 Problem Areas In Diabetes (PAID) scale is a well-validated, psychometrically robust questionnaire with 20 items.³⁶ It is sometimes referred to as the PAID-20, to distinguish it from the eleven-item (PAID-11),⁴³ five-item (PAID-5), and one-item (PAID-1) short forms.⁴⁴

How to Use the PAID in Clinical Practice

Respondents are asked to indicate the degree to which each of the items is currently a problem for them, from 0 (not a problem) to 4 (a serious problem).

Clinically, the PAID can be used two ways:

1. Taking note of the higher scoring items and using these to start a conversation (sources of diabetes distress).
2. Calculating a total score (e.g., to assess change over time). The total score provides an indication of the severity of diabetes distress.



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

Interpretation of Scores

The scores for each item are summed, then multiplied by 1.25 to generate a total score out of 100.

- › Total scores of 40 and above: severe diabetes distress.¹³
- › Individual items scored 3 or 4: moderate to severe distress;¹³ to be discussed during the appointment following completion of the questionnaire.

Questionnaire: Diabetes Distress Scale (DDS-17)

Instructions: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle 1. If it is very bothersome to you, you might circle 6.

	Not a problem	Slight problem	Moderate problem	Somewhat serious problem	Serious problem	Very serious problem
1 Feeling that diabetes is taking up too much of my mental and physical energy every day.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
2 Feeling that my doctor doesn't know enough about diabetes and diabetes care.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
3 Not feeling confident in my day-to-day ability to manage diabetes.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
4 Feeling angry, scared, and/or depressed when I think about living with diabetes.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
5 Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
6 Feeling that I am not testing my blood sugars frequently enough.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
7 Feeling that I will end up with serious long-term complications, no matter what I do.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
8 Feeling that I am often failing with my diabetes routine.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
9 Feeling that friends or family are not supportive enough of self-care efforts (e.g., planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
10 Feeling that diabetes controls my life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
11 Feeling that my doctor doesn't take my concerns seriously enough.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
12 Feeling that I am not sticking closely enough to a good meal plan.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
13 Feeling that friends or family don't appreciate how difficult living with diabetes can be.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
14 Feeling overwhelmed by the demands of living with diabetes.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
15 Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
16 Not feeling motivated to keep up my diabetes self management.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
17 Feeling that friends or family don't give me the emotional support that I would like.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

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Questionnaire: Type 1 Diabetes Distress Scale (T1-DDS)

Instructions: Living with type 1 diabetes can be tough. Listed below are a variety of distressing things that many people with type 1 diabetes experience. Thinking back over the past month, please indicate the degree to which each of the following may have been a problem for you by circling the appropriate number. For example, if you feel that a particular item was not a problem for you over the past month, you would circle 1. If it was very tough for you over the past month, you might circle 6.

		Not a problem	Slight problem	Moderate problem	Somewhat serious problem	Serious problem	Very serious problem
1	Feeling that I am not as skilled at managing diabetes as I should be.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
2	Feeling that I don't eat as carefully as I probably should.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
3	Feeling that I don't notice the warning signs of hypoglycemia as well as I used to.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
4	Feeling that people treat me differently when they find out I have diabetes.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
5	Feeling discouraged when I see high blood glucose numbers that I can't explain.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
6	Feeling that my family and friends make a bigger deal out of diabetes than they should.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
7	Feeling that I can't tell my diabetes doctor what is really on my mind.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
8	Feeling that I am not taking as much insulin as I should.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
9	Feeling that there is too much diabetes equipment and stuff I must always have with me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
10	Feeling like I have to hide my diabetes from other people.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
11	Feeling that my friends and family worry more about hypoglycemia than I want them to.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
12	Feeling that I don't check my blood glucose level as often as I probably should.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
13	Feeling worried that I will develop serious long-term complications, no matter how hard I try.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
14	Feeling that I don't get help I really need from my diabetes doctor about managing diabetes.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
15	Feeling frightened that I could have a serious hypoglycemic event when I'm asleep.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
16	Feeling that thoughts about food and eating control my life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
17	Feeling that my friends or family treat me as if I were more fragile or sick than I really am.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
18	Feeling that my diabetes doctor doesn't really understand what it's like to have diabetes.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
19	Feeling concerned that diabetes may make me less attractive to employers.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

20	Feeling that my friends or family act like “diabetes police” (bother me too much).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Feeling that I’ve got to be perfect with my diabetes management.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Feeling frightened that I could have a serious hypoglycemic event while driving.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	Feeling that my eating is out of control.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	Feeling that people will think less of me if they knew I had diabetes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	Feeling that no matter how hard I try with my diabetes, it will never be good enough.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	Feeling that my diabetes doctor doesn’t know enough about diabetes and diabetes care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27	Feeling that I can’t ever be safe from the possibility of a serious hypoglycemic event.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28	Feeling that I don’t give my diabetes as much attention as I probably should.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Background

The Diabetes Distress Scale (DDS) scale has 17 items (4 subscales and total score) and is used primarily with adults with type 2 diabetes. The T1-DDS has 28 items (7 subscales and total score) designed specifically for type 1 diabetes. Both are psychometrically robust and well validated.

How to Use the DDS/T1-DDS in Clinical Practice

Respondents are asked to indicate the degree to which each of the items is currently a problem for them, from 1 (not a problem) to 6 (a very serious problem).

Clinically, the DDS and T1-DDS can be used two ways:

1. Taking note of the higher scoring items and/or subscales and using these to start a conversation (sources of diabetes distress).
2. Calculating a total score (e.g., to assess change over time). The total score provides an indication of the severity of diabetes distress.



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

Interpretation of Scores

- The DDS⁶ yields a total diabetes distress score plus 4 subscale scores, each addressing a different kind of distress (emotional burden, regimen, interpersonal, and physician distress).
- The T1-DDS⁸ yields a total diabetes distress score plus 7 subscale scores (powerlessness, management, hypoglycemia, family and friends, physician, negative social perceptions, and eating distress).
- To score, simply add the person’s responses to the appropriate items and divide by the number of items in that subscale or all items for the total scale score (see <https://diabetesdistress.org/> for subscale scoring). Total mean distress scores on the DDS or T1-DDS in the 1–1.9 are considered low distress, scores of 2–2.9 indicate moderate distress, and scores of 3.0 or greater indicate severe diabetes distress.³⁷
- Individual items scored 3.0 or greater—“moderate to severe distress”—need to be discussed during the appointment following completion of the questionnaire.

Resources

For Health Professionals

Peer-Reviewed Literature

› Addressing diabetes distress in clinical care: A practical guide

Description: A review paper outlining practical strategies to assist diabetes health professionals in addressing diabetes distress in clinical settings.

Source: Fisher L, Polonsky WH, et al. *Diabetic Medicine*. 2019;36:803-812.

› Differentiating symptoms of depression from diabetes-specific distress: Relationships with self-care in type 2 diabetes

Description: An empirical paper reporting on the results of a cross-sectional survey of people with type 2 diabetes to examine the relationship between depressive symptoms and diabetes distress. The independent relationship of depression and diabetes distress with diabetes self-care was also examined.

Source: Gonzalez JS, Delahanty LM, et al. *Diabetologia*. 2008;51:1822-1825.

› The confusing tale of depression and distress in patients with diabetes: A call for greater clarity and precision

Description: A review paper examining the differences between the definitions of depression and diabetes-specific distress, as well as the differences between the approaches of measurement of depression and diabetes-specific distress.

Source: Fisher L, Gonzalez JS, et al. *Diabetic Medicine*. 2014;31(7):764-772.

Book chapter

› Diabetes Distress

Description: This book chapter on diabetes-related emotional distress outlines its prevalence, and relationship with depression, as well as its clinical assessment and management.

Source: Hermanns, et al. Chapter 8: Diabetes distress. In Ismail K, Barthel A, et al., eds., *Depression and type 2 diabetes*. U.K., Oxford University Press. 2018

› Problem-Solving Skills

Description: This book chapter outlines the role of problem solving in diabetes self-management and the key principles of effective problem solving. The

chapter was developed for health professionals who consult with people with type 1 diabetes, but the key principles of problem solving could also be incorporated (with adaptation, as necessary) into type 2 diabetes consultations. An electronic version can be downloaded from the “Publications” section of the Australian Diabetes Society website.

Source: Conn J, et al. *Enhancing your consulting skills: supporting self-management and optimising mental health in people with type 1 diabetes*. Canberra, The National Diabetes Services Scheme and Australian Diabetes Society. 2014:58-65.

URL: <https://diabetessociety.com.au/publications.asp>

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: ADA offers resources through which people with diabetes and their family/friends can access diabetes information, education programs, and other events.

Phone: (800) 342-2383

URL: www.diabetes.org

› Juvenile Diabetes Research Foundation (JDRF) (for type 1 diabetes)

Description: Type 1 diabetes resources and events related to resilience and distress.

URL: <https://www.jdrf.org/arizona/2019/05/01/helpful-t1d-resources-for-resilience-and-distress/>

URL: <https://www.jdrf.org/t1d-resources/living-with-t1d/mental-health/>

› Peer Support for Diabetes

Description: An information sheet for people with diabetes about peer support opportunities.

Source: Association of Diabetes Care & Education Specialists, 2020.

URL: <https://www.diabeteseducator.org/living-with-diabetes/Tools-and-Resources/peer-support>

Information

> **Diabetes Distress Assessment and Resource Center**

Description: Information and resources for clinicians and people with diabetes about diabetes distress. Access to paper and electronic automated scoring of scales to assess diabetes distress.

URL: <https://diabetesdistress.org/>

> **Diabetes Distress**

Description: Information handout for people with diabetes about diabetes distress, including suggestions that the person may try in order to reduce their distress. 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>

> **Behavioral Diabetes Institute (BDI)**

Description: The BDI provides tools and programs focused on the psychological demands of diabetes including audio and video resources for individuals with diabetes, events, and programs.

URL: www.behavioraldiabetes.org

> **Diabetes Etiquette for People Who Don't Have Diabetes**

Description: A leaflet for people without diabetes describing the “do’s” and “don’ts” when offering support to a person with type 1 or type 2 diabetes.

Source: Behavioral Diabetes Institute, 1999.

URL: <https://behavioraldiabetes.org/xwp/wp-content/uploads/2015/12/BDIAdultEtiquetteCard.pdf>

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

Description: This book combines real-life stories of people with diabetes and information about the interplay between emotional and diabetes self-care. It includes self-evaluation questionnaires to help with identifying personal barriers to self-care, and easy-to-use strategies to overcome these barriers. It is available for purchase from the ADA website.

Source: Polonsky W. Diabetes Burnout. Arlington, VA, American Diabetes Association. 1999.

URL: <https://shopdiabetes.org/products/diabetes-burnout-what-to-do-when-you-cant-take-it-anymore>

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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^a



Type 2 diabetes^a

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).¹ 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.² 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.^{3–5} 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^b (often complicated by loss of consciousness or hospitalization, or affecting work, or nocturnal),^{6–12} or who have impaired awareness of hypoglycemia.⁷

In adults with type 2 diabetes, fear of hypoglycemia is greater in those using insulin compared to those using sulfonylureas,¹³ 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^c is very similar to adults with type 1 diabetes,¹⁴ 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.¹ 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.^{15,16} It can also affect family members’ quality of life (e.g., with sleep disturbances or worrying about the person’s safety when alone).¹⁷ 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.¹⁸

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.²

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

- › 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.¹⁹
- › Certain personality traits, for example neuroticism (type 1 diabetes),²⁰ high-trait anxiety, and general fear (type 1 and type 2 diabetes)^{9,10} are associated with fear of hypoglycemia; this relationship is most likely bi-directional.⁶ 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.²¹
- › 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.^{19,21} 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^{21,22}
- › reduced engagement with diabetes management^{22–24}
- › and impaired diabetes outcomes.^{23,25}

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.² Qualitative studies revealed that some of these people are not concerned about their loss of awareness and, therefore, do not appear to fear hypoglycemia.^{26,27} 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.²⁶ 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:²⁸

- › 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).

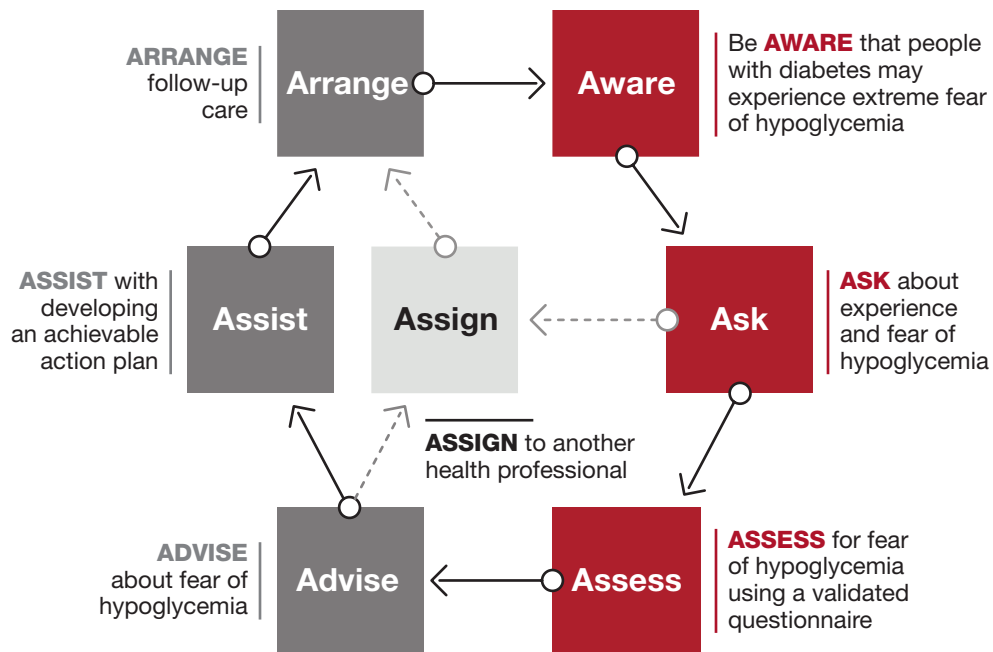
Explore the causes of the person’s fear—this will help to inform the action plan. Strategies to reduce the fear may include diabetes education, behavioral therapy, desensitization or distraction, and relaxation.

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)²⁹ 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.¹³ 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.³⁰
- 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.¹⁸
- 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 treatment³¹ (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:³²
 - 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).³³ 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.³³

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^d

- 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.

^d 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.³⁴ 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.^{34,35} 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.³⁶

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.^{3,5} 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,^{37,38} 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.^{35,39}

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) 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.²⁹ 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

- › **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

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

› *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>

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Chapter 5

Psychological Barriers to Insulin Use



Key Messages

- Psychological barriers to insulin use are the negative thoughts or feelings that people with diabetes may have about starting, using, or intensifying insulin.^a
- Of those people with type 2 diabetes for whom insulin is clinically indicated, around one in four report being “not at all willing” to start insulin.
- People already using insulin are sometimes reluctant to optimize or intensify insulin (but no prevalence data are available). One in 10 people with type 2 diabetes using insulin are dissatisfied with it.
- Psychological barriers can be associated with the delay, reduction, or discontinuation of insulin use, which can lead to suboptimal blood glucose levels and increased risk of diabetes complications.
- A brief questionnaire, such as the Insulin Treatment Appraisal Scale (ITAS), is useful for identifying psychological barriers to insulin use.
- There is little empirical evidence about the best ways to minimize psychological barriers to insulin. Recommendations based on clinical experience emphasize anticipating and acknowledging psychological barriers, and then working together with the individual to develop strategies to overcome them.



Practice Points

- Help people to understand the natural course and progressive nature of type 2 diabetes, and the likelihood that their treatment will change over time. Emphasize that needing insulin does not indicate that they have “failed,” and that insulin is simply the best treatment to meet their body’s needs right now.
- Be aware that people using insulin, as well as those not yet using insulin, experience psychological barriers to insulin. Every person will have different concerns; ask them what their concerns are, rather than making assumptions.
- Monitor for signs of psychological barriers to insulin, particularly when a person’s A1C has been above target for some time, and there is no sign that they are ready to transition to or intensify insulin.

^a The main focus of this chapter is on the concerns of people with type 2 diabetes. The concerns of people with type 1 diabetes are covered in Chapter 4: Fear of Hypoglycemia (and Other Diabetes-Specific Fears).

How Common Are Psychological Barriers to Insulin Use?



Type 2 diabetes (no insulin)^{b,1}



Type 2 diabetes (insulin)^{c,2}



WHAT ARE Psychological Barriers to Insulin Use?

People with type 2 diabetes often have negative thoughts or feelings about starting, using, or intensifying insulin.³ This is also known as “psychological insulin resistance” or “negative appraisals of insulin.”

Concerns about insulin among people with type 2 diabetes can be grouped into five main themes:⁴⁻⁹

- › concerns about medications (e.g., doubts about effectiveness or dependence on insulin) and possible side effects (e.g., weight gain or hypoglycemia)
- › anxieties about injections (e.g., fear of injections, needles, or pain; experiences of pain, bruising, scarring, or sensitivity from injections)
- › lack of confidence/skills (e.g., in their ability to use insulin; coping with a complex regimen, or injecting in public)
- › impact on self-perception and life (e.g., feelings of personal failure or self-blame for needing insulin, injections interfering with daily activities; or social stigma)
- › and fears about diabetes progression (e.g., insulin as a sign that diabetes is “getting worse,” insulin as the “last resort,” or mistaken beliefs that insulin leads to diabetes complications).



A person with diabetes may be aware of the benefits of insulin but still have worries or concerns about using insulin.

Concerns about insulin use can delay the transition from oral medication to insulin and result in missing injections

or stopping insulin.⁵ This has consequences for medical and psychological outcomes, including:¹⁰⁻¹⁴

- › glucose levels (including A1C) above recommended targets for prolonged periods, leading to increased risk of developing long-term complications
- › reduced satisfaction with treatment
- › impaired quality of life
- › or increased burden/costs to the individual and the healthcare system.



For some people, an alternative option to insulin may be a non-insulin injectable (see Box 5.1).

BOX 5.1 What about Other Injectable Therapies?

Typically, people with type 2 diabetes prefer oral medications to insulin.¹⁵ In recent years, new non-insulin injectable agents have become available. Like insulin, incretin-based agents (i.e., GLP-1) reduce blood glucose and require injections but have the advantage of a lower risk of hypoglycemia and weight gain. In clinical trials, people with type 2 diabetes report greater treatment satisfaction and quality of life using GLP-1s compared to insulin.¹⁶ It is possible that the perceived benefits of GLP-1s outweigh the perceived shortcomings of injections.¹⁶ Further research is required to evaluate this in clinical practice. Note that GLP-1 agents may be contra-indicated for some people.

b 30% of people with type 2 diabetes for whom insulin was clinically indicated “declined” to commence insulin.

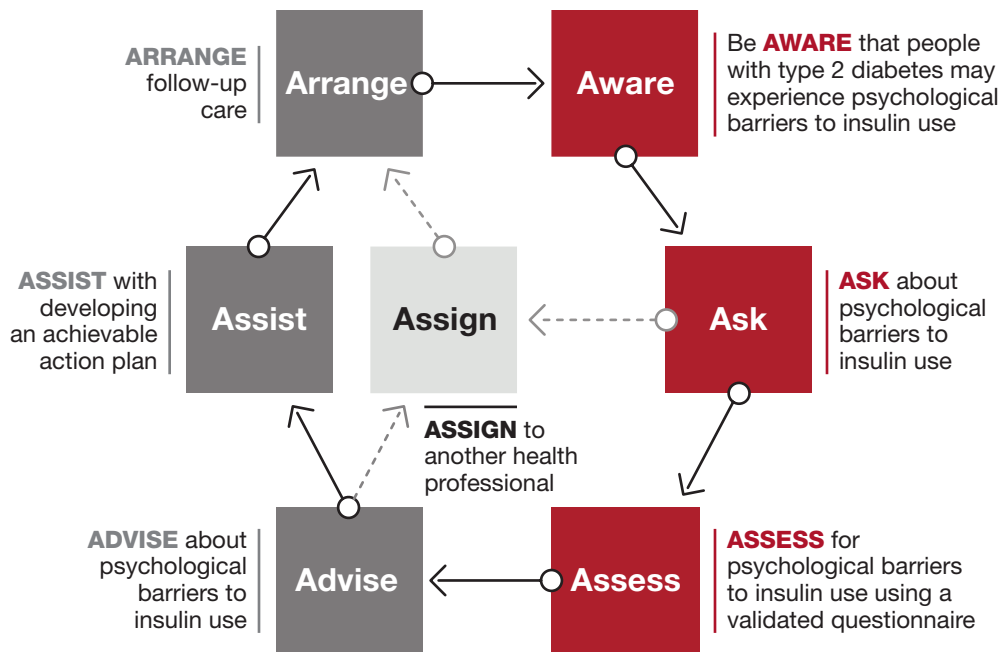
c 10% of people with diabetes expressed dissatisfaction with insulin. Note: the sample combined people with type 1 (n=180) and type 2 (n=1350) diabetes, but there were no significant differences between the groups for dissatisfaction with insulin.

7 A's Model: Psychological Barriers to Insulin Use

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 psychological barriers to insulin use?
- How can I support a person with psychological barriers to insulin use?

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



HOW CAN I IDENTIFY Psychological Barriers to Insulin Use?

■ Be **AWARE**

Individuals with psychological barriers to insulin may show this by:^{3,17,18}

- › avoiding or being reluctant to talk about, begin, or intensify insulin use
- › expressing concerns or becoming upset at the suggestion of beginning or intensifying insulin
- › expressing concerns about injecting or possible side effects of insulin (e.g., complexity of injection technique, effect on lifestyle, perceptions of self and others, or weight gain)
- › “negotiating” to “do better” with their current management plan to improve diabetes outcomes

- › “dropping out” (e.g., missing appointments or filling fewer insulin prescriptions)
- › appearing not to care about, or seeming uninterested in, managing their diabetes
- › talking about discontinuing insulin use (now or in the future)
- › or misusing insulin (e.g., missing doses or taking smaller doses than recommended) or stopping insulin altogether.

Some people may be embarrassed to raise concerns about insulin. Common remarks are shown in **Box 5.2**.

BOX 5.2 Remarks Indicating Possible Psychological Barriers to Insulin Use

"I worry I'll never be able to get off insulin"

"Insulin means you run the risk of hypos"

"No more spontaneity"

"It's not fair; I've tried so hard with diet, exercise, and medication"

"Needing insulin means I haven't done well managing my diabetes—I have failed, this is the end of the road"

"Others will worry a lot about me"

"I don't like needles"

"Insulin means my diabetes is worse"

"Insulin is too complicated and overwhelming—I will never be able to learn how to inject and get the right dose"

"I can improve my blood glucose/A1C numbers without insulin—just give me some more time to improve my numbers/lose weight/exercise more, etc."

"Insulin won't help my diabetes—nothing good will come of insulin"

"Since starting insulin my diabetes has not improved, but I have gained all this weight"

ASK

Ask open-ended questions during the consultation to explore the individual's beliefs and concerns about insulin. Have this conversation:

- shortly after the diagnosis of type 2 diabetes
- when you notice signs of concerns or worries about insulin (see **AWARE**)
- or if the person has suboptimal A1C despite being on (near) maximal oral agents.



Before asking the following questions for the first time, make sure the person realizes that diabetes is a progressive condition and that they are likely to need insulin in the future. Raise the use of insulin as a potential treatment option early (soon after diagnosis). Continue to have the conversation when you notice signs of psychological barriers to insulin, or when the person expresses concerns about insulin.

For example, for people who are not yet using insulin, you could ask:

- "How do you feel about going on insulin [now or in the future]? Can you tell me more about that?"
- "What questions do you have about insulin?"
- "How do you think insulin might affect your health and lifestyle?"
- "What do you think might be the benefits of using insulin for you?"
- "What do you think might be the disadvantages of using insulin for you?"
- "Some people have concerns about insulin. What concerns do you have? What is your main concern?"
- "What have you heard from other people with diabetes who use insulin?"

Or, for people who currently use insulin, you could ask:

- "Tell me about your experiences using insulin. How is that going?"
- "How do you feel about using insulin?"
- "What concerns do you have about insulin? Which is your main concern?"
- "What questions do you have about insulin?"

- › “How does insulin make your [life/diabetes] easier?”
- › “How does insulin make your [life/diabetes] more difficult?”
- › “What advantages have you noticed when using insulin?”
- › “What disadvantages have you noticed when using insulin?”



It is important to establish whether the person’s concerns are only related to insulin or related to their diabetes more broadly (see Chapter 3). To explore their broader concerns about diabetes, you might like to ask a question such as, “What is the most difficult part of having diabetes for you? Can you tell me more about that?”¹⁹

If the person indicates that they have concerns about using insulin, you may want to explore this further (see **ASSESS**). Using a validated questionnaire will help you both to identify additional barriers that were not raised through conversation. Importantly, it will also give you a benchmark for tracking an individual’s barriers to insulin use over time.

However, only use a questionnaire if there is time during the consultation to talk about the scores and discuss with the person what is needed to address the identified concerns about insulin. For information about using questionnaires in clinical practice, see pages 10 and 11.

■ ASSESS

Validated Questionnaire

The Insulin Treatment Appraisal Scale (ITAS; 20 items) is the most widely used measure of psychological barriers to insulin use.²⁰ A copy is included on page 87.

Each item is scored on a five-point rating scale from 1 (strongly disagree) to 5 (strongly agree). The items form two subscales:

- › **positive appraisal of insulin** (items 3, 8, 17, and 19): higher scores indicate more positive attitudes to insulin
- › and **negative appraisal of insulin** (all remaining items): higher scores indicate more negative attitudes to insulin.

There is no recommended cut-off value to indicate the presence or absence of psychological barriers to insulin use.

Subscale total scores may be valuable for assessing change over time. Responses to individual items will be helpful in guiding the conversation about insulin use and for understanding and addressing concerns.

Invite the person to explore their concerns (negative attitudes) about insulin in a conversation about their responses, for example, “I note here that you are concerned about [issue]. Can you tell me more about that?” If the person has several concerns, ask which are their priority issues, for example, “You seem to have a few worries about insulin. Which of these would you find most helpful to talk about today?”

Additional Considerations

Be aware of and explore other factors that may contribute to a person’s concerns about using insulin, such as:^{21–26}

- › the complexity of their current medication regimen in addition to insulin (e.g., other medications or the number of daily doses)
- › cultural factors (e.g., health beliefs, language barriers, or their level of trust in the healthcare system and treatments)
- › health literacy (see **Chapter 1**)
- › any physical and mental impairment or disability (e.g., vision or hearing loss, dexterity, memory, or cognitive function)
- › costs and access (e.g., insulin and related supplies, or medical appointments)
- › practical skills (e.g., planning and problem solving)
- › and the beliefs and attitudes of their partner, family members, and wider social network.



HOW CAN I SUPPORT A PERSON with Psychological Barriers to Insulin Use?

The decision to begin, intensify, and continue insulin use is the choice of the person with diabetes. Your role is to help them make an informed choice by providing open communication, information, and support. It is your duty-of-care to make sure they are informed about the consequences of their decision. Keep in mind that even if they are not open to the idea initially, they may become more open over time (e.g., through discussion and education).

■ ADVISE

Talk with the person about insulin and its role in diabetes management (relating it back to their ITAS responses, when assessed):

- acknowledge the specific barriers the person has raised (see **ASK** and **ASSESS**)
- acknowledge that it is common to have questions and concerns
- reassure them that needing insulin does not indicate they have “failed”
- advise that many people need insulin as a 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 with food and planning of meals
 - improves their 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
- offer the person opportunities to ask questions
- and make a joint plan about the “next steps” (e.g., what needs to be achieved and who will help).



Choose your words carefully. If the person views insulin as a veiled threat or associates insulin with a sense of “failure,” they may want to continue negotiating to delay insulin. They may feel that if they can just “do a bit better” with their current management plan they will not need insulin—and this is unlikely to be the case. For more information about the impact of language, see Chapter 1.

NEXT STEPS: ASSIST OR ASSIGN?

- As psychological barriers to insulin use are intertwined with diabetes management, they are 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.
- In most cases, you will be able to address psychological barriers to insulin use without referral, through education and counselling. The following factors will inform your decision:
 - your scope of practice, and whether you have the time and resources to offer an appropriate level of support
 - your knowledge, skills, and confidence to address the identified barriers
 - the needs and preferences of the person with diabetes
 - the severity of the psychological barriers (e.g., worries about injections versus injection phobia)
 - and whether other psychological problems are also present, such as depression (see **Chapter 6**) or an anxiety disorder (see **Chapter 7**).
- If you believe referral to another health professional 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 would like to gain from the referral, as this will influence to whom the referral will be made.

■ ASSIST

Recent studies have investigated strategies to overcome psychological insulin resistance.²⁷ Demonstrating the injection process, explaining benefits of insulin, and a collaborative style were the three most helpful actions of health professionals in facilitating insulin initiation. Recommended strategies are based on recent research, clinical experience, and expertise. For most people, an initial reluctance to use insulin can usually be overcome.

Common barriers and practical strategies for minimizing these barriers are listed in Appendix D. Not all strategies will suit everyone, so you will need to work with the person to tailor appropriate solutions to their specific barriers, needs, and preferences.²⁸ Discussing the individual’s responses to the ITAS items (see **ASSESS**) is useful for this purpose.

For people who are new to insulin use, it will often be most appropriate to begin by exploring their thoughts and feelings about insulin. Postponing other changes to their treatment regimen will help to prevent additional disruptions to their routine.^{10,28}

Three key strategies that may be particularly useful are: demonstrating the insulin injection process, “decisional balancing,” and offering a time-bound “insulin trial.”

Demonstrate the Insulin Injection Process

People who were initially unwilling but then initiated insulin have said that the most helpful action of their health professional was to demonstrate the injection process.^{28,29} People who had experienced a demonstration of the process were less likely to delay insulin initiation.²⁸ This can be done in three easy steps.

First, show the person an insulin pen, and the size of the needle—many people are surprised by how small the needle is. The next step is to demonstrate the process of taking an injection, to show how simple it is. Finally, invite the person to try an injection for themselves, during the consultation with you. Invariably, this process helps a person to realize that injecting insulin is not as difficult or as painful as they imagined it would be.²⁹

Decisional Balancing

“Decisional balancing”³⁰ is a technique used in motivational interviewing.^{31,32} It enables the person to explore the relative merits of each treatment option (and how they feel about this). This tool (see **Box 5.3**) helps to build rapport and helps you assess their readiness for change. It is a way of supporting the person to work through the ambivalence in their thoughts and to make an informed decision.

Invite the person to list the three most relevant pros and cons per treatment (preferably in writing). If the person lists only one, encourage them to list one or two more (e.g., “Any other pros/cons to add?”).

After they complete the tool, you can use their responses as the basis for a conversation. Rather than starting with problems or concerns about insulin, begin with the positives of their current treatment, and then discuss the perceived disadvantages. This may help the person realize for themselves that remaining on the current treatment is not ideal. The next step is to explore the extent to which switching to insulin would be a way to overcome these disadvantages. This elicits the advantages of using insulin. Finally, ask which of the disadvantages of using insulin would be easiest for the person to overcome and brainstorm strategies.

Note that the “pros” and “cons” of each treatment may not be of equal importance to the individual.



The “Diabetes Medication Choice” decision aid³³ may be a helpful tool for comparing treatment options in terms of various concerns (e.g., side effects or regimen). See “Resources” page 89.

BOX 5.3 Decisional Balancing Tool

	Pros	Cons
Continue with current diabetes treatment (e.g., oral meds)	1.	1.
	2.	2.
	3.	3.
Start insulin	1.	1.
	2.	2.
	3.	3.

An “Insulin Trial”

A time-bound “insulin trial” is a way to encourage the person to “experiment” with insulin for a period of time that you both agree on. The length of the experiment should depend on the intended outcomes. For example, a one-month “trial” may be long enough for a person to experience how they can fit an insulin regimen into their lifestyle. If they are comfortable with that, extending the “trial” to three months will enable them to notice improvements in glycemic outcomes (A1C).

Make sure the person feels confident that they have the option of reverting back to their previous treatment if this experiment has not worked out for them. At the end of the experiment, review their experience together: reflect on the perceived advantages and disadvantages and whether or not these were expected.

■ ASSIGN

If a decision is made to refer, consider:

- **a certified diabetes educator or other diabetes health professional** (e.g., an endocrinologist or a dietitian) for self-management training (e.g., injection technique and carbohydrate counting) and support
- **a mental health professional** (preferably with an understanding of diabetes and insulin) if the problem is ongoing, or if it is evident that there is an underlying personal or psychological problem (e.g., needle phobia or an anxiety disorder), or the person with diabetes feels that it could benefit them
- **or a structured diabetes education group**, because insulin initiation in a group setting is as effective as an individual session and takes half the time;³⁴ it also offers important opportunities for people to share their concerns and ideas about insulin.

Most of these health 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

Make any necessary arrangements for the person to receive the care you have agreed on:

- arrange a follow-up appointment; if the person is happy to do so, book a follow-up appointment while they are at your clinic
- and use the follow-up appointment to oversee their progress, and to monitor and address any ongoing obstacles.

Be prepared to support the person more than usual during this time. For example, more frequent or extended appointments may be necessary. Telephone/video conferencing may be a practical and useful way to provide support in addition to face-to-face appointments.



CASE STUDY

Bruce

72-year-old man, living with wife Martha

Type 2 diabetes, managed with oral medications; overweight

Health professional: Dr. Amy Saunders (PCP)

■ Be AWARE

Dr. Saunders is concerned because, after some high blood glucose readings, Bruce has stopped bringing his blood glucose diary to his appointments. She has raised the idea of transitioning to insulin with Bruce, but he has insisted that, *“I’m sure I can get my blood sugar back down with some hard work and persistence.”* Dr. Saunders knows that it is common for people with diabetes to have concerns about starting insulin and suspects that Bruce may feel this way. She has, therefore, made a note in Bruce’s file to follow it up next time she sees him.

■ ASK

At the next appointment, she asks him how he is feeling generally and how he is feeling about his diabetes. Bruce says, *“I’m okay, but I have been finding things a bit tough because I just can’t keep my numbers down, even though I exercise daily and take my pills.”* Dr. Saunders reminds Bruce that they have spoken previously about insulin. Remembering that it can be helpful to anticipate and normalize diabetes-related concerns, she invites Bruce to share his feelings. *“Some people do have concerns about insulin. How do you feel about it?”* Bruce tells Dr. Saunders that his neighbor, Eloise, has diabetes, and since she started insulin a year ago she has gained weight and developed vision problems. He says, *“I’m not going to let that happen to me—I won’t start using insulin.”*

■ ASSESS

Dr. Saunders says, *“It sounds like you do have some concerns about using insulin. Would you like to complete a questionnaire so we can better understand how you feel about it?”* Bruce agrees, so she gives him a copy of the ITAS.

Bruce’s responses show he has four main psychological barriers to insulin:

- “taking insulin means I have failed to manage my diabetes with diet and tablets” (agree)
- “insulin causes weight gain” (agree)
- “taking insulin means my health will deteriorate” (strongly agree)
- and “taking insulin helps to prevent complications of diabetes” (strongly disagree).

■ ADVISE

Dr. Saunders suspects that many of Bruce’s concerns can be resolved with discussion and education. She tells Bruce that she:

- would like to talk to him about his responses to the questionnaire
- would like to help him to better understand insulin treatment
- is not trying to pressure him into starting insulin
- and just wants to make sure he is well-informed about his treatment options.

Bruce agrees to have the conversation.

■ ASSIST

Dr. Saunders begins by asking Bruce if he would like to say a bit more about his feeling of failure. She listens to his reply, then explains that many people need to use insulin for their diabetes, not because they have failed, but because it is the best way to manage their diabetes at that point. She explains that type 2 diabetes is a progressive condition, and after some time many people need the treatment to be intensified to manage it effectively. Often, this means transitioning to insulin.

She also talks with Bruce about the benefits of insulin, relating it back to his specific example of Eloise. She explains, *“Diabetes-related complications, like Eloise’s vision problems, are caused by the sugar in your blood remaining too high for too long. Insulin helps to lower the sugar in your blood and is the best method we have to do that effectively. I’ve suggested that you begin using insulin so we can prevent those kinds of health problems.”* Dr. Saunders also:

- Suggests that a short “trial” of insulin (for about four weeks) might give him some experience and alleviate some of his concerns. She says, *“Many of the people with diabetes I see have some concerns about insulin at first, just like you do. But I usually find that once they try it, it really helps them to feel better. If you don’t find it useful after a few weeks then we’ve learned that it’s not the right diabetes treatment for you at this time. I am wondering whether you will consider trying this, Bruce?”*
- Explains the potential benefits of insulin in addition to better glucose levels—feeling less tired, fewer medications (he may be able to reduce the number of oral hypoglycemic agents), and possibly having fewer side effects than the medications he is currently taking.
- Talks about the possibility of weight gain with insulin use and offers to write a referral to a local dietitian who could help him to prevent weight gain.
- Reassures him that he does not need to decide about the “insulin trial” today.
- Recommends that he talk with his wife, Martha, and then come back to see her in a week.
- Suggests that he make an appointment with the receptionist before he leaves.

At the next appointment, Bruce tells Dr. Saunders that he will give insulin “a try.” Dr. Saunders draws up a diabetes care plan and writes a prescription for long-acting insulin, which he will need to inject once a day. She explains that Bruce will need to see the certified diabetes educator to learn about insulin (e.g., how it works, dosage, timing of injections, how long it will take to notice an effect, and the effects of food and exercise), injection technique, and hypoglycemia (prevention, recognition, and treatment), and to have the dose adjusted. This will involve a couple of appointments and telephone calls. She gives him plenty of opportunities to ask questions.

■ ARRANGE

Dr. Saunders writes a referral letter to the diabetes nurse educator with instructions about the starting dose and regular dose titration until Bruce’s next review. She suggests that Bruce sees her again in four weeks so they can discuss how he is doing, but he can visit her sooner or speak to the diabetes educator if he has any problems or questions. At the next appointment, Bruce can decide whether he will continue to use insulin, and Dr. Saunders will prescribe the most appropriate type and dose of insulin for him. Bruce agrees with this plan.



CASE STUDY

Riana

54-year-old woman

Type 2 diabetes, managed with one daily basal insulin injection

Health professional: Angela Smith (certified diabetes educator), following a referral

■ Be AWARE

Angela has received a referral letter from Riana's PCP, who explains Riana has had "*suboptimal A1C over the past year*" and has "*recommended increasing her insulin dose from one basal injection to basal plus rapid-acting at her largest meal (at least), but Riana disagrees.*" Angela is aware that many people experience psychological barriers to intensifying an insulin regimen and wants to explore Riana's reluctance to increasing her insulin dose.

■ ASK

At their first appointment, Angela thanks Riana for coming and asks how she can help. Riana says, "*I'm here because my doctor sent me.*" Angela replies, "*I understand that he has suggested some changes to your treatment plan, can you tell me more about that?*" Riana tells Angela about the plan to increase her insulin injections to multiple times daily. Angela asks Riana how she feels about that plan and Riana responds that she is "*not happy.*"

Angela asks about Riana's experiences using insulin and how she feels about it. Riana responds that she is generally doing okay with her current insulin injections.

Angela also explores whether there have been changes in Riana's life in the past year that could explain her increasing blood glucose levels. Riana describes nothing that would contribute significantly to her elevated blood glucose levels or to her reluctance to increase the frequency of her insulin injections.

■ ASSESS

Angela asks Riana whether she would like to complete a brief questionnaire so they can both better understand her concerns about insulin. Riana agrees and completes the copy of the ITAS that Angela gives her.

Riana's responses indicate four key psychological barriers to insulin:

- › "managing insulin injections takes a lot of time and energy" (agree)
- › "injecting insulin is painful" (agree)
- › "taking insulin helps to maintain good control of blood glucose" (disagree)
- › and "taking insulin helps to improve my energy level" (disagree).

■ ADVISE

Before discussing Riana's responses, Angela asks Riana what she thought of the questionnaire. Riana replies, "*It was alright, good really—no-one has ever asked me these sorts of questions before.*" She tells Angela that when she first began using insulin she had struggled with the injections. At the time, her PCP had demonstrated the insulin injection technique and he'd been "encouraging." But months later, "*I still hadn't got the hang of it and I felt silly asking questions all the time. My numbers went up, and I felt less supported as time passed. I already struggle with one injection; how can he expect me to do more? I just want to go back to pills.*" Angela responds that:

- › it is common to feel distressed about diabetes from time to time

- › Riana should not feel embarrassed about asking questions
- › and she has noticed a pattern in Riana’s ITAS responses—she feels pain while injecting and is not experiencing the expected benefits of insulin (for her blood glucose and energy levels).

■ ASSIST

Angela asks Riana to demonstrate her injecting technique using saline solution. Riana agrees and she injects the saline slowly and directly into her abdomen, then quickly withdraws the pen. Some of the saline dribbles down Riana’s abdomen as the pen is withdrawn. Angela asks whether Riana has noticed it leaking out before, and Riana replies, “Yes, but that’s normal isn’t it?” Angela explains that it is not normal, and she may not be getting all the insulin she needs, which might explain her high glucose readings. Angela also checks that Riana is rotating her injection sites regularly. Then Angela:

- › demonstrates how to improve injection technique so that it will be less painful and Riana will receive the full dose of insulin
- › asks Riana to practice a few times until they both feel comfortable with Riana’s injection technique
- › and suggests that Riana continue with her current daily injection for a few more weeks using the new technique, and Riana agrees with this plan.

■ ARRANGE

Before the consultation ends, Angela:

- › checks whether Riana has any more questions or concerns
- › encourages her to keep a record of her injections and blood glucose readings, so they can monitor her progress and devise a plan of action together if the numbers have not improved
- › encourages Riana to also record her injection sites and level of pain while injecting, from 1 (no pain) to 5 (extreme pain), so they can check whether the new technique is helping to reduce her pain, and whether her pain is related to specific injection sites
- › suggests that Riana visit Angela again in two weeks
- › and asks Riana when she will next see her PCP, which is three months from now. Angela confirms that this will allow enough time to see an improvement in Riana’s blood glucose levels as a result of the new technique.

Questionnaire: Insulin Treatment Appraisal Scale (ITAS)

Instructions: The following questions are about your perception of taking insulin for your diabetes. If you do not use insulin therapy, please answer each question from your current knowledge and thoughts about what insulin therapy would be like. Tick the box that indicates to what extent you agree or disagree with each of the following statements (select one option on each line).

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
1 Taking insulin means I have failed to manage my diabetes with diet and pills	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2 Taking insulin means my diabetes has become much worse	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3 Taking insulin helps to prevent complications of diabetes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4 Taking insulin means other people see me as a sicker person	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5 Taking insulin makes life less flexible	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6 I'm afraid of injecting myself with a needle	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7 Taking insulin increases the risk of low blood glucose levels (hypoglycemia)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8* Taking insulin helps to improve my health	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9 Insulin causes weight gain	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10 Managing insulin injections takes a lot of time and energy	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11 Taking insulin means I have to give up activities I enjoy	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12 Taking insulin means my health will deteriorate	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13 Injecting insulin is embarrassing	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14 Injecting insulin is painful	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15 It is difficult to inject the right amount of insulin correctly at the right time every day	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
16 Taking insulin makes it more difficult to fulfill my responsibilities (at work, at home)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
17* Taking insulin helps to maintain good control of blood glucose	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
18 Being on insulin causes family and friends to be more concerned about me	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
19* Taking insulin helps to improve my energy level	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
20 Taking insulin makes me more dependent on my doctor	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

* Positive appraisal subscale.

© Novo Nordisk and Frank Snoek 2007. The copyright holder/developer has given permission for the questionnaire to be reproduced in this guide. Readers of the guide are permitted to reproduce the questionnaire for clinical use and non-commercial research purposes. Readers of the guide are not permitted to use the questionnaire for commercial research purposes and must seek permission from the copyright holder/developer to do so.

Background

The Insulin Treatment Appraisal Scale (ITAS) is a 20-item questionnaire for measuring a person's perceptions of insulin use.²⁰ The ITAS comprises two subscales:

- › positive appraisal (four positive statements about insulin, such as “*Taking insulin helps to improve my health*”)
- › and negative appraisal (16 negative statements about insulin, such as “*Taking insulin is embarrassing*”).

How to Use the ITAS in Clinical Practice

Respondents are asked to indicate their level of agreement with each statement. Items are scored from 1 (strongly disagree) to 5 (strongly agree). The most useful way to use this questionnaire clinically is to “eyeball” the responses to individual items. Positive appraisal subscale items that scored two or lower, and negative appraisal subscale items that scored four or higher indicate likely barriers to insulin use and require further discussion.



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

Interpretation of Scores

Positive appraisal subscale: items 3, 8, 17, and 19 are summed to produce a score between 4 and 20, with higher scores indicating more positive attitudes towards insulin.

- › Positive appraisal subscale items have been marked with an asterisk on the previous page.

Negative appraisal subscale: all 16 remaining items are summed to produce a score between 16 and 80, with higher scores indicating more negative attitudes to insulin.

Total score: a score ranging from 20 to 100 is produced by reverse-scoring the positive items, then adding together all 20 items, with higher scores indicating more negative attitudes towards insulin.

- › Although it is possible to calculate a total score on the ITAS, there are no ITAS cut-off values to indicate a presence or severity of psychological barriers. For this reason, calculating a total score is mostly useful only for research purposes or to measure changes over time.
- › Research has demonstrated that it is preferable to use the positive and negative appraisal subscale scores separately, rather than the total score.³⁵



Many people endorse the benefits of insulin despite having reservations about its use. So, endorsement of positive appraisals of insulin does not suggest an absence of psychological barriers.

Resources

For Health Professionals

Peer-Reviewed Literature

> **Psychological insulin resistance: a critical review of the literature**

Description: A systematic review of common causes of psychological insulin resistance and available strategies to reduce it.

Source: Gherman A, Veresiu IA, et al. *Practical Diabetes International*. 2011;28(3):125-128d.

> **Identifying solutions to psychological insulin resistance: An international study**

Description: Practical tips for recognizing and addressing psychological insulin resistance in clinical practice.

Source: Polonsky WH, Fisher L, et al. *Clinical Diabetes*. 2019;33(4) 307-314.

Tools

> **The diabetes mellitus medication choice decision aid: a randomized trial**

Description: A tool that can be used in consultations to facilitate decision-making regarding diabetes treatment.

Source: Mullan JR, Montori VM, et al. *Archives of Internal Medicine*. 2009;169(17):1560-1568.

URL: diabetesdecisionaid.mayoclinic.org

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: ADA offers resources through which people with diabetes and their family/friends can access diabetes information, education programs, and other events.

Phone: (877) 964-0916

URL: www.diabetes.org

> **Peer Support for Diabetes**

Description: An information sheet for people with diabetes about peer support opportunities.

Source: Association of Diabetes Care & Education Specialists, 2020.

URL: <https://www.diabeteseducator.org/living-with-diabetes/Tools-and-Resources/peer-support>

Information

> **Concerns About Starting Insulin (for People with Type 2 Diabetes)**

Description: A handout for people with type 2 diabetes who have concerns about commencing or intensifying insulin therapy.

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

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

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Chapter 6

Depression



Key Messages

- Major depression^a is a psychological condition indicated by a persistent (minimum of two weeks) state of sadness or depressed mood and/or lack of interest and pleasure in usual activities. This is in addition to other symptoms, such as significant changes in weight and sleep, a lack of energy, difficulty concentrating, irritability, feelings of worthlessness or guilt, or recurrent thoughts about death or suicide.
- Moderate-to-severe depressive symptoms, an indicator of depression, affect one in three people with insulin-treated type 2 diabetes, one in five people with non-insulin-treated type 2 diabetes, and one in four people with type 1 diabetes; this is two to three times more likely than the general population. Rates of clinical depression affect approximately one in eight people with diabetes.
- Depressive symptoms in people with diabetes are:
 - associated with suboptimal diabetes self-management and A1C, increased diabetes distress, less satisfaction with treatment, and impaired quality of life
 - highly recurrent
 - persistent/long-lasting
 - and different from, yet sometimes confused with, diabetes distress.
- Some depressive symptoms overlap with symptoms of diabetes (e.g., fatigue, sleep disturbance, changes in weight, and altered eating habits).
- A brief questionnaire, such as the Patient Health Questionnaire Nine (PHQ-9), can be used for assessing the severity of depressive symptoms. A clinical interview is needed to confirm major depression.
- Mild and major depression can be treated effectively (e.g., with psychological therapies and medications).



Practice Points

- Assess people with diabetes for depressive symptoms using a brief validated questionnaire; remember that major depression needs to be confirmed by a clinical interview.
- Treatment of depression will depend on severity, context, and the preferences of the individual. Helping people with major depression to access suitable treatment may require a collaborative care approach beginning with the person's PCP.
- Elevated depressive symptoms and mild depression also need attention, as they can develop into major depression.

^a In this chapter, the terms “mild depression” or “major depression” (collectively referred to as “depression”) are used when diagnosis is confirmed by a clinical interview according to DSM-5 or ICD-11 criteria. The term “depressive symptoms” is used where self-report is not yet confirmed by a clinical interview.

How Common Are Symptoms of Depression?



Type 1 diabetes^{b,1}



Type 2 diabetes (insulin)^{b,1}



Type 2 diabetes (no insulin)^{b,1}



WHAT IS Depression?

Depression is “an emotional, physical, and cognitive (thinking) state that is intense, long-lasting, and has negative effects on a person’s day-to-day life.”² In contrast to just “feeling down” or sad, depression is a serious mental health problem.

The diagnostic criteria for depression are described in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM-5),³ and the *International Statistical Classification of Diseases and Related Health Problems*, 11th revision (ICD-11).⁴ The “gold standard” for diagnosing depression is a standardized clinical diagnostic interview, for example the Structured Clinical Interview for DSM-5 (SCID-5; www.scid5.org).

Major depression (also known as major depressive disorder or clinical depression) is indicated by five or more of the following symptoms being present during a two-week period, representing a change from previous functioning.³

- At least one of the symptoms is persistent depressed mood or loss of interest/pleasure in regular activities.^{3,5}
- Other symptoms include significant weight loss or gain, insomnia or excessive sleeping, lack of energy, inability to concentrate, indecisiveness, feelings of worthlessness, excessive/inappropriate guilt, and recurrent thoughts of death or suicide.³

Mild depression (also known as subthreshold or minor depression) is characterized by the presence of depressive symptoms that do not meet the full diagnostic criteria for major depression.⁶ Although mild depression is less severe than major depression, it still significantly affects the person and deserves attention in clinical practice. Furthermore, if not treated, mild depression can develop into major depression.

Depression in People with Diabetes

There is evidence of a bi-directional association between depression and diabetes. People with depression are more likely to develop type 2 diabetes.⁷

People with diabetes are two to three times more likely than the general population to be affected by symptoms of depression.^{8,9} There is also a bi-directional relationship between depression and diabetes-related complications.¹⁰ As in the general population, depression is highly recurrent in people with diabetes.¹⁰

The causes of depression in people with diabetes are not well understood, but proposed mechanisms include biological, behavioral, social, psychological, and environmental factors.¹¹ Non-diabetes-specific contributors may include stressful life circumstances, substance use, and a personal or family history of depression.¹² Diabetes-specific contributors may include the chronic nature of the condition and complex management regimens.^{8,13} As various factors can contribute, the exact cause will be different for every person.¹²

In people with diabetes, depression or depressive symptoms are associated with adverse medical and psychological outcomes, including:

- suboptimal self-management (e.g., reduced physical activity, less healthy eating, not taking medication as recommended, less frequent self-monitoring of blood glucose, and smoking)^{14–19}
- elevated A1C, hypoglycemia, and hyperglycemia^{14,15,20}
- increased prevalence, and earlier onset, of complications and disability^{21–23}
- increased risk of diabetes distress^{24–27} and elevated anxiety symptoms²⁷
- impaired quality of life and social role/functioning^{27–29}
- increased burden/costs to the individual and the healthcare system^{14,17,30}
- and greater risk of premature mortality.^{31,32}



People with coexisting depressive and anxiety symptoms are likely to experience greater emotional impairment and take longer to recover.^{33,34}

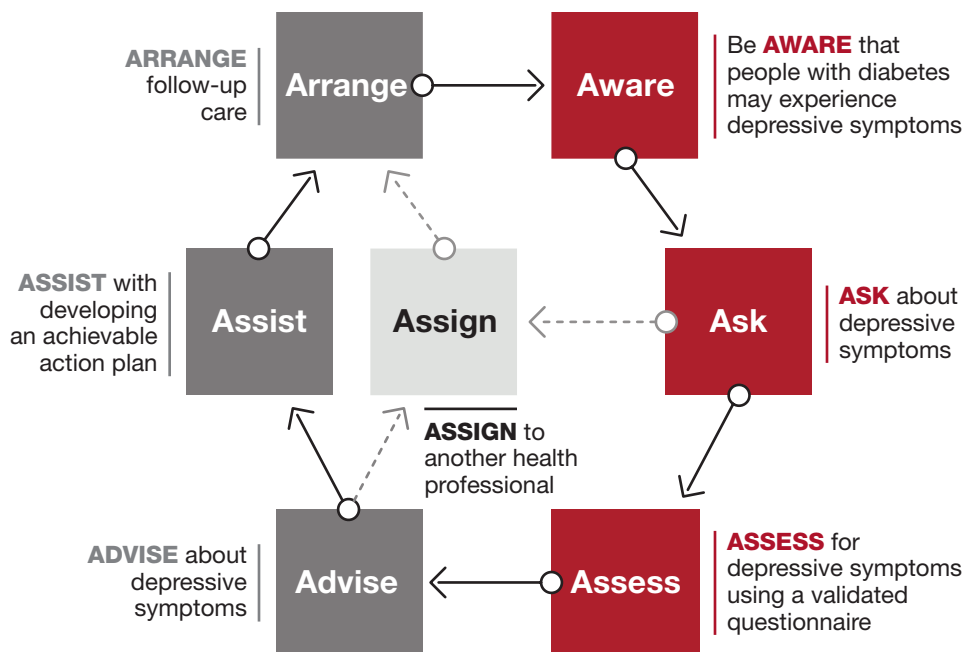
^b 25%, 32%, and 20% respectively have moderate-to-severe depressive symptoms (PHQ-9 total score ≥ 10).

7 A's Model: Depression

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 depressive symptoms?
- How can I support a person with depression?

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



HOW CAN I IDENTIFY Depressive Symptoms?

■ Be **AWARE**

Depression has physical, cognitive, behavioral, and emotional symptoms. Some common signs to look for include lowered mood (e.g., sadness, hopelessness, or tearfulness), loss of interest or pleasure in usual activities, irritability (e.g., exaggerated sense of frustration over minor matters or persistent anger), difficulties concentrating, lack of energy, weight loss or gain, reduced self-esteem/self-confidence, feelings of worthlessness or excessive/inappropriate guilt,

psychomotor changes (agitation or retardation), social withdrawal, and recurrent thoughts about death or suicide.^{2-4,35} Also, look for signs that the person is not coping adaptively, such as disturbed sleep or substance abuse (e.g., alcohol, sedatives, or other drugs).^{2-4,35} Each person will experience different symptoms of depression.

Two classification systems are commonly used for diagnosing depression: DSM-5³ and ICD-11.⁴ Consult these for a full list of symptoms and specific diagnostic criteria.



Depressive symptoms can overlap with somatic symptoms of diabetes⁸ (see Box 6.1) or with symptoms of diabetes distress (see Box 6.2). As a result, depression may be overlooked in diabetes clinical practice.³⁶

Although depression does not always develop in direct response to diabetes, some common signs include declining motivation to engage in diabetes self-care tasks, more frequent presentations to health professionals with the same symptoms, and missed appointments.

BOX 6.1 Symptoms of Depression or Diabetes

Depression and diabetes share some similar somatic and behavioral characteristics (e.g., fatigue, sleep disturbance, and appetite change). This poses a challenge, as symptoms of depression can be overlooked or mistaken for symptoms of diabetes and vice versa.

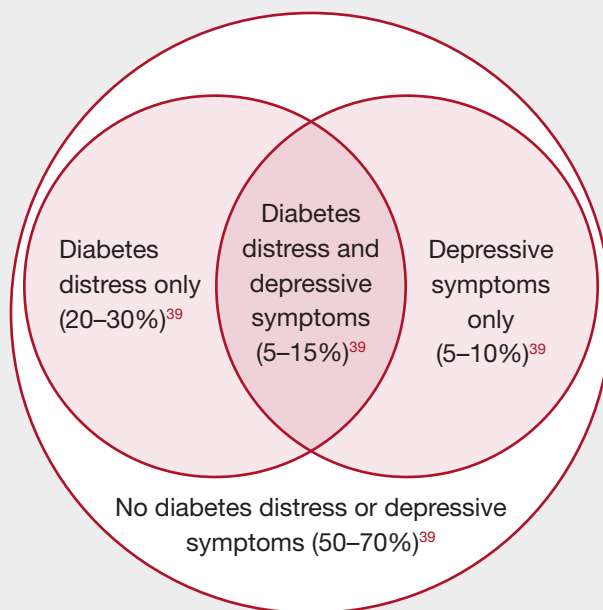
It is important to note that depression questionnaires do not have the capacity to distinguish the underlying cause of the symptoms. For example, a person may feel tired due to disturbed sleep because of depression or because they have had several nighttime episodes of hypoglycemia recently. This can result in elevated scores that do not necessarily indicate depressive disorder. Health professionals need to be mindful of these limitations.

This does not mean that depression questionnaires are not useful in clinical practice—it means that a clinical interview is needed to confirm a diagnosis of depression in people with diabetes. It is important to clarify the context and cause of the symptoms.

BOX 6.2 Depression or Diabetes Distress?

Depression is often confused with diabetes distress—both in academic literature and clinical practice. While depression can influence how people feel about living with diabetes, it is broader, affecting how they feel about life in general. Conversely, diabetes distress is the emotional distress arising specifically from living with and managing diabetes and does not necessarily affect how people feel about their life in general.³⁷ Diabetes distress includes problems related to the relentlessness and frustrations of everyday diabetes self-care and worries about future complications (see Chapter 3).

While diabetes distress and depression are separate constructs, they are risk factors for each other.^{23–25} This means that people with depression are more likely to develop diabetes distress, and vice versa. In practice, this means that both depressive symptoms and diabetes distress need to be assessed in clinical practice, to inform the type and intensity of intervention.^{37,38}



■ ASK

You may choose to ask about depressive symptoms:

- › in line with clinical practice guidelines (e.g., on a routine or annual basis; see Introduction, page viii)
- › when the person reports symptoms or you have noted signs (e.g., changes in mood/behaviors)
- › at times when the risk of developing depression is higher, such as:
 - during or after stressful life events (e.g., bereavement, traumatic experience, or diagnosis of life-threatening or long-term illness)
 - periods of significant diabetes-related challenge or adjustment (e.g., following diagnosis of diabetes or complications, hospitalization, or significant changes to the treatment regimen)
- › or if the individual has a history of depression or other mental health problems.⁵



Asking “*How are you doing?*” or, “*How have you been feeling lately?*” may seem like rhetorical questions but the responses can be very revealing and are often the key to what you do next. Take the time to listen to their answers and look for any sign that they may not be doing as well as usual.

Create a supportive and safe environment so the person feels able to be open with you about how they are feeling. People will be more likely to share their innermost thoughts and feelings with you if they are emotionally engaged in the appointment and have confidence that you care and will support them. For more information about having conversations about the emotional aspects of diabetes, see Chapter 1.

There are various ways to ask about depressive symptoms. You may choose to use open-ended questions, a brief structured questionnaire, or a combination of both.

Option 1: Ask Open-Ended Questions

The following open-ended question can be integrated easily into a routine appointment:

- › “*Have you noticed any change in how you have been feeling in the last couple of weeks? What have you noticed?*”

If something during the conversation makes you think that the person may be experiencing depressive symptoms, ask more specific questions, such as:

- › “*I know you as a [very active] person, but you’ve just told me that you haven’t felt motivated to [go running] lately. Do you think this is related to your mood?*”
- › “*Have there been any changes in your [sleeping/ eating] patterns? What have you noticed?*”

If the conversation suggests the person is experiencing depressive symptoms, further investigation is warranted (see **ASSESS**).

Option 2: Use a Brief Questionnaire

Alternatively, you can use a brief questionnaire to ask about depressive symptoms in a systematic way. Collectively, the following two questions are referred to as the Patient Health Questionnaire Two (PHQ-2).⁴⁰ They are the core symptoms required for a diagnosis of depression.

Over the last two weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Feeling down, depressed, or hopeless	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

PHQ-2: www.phqscreeners.com



Instead of administering this as a questionnaire, you could integrate these questions into your conversation.

Add the responses to the two questions to form a total score. A total score of 3 or more indicates depressive symptoms,⁴⁰ and further assessment for depression is warranted.

At this stage, it is advisable to ask whether they have a current diagnosis of depression and, if so, whether and how it is being treated

If the total score is 3 or more and the person is not currently receiving treatment for depression, you might say something like, “*It seems like you are experiencing depressive symptoms, which can be a normal reaction to [...]. There are several effective treatment options for depression, but first we need to find out more about your symptoms. So, I’d like to ask you some more questions if that’s okay with you.*”

You may then decide to assess for depression using a more comprehensive questionnaire (see **ASSESS**). For information about using questionnaires in clinical practice, see pages 10 and 11.

If the total score is less than 3 but you suspect a problem, consider whether the person may be experiencing diabetes distress (see [Chapter 3](#)), elevated anxiety symptoms (see [Chapter 7](#)), or another mental-health problem.

ASSESS

Validated Questionnaire

The nine-item Patient Health Questionnaire (PHQ-9)⁴¹ is widely used to assess depression. A copy is included on page 105. It mirrors the DSM-5 criteria for depression. It is quick to administer and freely available online (www.phqscreeners.com). Each item is measured on a four-point scale, from 0 (not at all) to 3 (nearly every day). Scores are added to form a total score ranging 0–27. In the general population, PHQ-9 scores are interpreted as follows:⁴²

- 0–4 indicates no depressive symptoms (or a minimal level)
- 5–9 indicates mild depressive symptoms; these people will benefit from watchful waiting
- 10–27 indicates moderate-to-severe depressive symptoms; these people will benefit from a more active method of intervention.



Asking the person to complete the PHQ-9 can be a useful way to start a dialogue about depressive symptoms and the effect they may have on the person's life and/or diabetes management. It can also be useful for systematically monitoring depressive symptoms (e.g., whether the symptoms are constant or changing over a period of time).



A PHQ-9 total score of 10 or more must be followed by a clinical interview using DSM-5³ or ICD-11⁴ criteria to confirm depression.



You may have access to other validated questionnaires, such as the Beck Depression Inventory,⁴³ Hospital Anxiety and Depression Scale,⁴⁴ Centre for Epidemiologic Studies Depression Scale,⁴⁵ or Hamilton Depression Scale.⁴⁶ While all of these tools are suitable for assessing depressive symptoms, they each have their own strengths and weaknesses. Summaries of these questionnaires can be accessed elsewhere.^{47,48}

Additional Considerations

Is this individual at risk of suicide? It is essential that you conduct a suicide risk assessment if you identify a person as having depressive symptoms or thoughts about self-harm or ending their life. Most depression questionnaires include an item about self-harm, suicidal ideation, or suicide (e.g., PHQ-9, item 9). If the person with diabetes endorses that item, further investigation and support is necessary (see [Box 6.3](#)), regardless of whether the total score indicates depressive symptoms.

What is the context of the depressive symptoms?

Are there any (temporary or ongoing) life circumstances that may be underlying the depressive symptoms⁴⁹ (e.g., a bereavement, chronic stress, changing/loss of employment, financial concerns, giving birth, or menopause)? What social support do they have? What role do diabetes-specific factors play (e.g., a lack of support for diabetes self-care, severe hypoglycemia, or burdensome complications)?

Are there any factors (physiological, psychological, or behavioral) that are co-existing or may be causing/ contributing to the depressive symptoms? This may involve taking a detailed medical history, for example:

- Do they have a history (or family history) of depression or another psychological problem, such as an anxiety disorder (see [Chapter 7](#)), diabetes distress (see [Box 6.2](#) and [Chapter 3](#)), personality disorder, post-traumatic stress disorder, dementia, or eating disorder (see [Chapter 8](#))? These conditions must also be considered and discussed where applicable (e.g., when and how was it treated, whether they thought this treatment was effective, and how long it took them to recover).⁴⁹
- Do they have any underlying medical conditions that may be contributing to the symptoms?
- What medications (including any complementary therapies) are they currently using?
- How frequently do they use alcohol and/or illicit drugs?

No depressive symptoms—what else might be going on?

If the person's responses to the questionnaire do not indicate the presence of depressive symptoms they may be reluctant to open up or may feel uncomfortable disclosing to you that they are feeling depressed, so consider whether the person may be experiencing diabetes distress (see [Box 6.2](#) and [Chapter 3](#)), elevated anxiety symptoms (see [Chapter 7](#)), or another psychological problem.



If any of these assessments are outside your expertise, you need to refer the person to another health professional (see [ASSIGN](#)).

BOX 6.3 Suicide

Whenever you suspect that a person is experiencing depression, or they appear to be feeling despair, unbearable pain, hopeless, trapped, or like they are a burden on others or don't belong, it is very important that you have a conversation about it and assess their risk of suicide. Making direct enquiries about suicide does not prompt a person to start to think about harming themselves.⁵⁰ Instead, addressing the issue is much more likely to enhance their safety and prevent an attempt.⁵¹

The procedures used to assess risk of suicide or self-harm are no different than those used for medical crises. The key is to know the steps and have the resources in place when the need arises.

Suicidality fluctuates and is influenced by such things as:⁵⁰

- › static risk factors, which are fixed and historical in nature (e.g., family history of depression, a history of self-harm or suicide attempts, or previous experience of abuse)
- › and dynamic risk factors, which fluctuate in duration and intensity (e.g., substance use, psychosocial stress, or suicidal ideation/communication/intent).

Policies and procedures for conducting a suicide risk assessment vary between settings, but this is a general guide:^{50,52}

1. Assess and ensure safety (the person with diabetes, yourself, and others).
2. Establish rapport (non-judgmental, professionally empathetic, compassionate, open body language, and active listening).
3. Assess the suicide risk, including factors such as:
 - any history of suicide attempts
 - any history of mental disorders
 - the existence of a suicide plan
 - access to the means to complete the plan

- duration and intensity of the suicidal ideation
- hopelessness or feeling trapped
- lack of belonging, feeling alone, or alienated
- feeling like a burden on others
- alcohol/substance use
- intention/desire to die
- family history of suicide
- protective factors
- or recent help-seeking behaviors.

There are several questionnaires for assessing suicide risk.⁵³⁻⁵⁵ These can be useful for directing the conversation systematically but there is a lack of evidence for their diagnostic accuracy.⁵¹ **These questionnaires cannot replace clinical interview.**

4. Collect and document relevant information (e.g., the person's medical history, current physical and mental state, and evidence of a suicide risk assessment).
5. Arrange additional psychosocial and psychiatric assessments, or referral to a specialist, if required.
6. Develop a safety plan with the person⁵⁶ (i.e., a written list of coping strategies and support services to which the person can refer when they are having suicidal thoughts).
7. Reassess as necessary and ensure that follow-up care is provided. For people who are at high risk, reassess within 24 hours; for moderate risk, reassess within one week; and low risk, reassess within one month.⁵²

If a person is actively suicidal: provide or arrange continuous supervision.

If a person is in immediate danger: follow your workplace's emergency procedure or contact 911.

Keep in mind that some individuals may decide not to share their suicide plans and deny they have suicidal thoughts.



HOW CAN I SUPPORT A PERSON with Depression?

■ ADVISE

Now that you have identified that the person is experiencing depressive symptoms, you can advise them on the options for next steps and then, together, decide what to do next.

- Explain that their responses to the PHQ-9 indicate they are experiencing depressive symptoms, and also that:
 - they may have major depression, which will need to be confirmed with a clinical interview
 - and that depressive symptoms fluctuate dependent on life stressors and that it may be necessary to reassess later (e.g., once the stressor has passed or is less intense).
- Elicit feedback from the person about their score (i.e., whether the score represents their current mood).
- Explain what major depression is, and how it might affect their life overall, as well as on their diabetes management.
- Advise that depression is common, and that help and support are available; depression is treatable and can be managed effectively.
- Recognize that identification and advice alone are not enough; explain that treatment will be necessary and can help to improve their life overall, as well as their diabetes management.
- Offer the person opportunities to ask questions.
- Make a joint plan about the “next steps” (e.g., what needs to be achieved to reduce depressive symptoms and the support they may need).



If the depression is clearly related to a particular stressor (e.g., financial or relationship problems), take into account the severity and likely duration of the problem, as this will help to inform the action plan.

■ NEXT STEPS: ASSIST OR ASSIGN?

- The decision about whether you support the person yourself or involve other health professionals will depend on:
 - the severity of the depressive symptoms, and the context of the problem(s)
 - your scope of practice, and whether you have the time and resources to offer an appropriate level of support
 - your qualifications, knowledge, skills, and confidence to address depressive symptoms
 - whether other psychological problems are also present, such as diabetes distress (see [Chapter 3](#)) or an anxiety disorder (see [Chapter 7](#))
 - and the needs and preferences of the person with diabetes.
- If you believe referral to another health professional is needed:
 - explain your reasons for the referral (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 would be made.

■ ASSIST

Neither mild nor major depression is likely to improve spontaneously,⁵⁷ so intervention is important. The stepped care approach provides guidance on how to address depressive symptoms and depression in clinical practice.^{58,59}

Once depression has been confirmed by a clinical interview, and if you believe that you can assist the person:

- Explain the appropriate treatment options (see [Box 6.4](#)), discussing the pros and cons for each option, taking into account:
 - the context and severity of the depression
 - the most recent evidence about effective treatments (e.g., a collaborative and/or a stepped care approach)

BOX 6.4 Treating Depression

It is not within the scope of this guide to recommend specific pharmacological or psychological treatments for depression in people with diabetes. Here are some general considerations based on the evidence available at the time this guide was published:

- › A combination of psychological intervention and pharmacological treatment is recommended for people with recurrent depression and major depression.⁵⁸
- › Psychological intervention and/or pharmacological treatment should be implemented through stepped care and/or collaborative care approaches.^{58,60}
- › Cognitive behavioral therapy (CBT) is the most effective psychological intervention.⁵⁸
- › Antidepressant medications are only effective for people with moderate-to-severe depression, not mild depression.⁶¹
- › Selective serotonin re-uptake inhibitors (SSRIs) are the most effective pharmacological treatment for depression in people with diabetes.⁵⁸
- › When combined with diabetes self-management education, psychotherapy is most effective for reducing depressive symptoms and A1C.⁶²
- › Some antidepressant medications can have adverse side effects (e.g., weight gain and metabolic abnormalities) and are associated with insulin resistance.⁵ Consider the risks and benefits before prescribing these medications, as they may not be appropriate for some people with diabetes.^{5,61}

- and the person's knowledge about, motivation, and preferences for, each option.
- › Offer them opportunities to ask questions.
- › Agree on an action plan together and set achievable goals for managing their depression and their diabetes. This may include adapting the diabetes management plan if the depression has impeded their self-care.
- › Provide support and treatment appropriate to your qualifications, knowledge, skills and confidence. For example, you may be able to prescribe medication but not undertake psychological intervention or vice versa.

- › Make sure the person is comfortable with this approach.
- › At the end of the conversation, consider giving them some information to read at home. At the end of this chapter (see page 107), there are resources that may be helpful for a person with diabetes who is experiencing depression or depressive symptoms. Select one or two of these that are most relevant for the person. It is best not to overwhelm them with too much information.

Some people will not want to proceed with treatment, at first. For these people, provide ongoing support and counselling about depression, to keep it on their agenda. This will reinforce the message that support is available and will allow them to make an informed decision to start treatment in their own time.

ASSIGN

If a decision is made to refer, consider the following health professionals:

- › **A primary care physician (PCP)** to undertake a clinical interview and diagnose major depression, make a referral to an appropriate mental health professional, and prescribe and monitor medications. An extended appointment is recommended.
- › **A psychologist** to undertake a clinical interview and provide psychological therapy (e.g., CBT or interpersonal therapy).
- › **A psychiatrist** to undertake a clinical interview, provide psychological therapy (e.g., CBT), and prescribe and monitor medications. A PCP referral may be required to access a psychiatrist. Referral to a psychiatrist may be necessary for complex presentations (e.g., if you suspect severe psychiatric conditions, such as bipolar disorder or schizophrenia, or complex co-morbid medical conditions).
- › **A mental health social worker** to help the person find ways to effectively manage situations that are contributing to their depression or inhibiting their treatment (e.g., trauma or life stresses), using psychologically based therapies and skills training (e.g., problem solving and stress management).
- › **An occupational therapist specializing in mental health** for therapy to increase independence and functioning (e.g., self-care, work and home roles, socialization, and coping), which may be impaired by depression.

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 possible, consider referring the person to health professionals who have knowledge about, or experience in, diabetes. For example, if their diabetes management is affected by their depression, they may need a new diabetes management plan that is better suited to their needs and circumstances at the time. This might require collaboration with a PCP or diabetes specialist (e.g., an endocrinologist, diabetes educator, and/or dietitian).



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

If there is need and scope, consider including more frequent follow-up visits or extended appointments in the action plan. Encourage the person to book a follow-up appointment with you within an agreed timeframe to monitor progress and address any issues arising. Telephone/ video conferencing may be a practical and useful way to provide support in addition to face-to-face appointments.

Mental health is important in its own right, but it is also likely to affect the person's diabetes self-management and their physical health. Therefore, it is important to follow up to check that they have engaged with the agreed treatment.

At the follow-up appointment, revisit the plan and discuss any progress that has been made. For example, you might say something like, *“When I saw you last, you were feeling depressed. We made a plan together to help you with that and agreed that [you would make an appointment to see Shirley, a psychologist, and I wrote a referral to her]. Have you had an opportunity to [see her]? How has this worked out for you?”*



CASE STUDY

Julie

65-year-old woman living alone

Type 2 diabetes, managed with diet and exercise;
history of depression

Health professional: Dr. Robert Stevens (PCP)

■ Be AWARE

When Julie arrives for her routine check-up, Dr. Stevens notices signs that she isn't her usual self—she is not wearing make-up, has dark circles under her eyes, and she doesn't greet him with her usual cheerfulness. He asks her how she has been, and she shrugs her shoulders replying, *"You know how it is, just a bit tired. I need a vacation I think."* As the discussion moves on to her general physical health and diabetes management, Dr. Stevens notes that Julie mentions again that she is tired, which has prevented her from exercising, and as a result her blood glucose has been a bit higher than usual and she has gained 10 lbs.

■ ASK

When Dr. Stevens enquires further using open-ended questions, Julie confides that in the past she had enjoyed exercising with a friend, but over the past month she has found herself making excuses not to leave the house. *"I just can't get motivated to exercise at the moment. I feel awful when I cancel my walks with Fran, but I'm just too tired these days—it feels like a chore. And I tell myself, 'just do it, it's not that hard, you'll enjoy it once you're outside.' But then I can't bring myself to leave the house."* Julie says she feels guilty for not exercising and has begun eating late at night, which she is ashamed about. She worries about her weight but when she feels down, she eats more. She feels unsure about how to break herself out of this cycle.

Dr. Stevens is concerned about Julie's struggles with motivation and about the impact her recent changes

in behavior and thought patterns will have on her diabetes if they continue in the longer term.

■ ASSESS

Dr. Stevens knows that Julie has a history of depression and wonders whether her negative thoughts about herself, her low mood, the changes in her eating and exercise patterns, and her tiredness might be linked. He invites Julie to complete the PHQ-9. Julie's score of 18 suggests she is experiencing moderately severe depressive symptoms. Because of her high PHQ-9 score, he also conducts a suicide risk assessment, and finds Julie to be at low risk of suicide.

■ ADVISE

Dr. Stevens explains the PHQ-9 score to Julie and asks her if this fits with how she has been feeling lately. Julie says that she recognizes the symptoms she has been experiencing from a couple of years ago when she was depressed after separating from her husband. Dr. Stevens asks Julie whether she had sought help for the depression at the time and whether she had needed antidepressants. Julie says she had consulted a psychologist who had been able to help her without antidepressants. He asks Julie whether this would be a good option for her this time. They agree that it will be the best course of action for Julie to return to the same psychologist, as they have a previously established rapport. The psychologist will conduct a formal assessment and discuss a treatment plan with Julie.

■ ASSIGN

Dr. Stevens encourages Julie to make an appointment with the psychologist. Dr. Stevens makes a comment in his EHR note to follow-up with Julie at her next visit to inquire about her status with her psychologist and her level of satisfaction with that portion of her care.

■ ARRANGE

Dr. Stevens encourages Julie to make another appointment to see him after she has met the psychologist to update him on her progress and assess whether there is a need for antidepressants at that stage. He also invites her to see him sooner if she needs to.



CASE STUDY

Luke

24-year-old man living with his older brother

Type 1 diabetes (diagnosed 23 years ago)

Health professionals: Dr. Glenn Jin (endocrinologist) and Thomas Mitchell (diabetes nurse)

■ Be AWARE

Dr. Jin is aware that people with diabetes are at a higher risk of emotional problems. He has decided to add a mental health questionnaire to the annual review process at his diabetes clinic. The questionnaire includes the Diabetes Distress Scale-17 (DDS-17; see page 46) to assess diabetes distress and the PHQ-2.

Thomas is a diabetes nurse working at the clinic who assists with some of the physical health checks. He has been given the task of explaining the purpose of the questionnaire and encouraging people to complete it on a tablet computer in the waiting room while awaiting their appointment. The person's questionnaire responses are automatically saved in their chart, for discussion during the appointment.

■ ASK

During Luke's annual visit, the check-in staff at the clinic ask Luke, *"We've added something new to our annual assessments. Dr. Jin has put together a brief set of questions about how living with diabetes affects your life and well-being. The questionnaire takes about 10 minutes, there's no writing—you just have to tick the boxes. You can do it now while you're waiting to see Dr. Jin. Will you fill in the questionnaire?"* Luke agrees. When Thomas meets with Luke, he asks him some general questions about his health and well-being, but Luke does not seem to be in the mood for talking.

■ ASSESS

At the appointment, Dr. Jin quickly looks over the questionnaire responses. Luke's DDS-17 score does not indicate a problem that needs immediate attention and he confirms this with Luke. However, Luke's PHQ-2 score indicates that he is likely to be experiencing depression.

Dr. Jin asks Luke about how he felt completing the questionnaire, and Luke replies, *"It was OK, y'know, a bit different, but OK."* Dr. Jin says to Luke, *"Looking at your responses, it looks like you've been feeling down over the past two weeks and not very interested in things. What's going on Luke?"* Luke tells him that he lost his job about six months ago, and he couldn't find work, which has affected his moods and relationships. *"I can't do anything right y'know; can't find a job... then my girlfriend left me... and I'm sleeping on my brother's couch because I couldn't pay the rent... I can't catch a break. I'm such a loser, I'm nothing."*

Dr. Jin acknowledges that Luke seems to have had a tough time lately, and that it is understandable that he has been feeling down. He explains to Luke that he may be experiencing depression and that help is available. Dr. Jin asks Luke whether he has been diagnosed with depression before; Luke has not. Dr. Jin then asks Luke to complete a few more questions to help him to be sure. Luke agrees, so Dr. Jin gives him a copy of the PHQ-9. Luke's PHQ-9 score is 23, indicating severe depressive symptoms. As Luke's score on item 9—"Thoughts that you would be better off dead or of hurting yourself in some way"—was 2 ("More than half the days"), Dr. Jin also conducts a suicide risk assessment and finds Luke to be at moderate risk.

■ ADVISE

Dr. Jin explains the scores to Luke and gives him some information about depression, including the phone number for the National Suicide Prevention Lifeline: (800) 273-8255. Dr. Jin tells Luke that depression is treatable and explains the various options available. He advises Luke to visit a PCP and the reasons for this—the PCP will help him to access the most appropriate treatment. He invites Luke to ask questions.

■ ASSIST

Dr. Jin checks whether Luke has a PCP that he would be comfortable to speak with, and whether he is OK to do so. Luke agrees to both queries. Dr. Jin also asks Luke if there is someone in his life (e.g., a friend or family member) that he can talk to if he has thoughts about ending his life. Luke says that he has a good relationship with his brother who is very understanding and supportive. He will talk with him or call the Lifeline about how he is feeling if things get too much. Dr. Jin discusses other suicide risk mitigation strategies with Luke; together they develop a safety plan.

■ ASSIGN

Dr. Jin writes a letter of referral to a mental health professional and sends a note to Luke's PCP. In the referral, Dr. Jin includes a copy of his PHQ-9 score and interpretation with the letter.

Luke's situation also prompts Dr. Jin to refer Luke to an onsite social worker who can assess any potential food insecurity issues and help Luke identify community resources and benefits he may need while unemployed.

■ ARRANGE

Dr. Jin asks Luke to come back to see him next month, so he can see how he is getting on with his PCP. They will also continue with his annual diabetes visit and consider whether any changes are needed to his diabetes management plan while Luke is receiving support for the depressive symptoms.

Questionnaire: Patient Health Questionnaire Nine (PHQ-9)

Instructions: For each statement, please tick the box below that best corresponds to your experience in the last two weeks.

Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1 Little interest or pleasure in doing things	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
2 Feeling down, depressed, or hopeless	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
3 Trouble falling or staying asleep, or sleeping too much	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
4 Feeling tired or having little energy	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
5 Poor appetite or overeating	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
6 Feeling bad about yourself—or that you are a failure or have let yourself or your family down	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
7 Trouble concentrating on things, such as reading the newspaper or watching television	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
8 Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
9 Thoughts that you would be better off dead or of hurting yourself in some way	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

(Office use only) Total score =

	Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues, with an educational grant from Pfizer, Inc. No permission is required to reproduce, translate, display, or distribute. See: www.phqscreeners.com

Background

The PHQ-9 is a nine-item questionnaire for assessing depressive symptoms and their severity.^{41,63} It has been validated for use with people with diabetes.⁶⁴ Each of the nine items corresponds with a DSM-5³ criterion for depression.

It is freely available online in more than 40 languages, quick to administer, and easy to score and interpret. Many of the translations are linguistically valid, but not all have been psychometrically validated against a diagnostic interview for depression⁶³ and few have been validated in people with diabetes.⁴⁷

How to Use the PHQ-9 in Clinical Practice

Respondents are asked to indicate how frequently they are bothered by each of the nine items (each describing a different symptom of depression).^{41,65} Items are scored on a scale from 0 (not at all) to 3 (nearly every day).⁶⁵

An additional supplementary item (which does not contribute to the total score) can also be asked to evaluate the level of social or occupational difficulty caused by the depressive symptoms. This question appears in the version on the website,⁶³ and has been included in the questionnaire.



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

Interpretation of Scores

The scores for each item are summed to generate a total score (range: 0–27).⁶⁵ Depressive symptom severity is indicated by the PHQ-9 total score.⁴² Generally, a PHQ-9 total score of 10 or more is an indicator of likely depression,⁴¹ and needs to be followed up with a clinical interview.



If the person scores 1 or more on item 9 (referring to suicidal ideation), further assessment for risk of suicide or self-harm is required, irrespective of the total score.⁴¹

PHQ-9 total score	Depressive symptom severity	Proposed treatment actions
0–4	None – minimal	None
5–9	Mild	Watchful waiting; repeat PHQ-9 at follow-up
10–14	Moderate	Treatment plan, consider counselling, follow-up, and/or pharmacotherapy
15–19	Moderately severe	Active treatment with pharmacotherapy and/or psychotherapy
20–27	Severe	Immediate initiation of pharmacotherapy and, if severe impairment or limited response to therapy, expedited referral to a mental health specialist for psychotherapy and/or collaborative management

Additional Information

Alternative cut-off values: For people with diabetes in specialty clinics (usually those with severe complications), a cut-off value of 12 or more has been recommended due to the overlap between symptoms of depression and diabetes.⁶⁶ For older people with diabetes in general practice, a cut-off of 7 or more has been recommended.⁶⁷

Short Form—PHQ-2

- › The PHQ-2⁶⁸ consists of two items from the PHQ-9: item 1, “Little interest or pleasure in doing things,” and item 2, “Feeling down, depressed, or hopeless.”
- › The timeframe and response options are the same as for the PHQ-9.
- › The two item scores are summed to form a total score. Total scores of 3 or more warrant further assessment for depression.⁶⁵

Resources

For Health Professionals

Peer-Reviewed Literature

- › **Depression and diabetes: treatment and health-care delivery**

Description: This paper makes recommendations for clinical practice for addressing depression and diabetes.

Source: Petrak F, Baumeister H, et al. *The Lancet Diabetes & Endocrinology*. 2015;3:472-485.
- › **The confusing tale of depression and distress in patients with diabetes**

Description: A commentary on diabetes distress and depression, and recommendations for clinical practice.

Source: Fisher L, Gonzalez JS, et al. *Diabetic Medicine*. 2014;31:764-772.
- › **Depression in diabetes mellitus: to screen or not to screen? A patient-centred approach**

Description: A review article discussing methods for routinely screening for depression in people with diabetes.

Source: Van der Feltz-Cornelis CM. *British Journal of Diabetes & Vascular Disease*. 2011;11:276-281.
- › **Safety planning intervention: a brief intervention to mitigate suicide risk**

Description: This paper describes how to develop a safety plan to mitigate suicide risk.

Source: Stanley B, Brown GK. *Cognitive and Behavioral Practice*. 2012;19(2):256-264.

Additional information: Information about safety planning from the same authors can also be accessed at www.suicidesafetyplan.com

Guidelines and Recommendations

- › **American Psychological Association Clinical Practice Guidelines for the Treatment of Depressions**

Description: Developed for psychiatrists, psychologists, physicians, and other health professionals with an interest in mental health, these evidence-based guidelines cover the management of depressive disorders.

Source: Gelenberg AJ, Freeman MP, et al. American Psychiatric Association practice guidelines for the

treatment of patients with major depressive disorder. *Am J Psychiatry*, 167(Suppl 10), 9-118.

URL: www.apa.org/depression-guideline/guideline.pdf

Books

- › **Treatments that Work (Series)**

The *Treatments that Work* book series describes evidence-based psychological interventions for a variety of mental health conditions. They have a wide array of therapist guides with accompanying patient workbooks.

Source: Oxford University Press

URL: www.oxfordclinicalpsych.com/page/ttwseries/treatments-that-work-series
- › **Management of Mental Disorders, 5th edition**

Description: A book that provides practical guidance for clinicians in recognizing and treating mental health problems, including depression. The book also includes worksheets and information pamphlets for people experiencing these problems and their families.

Source: Andrews G, Dean K, et al. Clinical Research Unit for Anxiety and Depression (CRUFAD). 2014.

Additional information: Sections of this book (e.g., treatment manuals and worksheets) are freely available to download from the “Support for clinicians” section on the CRUFAD website at www.crufad.org

Websites

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

Description: ADA and the American Psychological Association partnered to create an educational program for mental health professionals interested in emotional issues specific to people with type 1 and type 2 diabetes. Clinicians who have completed this training can be found on the ADA website in their Mental Health Provider Directory Listing.

URL: professional.diabetes.org/mhp_listing

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

> National Suicide Prevention Lifeline

Description: Confidential telephone and online crisis support service for people experiencing a personal crisis or thinking about suicide.

Phone: 800-273-8255 (24 hours a day, seven days a week)

URL: www.suicidpreventionlifeline.org online crisis support chat 24/7

> Mental Health America

Description: A good resource for finding peer support. Also includes access to screeners for anxiety and depression, which can then help connect patients with an appropriate referral. Individuals who indicate they have diabetes will also be routed through to the ADA Mental Health Provider Directory.

URL: <https://mhanational.org/finding-help>

> Local State Psychological Associations

Description: Most states have a local directory for mental health professionals, and many have a phone number for more information.

Information

> Diabetes and Depression

Description: A handout for people with diabetes about depression designed along with this practical guide.

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

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

> Breaking Free from Depression and Diabetes

Description: An information leaflet for people with diabetes about depression from the Behavioral Diabetes Institute that covers a broad range of topics related to depression and diabetes, including ways to get support.

Source: Behavioral Diabetes Institute, 2014.

URL: <https://behavioraldiabetes.org/xwp/wp-content/uploads/2015/12/BDIDepressionBookletFINAL.pdf>

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Chapter 7

Anxiety Disorders



Key Messages

- An anxiety disorder^a is a psychological condition indicated by frequent, intense, and excessive worry, occurring for at least six months, and substantially affecting daily functioning and causing significant distress. It includes feeling nervous, anxious, or on edge, and not being able to stop or control these feelings.
- Moderate-to-severe anxiety symptoms, an indication of an anxiety disorder, affect one in five people with insulin-treated type 2 diabetes, type 1 diabetes, or non-insulin-treated type 2 diabetes; this is 20% more likely than the general population.
- Elevated anxiety symptoms in people with diabetes:
 - are associated with suboptimal diabetes self-management and metabolic outcomes, diabetes complications, depressive symptoms, and impaired quality of life
 - and can be difficult to recognize, as severe anxiety and panic attacks share some similar physical symptoms to hypoglycemia (e.g., sweating, increased heart rate, shaking, and nausea).
- A brief questionnaire, such as the Generalized Anxiety Disorder Seven (GAD-7), can be used for identifying people with elevated anxiety symptoms. However, a clinical interview is needed to confirm an anxiety disorder.
- Anxiety disorders can be treated effectively (e.g., with psychological therapies and medications).



Practice Points

- Assess people with diabetes for elevated anxiety symptoms using a brief validated questionnaire; remember that anxiety disorders need to be confirmed by a clinical interview.
- Treatment of an anxiety disorder will depend on severity, context, and the preferences of the individual. Helping people with an anxiety disorder to access suitable treatment may require a collaborative care approach beginning with the person's PCP.
- Remain mindful that elevated anxiety symptoms also need attention, as they can develop into an anxiety disorder.

^a In this chapter, the term “anxiety disorder” is used when diagnosis is confirmed by a clinical interview according to DSM-5 or ICD-11 criteria. The term “elevated anxiety symptoms” is used where self-report is not confirmed by a clinical interview. An anxiety disorder is different from a diabetes-specific anxiety (e.g., fear of hypoglycemia, hyperglycemia, injections, or complications), which are discussed in Chapter 4.

How Common Are Elevated Symptoms of Anxiety?



Type 1 diabetes^{b,1,2}



Type 2 diabetes (insulin)^{b,1}



Type 2 diabetes (no insulin)^{b,1}



WHAT IS an Anxiety Disorder?

An anxiety disorder is a psychological condition characterized by persistent and excessive anxiety and worry.³ This is also known as clinical anxiety. The worry is accompanied by a variety of symptoms:⁴

- › emotional (feeling uneasy, worried, irritable, or panicked, including experiencing panic attacks)
- › cognitive (thinking that one cannot cope or having difficulty concentrating)
- › behavioral (aggression, restlessness, fidgeting, or avoidance)
- › and physical (a rapid heartbeat, trembling, dizziness, sweating, or nausea).

In contrast to non-clinical anxiety, which is a normal response to a perceived threat or stressful situation, an anxiety disorder is problematic as it affects day-to-day functioning and causes significant distress.³ It cannot be attributed to the effects of a substance (e.g., medication), a medical condition (e.g., hyperthyroidism), or another mental health problem (e.g., depression).

Anxiety disorders can take many forms, including:^{5,6}

- › generalized anxiety disorder: intense excessive and daily worries about multiple situations
- › social anxiety disorder: intense excessive fear of being scrutinized by other people, resulting in avoidance of social situations
- › panic disorder: recurrent, unpredictable, and severe panic attacks
- › and specific phobia: intense irrational fear of specific everyday objects or situations (e.g., phobia of spiders, injections, or blood).

The “gold standard” for diagnosing an anxiety disorder is a standardized clinical diagnostic interview, for example the Structured Clinical Interview for DSM-5 (SCID-5; www.scid5.org). Comprehensive descriptions of anxiety disorders, symptoms and diagnostic criteria are included in the *Diagnostic and Statistical Manual of Mental*

Disorders, 5th edition (DSM-5)⁶ and the *International Statistical Classification of Diseases and Related Health Problems*, 11th revision (ICD-11).⁵ For example, generalized anxiety disorder is indicated by persistent and excessive anxiety and worry that is difficult to control, occurring more days than not, in addition to three or more of the following symptoms being present on more days than not, for at least six months:⁶

- › restlessness or feeling “on edge”
- › being easily fatigued
- › difficulty concentrating or mind going blank
- › irritability
- › muscle tension
- › and sleep disturbance (difficulty falling or staying asleep, or restless, unsatisfying sleep).

People with an anxiety disorder may experience panic attacks, which are sudden surges of intense fear. The symptoms of panic attack vary from person to person but commonly include a combination of quickened heartbeat, heart palpitations, shortness of breath, dizziness, nausea, sweating, shaking, dry mouth, numbness sensations, hot flushes or cold chills, feelings of choking, derealization (feelings of detachment from one’s surroundings), depersonalization (feeling detached from oneself), and fear of “going crazy,” “losing control,” fainting, or dying.^{5,6}

A subthreshold anxiety disorder is characterized by the presence of elevated anxiety symptoms that do not meet the full diagnostic criteria for an anxiety disorder. Although less severe, such symptoms are typically persistent, can also cause significant burden and impairment,⁷ and deserve attention in clinical practice.

Anxiety Disorders in People with Diabetes

There is evidence of a bi-directional association between anxiety and diabetes.^{8,9} However, this has not been confirmed, as most studies have been cross-

b 21%, 20%, and 18% respectively have moderate-to-severe anxiety symptoms (GAD-7 total score ≥ 10).

sectional.¹⁰ Therefore, it is possible that people with elevated anxiety symptoms or an anxiety disorder may be at increased risk of developing type 2 diabetes, while having type 1 or type 2 diabetes may place people at increased risk of developing elevated anxiety symptoms or an anxiety disorder.

Overall, the prevalence of elevated anxiety symptoms and anxiety disorders in people with diabetes is within the range of general population estimates.¹⁰ Further research is needed regarding the specific types of anxiety disorders associated with type 1 and type 2 diabetes.¹⁰

Many factors may contribute to the development of elevated anxiety symptoms or an anxiety disorder. These include: personal or family history, personality, stressful life circumstances, substance use, and physical illness.¹¹ Diabetes may be completely unrelated for some people, while for others, it may be a contributing factor. As various factors can contribute, the exact cause will be different for every person.¹¹

In people with diabetes, elevated anxiety symptoms are associated with adverse medical and psychological outcomes, including:

- > suboptimal self-management and unhealthy behaviors (e.g., reduced physical activity, smoking, or heavy use of alcohol)¹²⁻¹⁸
- > elevated A1C^{12,19-21} 11,18-20 and other suboptimal metabolic indicators (e.g., higher BMI, waist-hip ratio, waist circumference, triglycerides, or blood pressure; lower HDL cholesterol)^{12,13,15,22}
- > increased prevalence of diabetes-related complications and comorbidities^{14,18,23,24}
- > and the presence of depressive symptoms^{c,18,21} and impaired quality of life.^{21,24,25}



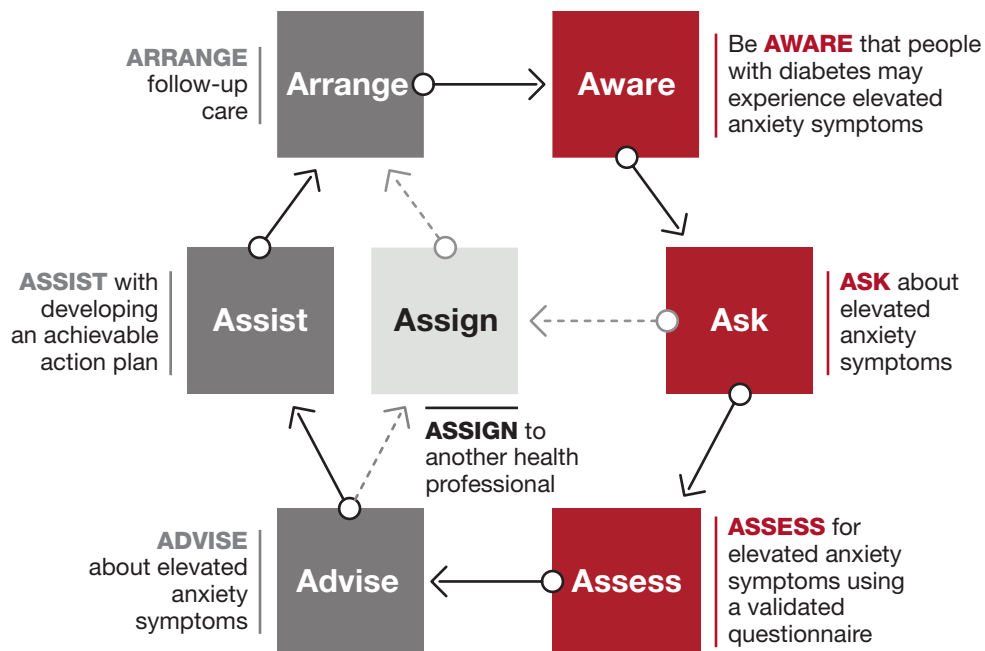
People with a coexisting anxiety disorder and depressive symptoms are likely to experience greater emotional impairment, take longer to recover, and have lower engagement with diabetes self-care.^{26,27}

7 A's Model: Anxiety Disorders

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 elevated anxiety symptoms?
- How can I support a person with elevated anxiety symptoms?

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



c. Evidence is currently only available for type 2 diabetes.



HOW CAN I IDENTIFY Elevated Anxiety Symptoms?

■ Be **AWARE**

Anxiety disorders have emotional, cognitive, behavioral, and physical symptoms. Some common signs to look for include: excessive and persistent worry, panic attacks, and irritability. Also, look for signs that the person is not coping, such as disturbed sleep. Each person will experience different symptoms of an anxiety disorder.

Two classification systems are commonly used for diagnosing anxiety disorders: DSM-5⁶ and ICD-11.⁵ Consult these for a full list of symptoms and the specific diagnostic criteria for each type of anxiety disorder.



Anxiety symptoms may be mistaken for symptoms of hypoglycemia (and vice versa). For example, pounding heart, confusion, shaking, sweating, dizziness, headache, and nausea are symptoms of both hypoglycemia and panic attacks.^{28,29} Consequently, elevated anxiety symptoms may be overlooked or misinterpreted (e.g., as a physical health condition) by people with diabetes and health professionals, and anxiety disorders may go unidentified and undiagnosed.^{28,29}

■ **ASK**

You may choose to ask about elevated anxiety symptoms:

- › when the person reports symptoms or you have noted signs (e.g., changes in mood/behaviors)
- › at times when the risk of developing an anxiety disorder is higher, such as:
 - during or after stressful life events (e.g., bereavement, traumatic experience, diagnosis of life-threatening, or long-term illness)
 - periods of significant diabetes-related challenge or adjustment (e.g., following diagnosis of diabetes or complications, hospitalization, or severe hypoglycemia with loss of consciousness)
- › if the individual has a history of anxiety disorder(s) or other mental health problems
- › and in line with clinical practice guidelines (see **Introduction, Box 1** on page viii).



Take the time to **ASK** about well-being at every appointment. It is a good way to create a supportive environment and build rapport. It may also help you gain some insight into things that may be affecting their diabetes self-management and outcomes that may not arise through discussion specifically about the physical or medical aspects of diabetes. For more information about having conversations about the emotional aspects of diabetes, see Chapter 1.

There are various ways to ask about elevated anxiety symptoms. You may choose to use open-ended questions, a brief structured questionnaire, or a combination of both.

Option 1: Ask Open-Ended Questions

The following open-ended questions can be integrated easily into a routine consultation:

- › “I haven’t seen you for quite a while; tell me about how you have been?”
- › “I know we’ve talked mainly about your diabetes management today but how have you been feeling lately? Tell me about how you have been feeling emotionally.”

If something during the conversation makes you think that the person may be experiencing elevated anxiety symptoms, ask more specific questions, such as:

- › “You seem to be worrying about many different things in your life at the moment; how is this affecting you?”
- › “You mention that you’ve been [very tired, feeling ‘on edge’/tense/stressed] lately. There’s a lot we can do to help you with this, so perhaps we could talk more about it?”

If the conversation suggests the person is experiencing elevated anxiety symptoms, further investigation is warranted (see **ASSESS**).

Option 2: Use a Brief Questionnaire

Alternatively, you can use a brief questionnaire to ask about elevated anxiety symptoms in a systematic way. Collectively, the following two questions are referred to as the Generalized Anxiety Disorder Two (GAD-2) questionnaire.³⁰ They are the core symptoms required for a diagnosis of generalized anxiety disorder.

Over the last two weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious, or on edge	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Not being able to stop or control worrying	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

GAD-2: www.phqscreeners.com



Instead of administering this as a questionnaire, you could integrate these questions into your conversation.

Add the responses to the two questions to form a total score. A total score of 3 or more indicates elevated anxiety symptoms,³⁰ further assessment is warranted.

At this stage, it is advisable to ask whether they have a current diagnosis of an anxiety disorder and, if so, whether and how it is being treated.

If the total score is 3 or more, and the person is not currently receiving treatment for an anxiety disorder, you might say something like, “*You seem to be experiencing some anxiety symptoms, which can be a normal reaction to [...]. There are several effective treatment options for anxiety, but first we need to find out more about your symptoms. So, I’d like to ask you some more questions, if that’s okay with you.*”

You may then decide to assess for an anxiety disorder using a more comprehensive questionnaire (see **ASSESS**). For information about using questionnaires in clinical practice, see pages 10 and 11.

If the total score is less than 3 but you suspect a problem, consider whether the person may be experiencing diabetes distress (see **Chapter 3**), depression (see **Chapter 6**), or another mental health problem.

ASSESS

Validated Questionnaire

The seven-item Generalized Anxiety Disorder questionnaire (GAD-7)³¹ was designed to identify symptoms of generalized anxiety disorder. It is also a helpful indicator of panic attack and social anxiety.^{30,32} A copy is included on page 123. It is quick to administer and freely available online (www.phqscreeners.com). Each item is measured on a four-point scale, from 0 (not at all) to 3 (nearly every day). Scores are added to form a total score ranging 0–21.

In the general population, GAD-7 scores are interpreted as follows:³³

- > 0–4 indicates no anxiety symptoms (or a minimal level)
- > 5–9 indicates mild anxiety symptoms
- > and 10–21 indicates moderate-to-severe anxiety symptoms.



Asking the person to complete the GAD-7 can be a useful way to start a dialogue about anxiety symptoms and the effect they may have on the person’s life and/or diabetes management. It can also be useful for systematically monitoring anxiety symptoms (e.g., whether the symptoms are constant or changing over a period of time).



Remember that anxiety symptoms can overlap with hypoglycemia symptoms (e.g., sweating, shaking). Therefore, take care to consider the context of somatic symptoms, as the GAD-7 items assess symptoms but cannot attribute the cause of the symptoms.



A GAD-7 total score of 10 or more must be followed by a clinical interview using DSM-5⁵ or ICD-11⁴ criteria to confirm an anxiety disorder.

Additional Considerations

What type of anxiety disorder is it and how severe is it? If the GAD-7 indicates a possible anxiety disorder, confirm this through discussion about the symptoms and a clinical interview. For example, is it generalized anxiety disorder, social anxiety disorder, or panic disorder?³⁴ It is important to consider whether the person has multiple comorbid anxiety disorders.³⁵

What is the context of the elevated anxiety symptoms? Are there any (temporary or ongoing) life circumstances that may be underlying the elevated anxiety symptoms (e.g., a traumatic event, chronic stress, changing/loss of employment, financial concerns, or family/relationship problems)? What social support do they have? What role do diabetes-specific factors play (e.g., fear of hypoglycemia; see [Chapter 4](#))?

Are there any factors (psychological, physiological, or behavioral) that are coexisting or may be causing/contributing to the elevated anxiety symptoms?

This may involve taking a detailed medical history, for example:

- › Do they have a history (or family history) of anxiety or another psychological problem? For example, depression (see [Chapter 6](#)), past trauma, bipolar disorder, alcohol or substance abuse, or somatic symptom disorder.^{29,34} These conditions must also be considered and discussed where applicable (e.g., when and how it was treated, whether they thought this treatment was effective, and how long it took them to recover).

- › Is there an underlying medical cause for the symptoms? For example, hypoglycemia; hyperthyroidism or hypothyroidism; an inner ear, cardiac, or respiratory condition; vitamin B deficiency; or medication side-effects.^{29,34}
- › Explore other potential contributors. For example, what medications (including any complementary therapies) are they currently using? Do they use illicit drugs and/or consume alcohol?

Is this person at risk of suicide?³⁵ See [Box 6.3](#) (in [Chapter 6](#)) for information about suicide risk assessment.

No elevated anxiety symptoms—what else might be going on? If the person's responses to the questionnaire do not indicate the presence of elevated anxiety symptoms:

- › they may be reluctant to open up or may feel uncomfortable disclosing to you that they are anxious
- › so consider whether the person may be experiencing another psychological problem (e.g., diabetes distress [see [Chapter 3](#)], depression [see [Chapter 6](#)], or a diabetes-specific fear [see [Chapter 4](#)]).



If any of these assessments are outside your expertise, you need to refer the person to another health professional (see [ASSIGN](#)).



HOW CAN I SUPPORT A PERSON with Elevated Anxiety Symptoms?

■ ADVISE

Now that you have identified that the person is experiencing elevated anxiety symptoms, you can advise them on the options for next steps and then, together, decide what to do next.

- Explain that their responses to the GAD-7 indicate they are experiencing elevated anxiety symptoms, and also that:
 - they may have an anxiety disorder, which will need to be confirmed with a clinical interview
 - and anxiety symptoms fluctuate dependent on life stressors and that it may be necessary to reassess later (e.g., once the stressor has passed or is less intense).
- Elicit feedback from the person about their score (i.e., whether the score represents their current mood).
- Explain what an anxiety disorder is and how it might impact on their life overall, as well as on their diabetes management.
- Advise that anxiety disorders are common and that help and support are available; anxiety disorders are treatable and can be managed effectively.
- Recognize that identification and advice alone are not enough; explain that treatment will be necessary and can help to improve their life overall, as well as their diabetes management.
- Offer the person opportunities to ask questions.
- Make a joint plan about the “next steps” (e.g., what needs to be achieved to reduce anxiety symptoms and the support they may need).



If the person confirms elevated anxiety symptoms in recent weeks, explore whether it is related to a specific temporary stressor (such as public speaking) or a continuous stress (such as ongoing work or financial problems), as this will help to inform the action plan.

NEXT STEPS: ASSIST OR ASSIGN?

- The decision about whether you support the person yourself or involve other health professionals will depend on:
 - the severity of the anxiety symptoms, and the context of the problem(s)
 - your scope of practice, and whether you have the time and resources to offer an appropriate level of support
 - your qualifications, knowledge, skills, and confidence to address elevated anxiety symptoms
 - whether other psychological problems are also present, such as diabetes distress (see **Chapter 3**) or depression (see **Chapter 6**)
 - and the needs and preferences of the person with diabetes.
- If you believe referral to another health professional 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 would be made.

■ ASSIST

Neither elevated anxiety symptoms or anxiety disorders are likely to improve spontaneously,³⁶ so intervention is important. The stepped care approach provides guidance on how to address elevated anxiety symptoms and anxiety disorders in clinical practice.³⁷⁻³⁹

Once an anxiety disorder has been confirmed by a clinical interview, and if you believe you can assist the person:

- Explain the appropriate treatment options (see **Box 7.1**), discussing the pros and cons for each option, and taking into account:

- the context and severity of the anxiety disorder
 - the most recent evidence about effective treatments (e.g., a collaborative and/or a stepped care approach)
 - and the person's knowledge about, motivation, and preferences for, each option.
- Offer them opportunities to ask questions.
 - Agree on an action plan together and set achievable goals for managing their anxiety disorder and their diabetes. This may include adapting the diabetes management plan if the anxiety disorder has impeded their self-care.
 - Provide support and treatment approaches appropriate to your qualifications, knowledge,

skills and confidence. For example, you may be able to prescribe medication but not undertake psychological intervention or vice versa.

- Make sure the person is comfortable with this approach.
- At the end of the conversation, consider giving them some information to read at home but remember that it is best not to overwhelm them with too much information.

Some people will not want to proceed with treatment, at first. For these people, provide ongoing support and counseling about anxiety disorders to keep it on their agenda. This will reinforce the message that support is available and will allow them to make an informed decision to start treatment in their own time.

BOX 7.1 Treating Anxiety Disorders

It is not within the scope of this guide to recommend specific pharmacological or psychological treatments for anxiety disorders in people with diabetes. Here are some general considerations based upon the evidence available^d at the time this guide was published:

- First-line pharmacological treatment for generalized anxiety disorder, social anxiety disorder, and panic disorder is usually selective serotonin re-uptake inhibitors (SSRIs).^{26,40} Pharmacological treatment is not standard first-line treatment for specific phobias.²⁶
- First-line psychological intervention for generalized anxiety disorder, social phobia, panic disorder, and specific phobia is usually cognitive behavioral therapy (CBT).^{26,40} Where avoidance behavior is present, CBT should be combined with exposure.⁴⁰
- The current evidence base does not support combining pharmacological and psychological approaches for generalized anxiety disorder or social anxiety disorder.^{26,40} Combined psychological intervention and pharmacological treatments can be beneficial for panic disorder.^{26,40}
- Some medications used to treat mental health problems (e.g., antidepressants, anxiolytics, and neuroleptics) can have adverse side effects, such as weight gain and metabolic abnormalities, and are associated with insulin resistance.⁴¹ Benzodiazepines are generally not recommended as a first-line treatment due to the risk of addiction.^{26,29} Before prescribing such medications, consider the risks and benefits and their appropriateness for the individual.
- There is evidence for applying stepped care and collaborative care models for anxiety disorders in the general population.^{37,38,42,43} A recent trial found a stepped care approach to be effective for reducing anxiety symptoms in people with diabetes.³⁹
- Early intervention is likely to benefit people with subthreshold anxiety disorder.⁷ A stepwise approach has been proposed, beginning with watchful waiting and gradually increasing the intensity of intervention as symptoms persist or increase.^{7,44}

^d Diabetes-specific references have been cited where available.

■ ASSIGN

If a decision is made to refer, consider the following health professionals:^{45–48}

- **A primary care physician (PCP)** to make a referral to an appropriate mental health professional and prescribe and monitor medications. An extended appointment is recommended.
- **A clinical psychologist or clinical social worker** to conduct a clinical interview, make a diagnosis, and provide psychological therapy (e.g., cognitive behavioral therapy [CBT] or exposure-based therapy).
- **A psychiatrist** to conduct a clinical interview, provide psychological therapy (e.g., CBT or exposure-based therapy), and prescribe and monitor medications.

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 possible, consider referring the person to health professionals who have knowledge about, or experience in, diabetes. For example, if their diabetes management is affected by their anxiety disorder, they may need a new diabetes management plan that is better suited to their needs and circumstances at the time. This might require collaboration and ongoing communication between the PCP or diabetes specialist (e.g., an endocrinologist, diabetes educator, and/or dietitian) and the mental health clinician.



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

If there is need and scope, consider including more frequent follow-up visits or extended consultations in the action plan. Encourage the person to book a follow-up appointment with you within an agreed timeframe to monitor progress and address any issues arising. Telephone/video conferencing may be a practical and useful way to provide support in addition to face-to-face appointments.

Mental health is important in its own right, but it is also likely to impact on the person's diabetes self-management and their physical health. Therefore, it is important to follow up to check that they have engaged with the agreed upon treatment.

At the follow-up appointment, revisit the plan and discuss any progress that has been made. For example, you might say something like, *“When I saw you last, you were feeling anxious. We made a plan together to help you with that and that you would make an appointment to see Tony, a psychologist I recommended. Have you had an opportunity to see him? How has it worked out for you?”*



CASE STUDY

Mary

37-year-old woman living with her partner, George
 Type 1 diabetes (for 21 years)
 Health professional: Dr. Ariadne Pappas (endocrinologist)

■ Be AWARE

Mary has not been feeling like herself lately. She finds herself worrying a lot about her diabetes and other aspects of her daily life. Often she feels irritable and tired for no reason, and wonders if this is related to her diabetes (e.g., lack of sleep due to late night hypoglycemia). She likes things in her life to be in order, so this change from the ordinary concerns her. Mary tells Dr. Pappas that she doesn't know what to do; she hopes that Dr. Pappas will have some answers for her. Dr. Pappas listens to Mary's concerns and acknowledges that some of the symptoms may be related to Mary's diabetes. However, Dr. Pappas does not want to rule out other causes yet because she is aware that irritability and tiredness are common symptoms of a range of conditions.

■ ASK

Through open-ended questions, Dr. Pappas learns more about Mary's symptoms. Sometimes Mary sweats or shakes, and when this happens her heart beats faster than usual. This has happened to Mary a few times on the train to work in the city. It is physically and mentally draining for Mary; it makes her feel "on edge." Sometimes a quick blood glucose check shows she is having a "hypo," which would explain her symptoms, but most of the time her glucose levels are in target. Her moods are affecting her relationship with her partner, George, and this causes her even more stress and worry.

■ ASSESS

Dr. Pappas decides further assessment is needed. She invites Mary to complete two screening questionnaires: for anxiety (GAD-7) and depression (PHQ-9). Mary scores 13 on the GAD-7, suggesting

that she is experiencing moderate levels of anxiety symptoms. She also scores 6 on the PHQ-9, indicating mild depressive symptoms. Dr. Pappas checks the file for her most recent A1C and asks to look at Mary's recent blood glucose readings. These and other assessments reveal no physiological causes for the anxiety symptoms.

■ ADVISE

Dr. Pappas explains the questionnaire scores to Mary and asks her if this fits with how she has been feeling lately. She also explains to Mary the symptoms of anxiety and depression and reassures her that there are several treatment options. These include medication, psychological therapy, or a combination of these. Mary appears interested in seeking treatment and support. Dr. Pappas advises Mary to speak with her PCP as soon as possible to discuss treatment options for her under her current insurance coverage. She offers Mary plenty of opportunity to ask questions, and Mary agrees to see her PCP.

■ ASSIGN

With Mary's permission, Dr. Pappas writes a letter to Mary's PCP and includes the scores and interpretation of the GAD-7 and PHQ-9 questionnaires.

■ ARRANGE

Dr. Pappas and Mary agree that Mary will make an appointment with her PCP and a follow-up appointment with Dr. Pappas once she has seen her PCP. With agreement from Mary, Dr. Pappas telephones Mary's PCP to check that they will make an appointment available to her in a timely manner. Dr. Pappas encourages Mary to contact her via telephone if she has any difficulty getting an appointment with the PCP.



CASE STUDY

Ned

47-year-old man living with his wife Faye and their children

Type 2 diabetes (diagnosed 3 months ago), managed without medication; dyslexia

Health professional: Liza Cooper (certified diabetes educator and dietitian)

■ Be AWARE

Ned was recently diagnosed with type 2 diabetes, and his dyslexia is causing him some challenges with self-management. His PCP has referred him to Liza for diabetes education. Liza and Ned have met twice and have begun to build a good rapport. Liza senses that Ned has adjusted quite well to the diagnosis of diabetes but feels that he needs to build his confidence in managing the condition. They have been working on this together. Liza has observed Ned to be quite an anxious person, as he:

- fidgets during consultations
- gets visibly nervous (shaky hands, sweaty palms), particularly when practicing reading food labels; his nervousness seems to be related to reading and interpreting written information
- and expresses worries about whether he is getting his diabetes management “right.”

Liza has started to develop concerns about Ned’s level of anxiety symptoms, so when he mentions that he has not been sleeping well she decides to investigate further.

■ ASK

Liza enquires about why Ned has not been sleeping. He tells her, “*I can’t switch my brain off... I worry about my dad—he’s been really sick from his diabetes—I think it’s his kidneys. I worry about my job and how the kids are doing in school, and now I have diabetes and I worry it’ll be just like with my dad...and the little things worry me too—noises in my neighborhood at night, whether I locked the car...*”

Faye says I worry too much. She won’t say it, but it annoys her...I can’t help it.” Liza asks Ned whether his level of worry bothers him too, and he tells her that it does. He says he worries, “*during the day sometimes, but the nights are worse.*”

■ ASSESS

Liza tells Ned that it is quite common for people with diabetes to develop problems with anxiety and worry. She asks Ned whether he will answer some questions to help better understand his worries. Ned agrees, so Liza:

- opens a copy of the GAD-7 on her computer screen
- and reads the questions and response options aloud to Ned and asks him to respond to each question.

Ned scores 17, indicating severe anxiety symptoms.

■ ADVISE

Liza explains that Ned’s score is high and that this is more than just worry—it indicates a possible anxiety disorder. She explains what this is and asks him if this fits with how he has been feeling lately. To reassure him, she says, “*Now that we know that there is a problem, there are things we can do to help you. The first step is for you to see your doctor. If you do have an anxiety disorder, then he will confirm it. And he can help you to treat it, too, with medication or counseling, or both. Treatment will help to lower your worry and anxiety symptoms, which will help you to sleep better.*”

Ned expresses concern about what people might think, especially at work on the building site. Liza tells him that anxiety is very common, with one in five men experiencing an anxiety disorder at some stage in their life.¹² Liza reassures Ned that it is his choice who he tells (or doesn't tell) about his anxiety. She suggests he talks initially just with the people he trusts, such as his wife and PCP.

■ ASSIGN

Liza explains that Ned can continue to see her for diabetes education, but he will also need to see his PCP to address the anxiety, as this is outside her expertise. She proposes that she share his

questionnaire responses and scores with his PCP and Ned agrees to make an appointment. Liza suggests that he sees the PCP as soon as possible, and that he requests an extended appointment so that they have plenty of time.

■ ARRANGE

They agree that Ned will return to see Liza in one week. They would like to continue with the diabetes education, and Liza would like to check Ned's progress with his PCP regarding his anxiety symptoms. Due to the severity of Ned's symptoms, Liza calls his PCP to check that the test scores were received and that an appointment will be made available to him as soon as possible.

Questionnaire: Generalized Anxiety Disorder Seven (GAD-7)

Instructions: For each statement, please tick the box below that best corresponds to your experience in the last 2 weeks.

Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1 Feeling nervous, anxious, or on edge	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
2 Not being able to stop or control worrying	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
3 Worrying too much about different things	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
4 Trouble relaxing	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
5 Being so restless that it is hard to sit still	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
6 Becoming easily annoyed or irritable	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
7 Feeling afraid, as if something awful might happen	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

(Office use only) Total score =

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues, with an educational grant from Pfizer, Inc. No permission is required to reproduce, translate, display, or distribute. See: www.phqscreeners.com

Background

The GAD-7^{30,32} is a seven-item questionnaire for assessing anxiety symptoms and their severity. It has satisfactory psychometric properties for screening for generalized anxiety disorder, panic disorder, and social anxiety disorder.^{30,32}

It is freely available online in more than 30 languages, quick to administer, and easy to score and interpret. Many of the translations are linguistically valid, though few have been psychometrically validated.³³

How to Use the GAD-7 in Clinical Practice

Respondents are asked to indicate how frequently they are bothered by each of the seven items (each describing a different symptom of generalized anxiety disorder).^{31,33} Items are scored on a scale from 0 (not at all) and 3 (nearly every day).³³

An additional supplementary item (which does not contribute to the total score) can also be asked to evaluate the level of social or occupational difficulty caused by the anxiety symptoms. This question appears in the original GAD-7 publication³¹ but not in the version on the website,⁴⁹ and has been included in the questionnaire.



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

Interpretation of Scores

The scores for each item are added to generate a total score (range: 0–21).³³ Anxiety symptom severity is indicated by the GAD-7 total score.³³ Generally, a GAD-7 total score of 10 or more is an indicator of likely anxiety disorder,^{32,33} and needs to be followed up with a clinical interview.

GAD-7 total score	Depressive symptom severity
0–4	None – minimal
5–9	Mild
10–14	Moderate
15–19	Moderately severe
20–27	Severe

Short Form—GAD-2

- › The GAD-2^{30,32} consists of two items from the GAD-7: item 1, “Feeling nervous, anxious, or on edge,” and item 2, “Not being able to stop or control worrying.”
- › The timeframe and response options are the same as the GAD-7.
- › The two item scores are summed to form a total score. Total scores of 3 or more warrant further assessment for anxiety disorder.^{30,32}

Resources

For Health Professionals

Peer-Reviewed Literature

› **Association of diabetes with anxiety: a systematic review and meta-analysis**

Description: Explores the relationship between diabetes and anxiety; in particular whether diabetes is associated with increased risk of anxiety disorders and symptoms.

Source: Smith KJ, Beland M, et al. *Journal of Psychosomatic Research*. 2013;74:89-99.

› **Diabetes and anxiety symptoms: a systematic review and meta-analysis**

Description: Another overview examining the relationship between anxiety and diabetes.

Source: Amiri S, Behnazhad S. *The International Journal of Psychiatry in Medicine*. 2019.

› **Comorbid elevated symptoms of anxiety and depression in adults with type 1 or type 2 diabetes: results from the International Diabetes MILES Study**

Description: An examination of the prevalence of symptoms of anxiety/depression, how these are correlated with demographics and clinical factors, and the associations with self-care behaviors by diabetes type.

Source: Nefs G, Hendrieckx C, et al. *Journal of Diabetes and Its Complications*. 2019;33(8):523-529.

Books

› **Management of Mental Disorders, 5th edition**

Description: A book that provides practical guidance for clinicians in recognizing and treating mental health problems, including generalized anxiety disorder, social phobia, and panic disorder. The book also includes worksheets and information pamphlets for people experiencing these problems and their families.

Source: Andrews G, Dean K et al. *Clinical Research Unit for Anxiety and Depression (CRUFAD)*. 2014.

Additional information: Sections of this book (e.g. treatment manuals and worksheets) are freely available to download from the “For Clinicians” section of the CRUFAD website.

URL: www.crufad.org

› **Treatments that Work (Series)**

Description: The *Treatments that Work* book series describes evidence-based psychological interventions for a variety of mental health conditions. They have a wide array of therapist guides with accompanying patient workbooks. The resources for anxiety disorders are especially comprehensive.

Source: Oxford University Press

URL: www.oxfordclinicalpsych.com/page/ttwseries/treatments-that-work-series

Websites

› **American Diabetes Association (ADA)**

Description: ADA and the American Psychological Association partnered to create an educational program for mental health professionals interested in emotional issues specific to people with type 1 and type 2 diabetes. Clinicians who have completed this training can be found on the ADA website in their Mental Health Provider Directory Listing.

URL: https://professional.diabetes.org/mhp_listing

› **Behavioral Diabetes Institute (BDI)**

Description: BDI is an educational nonprofit organization dedicated to better identify, understand, and treat emotional issues related to diabetes. It provides direct clinical care and other programming for people with diabetes and their families, educational programs for health professionals, and conducts research on behavioral health issues in diabetes.

URL: www.behavioraldiabetes.org

› **American Psychological Association (APA)**

Description: APA is the largest scientific and professional organization of psychologists in the U.S. APA Press offers academic publications for health professionals and books on mental health topics for adults and children. Its Psychology Help Center provides educational information about mental health issues and also offers confidential telephone counseling.

URL: www.apa.org

› **Anxiety and Depression Association of America (ADAA)**

Description: ADAA is an international nonprofit organization of mental health professionals

dedicated to the prevention and treatment of anxiety, depression, and other co-occurring disorders through education, practice, and research.

URL: www.adaa.org

For People with Diabetes

Support

> Mental Health America

Description: The website for Mental Health America has a number of good resources for those dealing with anxiety.

URL: <https://mhanational.org/conditions/anxiety>

Information

> Diabetes and Anxiety

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

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

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

References

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“I used to think that if I had to go on insulin I would have felt like a failure, it would have meant that I wasn’t looking after myself properly. But peer support really helped me, because listening to other people talking about using insulin and reading about it helped me to change my view. I started to think of needing insulin as a natural progression.”

—Person with type 2 diabetes

Chapter 8

Eating Problems



Key Messages

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



Practice Points

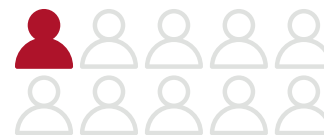
- Ask the person directly, in a sensitive/non-judgmental way, about eating behaviors and attitudes towards food, insulin restriction/omission, and concerns about body weight/shape/size.
- Be aware not to positively reinforce weight loss or low A1C when eating problems are (likely) present.
- Be aware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

How Common Are Eating Problems?

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



Type 1 diabetes^{a,1-3}



Type 2 diabetes^{2,4}

Disordered eating behaviors



Type 1 diabetes⁵⁻⁸



Type 2 diabetes⁹⁻¹¹



WHAT ARE Eating Problems?

Eating Disorders

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

- › **Anorexia nervosa:** characterized by severe restriction of energy intake, resulting in abnormally low body weight for age, sex, developmental stage, and physical health; intensive fear of gaining weight or persistent behavior interfering with weight gain; and disturbance in self-perceived weight or shape. There are two subtypes:

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

a Based on young women only.

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

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

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

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

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

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

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

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

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

- › the prevalence of anorexia nervosa in female adolescents and young women with diabetes is low and not more prevalent than in the general population¹⁸
- › and people with diabetes are more likely to present with periodic overeating, binge eating, and compensatory weight control behaviors,¹⁹ with more frequent and severe behaviors likely to meet criteria for a full syndrome eating disorder such as bulimia nervosa or binge eating disorder.

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

Disordered Eating Behaviors

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

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

Intentional Insulin Restriction or Omission

- › The restriction or omission of insulin for the purposes of weight loss is unique to people with diabetes and the most common form of compensatory weight control behavior.¹⁷ Intentional insulin restriction or omission induces hyperglycemia and loss of glucose (and calories) in the urine, enabling a person to eat with reduced concerns about gaining weight.
- › In individuals with type 1 diabetes and disordered eating behaviors, rates of insulin omission have been reported in up to 40% of people.²¹ However, people omit or restrict insulin for other reasons than weight loss (e.g., fear of hypoglycemia, or rationing insulin for financial reasons).

BOX 8.2 Eating Styles

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

- › **Emotional eating** (in response to negative emotional states, such as anxiety, distress, and boredom) provides temporary comfort or relief from negative emotions, as a way of regulating mood. It is associated with weight gain in adults over time²⁴ and tends to be more common in people who are overweight or obese.²⁵
- › **External eating** (in response to food-related cues, such as the sight, smell, or taste of food) accounts for approximately 55% of episodes of snacking on high-fat or high-sugar foods in people who are overweight or obese.²⁶

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

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

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

- › Not all people with diabetes and an eating disorder restrict or omit insulin for weight loss. They may restrict food/calories while taking insulin as recommended and they may also compensate for overeating with more typical eating disorder symptoms.²¹
- › Both negative affect and diabetes distress substantially increase the odds of insulin restriction.²²

Eating Problems in People with Diabetes

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

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

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

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

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

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

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

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

- › blood glucose levels above recommended targets³⁶
- › and other mental health problems.³⁶

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

- › earlier onset¹⁷ and increased risk of microvascular complications^{7,37} (e.g., retinopathy or neuropathy)
- › more frequent episodes of diabetic ketoacidosis and diabetes-related hospital admissions^{5,38,39}
- › and up to three times greater risk of mortality over a 6–10 year period.^{16,40}

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

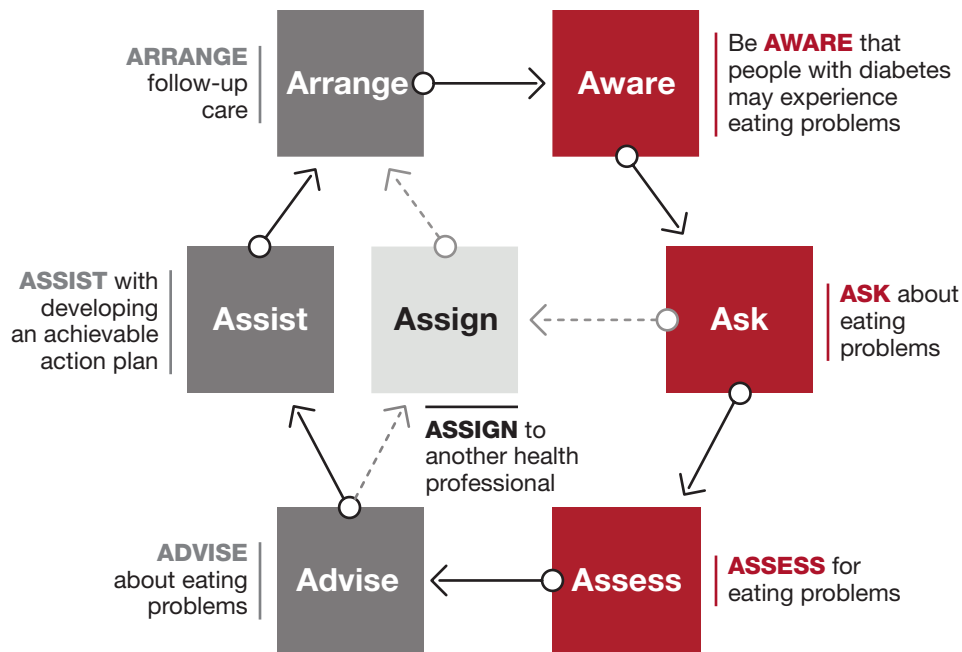
- › overweight and obesity^{41,42}
- › lower self-efficacy for diet and exercise self-management⁴³
- › suboptimal dietary and glucose levels, but not A1C⁴⁴
- › not taking medications as recommended⁴⁵
- › and impaired mental health⁴⁶ and quality of life.^{4,43,47}

7 A's Model: Eating Problems

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

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

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



HOW CAN I IDENTIFY Eating Problems?

■ Be AWARE

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

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

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

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

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

Two classification systems are commonly used for diagnosing eating disorders: DSM-5¹³ and ICD-11.¹² Consult these for a full list of symptoms and the specific diagnostic criteria for each type of eating disorder.



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



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

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

■ ASK

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

Option 1: Ask Open-Ended Questions

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

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

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

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

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

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

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



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

People may restrict/omit insulin for weight loss purposes after they have overtreated a hypoglycemic episode. You might like to use following questions²² related to hypoglycemia:

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

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



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

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

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



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



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

Option 2: Use a Brief Questionnaire

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

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

The mSCOFF consists of five questions:

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

© American Diabetes Association, 2014.⁴⁹

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



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



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



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

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

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

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

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

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

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

NEXT STEPS: ASSIST OR ASSIGN?

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

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

ASSESS

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

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

Clinical Interview

A clinical interview assesses:

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

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

Clinical Examination

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

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



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



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

Additional Considerations

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



HOW CAN I SUPPORT A PERSON with an Eating Problem?

■ ADVISE

Now that you have identified signs of an eating problem:

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

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

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

NEXT STEPS: ASSIST OR ASSIGN?

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

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

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

(cont.)

(cont.)

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

- › Options for support and treatment vary accordingly to geography and include outpatient, day program, and inpatient treatment in severe cases.¹⁴ Where to **ASSIGN** will depend on multiple factors (e.g., availability of services, type and severity of the eating disorder, and geography). Treatment in the least restrictive context is recommended utilizing a stepped care approach.
 - › The safety of the person is the first priority; therefore, inpatient treatment may be required depending on the severity of the eating disorder.
 - › Involuntary assessment and treatment may be required if the person has impaired decision-making capacity and cannot or will not consent to life-preserving intervention. However, most specialty eating disorder treatment centers in the U.S. are voluntary admission only.¹⁴
- psychological therapies: for example, family-based therapy (if the person is still living with family), enhanced cognitive behavior therapy (CBT-E) or interpersonal therapy (IPT). These aim to address maladaptive thoughts, emotions, and behaviors (CBT-E) or problems in relationships (IPT)^{56,57} and pharmacological treatments.¹⁴
 - Assist the person to identify and access appropriate support and treatment (e.g., if you are a PCP, establish a collaborative care team and write a treatment plan⁵⁸ and/or a referral to a relevant health professional who can provide psychotherapy).
 - Explain that a collaborative approach is needed, and which health professionals will be part of the team.
 - Agree on an action plan together and set achievable goals for managing their diabetes and eating problem.
 - Make sure the person is comfortable with this approach.
 - At the end of the conversation, consider giving them information to read at home or refer them to online resources. At the end of this chapter (see page 145), there are resources that may be helpful for a person with diabetes who is experiencing eating problems.

■ ASSIST

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

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

- › Provide information about the specific eating problem that was identified during the comprehensive clinical assessment, and its likely impact on diabetes management/outcomes and general health.
- › Explain and discuss treatment options with the person to enable them to make a well-informed decision. This will help them to engage with the treatment/therapy, which will likely be a combination of:
 - an adapted diabetes management and dietary plan: with more flexible and realistic blood glucose targets, and with less focus on weight loss or strict dietary plans



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



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

■ ASSIGN

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

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

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



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

■ ARRANGE

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

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



CASE STUDY

Sarah

59-year-old woman living alone

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

Health professional: Dr. Lydia Morris (PCP)

■ Be AWARE

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

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

■ ASK and ASSESS

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

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

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

Lydia goes through the mSCOFF with Sarah. Sarah replies "yes" to two items: "Do you make yourself sick because you feel uncomfortably full?" and, "Do you worry you have lost control over how much you eat?" Sarah's responses suggest that she may be experiencing eating problems, most likely, disordered eating. Sarah confides that she feels

distressed about her overeating and resulting weight gain, and has a tendency to restrict her food intake, but also to overeat at the end of the day and in response to negative emotions.

■ ADVISE

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

■ ASSIGN

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

■ ARRANGE

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



CASE STUDY

Eliza

25-year-old woman, lives at home with her family
 Type 1 diabetes (14 years), managed with insulin pump;
 BMI=19
 Health professional: Dr. Mark Haddad (endocrinologist)

■ Be AWARE

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

■ ASK

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

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

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

Mark asks Eliza what she thinks may be causing the higher A1C. First, she says she has “no idea,” but then confides that she is “not eating well” and that she sometimes “forgets” to bolus. Based on what Mark has observed and Eliza's recent hospitalizations, Mark is concerned that Eliza might

be at an early stage of an eating disorder and is omitting insulin for weight-loss purposes (she has missing data in her pump downloads).

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

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

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

■ ADVISE

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

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

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

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

■ ASSIST

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

■ ARRANGE

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

Resources

For Health Professionals

Peer-Reviewed Literature

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

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

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

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

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

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

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

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

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

Books

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

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

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

Websites (not diabetes specific)

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

Description: AED helps physicians, psychiatrists, psychologists, nutritionists, academic researchers,

students, and experts connect and collaborate with each other and keep abreast of recent developments in eating disorders research.

URL: www.aedweb.org

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

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

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

Phone/Text: (800) 931-2237^c

For People with Diabetes

Support

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

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

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

- › **We Are Diabetes**

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

URL: <http://www.wearediabetes.org>

- › **Diabulimia Helpline (DBH)**

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

URL: <http://www.diabulimiahelpline.org>

Phone: (425) 985-3635^c

Information

- › **Diabetes and Disordered Eating**

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

^c Call charges may apply.

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

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

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

—Person with type 1 diabetes

Chapter 9

Referring to a Mental Health Professional



Key Messages

- In general, people with diabetes tend to prefer their diabetes health professional to support them with the emotional aspects of diabetes (e.g., diabetes distress, psychological barriers to insulin, or fear of hypoglycemia).
- If the person is experiencing a mental health problem (e.g., eating disorder, depression, or anxiety) and you do not have the expertise to assist, a referral to a primary care physician (PCP) or mental health professional will be necessary.
- Some mental health problems require immediate attention and referral to a specialist or admission to the hospital (e.g., an eating disorder with direct risk for the person, or acute suicide risk). Contact emergency services immediately for crisis referrals.



Practice Points

- Talk with the person with diabetes about the reasons for the referral and ask them about their thoughts and feelings on this.
- Continue to see the person with diabetes after the referral to help reassure them that you remain interested in their ongoing care. Take this opportunity to check their progress and revise the action plan if needed. Post-referral follow-up is important.
- Maintain ongoing communication with the health professional to whom you made the referral to ensure a coordinated approach to the person's ongoing care.

Background

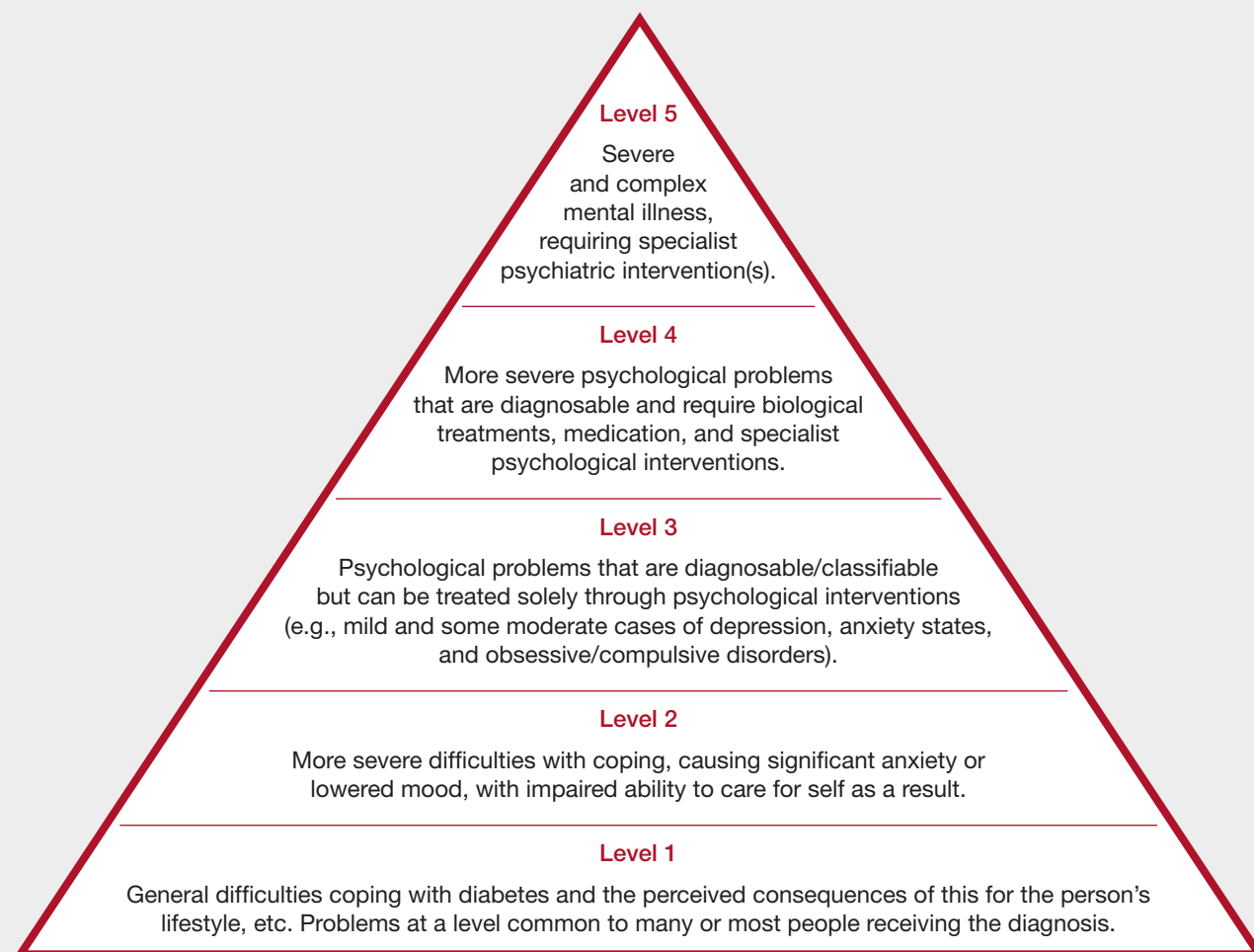
One of the challenges of attending to the emotional and mental health needs of people with diabetes is knowing which problems you can address as part of a person-centered approach to diabetes care and which problems need referral to a mental health professional.

Many people with diabetes (Level 1 of the pyramid in **Box 9.1**) experience only general or mild difficulties in coping with their diabetes and will benefit largely from the support and counselling that their usual diabetes health professionals can offer. Moving up the pyramid, the more severe and complex the psychological problem is, the more likely it is that the individual will need

specialist psychological support. Level 5 of the pyramid also demonstrates that severe and complex mental health problems are, fortunately, relatively rare among people with diabetes.

Psychological problems can coexist alongside or be caused by diabetes. Even when diabetes is not a contributing factor, the more severe the psychological problem, the more likely it is that diabetes management (and consequently, diabetes outcomes) will be impaired. In most circumstances, a multidisciplinary, collaborative care model is the best approach.

BOX 9.1 Pyramid of Psychological Problems



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Making the Referral

Before deciding whether to assist the person or to refer them to a mental health professional, consider the context and severity of the problem as well as your qualifications, knowledge, skills, confidence, time, and resources to address the problem. Most importantly, discuss these considerations with the person with diabetes, as they may also have their own preferences.



The information in this section applies to situations where there is no emergency or immediate risk of harm (to self or others). If you need information on what to do in the event of a crisis, see “Crisis Referrals” on pages 154–155.

Tips for Making a Mental Health Referral

Where you believe a referral is required, it is important to talk about the options and processes with the person with diabetes.

- › **Discuss the person’s preferences for the referral.** The person may have a preferred mental health professional (e.g., someone they have seen previously), or they may have specific requirements about whom they are willing to see (e.g., someone of the same gender or cultural background).
- › **Explain that finding the “right match” is important.** Every health professional has an individual consultation style and approach; some will suit the individual better than others will. If the person finds that the mental health professional’s style/approach does not meet their needs, or they do not feel comfortable, explain that this can happen and that you can assist them in exploring and accessing other specialists.²
- › **Prepare the person for what to expect at the mental health consultation.**² For example, if you have referred the person with diabetes to a psychologist for assessment, explain that they will probably be asked to complete questionnaires, and answer questions about their life, including family background, medical history, and relationships. If you have referred them to a psychiatrist, explain what a psychiatrist does and why you feel psychiatric intervention is necessary for their presenting problem. You may need to clarify the difference between a psychologist and a psychiatrist.
- › **Prepare the person for what will be expected of them.** Inform them that mental health interventions vary in their duration and course, depending on the type of problem. There will also be a time commitment required for the initial session (e.g., 45–60 minutes) and subsequent sessions; the duration of the therapy will be decided together with the mental health professional. There may also be tasks they need to complete between sessions (e.g., keeping a record of their mood). The person will usually be required to make their own appointments with the mental health professional, except in urgent situations.²
- › **Explain to the person why you believe a referral is needed.** Clarify what a mental health professional can offer that you cannot, and what the expected benefits of seeing a mental health professional will be for the person.² For example, will support from a mental health professional assist them with diabetes management? Or help to reduce their depressive symptoms? Or both?
- › **Ascertain how comfortable the person feels about being referred to a mental health professional.** You may prefer to take some time to first gauge an understanding of their emotional state and readiness to seek and accept such support.² Then, assist them in making an informed decision about whether to seek and access appropriate support when they feel ready to do so.³ If they feel nervous or unsure about whether they are ready, normalize this experience for them—let them know that it is common to feel this way and give them time to think about it.
- › **Be familiar with your local referral pathways.** If you can personally recommend a particular mental health professional or service (e.g., with a specific interest in diabetes) this can be reassuring for the person with diabetes.² Also see **Box 9.2** for tips about establishing referral pathways.

BOX 9.2 Establishing Referral Pathways

It can be challenging to build referral pathways. For providers who work in settings with integrated behavioral health within the primary care setting, referrals may take place with an in-person introduction (i.e., a warm hand-off). Also, be aware of co-located behavioral health services that may exist within your health system but separate from your primary care or specialty practice.

In addition to asking people in your existing networks for recommendations, you might also choose to develop new networks.

Many of the mental health professional organizations, including state psychological associations, have directories on their websites, through which you can search for a relevant mental health professional by location, interest area (e.g., chronic disease or depression), and other characteristics. For example:

- › American Diabetes Association Mental Health Provider Directory: https://professional.diabetes.org/mhp_listing
- › American Psychological Association website: <https://locator.apa.org/>
- › National Association of Social Workers website: <https://www.socialworkers.org/practice/behavioral-health>

Also consider community resources that may serve patients, including pastoral counseling.

Finally, people with diabetes with significant eating disorders would benefit from referral to a multidisciplinary eating disorder clinic that is designed to simultaneously address the emotion, nutritional, and medical needs of these patients.

- › **Inform the person of any potential financial costs to them.** For example, costs can vary significantly based on coverage and there are usually out-of-pocket expenses and/or specialist co-pays to access a psychologist or psychiatrist.² Local state psychological associations will typically list which plans are accepted by individual psychologists, and it is helpful to have a list of mental health professionals who are part of your insurance network for referrals. Plan websites will also often list in-network providers, which can then be matched to professionals on the American Diabetes Association Mental Health Provider Directory (https://professional.diabetes.org/mhp_listing).

- › **Explain waiting times and service limitations.** You may need to continue to see the person until they can see the mental health professional so that they remain supported and do not fall between service gaps.
- › **If the person is reluctant or chooses not to consult a mental health professional at this time,** explain the limitations of your expertise (e.g., you are not an expert in managing mental health problems) and provide them with basic support (e.g., give them the opportunity to talk about how their problems are impacting on their diabetes).² Monitor the person and make a plan to revisit the option of a mental health referral at another time, as needed.

Writing the Referral

After agreeing with the person with diabetes that referral is the best option, you can then request a referral within your healthcare system, if applicable, or to a mental health provider outside your system. In addition, you may also choose to have a more detailed conversation about the problem (by telephone or video conference) with the mental health professional to whom you are referring the person.

Retain a copy of the plan/letter in the patient's medical record.

Referral Letter

If you are a diabetes health professional, you will need to write a referral letter to arrange further assessment (with a clinical interview) and treatment for identified mental health problems. It is usually best to first refer the person to a PCP.

PCPs can assess for mental health problems and make referrals. PCPs can also prescribe medications for mental health problems. Keep in mind that PCPs' individual levels of interest and expertise in mental health assessment and treatment vary.

You may already have a standardized template for the referral letter, or a template built into your electronic medical records platform that will auto-fill with pertinent information. If not, a general guide about what to include is offered in **Box 9.3**.²

BOX 9.3 Checklist of Suggested Content for a Mental Health Referral Letter

<input type="checkbox"/> Identifying information	<p>The person's:</p> <ul style="list-style-type: none"> • name • gender • age • date of birth • address • and patient record number (if applicable).
<input type="checkbox"/> Purpose of the referral	<p>Your reason for writing the referral (e.g., to establish a diagnosis, improve adherence to a diabetes regimen, or to treat major depression).</p>
<input type="checkbox"/> Presenting problem	<p>A brief summary followed by a more detailed description (i.e., what the person reports and what you observe). Be concise but include enough detail for the health professional to know how to approach the initial consultation and to provide optimal care to the person.</p> <p>Respect the person's privacy—first check whether there are any parts of your conversation that they would prefer not to be included in the referral.</p> <p>Document any safety concerns you have (i.e., risk to themselves or others).</p>
<input type="checkbox"/> Assessment results	<p>Where available, include validated questionnaire scores (and/or a copy of the completed questionnaire), and interpretation of the results of any suicide risk assessment.</p>
<input type="checkbox"/> Medical history	<p>Relevant details of the person's broader medical history. For example:</p> <ul style="list-style-type: none"> • diabetes type, duration, and treatment • current medications • known allergies • history of mental health problems, including details about severity, duration, and treatment (e.g., names of medications, types of psychological therapy, and contact details of their mental health professional).
<input type="checkbox"/> Follow-up plan	<p>Include a projected timeframe for the person's medical treatment. Clarify who will be responsible for follow-up. You may also like to request written updates of the person's progress and treatment.</p>
<input type="checkbox"/> Consent	<p>Document that the person has provided consent for the referral.</p>
<input type="checkbox"/> Your contact details	<p>For example, your:</p> <ul style="list-style-type: none"> • name • practice name • address • telephone • fax • and email address.
<input type="checkbox"/> Your signature and the date	<p>Complete the referral with your signature and the date.</p>

What to Do After Making a Referral

Once you have made a referral, it is your responsibility to ensure that it has been received and accepted. If the person with diabetes is placed on a waiting list, both service providers should agree who is responsible for monitoring the individual. It is important that the person is not left waiting for their appointment without anyone to support them, especially if you have concerns for their well-being or safety.

Continue to support the person with regular appointments especially while they are establishing a therapeutic relationship with the mental health professional. When you see the person with diabetes:

- › Talk about their experience of the mental health intervention. For example, *“You had a few sessions with Julia. How is that working out for you? How have things been since you’ve been seeing her?”* Keep in mind that the issues discussed with the mental health professional may be highly sensitive and respect the person’s right to privacy.²
 - If the person with diabetes does not feel the intervention is helping them, find out why. Let them know that there are other options and that you are happy to explore these options with them.² For example, you might say something like, *“It can take time to find a [psychologist] that you feel comfortable with. Sometimes, it takes a bit of trial and error to find the right person; this is normal and there is no need for this to stop you from seeking help.”*

- › If psychotropic medication(s) have been prescribed, enquire about these. For example, *“How have you been feeling since starting your medication(s)? Have you noticed any changes in how you feel—positive or negative?”* Some psychotropic medications can affect blood glucose levels, so check that the medication has not had a negative impact on the person’s diabetes management.²
- › Maintain ongoing communication with the referring health professional to review the referral and person’s progress, and to ensure a coordinated approach.

Crisis Referrals

Keep a completed mental health crisis referral template in an accessible location. Refer to the template in emergencies. A blank copy of a template is included in **Box 9.4**.

Also, read **Box 6.3** about suicide on page 97 for more information about what to do if a person is in immediate danger of suicide.

BOX 9.4 Mental Health Crisis Referral Template

If a person is at immediate risk of harming themselves or others, telephone 911 for police, ambulance, or fire services IMMEDIATELY for emergency assistance.

Where there is immediate risk of harm and the person consents to attending emergency services, contact your nearest hospital (with emergency services) and make the necessary arrangements with the hospital and the person with diabetes.

Nearest Hospital (with Emergency Services)	
Name:	
Address:	
Phone:	Triage:

As an alternative to hospitalization, contact the nearest Crisis Intervention services to arrange emergency psychiatric care in the community. Each county and state has their own system for mental health emergencies—please contact your county office of mental health or social services to find out your contact phone numbers. In some areas these services are carried out by police or EMS services.

Crisis Intervention Services	
Name of Service:	
Contact person:	Phone:
Additional contact:	Phone:

When the person is not at immediate risk, but you have concerns for their welfare and/or the welfare of others, consider consulting a mental health professional for advice.

Mental Health Professional Contacts	
Name:	
Phone:	Availability:
Name:	
Phone:	Availability:
Other contacts	
Note the contact details of other resources (e.g., help lines) in your area that may be suitable in the event of an emergency/crisis:	

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I told my doctor that I was struggling. After that, every time we would get together he asked, ‘*Mentally, how are you doing?*’ Asking that question was really, really helpful... then I didn’t have to bring it up every time, you know, when I didn’t really want to.

—Person with type 2 diabetes

Appendix A

American Diabetes Association's Position Statement on Psychosocial Care

Psychosocial Care for People with Diabetes: A Position Statement of the American Diabetes Association

Deborah Young-Hyman, Mary de Groot, Felicia Hill-Briggs, Jeffrey S. Gonzalez, Korey Hood, and Mark Peyrot

Corresponding author: Deborah Young-Hyman, younghyd@od.nih.gov.

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Introduction

Complex environmental, social, behavioral, and emotional factors, known as psychosocial factors, influence living with diabetes, both type 1 and type 2, and achieving satisfactory medical outcomes and psychological well-being. Thus, individuals with diabetes and their families are challenged with complex, multifaceted issues when integrating diabetes care into daily life. To promote optimal medical outcomes and psychological well-being, patient-centered care is essential, defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions”.¹ Practicing personalized, patient-centered psychosocial care requires that communications and interactions, problem identification, psychosocial screening, diagnostic evaluation, and intervention services take into account the context of the person with diabetes (PWD) and the values and preferences of the PWD.

This article provides diabetes care providers with evidence-based guidelines for psychosocial assessment and care of PWD and their families. Recommendations are based on commonly used clinical models, expert consensus, and tested interventions, taking into account available resources, practice patterns, and practitioner burden. Consideration of life span and disease course factors (Figure A.1) is critical in the psychosocial care

of PWD. This Position Statement focuses on the most common psychological factors affecting PWD, including diabetes distress and psychological comorbidities, while also considering the needs of special populations and the context of care.

General Considerations In Psychosocial Care

Recommendations

- Psychosocial care should be integrated with collaborative, patient-centered medical care and provided to all people with diabetes, with the goals of optimizing health outcomes and health-related quality of life. **A**
- Providers should consider an assessment of symptoms of diabetes distress, depression, anxiety, and disordered eating and of cognitive capacities using patient-appropriate standardized/validated tools at the initial visit, at periodic intervals, and when there is a change in disease, treatment, or life circumstance. Including caregivers and family members in this assessment is recommended. **B**
- Consider monitoring patient performance of self-management behaviors as well as psychosocial factors impacting the person's self-management. **E**

		Continuum of psychosocial issues and behavioral health disorders in people with diabetes	
		Nonclinical (normative) symptoms/behaviors	Clinical symptoms/diagnosis
Phase of living with diabetes	Behavioral health disorder prior to diabetes diagnosis	None	<ul style="list-style-type: none"> • Mood and anxiety disorders • Psychotic disorders • Intellectual disabilities
	Diabetes diagnosis	Normal course of adjustment reactions, including distress, fear, grief, anger, initial changes in activities, conduct, or personality	<ul style="list-style-type: none"> • Adjustment disorders*
	Learning diabetes self-management	Issues of autonomy, independence, and empowerment. Initial challenges with self-management demonstrate improvement with further training and support	<ul style="list-style-type: none"> • Adjustment disorders* • Psychological factors affecting medical condition**
	Maintenance of self-management and coping skills	Periods of waning self-management behaviors, responsive to booster educational or supportive interventions	<ul style="list-style-type: none"> • Maladaptive eating behaviors • Psychological factors** affecting medical condition
	Life transitions impacting disease self-management	Distress and/or changes in self-management during times of life transition***	<ul style="list-style-type: none"> • Adjustment disorders* • Psychological factors** affecting medical condition
	Disease progression and onset of complications	Distress, coping difficulties with progression of diabetes/onset of diabetes complications impacting function, quality of life, sense of self, roles, interpersonal relationships	<ul style="list-style-type: none"> • Adjustment disorders* • Psychological factors** affecting medical condition
	Aging and its impact on disease and self-management	Normal, age-related forgetfulness, slowed information processing and physical skills potentially impacting diabetes self-management and coping	<ul style="list-style-type: none"> • Mild cognitive impairment • Alzheimer or vascular dementia
		<p style="text-align: center;"> </p> <p style="text-align: center;"> All health care team members (e.g., physicians, nurses, diabetes educators, dieticians) as well as behavioral providers Behavioral or mental health providers (e.g., psychologists, psychiatrists, clinical social workers, certified counselors or therapists) </p> <p style="text-align: center;">Providers for psychosocial and behavioral health intervention</p>	

FIGURE A.1 Psychosocial care for PWD: life and disease course perspectives. *With depressed mood, anxiety, or emotion and conduct disturbance. **Personality traits, coping style, maladaptive health behaviors, or stress-related physiological response. ***Examples include changing schools, moving, job/occupational changes, marriage or divorce, or experiencing loss.

- Consider assessment of life circumstances that can affect physical and psychological health outcomes and their incorporation into intervention strategies. **E**
- Addressing psychosocial problems upon identification is recommended. If an intervention cannot be initiated during the visit when the problem is identified, a follow-up visit or referral to a qualified behavioral health care provider may be scheduled during that visit. **E**

Practitioners should identify behavioral/mental health providers, ideally those who are knowledgeable about diabetes treatment and the psychosocial aspects of diabetes, with whom they can form alliances and use for referrals (Table A.1) in the psychosocial care of PWD. Ideally, psychosocial care providers should be embedded in diabetes care settings. Shared resources such as electronic health records, management data, and patient-reported information regarding adjustment

to illness and life course issues facilitate providers' capacity to identify and remediate psychosocial issues that impede regimen implementation and improve diabetes management and well-being. Care models that take into account cultural influences, as well as personal, family, and community resources, and tailor care to the core values and lifestyle of the individual are more likely to be successful.² Regardless of how the diabetes care team is constituted, the PWD is central to the care process. If a PWD cannot act on behalf of him/herself in the care process, a support person needs to be identified to participate in treatment decisions and facilitate disease management. It is also important that providers enlist members of the patient's social support network to aid in the identification, prevention, and resolution of psychosocial problems.

Medical management of diabetes requires patient implementation of a treatment regimen. Thus, psychosocial factors impacting self-care such as diabetes distress (burdens of diabetes and its treatment, worries about adverse consequences), lack of social and economic resources, and other psychological states (e.g., depression, anxiety, eating disorders, cognitive impairment)³, as well as health literacy and numeracy, should be monitored. To detect problems early and prevent health deterioration, all PWD should be evaluated at the initial visit and on a

periodic basis going forward even if there is no patient specific indication.⁴ In addition, evaluation is indicated during major disease and life transitions, including the onset of complications and significant changes in treatment (i.e., initiation of insulin pump or other forms of intensification) or life circumstances (i.e., living arrangements, job, and significant social relationships), with prospective monitoring for 6 months (a period of increased risk).⁵

All care providers should include queries about well-being in routine care. Standardized and validated tools (Table A.2) for psychosocial monitoring, assessment, and diagnosis can be used by providers in a stepped sequence with positive findings leading to further evaluation, starting with informal verbal inquiries for monitoring followed by questionnaires for assessment (e.g., PHQ-9) and finally by structured interviews for diagnosis (e.g., Structured Clinical Interview for the DSM-V). For example, the diabetes care provider can ask whether there have been changes in mood during the past 2 weeks or since their last visit. Further, providers should consider asking whether there are new or different barriers to treatment and self-management, such as feeling overwhelmed or stressed by diabetes or other life stressors. Positive responses can be probed with additional questions and/or use of standardized measures to inform assessment and guide the selection of appropriate interventions.

TABLE A.1 Situations that warrant referral of a person with diabetes to a mental health provider for evaluation and treatment

- › If self-care remains impaired in a person with diabetes distress after tailored diabetes education
- › If a person has a positive screen on a validated screening tool for depressive symptoms
- › In the presence of symptoms or suspicions of disordered eating behavior, an eating disorder, or disrupted patterns of eating
- › If intentional omission of insulin or oral medication to cause weight loss is identified
- › If a person has a positive screen for anxiety or FoH
- › If a serious mental illness is suspected
- › In youth and families with behavioral self-care difficulties, repeated hospitalizations for diabetic ketoacidosis, or significant distress
- › If a person screens positive for cognitive impairment
- › Declining or impaired ability to perform diabetes self-care behaviors
- › Before undergoing bariatric surgery and after if assessment reveals an ongoing need for adjustment support

TABLE A.2 Selected measures for the evaluation of psychosocial constructs in the clinical setting

Measure title	Citations	Description	Validated population
Diabetes-related distress			
Problem Areas in Diabetes (PAID)	Polonsky WH, Anderson BJ, Lohrer PA, et al. Assessment of diabetes-related distress. <i>Diabetes Care</i> 1995;18:754–760	20-item measure of diabetes-specific distress measuring emotional distress and burden associated with diabetes	Adults with type 1 and type 2 diabetes
	Welch G, Weinger K, Anderson B, Polonsky WH. Responsiveness of the Problem Areas in Diabetes (PAID) questionnaire. <i>Diabet Med</i> 2003;20:69–72		
Diabetes Distress Scale (DDS)	Polonsky WH, Fisher L, Earles J, et al. Assessing psychosocial stress in diabetes: development of the Diabetes Distress Scale. <i>Diabetes Care</i> 2005;28:626–631	17-item questionnaire measuring diabetes-specific distress in four domains: emotional burden, diabetes interpersonal distress, physician-related distress, and regimen-related distress	Adults with type 1 and type 2 diabetes
	Fisher L, Hessler DM, Polonsky WH, Mullan J. When is diabetes distress clinically meaningful? Establishing cut points for the Diabetes Distress Scale. <i>Diabetes Care</i> 2012;35:259–64 (39)		
PAID–Pediatric Version (PAID-Peds)	Markowitz JT, Volkening LK, Butler DA, Laffel LM. Youth-perceived burden of type 1 diabetes: Problem Areas in Diabetes Survey–Pediatric Version (PAID-Peds). <i>J Diabetes Sci Technol</i> 2015;9:1080–1085	20-item measure of diabetes burden	Youth (ages 8–17 years) with type 1 diabetes
PAID–Teen Version	Weissberg-Benchell J, Antisdell-Lomaglio, J. Diabetes-specific emotional distress among adolescents: feasibility, reliability, and validity of the problem areas in diabetes-teen version. <i>Pediatr Diabetes</i> 2011;12:341–344	26-item questionnaire measuring perceived burden of diabetes	Adolescents (ages 11–19 years) with diabetes
PAID–Parent Revised version (PAID-PR)	Markowitz JT, Volkening LK, Butler DA, Antisdell-Lomaglio JH, Anderson BJ, Laffel LM. Re-examining a measure of diabetes-related burden in parents of young people with type 1 diabetes: the Problem Areas in Diabetes Survey–Parent Revised version (PAID-PR). <i>Diabet Med</i> 2012;29:526–530	18-item questionnaire assessing perceived parental burden of diabetes	Parents of children and adolescents (ages 8–18 years) with type 1 diabetes
Depression			
Patient Health Questionnaire (PHQ-9)	Spitzer RL, Williams JB, Kroenke K, et al. Utility of new procedure for diagnosis mental-disorders in primary-care: the PRIME-MD 1000 Study. <i>JAMA</i> 1994;272:1749–1756	9-item measure of depressive symptoms (corresponding to criteria for major depressive disorder)	Adults
Beck Depression Inventory–II (BDI-II)	Beck AT, Steer RA, Brown GK. Manual for the Beck Depression Inventory–II, 2nd ed. San Antonio, TX, Harcourt, Brace & Company, 1996	21-item questionnaire evaluating somatic and cognitive symptoms of depression	Adults
Child Depression Inventory (CDI) (current edition is CDI-2)	Kovacs, M. The Children’s Depression Inventory (CDI): Technical Manual Update. North Tonawanda, NY, Multi-Health Systems, 2003	27-item measure assessing depressive symptoms using child and parent report	Youth (ages 7–17 years)
Geriatric Depression Scale (GDS)	Sheikh JI, Yesavage JA. Geriatric Depression Scale (GDS): recent evidence and development of a shorter version. <i>Clinical Gerontologist</i> 1986;5:165–172	15-item measure was developed to assess depression in older adults	Adults (ages 55–85 years)

(cont.)

Measure title	Citations	Description	Validated population
Eating disorders			
Eating Disorders Inventory–3 (EDI-3)	Garner DM. Eating Disorder Inventory-3: Professional Manual. Odessa, FL, Psychological Assessment Resources, 2004	2 interview and self-report surveys aimed at the measurement of psychological traits or symptom clusters relevant to the development and maintenance of eating disorders	Females (ages 13–53 years)
Diabetes Eating Problems Survey (DEPS-R)	Markowitz JT, Butler DA, Volkening LK, Antisdel JE, Anderson BJ, Laffel LM. Brief screening tool for disordered eating in diabetes: internal consistency and external validity in a contemporary sample of pediatric patients with type 1 diabetes. <i>Diabetes Care</i> 2010;33:495–500	16-item self-report measure designed to assess diabetes-specific eating issues	Youth (ages 13–19 years) with type 1 diabetes
Diabetes Treatment and Satiety Scale (DTSS-20)	Young-Hyman D, Davis C, Grigsby C, Looney S, Peterson C. Development of the Diabetes Treatment and Satiety Scale: DTSS-20 (Abstract). <i>Diabetes</i> 2011;60(Suppl. 1):A218	20-item self-report measure that assesses perception of satiety and fullness in the context of food intake, physical activity, medication dosing, and glycemic levels	Youth (ages 10–17 years) with type 1 diabetes
Health literacy and numeracy			
General Health Numeracy Test (GHNT)	Osborn CY, Wallston KA, Shpigel A, Cavanaugh K, Kripalani S, Rothman RL. Development and validation of the General Health Numeracy Test (GHNT). <i>Patient Educ Couns</i> 2013;91:350–356	21-item self-report questionnaire designed to assess patient level of understanding of the use of numbers in medications and health	Adults
Diabetes Numeracy Test (DNT)	Huizinga MM, Elasy TA, Wallston KA, et al. Development and validation of the Diabetes Numeracy Test (DNT). <i>BMC Health Ser Res</i> 2008;1:96	5-, 15-, and 43-item word problem–based test to assess understanding of tables, graphs, and figures specific to the management of diabetes	Adults (ages 18–80 years)
Brief Health Literacy Scale (BHLS)	Wallston KA, Cawthon C, McNaughton CD, Rothman RL, Osborn CY, Kripalani S. Psychometric properties of the Brief Health Literacy Screen in clinical practice. <i>J Gen Intern Med</i> 2014;29:119–126	3-item measure read aloud to patients in an outpatient and emergency department setting to assess understanding of health concepts	Adults
Self-care efficacy			
Diabetes self-efficacy	Ritter PL, Lorig K, Laurent D. Characteristics of the Spanish- and English-language self-efficacy to manage diabetes scales. <i>Diabetes Educ</i> 2016;42:167–177	8-item self-report scale designed to assess confidence in performing diabetes self-care activities	Adults
Self-efficacy for diabetes management	Iannotti RJ, Schneider S, Nansel TR, et al. Self-efficacy, outcome expectations, and diabetes self-management in adolescents with type 1 diabetes. <i>J Dev Behav Pediatr</i> 2006;27:98–105 (26)	10-item self-report self-efficacy scale	Adolescents (ages 10–16 years) with type 1 diabetes
Anxiety			
State-Trait Anxiety Inventory for Children (STAIC)	Spielberger CD, Edwards CD, Lushene R, Monturi J, Plotzek D. State-Trait Anxiety Inventory for Children Professional Manual. Menlo Park, CA, Mind Garden, Inc., 1973	40 items on two dimensions—trait and state anxiety	Youth with and without type 1 diabetes
Beck Anxiety Inventory (BAI)	Beck AT, Steer RA. Beck Anxiety Inventory Manual. San Antonio, TX, The Psychological Corporation, 1993	21 items assessing self-reported anxiety	Adults

(cont.)

Measure title	Citations	Description	Validated population
Hypoglycemia Fear Survey-II (HFS-II)	Cox DJ, Irvine A, Gonder-Frederick L, Nowacek G, Butterfield J. Fear of hypoglycemia: quantification, validation, and utilization. <i>Diabetes Care</i> 1987;10:617–621 (63)	33 items assessing behavioral and worry dimensions of hypoglycemia in adults	Adults with type 1 diabetes
	Gonder-Frederick LA, Schmidt KM, Vajda KA, et al. Psychometric properties of the Hypoglycemia Fear Survey-II for adults with type 1 diabetes. <i>Diabetes Care</i> 2011;34:801–806 (71)		
Children's Hypoglycemia Index (CHI)	Kamps JL, Roberts MC, Varela RE. Development of a new fear of hypoglycemia scale: preliminary results. <i>J Pediatr Psychol</i> 2005;30:287–291	Designed to assess FoH (25 items)	Youth (ages 8–16 years) with type 1 diabetes

Cognitive screening in older adults

Mini-Mental State Examination (MMSE)	Folstein MF, Folstein SE, McHugh PR. "Mini-mental" state: a practical method for grading the cognitive state of patients for the clinician. <i>J Psychiatr Res</i> 1975;12:189–198	11-item (30-point) screen for cognitive impairment in adults	Adults (ages 18 – 100 years)
	Crum RM, Anthony JC, Bassett SS, Folstein MF. Population-based norms for the Mini-Mental State Examination by age and educational level. <i>JAMA</i> 1993;269:2386–2391		
Telephone Interview for Cognitive Status (TICS)	Brandt J, Spencer M, Folstein M. The Telephone Interview for Cognitive Status. <i>Neuropsychiatry Neuropsychol Behav Neurol</i> 1988;1:111–117	11-item measure assessing cognitive status by telephone	Adults (ages 60–98 years)
	Brandt J, Folstein MF. Telephone Interview for Cognitive Status (TICS) Professional Manual. Lutz, FL, Psychological Assessment Resources, 2003		
Cognitive assessment toolkit	Cordell CB, Borson S, Boustani M, et al. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. <i>Alzheimers Dement</i> 2013;9:141–150	Designed for use during a medical office visit to screen for cognitive impairment in older adults (includes informant interviews also)	Adults

Chronic pain

Short-form McGill Pain Questionnaire (SF-MPQ-2)	Dworkin RH, Turk DC, Revicki DA, et al. Development and initial validation of an expanded and revised version of the Short-form McGill Pain Questionnaire (SF-MPQ-2). <i>Pain</i> 2009;144:35–42	22-item questionnaire designed to assess pain	Adults
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Adherence to self-care

Summary of Diabetes Self-Care Activities (SDSCA)	Toobert DJ, Hampson SE, Glasgow RE. The Summary of Diabetes Self-Care Activities measure: results from 7 studies and a revised scale. <i>Diabetes Care</i> 2000;23:943–950	11-item and expanded 25-item measure of diabetes self-care behaviors	Adults with type 1 and type 2 diabetes
Adherence to Refills and Medications Scale (ARMS-D)	Kripalani S, Risser J, Gatti ME, Jacobson TA. Development and evaluation of the Adherence to Refills and Medications Scale (ARMS) among low-literacy patients with chronic disease. <i>Value Health</i> 2009;12:118–123	11-item self-report questionnaire designed to assess the extent to which patients take and refill their diabetes-related medications	Adults
	Mayberry LS, Gonzalez JS, Wallston KA, Kripalani S, Osborn CY. The ARMS-D outperforms the SDSCA, but both are reliable, valid, and predict glycemic control. <i>Diabetes Res Clin Pract</i> 2013;102:96–104		
Barriers to diabetes adherence	Mulvaney SA, Hood KK, Schlundt DG, et al. Development and initial validation of the barriers to diabetes adherence measure for adolescents. <i>Diabetes Res Clin Pract</i> 2011;94:77–83	21-item self-report questionnaire designed to assess barriers to diabetes self-care behaviors	Adolescents (ages 12–17 years) with diabetes

When referral is warranted (Table A.1), formal diagnostic assessments and interviews should be conducted by a qualified behavioral health provider familiar with the care of PWD. Standardized, age- and literacy-appropriate assessment and diagnostic tools should be used (Table A.2). These established measures were selected from a wider literature on the basis of the scientific rigor used in their development and the availability of norms for clinical use. The recommendation of specific measures for clinical use is beyond the scope of this statement. Care providers should implement interventions to address the day-to-day problems of living with diabetes, particularly diabetes-related distress related to self-management behaviors, as well as diabetes-related family conflict.⁶⁻⁸ Support from a behavioral health provider may be effective when difficulties are persistent. However, as soon as there is indication of a diagnosable psychological condition, consultation and/or referral should be sought with a provider having the appropriate mental health expertise. Standardized/validated intervention strategies specific to PWD should be utilized whenever possible.

Psychosocial Issues Impacting Diabetes Self-Management

Recommendations

- › People with diabetes should be evaluated and receive training until they attain competence in diabetes self-care skills and the use of technologies at the time of diagnosis, annually, if/when complications arise, and if/when transitions in care occur. The diabetes care team is encouraged to directly and regularly assess these self-management behaviors. **B**
- › Providers should consider the burden of treatment and patient levels of confidence/self-efficacy for management behaviors as well as level of social and family support when making treatment recommendations. **E**

While following treatment regimens consistently improves A1C,⁹⁻¹² the impact is modest. Multiple factors other than patient behavior affect diabetes treatment outcomes, including adequacy of medical management, duration of diabetes, weight gain, and other health-related (e.g., comorbid illness and concomitant medication) and social-structural factors (e.g., poverty, access to care, health insurance coverage).¹³⁻¹⁶ Therefore, it is not appropriate to automatically attribute suboptimal A1C and adverse events such as hypoglycemia¹⁷ solely to self-management behaviors without their direct assessment.

Provider communications with patients/families should acknowledge that multiple factors impact glycemic management but also emphasize that following collaboratively developed treatment regimens and recommended lifestyle changes can significantly improve disease outcomes and well-being.^{14,18-20} Thus, the goal of provider-patient communication should be to empower the PWD without blaming them for “noncompliance” when the outcomes of self-management are not optimal.

The familiar term, noncompliance, denotes a passive, obedient role for PWD in “following doctor’s orders” that is at odds with the active role PWD are asked to take in directing the day-to-day planning, monitoring, evaluation, and problem-solving involved in diabetes self-management.²¹ Patient perceptions about their own ability, or self-efficacy, to self-manage diabetes are one important psychosocial factor related to improved diabetes self-management and treatment outcomes in diabetes²²⁻²⁶ and should be a target of ongoing assessment and treatment planning.

Suboptimal self-management may be due to functional limitations (e.g., blindness, problems with dexterity, low health literacy and numeracy), lack of appropriate diabetes education, forgetting and disruption in routines, or psychosocial barriers, such as inadequate family and/or social support, misinformation or inaccurate beliefs about illness and treatment, emotional distress/depressive symptoms, or deficits in problem-solving or coping skills.^{23,27-30} Therefore, individual needs should be evaluated so that interventions can be tailored to the problem.³¹⁻³⁵ Self-report measures are available and can be used in most practice settings (see Table A.2). Using a nonjudgmental approach that normalizes periodic lapses in self-management may help minimize patients’ resistance to reporting problems with self-management.

Making healthy food choices on a daily basis is among the most difficult aspects of diabetes self-care.³⁶ Current medical nutrition therapy guidelines promote flexible and healthy eating patterns personalized to the individual rather than defining a wide range of behaviors as dietary “nonadherence”.³⁷ Self-monitoring of food intake may help the individual with diabetes become more aware of their own eating patterns while providing information that helps the registered dietitian nutritionist assist with meal planning and develop personalized dietary recommendations. Through monitoring, it is important to assess for disordered eating behaviors (see disordered eating behavior: clinical and subclinical).

Diabetes Distress

Recommendation

- › Routinely monitor people with diabetes for diabetes distress particularly when treatment targets are not met and/or at the onset of diabetes complications. **B**

Diabetes distress is very common and is distinct from a psychological disorder.^{38–40} The constant behavioral demands (medication dosing, frequency, and titration; monitoring blood glucose, food intake and eating patterns, and physical activity) of diabetes self-management and the potential or actuality of disease progression are directly associated with reports of diabetes distress.³⁹ Its prevalence is reported to be 18–45% with an incidence of 38–48% over 18 months.⁴¹ High levels of diabetes distress significantly impact medication-taking behaviors and are linked to higher A1C, lower self-efficacy, and poorer dietary and exercise behaviors.^{39,41,42} It may be helpful to provide counseling regarding expected diabetes-related versus generalized psychological distress at diagnosis and when disease state or treatment changes.⁴³

About one-third of adolescents with diabetes develop diabetes distress, which may be associated with declines in self-management behaviors and suboptimal blood glucose levels.⁴⁴ Parents of children with type 1 diabetes are also prone to diabetes distress,⁴⁵ which could impact their ability to provide psychological and diabetes management support for their child.

Diabetes distress should be routinely monitored⁴⁶ using patient-appropriate validated measures (**Table A.2**). If diabetes distress is identified, the person should be referred for diabetes education to address areas of diabetes self-care that are most relevant to the patient and have the most impact on diabetes outcomes. People whose self-care remains impaired after tailored diabetes education should be referred by their care team to a behavioral health provider for evaluation and treatment.

Psychological Comorbidities

Prevalence of clinically significant psychopathology in PWD ranges across diagnostic categories, and some diagnoses are considerably more common in PWD than in those without the disease.^{47–52} Symptoms, both clinical and subclinical, that interfere with the person's ability to carry out diabetes self-management must be addressed.

Depression

Recommendations

- › Providers should consider annually screening all patients with diabetes and/or a self-reported history of depression for depressive symptoms with age-appropriate depression screening measures, recognizing that further evaluation will be necessary for individuals who have a positive screen. **B**
- › Beginning at diagnosis of complications or when there are significant changes in medical status, consider assessment for depression. **B**
- › Referrals for treatment of depression should be made to mental health providers with experience using cognitive behavioral therapy, interpersonal therapy, or other evidence-based treatment approaches in conjunction with collaborative care with the patient's diabetes treatment team. **A**

History of depression, current depression, and antidepressant medication use are risk factors for the development of type 2 diabetes, especially if the individual has other risk factors such as obesity and family history of type 2 diabetes.^{53–55}

Elevated depressive symptoms and depressive disorders affect one in four patients with type 1 or type 2 diabetes.⁴⁷ Thus, routine screening for depressive symptoms is indicated in this high-risk population including people with prediabetes (particularly those who are overweight), type 1 and/or type 2 diabetes, gestational diabetes mellitus, and postpartum diabetes. Regardless of diabetes type, women have significantly higher rates of depression than men.⁵⁶

Routine monitoring with patient-appropriate validated measures (**Table A.2**) can help to identify whether referral is warranted. Remission of depressive symptoms or disorder in adult patients suggests the need for ongoing monitoring of depression recurrence within the context of routine care.⁵³

Integrating mental and physical health care can improve outcomes. The mental health provider should be incorporated into the diabetes treatment team when a patient is in psychological therapy (talk therapy).⁵⁷ Incorporation of a physical activity regimen into routine self-management has also been shown to improve the health and mental well-being of PWD.^{58,59} Please refer to the Position Statement of the American Diabetes Association (ADA) on physical activity/exercise and diabetes⁶⁰ for additional information.

Anxiety Disorders

Recommendations

- › Consider screening for anxiety in people exhibiting anxiety or worries regarding diabetes complications, insulin injections or infusion, taking medications, and/or hypoglycemia that interfere with self-management behaviors and in those who express fear, dread, or irrational thoughts and/or show anxiety symptoms such as avoidance behaviors, excessive repetitive behaviors, or social withdrawal. Refer for treatment if anxiety is present. **B**
- › People with hypoglycemia unawareness, which can co-occur with fear of hypoglycemia, should be treated using Blood Glucose Awareness Training (or other evidence-based similar intervention) to help re-establish awareness of hypoglycemia and reduce fear of hypoglycemia. **A**

Anxiety symptoms and diagnosable disorders (e.g., generalized anxiety disorder [GAD], body dysmorphic disorder, obsessive compulsive disorder [OCD], specific phobias, and posttraumatic stress disorder [PTSD]) are common in PWD⁶¹; the Behavioral Risk Factor Surveillance System estimated the lifetime prevalence of GAD to be 19.5% in people with either type 1 or type 2 diabetes.⁶² Common diabetes-specific concerns include fears related to hyperglycemia,^{63,64} not meeting blood glucose targets,⁶¹ and insulin injections or infusion.⁶⁵ General anxiety is a predictor of injection-related anxiety and associated with fear of hypoglycemia (FoH).^{64,66}

Preoccupation with an imagined defect in appearance associated with having diabetes that interferes with social, occupational, or other important areas of function may reflect body dysmorphic disorder.⁵¹ When ideas and symptoms (e.g., perceived deficits in strength, attractiveness, and sexual function) do not reach the level of clinical diagnosis, identification of these beliefs provides a context for provider education about disease processes, reframing disease processes as distinct from the emotional response to having diabetes and questioning the inevitability of health decline. Onset of complications presents another critical point where these thoughts/beliefs can occur and may require re-education and disease-based counseling.⁶⁷

If the PWD exhibits excessive diabetes self-management behaviors well beyond what is prescribed or needed to achieve glycemic targets, reports repetitive negative thoughts about inability to prevent poor health outcomes, and/or has related thoughts and behaviors that interfere with other functions of daily living, the PWD may be experiencing symptoms of OCD.⁶⁸ OCD symptoms can

represent generalized anxiety or be diabetes specific, and referral to a mental health professional (such as a psychiatrist) familiar with OCD treatment should be considered, especially if diabetes re-education does not prove effective in reducing obsessive thoughts, behaviors, or feelings of general anxiety. Caution should be exercised in diagnosing OCD-like symptoms, as regimen behaviors contain similar characteristics, such as repetition, and are aimed at achieving control over a perceived threat.

FoH and hypoglycemia unawareness often co-occur, and interventions aimed at treating one often benefit both.⁶⁹ FoH may explain avoidance of behaviors associated with lowering glucose such as increasing insulin doses or frequency of monitoring. If FoH is identified and a person does not have symptoms of hypoglycemia, a structured program, Blood Glucose Awareness Training, delivered in routine clinical practice can improve A1C, reduce the rate of severe hypoglycemia, and restore hypoglycemia awareness.^{70,71} Such improvements in disease state have been shown to reduce diabetes distress and improve psychological well-being.^{69,72,73}

Occurrence of severe hypoglycemia has been shown to be associated with PTSD and PTSD-like and panic disorder symptoms.^{74,75} The potential for increased prevalence of PTSD and panic disorder in this population, though not well studied, is intuitive given the potentially life-threatening nature of the disease, particularly for those who use exogenous insulin. Given that potential stimuli for PTSD-like symptoms are recurrent for PWD, PTSD should be considered among other anxiety disorders.

Disordered Eating Behavior: Clinical and Subclinical

Recommendations

- › Providers should consider re-evaluating the treatment regimen of people with diabetes who present with symptoms of disordered eating behavior, an eating disorder, or disrupted patterns of eating. **B**
- › Consider screening for disordered or disrupted eating using validated screening measures when hyperglycemia and weight loss are unexplained by self-reported behaviors related to medication dosing, meal plan, and physical activity. In addition, a review of the medical regimen is recommended to identify potential treatment-related effects on hunger/caloric intake. **B**

Estimated prevalence of disordered eating behaviors and diagnosable eating disorders in PWD varies.^{51,76,77} PWD with diagnosable eating disorders have high rates of comorbid psychiatric disorders.⁷⁸ People with type 1 diabetes and eating disorders have high rates of diabetes distress and FoH.⁷⁹ For people with type 1 diabetes, insulin omission causing glycosuria in order to lose weight is the most commonly reported disordered eating behavior,^{80,81} and in people with type 2 diabetes, bingeing (excessive food intake with an accompanying sense of loss of control) is most commonly reported. For people with type 2 diabetes treated with insulin, intentional omission is also frequently reported.⁸² Binge eating disorder has been found to be more likely in PWD than in the nondiabetes population, though studies of prevalence in specific diabetes samples show varying rates.^{77,83} Other diagnostic categories of eating disorders have a very low prevalence in PWD.⁷⁷

Potential confounders to the identification of symptoms of disordered eating are behaviors that are prescribed as part of treatment (e.g., carbohydrate counting and calorie restriction), behaviors or effects that are part of the disease (e.g., loss of control over satiety regulation secondary to disease processes), and adverse effects of treatment such as excessive hunger secondary to hypoglycemia. When evaluating symptoms of disordered or disrupted eating in PWD, etiology and motivation for the behavior should be considered.^{51,84} For example, missed insulin injections as a result of suboptimal self-management differ significantly from intentional medication omission to produce weight loss. Assessment and screening of disordered and disrupted eating requires methods that account for treatment prescription, regimen behaviors, and diabetes-specific eating problems attributable to disease processes (see **Table A.2**). If night eating syndrome, which is recurrent eating at night either after awakening from sleep or excessive eating after dinner, is diagnosed, changes to the medication regimen are required until maladaptive eating patterns can be modified.⁸⁵ Adjunctive medication such as glucagon-like peptide 1 receptor agonists⁸⁶ may not only help individuals meet glycemic targets but also help regulate hunger and food intake, thus having the potential to reduce uncontrollable hunger and bulimic symptoms.

Serious Mental Illness

Recommendations

- › Annually screen people who are prescribed atypical antipsychotic medications for prediabetes/diabetes. **B**

- › Incorporate monitoring of diabetes self-care activities into treatment goals in people with diabetes and serious mental illness. **B**

Studies of people with serious mental illness, particularly schizophrenia and other thought disorders, show significantly increased rates of type 2 diabetes.⁸⁷ People with schizophrenia should be monitored for type 2 diabetes because of the known comorbidity. Disordered thinking and judgment can be expected to make it difficult to engage in behaviors that reduce risk factors for type 2 diabetes, such as restrained eating for weight management. Individuals with major psychiatric disorders may need consistent monitoring and oversight in their diabetes management, even if thought disorders remit. Coordinated management of diabetes or prediabetes and serious mental illness is recommended to achieve diabetes treatment targets. In addition, those taking olanzapine require greater monitoring because of an increase in risk of type 2 diabetes associated with this medication.⁸⁸ Further study is needed to examine the association of other antipsychotic medications with the onset of diabetes and glycemic management.^{48,89}

Life Course Considerations

PWD are diagnosed earlier (e.g., type 2 diabetes in childhood)⁹⁰ and living longer.⁴⁸ At each point in the life course, providers should consider which resources and accommodations are needed to maximize disease outcomes and well-being. In particular, identification of psychosocial factors influencing self-management are recommended (e.g., culture, environment, social determinants, life roles and responsibilities, and interpersonal dynamics, as well as person-based characteristics such as sex, race/ethnicity, age, language, and socioeconomic status).⁹¹

Youth and Emerging Adults

Recommendations

- › At diagnosis and during routine follow-up care, consider assessing psychosocial issues and family stresses that could impact diabetes management and provide appropriate referrals to trained mental health professionals, preferably experienced in childhood diabetes. **E**
- › Providers should consider monitoring youth and their parents about social adjustment (peer relationships) and school performance to determine whether further evaluation is needed. **B**

- › Consider assessing youth with diabetes for generic and diabetes-related distress starting at about 7–8 years of age. **B**
- › Providers should encourage developmentally appropriate family involvement in diabetes management tasks for children and adolescents, recognizing that premature transfer of diabetes care to the child can result in poor self-management behaviors and deterioration in glycemic management. **A**
- › Consider the inclusion of children in consent processes as early as cognitive development indicates understanding of health consequences of behavior. **E**
- › Adolescents may have time by themselves with their care provider(s) starting at age 12 years. **E**
- › Providers should consider initiating discussions about care transition to an adolescent medicine/transition clinic/adult provider no later than 1 year prior to starting the transfer but preferably during early adolescence (~14 years of age). **E**
- › Consider monitoring support from parents/caretakers of emerging adults with diabetes and encouraging instrumental support (e.g., ordering supplies) and collaborative decision making among caregivers. **E**
- › Starting at puberty, preconception counseling should be incorporated into routine diabetes clinic visits for all females of childbearing potential. **A**
- › Consider counseling males, starting at puberty, regarding adoption of a healthy lifestyle to reduce risk for sexual dysfunction. **E**

Given the rapid and dynamic nature of cognitive, developmental, and emotional changes in youth, early detection of depression, anxiety disorders, eating issues, and learning disabilities enhance the range and effectiveness of potential treatment options and may help to minimize adverse effects on diabetes management and disease outcomes.

Because youth are dependent on social support systems (family and care providers) and must eventually transition to independent diabetes self-management, their families and related social networks need to be included in psychosocial assessment and treatment.^{92–94} Parents of children with type 1 diabetes are prone to high rates of depression, especially around the time of diagnosis.^{95,45} Persistence of parental depression is associated with poorer child adjustment and diabetes management, especially in younger children.⁹⁶ Teaching family members effective problem-solving and conflict-resolution skills can improve diabetes management and

facilitate better glycemic management, with the potential to reduce diabetes distress.⁹²

The adolescent years are known for disruption in diabetes care and communication between family members, youth, and providers. Hallmarks of normal adolescence are increased independence in decision making and turning to the peer group for validation of self-concept and self-worth. Wishing to “fit in” may contribute to youth hiding or minimizing diabetes care behaviors, thereby compromising management in the school setting.⁹⁷ Cognitive development and medical decision-making skills will impact a wide variety of risk-taking behaviors and acceptance of self-management behaviors into daily life.^{98,99} Suboptimal glycemic management should not automatically be attributed to adolescent rebellion or lack of concern for health. A thorough age-appropriate psychosocial evaluation and review of the medical regimen will suggest targets for modification to facilitate self-management and well-being. If the adolescent is resistant to accepting support from clinicians, family, and friends, the possibility of a more serious psychological issue must be considered and evaluated.

Although legal and ethical issues of youth accepting or refusing treatment components (e.g., an insulin pump) has not been extensively studied, these issues will undoubtedly surface in the process of treatment decisions. Thus, the issue of treatment consent must be considered when making regimen choices. Although cognitive abilities vary, the ethical position often adopted is the “mature minor rule,” whereby children after age 12 or 13 years who appear to be “mature” ought to have the right to consent or to withhold consent to general medical treatment, except in cases in which refusal would significantly endanger health.⁹⁹ Emerging technologies, such as phone and computer transmission of management data, can be useful in maintaining communication of information through nonconfrontational channels and may provide a means for youth to communicate directly with care providers as they transition to more independent self-management.¹⁰⁰

Adolescents should have time by themselves with their care provider(s) starting at age 12 years. Care should be taken to respect a teen/young adult’s privacy, as lack of confidentiality is known to negatively affect adolescents’ health behavior, especially regarding what are considered taboo or risky behaviors.¹⁰¹ Discussions with adolescents should include questions about well-being in general, diabetes distress, and risk behaviors (e.g., substance use and sexual activity).^{102,103}

Preconception counseling for females during reproductive years increases knowledge about diabetes-related risk, delays age of sexual initiation, decreases unprotected sex, and improves preconception care and health.^{104,105} Less research is available regarding sexual health for males, particularly in youth; however, males with diabetes have a threefold increased risk of erectile dysfunction compared with men who do not have diabetes.^{106,107} Open and factual discussions of these topics facilitate future comfort in disclosing any concerns regarding sexual function. As less frequent attendance to diabetes care visits is typical in the 18- to 30-year-old age-group, screening regarding risk behaviors may be necessary at each visit.

Adults

Recommendations

- › In the care of adults with childbearing potential, include a discussion of life choices that could be impacted by diabetes self-management, such as pregnancy and sexual functioning. **B**
- › Providers should consider assessing for the presence of social support providers (e.g., family, peer support, lay diabetes educators/caretakers) who may facilitate self-management behaviors, reduce burden of illness, and improve diabetes and general quality of life. **B**

As people enter adulthood, establishment of a work role, intimate partnering, childbearing, and parenting are typical life tasks.⁷ Living with and self-managing diabetes can be expected to impact all life-course decisions for PWD and their partners. PWD may question whether intimate partnering and biological parenthood are viable in the context of their health status.¹⁰⁸ High-quality relationships with and diabetes management support from intimate partners improve diabetes-specific and general quality of life, self-management behaviors, and metabolic outcomes.⁷ Partner roles may change if functional ability is impacted by poor health outcomes.¹⁰⁹ Sexual dysfunction is often associated with depression and is routinely reported in clinical encounters (see depression). In one study of individuals with type 1 diabetes, sexual dysfunction was reported in as many as 50% of male patients.¹⁰⁷ It is beyond the scope of these guidelines to discuss psychosocial issues related to pregnancy and gestational diabetes mellitus.¹¹⁰

Older Adults

Recommendations

- › Annual screening for early detection of mild cognitive impairment or dementia is indicated for adults aged 65 years or older. **B**
- › Assessment of neuropsychological function and dementia using available standards for conducting evaluations of dementia and age-related cognitive changes is recommended. **E**
- › Within the primary care setting, a collaborative care model, incorporating structured nurse care management intervention, is recommended for treatment of comorbid depression in older adults with diabetes. **A**

Older adults with diabetes may be functional and cognitively intact and have significant life expectancy, and they may not require psychosocial care beyond that of younger adults. However, older adults may have issues particular to their age, such as advanced disease, cognitive dysfunction, complex treatment regimens, comorbid health conditions, functional impairment, limited social and financial resources, and depression.¹¹¹ Meeting glycemic targets may be impacted by unique nutritional requirements, physical limitations (such as reduced sensation), memory loss, and low literacy and numeracy skills. As older adults with diabetes may receive care support from family members and staff at assisted living facilities, during hospitalizations, and in long-term care facilities, the treatment regimen must consider context and caregiver capacities. Support people (e.g., adult children, caretakers) who provide instrumental, social, or emotional support for older adults with diabetes should be included in diabetes management discussions and shared decision making.

Psychosocial targets for intervention include self-management support, access to health care, and financial and emotional support, as well as day-to-day facilitation of physical and mental well-being. Within the primary care setting, older adults with diabetes and comorbid depression are likely to benefit from a collaborative care intervention approach, which uses a nurse care manager supervised by a primary care physician and psychiatrist.^{58,112,113}

Compared with older adults without diabetes, those with the disease are at an increased risk of mild cognitive impairment.¹¹⁴ A meta-analysis of prospective and observational studies in PWD showed a 73% increased risk of all types of dementia, a 56% increased risk of Alzheimer dementia, and a 127% increased risk of vascular dementia compared with individuals without

diabetes.¹¹⁵ For detection of cognitive dysfunction, people >65 years of age should receive cognitive screening annually within routine health care, using recommended procedures and resources for practitioners (Table A.2).¹¹⁶⁻¹¹⁸ Medical providers should address reversible contributors to cognitive dysfunction including but not limited to depression, combinations of medications, thyroid disease, and delirium.¹¹⁶

PWD in Need of Special Considerations

People With Diabetes Complications and Functional Limitations

Recommendation

- › Care providers should consider routinely monitoring for chronic pain associated with diabetes complications and its impact on quality of life. Appropriate pain management interventions, including referral to a behavioral health provider for pain management strategies, should be provided. **B**

Diabetes complications, including peripheral neuropathy, foot ulcers, limb amputation, diabetic kidney disease, vision impairment, stroke, and heart attack, are associated with depression, anxiety, reduced autonomy, role impairment, and reduced overall physical function and quality of life.¹¹⁹⁻¹²² Fear of complications is a major component of diabetes distress, and depression associated with complications increases mortality.^{123,124} Care should be taken when discussing rates, causes, and probability of diabetes complications. Providers should acknowledge that discussing complications can be uncomfortable and distressing and should encourage dialogue over multiple visits.

Chronic pain from neuropathy is associated with prevalent psychosocial distress, depression, and sleep disturbance.^{125,126} Care providers should routinely monitor for chronic pain associated with diabetes complications and its impact on quality of life. Appropriate pain management therapies, including referral to a mental health provider for pain self-management strategies, should be provided.

Onset of diabetes complications threatens independence, self-image, and quality of life. To identify the level of self-care independence and necessary adjunctive supports, providers should evaluate whether individuals have a cognitive impairment impacting the ability to do a task (e.g., poor memory or information processing), a functional limitation that interferes with task performance (e.g., poor motor control or impaired vision), a disability that impacts doing the task without

assistance or accommodation (e.g., paralysis or amputation); or a combination of the above.¹²⁷ Unless limitations are profound and/or formal evaluation clearly determines decreased capabilities, providers should not assume a patient is unable to self-manage. Reassessment of self-management efficacy, abilities, and need for adaptations or assistance is indicated with the onset or worsening of functional limitations or disabilities including vision, hearing, or physical impairment. For example, people with visual disability may benefit from materials that meet low-vision guidelines.¹²⁸

Bariatric Surgery

Recommendations

- › People presenting for bariatric surgery should receive a comprehensive mental health assessment by a professional familiar with weight-loss interventions and postbariatric surgery behavioral requirements. **B**
- › If psychopathology is evident, particularly suicidal ideation and/or significant depression, postponement of surgery should be considered so that patient suffering can be addressed before adding the burden of recovery and lifestyle/psychosocial adjustment. **E**
- › For people who undergo bariatric surgery, consider assessment for need of ongoing mental health services to help them adjust to medical and psychosocial changes postsurgery. **C**

Bariatric surgery supports weight loss in people with severe obesity, often with adjunctive remission of type 2 diabetes.^{129,130} People presenting for bariatric surgery have increased rates of depression and other major psychiatric disorders compared with healthy people and are prone to clinically significant body image disorders, sexual dysfunction, and suicidal behavior.¹³¹ Psychosocial well-being and depression, anxiety, and self-care behaviors should be an essential component of the pre- and postsurgical evaluation and monitored during the year after surgery.¹³²

People with preoperative psychopathology should be assessed at regular intervals following surgery to optimize control over psychiatric conditions and to ensure that psychiatric symptoms do not interfere with weight loss and/or lifestyle change. History of eating patterns, disordered eating behaviors, and clinically significant eating disorders, including night eating syndrome, should be evaluated and monitored pre- and postsurgically at regularly scheduled medical management visits. Bariatric surgery in and of itself does not alleviate psychiatric symptoms, but it may result in remission of food addiction among those who were extremely obese.¹³³

Conclusions: Psychosocial Care in Context

PWD must master many complex tasks and behaviors to successfully incorporate diabetes care into daily life. Disease management cannot be successful unless the lifestyle and emotional status of the individual is taken into consideration. As detailed in this Position Statement, routine monitoring and screening for diabetes distress, depression, anxiety, eating issues, and appropriate levels of social and family support, as well as contextual factors that impede implementation of care, are clearly indicated. Effectiveness of regimen and care provision will be enhanced by the inclusion of behavioral health services into the diabetes treatment team. Collaborative care shows the most promise for supporting physical and behavioral health outcomes.

The integration of screening into clinical settings, with appropriate referrals to qualified mental health professionals for reasons noted in **Table A.1**, can improve outcomes. Challenges to accomplishing this standard of care are considerable, including too few qualified mental health professionals who understand living with diabetes and medical care models that are not conducive to team care. Those in most need, the disadvantaged lower socioeconomic level families, have the poorest access to diabetes services.¹³⁴ The psychosocial services recommended are reimbursable for mental health providers in routine medical care under Centers for Medicare & Medicaid Services (CMS). In addition, new CMS reimbursement is planned for the Collaborative Care Model in routine care. With changing laws mandating minimum standards and payment for diabetes care services¹³⁵ and the availability of low-cost insurance that also reimburses preventive services, this balance is changing, allowing the practitioner to incorporate previously unsupported services into routine practice. Knowing how to evaluate and treat common psychosocial issues that impact PWD can inform routine care. The integration of psychosocial care and ensuring access to services will benefit the PWD and the care team.

Article Information

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Footnotes

This position statement was reviewed and approved by the American Diabetes Association Professional Practice Committee in September 2016 and ratified by the American Diabetes Association Board of Directors in October 2016.

See accompanying articles, pp. 2122, 2141, 2149, 2158, 2165, 2174, 2182, 2190, and 2197.

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Appendix B

Peer Support

Peer support links people living with a chronic condition, such as diabetes, so they can share their experiences to support and encourage each other. It can be an effective supplement to the knowledge, expertise, and support offered by health professionals and consumer organizations.

What Is Peer Support?

Peer support takes many forms, including one-to-one mentoring, support groups, and online forums. Peer support is best defined by what it does, not by how it is delivered or who is doing it. Peer support has four key functions:¹

- › assistance with self-management—practical tips, problem solving, and resourcefulness, based on experience of living with the condition
- › social and emotional support—empathic listening, encouragement, and coping with negative emotions
- › linkages to formal healthcare or community resources—help with navigating the health system
- › and ongoing support reflecting the long-term nature of the condition—encouraging and engaging with proactive follow-up.

The Effect of Peer Support on A1C

There is strong evidence from meta-analyses that peer support (for type 1 and type 2 diabetes) produces small but statistically significant improvements in A1C.²⁻⁴ One meta-analysis showed a clinically significant pooled mean reduction of 0.57%.² It is important to note that trials of peer support vary considerably in their designs, populations, and interventions, so the mean A1C reduction across all studies may not be the best indicator of effectiveness. We need to consider who benefits most and in which circumstances (see below).

The Effect of Peer Support on Other Outcomes

A1C may not be the most important indicator of effectiveness. Peer support can improve many outcomes important to a person with diabetes:⁵⁻⁹

- › behavioral (e.g., self-monitoring, medication-taking, healthy eating, and physical activity)
- › psychosocial (e.g., diabetes knowledge, self-efficacy, emotional well-being, and diabetes distress)
- › and health (e.g., blood glucose, blood pressure, lipids, body fat, and body mass index).

Outcomes and experiences of peer support cannot always be quantified easily or meaningfully. A review of qualitative studies found that people with chronic conditions use online communities (e.g., forums, live chats) for many purposes.¹⁰ For example:

- › to find illness-related social support outside their own networks (so as not to “burden” family and friends with detailed discussions)
- › to normalize their illness identities (e.g., through sharing and responding to each others’ stories)
- › to offer and receive experiential knowledge (e.g., problem-solving how to put their health professional’s recommendations into practice in daily life)
- › and to find a collective voice for advocacy.

The Diabetes Online Community (DOC) is one such example of people with diabetes, caregivers, health professionals, and associations engaging online to find diabetes-related support and information. A recent scoping review suggests that DOCs are highly beneficial.¹¹ However, it is an emerging area of research, and further research is needed to identify the consequences of the DOC for those who engage with it.¹¹

Is Peer Support Cost-Effective?

Few studies have evaluated diabetes peer support in terms of its cost-effectiveness. Peer support models, programs, and interventions vary, as do the healthcare contexts in which they are implemented. This makes it difficult to extrapolate the findings of one study to other peer support initiatives. Structured peer support interventions in primary care settings may be either cost-neutral or cost-saving, depending on the outcome of interest, with >80% probability of such peer support interventions being cost-effective in the long term.¹²⁻¹⁴

Ultimately, the various benefits of peer support described above may lead to reduced healthcare utilization and reduced healthcare costs.

Who Benefits Most from Peer Support?

The three meta-analyses (focused on A1C as the outcome)²⁻⁴ found that the benefits of peer support are most evident for people who:

- › have a baseline A1C above recommended target range
- › are from a culturally and linguistically diverse background

- › have greater social disadvantage
- › and are less engaged with their diabetes self-management.

The benefits are also most evident when there is:

- › at least one peer support contact per month
- › and structured peer supervision is provided for the peer leaders.

Similarly, a review of 47 studies assessing peer support for groups identified as “hardly reached” found that 84% of the studies (in which a control group was included) reported significant between-group differences favoring peer support.¹⁵ The review also noted that the benefits of peer support were greater among people with higher levels of disadvantage (e.g., lower health literacy or lower education) and disengagement (e.g., less optimal self-management and medication taking).

How Can People with Diabetes Access Peer Support?

Table B.1 offers some examples of, and contact details

TABLE B.1 Diabetes Peer Support Initiatives in the U.S.

Organization/Initiative	Program Details	Contact
American Diabetes Association	The American Diabetes Association offers a number of opportunities for peer support via local state offices, diabetes camps, online forums, and more.	www.diabetes.org/community (800) DIABETES
Online Forums and Peer Support	Online outlets and forums offer opportunities for people living with diabetes to interact and provide support from anywhere. The Association of Diabetes Care and Education Specialists has created a downloadable handout collecting a number of online options, available on their peer support page.	www.diabeteseducator.org/peersupport
Juvenile Diabetes Research Foundation (JDRF) Peer Support Programs	JDRF administers face-to-face support groups and one-to-one peer support for families and individuals living with type 1 diabetes. To find out more, call your local branch (offices in most states) or visit the JDRF website.	(800) 533-CURE www.jdrf.org
Diabetes Online Community (DOC)	DOC offers online peer support through Tweetchats (online discussion via Twitter) for adults with diabetes (all types).	To find out more, on Twitter, search for #DOC

for, diabetes peer support initiatives.

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Appendix C

Examples of Strategies to Address Diabetes Distress

This table presents some examples of strategies that may help you reflect on how you could support someone who is experiencing diabetes distress, and offers suggestions for questions and actions. The strategies are categorized according to the most common sources of diabetes distress. The examples may apply/work for some people but not for others. Select the strategies that are appropriate for the individual and their needs.

TABLE C.1 Examples of Strategies to Address Diabetes Distress

Source of Distress: Negative Emotions		
Explore how negative feelings could be reduced:	Explore ways of coping with stress:	Explore worries related to diabetes complications:
<ul style="list-style-type: none"> › Ask questions that acknowledge and label feelings, for example: “When have you been feeling like this?” “Where do you think these feelings come from?” and, “What needs to happen for you to feel better?” › Have there been times when the person was feeling less distressed about their diabetes? How was it different compared with today? Would past strategies be useful to respond to current negative feelings? › Are these negative feelings present all the time, or are some days better than others? What is different? › Decide together on realistic changes the person will make. 	<ul style="list-style-type: none"> › Ask, “What might help you to relax?” (e.g., going for a walk, having a coffee with a friend, doing yoga, or reading a book). › How could the person incorporate “their quality time” into their daily schedule? › Explore whether—and how—social support could help in reducing diabetes distress: › Is there someone they can talk to? › Would they like to join a peer support group? Provide details of peer support initiatives (see Appendix B). 	<ul style="list-style-type: none"> › Explore what complication they worry about. Ask, “What worries you the most?” › Are they aware of their A1C and how do they feel about this number. How much do they believe it has to change to reduce risk? › Identify whether the person’s perceptions of their risks are realistic and what are their beliefs about risk. Are these beliefs valid? › Provide information about their actual risk and the evidence today about the percentage of people with diabetes developing complications. › Talk about complications in a motivational (instead of scary) way: <ul style="list-style-type: none"> • complications are not inevitable; modern treatments are very effective in preventing complications • how they can reduce the risk of complications by making management or lifestyle changes • and how can they live a long and healthy life with diabetes. › Acknowledge that there are things they are doing well in managing their diabetes.

Source of Distress: Diabetes Management

Review the current management plan:	Review the person's self-management skills:	Review goal setting and barriers:
<ul style="list-style-type: none"> › Normalize the person's feelings about their current management plan. › Ask the person if they have thought about how their management could be adjusted (e.g., with new medication or technologies). › Ask about alternative treatment options they have thought of. › Inform the person about the pros and cons of various options. › Ask about the person's preferences. › Together, tailor the management plan to suit the individual. › Ask the person how they feel about the new plan or how they might feel and how will they manage that. 	<ul style="list-style-type: none"> › Talk about the person's skills and confidence to manage their diabetes. › Talk about small behavioural changes that could help—such as, how to remember to do certain tasks (e.g., taking medication or self-monitoring of blood glucose), or to how to reduce the burden (e.g., a reward system). › Focus on the benefits of these changes. › Provide additional training, if required/preferred, or suggest a consultation with a certified diabetes educator. › Ask whether the person would like to receive information about structured diabetes education programs. 	<ul style="list-style-type: none"> › Verify that the goals the person has set are achievable. For example, striving for “perfect” blood glucose levels is not realistic and likely to result in frustration; similarly, moving from no physical activity to attending the gym five days per week may also be unrealistic. › Identify (with the person) the perceived barriers to self-care tasks/lifestyle changes and how to overcome them. › Ask the person about what support would be most helpful in making self-care/lifestyle changes. › Talk about the benefits of peer support and provide contacts of peer support initiatives (see Appendix B).

Source of Distress: Interpersonal Relationships

Ask the person if it would be helpful to invite their partner or family/friends to join them at the next appointment:	Support the person to become more assertive in their interactions with their partner or family/friends:	Promote peer support:
<ul style="list-style-type: none"> › It could enhance the other person's understanding of the condition, its management, and daily hassles. › The other person will observe how their partner/relative manages their diabetes on a daily basis and the challenges they experience in maintaining blood glucose within target. 	<ul style="list-style-type: none"> › Acknowledge that well-intended support can often lead to frustration. › Advise the person to share with their partner or family/friends: <ul style="list-style-type: none"> • how they feel about living with diabetes, and invite the other person to do the same • and what help they would appreciate from their partner or family/friends. 	<ul style="list-style-type: none"> › Describe what peer support is, and the benefits. › Provide details of peer support initiatives (see Appendix B).

Source of Distress: Relationships with Health Professionals

Reflect on your relationship with the person and your communication style:	Support people with diabetes to become more assertive in their interactions with health professionals:	Encourage the person to:
<ul style="list-style-type: none"> › Do you provide the right amount of information, using words that can be easily understood? › Are you a good listener? › Do you respond in a non-judgemental and respectful way? › Do you acknowledge and encourage people in their efforts in managing diabetes on a daily basis? › Do you provide adequate support? 	<ul style="list-style-type: none"> › To enable the person to set their own agenda, ask what they would like to discuss today at the start of the consultation. › To enable them to make informed decisions about their diabetes management, inform them about the latest treatments and technologies; discuss what would be realistic options for them. › Ask whether they are receiving the support they need from you and other (diabetes) health professionals. 	<ul style="list-style-type: none"> › Ask questions or seek clarification (e.g., regarding their medical examination results, general health, or treatment). › Be actively involved in decision making about their diabetes management plan. › Prepare for their next consultation and think about what they would like to discuss.

At the End of the Conversation about Diabetes Distress:

- › Ask the person how they are feeling now that you have talked about their concerns; the conversation may have already brought some relief.
- › Summarise the conversation and any actions you have agreed on. As part of this:
 - Check that they feel confident and willing to implement the action plan, and whether they expect major obstacles.
 - Reassure them that the plan can be revised if needed.
 - Suggest some information to read at home. At the end of **Chapter 3** on pages 49 and 50, there is a list of resources that may be helpful for a person who is experiencing diabetes distress. Select **one** or **two** of these that are most relevant for the person; it is best not to overwhelm them with too much information.

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Appendix D

Examples of Strategies for Overcoming Psychological Barriers to Insulin Use (for People with Type 2 Diabetes)

There is no single strategy to address psychological barriers to insulin. The examples in this table may work for some, but not for others. However, the strategies may help you reflect on how you can support someone who experiences one or more of these barriers. Select the strategies that are appropriate for the individual and their needs.

TABLE D.1 Examples of Strategies for Overcoming Psychological Barriers to Insulin Use (for People with Type 2 Diabetes)

Barrier: Myths and Misunderstandings About Insulin (e.g., insulin causes diabetes to worsen, insulin causes complications, or taking insulin as recommended is not important)		
Explore the barrier through conversation	Inform about the barrier	Together, develop an action plan
<ul style="list-style-type: none"> › Explore what they know and how they feel about insulin. › Enquire about their overall concerns about and problems with diabetes (e.g., the side effects of hyperglycemia could be a motivator to change). › Ask whether: <ul style="list-style-type: none"> • they know other people with type 2 diabetes using insulin • or they have shared their (negative and positive) experiences, as this could influence their own beliefs/feelings. 	<ul style="list-style-type: none"> › Dispel misconceptions about insulin (e.g., correctly used, insulin is not the cause of complications, but can actually help to prevent them). › Emphasize that diabetes is a progressive condition, and insulin is almost inevitable. › Counterbalance their concerns with benefits (e.g., insulin helps to improve glycemic outcomes/gives more flexibility/energy levels/well-being/treatment satisfaction, gives more flexibility, and prevents long-term complications). › Dispel the belief that not having symptoms of high blood glucose levels indicates that insulin is not needed. 	<ul style="list-style-type: none"> › Invite the person to complete the “Decisional balancing tool” (see Box 5.3 on page 81), as it will help the cognitive process of weighing up pros and cons. › After completing the tool, ask them to talk about their responses. This will inform the action plan. <p>NB: It is best to postpone other changes to their treatment regimen while they process the new information and come to a decision.</p>

Barrier: Concerns about Injecting

(e.g., lack of confidence, pain, or worries)

Explore the barrier through conversation	Inform about the barrier	Together, develop an action plan
<ul style="list-style-type: none"> › Explore in more detail the cause(s) of their concern. › Ask if they have seen an insulin injection pen. › Ask about previous experiences with injections or needles. › If pain is experienced, explore what the reason may be. <p>NB: For information about fear of injections, see Box 4.2 on page 56.</p>	<p>Explain:</p> <ul style="list-style-type: none"> › that many people fear injecting at first, but with practice this fear disappears › how to reduce pain (e.g., deep breath relaxation before injecting, or using less sensitive sites) › and the reason for the treatment regimen (type of insulin and number of injections, such as why two injections are recommended rather than one). 	<ul style="list-style-type: none"> › If the person is experiencing pain while injecting: <ul style="list-style-type: none"> • invite them to do an injection with you, so you can observe/talk about the technique. • check their insulin sites • discuss insulin use (e.g., storage) • and consider new technologies and treatments (e.g., finer needles, insulin pump, and longer-acting insulins). › If the person is new to insulin: <ul style="list-style-type: none"> • show them how small the needle is of an insulin injection pen • demonstrate the injection (see ASSIST on pages 61 and 62) • invite them to do their first injection at the appointment with you (for reassurance/encouragement) • for their first injection, leave them time to feel comfortable • check if they would like to make appointments for a few consecutive days, until they feel confident injecting on their own. • and suggest a short “trial” period of insulin use (see ASSIST on pages 61 and 62) › Assist in referring them to a certified diabetes educator to learn or improve injection techniques and work through the barriers.

Barrier: Concerns about Weight Gain

Explore the barrier through conversation	Inform about the barrier	Together, develop an action plan
<ul style="list-style-type: none"> › Ask about their general concerns about their weight and body shape. › Explore what the main obstacles are to maintaining or reducing weight. › Ask about their expectations in relation to weight gain. › For those already using insulin, ask about their experiences of the impact of insulin on their weight. 	<ul style="list-style-type: none"> › Reassure the person that although some people gain weight when they begin insulin, the weight gain is often (a) short term, and (b) counteracted with small changes to lifestyle. › Emphasize that most people feel better physically once they begin insulin use. › Explain that a collaborative approach (involving their PCP/endocrinologist, dietitian and/or diabetes educator) can help in minimizing the impact. 	<ul style="list-style-type: none"> › Assist in developing an action plan to minimize the impact of insulin on weight (e.g., optimizing their insulin regimen and/or meal plan). › Explain how to titrate insulin doses based on blood glucose readings and meals. › Suggest they consider asking for help from their partner or family member in maintaining healthy eating and/or exercising. › Assist in referring them to another health professional (e.g., a dietitian). <p>NB: Optimize their insulin dose to avoid over-treating.</p> <p>NB: Explore weight-neutral or weight-reducing diabetes therapies (e.g., incretin-based therapies, or metformin).</p>

Barrier: Self-Perception

(e.g., feelings of failure or guilt)

Explore the barrier through conversation	Inform about the barrier	Together, develop an action plan
<ul style="list-style-type: none"> › Ask how they feel about living with diabetes. › If appropriate, assess for diabetes distress (see Chapter 3), depression (see Chapter 6), and/or an anxiety disorder (see Chapter 7). 	<ul style="list-style-type: none"> › Dispel feelings of failure, blame, shame, etc. › Emphasize that: <ul style="list-style-type: none"> • diabetes is a progressive condition • many people with type 2 diabetes need insulin • and insulin is a powerful way to prevent long-term complications. 	<ul style="list-style-type: none"> › See Chapter 3 about how to help a person who has negative feelings around diabetes. › Refer them to a mental health professional if negative feelings are persistent.

Barrier: Impact on Lifestyle

(e.g., reduced flexibility or spontaneity, time consuming, having to give up other activities, effect on work, or cost)

Explore the barrier through conversation	Inform about the barrier	Together, develop an action plan
<ul style="list-style-type: none"> › Ask about how they believe insulin will affect their lifestyle. › Explore in more detail what aspect(s) of their lifestyle will be impacted, as this will inform the action plan to address the barrier. 	<ul style="list-style-type: none"> › Explain the benefits of insulin, relating back to their specific concerns (e.g., more flexibility in the timing of meals or food choices; and feeling more energetic, allowing more activities instead of less). › Explain that being active will have a positive effect on insulin sensitivity. › If they are experiencing discrimination because of their diabetes (e.g., at work), encourage them to contact the American Diabetes Association at (800) DIABETES for advocacy support. › Provide information about the costs of insulin and what subsidies are available/how to access them. 	<ul style="list-style-type: none"> › Problem-solve situations in which they would feel uncomfortable to inject (e.g., with colleagues, or in public) or how to continue activities after starting insulin. › Explain how to titrate insulin doses based on blood glucose readings and planned activities and meals to avoid giving up activities. › Suggest a short “trial” period of insulin use (see ASSIST on page 82). <p>NB: For some people, a once-daily injection would reduce the impact on their lifestyle, while, for others, multiple daily injections can increase flexibility.</p> <p>NB: Consider the method of insulin delivery (e.g., pen versus pump).</p>

Barrier: Perceived Attitudes and Behaviours of Others

(e.g., social embarrassment, or concerns from others)

Explore the barrier through conversation	Inform about the barrier	Together, develop an action plan
<p>Ask whether:</p> <ul style="list-style-type: none"> › they have discussed going on insulin with other people and what the reaction was › others support them in going onto insulin › or if they feel comfortable about injecting in front of others. 	<ul style="list-style-type: none"> › Talk about how we cannot control what others think or say but we can control how we react to it. › Discuss how other people sometimes make fun or ridicule because they don't understand or are fearful. › Advise that they explain to people their need for insulin and suggest they show others their insulin pen. This may deter other people from making any further negative comments about insulin. 	<p>If a close family member or friend does not understand the need for insulin or is worried about it, suggest they:</p> <ul style="list-style-type: none"> › invite them to attend the next appointment or to attend a diabetes information session (if available) › and give the family member or friend an information leaflet about insulin. <p>Inform them about online and face-to-face diabetes peer support services in their local area and encourage them to participate to strengthen their support networks. See Appendix B.</p>

Barrier: Risk of Hypoglycemia

Explore the barrier through conversation	Inform about the barrier	Together, develop an action plan
<p>Ask about:</p> <ul style="list-style-type: none"> › their understanding of hypoglycemia › their concerns about the risk of hypoglycemia › and what they fear most about hypoglycemia (see Chapter 4). 	<p>Explain that:</p> <ul style="list-style-type: none"> › hypoglycemia is a side-effect of insulin use › there are strategies to prevent low glucose levels (e.g., checking blood glucose and timely treatment) › the risk of severe hypoglycemia (very low blood glucose) is low in people with type 2 diabetes › and training in hypoglycemia prevention/management is available. 	<ul style="list-style-type: none"> › Assist the person in accessing appropriate hypoglycemia prevention and management training. › Implement/adapt the insulin regimen step-by-step, so that the person is safe and feels confident in their insulin use. <p>NB: Consider lower-risk treatments (e.g., longer-acting insulin, or alternatives to insulin).</p>

Barrier: Concerns about Regimen Complexity

Explore the barrier through conversation	Inform about the barrier	Together, develop an action plan
<p>Ask about:</p> <ul style="list-style-type: none"> › what aspects of their regimen they find complex or challenging › how adding insulin to their treatment plan would impact on this complexity › and the experienced challenges (for those already using insulin). 	<ul style="list-style-type: none"> › Recognize that at first insulin may seem to be a more complex regimen, but that they can take it step-by-step (e.g., starting off with a once-daily long-acting injection). 	<ul style="list-style-type: none"> › Discuss and decide on a regimen that will suit the person's lifestyle, health needs, and confidence levels. › Provide or assist the person to access training/resources about how to manage diabetes (e.g., how to administer insulin and check blood glucose), with specific attention to the aspects of their regimen that they find most challenging. › Suggest a short "trial" period of insulin use (see ASSIST on page 82).

Barrier: Loss of Independence

Explore the barrier through conversation	Inform about the barrier	Together, develop an action plan
<p>Explore:</p> <ul style="list-style-type: none"> › how they perceive loss of independence › what part of their life is most likely going to change › and any effects on their "freedom." 	<ul style="list-style-type: none"> › Reassure them that using insulin does not mean loss of independence. › Explain that using insulin most likely means they will gain more independence (e.g., more energy and more flexibility in when and what they eat) and be able to live a normal, healthy life. 	<ul style="list-style-type: none"> › Discuss and decide on a regimen that will suit the person's lifestyle, health needs, and confidence levels. › Provide or assist the person to access training/resources about how to manage diabetes (e.g., how to administer insulin/check blood glucose/avoid hypoglycemia), with specific attention to the aspects of their regimen that they find most challenging. › Suggest a short "trial" period of insulin use (see ASSIST on page 82).

At the End of the Conversation about Psychological Barriers to Insulin Use:

- Ask the person how they are feeling now that you have talked about their concerns.
- Summarize the conversation and any actions you have agreed on. As part of this:
 - Check that they feel confident and are willing to implement the action plan, and whether they expect major obstacles.
 - Reassure them that the plan can be revised if needed.
 - Suggest some information to read at home. At the end of **Chapter 5** (see page 89), there is a list of resources that may be helpful for a person who is experiencing psychological barriers to insulin use. Select **one** or **two** of these that are most relevant for the person; it is best not to overwhelm them with too much information.

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Definition of Terms

Various words, phrases, and technical terms are explained below in plain language with reference to how they are used in this practical guide.

Word or Phrase	Meaning
Active listening	A communication technique, in which the listener re-states or paraphrases in their own words what the speaker has said, to confirm what they have heard and moreover, to confirm mutual understanding.
Adjustment	The process of adapting or becoming used to a new situation.
Anxiety	The anticipation of a perceived or real future threat; associated with fear, vigilance, and avoidance behavior.
Anxiety disorder (also known as clinical anxiety)	A diagnosable mental condition characterized by frequent, intense, and excessive anxiety symptoms, typically occurring for a minimum of six months; interfering with a person's ability to function, and causing significant distress.
Avoidance behaviors/ strategies	Pervasive pattern of withdrawing from fear or anxiety provoking situations.
Binge eating	Eating a very large amount of food within a relatively short period of time (e.g., within two hours), and feeling a sense of loss of control while eating (e.g., feeling unable to stop oneself from eating).
Body dissatisfaction	Negative perception of weight and shape of one's physical self and negative feelings resulting from it.
Body image	How a person thinks and feels about the way they look, including how they think others perceive them.
Body language	A form of non-verbal communication where thoughts, intentions, or feelings are expressed by physical signs, such as facial expressions, body posture, gestures, eye movement, and the use of space.
Brief solution-focused therapy	Goal-directed form of therapy with focus on solutions rather than on the symptoms or issues that brought the person to therapy.
Clinical interview	A structured conversation during which a clinician gathers valuable information (behavioral observations, idiosyncratic features of the person, the nature and history of the problem, experience of symptoms) from the person, to inform an accurate diagnosis.
Closed, directive communication style	A form of communication where one person is actively communicating and seeks little feedback or input from the other person, rarely inviting expression of emotion or detail. Questions typically invite single word (yes/no) answers.
Cognitive behavioral therapy (CBT)/Enhanced CBT	A form of psychotherapy that aims to identify and change unhelpful thinking and behavior; used to treat various emotional and behavioral problems or mental disorders. Enhanced CBT is a modified version of CBT, used to treat eating disorders.

Word or Phrase	Meaning
Cognitive impairment	When a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life.
Collaborative care (also known as multidisciplinary approach)	Multiple health providers (from various professions and settings) providing comprehensive healthcare services by working with people, their families, care providers, and communities. Practice includes both clinical and non-clinical health-related work, such as diagnosis, treatment, surveillance, health communications, management, and support services.
Compensatory behavior	Deliberate act undertaken in an effort to “undo” another behavior (e.g., self-induced vomiting to counteract calories consumed) or to counteract a negative experience (e.g., taking too little insulin to avoid hypoglycemia).
Decisional balancing	A technique that enables an individual to work through ambivalent thoughts to make an informed decision (origins in motivational interviewing).
Depression (also known as depressive disorder or major depression)	A diagnosable mental condition characterized by a persistent (minimum two weeks) state of low mood and lack of interest and pleasure in regular activities, in addition to other symptoms, such as significant changes in weight and sleep, lack of energy, difficulty concentrating, feelings of worthlessness or guilt, or suicidal ideation.
Depressive symptoms	A range of symptoms shared with diagnosable major depression (e.g., significant changes in weight and sleep, lack of energy, difficulty concentrating, feelings of worthlessness or guilt, or suicidal ideation), but of insufficient severity or frequency to meet the full diagnostic criteria.
Desensitization	Diminished emotional responsiveness to a negative stimulus after repeated exposure to it; a behavioral technique commonly used to treat phobias and anxiety disorders.
Diabetes burnout	A state of physical or emotional exhaustion caused by severe and long-lasting diabetes distress.
Diabetes distress	The emotional burden arising from living with and managing diabetes, including problems related to the relentlessness of diabetes self-care, worries about the future, feelings of guilt, anxiety or frustration, and interpersonal problems (e.g., with health professionals or significant others).
Diabetes-specific fears	The emotional response to real or perceived threats specific to diabetes, often associated with the “fight or flight” response (e.g., fear of hypoglycemia, hyperglycemia, diabetes-related complications, and injections/needles).
Diabetic ketoacidosis	A potentially life-threatening medical condition arising from a lack of insulin (intentional or unintentional insulin omission). Without insulin, the body cannot use glucose for energy, and the body breaks down fat (producing ketones) as an alternate energy source. If ketones build up, they are toxic to the body (acidosis). Diabetic ketoacidosis can also be present at diagnosis of type 1 diabetes (and occasionally type 2 diabetes) or occur during illness or infection if there is a lack of insulin in the body.
Disordered eating/ behaviors	A wide range of unhealthy eating behaviors (e.g., restrictive dieting, compulsive eating, skipping meals), and associated emotional disturbances (e.g., feelings of shame, guilt, lack of control). Many of these symptoms are shared with diagnosable eating disorders but they are of insufficient severity or frequency to meet the full diagnostic criteria.
Eating disorder	Diagnosable mental condition characterized by preoccupation with food, body weight, and shape, resulting in disturbed eating behaviors with or without disordered weight control behaviors (e.g., food restriction, excessive exercise, vomiting, medication misuse).
Emotional eating	A form of disordered eating, in response to negative emotional states, such as anxiety, distress, and boredom; and where a person eats to temporarily suppress or ease unpleasant feelings.

Word or Phrase	Meaning
Emotional health	A state of positive affect or well-being; the ability to understand, express, and respond to feelings in an appropriate way (without being overwhelmed by them).
Empathy	The ability to understand and share the feelings, thoughts, or attitudes of another person.
Empowerment	Realization of one’s own abilities and potential; the philosophy and practice of sharing information, skills, and opportunities to enable another person to discover and develop the capacity to be responsible for their own health, and for this to contribute to their engagement, competence, and satisfaction. In diabetes, it is defined as a person-centered, collaborative approach tailored to match the realities of diabetes care (i.e., that the person with diabetes is responsible for their own outcomes and lives with the consequences of their decisions).
Exposure-based therapy	A specific type of cognitive behavioral therapy designed to help people confront their fears, by exposing them to the feared objects, activities, or situations in a safe environment. It helps the person to break the pattern of avoidance and fear, and overcome their feelings; often used in the treatment of post-traumatic stress disorder and phobias.
External eating	Eating in response to food-related cues, such as the sight, smell, or taste of food.
Fear management	A method used to reduce negative emotions and the physiological arousal that fear causes, to change unhelpful beliefs, reduce unnecessary fear, and to promote positive coping mechanisms.
Fear of hypoglycemia	Extreme worry or anxiety about low blood glucose and its consequences; this specific fear is evoked by the risk and/or occurrence of hypoglycemia but is not necessarily related to the frequency or severity of current hypoglycemia.
Generalized anxiety disorder	A diagnosable mental condition characterized by persistent, excessive, or disproportionate worry about a number of events or activities, that is difficult to control and long lasting (minimum six months), and accompanied by symptoms such as restlessness, fatigue, sleep disturbance, irritability, muscle tension, and difficulties concentrating.
Health literacy	The ability to obtain, understand, and apply health-related information and to navigate the health system to enable appropriate health decisions.
Insulin stacking	Injecting insulin too soon after a previous dose, resulting in too much active insulin in the body (“insulin on board”) and the risk of low blood glucose.
Interpersonal therapy (IPT)	A form of psychotherapy concerned with the “interpersonal context”—the relational factors that predispose, precipitate, and perpetuate distress; the aim is to help the person improve their relationships or change their expectations about them.
Impaired awareness of hypoglycemia	Diminished ability to perceive the onset of hypoglycemia, due to reduction in symptom intensity or change in symptom profile or both; an acquired complication associated with longer duration of insulin therapy.
Maladaptive coping strategies	Attempts to cope with a stressor that are either ineffective or provide only temporary relief, while the stressor maintains its strength. For example, “comfort eating” or drinking alcohol to “forget” a problem (but the situation continues to be stressful as it has not been resolved).
Mental health	A state of emotional, psychological, and social well-being, in which the person is able to realize their own potential, cope with the normal stresses of life, work productively, and make a contribution to the community.

Word or Phrase	Meaning
Minor depression (also known as mild, subthreshold, or sub-clinical depression)	Characterized by the presence of depressive symptoms that are of insufficient severity or frequency to meet the full diagnostic criteria for diagnosis of major depression.
Monitoring	Observing and checking progress over a period of time, maintaining regular surveillance (e.g., of emotional/mental health and well-being); typically using open-ended questions and/or validated questionnaires.
Motivational interviewing	A goal-oriented, counselling style for eliciting behavior change by helping people to explore and resolve ambivalence to change.
Neuroglycopenia (neuroglycopenic symptoms)	A shortage of glucose in the brain, usually due to hypoglycemia (low blood glucose). Neuroglycopenic symptoms include confusion; difficulty concentrating; weakness, tiredness or dizziness; blurred vision; and inappropriate behavior (sometimes mistaken for inebriation).
Neuroticism	A personality trait characterized by anxiety, fear, moodiness, worry, envy, frustration, jealousy, and loneliness.
Normalization/normalize	A process by which the health professional helps the person to view their experience as common, “natural,” or “human.”
Open, empathic communication style	A form of interaction where all parties actively share and are able to express their ideas. Questions typically encourage full, descriptive responses because the person asking is genuinely interested in understanding the other person’s experience or perspective.
Panic attack	Sudden surge of intense fear, either due to an external or internal trigger, that involves various anxiety symptoms, such as increased heart rate, heart palpitations, shortness of breath, dizziness, sweating, and shaking.
Panic disorder	A clinically diagnosed mental condition characterized by recurrent, unpredictable, and severe panic attacks.
Paraphrase	To express the meaning of what someone has written or spoken, using your own words, to achieve greater clarity.
Peer support	A system of giving and receiving help from a person (or people) with similar experience (e.g., living with diabetes). It can involve sharing knowledge and experiences of daily self-management, social and emotional support, and linkages to clinical care and community resources. Peer support can take many forms, including phone calls, text messaging, group meetings, home visits, and online forums.
Perfectionism	A personality trait characterized by striving for flawlessness and refusal to accept any standard short of excellence, accompanied by overly critical self-evaluations and concerns regarding others’ evaluations.
Person-centered approach/ care	A non-directive approach that places the person at the heart of decisions relating to and affecting their life; considering the person as an individual, respecting their rights, priorities, and preferences, believing in their potential and ability to make choices that are right for them, regardless of the health professional’s own values, beliefs, and ideas.
Post-traumatic stress disorder	A diagnosable mental condition characterized by persistent psychological stress occurring as a result of injury or severe trauma, typically involving disturbance of sleep and continual or frequent vivid recall of the experience, interfering with the person’s ability to continue with their everyday life, activities, or relationships.
Problem solving training	A method used to increase a person’s adaptive skills as a means of resolving and/or coping more effectively with stressful situations or problems.

Word or Phrase	Meaning
Psycho-educational intervention	An approach combining both education and psychological principles or activities (e.g., counselling or motivational interviewing); typically offered to people for whom the problem to be resolved is more than the absence of knowledge or skills but is more deep-rooted in attitudes and beliefs.
Psychological barriers to insulin use (also known as psychological insulin resistance or negative appraisals of insulin)	The negative thoughts or feelings that people with diabetes may have about starting, using, or intensifying insulin.
Quality of life	Subjective satisfaction (or dissatisfaction) with aspects of life (e.g., family, friendships, work, hobbies, holidays, finances) considered by the individual to be important to them.
Resilience	An individual's ability/capacity to adapt to or recover quickly from stress or adversity.
Restrained eating	Restriction of food intake, or avoiding certain foods, food categories, or ingredients; similar to being on a diet, for the purpose of weight loss or maintenance.
Screening	Systematic assessment to detect risks or problems (e.g., using validated questionnaires to identify specific emotional or mental health problems).
Self-efficacy	A person's belief or confidence in their ability to succeed in specific situations or accomplish a task, to exert control over their own motivation, behavior, and social environment. Low self-efficacy refers to a person lacking such confidence or self-belief.
Self-esteem	A person's subjective emotional evaluation of their own worth.
Self-harm	Deliberate injury to oneself, typically as a manifestation of mental health problems but without suicidal intent; maladaptive behavior used to cope with difficult or painful feelings.
Sick role	The culturally accepted behavior pattern or role that a person is permitted to exhibit during illness or disability; the social role of being ill or having a chronic condition; adoption of the "sick role" changes the behavioral expectations of others towards the person, they are exempted from usual social responsibilities and not held responsible for their condition.
Social anxiety disorder	A diagnosable mental condition characterized by intense, excessive fear of being scrutinized by other people, resulting in avoidance of social situations.
Specific phobia disorder	A diagnosable mental condition characterized by intense irrational fear of specific everyday objects or situations (e.g., phobia of spiders, injections, blood).
State anxiety	The experience of unpleasant feelings in response to a perceived threat or specific, negative situations, demands, or events; when the threat is removed, the person no longer experiences anxiety; differs from "trait anxiety."
Stigma	A mark of disgrace that sets a person apart from others; a strong feeling of disapproval towards a thing, a person, or a group based upon a shared negative characteristic (often a stereotype), which may or may not lead to negative actions, unfair treatment, and discrimination.
Stress management	A wide spectrum of techniques and psychotherapies used to manage a person's level of stress, especially chronic stress, for the purpose of improving everyday functioning.
Suicidal ideation/ thoughts	Thoughts about killing oneself, ranging from fleeting thoughts, to preoccupation and extensive thoughts, to detailed planning and incomplete attempts at suicide.

Word or Phrase	Meaning
Trait anxiety	A relatively enduring disposition or stable tendency to feel stress, worry, and discomfort; people with high trait anxiety experience more intense degrees of state anxiety than those without trait anxiety; a personality characteristic not a temporary feeling; differs from “state anxiety.”
Traumatic hypoglycemic event	An episode of hypoglycemia (low blood glucose) that is typically complicated by loss of consciousness or hospitalization, injury to oneself or others, or happening while asleep, often leaving the person with residual fear of hypoglycemia or feelings of embarrassment or vulnerability.
Tweetchat	A live Twitter event, usually moderated and focused around a general topic (e.g., for the purposes of providing and receiving support). A hashtag (#) is used and a set time is established so that the moderator/host and participants are available to engage in the online conversation.
Validated questionnaire	A questionnaire that has undergone rigorous design and psychometric testing to ensure it effectively measures the topic under investigation (e.g., depression) within the population under investigation (e.g., people with diabetes). Psychometric tests typically include “reliability” (the ability of the instrument to produce consistent results), “validity” (the ability to produce true results), “sensitivity” (the likelihood of correctly classifying a person with the condition), and “responsiveness,” (the ability of the instrument to detect change, e.g., following treatment). “Unvalidated” questionnaires may be subject to measurement error and any conclusions drawn may be flawed. Validated questionnaires should not be modified without permission from the developer, as this may also introduce errors.
Validation (of feelings)	“Normalization”; recognizing/acknowledging someone’s feelings as important or appropriate; a technique that helps the person to feel that you care about and understand them.
Well-being (emotional or psychological well-being)	The state of being comfortable, healthy, or happy; a general term for a person’s mental condition; a high level of well-being means in some sense the individual experience is positive, while low well-being is associated with negative happenings.