



Diabetes and emotional health

A practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes



This practical guide, UK edition (2019) was produced by Diabetes UK under a royalty-free, UK only, non-exclusive sub-license from Diabetes Australia.

The original Australian handbook (2016) was developed by the Australian Centre for Behavioural Research in Diabetes (ACBRD) as an activity of the Mental Health and Diabetes National Development Programme, which was funded as part of the National Diabetes Services Scheme (NDSS). The NDSS is an initiative of the Australian Government administered with the assistance of Diabetes Australia. Leadership for the Mental Health and Diabetes National Development Programme is provided by Diabetes Victoria. The ACBRD is a partnership for better health between Diabetes Victoria and Deakin University.

The UK Expert Reference Group overseeing the adaptation to the UK cultural, linguistic and healthcare context is listed on page 5.

Suggested citation: Hendrieckx C, Halliday JA, Beeney LJ, Speight J. **Diabetes and emotional health: a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes.** London: Diabetes UK, 2019, 2nd Edition (UK).

© The Commonwealth of Australia as represented by the Department of Health, 2016 (original Australian edition), and 2019 (UK edition).

The views expressed are those of the authors and do not necessarily reflect those of the Australian Government. The Commonwealth is not responsible for any recommendations, views, ideas or strategies expressed in this document.

Diabetes UK and Diabetes Australia believe that the information contained in this resource was accurate and reliable at the time of publication. The websites quoted in the resource were accessible at the time of publication. Diabetes UK and Diabetes Australia cannot take responsibility for the accuracy or future availability of these sites. Furthermore, on behalf of the authors, Diabetes UK and Diabetes Australia take no responsibility for any adverse consequences that may arise as a result of using the content of the resources for clinical purposes. Health professionals need to take into account the individual circumstances and needs of people with diabetes when they apply the skills outlined in this resource in their clinical practice.

For permission to copy or use any part of this resource, contact Diabetes UK on 0345 123 2399.

Selected photographs from Shutterstock, iStock and Gary Radler Photography.

Table of contents

Foreword	4
Expert Reference Group	5
Acknowledgements	6
Acronyms and abbreviations.....	7
Introduction.....	8
How to use this guide	13
Chapter 1 – Communication and engagement.....	21
Chapter 2 – Facing life with diabetes	40
Chapter 3 – Diabetes distress.....	53
Chapter 4 – Fear of hypoglycaemia (and other diabetes-specific fears).....	71
Chapter 5 – Psychological barriers to insulin use.....	95
Chapter 6 – Depression	114
Chapter 7 – Anxiety disorders	138
Chapter 8 – Eating problems	159
Chapter 9 – Referring to a mental health professional	181
Appendix A: Peer support	188
Appendix B: Examples of strategies to address diabetes distress	191
Appendix C: Examples of strategies for overcoming psychological barriers to insulin use.....	195

Foreword

It is a great pleasure for me to introduce you to **Diabetes and emotional health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes**.

This guide will be of real help to healthcare professionals in supporting people living with diabetes with their emotional needs. Currently in the UK 3.8 million people are living with diabetes, an increase in 100,000 since the previous year. Numbers of people affected by diabetes are expected to rise to 5.5 million by 2030.

Treating diabetes costs the NHS at least 10 billion pounds each year, with almost 80% of that being spent on treating the complications of diabetes. The NHS is in danger of being overwhelmed by diabetes. With so much being spent on complications, there has never been a more important time to make sure people with diabetes get the support they need to manage their condition.

We know that diabetes doesn't just affect people's physical health. It can also have a huge impact on their emotional health too. Diabetes is relentless, and requires constant attention, awareness and decision making. It was not surprising then, that our Future of Diabetes report (2017) found that 64% of people sometimes or often feel down because of their diabetes. And that less than 25% of people with diabetes get the emotional and psychological support they need from the NHS. As well, people with diabetes are twice as likely to suffer from depression, and they are more likely to be depressed for longer and more frequently than those without diabetes. There are also specific psychological conditions relating to diabetes such as diabetes distress, fear of injections or hypos and eating disorders. Poor emotional and psychological wellbeing is associated with poorer quality of life, poorer management of diabetes and an estimated 50% increase in healthcare costs.

Against this background, there has never been a greater need for practical resources to support healthcare professionals in looking after the emotional needs of people with diabetes.

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 healthcare professionals specialising in psychology and diabetes. It has been adapted for a UK audience by an equivalent expert group of UK clinicians. The guide will help any healthcare professionals working with people with diabetes to discuss emotional needs, use consultation time more effectively and to know when to refer on. There are also dedicated chapters on the common emotional issues faced by people living with diabetes, such as eating problems, depression, diabetes distress and adjusting to life with diabetes.

Diabetes and emotional health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes provides an evidence-based and practical resource for all healthcare professionals involved in the care of adults with diabetes. It will be invaluable in helping support their emotional health as well as physical, and so provide true holistic care.

Chris Askew
CEO, Diabetes UK

Expert Reference Group

Dr Jen Bateman

Dr. Jen Bateman (née Nash) is a Clinical Psychologist, specialising in diabetes and weight management. She is the author of two 5* Amazon rated books, 'Diabetes and Wellbeing' (Wiley-Blackwell, 2013) and 'Your Weight Isn't About Food' (2016). Jen is an Editorial Board Member of the 'Journal of Diabetes Nursing' and 'Diabetes & Primary Care'. Jen was named an 'Outstanding Educator' Finalist in the Quality in Care Awards 2014 and was awarded the honour of a 'World Diabetes Day Hero' in 2012 by the International Diabetes Federation. She has served as an Advisory Board Member and Consultant on numerous strategic health initiatives, including the NHS England, 'Language Matters' (2018) Diabetes Position Statement.

Jen has been living with diabetes since childhood and is open about her personal experiences of recovery from emotional eating difficulties, to encourage others who may be struggling. Get free educational resources at www.DrJenBateman.com.

Dr Mark Davies

Mark graduated from Queen's University Belfast in 1998 with a doctorate in Clinical Psychology. Prior to this he worked as a Research Psychologist at St George's Hospital Medical School, University of London. Since June 2000 he has worked at Belfast City Hospital where he provides a clinical psychology service to people with diabetes and the healthcare professionals who care for them across Belfast Health & Social Care Trust. Most his working time is spent talking to people with diabetes about a wide range of psychological issues that can impair their ability or willingness to look after their diabetes. In addition, he provides supervision and training to a range of healthcare professionals both locally and nationally. He has published widely. He is particularly interested person-centred practice and is a member of the Knuston Ireland faculty, which runs an empowerment and counselling skills training course each year for diabetes healthcare professionals across Ireland.

Professor Jackie Sturt

Professor Jackie Sturt is a behavioural scientist and both a registered general and mental health nurse in the Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London. Much of her academic career has been spent working in diabetes, developing, evaluating and supporting the implementation of complex interventions to support patient self-management. She has undertaken a number of systematic reviews in diabetes distress and is also interested in how timely access to healthcare, via digital consulting, can support people to self-manage their diabetes. Whilst working at Warwick Medical School she held an NHS clinical secondment from 2010-12 to develop "The Diabetes Listener service" supporting patients struggling to cope with their diabetes.

Rosie Walker

Rosie owns and runs the independent company Successful Diabetes (www.successfuldiabetes.com), which provides workshops, books resources, education and consultancy for people living and working with diabetes.

She's a former diabetes specialist nurse and has worked both locally and nationally in developing diabetes services and education since 1985. In addition to nursing and diabetes, she's gathered additional academic qualifications and expertise in psychology, higher education, active listening and counselling.

She's inspired by a person-centred philosophy and cares deeply about supporting people with the emotional and psychological aspects of living and working with diabetes. Rosie is proud to have worked with Diabetes UK on adapting this unique and special, practical resource for UK health professionals.

Dr Nicole de Zoysa

Dr Nicole de Zoysa is a Clinical Psychologist who specialises in long-term physical health conditions. Since 2008, she has worked in the Diabetes and Cardiac Rehabilitation teams at King's College Hospital, London, offering a clinical service to patients. She has also provided teaching on the psychological aspects of diabetes and cardiovascular disease for several therapist training programmes and has worked on three NIHR funded trials to evaluate the efficacy of psychological approaches for people with diabetes. She is a member of the Motivational Network of Trainers and provides training and supervision to healthcare professionals working with people with diabetes. Nicole also has an interest in the application of mindfulness meditation in the NHS and has published in this area as well as psychological aspects of diabetes.

Acknowledgements

The UK Expert Reference Group would like to thank the following people for their support in creating this edition:

- Libby Dowling, Senior Clinical Advisor, Diabetes UK
- Christel Hendrieckx, Senior Research Fellow, The Australian Centre for Behavioural Research in Diabetes
- Emma Hook, Content Manager, Diabetes UK
- Jane Speight, Foundation Director of The Australian Centre for Behavioural Research in Diabetes

You can find the original Australian Handbook (2016), including the foreword, author biographies, acknowledgements and expert reference group at www.ndss.com.au/health-professionals-resources

Acronyms and abbreviations

Acronym/abbreviation	Term
7 As	Aware, Ask, Assess, Advise, Assist, Assign, Arrange
BMI	Body Mass Index
CBT	Cognitive Behavioural Therapy
CBT-E	Enhanced Cognitive Behavioural Therapy
DAFNE	Dose Adjustment for Normal Eating
DDS	Diabetes Distress Scale
DEPS-R	Diabetes Eating Problem Survey – Revised
DESMOND	Diabetes Education and Self-Management for Ongoing and Newly Diagnosed
DOC	Diabetes Online Community
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
GAD-2	Generalised Anxiety Disorder (questionnaire); two-item version
GAD-7	Generalised Anxiety Disorder (questionnaire); seven-item version
GBDOC	Great Britain Diabetes Online Community
GP	General Practitioner
HbA1c	Haemoglobin A1C
HFS-II W	Hypoglycaemia Fear Survey version two: Worry Scale
ICD-10	International Statistical Classification of Disease and Related Health Problems, 10th revision
ITAS	Insulin Treatment Appraisal Scale
JDRF	Juvenile Diabetes Research Foundation
mSCOFF	Modified SCOFF
PAID	Problem Areas in Diabetes (scale)
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)

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 behavioural, 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 impacts upon 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 sub-optimal self-management, diabetes-related complications, reduced quality of life, and increased health care 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 recognise 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 labelling the emotional aspects of diabetes a pathological condition. The two are so intertwined and interrelated that simply calling the emotional side a co-morbidity is counterproductive.”

(Lawrence Fisher, Jeffrey Gonzalez and William Polonsky)¹⁰

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 International guidelines reflect this view; recommending awareness and assessment of psychological problems in diabetes clinical practice (see Box 1).

Furthermore, the need for mental health care for people with diabetes is acknowledged in many of the UK National Diabetes Strategies (see Box 1), although often limited to anxiety and depression diagnoses.

Despite the numerous guidelines, and recognition by health professionals and Governments, the emotional and mental health needs of people with diabetes are often undetected and unmet in clinical practice.^{12,13} Furthermore, there is little evidence to demonstrate significant progress in the implementation of such recommendations.^{14,15} Health professionals cite lack of skills, confidence, time, and limited access to practical resources as common barriers.¹⁶ Whilst 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
- provide the practical tools (e.g. questionnaires, information leaflets, and other resources) to support health professionals in this endeavour.

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

“Commissioners and service providers should work together to ensure.... emotional and psychological support for people with diabetes of all ages is embedded in each step of the diabetes care pathway and is not limited to people with ‘diagnosable/classifiable’ psychological problems”

(Diabetes UK, 2018)¹⁸

“Provide psychological assessment and appropriate treatment for service users with diabetes and identified mental health issues, such as anxiety or depression”

(NHS Right Care for Diabetes, Core Service Component 9, 2018)¹⁹

“Providers should consider an assessment of symptoms of depression, anxiety, and disordered eating, and of cognitive factors using patient-appropriate, validated tools at the initial visit, at periodic intervals and when there is a change in disease, treatment or life circumstance.” (p. S42)

“Routinely monitor people with diabetes for diabetes distress, particularly when treatment targets are not met and/or at the onset of diabetes complications.” (p. S54)

“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.” (p. S54)

(American Diabetes Association, 2019)²⁰

“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, 2015)²¹

“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, 2013)²²

Guidelines for Type 1 diabetes clinical care only

“Members of professional teams providing care or advice to adults with Type 1 diabetes should be alert to the development or presence of clinical or subclinical depression and/or anxiety, in particular if someone reports or appears to be having difficulties with self-management.”

(National Institute for Health and Care Excellence, 2015)²³

“Regular assessment of a broad range of psychological and behavioural 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, 2010)²⁴

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 assessing diabetes distress through the use of the PAID questionnaire and depression with the Patient Health Questionnaire-2 (PHQ-2).”

“Referral when appropriate to: psychologist – if issues identified, such as adjustment disorder, depression and/or anxiety.”

(Royal Australian College of General Practitioners, 2014)²⁵

“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, 2012)²⁶

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, 2013)²⁷

What does this practical guide offer?

“I’m really excited... it’s really important and if any health professional reads even any chapter of it, 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 guide is informed by evidence, it is not an evidence-based guideline. As recommendations for routine monitoring of emotional well-being have existed in guidelines for 25 years,¹⁷ there is little evidence that producing yet another guideline would benefit people with diabetes.

The original Australian edition (2016) of the handbook, upon which the UK practical guide (2019) is based, was developed by a team with expertise in psychology and diabetes. Their work has been overseen by a multidisciplinary Expert Reference Group. The handbook was also peer-reviewed by academic and clinical experts with relevant expertise, and by end users (people with diabetes and health professionals). See page 6 for acknowledgments.

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: general practitioners (GPs), specialist and primary care nurses, dietitians, diabetologists, and other health professionals supporting adults with diabetes. Mental health professionals including psychologists, psychiatrists, mental health nurses, and social workers may also find this 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 13 to 18.

What is the scope of the guide?

The practice points in this guide have been developed for use specifically with adults with Type 1 and Type 2 diabetes, in the context of the UK 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 these are noted in the chapter. In the absence of evidence specific to these groups, it may be reasonable to extrapolate from this guide and use your professional judgement.

Furthermore, we emphasise 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 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 impacting upon the person’s emotional well-being
 - address psychological problems that are within their skillset and remit
 - make referrals to specialist care providers, as needed.
- People with diabetes will appreciate that their health professionals ask about how diabetes is impacting upon 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-centred approach to care for their psychological problems.

Organisational 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 recognise 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 behaviours 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 access to this practical guide.
- Provide opportunities for all staff to enhance their communication skills using a person-centred 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.
- Incorporate an holistic approach to diabetes care in:
 - staff position descriptions
 - staff induction programmes
 - staff performance reviews.

“Diabetes 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 about 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)

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 recognise 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 to 8: each focuses on an emotional problem experienced by adults with diabetes
- Chapter 9: Referring to a mental health professional.

There are three appendices:

- Appendix A: Peer support opportunities for people with diabetes
- Appendix B: Examples of strategies to address diabetes distress
- Appendix C: 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 everything, to gain an in-depth understanding
- read the key messages and practice points, then read the relevant detailed sections of the guide as you need them
- dip in-and-out of the specific sections 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 section.

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 here.

Boxes and symbols are used throughout (see below).

Boxes and symbols

Key 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.

Key messages and practice points

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.



Key messages

- People with diabetes want supportive health professionals with whom they can discuss...



Practice points

- Seek to 'meet the person' where they are in their life – rather than where you would like them...

How common...?

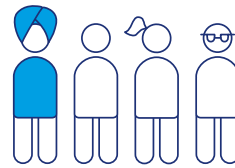
An estimate of how common the emotional health problem is among people with diabetes.

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).

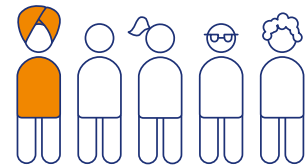
Underneath the symbols are descriptions of the population to whom the statistic applies. Typically, this refers to three groups: people with Type 1 diabetes, people with Type 2 diabetes who use insulin, and people with Type 2 diabetes who do not use insulin.

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.

How common is diabetes distress?



Type 1 diabetes^b



Type 2 diabetes^b

What is...?

Background information about the emotional health problem and its consequences.

What is diabetes distress?

How can I identify...?

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.

It describes the first three of the 7 As (see here): **Be AWARE, ASK, and ASSESS.**

How can I identify diabetes distress?

**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 As (see here): **ADVISE, ASSIST, ASSIGN, and ARRANGE.**

How can I support a person with diabetes distress?

**ADVISE
ASSIST
ASSIGN
ARRANGE**

Case studies

Examples of how the 7 As 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



Elizabeth

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...

Questionnaire

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

Questionnaire

Problem Areas...

Instructions: Which of the following...

	No	Minor	Moderate	Somewhat	Serious
Q1...	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q2...	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q3...	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4...	<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)
- 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.

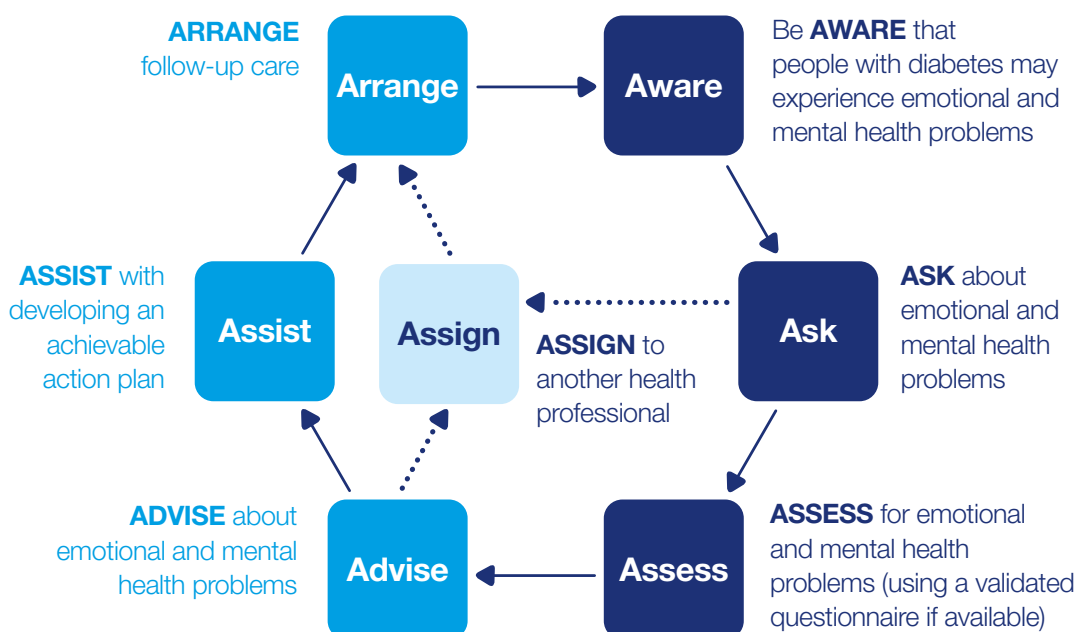
References

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.
2. Funnell MM, Anderson RM. Empowerment and self-management of diabetes. *Clinical Diabetes*. 2004;22(3):123-7.
3. Speight J, Browne JL, et al. Diabetes MILES – Australia 2011 Survey Report. *Diabetes Australia – Vic, Melbourne*: 2011.

7As Model



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

The original model included: ‘Ask’, ‘Assess’, ‘Advise’, ‘Assist’ and ‘Arrange’. The Australian originator’s additions to the model have also been adopted. These are, ‘be Aware’ and ‘Assign’ and reflect the need for vigilance about emotional distress and the potential need for referrals to specialists.

The 7 As 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 As (e.g. **Be AWARE, ASK**), providing guidance about how to apply each of the steps within a clinical setting. The steps have been colour-coded to facilitate ease of use.

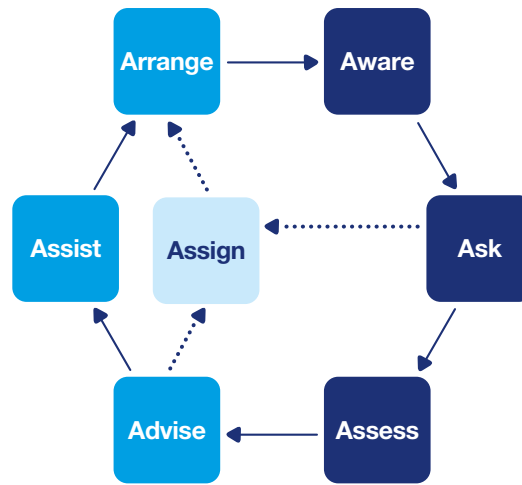
The model is designed to be flexible and dynamic. When applying the model in clinical practice, health professionals need to take into account their own characteristics (e.g. their role, qualifications, and skills) and the context (e.g. the needs and preferences of the person with diabetes, the severity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

How can I support a person who experiences diabetes distress?

ADVISE
ASSIST
ASSIGN
ARRANGE



How can I identify diabetes distress?

Be AWARE
ASK
ASSIST

The 7 As model summary sheets

Using the 7 As model, each sheet provides a summary of an emotional health problem: how to recognise it and how to support the person experiencing it. Find the summary sheets at www.diabetes.org.uk/emotional-health-professionals-guide

Information leaflets (for people with diabetes)

Each leaflet focuses on a specific psychological problem, corresponding with the guide chapters. The leaflets 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
- give a copy to the person to take home with them after having a conversation about an emotional health problem.

References

1. American Association of Diabetes Educators. AADE7 self-care behaviors. *Diabetes Educator*. 2008;34(3):445-9.
2. Funnell MM, Anderson RM. Empowerment and self-management of diabetes. *Clinical Diabetes*. 2004;22(3):123-7.
3. Speight J, Browne JL, et al. Diabetes MILES – Australia 2011 Survey Report. *Diabetes Australia – Vic, Melbourne*: 2011.
4. Jones A, Vallis M, et al. If it does not significantly change HbA1c levels why should we waste time on it? A plea for the prioritization of psychological well-being in people with diabetes. *Diabetic Medicine*. 2015;32(2):155-63.
5. Davies M, Dempster M, et al. Do people with diabetes who need to talk want to talk? *Diabetic Medicine*. 2006;23(8):917-19.
6. Hendrieckx C, Bowden J, et al. An audit of psychological well-being in adults with type 1 diabetes. Paper presented at: Australian Diabetes Society and Australian Diabetes Educators Society Annual Scientific Meeting; 2012; Brisbane, Australia.
7. Snoek FJ, Kersch NY, et al. Monitoring of Individual Needs in Diabetes (MIND): baseline data from the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) MIND study. *Diabetes Care*. 2011;34(3):601-3.
8. Snoek FJ, Kersch NY, et al. Monitoring of Individual Needs in Diabetes (MIND)-2: follow-up data from the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) MIND study. *Diabetes Care*. 2012;35(11):2128-32.
9. Novo Nordisk. The DAWN experiment – an exercise in communication, [cited 9 July 2015]. Available from: www.dawnstudy.org/News_and_activities/Documents/DAWN_Experiment.pdf.
10. Fisher L, Gonzalez J, et al. The confusing tale of depression and distress in patients with diabetes: a call for greater clarity and precision. *Diabetic Medicine*. 2014;31(7):764-72.
11. van der Feltz-Cornelis CM. Depression in diabetes mellitus: to screen or not to screen? A patient-centred approach. *The British Journal of Diabetes & Vascular Disease*. 2011;11(6):276-81.
12. Li C, Ford ES, et al. Undertreatment of mental health problems in adults with diagnosed diabetes and serious psychological distress: the behavioral risk factor surveillance system, 2007. *Diabetes Care*. 2010;33(5):1061-4.
13. Pouwer F, Beekman AT, et al. Nurses' recognition and registration of depression, anxiety and diabetes-specific emotional problems in outpatients with diabetes mellitus. *Patient Education and Counseling*. 2006;60(2):235-40.
14. Fisher L, Glasgow RE. A call for more effectively integrating behavioral and social science principles into comprehensive diabetes care. *Diabetes Care*. 2007;30(10):2746-9.
15. Speight J. Managing diabetes and preventing complications: what makes the difference? *Medical Journal of Australia*. 2013;198(1):16-7.
16. Mosely K, Aslam A, et al. Overcoming barriers to diabetes care: perceived communication issues of healthcare professionals attending a pilot Diabetes UK training programme. *Diabetes Research and Clinical Practice*. 2010;87(2):e11-4.
17. Bradley C, Gamsu D. Guidelines for encouraging psychological well-being: report of a Working Group of the World Health Organization Regional Office for Europe and International Diabetes Federation European Region St Vincent Declaration Action Programme for Diabetes. *Diabetic Medicine*. 1994;11(5):510-6.
18. Diabetes UK. Emotional and psychological support for people with diabetes. Position Statement. July 2018 (Accessed 1 October 2018). Available from <https://www.diabetes.org.uk/professionals/position-statements-reports/diagnosis-ongoing-management-monitoring/emotional-and-psychological-support-for-people-with-diabetes>

19. NHS. Right Care pathway for Diabetes. June 2018. (Accessed 1 October 2018). Available from: <https://www.england.nhs.uk/rightcare/products/pathways/diabetes-pathway/>
 20. American Diabetes Association (ADA). Standards of medical care in diabetes, section 5: lifestyle management. Diabetes Care. 2019;42(Supplement 1):S46–S60.
 21. American Association of Clinical Endocrinologists Task Force for Developing a Diabetes Comprehensive Care Plan, Handelsman Y, et al. American Association of Clinical Endocrinologists and American College of Endocrinology – clinical practice guidelines for developing a diabetes mellitus comprehensive care plan. Endocrine Practice. 2015;21(Supplement 1):S1-87.
 22. Robinson DJ, Luthra M, et al. Canadian Diabetes Association 2013 clinical practice guidelines for the prevention and management of diabetes in Canada: diabetes and mental health. Canadian Journal of Diabetes. 2013;37(Supplement 1):S87-S92.
 23. National Institute for Health and Care Excellence (NICE). Type 1 Diabetes in adults 2015 [Accessed 1 October 2018]. Available from: <https://www.nice.org.uk/guidance/ng17> P.42
 24. Scottish Intercollegiate Guidelines Network. Management of diabetes: a national guideline. Edinburgh: 2010.
 25. Royal Australian College of General Practitioners. General practice management of type 2 diabetes 2014-15. East Melbourne: 2014.
 26. International Diabetes Federation (IDF). Global guidelines for type 2 diabetes. Belgium: 2012.
 27. International Diabetes Federation (IDF). Global guideline for managing older people with type 2 diabetes. 2013
- a. Participant of the stakeholder consultation for the original Australian edition 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.

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 non-verbal) improves the quality of consultations and is essential for best clinical practice.
- Reflect on the proportion of the consultation time that you spend talking rather than listening. Is the balance right? Consultations are typically more effective when the person with diabetes talks more than the health professional.

Talking about emotional health is an essential part of the diabetes consultation

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

(William H Whyte)¹

Arguably, the fundamental skills in any healthcare consultation 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 recognise 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 impacts on the person's emotional health can help them to 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 nurse)²

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 issues⁹ 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 a consultation. 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.

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 realise 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.

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 Tracy)¹²

As a health professional, you bring considerable experience and a certain perspective to your consultations. 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. Communication skills take time and practice to develop, and they can always be improved. Take this opportunity to reflect on how you incorporate these general techniques into your consultations.

Box 1.1

Open and closed communication styles

People with diabetes seek out health professionals as much for their personal communication skills and consultation 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.¹¹ 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 a stereotypically brief consultation 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, which matter to them and they could not raise; they may leave the consultation 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 summarised 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
personalised care plans	general care plans
increased engagement with self-care activities (e.g. medication taking)	at best, passive ‘compliance’, but 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)
reduced errors/mistakes (e.g. in prescribing or taking medication).	misunderstandings and misinterpretation of advice/recommendations.

Box 1.2**The ABCs of effective communication****Active listening**

- Active listening is a fundamental communication technique that includes a range of verbal and non-verbal 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 ‘go on...’, ‘uh huh...’.
- 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

- Look for signs that someone is not doing OK, despite what they may be saying verbally.
- Observe the person’s non-verbal communications (i.e. facial expressions, body language) and any inconsistencies between their verbal and non-verbal 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 judgemental).

Clarify information and paraphrase

- 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, ‘You said it has been very hard to [...]?’.
- Paraphrasing means capturing the meaning in your own words: place the onus of understanding on yourself. For example, ‘So I can be sure I’ve got this right, you are saying that [...]. Is that right?’.
- 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 want to check that I’ve explained this clearly, so can you please tell me in your own words ...’. If your message has not been understood, explain it again in a different way.
- Repeat key information (in different ways, if necessary).

Develop rapport

- 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 criticises them.
- Use motivational, collaborative language to appreciate the efforts the person makes and gain their confidence. For example, ‘I can see how hard you have been working on your [blood glucose/activity levels/weight] since we last met’.
- 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 consultations and interactions.

Explain clearly

- Use plain English, avoid jargon, acronyms or shorthand without explanation.
- Provide information in writing that is appropriate to the audience – use plain English, bullet 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

- 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, ‘We talked about doing blood glucose checks before every meal. How do you feel about giving this a try in the next few weeks?’.
- Also, ask for feedback about your service. This can be done routinely and anonymously. It will be enlightening.

Give clear signals

- Set up expectations at the start of the consultation (e.g. how much time is available, what will happen at the end/and next time).
- Let the person know (by signposting) that you need to move onto another issue or to draw the consultation to a close.
- It is important that the person does not feel dismissed or irrelevant. If the issue they are concerned about needs further discussion, arrange for them to return another day when there will be more time or follow up by email or telephone.
- 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

- 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

- Summarise the main issues at the end of the consultation, including any agreed 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 or email or telephone contact to demonstrate that you are interested to continue the conversation and to find out what happens when they try out the agreed 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 nurse)²

“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.”

(Diabetologist)²

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.

Start the conversation

Begin the conversation with an opening comment to **build trust and rapport** (e.g. normalising statement, or referring to a previous conversation/consultation), 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 getting on 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 has been most challenging about it for you?’
- ‘What thoughts do you have about why that keeps happening?’
- ‘How does that make you feel?’

Normalise the issues raised by the person, by helping them to view their experience as common, ‘natural’ or ‘human’. Normalising helps:

- the person to disclose an experience, thought, or feeling that may be very sensitive for them
- the person 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, hypoglycaemia, or that they feel guilty about not coping well with diabetes.

Continue the conversation

Afford the person time to share their experience (without interruption, question, or judgement). 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 is a myriad of 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 ‘normalise the issues’ – did you do enough to put the person at their 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 guide. Each chapter will guide you through the options relevant to 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 guide is a series of information leaflets, which cover the same topics as [Chapters 2 to 8](#) and [Appendix A](#). You can give these leaflets to the person with diabetes – they are designed to help them understand the issues they are facing and what help is available to them.

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 consultation. 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, non-verbal 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?
NB: 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? Would contact by phone or email in a few days’ time be helpful?
- **Seems to need more time than you have available in this consultation:** 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 continue to discuss**’. If time is becoming an issue during the consultation, 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 nurse)²

“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 nurse)²

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

(Diabetes specialist nurse)²

As these quotes show, health professionals face many challenges and barriers in providing adequate psychosocial support to people with diabetes.^{2,13}

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.¹³ 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 consultations and what you can do to reduce those challenges.

Lack of time/fixed consultation times

From a practical perspective, lack of time remains a perennial barrier to a more person-centred 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-centred care.¹³ 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? One way to deal with time constraints is to agree with the person at the beginning of the consultation 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 arrange follow-up contact. Even if initial consultations 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 consultations 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-centred 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 GP rather than with a mental health specialist.³ For example, as diabetes distress (see Chapter 3) is so common and intertwined with diabetes management,¹⁴ it is best addressed by a diabetes health professional (or the GP 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. However, the Improving Access to Psychological Therapy (IAPT) service ^(a) is available in every clinical commissioning group (CCG) in England and is expected to integrate their services into physical health care pathways for people with long-term conditions and medically unexplained symptoms. These services are called IAPT-LTC.

It is also important to realise that only a small number of people with diabetes may need a referral. Up to one in three adults with diabetes have impaired emotional well-being¹⁵ but they 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). They may also benefit from the support of other people with diabetes (see Appendix A).

Different agendas

You and the person with diabetes may come to the consultation 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 consultation?'. People with diabetes may not be aware that they have the right to ask questions in consultations,¹³ especially about psychosocial issues. 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 expensive to integrate routine monitoring of emotional health into their consultations, 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.¹⁶⁻¹⁸ 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.¹⁹ 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 consultation. In extreme cases the consultation 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 consultations, or seeking professional support.²⁰⁻²³ Health professionals may convey stigmatising attitudes unintentionally in their language, actions, and reactions. Consider how your words and actions might inadvertently reflect negative attitudes about mental health²⁴ and diabetes (see 'Language Matters' at www.diabetes.org.uk/emotional-health-professionals-guide).

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 behaviours.

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.”¹⁹

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 realise that they had the skills to do so and that they applied them successfully during the consultation.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 professional)²

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)²⁵

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

NHS England has published a position statement about language²⁶ (see www.diabetes.org.uk/emotional-health-professionals-guide), which highlights that:

- **Words have impact:** Words can impact positively or negatively on the person with diabetes. The language you use can affect the person’s willingness to confide in you; it can also impact 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 which are equally salient for them, and that they are functioning successfully in their own home/work environment.

- **Words can be judgemental or demotivating:** Many people with diabetes report feeling criticised 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 demoralised and that their efforts are under-valued. The words you choose to use may stay with that person long after you have forgotten the consultation. It is important to acknowledge how challenging diabetes can be.
- **Words can lead to missed opportunities, or create them:** Diabetes is a life-long condition and people will, naturally, have times when diabetes is not their main priority, or when they are struggling with self-management. Labelling 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 impact upon the relationship between the health professional and person with diabetes:** It is best to use words that neutralise any judgement 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 consultations

“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 nurse)²

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 consultation 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.²⁷ People with diabetes and health professionals alike value the assessment and discussion of outcomes, and generally express greater satisfaction with consultations in which this has taken place.^{6,28} Follow-up studies have shown that using questionnaires and discussing the outcomes, leads to reductions in diabetes distress and improvements in HbA1c.⁶

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).

Before using questionnaires in your consultations, 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 their diabetes management 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 realise 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. 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 makes the conversation more personal.

Do something with the results

Screening alone is not enough to improve health outcomes.²⁹ 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.¹⁹

Creating an enabling environment

“I don’t mind discussing sensitive issues. The problem is finding enough privacy.”

(Health professional)²

The room set-up is very important for enabling personal disclosure. Ideally, your consulting 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 or complications, or magazines focused on diets and body image? Perhaps it is better not to have such 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? How is the room set up? 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 diversity

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

(Anonymous)³⁰

In this guide, we refer to people with diabetes from the general adult population but, of course, the UK is a country of diversity. It is beyond the scope of this book to consider the specific needs of every social and cultural group, or the specific approaches they may require. However, this section offers some tips for those working with diverse groups, and signposts to appropriate resources. Guidelines and checklists are less important than ‘a reflective approach that avoids stereotypes and assumptions in providing care that is culturally sensitive and aware’.³¹

Social and cultural factors play an important role in determining:

- why and when people attend healthcare appointments
- the health professional – person with diabetes (‘patient’) relationship
- 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
- 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 minimise 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 consultation. 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.³² Low health literacy is very common – between 43% and 61% of English working age adults routinely do not understand health information³³ 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 judgement or embarrassment.³⁴ 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 consultation – 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 consultation 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 impact on their self-care and health outcomes. Now, imagine having to do this not only for diabetes but for eye screening, foot care and other aspects of healthcare relevant to diabetes.

Some of the tips listed in Box 1.4 will be particularly helpful for people with lower levels of health literacy. These tips include using plain English and anecdotes/ storytelling/visual aids, encouraging questions, repeating key information, and checking understanding (yours and theirs).

Box 1.4

Signs that someone may have low health literacy

Signs that the person is having difficulty understanding and applying health information include:³⁴

- 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
- 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?**'.³⁵ If you choose to do this, be sensitive and tactful in your approach.

Cultural and linguistic diversity

Cultural and linguistic diversity is a broad term referring to country of origin, culture, religion, first language, and other characteristics. Given this, it is impossible to provide specific advice to suit everyone, but here are some broad considerations to reflect on:

- **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. For example, people may have varied:

- understandings of and beliefs about health (e.g. mental health and diabetes)³⁶,
- communication styles (e.g. a preference for written, pictorial, or verbal communication, or a passive or assertive manner)³⁶,
- expectations and preferences for their healthcare (e.g. the expected role of the health professional, a preference for a same-sex health professional, or a preference for traditional cultural remedies over modern western medicines).

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

- **Recognise and adapt to language challenges**

While English is the primary language of over 90% of UK residents,³⁷ 138,000 people living in the UK cannot speak English at all and over 60% of these are women.³⁷ 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 impact on the quality and uptake of care, and physical and mental health outcomes.^{38–40} 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.

See 'Resources' section for information about translating and interpreting services.

- **Cater to individuals' needs and preferences^{31,40}**

A 'one size fits all' approach is not appropriate and does not work.

- **Seek advice and engage other experts**

Familiarise yourself with culturally appropriate services in your local area. 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, counselling, and interpretation for the person with diabetes. They can also provide sociocultural insight for health professionals⁴⁰ – some may specialise in diabetes or mental health.
- Trained and accredited interpreters for help overcoming language barriers^{31,40, 41} and preventing miscommunications and mistakes.⁴² It is advisable to consult guidelines for working with interpreters (see 'Resources' section).

- **Upskill**

Consider participating in accredited cultural awareness or cultural safety training.³⁹

- **Questionnaires**

While several questionnaires have been translated into other languages, their cultural appropriateness may not be guaranteed. Health professionals to exercise caution when administering questionnaires originally developed and validated in English.

Disability

Finally, bear in mind that disabilities (e.g. physical, intellectual, cognitive) may impact on 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 recognising diversity.

Resources for healthcare professionals

Communication

- **The art of empowerment: stories and strategies for diabetes educators**

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. American Diabetes Association. 2005. Available as a PDF in the UK by permission of the authors by emailing Successful Diabetes enquiries@successfuldiabetes.com

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

Description: A chapter providing advice on how to achieve person-centred consultations.

Source: Chapter by Cradock S and Barnard KD in the book by Barnard KD and Lloyd CE eds., Psychology and diabetes care: a practical guide. Springer, London. 2012.

- **The art of communication**

Description: A paper that outlines key skills for communication during general practice consultations.

Source: Warnecke E. The art of communication. Australian Family Physician. 2014;43(3):156-158.

Website: www.racgp.org.au

- **Person-centred practice for long-term conditions: a concise guide to success**

Description: A UK book for health professionals about how to adopt a person-centred approach.

Source: Walker R. e-book, London. 2013.

Website: <http://www.successfuldiabetes.com/working-with-diabetes/books/book-list/item/78-person-centred-practice-for-long-term-conditions-a-concise-guide-to-success>

Cultural diversity

- Zeh, P, Sandhu HK, Cannaby AM, Sturt JA (2012). The impact of culturally competent Diabetes Care interventions for improving diabetes-related outcomes in ethnic minority groups: a systematic review. Diabetic Medicine, 29 (10) 1237 – 1252
- This paper shows that where a culturally competent intervention was used, it had a positive effect. Plus describes the culturally competent assessment.

Translating and Interpreters

- A draft Principles Framework for using interpreters was published by NHS England in 2015. No final document was available at the time of writing www.england.nhs.uk/commissioning/primary-care/primary-care-comm/interpreting/
- NHS Shared Business Services' 'NHS Language Services' offers NHS organisations access to their services

Website: www.nhs-translation.com

Health literacy

- **Improving health literacy for people with diabetes**

Health Literacy and Health Outcomes in Diabetes: A Systematic Review (2013)

Website: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3579965/>

Health Literacy in relation to diabetes is discussed and referenced in this review.

Resources for people with diabetes

Communication

- **Have the conversation with your health professional**

Questions to ask the doctor (general, including mental health)

Description: NHS guidance on what to include in your consultation

Website: <https://www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/questions-to-ask-the-doctor.aspx>

- **Making the most of your consultation (diabetes specific)**

Description: 'SD Tips for Living with Diabetes' A booklet giving helpful tips on a range of diabetes related topics, including 'Consultations – A Survival Guide'

Website: <http://www.successfuldiabetes.com/living-with-diabetes/sd-downloads>

References

1. Whyte WH. Fortune Magazine. 1950.
2. Mosely K, Aslam A, et al. Overcoming barriers to diabetes care: perceived communication issues of healthcare professionals attending a pilot Diabetes UK training programme. *Diabetes Research and Clinical Practice*. 2010;87(2):e11-4.
3. Davies M, Dempster M, et al. Do people with diabetes who need to talk want to talk? *Diabetic Medicine*. 2006;23(8):917-19.
4. Malone A, Dempster M, et al. Providing psychological services for people with diabetes. *Practical Diabetes International*. 2005;22(7):244-8.
5. Hendrieckx C, Bowden J, et al. An audit of psychological well-being in adults with type 1 diabetes. Paper presented at: Australian Diabetes Society and Australian Diabetes Educators Society Annual Scientific Meeting; 2012; Brisbane, Australia.
6. Snoek FJ, Kersch NY, et al. Monitoring of Individual Needs in Diabetes (MIND)-2: follow-up data from the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) MIND study. *Diabetes Care*. 2012;35(11):2128-32.
7. Snoek FJ, Kersch NY, et al. Monitoring of Individual Needs in Diabetes (MIND): baseline data from the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) MIND study. *Diabetes Care*. 2011;34(3):601-3.
8. Pouwer F, Beekman AT, et al. Nurses' recognition and registration of depression, anxiety and diabetes-specific emotional problems in outpatients with diabetes mellitus. *Patient Education and Counseling*. 2006;60(2):235-40.
9. Holt R, Nicolucci A, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2™): cross-national comparisons on barriers and resources for optimal care—healthcare professional perspective. *Diabetic Medicine*. 2013;30(7):789-98.
10. Nicolucci A, Kovacs Burns K, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2™): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabetic Medicine*. 2013;30(7):767-77.
11. Adams K, Cimino JE, et al. Why should I talk about emotion? Communication patterns associated with physician discussion of patient expressions of negative emotion in hospital admission encounters. *Patient Education and Counseling*. 2012;89(1):44-50.
12. Tracy B. 2011 [cited 6 June 2016]. Available from: www.facebook.com/BrianTracyPage/posts/10150364248348460.
13. Stuckey HL, Vallis M, et al. 'I do my best to listen to patients': Qualitative insights into DAWN2 (diabetes psychosocial care from the perspective of health care professionals in the second Diabetes Attitudes, Wishes and Needs Study). *Clinical Therapeutics*. 2015;37(9):1986-98.
14. Fisher L, Gonzalez J, et al. The confusing tale of depression and distress in patients with diabetes: a call for greater clarity and precision. *Diabetic Medicine*. 2014;31(7):764-72.
15. Dennick K, Sturt J, Hessler D, Purssell E, Hunter B, Oliver J, Fisher L. High rates of elevated diabetes distress in research populations: a systematic review and meta-analysis. *International Diabetes Nursing*. 2015 Sep 2;12(3):93-107.
16. Egede LE, Nietert PJ, et al. Depression and all-cause and coronary heart disease mortality among adults with and without diabetes. *Diabetes Care*. 2005;28(3):1339-43.
17. Egede LE, Zheng D, et al. Comorbid depression is associated with increased health care use and expenditures in individuals with diabetes. *Diabetes Care*. 2002;25:464-70.
18. Hofmann M, Köhler B, et al. Depression as a risk factor for mortality in individuals with diabetes: a meta-analysis of prospective studies. *PLoS One*. 2013;8(11):e79809.

19. Davies M. Should diabetes services routinely screen for psychological distress? *Practical Diabetes International*. 2007;24(9):483-6.
20. Browne JL, Ventura A, et al. 'I'm not a druggie, I'm just a diabetic': a qualitative study of stigma from the perspective of adults with type 1 diabetes. *BMJ Open*. 2014;4(7):e005625.
21. Browne JL, Ventura A, et al. 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open*. 2013;3(11):e003384.
22. Thornicroft G, Rose D, et al. Discrimination in health care against people with mental illness. *International Review of Psychiatry*. 2007;19(2):113-22.
23. Barney LJ, Griffiths KM, et al. Exploring the nature of stigmatising beliefs about depression and help-seeking: implications for reducing stigma. *BioMed Central Public Health*. 2009;9(1):61.
24. Hocking B. A life without stigma: a SANE report. South Melbourne: SANE Australia; 2013.
25. Rowling JK. *Harry Potter and the Deathly Hallows*. London: Bloomsbury; 2007.
26. NHSE. Language and Diabetes. <https://www.england.nhs.uk/wp-content/uploads/2018/06/language-matters.pdf> 2018. .
27. Hermanns N, Kulzer B, et al. How to screen for depression and emotional problems in patients with diabetes: comparison of screening characteristics of depression questionnaires, measurement of diabetes-specific emotional problems and standard clinical assessment. *Diabetologia*. 2006;49(3):469-77.
28. Pouwer F, Snoek FJ, et al. Monitoring of psychological well-being in outpatients with diabetes effects on mood, HbA1c, and the patient's evaluation of the quality of diabetes care: a randomized controlled trial. *Diabetes Care*. 2001;24(11):1929-35.
29. Pouwer F, Tack C, et al. Limited effect of screening for depression with written feedback in outpatients with diabetes mellitus: a randomised controlled trial. *Diabetologia*. 2011;54(4):741-8.
30. Quote Investigator. We Don't See Things As They Are, We See Them As We Are, 2014 [cited 6 June 2016]. Available from: www.quoteinvestigator.com/2014/03/09/as-we-are.
31. Furler J, Kokanovic R. Mental health: cultural competence. *Australian Family Physician*. 2010;39(4):206-8.
32. Misra-Hebert AD, Isaacson JH. Overcoming health care disparities via better cross-cultural communication and health literacy. *Cleveland Clinic Journal of Medicine*. 2012;79(2):127-33.
33. Berry J. Does health literacy matter? NHS England 2016. <https://www.england.nhs.uk/blog/jonathan-berry/>.
34. Conn JJ, Silberberg CL, et al. Enhancing your consulting skills – supporting self-management and optimising mental health in people with type 1 diabetes. Canberra: National Diabetes Services Scheme; 2014.
35. Chew L, Bradley K, et al. Brief questions to identify patients with inadequate health literacy. *Family Medicine*. 2004;36(8):588-94.
36. Shaw SJ, Huebner C, et al. The role of culture in health literacy and chronic disease screening and management. *Journal of Immigrant and Minority Health*. 2009;11(6):460-7.
37. Gov UK. English Language Skills. Feb 2018. <https://www.ethnicity-facts-figures.service.gov.uk/british-population/demographics/english-language-skills/latest> (accessed 25 January 2019)
38. van den Muijsenbergh M, van Weel-Baumgarten E, et al. Communication in cross-cultural consultations in primary care in Europe: the case for improvement. The rationale for the RESTORE FP 7 project. *Primary Health Care Research & Development*. 2014;15(2):122-33.
39. Komaric N, Bedford S, et al. Two sides of the coin: patient and provider perceptions of health care delivery to patients from culturally and linguistically diverse backgrounds. *BioMed Central Health Services Research*. 2012;12(1):322.
40. Johnson M, Noble C, et al. Bilingual communicators within the health care setting. *Qualitative Health Research*. 1999;9(3):329-43.

41. Furler J, Kokanovic R, et al. Managing depression among ethnic communities: a qualitative study. *The Annals of Family Medicine*. 2010;8(3):231-6.
42. Bird S. Failure to use an interpreter. *Australian Family Physician*. 2010;39(4):241-2.
- a. Guidance and responsibilities for IAPT are published by the Royal College of Psychiatrists can be found here www.rcpsych.ac.uk/improving-care/ccqi/quality-networks-accreditation/psychological-therapies and examples from the London region can be found at <https://www.healthylondon.org/wp-content/uploads/2017/11/IAPT-LTC-Full-Implementation-Guidance.pdf>

Facing life with diabetes



Key messages

- Living with diabetes involves acquiring new knowledge, and developing skills to self-manage a life-long condition.
- Responses to diagnosis can vary: some people experience a range of negative emotions (e.g. shock, grief, anger, distress, 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, 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. No-one 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 hyperglycaemia.^{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 diabetes)³

“[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 diabetes)⁴

“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 diabetes)¹

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 hyperglycaemia). Sometimes, diagnosis follows a brief period of ill health and hospitalisation 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.

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 diabetes)⁴

“[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 diabetes)¹

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 impacting very little upon 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 realise how diabetes impacts on their life and future. Not acknowledging the need to adopt or change certain self-care behaviours can be a sign of low self-efficacy (i.e. that the person lacks confidence in their ability to make behavioural 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 diabetes)⁵

“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 diabetes)⁶

“I don't think I fully accept that it's [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 diabetes)³

“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 diabetes)⁸

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.

Irrespective 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 in 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 diabetes)¹⁰

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 behavioural) and how to provide appropriate support are included in Chapter 3 and Appendix B.

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 impact on 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 think will be the hardest thing for you in 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 ‘normalise’ the adjustment process and help the person to realise 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’.

If you recognise 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 normalise 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.

Diabetes diagnosis: the start of a life-long relationship with health professionals

For many people, the diagnosis of diabetes is the start of a life-long relationship with health professionals and the healthcare system. Although the time you will spend with the person is minimal, they will value your expertise and guidance when you show genuine respect and empathy (see [Box 2.3](#)).

Remaining supportive will help the person with diabetes realise 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 excerpt 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. The blog is by Renza Scibilia, who lives with Type 1 diabetes.

It illustrates that it is important to use appropriate language and not to trivialise people's diabetes management efforts and/or the challenges they face with ongoing self-care of this life-long 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?'¹¹
- 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, and self-monitoring of blood glucose, dietary changes, physical activity, and foot care. Then, there are the regular health check-ups (e.g. HbA1c checks, blood pressure, and eye screening).¹² 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.¹³ 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.¹⁴
- 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 hypoglycaemic episodes and 40-60 severe hypoglycaemic 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 favourite foods, dealing with well-meaning family/friends who say things like 'just one won't hurt', finding healthy eating advice confusing).
- Many people with diabetes describe it as 'more than a full-time' job.¹⁵ And so it is – but without any pay or holidays, without assurance that your efforts will be rewarded.¹⁶ How would you feel if you were asked to keep doing your job 24/7 for a year, but without holidays and without the guarantee of being paid at the end of the year?

Box 2.4**‘Dear doctor’, excerpt from the Diabetogenic blog**

I frequently give talks about how to get the most out of our healthcare professionals. One of the things I talk about is making sure that we find the healthcare professionals 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 healthcare professional, 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 healthcare professional 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.

Judgement 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 arse!

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 learnt 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 humour a lot to try to deal with what is, at times, a really scary thing to live with. Sometimes you may think that my humour is not particularly appropriate. A lot of the time you won’t find me funny (but for both of our sake, 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 and 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 approach¹⁸ 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; minimise 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-demographical 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:** summarise 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-controlled diabetes is the leading cause of nothing’**¹⁹
- 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 minimising 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, which 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-criticise’ and ‘honour 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,²⁰ 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 the changes that would be 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 realise 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 'road blocks' 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 behaviours. When someone is asking for help to achieve **their** goals, help them to 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 people'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 individualised 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 T Dunning (Ed)

Diabetes Education: Art, Science and Evidence. John Wiley & Sons. Oxford: 2013.

- **The skilled helper**

Description: Now in its tenth 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. Thomson Learning. US: 2013.

- **Motivational Interviewing in Diabetes Care**

Description: A US book based on Motivational Interviewing principles, showing how these can help in consultations with people living with diabetes

Source: Steinberg, MP., Miller, WR. Motivational Interviewing in Diabetes Care. Guilford Press, 2015

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

- **Diabetes UK**

Description: Diabetes UK is the major organisation for support, information and research relating to all types of diabetes mellitus.

Phone: 0345 123 2399

Email: helpline@diabetes.org.uk

Website: www.diabetes.org.uk

- **Peer support for diabetes**

Description: There are various ways of accessing peer support in the UK to share experiences and information with others living with diabetes. See [Appendix A](#) for full listing.

- **Leaflet about peer support for diabetes**

Description: An information leaflet for people with diabetes about peer support opportunities. The leaflet can be downloaded from www.diabetes.org.uk/emotional-health-professionals-guide

Information

There are various opportunities for adults newly diagnosed with Type 1 or Type 2 diabetes and for helping learn about living with diabetes in the long term

- **Diabetes UK (details as above)**

- **Adjusting to Life with Diabetes**

Description: An information leaflet for people with diabetes about peer support opportunities. The leaflet can be downloaded from www.diabetes.org.uk/emotional-health-professionals-guide

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

Description: providing information, support and research for Type 1 Diabetes:

Website: <https://jdrf.org.uk/information-support/newly-diagnosed/>

- **Type 1 Resources**

Description: A collection of resources helpful in all aspects of living with Type 1 diabetes, gathered and monitored by health professionals and people living with diabetes

Website: <https://www.t1resources.uk/home/>

- **Diabetes Research and Wellness Foundation**

Description: an organization that offers support for living well with diabetes and supports education and research

Website: <https://www.drwf.org.uk>

- **Diabetes Stories**

Description: An online collection of interviews with people with diabetes, family members and health professionals, from the 1920s to the 2000s, collected and collated by Oxford University Diabetes Department

Website: <http://www.diabetes-stories.com/>

- **100 Things I wish I'd known about living with diabetes**

Description: A book compiled by Diabetes UK, based on reflections from the experience of people living with diabetes

Source: Diabetes UK

Website: https://www.diabetes.org.uk/how_we_help/community/100-things-book

- **Don't freak out: 10 important things to know when you've been diagnosed with type 2 diabetes (American)**

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.

Website: <https://behavioraldiabetes.org/products/>

References

1. Peel E, Parry O, et al. Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions and views about information provision. *Patient Education and Counseling*. 2004;53(3):269-75.
2. Beeney LJ, Bakry AA, et al. Patient psychological and information needs when the diagnosis is diabetes. *Patient Education and Counseling*. 1996;29:109-16.
3. Wilkinson E, Randhawa G, et al. What's the worry with diabetes? Learning from the experiences of White European and South Asian people with a new diagnosis of diabetes. *Primary Care Diabetes*. 2014;8(3):181-6.
4. Clark M. *Understanding diabetes*. West Sussex: John Wiley & Sons; 2004.
5. Hörnsten Å, Sandström H, et al. Personal understandings of illness among people with type 2 diabetes. *Journal of Advanced Nursing*. 2004;47(2):174-82.
6. Ockleford E, Shaw RL, et al. Education and self-management for people newly diagnosed with type 2 diabetes: a qualitative study of patients' views. *Chronic Illness*. 2008;4(1):28-37.
7. American Diabetes Association. Denial, 2015 [accessed 12 January 2015]. Available from: www.diabetes.org/living-with-diabetes/complications/mental-health/denial.html
8. Gillibrand W, Flynn M. Forced externalization of control in people with diabetes: a qualitative exploratory study. *Journal of Advanced Nursing*. 2001;34(4):501-10.
9. Nicolucci A, Kovacs Burns K, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2): Cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabetic Medicine*. 2013;30:767-77.
10. Kneck Å, Klang B, et al. Learning to live with illness: experiences of persons with recent diagnoses of diabetes mellitus. *Scandinavian Journal of Caring Sciences*. 2011;25(3):558-66.
11. Davies M. Psychological aspects of diabetes management. *Medicine*. 2014;43:57-9.
12. Coyle ME, Francis K, et al. Self-management activities in diabetes care: a systematic review. *Australian Health Review*. 2013;37(4):513-22.
13. Boran SA. Self-care behaviours: systematic reviews. *The Diabetes Educator* 2007;33(6):866-71.
14. Peyrot M, Rubin RR, et al. Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) study. *Diabetic Medicine*. 2005;22(10):1379-85.
15. Hinder S, Greenhalgh T. 'This does my head in'. Ethnographic study of self-management by people with diabetes *BMC Health Services Research* 2012;12:83.
16. Polonsky WH. Diabetes burnout: what to do if you can't take it anymore. *American Diabetes Association*; 1999.
17. Diabetogenic: real life with diabetes. Dear doctor, 2015 [accessed 25 January 2019]. Available from: <https://diabetogenic.wordpress.com/2015/08/07/dear-doctor/>
18. Baile W.F., Buckman R., et al. A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5(4):302-11.
19. Polonsky WH. Engaging the disengaged patient webinar, 2015 [accessed 1 October 2018]. Available from: <https://www.niddk.nih.gov/health-information/professionals/clinical-tools-patient-education-outreach/engaging-disengaged-patient>
20. Lawson VL, Bundy C, et al. The development of personal models of diabetes in the first 2 years after diagnosis: a prospective longitudinal study. *Diabetic Medicine*. 2008;25:482-90.

Diabetes distress



Key messages

- Diabetes distress is the emotional distress resulting from living with diabetes and the burden of relentless daily self-management.
- Severe diabetes distress affects one in four people with type 1 diabetes, one in five people with insulin-treated type 2 diabetes, and one in six people with non-insulin treated type 2 diabetes.
- Greater diabetes distress is associated with sub-optimal diabetes self-management, HbA1c, 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 is 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 HbA1c, optimal HbA1c is not necessarily an indicator of low diabetes distress.

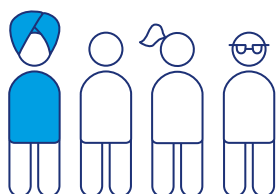


Practice points

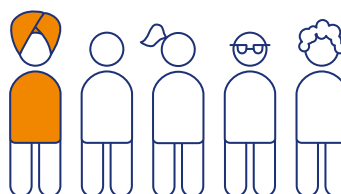
- As diabetes distress is relatively common, and also impacts upon self-care, it is important that every consultation includes opportunity for the person to express how they are feeling about life with diabetes.
- Remain mindful that certain treatment options may increase the burden of diabetes self-management and increase the likelihood of diabetes distress.
- Collaboratively set an agenda for the consultation – 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 undertaken across the world tells us that 1 in 4 people with Type 1 and 1 in 5 people with Type 2 diabetes have high levels of diabetes distress that is likely to be negatively effecting how they manage their diabetes.¹



Type 1 diabetes^b



Type 2 diabetes^b

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.² 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)³ and the financial implications (e.g. insurance and treatment costs) of the condition.⁴

Diabetes distress occurs on a continuum defined by its content and severity.⁴ 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. If left untreated, mild diabetes distress may develop into severe diabetes distress and/or depression (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'.^{5,6} Although there are common stressors irrespective of the type of diabetes, distress can differ by diabetes type (e.g. for Type 1 diabetes more often related to the insulin treatment and hyper/hypoglycaemia, for Type 2 diabetes more often related to social consequences, food restriction, and obesity).⁷

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 recognised mental health conditions, such as depression (see Chapter 6 and Box 6.2).⁴ 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.²

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

- sub-optimal self-management (e.g. reduced physical activity, less healthy eating, not taking medication as recommended, and less frequent self-monitoring of blood glucose)^{8–10}
- elevated HbA1c^{11–15}
- more frequent severe hypoglycaemia^{8,16}
- impaired quality of life.^{9,17}

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).¹⁸ Typically, the individual feels that despite their best efforts, their blood glucose levels are unpredictable and disappointing. This often leads to feeling helpless and disengaged from diabetes management. 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’ (see [Language Matters](#)), while they are actually struggling with the relentlessness of managing a life-long condition.

Signs of diabetes burnout include:

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

People with diabetes burnout understand the importance of diabetes self-management for their future health, but feel unable to take control of their diabetes. If and when someone with diabetes burnout attends their consultation, 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’.¹⁸

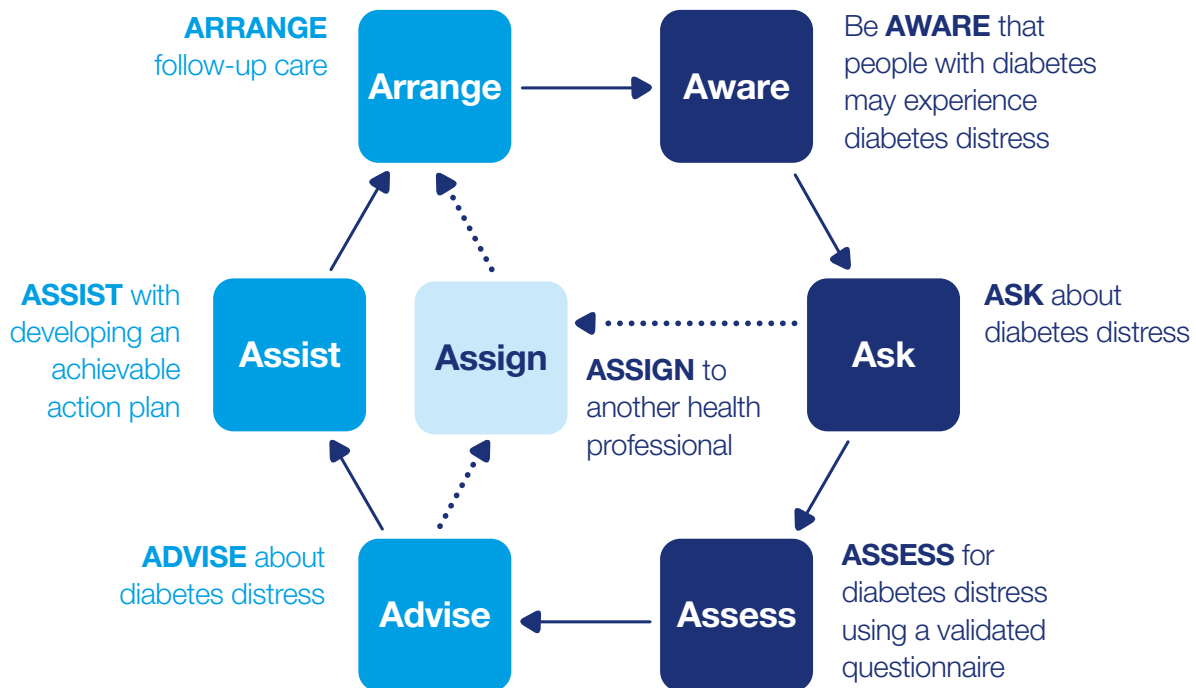
Diabetes burnout can co-occur with depression (see [Chapter 6](#)), anxiety (see [Chapter 7](#)), and negative mood. In contrast to diabetes distress, very little research has been conducted specifically about diabetes burnout.

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.

7 As 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-centred 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:

- sub-optimal HbA1c 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, homelessness)
- impaired relationships with health professionals, partners, family or friends
- appearing passive or aggressive during consultations.



Even if HbA1c 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 impacting on other areas of their life (e.g. social activities, 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-centred consultation, 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 find living with diabetes quite challenging'**. This 'normalises' diabetes distress.

There are many ways you can ask about diabetes distress; 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?'¹⁹
- 'What are your greatest concerns about your diabetes?'¹⁹
- '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, behavioural or social) that they are facing
- 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 consultation. 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 behaviours and worsen diabetes distress. Therefore, at every consultation, it is always a good idea to ask the person how they are going 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 to 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 consultation 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 [Chapter 1](#).

ASSESS

Validated questionnaire

The Problem Areas In Diabetes (PAID) is a 20-item questionnaire, widely used to assess diabetes distress.²⁰ A copy is included in this chapter. 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.⁶ 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.

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

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

Another widely used questionnaire for diabetes distress is the Diabetes Distress Scale (DSS), which has 17 items.²¹ A new version of the DDS specifically designed for people with Type 1 diabetes (T1-DDS) has been validated recently in the USA and Canada.²²



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

Additional considerations

No diabetes distress – what else might be going on?

- 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 consultations.

- 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)²³ could be informative in this instance, as the person may be experiencing other life stressors that are causing general distress and impacting on their diabetes self-management and outcomes. Explaining and normalising 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, 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.
- 'Normalise' negative emotions about diabetes.

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 general practitioner (GP) rather than with a mental health specialist.²⁴
- As diabetes distress is so common and intertwined with diabetes management,⁴ it is best addressed by a diabetes health professional (or the GP 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.
- 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)
 - 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
 - discuss what they want to gain from the referral, as this will influence to whom the referral will be made.

- 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 about being 'a failure' (see Language Matters). 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).

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 B. The strategies are based on clinical experience and expertise. 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 (see ASSESS) is useful for this purpose. If multiple stressors are identified, prioritise 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, the diabetes outcomes (e.g. high blood glucose levels) leading to these feelings, or whether it is related to how diabetes impacts on 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 personalised 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 answers on the PAID, 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 consultation.** 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 consultation with you or someone else in 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 the routine consultation, if the person shows no improvement it may be necessary to:

- reconsider referring the person to a mental health professional
- 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 diabetes specialist health professional for difficulties with diabetes management and support
- **a mental health professional** such as IAPT, a psychologist or psychiatrist (preferably with an understanding of diabetes) for stress management or if other emotional problems such as depression (see Chapter 6) or 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 behavioural therapy, motivational interviewing and brief solution-focused therapy have been successfully applied in diabetes.

These health professionals can be accessed via your local Improving Access to Psychological Therapies service (IAPT) by you, by the person self-referring or by a GP referral.

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 involved in their ongoing care
- 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, text or email support may be a practical and useful way to provide support in addition to face-to-face appointments or text or email support is valued.²⁵

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 the PAID scale routinely 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 follow-up contacts, 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 specialist nurse 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



Elizabeth

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 Brown GP

Be AWARE

Andrew is aware that UK and international guidelines recommend assessment for diabetes distress in people with Type 2 diabetes. He invites Elizabeth to complete the PAID while she is waiting for her consultation.

ASK and ASSESS

When Elizabeth hands over the completed questionnaire, Andrew notices immediately that 12 of 20 items have scores of three and four. It is clear that Elizabeth 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 realise she was struggling so much. Her medical results had been improving.

He thanks Elizabeth for completing the questionnaire and asks ‘How was it for you to answer all these questions?’ Elizabeth responds, ‘Well, it does not 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 blood test results; and Elizabeth agrees.

The high PAID scores are mostly related to the emotional impact of living with diabetes and difficulties with diabetes management. Elizabeth confirms that, indeed, these are the most important problems she is experiencing at the moment. Andrew asks Elizabeth to tell him a bit more about these difficulties. Elizabeth responds, ‘It is so hard for me to control what I eat, to take all these tablets 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 Elizabeth 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?’ Elizabeth tells him that her husband and friends are very supportive, and that having her grandchildren around makes her feel better too.

Andrew acknowledges Elizabeth’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. Elizabeth 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 Elizabeth that it is not her fault that she developed diabetes – weight is only one of many reasons people get Type 2 diabetes. Elizabeth 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. Elizabeth says she has not thought about it in that way, but that he is probably right. Andrew summarises the different issues that Elizabeth has described to him and he also mentions the support she gets from her husband. He checks with Elizabeth which of the difficulties she has raised she would like to address first. Elizabeth 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 Elizabeth would like to talk to a specialist diabetes dietitian to help her find an eating plan that is more achievable and sustainable – a healthy lifestyle change, rather than a 'diet'. Elizabeth agrees that she would like to try this and that Andrew may write her a referral to a dietitian.

ARRANGE

Elizabeth feels understood by Andrew; the conversation has helped her to feel a little bit less stressed about her diabetes. She feels positive about the plan they have made and looks forward to her appointment with the dietitian. 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 her 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 HbA1c 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 (Diabetes Specialist Nurse)

Be AWARE

The staff at the diabetes clinic that John attends are trialling diabetes distress monitoring as a part of their routine care. The receptionist is asking all people with diabetes to complete the Problem Areas In Diabetes (PAID) questionnaire while waiting to see their health professional. She invites John to complete the questionnaire and explains that Sarah will go through his responses with him during the consultation. 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 his diabetes was diagnosed, had not been aware of John's difficulties until now. John has never mentioned a problem and, since he began using a pump, his HbA1c has always been in 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 really 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 PAID responses. He has scored most of the items a '1' or '2' indicating that they are only a minor or moderate problem for him. Sarah notes that he has scored a few items with '4', indicating they are serious problems for him. These problems were:

- not 'accepting' diabetes
- feeling 'burned out' by the constant effort needed to manage diabetes
- feeling overwhelmed by diabetes
- feeling that diabetes is taking up too much mental and physical energy every day
- worrying about low blood glucose reactions.

These responses, in combination with John's comments, give her a good understanding

of how he is feeling. His total score indicates that he is just below the threshold for severe diabetes distress. The PAID scores give Sarah a baseline level against which to compare future scores as they work to reduce his distress.

burden others with his worries, as there was no time to address this today.

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 PAID, they will take this up in the next consultation.

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 talk about how he feels about continuing with the pump. Sarah also makes a note to talk with John about not wanting to

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

© Joslin Diabetes Center, 1999 (www.joslin.org). All rights reserved.

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 Problem Areas In Diabetes (PAID) scale²⁰ is a well-validated, psychometrically robust questionnaire with 20 items. It is sometimes referred to as the PAID-20, to distinguish it from the five-item (PAID-5) and one-item (PAID-1) short forms.²⁶

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 consultations' (Chapter 1).

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.⁶
- Individual items scored 3 or 4: moderate to severe distress;²⁷ to be discussed during the consultation following completion of the questionnaire.

Resources

For health professionals

Peer-reviewed literature

- **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

- **Problem-solving skills**

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*. The National Diabetes Services Scheme and Australian Diabetes Society. Canberra, 2014:58-65.

Website: www.diabetessociety.com.au

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

- **Diabetes UK**

Diabetes UK is the major organisation for support, including emotional and peer support, information and research relating to diabetes.

Phone: 0345 123 2399

Email: helpline@diabetes.org.uk

Website: www.diabetes.org.uk

- **Peer support for diabetes**

There are various ways of accessing peer support in the UK to share experiences and information with others living with diabetes. See [Appendix A](#).

- **Juvenile Diabetes Research Foundation (JDRF) (for Type 1 diabetes)**

Description: Pages to help with emotional support and reducing diabetes related distress for Type 1 diabetes, including links to many other organisations who might help

Source: JDRF

Website: <https://jdrf.org.uk/information-support/living-with-type-1-diabetes/health-and-wellness/emotional-wellbeing/>

Information

- **Diabetes distress**

An information leaflet to accompany this guide about diabetes distress. The leaflet includes suggestions that the person may try, in order to reduce their distress, and offers suggestions for support and additional information. The leaflet can be downloaded from

www.diabetes.org.uk/emotional-health-professionals-guide

- **Diabetes and Mood Information**

Prescription:

Diabetes UK's information for people with diabetes about how it can affect your mood, and some ways to cope.

Website: <https://www.diabetes.org.uk/resources-s3/2018-02/Diabetes%20UK%20Information%20Prescription%20Mood.pdf>

- **Diabetes UK: Emotional Wellbeing**

Pages providing information and sources of emotional support for reducing diabetes related distress for anyone with diabetes

Source: Diabetes UK

Website: <https://www.diabetes.org.uk/guide-to-diabetes/life-with-diabetes/emotional-issues>

- **Diabetes and Wellbeing: Managing the psychological and Emotional Challenges of Diabetes Types 1 and 2**

This book covers all aspects of diabetes related distress and offers practical strategies to cope

Website: <https://www.wiley.com/en-gb/Diabetes+and+Wellbeing:+Managing+the+Psychological+and+Emotional+Challenges+of+Diabetes+Types+1+and+2-p-9781119967187>

- **Diabetes burnout: what to do when you can't take it anymore**

This book combines real-life stories of people with diabetes, with 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 Behavioral Diabetes Institute website and from online booksellers in the UK

Polonsky W, 1999, American Diabetes Association, ISBN: 1-58040-003-7.

Website: https://www.amazon.co.uk/Diabetes-Burnout-Anymore-Preventing-Surviving/dp/1580400337/ref=sr_1_1?ie=UTF8&qid=1548671908&sr=8-1&keywords=diabetes+burnout

References

1. Dennick K, Sturt J, Hessler D, Purssell E, Hunter B, Oliver J, Fisher L. High rates of elevated diabetes distress in research populations: A systematic review and meta-analysis. *International Diabetes Nursing*. 2016 Jul 21:1-5.
2. Gonzalez JS, Fisher L, et al. Depression in diabetes: have we been missing something important? *Diabetes Care*. 2011;34(11):2488.
3. Polonsky WH, Fisher L, et al. Assessing psychosocial distress in diabetes development of the Diabetes Distress Scale. *Diabetes Care*. 2005;28(3):626-31.
4. Fisher L, Gonzalez JS, et al. The confusing tale of depression and distress in patients with diabetes: a call for greater clarity and precision. *Diabetic Medicine*. 2014;31(7):764-72.
5. Delahanty L, Grant R, et al. Association of diabetes-related emotional distress with diabetes treatment in primary care patients with type 2 diabetes. *Diabetic Medicine*. 2007;24(1):48-54.
6. Snoek FJ, Kersch NYA, et al. Monitoring of Individual Needs in Diabetes (MIND): baseline data from the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) MIND study. *Diabetes Care*. 2011;34(3):601-3.
7. Sturt J, Dennick K, et al. The detection and management of diabetes distress in people with type 1 diabetes. *Current Diabetes Reports*. 2015;15(11):1-14.
8. Snoek FJ, Pouwer F, et al. Diabetes-related emotional distress in Dutch and US diabetic patients: cross-cultural validity of the problem areas in diabetes scale. *Diabetes Care*. 2000;23(9): 1305-9.
9. Fisher L, Mullan JT, et al. Predicting diabetes distress in patients with type 2 diabetes: a longitudinal study. *Diabetic Medicine*. 2009;26(6):622-7.
10. Ting RZ, Nan H, et al. Diabetes-related distress and physical and psychological health in Chinese type 2 diabetic patients. *Diabetes Care*. 2011;34(5):1094-6.
11. Weinger K, Jacobson AM. Psychosocial and quality of life correlates of glycemic control during intensive treatment of type 1 diabetes. *Patient Education and Counseling*. 2001;42(2):123-31.
12. van der Ven NC, Lubach CH, et al. Cognitive behavioural group training (CBGT) for patients with type 1 diabetes in persistent poor glycaemic control: who do we reach? *Patient Education and Counseling*. 2005;56(3):313-22.
13. Fisher L, Mullan JT, et al. Diabetes distress but not clinical depression or depressive symptoms is associated with glycemic control in both cross-sectional and longitudinal analyses. *Diabetes Care*. 2010;33(1):23-8.
14. Van Bastelaar K, Pouwer F, et al. Diabetes-specific emotional distress mediates the association between depressive symptoms and glycaemic control in type 1 and type 2 diabetes. *Diabetic Medicine*. 2010;27(7): 798-803.
15. Reddy J, Wilhelm K, et al. Putting PAID to diabetes-related distress: the potential utility of the Problem Areas In Diabetes (PAID) scale in patients with diabetes. *Psychosomatics*. 2013;54(1):44-51.
16. Hendrieckx C, Halliday JA, et al. Severe hypoglycaemia and its association with psychological well-being in Australian adults with type 1 diabetes attending specialist tertiary clinics. *Diabetes Research and Clinical Practice*. 2014;103(3):430-6.
17. Balfe M, Doyle F, et al. What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. *BMC Endocrine Disorders*. 2013;13(1):25.
18. Polonsky WH. *Diabetes burnout: what to do when you can't take it anymore*. Virginia, USA: American Diabetes Association; 1999.
19. Anderson B, Funnell M. *The art of empowerment – stories and strategies for diabetes educators*. Virginia, USA: American Diabetes Association; 2000.

20. Polonsky WH, Anderson BJ, et al. Assessment of diabetes-related distress. *Diabetes Care*. 1995;18(6):754-60.
21. Fisher L, Glasgow RE, et al. Development of a brief diabetes distress screening instrument. *Annals of Family Medicine*. 2008;6(3):246-52.
22. Fisher L, Polonsky WH, et al. Understanding the sources of diabetes distress in adults with type 1 diabetes. *Journal of Diabetes and its Complications*. 2015;29(4):572-7.
23. Kessler RC, Andrews G, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine*. 2002;32(6):959-76.
24. Davies M, Dempster M, et al. Do people with diabetes who need to talk want to talk? *Diabetic Medicine*. 2006;23(8):917-9.
25. Griffiths F, Bryce C, Cave J, Dritsaki M, Fraser J, Hamilton K, Caroline H, Ignatowicz A, Kim SW, Kimani P, Madan J, Anne-Marie S, Sujan M, Sturt J. Timely digital patient-clinician communication in specialist NHS clinical services serving young people: findings from a mixed methods study (The LYNC study). *J Med Internet Res* 2017. April. 19 (4).
26. McGuire BE, Morrison TG, et al. Short-form measures of diabetes-related emotional distress: The Problem Areas In Diabetes Scale (PAID)-5 and PAID-1. *Diabetologia*. 2010;53(1):66-9.
27. Snoek FJ, Kersch NYA, et al. Monitoring of individual needs in diabetes (MIND)-2: follow-up data from the cross-national diabetes attitudes, wishes, and needs (DAWN) MIND study. *Diabetes Care*. 2012;35(11):2128-3

Fear of hypoglycaemia (and other diabetes-specific fears)



Key messages

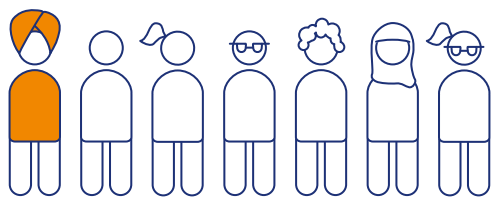
- This chapter focuses mainly on fear of hypoglycaemia. Other diabetes-specific fears (worries about complications, and fear of hyperglycaemia and needles) are briefly described. Fear of hypoglycaemia refers to extreme fear that impacts on quality of life and diabetes outcomes, which differs from an appropriate level of concern about hypoglycaemia.
- Fear of hypoglycaemia is a specific and extreme fear evoked by the risk and/or occurrence of low blood glucose levels.
- Fear of hypoglycaemia affects one in seven people with type 1 diabetes or type 2 diabetes. These fears can also affect family members.
- Fear of hypoglycaemia is associated with impaired quality of life and emotional well-being, sub-optimal diabetes self-management and HbA1c, and more diabetes-related complications and symptoms.
- The Hypoglycaemia Fear Survey-II Worry scale (HFS-II W) is useful for assessing fear of hypoglycaemia and to guide conversations about fears.
- Psycho-educational interventions are effective for reducing fear of hypoglycaemia.
- People with diabetes and their families often have limited knowledge about hypoglycaemia beyond 'survival skills', which may lead to fear of hypoglycaemia.
- People with diabetes may also experience other types of diabetes-specific fears, including fear of hyperglycaemia, diabetes-related complications, and injections/needles.



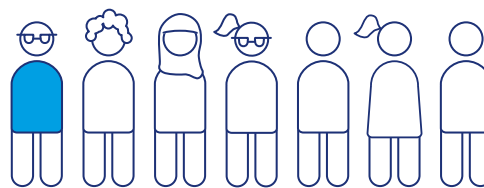
Practice points

- Acknowledge that fear is a normal response to a threat (e.g. hypoglycaemia) and that a certain level of fear is adaptive (e.g. keeping the person alert for symptoms or motivated for self-management), but 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 hypoglycaemia in the absence of actual hypoglycaemia and irrespective of their HbA1c.
- Remain mindful that people may be reluctant to talk about their fear (or experience) of hypoglycaemia with a health professional (e.g. fearing loss of driver licence).

How common is fear of hypoglycaemia?



Type 1 diabetes^b



Type 2 diabetes^b

What is fear of hypoglycaemia?

Fear of hypoglycaemia is a specific and extreme fear evoked by the risk and/or occurrence of hypoglycaemia (low blood glucose).¹ Hypoglycaemia is a side-effect of glucose-lowering medications (e.g. insulin, 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 hypoglycaemia (a very low blood glucose level, requiring the assistance of another person to treat it). Also, hypoglycaemia can lead to a 'vicious cycle' of recurrent hypoglycaemic episodes. Unsurprisingly, many people with diabetes worry about having hypoglycaemia.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 hypoglycaemia is more pronounced in those with a history of severe hypoglycaemia^c (often complicated by loss of consciousness or hospitalisation, or affecting work, or nocturnal),⁶⁻¹² or who have impaired awareness of hypoglycaemia.⁷

In adults with type 2 diabetes, fear of hypoglycaemia is greater in those using insulin compared to those using sulfonylureas,¹³ which can also increase the risk of hypoglycaemia. As the prevalence of severe hypoglycaemia in adults with type 2 diabetes using insulin for more than five years^d is very similar to adults with type 1 diabetes,¹⁴ they share the same concerns

about hypoglycaemia. In those using oral agents, anticipation of problematic hypoglycaemia can be a psychological barrier to insulin initiation (see Chapter 5).

Being concerned about hypoglycaemia is both rational and adaptive, as it keeps a person attentive and responsive to hypoglycaemic 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. It can also affect the quality of life of family members (e.g. with sleep disturbances or worrying about the person's safety when alone).¹⁵ The absence of concerns about hypoglycaemia is discussed in Box 4.1.



Although the focus of this chapter is on extreme fear of hypoglycaemia, other diabetes-specific fears are discussed briefly: fear of needles, injections and finger pricks (see Box 4.2), extreme concern about hyperglycaemia (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 hypoglycaemia. Striving to maintain HbA1c within target while avoiding hypoglycaemia is challenging, and understandably may lead to high levels of fear of hypoglycaemia.²⁰

Fear of hypoglycaemia may develop for many reasons:

- Limited understanding of hypoglycaemia and skills in preventing, recognising, and treating hypoglycaemia can cause more frequent and severe hypoglycaemia episodes, which can evoke fear of hypoglycaemia.
- Awareness of hypoglycaemic 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 recognise 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 hypoglycaemic episode – especially one complicated by loss of consciousness or hospitalisation, or happening while asleep – can make people fear another episode. One severe hypoglycaemic event, as well as recurrent mild episodes, can trigger fear of hypoglycaemia.²¹
- Certain personality traits, for example neuroticism (type 1 diabetes),²² high trait anxiety, and general fear (type 1 and type 2 diabetes),^{9,10} are associated with fear of hypoglycaemia; this relationship is most likely bi-directional.⁶ A person with trait anxiety may be distracted and miss out on recognising hypoglycaemic symptoms, increasing their risk of a low blood glucose level. Conversely, the experience of recurrent severe hypoglycaemia may induce fear and anxiety in people who were not previously anxious.²³
- The autonomic symptoms of hypoglycaemia (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 behaviours' to avoid hypoglycaemia and thus reduce their fear. The most common behavioural strategies include reducing insulin doses, omitting injections, or snacking continually to maintain higher blood glucose levels; this may lead to a higher HbA1c.^{21,23} Over time these behaviours 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 hypoglycaemia is associated with:

- impaired quality of life and emotional well-being^{23,24}
- reduced engagement with diabetes management²⁴⁻²⁶
- impaired diabetes outcomes.^{25,27}

Box 4.1

An absence of fear can also be a ‘problem’

People who have impaired awareness of hypoglycaemic symptoms have a six-fold higher risk of severe hypoglycaemic events.¹⁶ Qualitative studies revealed that some of these people are not concerned about their loss of awareness and, therefore, do not appear to fear hypoglycaemia.^{17,18} Beliefs underlying this lack of concern include:

- normalising impaired awareness of hypoglycaemia: loss of awareness and hypoglycaemia 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
- minimising the consequences of impaired awareness of hypoglycaemia: they believe they function well even when their glucose level is below 3.0 mmol/L
- 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

- overestimating the risk and impact of hyperglycaemia: responses emphasise significant anxiety about developing long-term complications and extreme behavioural responses to high blood glucose levels.

These beliefs and attitudes are likely to prevent people with diabetes from being motivated to regain awareness or minimise severe hypoglycaemic events.¹⁷ 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 hypoglycaemia and/or the ones who have to manage a severe hypoglycaemic 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 minimise 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 have an impact on:¹⁹

- diabetes management (e.g. by reducing the number of injections or blood glucose checks)
- diabetes outcomes (e.g. elevated HbA1c, greater risk of long-term diabetes complications)
- emotional well-being (e.g. impaired general well-being, diabetes distress).

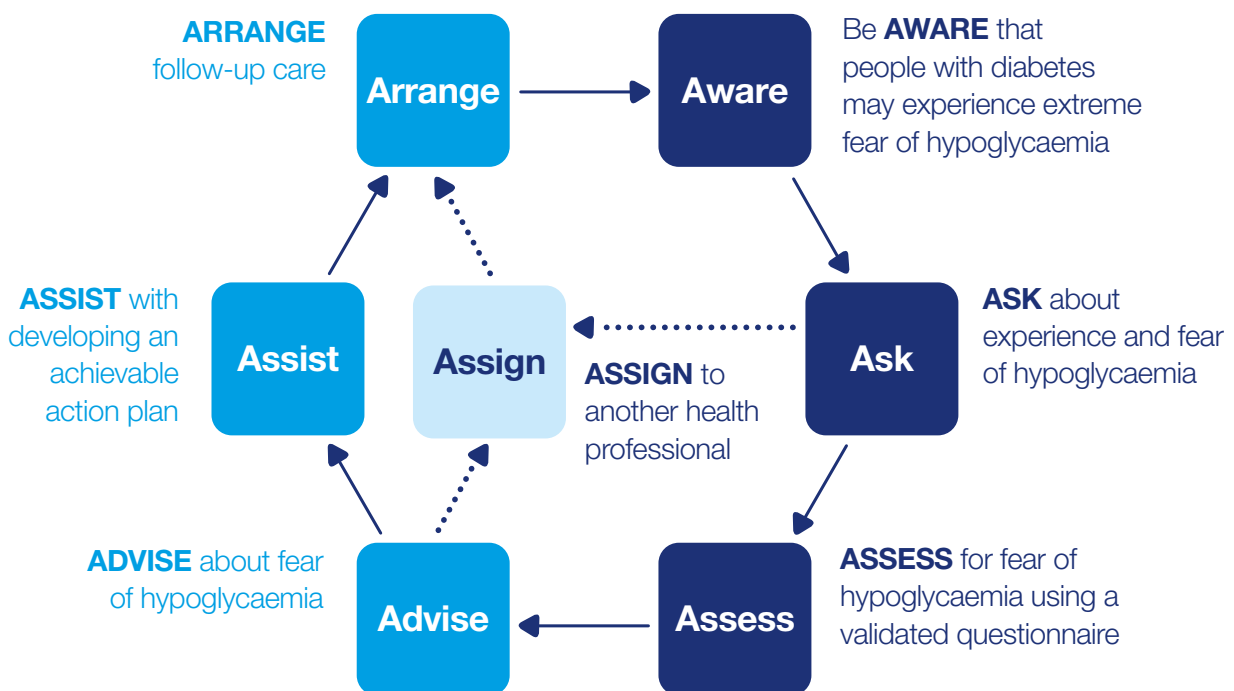
Explore the causes of the person’s fear – this will help to inform the action plan. Strategies to reduce the fear may include: diabetes education, behavioural therapy, desensitisation or distraction, and relaxation.

7 As model: Fear of hypoglycaemia

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

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



How can I identify fear of hypoglycaemia?

Be AWARE

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

- ‘over-compensatory behaviours’ (e.g. taking less insulin than needed or frequent snacking)
- ‘avoidance behaviours’ (e.g. limiting physical or social activities, avoiding being alone or situations in which hypoglycaemia may be more likely)
- acceptance of persistently high blood glucose levels

- excessive daily blood glucose checks
- not implementing ‘agreed’ treatment changes to lower blood glucose levels.



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

ASK

Hypoglycaemia 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 hypoglycaemia at every consultation. If this conversation reveals or the person exhibits signs that they fear hypoglycaemia (see **AWARE**), explore this further with them.

As fear of hypoglycaemia 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

hypoglycaemia (hypos), to explore frequency and severity, how they manage a hypoglycaemic 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 hypoglycaemia?
 - Did they access health services (e.g. ambulance, emergency room, 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 hypoglycaemia, and at what level they usually recognise symptoms.
 - Explore how they identified hypoglycaemia (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, physical activity; or heat, illness, stress, alcohol).

- ‘How did you react to this hypo?’
 - Explore both behavioural and emotional reactions.
 - Check for inappropriate behaviours e.g. delaying treatment or using ineffective foods/drinks as ‘hypoglycaemia treatments’).
 - Check for psychological barriers (e.g. feeling embarrassed or criticised when taking a sugary food/drink in the presence of others or in public places).
 - Ask whether they reduced their insulin to avoid future hypoglycaemia.
- ‘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 hypoglycaemia, this does not necessarily mean that they have no fear of hypoglycaemia. Ask the following questions regardless of the person’s responses above.

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

- ‘People with diabetes using [insulin/tablets (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 hypoglycaemia.
 - If the person is highly concerned, explore whether it impacts on 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 behaviours, in a sensitive and non-judgemental way:

- ‘Some people take less insulin because they are worried about having a hypo. Are there times 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 hypoglycaemia, as it may be impacting on 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 hypoglycaemia because of:

- concerns about losing their driver’s licence or their job
- the associated stigma – losing control as a result of a hypoglycaemic 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 hypoglycaemia (particularly if they have lived with diabetes for many years)
- an unrealistic blood glucose target range they may have set for themselves.

If there is an indication that the person experiences fear of hypoglycaemia, 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 consultation 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 [Chapter 1](#).

ASSESS

Validated questionnaire

The Hypoglycaemia Fear Survey-version II Worry scale (HFS-II W)²⁸ is an 18-item questionnaire for people with type 1 diabetes or those with type 2 diabetes using insulin. It is the most widely used questionnaire to assess fear of hypoglycaemia. 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 hypoglycaemia. 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 hypoglycaemia 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 behaviours the person may use to avoid hypoglycaemia (e.g. keep blood glucose at a higher level). This provides insights into the person’s acceptance of hyperglycaemia in order to cope with their fear of hypoglycaemia.

Additional considerations

- **Is the fear a sign of post-traumatic stress disorder?** If a person develops fear of hypoglycaemia after a traumatic hypoglycaemic 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 hypoglycaemia?

ADVISE

Now that you have identified that the person has fear of hypoglycaemia, 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 items 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 hypoglycaemia.
- Explain that ‘fear of hypoglycaemia’ is a normal response to a threat, and a certain amount of fear is okay – because it will help to keep

them alert for hypoglycaemic 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 hypoglycaemia).
- Explain:
 - that hypoglycaemia is the result of an imbalance between insulin, carbohydrate intake (including alcohol) and physical activity
 - that not every person with diabetes will experience severe hypoglycaemia (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 hypoglycaemia without delay
 - the mechanisms underlying hypoglycaemic symptoms (e.g. counter-regulation and neuroglycopenia), if it seems helpful for the person.
- Acknowledge that frequent mild (self-treated) hypoglycaemic episodes may be as disruptive as one severe hypoglycaemic episode.
- Indicate that you recognise that the person may choose to keep their blood glucose levels in a higher range to avoid hypoglycaemia in general or in specific situations. However, if this behaviour 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 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 general practitioner (GP) rather than with a mental health specialist.²⁹
- As fear of hypoglycaemia is intertwined with diabetes management, it is best addressed by a diabetes health professional or GP (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.²⁰
- 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 hypoglycaemia
 - the severity of the fear of hypoglycaemia, 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 hypoglycaemic episode)
 - whether other life stressors co-occur
 - 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
 - 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 hypoglycaemia 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 hypoglycaemia 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 hypoglycaemia management^e

- Effective and timely treatment of hypoglycaemia is crucial because of the small window of opportunity to respond before awareness and judgement are compromised.
- Review the person's knowledge about recognising the symptoms of hypoglycaemia and how to treat it. Verify that they understand:
 - Not to delay treatment, and to treat with appropriate food/drinks. Explore their barriers to hypoglycaemic treatment³⁰ (e.g. feeling embarrassed when eating in front of others, dislike of recommended food), and talk about strategies to overcome these barriers.
 - The external cues (e.g. the interplay between insulin, food, physical activity, alcohol).
 - How to recognise various internal symptoms: physical, cognitive, and emotional. Over the years people with diabetes often rely on one or two hypoglycaemic 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, cognitive impairment). Many people with diabetes and their families are not aware how lack of glucose (e.g. below 3mmol/L) can affect the brain.
 - That reduced awareness of hypoglycaemic symptoms can limit their ability to treat hypoglycaemia.

- That hypoglycaemic episodes can be asymptomatic and treatment should therefore be based on a blood glucose reading, not on perceived symptoms.
- Provide additional education on hypoglycaemia management to fill identified knowledge gaps, enhance skills and restore confidence:
 - Suggest that they keep a record of their hypoglycaemic episodes (e.g. glucose readings below 4mmol/L) for two weeks noting:³¹
 - 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)
 - the actions taken.
- 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 hypoglycaemic 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 hypoglycaemia.
- If the person's partner/family member worries excessively about hypoglycaemia, suggest that they join the person with diabetes at the next consultation. At the consultation, talk with the partner/family member about the causes of their worry, and how they can support the person with diabetes (and vice versa).

Use the recorded information as a learning opportunity, to review their personal reliable hypoglycaemic 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 hypoglycaemic episodes.
- Support the person to build confidence and assertiveness to respond/act immediately to low blood glucose or hypoglycaemic 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).



Older people may have cognitive impairment, which makes them more vulnerable to not recognising hypoglycaemic symptoms. In older people, hypoglycaemia symptoms become less specific (e.g. feeling unwell or dizzy) and some are similar to signs of dementia (e.g. agitation, confusion).³² Furthermore, recurrent hypoglycaemia 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 hypoglycaemic episode they may be more likely to experience fractures.³² Guidelines for hypoglycaemia management in older people can be found in 'The International Diabetes Federation Managing Older People with Type 2 Diabetes Global Guideline'³³.



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 **hyperglycaemia** (see Box 4.3) more than **hypoglycaemia**, as this may be a barrier to making changes to avoid hypoglycaemia.

Focusing on fear management^f

- 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
 - the kind of support they need from you or others.
- If the person lives alone and this is causing fear:
 - talk about prevention of hypoglycaemia (e.g. frequent blood glucose checks, immediate treatment)
 - discuss whether the person would find it helpful to have someone check on them e.g. neighbours or friends) on a regular basis
 - 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 hypoglycaemia 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 ‘individualised’ target may be higher than the standard targets
 - when and by how much the target range can be reduced
 - ‘experiments’ to bring their blood glucose levels back, gradually, to the recommended targets, (e.g. reduce 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 minimise 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 **hyperglycaemia** will motivate a person with fear of **hypoglycaemia** to reduce their blood glucose levels. Fear of hypoglycaemia is related to the ‘here and now’, not to long-term health risks. For points to consider when supporting someone with fear of hyperglycaemia, see [Box 4.3](#).

Box 4.3

Fear of hyperglycaemia

Little is known about fear of hyperglycaemia (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
- perfectionist tendencies.

A person may respond to their fear of hyperglycaemia by keeping their blood glucose levels (too) low, resulting in an increased risk of recurrent mild or severe hypoglycaemia. In turn, this will increase their likelihood of impaired awareness of hypoglycaemic symptoms (due to recurrent hypoglycaemia), and their risk of adverse consequences of undetected hypoglycaemic episodes (e.g. while driving, or at work). Maintaining blood glucose levels within target while avoiding hypoglycaemia and hyperglycaemia is a challenging task and, fear of hypoglycaemia/ hyperglycaemia can co-exist.^{34,35} Micro-managing blood glucose levels (i.e. continually correcting levels with extra insulin or food) may be a sign of high fear of hypoglycaemia/hyperglycaemia.

Understanding the reason(s) for the person's underlying fear of hyperglycaemia 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 training (e.g. DAFNE).⁹

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 perfectionist 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 recognise 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 unnecessary high levels of fear. People who are very concerned about complications are also more likely to be emotionally distressed, anxious, and depressed.^{34,38}

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 individualised

risk is more effective in adjusting the person's risk perceptions and enhancing engagement in healthy self-care behaviours. 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 individualised, relevant information about the person's actual risk.
- Advise them that diabetes complications:
 - are avoidable and that not every person with diabetes develops complications
 - 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 hypoglycaemia
 - living with hypoglycaemia 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 diabetes specialist nurse**, for hypoglycaemia management, general diabetes education (e.g. to review blood glucose monitoring and injection techniques/ skills), and support
- **an diabetologist** for a review of the current diabetes regimen
- **a structured type 1 diabetes education program**, for example, DAFNE; this group education has been shown to halve the rate of severe hypoglycaemia and improve awareness of hypoglycaemic symptoms^{39,h}
- **a mental health professional** (e.g. a psychologist or psychiatrist, preferably with an understanding of diabetes) if the strategies in [ASSIST](#) do not reduce the person's fear of hypoglycaemia or for post-traumatic stress disorder as a result of an 'unprocessed' traumatic hypoglycaemic experience in the past.

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
- 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 less fearful about hypoglycaemia and is confident in sustaining the behavioural 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 hypoglycaemic episode, to assess both their behavioural 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 hypoglycaemic 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, for example, 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 not, enquire what else is needed.
- If you previously used a questionnaire (e.g. HFS-II W), you could consider using it again to reassess their level of fear of hypoglycaemia.

Case Study



Irena

31-year-old woman, moved from Greece to the UK 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 optimising Irena's diabetes management plan, as her daily blood glucose and HbA1c levels are above target. Irena is very motivated and open to Anna's advice to improve her diabetes outcomes. Irena has participated in an DAFNE 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 DAFNE, 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 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 reactions'
- 'feelings of guilt and anxiety when off track with diabetes management'
- '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. 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's 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 hypo in time

- no longer drives a car, which affects her social life and independence
- avoids going out alone
- 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 hypoglycaemia. Irena has thought about it, but doesn't know where to start. Anna suggests that she contact her GP for advice and possible referral to a psychologist.

ARRANGE

They agree on a time for the next visit. Anna explains that while Irena is consulting the psychologist, they will together work out a diabetes management plan that is both 'safe' and achievable for Irena. In time to come, 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 HbA1c ranges between 41 and 46 mmol/mol (5.9 and 6.4%)

Health professionals: Dr Paul Asher (endocrinologist) and Steven Mazumdar (diabetes specialist nurse)

Be AWARE

Aaron is highly motivated and well-informed about diabetes. But Dr Asher has concerns about Aaron's frequent hypoglycaemic 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 diabetes specialist nurses in the team, to review his diabetes management plan with the aim to reduce the frequency of hypoglycaemia.

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 HbA1c was 6.1%, and my tests were all fine'. Hannah, clearly unhappy with Aaron's reaction, tells Steven about Aaron's severe hypo 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 hypoglycaemia 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 3.7 mmol/L. 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 time, 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 3.5 and 7.5'. He gets annoyed if his blood glucose gets higher than 8.0mmol/L 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 hypo 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 4 mmol/L) and is afraid that he will have an accident while Leila is in the car

- is frustrated that Aaron does not appreciate how worried she feels.

Steven considers whether Aaron may be more anxious about hyperglycaemia than about hypoglycaemia and that maybe he is avoiding blood glucose levels above 8 mmol/L 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 8 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
- 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 hypoglycaemia 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 HbA1c results and annual screenings, is relatively low
- the consequences of living 'on the edge' of hypoglycaemia.

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 hyperglycaemia and Hannah's fear of hypoglycaemia. 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 Hypoglycaemia Fear Survey-II Worry (HFS-II W) scale

Instructions: Below is a list of concerns people with diabetes sometimes have about low blood glucose. Please read each item carefully (do not skip any). Place an X in the box that best describes how often in **the last six months** you **worried** about each item because of low blood glucose.

Because my blood glucose could go low, I worried about...	Never	Rarely	Sometimes	Often	Almost always
1 Not recognising/realising I was having low blood glucose	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2 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
3 Passing out in public	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4 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
5 Having a hypo while alone	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6 Appearing stupid or drunk	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7 Losing control	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8 No one being around to help me during a hypo	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9 Having a hypo while driving	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10 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
11 Getting a bad evaluation or being criticised	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12 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
13 Feeling lightheaded or dizzy	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14 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
15 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
16 Low blood glucose 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
17 Becoming hypoglycaemic during sleep	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18 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

© Gonder-Frederick, L 1994.

The copyright holder/developer has given permission for the questionnaire to be reproduced in this handbook. Readers of the handbook are permitted to reproduce the questionnaire for clinical use and non-commercial research purposes. Readers of the handbook 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 Hypoglycaemia Fear Survey-II Worry scale (HFS-II W) is an 18-item subscale of the HFS-II.²⁸ It was developed to assess specific concerns people with diabetes may have related to their risk of having hypoglycaemia.

How to use the HFS-II Worry scale in clinical practice

Respondents are asked to indicate how much they 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 hypoglycaemia.



For tips about using questionnaires, see 'Using questionnaires to inform consultations' (Chapter 1).

Resources

For health professionals

Peer-reviewed literature

- **A critical review of the literature on fear of hypoglycaemia in diabetes: implications for diabetes management and patient education**

Description: Based on a review of 34 papers, the authors have integrated the findings about fear of hypoglycaemia, predictors and correlates, its impact on behaviour and potential benefits of intervention to reduce fear.

Source: Wild D, von Maltzahn R, et al. Patient Education & Counselling. 2007;68:10-15.

- **The impact of hypoglycaemia on quality of life and related patient-reported outcomes in type 2 diabetes: a narrative review**

Description: This review provides a synthesis of research findings, showing that hypoglycaemia is associated with depressive symptoms and higher anxiety, impaired ability to drive, work and function in people living with type 2 diabetes.

Source: Barendse S, Singh H, et al. Diabetic Medicine. 2012;29:293-302.

- **Managing hypoglycaemia 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 hypoglycaemia.

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

- **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.

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

Description: This systematic review summarises 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.

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

- **Diabetes UK**

Diabetes UK is the major organisation for support, information and research relating to all types of diabetes mellitus.

Phone: 0345 123 2399

Email: helpline@diabetes.org.uk

Website: www.diabetes.org.uk

- **Peer support for diabetes**

There are various ways of accessing peer support in the UK to share experiences and information with others living with diabetes. See [Appendix A](#) for full listing

Information

- **Fear of hypoglycaemia**

Information leaflet for people with diabetes about fear of hypoglycaemia. The leaflet includes suggestions that the person may try in order to reduce their fear, and offers suggestions for support and additional information. This leaflet can be downloaded from www.diabetes.org.uk/emotional-health-professionals-guide

- **Diabetes UK website pages about hypo anxiety**

A webpage explaining some of the causes of hypo related anxiety and practical strategies and techniques to manage this.

Source: Diabetes UK, 2018.

Website: <https://www.diabetes.org.uk/guide-to-diabetes/life-with-diabetes/hypo-anxiety>

- **Dose Adjustment For Normal Eating (DAFNE)**

DAFNE is a five-day structured type 1 diabetes training programme. People attend in small groups, with others who have type 1 diabetes, to learn more about self-managing the condition. Studies have shown that DAFNE can help people with problematic hypos. On average, rates of severe hypo are halved following DAFNE training. Courses are available in many areas of the UK and you can be referred by your diabetes health professional

Website: www.dafne.uk.com

- **Managing Fear, Anxiety and Worry**

A chapter in the book 'Diabetes and Wellbeing' by Dr Jen Nash, explaining fear of hypoglycaemia (and other fears) and giving strategies to cope

Book Reference: Diabetes and Wellbeing: Managing the Psychological and Emotional Challenges of Diabetes Types 1 and 2. 2013. John Wiley and Sons Ltd, Chapter 5, pages 80-108

Website: <https://www.wiley.com/en-gb/Diabetes+and+Wellbeing:+Managing+the+Psychological+and+Emotional+Challenges+of+Diabetes+Types+1+and+2-p-9781119967187>

- **Diabetes burnout: what to do when you can't take it anymore**

Chapter 17 of this book focuses on 'Worrying about hypoglycaemia' (page 286) and Chapter 10 on 'Worrying about long-term complications' (page 159). The book provides easy-to-use strategies to overcome these concerns. It is available for purchase from the Behavioral Diabetes Institute website.

Source: Polonsky W (1999), American Diabetes Association, ISBN: 1-58040-003-7.

Website: www.behavioraldiabetesinstitute.org

References

1. Gonder-Frederick L. Fear of hypoglycemia: a review. *Diabetic Hypoglycemia*. 2013;5(3):3-11.
2. Graveling AJ, Frier BM. Hypoglycaemia: an overview. *Primary Care Diabetes*. 2009;3(3):131-9.
3. Snoek F, Pouwer F, et al. Diabetes-related emotional distress in Dutch and US diabetic patients: cross-cultural validity of the Problem Areas in Diabetes Scale. *Diabetes Care*. 2000;23(9):1305-9.
4. Nicolucci A, Kovacs Burns K, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2™): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabetic Medicine*. 2013;30(7):767-77.
5. Speight J, Browne JL, et al. Diabetes MILES – Australia 2011 survey report. Diabetes Australia: Canberra. 2011.
6. Anderbro T, Gonder-Frederick L, et al. Fear of hypoglycemia: relationship to hypoglycemic risk and psychological factors. *Acta Diabetologica*. 2014;52(3):581-9.
7. Anderbro T, Amsberg S, et al. Fear of hypoglycaemia in adults with type 1 diabetes. *Diabetic Medicine*. 2010;27(10):1151-8.
8. Gold AE, Macleod KM, et al. Frequency of severe hypoglycemia in patients with type 1 diabetes with impaired awareness of hypoglycemia. *Diabetes Care*. 1994;17(7):697-703.
9. Polonsky WH, Davis CL, et al. Correlates of hypoglycemic fear in type 1 and type 2 diabetes mellitus. *Health Psychology*. 1992;11(3):199-202.
10. Irvine AA, Cox D, et al. Fear of hypoglycemia: relationship to physical and psychological symptoms in patients with insulin-dependent diabetes mellitus. *Health Psychology*. 1992;11(2):135-8.
11. Nixon R, Pickup JC. Fear of hypoglycemia in type 1 diabetes managed by continuous subcutaneous insulin infusion: is it associated with poor glycemic control? *Diabetes Technology & Therapeutics*. 2011;13(2):93-8.
12. Tak-Ying Shiu A, Yee-Man Wong R. Fears and worries associated with hypoglycaemia and diabetes complications: perceptions and experience of Hong Kong Chinese clients. *Journal of Advanced Nursing*. 2002;39(2):155-63.
13. Hajós TR, Polonsky WH, et al. Toward defining a cutoff score for elevated fear of hypoglycemia on the Hypoglycemia Fear Survey Worry subscale in patients with type 2 diabetes. *Diabetes Care*. 2014;37(1):102-8.
14. UK Hypoglycaemia Study Group. Risk of hypoglycaemia in types 1 and 2 diabetes: effects of treatment modalities and their duration. *Diabetologia*. 2007;50(6):1140-7.
15. Jørgensen HV, Pedersen-Bjergaard U, et al. The impact of severe hypoglycemia and impaired awareness of hypoglycemia on relatives of patients with type 1 diabetes. *Diabetes Care*. 2003;26(4):1106-9.
16. Graveling AJ, Frier BM. Impaired awareness of hypoglycaemia: a review. *Diabetes & Metabolism*. 2010;36:S64-S74.
17. Rogers HA, de Zoysa N, et al. Patient experience of hypoglycaemia unawareness in type 1 diabetes: are patients appropriately concerned? *Diabetic Medicine*. 2012;29(3):32-7.
18. Speight J, Barendse SM, et al. Cognitive, behavioural and psychological barriers to the prevention of severe hypoglycaemia: A qualitative study of adults with type 1 diabetes. *SAGE Open Medicine*. 2014;2:1-10.
19. Fu AZ, Qiu Y, et al. Impact of fear of insulin or fear of injection on treatment outcomes of patients with diabetes. *Current Medical Research and Opinion*. 2009;25(6):1413-20.
20. Vallis M, Jones A, et al. Managing hypoglycemia in diabetes may be more fear management than glucose management: a practical guide for diabetes care providers. *Current Diabetes Reviews*. 2014;10(6):364-70.
21. Leiter LA, Yale JF, et al. Assessment of the impact of fear of hypoglycemic episodes on glycemic and hypoglycemia management. *Canadian Journal of Diabetes*. 2005;29(3):186-92.

22. Hepburn DA, Deary IJ, et al. Structural equation modeling of symptoms, awareness and fear of hypoglycemia, and personality in patients with insulin-treated diabetes. *Diabetes Care*. 1994;17(11):1273-80.
 23. Wild D, von Maltzahn R, et al. A critical review of the literature on fear of hypoglycemia in diabetes: implications for diabetes management and patient education. *Patient Education and Counseling*. 2007;68(1):10-5.
 24. Barendse S, Singh H, et al. The impact of hypoglycaemia on quality of life and related patient-reported outcomes in type 2 diabetes: a narrative review. *Diabetic Medicine*. 2012;29(3):293-302.
 25. Cox DJ, Irvine A, et al. Fear of hypoglycemia: quantification, validation, and utilization. *Diabetes Care*. 1987;10(5):617-21.
 26. Böhme P, Bertin E, et al. Fear of hypoglycaemia in patients with type 1 diabetes: do patients and diabetologists feel the same way? *Diabetes and Metabolism*. 2012;39(1):63-70.
 27. Tak-Ying Shiu A, Yee-Man Wong R. Fear of hypoglycaemia among insulin-treated Hong Kong Chinese patients: implications for diabetes patient education. *Patient Education and Counseling*. 2000;41(3):251-61.
 28. Gonder-Frederick LA, Schmidt KM, et al. Psychometric properties of the Hypoglycemia Fear Survey-II for adults with type 1 diabetes. *Diabetes Care*. 2011;34(4):801-6.
 29. Davies M, Dempster M, et al. Do people with diabetes who need to talk want to talk? *Diabetic Medicine*. 2006;23(8):917-9.
 30. Lawton J, Rankin D, et al. Self-treating hypoglycaemia: a longitudinal qualitative investigation of the experiences and views of people with type 1 diabetes. *Diabetic Medicine*. 2013;30(2):209-15.
 31. Cox DJ, Gonder-Frederick L, et al. Blood glucose awareness training: what is it, where is it, and where is it going? *Diabetes Spectrum*. 2006;19(1):43-9.
 32. Abdelhafiz AH, Rodríguez-Mañas L, et al. Hypoglycemia in older people – a less well recognized risk factor for frailty. *Aging and Disease*. 2015;6(2):156.
 33. International Diabetes Federation. Managing older people with Type 2 diabetes global guideline. 2013. <https://www.idf.org/e-library/guidelines/78-global-guideline-for-managing-older-people-with-type-2-diabetes.html> (accessed 25 January 2019)
 34. Singh H, Gonder-Frederick L, et al. Assessing hyperglycemia avoidance in people with type 1 diabetes. *Diabetes Management*. 2014;4(3):263-71.
 35. Olsen SE, Åsvold BO, et al. Hypoglycaemia symptoms and impaired awareness of hypoglycaemia in adults with type 1 diabetes: the association with diabetes duration. *Diabetic Medicine*. 2014.
 36. Basco MR. Perfectionism and diabetes care. *Diabetes Spectrum*. 1998;11(1):43-8.
 37. Asimakopoulou KG, Fox C, et al. The impact of different time frames of risk communication on type 2 diabetes patients' understanding and memory for risk of coronary heart disease and stroke. *Diabetic Medicine*. 2008;25(7):811-7.
 38. Meltzer D, Egleston B. How patients with diabetes perceive their risk for major complications. *Effective Clinical Practice*. 2000;3(1):7-15.
 39. Hopkins D, Lawrence IAN, et al. Improved biomedical and psychological outcomes 1 year after structured education in flexible insulin therapy for people with type 1 diabetes the U.K. DAFNE experience. *Diabetes Care*. 2012;35(8):1638-42
- b. Fear of hypoglycaemia is usually assessed with the Hypoglycaemia 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).
 - c. Annual prevalence of severe hypoglycaemia (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
 - d. Annual prevalence of severe hypoglycaemia in adults with type 2 diabetes: 25% who have been using insulin >5 years; 7% using oral medications.^{2,14}

- e. For a comprehensive overview of diabetes management strategies to support people with problematic hypoglycaemia, read the review by Choudhary and colleagues (2015) (see [‘Resources’ section](#))
- f. For a comprehensive description of fear management skills and strategies, read the paper by Vallis and colleagues (2014) (see [‘Resources’ section](#)).
- g. DAFNE (Dose Adjustment For Normal Eating) programme is available in centres across the UK. See [‘Resources’ section](#) for more information.
- h. Formal group interventions have been effective in restoring hypoglycaemic symptom awareness and reducing fear. Read the review by Choudhary and colleagues (2015) for more information (see [‘Resources’ section](#)).

Psychological barriers to insulin use



Key messages

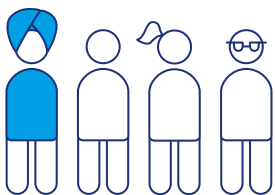
- Psychological barriers to insulin use are the negative thoughts or feelings that people with diabetes may have about starting, using, or intensifying insulin.
- Of those people with type 2 diabetes^a for whom insulin is clinically indicated, around one in four report being 'not at all willing' to start insulin.
- People already using insulin are sometimes reluctant to optimise 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 sub-optimal 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 minimise psychological barriers to insulin. Recommendations based on clinical experience emphasise anticipating and acknowledging psychological barriers, and then working together with the individual to develop strategies to overcome them.



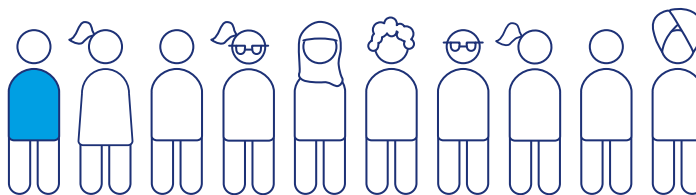
Practice points

- Help people to understand the natural course and progressive nature of type 2 diabetes, and the likelihood that their treatment will change over time. Emphasise that needing insulin does not indicate that they have 'failed'.
- 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 HbA1c has been above target for some time, and there is no sign that they are ready to transition to or intensify insulin.

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; dependence on insulin) and possible side effects (e.g. weight gain, hypoglycaemia)
- 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, 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; social stigma)
- fears about diabetes progression (e.g. insulin as a sign that diabetes is ‘getting worse’, insulin as the ‘last resort’, 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, or among those already using insulin, this could result in misuse

or stopping insulin.³ This has consequences for medical and psychological outcomes, including:¹⁰⁻¹⁴

- glucose levels (including HbA1c) above recommended targets for prolonged periods, leading to increased risk of developing long-term complications
- reduced satisfaction with treatment
- impaired quality of life
- 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?

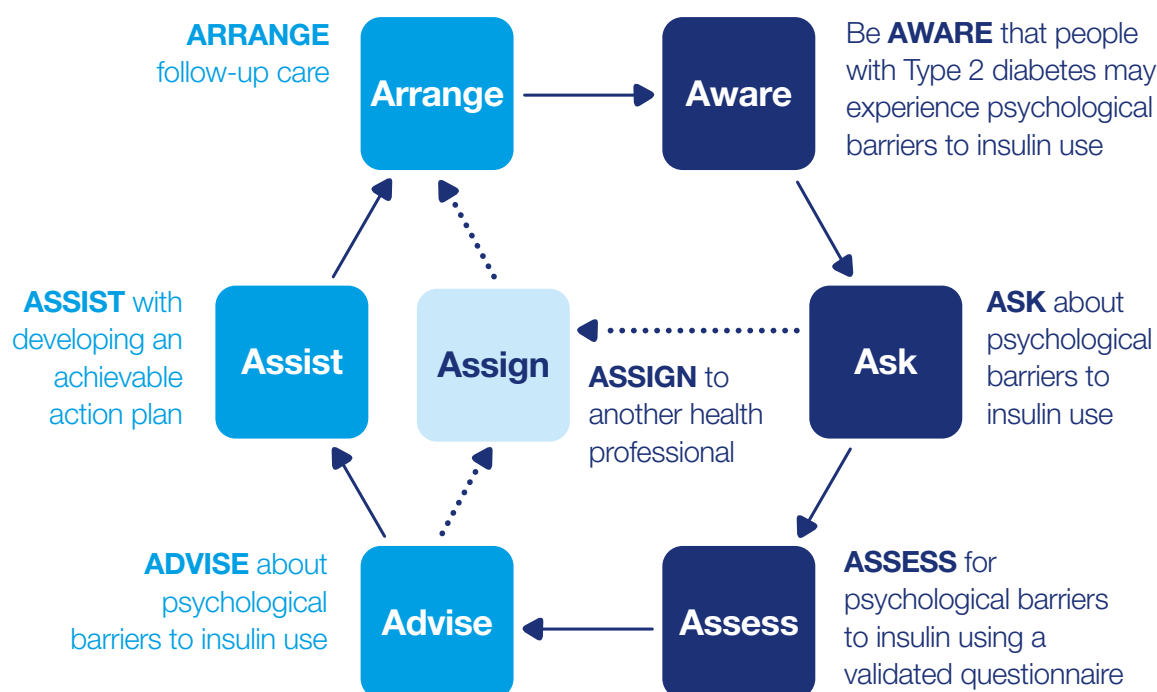
Typically, people with type 2 diabetes prefer tablets to insulin.¹⁵ In recent years, new (non-insulin) injectable agents have become available. Like insulin, incretin-based agents (e.g. GLP-1) reduce blood glucose and require injections but have the advantage of a lower risk of hypoglycaemia and weight 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

7 As 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-centred 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, weight gain)
- ‘negotiating’ to ‘do better’ with their current management plan to improve diabetes outcomes

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'

'I can improve my blood glucose/HbA1c numbers without insulin – just give me some more time to improve my numbers/ lose weight/exercise more etc'

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

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

'Insulin means my diabetes is worse'

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

- 'dropping out' (e.g. missing appointments, 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)
- 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](#).

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](#))
- if the person has sub-optimal HbA1c despite being on (near) maximal oral agents.



Before asking the following questions for the first time, make sure the person realises 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 Chapter 1.

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 in this chapter.

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
- **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, the number of daily doses)
- cultural factors (e.g. health beliefs, language barriers, 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, cognitive function)
- costs and access (e.g. insulin and related supplies, medical appointments)
- practical skills (e.g. planning, problem solving)
- 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, 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
- 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](#) and [Language Matters](#) - you can download this at www.diabetes.org.uk/emotional-health-professionals-guide

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 GP (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)
 - 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
 - discuss what they would like to gain from the referral, as this will influence to whom the referral will be made.

ASSIST

To date there is limited evidence for strategies to overcome psychological barriers to insulin use.³ Thus, recommended strategies are based on clinical experience and expertise. For most people, an initial reluctance to use insulin can usually be overcome.

Common barriers and practical strategies for minimising these barriers are listed in [Appendix C](#). 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.²⁷ 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.^{8,27}

Two key strategies that may be particularly useful are 'decisional balancing' and an 'insulin trial'²⁸.

Decisional balancing

'Decisional balancing'²⁹ is a technique used in motivational interviewing.^{29,30} 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. 'What other pros/cons might there be?').

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 realise 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 aid³¹ may be a helpful tool for comparing treatment options in terms of various concerns (e.g. side effects, regimen). See ‘Resources’ section.

An ‘insulin trial’

An ‘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. Extending the ‘trial’ to three months will enable them to notice improvements in glycaemic outcomes (HbA1c).

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 diabetes specialist nurse or other diabetes health professional** (e.g. an diabetologist or a dietitian) for self-management training (e.g. injection technique, 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, an anxiety disorder), or the person with diabetes feels that it could benefit them
- **a structured diabetes education group**, because insulin initiation in a group setting is as effective as an individual session and takes half the time;³² it also offers important opportunities for people to share their concerns and ideas about insulin.

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.

Box 5.3

Decisional balancing tool

	Pros	Cons
Continue with current diabetes treatment (e.g. tablets)	<ol style="list-style-type: none"> 1. 2. 3. 	<ol style="list-style-type: none"> 1. 2. 3.
Start insulin	<ol style="list-style-type: none"> 1. 2. 3. 	<ol style="list-style-type: none"> 1. 2. 3.



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
- 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
- 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 consultations may be necessary. Telephone/video conferencing may be a practical and useful way to provide support in addition to face-to-face appointments.

“I know eventually I probably will have to go to insulin and that’s going to be an absolute pain... but then it’s going to be an absolute pain if I don’t do it. So that’s going to happen...”

(Person with Type 2 diabetes)

Case Study



Bruce

72-year-old man, living with wife Martha

Type 2 diabetes, managed with oral medications; overweight

Health professional: Dr Amy Saunders (GP)

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 normalise 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 neighbour, Prue, 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)
- ‘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
- 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.

The doctor also talks with Bruce about the benefits of insulin, relating it back to his specific example of Prue. She explains, **‘Diabetes-related complications, like Prue’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 hypoglycaemic 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 diabetes specialist nurse to learn about insulin (e.g. how it works, dosage, timing of injections, how long it will take to notice an effect, effects of food and exercise), injection technique, and hypoglycaemia (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 specialist nurse, with instructions about the starting dose and regular dose titration until Bruce’s next review. She suggests that Bruce comes back to see her in four weeks so they can discuss how he is going, but he can visit her sooner or speak to the diabetes specialist nurse 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



Tina

44-year-old woman

Type 2 diabetes, managed with twice-daily insulin injections

Health professional: Angela Smith (diabetes specialist nurse), following a referral

Be AWARE

Angela has received a referral letter from Tina's diabetologist, who explains Tina has had 'sub-optimal HbA1c over the past year' and has 'recommended increasing her insulin dose from two to four daily injections, but she disagrees'. Angela is aware that many people experience psychological barriers to intensifying an insulin regimen and wants to explore Tina's reluctance to increasing her insulin dose.

ASK

At their first appointment, Angela thanks Tina for coming and asks how she can help. Tina 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?' Tina tells Angela about the plan to increase her insulin injections to four times daily. Angela asks Tina how she feels about that plan and Tina tells her she is 'not happy'.

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

Angela also explores whether there have been changes in Tina's life in the past year that could explain her increasing blood glucose levels. Tina 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 Tina whether she would like to complete a brief questionnaire so they can both better understand her concerns about insulin. Tina agrees and completes the copy of the ITAS that Angela gives her.

Tina'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)
- 'taking insulin helps to improve my energy level' (disagree).

ADVISE

Before discussing Tina's responses, Angela asks Tina what she thought of the questionnaire. Tina replies, 'It was alright, quite 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 diabetologist had demonstrated the insulin injection technique and he'd been 'quite 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 two injections, how can he expect me to go to four? I just want to go back to tablets’.

Angela responds that:

- it is common to feel distressed about diabetes from time to time
- Tina should not feel embarrassed about asking questions
- she has noticed a pattern in Tina’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 Tina to demonstrate her injecting technique using saline solution. Tina agrees and she injects the saline slowly and directly into her abdomen, then quickly withdraws the pen. Some of the saline dribbles down Tina’s abdomen as the pen is withdrawn. Angela asks whether Tina has noticed it leaking out before, and Tina 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 Tina is rotating her injection sites regularly. Then Angela:

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

ARRANGE

Before the consultation ends, Angela:

- checks whether Tina 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 Tina 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 Tina visit Angela again in two weeks
- asks Tina when she will next see her diabetologist, which is three months from now. Angela confirms that this will allow enough time to see an improvement in Tina’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 tablets	<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 (hypoglycaemia)	<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 fulfil 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 handbook. Readers of the handbook are permitted to reproduce the questionnaire for clinical use and non-commercial research purposes. Readers of the handbook 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, e.g. 'Taking insulin helps to improve my health')
- negative appraisal (16 negative statements about insulin, e.g. '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 consultations' (Chapter 1).

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 opposite 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.³⁴



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**

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

- **What's so tough about taking insulin? Addressing the problem of psychological insulin resistance in Type 2 diabetes**

Practical tips for recognising and addressing psychological insulin resistance in clinical practice.

Source: Polonsky WH, Jackson RA. Clinical Diabetes. 2004;22(3):147-150.

Tools

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

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.

Website: diabetesdecisionaid.mayoclinic.org

- **Initiating insulin: How to help people with Type 2 diabetes start and continue insulin successfully**

Three tables presenting 'The insulin conversation'; 'Responses to patient's questions about insulin' and 'Insulin education'.

Source: Polonsky et al. International Journal of Clinical Practice 2017;71(8):e12973

- **Peer support**

A listing of opportunities for people with diabetes to share experiences and information with others living with diabetes.

(See Appendix A)

- **Motivational Interviewing in Diabetes Care**

A book describing the consulting techniques of motivational interviewing, including a chapter on Insulin Use in Type 2 Diabetes

Source: Steinberg and Miller, 2015. Guilford Press, New York

Website: <https://www.amazon.co.uk/Motivational-Interviewing-Diabetes-Care-Facilitating/dp/1462521630>

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.

Information

- **Treating your diabetes with insulin**

Diabetes UK's web pages covering insulin treatment

Source: Diabetes UK

Website: www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/treating-your-diabetes/insulin

- **Concerns about starting insulin (for people with Type 2 diabetes)**

Description: A fact sheet to accompany this guide, for people with Type 2 diabetes who have concerns about commencing or intensifying insulin therapy. The leaflet can be downloaded from www.diabetes.org.uk/emotional-health-professionals-guide

Source: Diabetes UK

- **Insulin myths and facts**

A fact sheet that dispels some of the myths about insulin injections. It also lists questions for people with diabetes to consider and discuss with their health professional

Source: American Diabetes Association. Clinical Diabetes. 2007;25(1):39

Support

- **Diabetes UK**

Diabetes UK is the major organisation for support, information and research relating to diabetes. Its confidential Helpline is available to discuss concerns about starting insulin treatment

Phone: 0345 123 2399

Email: helpline@diabetes.org.uk

URL: www.diabetes.org.uk

- **Peer support - Factsheet**

A fact sheet to accompany this guide, which gives people with diabetes information about peer support opportunities. The leaflet can be downloaded from www.diabetes.org.uk/emotional-health-professionals-guide

References

1. Holmes-Truscott E, Speight J, et al. Clinical and psychosocial factors associated with “willingness to start insulin” among adults with type 2 diabetes in primary care: Stepping Up Study. Paper presented at: Australian Diabetes Society and Australian Diabetes Educators Society Annual Scientific Meeting; Adelaide, Australia. 2015.
2. Peyrot M, Barnett A, et al. Insulin adherence behaviours and barriers in the multinational Global Attitudes of Patients and Physicians in Insulin Therapy study. *Diabetic Medicine*. 2012;29(5):682-9.
3. Gherman A, Veresiu I, et al. Psychological insulin resistance: a critical review of the literature. *Practical Diabetes International*. 2011;28(3):125-8.
4. Holmes-Truscott E, Skinner T, et al. Negative appraisals of insulin therapy are common among adults with type 2 diabetes using insulin: results from Diabetes MILES – Australia cross-sectional survey. *Diabetic Medicine*. 2015;32(10):1297-303.
5. Larkin ME, Capasso VA, et al. Measuring psychological insulin resistance: barriers to insulin use. *Diabetes Educator*. 2008;34(3):511-7.
6. Karter AJ, Subramanian U, et al. Barriers to insulin initiation: the translating research into action for diabetes insulin starts project. *Diabetes Care*. 2010;33(4):733-5.
7. Blonde L. Easing the transition to insulin therapy in people with type 2 diabetes. *Diabetes Educator*. 2007;33(Suppl 7):S232-40.
8. Funnell MM. Quality of life and insulin therapy in type 2 diabetes mellitus. *Insulin*. 2008;3(1):31-6.
9. Makine C, Kar C, et al. Symptoms of depression and diabetes-specific emotional distress are associated with a negative appraisal of insulin therapy in insulin-naive patients with type 2 diabetes mellitus. A study from the European Depression in Diabetes [EDID] Research Consortium. *Diabetic Medicine*. 2009;26(1):28-33.
10. Hex N, Bartlett C, Wright D et al. Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. *Diabetic Medicine*. 2012 Jul;29(7):855-62
11. Ho PM, Rumsfeld JS, et al. Effect of medication nonadherence on hospitalization and mortality among patients with diabetes mellitus. *Archives of Internal Medicine*. 2006;166(17):1836-41.
12. Klein R, Klein BE. Relation of glycemic control to diabetic complications and health outcomes. *Diabetes Care*. 1998;21 (Suppl 3):C39-43.
13. Donnelly LA, Morris AD, et al. Adherence to insulin and its association with glycaemic control in patients with type 2 diabetes. *Quarterly Journal of Medicine*. 2007;100(6):345-50.
14. Brod M, Kongsø JH, et al. Psychological insulin resistance: patient beliefs and implications for diabetes management. *Quality of Life Research*. 2009;18(1):23-32.
15. Peyrot M, Rubin RR, et al. Resistance to insulin therapy among patients and providers results of the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) study. *Diabetes Care*. 2005;28(11):2673-9.
16. Davies M, Speight J. Patient-reported outcomes in trials of incretin-based therapies in patients with type 2 diabetes mellitus. *Diabetes, Obesity and Metabolism*. 2012;14(10):882-92.
17. Kunt T, Snoek F. Barriers to insulin initiation and intensification and how to overcome them. *International Journal of Clinical Practice*. 2009;63(s164):6-10.
18. Wang HF, Yeh MC. Psychological resistance to insulin therapy in adults with type 2 diabetes: mixed-method systematic review. *Journal of Advanced Nursing*. 2012;68(4):743-57.
19. Novo Nordisk. The DAWN experiment – An exercise in communication [cited 9 July 2015]. Available from: www.dawnstudy.org/News_and_activities/Documents/DAWN_Experiment.pdf.

20. Snoek F, Skovlund S, et al. Development and validation of the insulin treatment appraisal scale (ITAS) in patients with type 2 diabetes. *Health and Quality of Life Outcomes*. 2007;5(1):69.
21. Peyrot M, Barnett A, et al. Factors associated with injection omission/non-adherence in the Global Attitudes of Patients and Physicians in Insulin Therapy study. *Diabetes, Obesity and Metabolism*. 2012;14(12):1081-7.
22. García-Pérez L-E, Álvarez M, et al. Adherence to therapies in patients with type 2 diabetes. *Diabetes Therapy*. 2013;4(2):175-94.
23. Campos C. Addressing cultural barriers to the successful use of insulin in Hispanics with type 2 diabetes. *Southern Medical Journal*. 2007;100(8):812-20.
24. Meetoo D, McAllister G, et al. In pursuit of excellence in diabetes care: trends in insulin delivery. *British Journal of Nursing*. 2012;21(10):588-95.
25. Ho EY, James J. Cultural barriers to initiating insulin therapy in Chinese people with type 2 diabetes living in Canada. *Canadian Journal of Diabetes*. 2006;30(4):390-6.
26. Humphry J, Jameson LM, et al. Overcoming social and cultural barriers to care for patients with diabetes. *Western Journal of Medicine*. 1997;167(3):138-44.
27. Polonsky WH, Jackson RA. What's so tough about taking insulin? Addressing the problem of psychological insulin resistance in type 2 diabetes. *Clinical Diabetes*. 2004;22(3):147-50.
28. Furler J, O'Neal D, Speight J. et al. Supporting insulin initiation in type 2 diabetes in primary care: results of the Stepping Up pragmatic cluster randomised controlled clinical trial. *bmj*. 2017 Mar 8;356:j783.
29. Miller W, Rollnick S. *Motivational interviewing: preparing people for change*. 2nd ed. New York: The Guilford Press; 2002.
30. Steinberg MP, Miller WR. *Motivational interviewing in diabetes care*. Guilford Publications; 2015 Aug 11
31. Mullan RJ, Montori VM, et al. The diabetes mellitus medication choice decision aid: A randomized trial. *Archives of Internal Medicine*. 2009;169(17):1560-68.
32. Yki-Järvinen H, Juurinen L, et al. Initiate Insulin by Aggressive Titration and Education (INITIATE): a randomized study to compare initiation of insulin combination therapy in type 2 diabetic patients individually and in groups. *Diabetes Care*. 2007;30(6):1364-69.
33. Holmes-Truscott E, Pouwer F, et al. Further investigation of the psychometric properties of the insulin treatment appraisal scale among insulin-using and non-insulin-using adults with type 2 diabetes: results from Diabetes MILES – Australia. *Health and Quality of Life Outcomes*. 2014;12(1):87
 - 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 Fear of hypoglycaemia (and other diabetes-specific fears) (Chapter 4).
 - b. 23% of people with type 2 diabetes for whom insulin was clinically indicated were 'not at all willing' 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.

Depression



Key messages

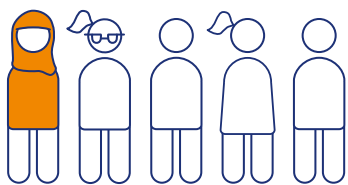
- Major depression^a is a psychological condition indicated by a persistent (minimum of two weeks) state of lowered mood and/or lack of interest and pleasure in usual activities. This is in addition to other symptoms, such as significant changes in weight and sleep, a lack of energy, difficulty concentrating, 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 four with non-insulin-treated type 2 diabetes and one in five with type 1 diabetes; this is two to three times more than the general population.
- Depressive symptoms in people with diabetes are:
 - associated with sub-optimal diabetes self-management and HbA1c, increased diabetes distress, less satisfaction with treatment, and impaired quality of life
 - highly recurrent
 - 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).



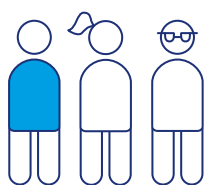
Practice points

- 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 GP.
- Remain mindful that depressive symptoms and mild depression also need attention, as they can develop into major depression.

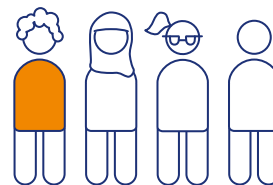
How common are symptoms of depression?



Type 1 diabetes^{b,1}



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



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

What is depression?

Depression refers to a wide range of mental health problems characterised by the absence of positive affect (a loss of interest and enjoyment in ordinary things and experiences), low mood and a range of associated emotional, cognitive, physical and behavioural symptoms.² In contrast to just ‘feeling down’ or having a low mood, 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, 10th revision (ICD-10).⁴ The ‘gold standard’ for diagnosing depression is a standardised clinical diagnostic interview, for example the Structured Clinical Interview for DSM Disorders (SCID; 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 either persistent depressed mood or loss of interest/pleasure in regular activities.³
- 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 characterised by the presence of depressive symptoms that do not meet the full diagnostic criteria for major depression.⁵

Although mild depression is less severe than major

depression, it still impacts significantly on 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.⁶

People with diabetes are two to three times more likely than the general population to be affected by symptoms of depression.⁷ As in the general population, depression is highly recurrent in people with diabetes.⁸

The causes of depression in people with diabetes are not well understood, but proposed mechanisms include biological, behavioural, social, psychological, and environmental factors.⁹ Non-diabetes-specific contributors may include stressful life circumstances, substance use, and a personal or family history of depression¹⁰. Diabetes-specific contributors may include the chronic nature of the condition and complex management regimens.^{7,11} As various factors can contribute, the exact cause will be different for every person¹⁰.

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

- sub-optimal self-management (e.g. reduced physical activity, less healthy eating, not taking medication as recommended, less frequent self-monitoring of blood glucose, smoking)¹²⁻¹⁶
- elevated HbA1c, hypoglycaemia and hyperglycaemia^{13,17}

- increased prevalence, and earlier onset, of complications and disability^{18,19}
- increased risk of diabetes distress²⁰⁻²², and elevated anxiety symptoms²³
- impaired quality of life, and social role/ functioning^{24,25}
- increased burden/costs to the individual and the healthcare system^{14,26}
- greater risk of premature mortality.^{27,28}



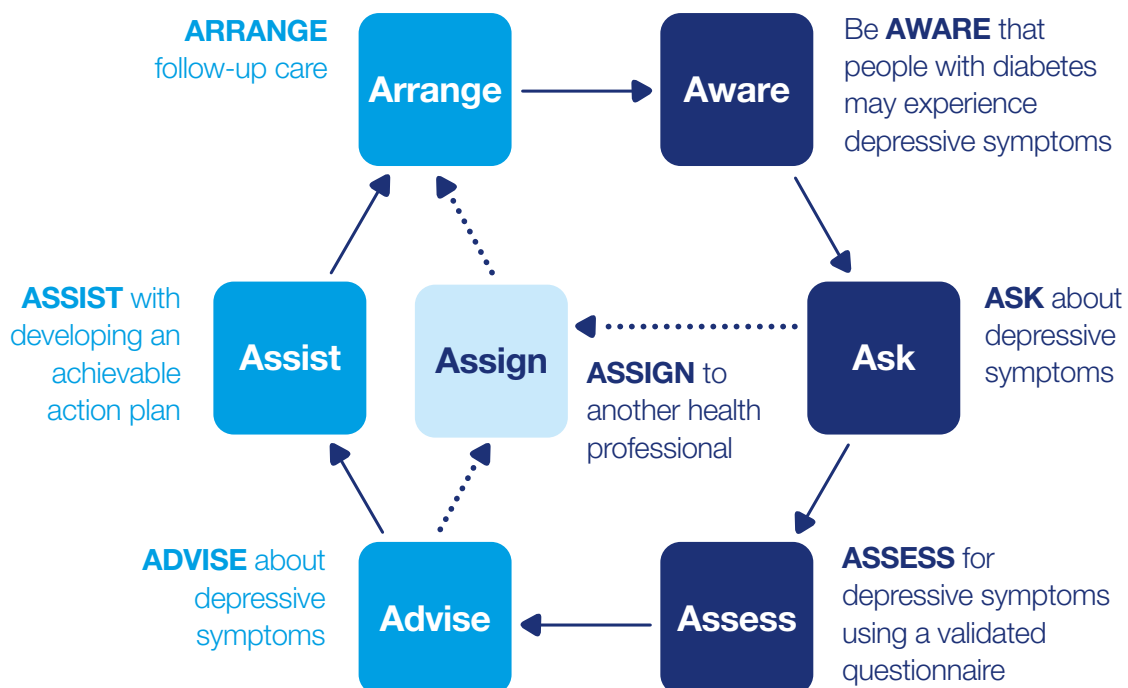
People with co-existing depressive and anxiety symptoms are likely to experience greater emotional impairment and take longer to recover.²⁹

7 As 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-centred approach to care.



How can I identify depressive symptoms?

Be AWARE

Depression has physical, cognitive, behavioural, and emotional symptoms. Some common signs to look for include: lowered mood (e.g. sadness, hopelessness, teariness), loss of interest or pleasure in usual activities, irritability (e.g. exaggerated sense of frustration over minor matters, 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 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 Each person will experience different symptoms of depression.

Two classification systems are commonly used for diagnosing depression: DSM-5³ and ICD-10.⁴ Consult these for a full list of symptoms and specific diagnostic criteria.



Depressive symptoms can overlap with somatic symptoms of diabetes⁷ (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.^{30,31}

Although depression does not always develop in direct response to diabetes, some common signs that people with diabetes may be experiencing depressive symptoms 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 behavioural 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.

Caution must be taken when assessing for depression using a questionnaire. It has been shown that these may falsely identify people with diabetes as having depression when they do not. These 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 night-time episodes of hypoglycaemia recently. Health professionals need to be mindful of these limitations.

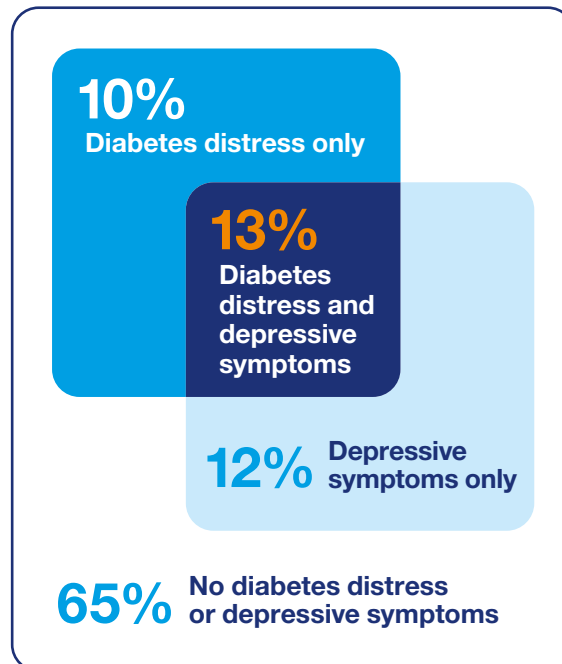
This does not mean that depression questionnaires are not useful in clinical practice – it means that a clinical interview is needed to confirm a diagnosis of depression in people with diabetes. It is important to clarify the context and cause of the symptoms.

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.³² 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.^{20,21} This means that people with depression are more likely to develop diabetes distress, and vice versa. In an Australian study, the co-occurrence for severe diabetes distress^c and moderate-to-severe depressive symptoms^d is approximately 13 per cent (see diagram below).¹ 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.^{32,33}



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)
- when the person reports symptoms or you have noted signs (e.g. changes in mood/behaviours)
- at times when the risk of developing depression 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, hospitalisation, or significant changes to the treatment regimen)
- if the individual has a history of depression or other mental health problems.⁸



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 consultation 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 consultation:

- ‘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. What has brought this about?’
- ‘You mentioned you’ve been [drinking more alcohol than usual] lately, what has brought that about?’
- ‘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).³⁴ 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.

Sum the responses to the two questions to form a total score. A total score of 3 or more indicates depressive symptoms,³⁴ 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 Chapter 1.

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)³⁵ is widely used to assess depression. 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 summed to form a total score ranging 0-27. In the general population, PHQ-9 scores are interpreted as follows:³⁶

- 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-10⁴ criteria to confirm depression.



You may have access to other validated questionnaires, such as the: Beck Depression Inventory;³⁷ Hospital Anxiety and Depression Scale;³⁸ Centre for Epidemiologic Studies Depression Scale;³⁹ or Hamilton Depression Scale.⁴⁰ 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.^{41,42}

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 symptoms (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 hypoglycaemia, or burdensome complications)?

Are there any factors (physiological, psychological, or behavioural) 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? For example, 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? How long it took them to recover?).
- 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

- 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.⁴⁴ Instead, addressing the issue is much more likely to enhance their safety and prevent an attempt.⁴⁵ Suicidality fluctuates and is influenced by such things as:⁴⁴

- 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)
- 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 guide⁴⁶:

1. Assess and ensure safety (the person with diabetes, yourself, and others).
2. Establish rapport (non-judgemental, 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
- recent help-seeking behaviours.

There are several questionnaires for assessing suicide risk.⁴⁷⁻⁴⁹ These can be useful for directing the conversation systematically but there is a lack of evidence for their diagnostic accuracy.⁴⁵ **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 psychological or psychiatric assessment
6. Develop a safety plan with the person⁵⁰ (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.

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

If a person is in immediate danger: follow your workplace's emergency protocol. In the absence of a formal written procedure contact the nearest Mental Health Crisis Intervention Team and/or refer to the nearest Accident and Emergency Department.

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
 - 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 impact on 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.
- Recognise 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 needs and preferences of the person with diabetes
 - your qualifications, knowledge, skills and confidence to address depressive symptoms
 - the severity of the depressive symptoms, and the context of the problem(s)
 - whether other psychological problems are also present, such as diabetes distress (see Chapter 3) or an anxiety disorder (see Chapter 7)
 - 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
 - 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,⁵¹ so intervention is important. The stepped care approach provides guidance on how

to address depressive symptoms and depression in clinical practice.^{52,53}

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, and 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)
 - 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, there are several 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.

Box 6.4

Treating depression

It is not within the remit of this handbook to recommend specific pharmacological or psychological treatments for depression in people with diabetes. Here are some general considerations based upon the evidence available⁹ at the time this handbook was published:

- A combination of psychological intervention and pharmacological treatment is recommended for people with recurrent depression and major depression.⁵²
- Psychological intervention and/or pharmacological treatment should be implemented through stepped care and/or collaborative care approaches.^{52,54}
- Cognitive behavioural therapy (CBT) is the most effective psychological intervention.⁵²
- Antidepressant medications are only effective for people with moderate-to-severe depression, not mild depression.⁵⁵
- Selective serotonin re-uptake inhibitors (SSRIs) are the most effective pharmacological treatment for depression in people with diabetes.⁵²
- When combined with diabetes self-management education, psychotherapy is most effective for reducing depressive symptoms and HbA1c.⁵⁶
- Some antidepressant medications can have adverse side effects (e.g. weight gain, metabolic abnormalities) and are associated with insulin resistance.⁵⁷ Consider the risks and benefits before prescribing these medications, as they may not be appropriate for some people with diabetes.^{55,57}

ASSIGN

The vast majority of specialist diabetes services in the UK do not have an integrated mental health professional, such as a clinical psychologist, to refer to.⁵⁸ Therefore, the majority of referrals will be made to professionals outside the diabetes service. These might include:

- **A general practitioner** to undertake a clinical interview and diagnose major depression, and/or 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. cognitive behavioural therapy or interpersonal therapy).
- **A psychiatrist** to undertake a clinical interview, and prescribe and monitor medications. A GP referral is usually required to access a psychiatrist. Referral to a psychiatrist is likely to 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).
- **Community Mental Health Teams** can 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).
- **Improving Access to Psychological Therapies – Long Term Conditions (IAPT-LTC)** are accessible in some areas in England. These services focus on people with long term conditions, including diabetes. (Local contact details can be found online on the NHS website).

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 GP or diabetes specialist (e.g. an diabetologist, diabetes specialist nurse, 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
- 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 more frequent follow-up visits or extended consultations are necessary until the person feels stronger emotionally. Encourage them to book a follow-up appointment with you within an agreed timeframe to monitor progress and address any issues arising. Telephone/ video conferencing, or text or email contact 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 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 a psychologist, and I wrote a referral letter How has this worked out for you?'

“A lot of the time people feel like they're alone. Having someone say “that's actually really common” is a really comforting thing to hear.”

(Person with type 1 diabetes)

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 (GP)

Be AWARE

When Julie arrives for her routine check-up, Robert 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 holiday I think'. As the discussion moves on to her general physical health and diabetes management, Robert 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 a couple of kilograms.

ASK

When Robert 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 feels 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.

Robert is concerned about Julie's struggles with motivation and about the impact her recent changes in behaviour and thought patterns will have on her diabetes if they continue in the longer term.

ASSESS

Robert 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

Robert explains the PHQ-9 score to Julie and asks her if this fits with how she has been feeling lately. Julie says that she recognises the symptoms she has been experiencing from a couple of years ago when she was depressed after separating from her husband. Robert 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

With Julie's permission, Robert makes contact with the psychologist to check that the referral was received and that an appointment can be made within an appropriate timeframe.

ARRANGE

Robert 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 (Consultant Diabetologist) and Thomas Mitchell (Diabetes Specialist Nurse)

Be AWARE

Glenn 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 Problem Areas in Diabetes (PAID) scale (to assess diabetes distress) and 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 and summarised in their chart, for discussion during the appointment.

ASK

During Luke's annual review, Thomas asks him some general questions about his health and well-being but Luke does not seem to be in the mood for talking. When it comes

time for the questionnaire, Thomas tells Luke: 'We've added something new to our annual assessments. We know that living with diabetes can be challenging and can, at times, feel like a burden for many people. So we've put together a brief set of questions about how living with diabetes affects your life and well-being. It will help us to know whether there are any specific issues you're facing at the moment so that we can help you live well with diabetes. 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 Glenn. Will you fill in the questionnaire?' Luke agrees.

ASSESS

At the appointment, Glenn quickly looks over the questionnaire responses. Luke's PAID 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.

Glenn asks Luke about how he felt completing the questionnaire, and Luke replies, 'It was OK, y'know, a bit different, but OK'. Glenn 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 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'm such a loser, I feel completely worthless'.

Glenn 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. Glenn asks Luke whether he has been diagnosed with depression before; Luke has not. Glenn then asks Luke to complete a few more questions to help him to be sure.

Luke agrees, so Glenn 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'), Glenn also conducts a suicide risk assessment, and finds Luke to be at moderate risk.

ADVISE

Glenn explains the scores to Luke and gives him some information about depression, including the phone number for Samaritans. Glenn tells Luke that depression is treatable and explains the various options available. He advises Luke to visit his GP and the reasons for this – the GP will help him to access the most appropriate treatment (e.g. psychological intervention and/or medication). He invites Luke to ask questions.

ASSIST

Glenn checks whether Luke has a GP that he would be comfortable to speak with, and whether he is ok to do so. Luke agrees to both queries. Glenn 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 Samaritans about how he is feeling if things get too much. Glenn discusses other suicide risk mitigation strategies with Luke; together they develop a safety plan.

ASSIGN

Glenn writes a letter of referral to Luke's GP, and includes a copy of his PHQ-9 score and interpretation with the letter. He encourages Luke to make an extended appointment to see his GP as soon as possible, preferably in the next few days. With Luke's permission, he contacts the GP to make sure that a timely appointment is made available to Luke.

ARRANGE

Glenn asks Luke to come back to see him next month, so he can see how he is getting on with his GP. They will also continue with his annual diabetes review 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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Developed by Drs Robert L. Spitzer, Janet BW 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.^{35,59} It has been validated for use with people with diabetes.⁶⁰ 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 depression⁵⁹ and few have been validated in people with diabetes.⁴¹

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).^{35,61} Items are scored on a scale from 0 (not at all) to 3 (nearly every day).⁶¹

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 consultations' (Chapter 1).

Interpretation of scores

The scores for each item are summed to generate a total score (range: 0-27).⁶¹ Depressive symptom severity is indicated by the PHQ-9 total score.³⁶ Generally, a PHQ-9 total score of 10 or more is an indicator of likely depression,³⁵ 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.³⁵

PHQ-9 total score	Depressive symptom severity	Proposed treatment actions ⁶¹
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 specialised 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.⁶⁰ For older people with diabetes in general practice, a cut-off of 7 or more has been recommended.⁶²

Short form – PHQ-2

- The PHQ-2⁶³ 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.⁶¹

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;3:472-85.

- **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):256-64.

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

Guidelines and recommendations

National Institute for Health and Clinical Excellence (Guideline 91): Depression in adults with a chronic physical health problem: recognition and management. Published October 2009. <https://www.nice.org.uk/guidance/cg91>

National Institute for Health and Clinical Excellence (Guideline 90): Depression in adults: recognition and management. First published: October 2008. Last updated April 2018. <https://www.nice.org.uk/guidance/cg90>

Books

- **Screening for depression and other psychological problems in diabetes: a practical guide.**

Lloyd CE, Pouwer F, et al., editors. London: Springer; 2013

- **Management of mental disorders (fifth edition)**

Description: A book that provides practical guidance for clinicians in recognising 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. CreateSpace. 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 Clinical Research Unit for Anxiety and Depression (CRUFAD) website at www.crufad.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.

Information

Books and Fact Sheets

- **Depressive Illness: The Curse of the Strong (3rd Edition).** Tim Cantopher 2016, Sheldon Press, ISBN: 978-1847092359
Consultant Psychiatrist, Tim Cantopher guides the reader through the nature of depression, its history, symptoms, causes and treatments. He covers the latest information on medications, and new guidelines about how best to manage depression.
Website: <http://www.sheldonpress.co.uk/depressive-illness>
- **Diabetes & Wellbeing: Managing the Psychological and Emotional Challenges of Diabetes Types 1 and 2.** Dr Jen Nash 2013, Wiley-Blackwell, ISBN: 978-1119967187.
Written by a Clinical Psychologist who lives with Type 1 diabetes, this book explores how to overcome the emotional and psychological challenges of living with diabetes. Includes Chapter 4 'Depression, Low Mood and Burnout'
Website: <https://www.wiley.com/engb/Diabetes+and+Wellbeing:+Managing+the+Psychological+and+Emotional+Challenges+of+Diabetes+Types+1+and+2-p-9781119967187>
- **Diabetes and Depression Fact Sheet**
Description: A fact sheet to accompany this guide with information and self-help ideas
Website: www.diabetes.org.uk/emotional-health-professionals-guide
- **Depression and Low Mood: An NHS Self-Help Guide:**
A booklet from the Northumberland Tyne and Wear NHS Trust containing information and practical ways to manage depression and low mood.
Website: <https://web.ntw.nhs.uk/selfhelp/>

Organisations

- **Diabetes UK information on emotional wellbeing and support:**
A website page giving information and ideas of ways to access emotional support
Website: <https://www.diabetes.org.uk/guide-to-diabetes/life-with-diabetes/emotional-issues>
 - **Rethink Mental Illness.**
Description: An organization giving information and support to people with mental illness, including depression
Website: <https://www.rethink.org/diagnosis-treatment/conditions/depression>
- ### Support and Peer Support
- **NHS 'Moodzone':** dedicated pages on the NHS website for mental health, including anxiety, depression, self-help and how to get urgent mental health help when necessary.
<https://www.nhs.uk/conditions/stress-anxiety-depression/>
 - **Samaritans:**
Description: 24 hours a day national UK confidential emotional support for those in distress or despair, including those with depression. Trained volunteers are available on telephone, email, face to face and text
Tel: 116 123
Email: jo@samaritans.org
Website: www.samaritans.org
 - **MIND:**
Description: Mental health charity offering information and telephone and online support, including discussion forum
Tel: 03001233393
Email: info@mind.org.uk
Website: www.mind.org.uk
 - **Rethink Mental Illness Advice and Helplines and Support Groups**
Description: Rethink provides a national and some local telephone Helplines for people living with mental illness including depression
Website: <https://www.rethink.org/services-groups/service-types/advice-and-helplines>

- **Improving access to psychological therapies (IAPT) :**

IAPT is an NHS service providing treatment for depression. There is a search function to find local IAPT services on the NHS website:

Website: [https://www.nhs.uk/Service-Search/Psychological-therapies-\(IAPT\)/LocationSearch/10008](https://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008)

- **Peer Support Fact Sheet**

Description: A fact sheet to accompany this guide, giving information about ways to access peer support and its benefits

Website: www.diabetes.org.uk/emotional-health-professionals-guide

- **Diabetes UK Forum:**

An online discussion forum for people living with diabetes to access information and support, with many different topics being discussed. The Welcome page explains more about it and where to find support for specific aspects of diabetes, including depression

Website: <https://forum.diabetes.org.uk/boards/forums/welcome-and-getting-started.37/>

References

1. Speight J, Browne JL, et al. Diabetes MILES – Australia 2011 Survey Report. Diabetes Australia – Vic, Melbourne: 2011.
2. National Institute for Health and Clinical Excellence. Depression in adults with a chronic physical health problem: recognition and management. Guideline 91; 2009.
3. American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders (DSM-5). 5th ed. Arlington, VA: American Psychiatric Association; 2013.
4. World Health Organization (WHO). International Statistical Classification of Diseases and Related Health Problems (ICD-10). 10th Revision: Version 2015 ed. Geneva: WHO; 2015.
5. Hood KK, Naranjo DM, et al. Chapter 6: measuring depression in children and young people. In: Lloyd CE, Pouwer F, et al., editors. Screening for depression and other psychological problems in diabetes: a practical guide. London: Springer; 2013. p. 110-38.
6. Mezuk B, Eaton WW, et al. Depression and type 2 diabetes over the lifespan: a meta-analysis. *Diabetes Care*. 2008;31(12):2383-90.
7. Roy T, Lloyd CE. Epidemiology of depression and diabetes: a systematic review. *Journal of Affective Disorders*. 2012;142:S8-21.
8. Nefs G, Pouwer F, et al. The course of depressive symptoms in primary care patients with type 2 diabetes: results from the Diabetes, Depression, Type D Personality Zuidoost-Brabant (DiaDDZoB) Study. *Diabetologia*. 2012;55(3):608-16.
9. Moulton CD, Pickup JC, et al. The link between depression and diabetes: the search for shared mechanisms. *The Lancet Diabetes & Endocrinology*. 2015;3(6):461-71.
10. Mind. Causes of Depression. <https://www.mind.org.uk/information-support/types-of-mental-health-problems/depression/causes/#.XFAs5S2cbUo> (accessed 29 January 2019)
11. Renn BN, Feliciano L, et al. The bidirectional relationship of depression and diabetes: a systematic review. *Clinical Psychology Review*. 2011;31(8):1239-46.
12. Egede LE, Ellis C, et al. The effect of depression on self-care behaviours and quality of care in a national sample of adults. *General Hospital Psychiatry*. 2009;31(5):422-7.
13. Ciechanowski P, Katon W, et al. The relationship of depressive symptoms to symptom reporting, self-care and glucose control in diabetes. *General Hospital Psychiatry*. 2003;25(4):246-52.
14. Ciechanowski PS, Katon WJ, et al. Depression and diabetes: impact of depressive symptoms on adherence, function, and costs. *Archives of Internal Medicine*. 2000;160(21):3278-85.
15. DiMatteo MR, Lepper HS, et al. Depression is a risk factor for noncompliance with medical treatment: meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine*. 2000;160(14):2101-7.
16. Gonzalez JS, Safren SA, et al. Depression, self-care, and medication adherence in type 2 diabetes: relationships across the full range of symptom severity. *Diabetes Care*. 2007;30(9):2222-7.
17. Lustman PJ, Anderson RJ, et al. Depression and poor glycemic control: a meta-analytic review of the literature. *Diabetes Care*. 2000;23(7):934-42.
18. Black SA, Markides KS, et al. Depression predicts increased incidence of adverse health outcomes in older Mexican Americans with type 2 diabetes. *Diabetes Care*. 2003;26(10):2822-8.
19. de Groot M, Anderson RJ, et al. Association of depression and diabetes complications: a meta-analysis. *Psychosomatic Medicine*. 2001;63(4):619-30.
20. Burns R, Deschênes S, et al. Cyclical relationship between depressive symptoms and diabetes distress in people with type 2 diabetes mellitus: results from the Montreal Evaluation of Diabetes Treatment Cohort Study. *Diabetic Medicine*. 2015;32(10):1272-8.

21. Ehrmann D, Kulzer B, et al. Longitudinal relationship of diabetes-related distress and depressive symptoms: analysing incidence and persistence. *Diabetic Medicine*. 2015;32(10):1264-71.
22. Kokoszka A, Pouwer F, et al. Serious diabetes-specific emotional problems in patients with type 2 diabetes who have different levels of comorbid depression: a Polish study from the European Depression In Diabetes (EDID) Research Consortium. *European Psychiatry*. 2009;24(7):425-30.
23. Buchberger B, Huppertz H, Krabbe L, et al. Symptoms of depression and anxiety in youth with type 1 diabetes: A systematic review and meta-analysis. *Psychoneuroendocrinology*, 2016, 70, 70-84.
24. Schram MT, Baan CA, et al. Depression and quality of life in patients with diabetes: a systematic review from the European Depression In Diabetes (EDID) Research Consortium. *Current Diabetes Reviews*. 2009;5(2):112-19.
25. Goldney RD, Phillips PJ, et al. Diabetes, depression, and quality of life: a population study. *Diabetes Care*. 2004;27(5):1066-70.
26. Egede LE, Zheng D, et al. Comorbid depression is associated with increased health care use and expenditures in individuals with diabetes. *Diabetes Care*. 2002;25:464-70.
27. Park M, Katon WJ, et al. Depression and risk of mortality in individuals with diabetes: a meta-analysis and systematic review. *General Hospital Psychiatry*. 2013;35(3):217-25.
28. Ismail K, Winkley K, et al. A cohort study of people with diabetes and their first foot ulcer: the role of depression on mortality. *Diabetes Care*. 2007;30(6):1473-9.
29. Baldwin DS, Anderson IM, et al. Evidence-based pharmacological treatment of anxiety disorders, post-traumatic stress disorder and obsessive-compulsive disorder: a revision of the 2005 guidelines from the British Association for Psychopharmacology. *Journal of Psychopharmacology*. 2014;28(5):403-39.
30. Reference removed during the process of adaptation from Australian to UK edition of the Guide. Please see reference 32
31. Pouwer F, Beekman AT, et al. Nurses' recognition and registration of depression, anxiety and diabetes-specific emotional problems in outpatients with diabetes mellitus. *Patient Education and Counseling*. 2006;60(2):235-40.
32. Fisher L, Gonzalez J, et al. The confusing tale of depression and distress in patients with diabetes: a call for greater clarity and precision. *Diabetic Medicine*. 2014;31(7):764-72.
33. Hessler D, Fisher L, et al. Causal and bidirectional linkages over time between depression and diabetes regimen distress in adults with type 2 diabetes. *Diabetes Research and Clinical Practice*. 2015;108(2):360-6.
34. Kroenke K, Spitzer R, et al. The Patient Health Questionnaire-2: validity of a two-item depression screener. *Medical Care*. 2003;41(11):1284-92.
35. Kroenke K, Spitzer RL, et al. The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*. 2001;16(9):606-13.
36. Kroenke K, Spitzer RL. The PHQ-9: a new depression diagnostic and severity measure. *Psychiatric Annals*. 2002;32(9):1-7.
37. Beck AT, Ward CH, et al. An inventory for measuring depression. *Archives of General Psychiatry*. 1961;4(6):561-71.
38. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*. 1983;67(6):361-70.
39. Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement*. 1977;1(3):385-401.
40. Hamilton M. A rating scale for depression. *Journal of Neurology, Neurosurgery, and Psychiatry*. 1960;23(1):56-62.
41. Roy T, Lloyd C, et al. Screening tools used for measuring depression among people with type 1 and type 2 diabetes: a systematic review. *Diabetic Medicine*. 2012;29(2):164-75.
42. Lloyd CE, Roy T. Top ten screening tools for measuring depression in people with diabetes. In: Lloyd CE, Pouwer F, et al., editors. *Screening for depression and other psychological problems in diabetes: a practical guide*. London: Springer; 2013.

43. Reference removed during the process of adapting from Australian to UK edition of the Guide
44. Mind. Talking about suicidal feelings. <https://www.mind.org.uk/information-support/helping-someone-else/supporting-someone-who-feels-suicidal/talking-about-suicidal-feelings/#.XFA92S2cbUo> (accessed 29 January 2019)
45. O'Connor E, Gaynes BN, et al. Screening for and treatment of suicide risk relevant to primary care: a systematic review for the US Preventive Services Task Force. *Annals of Internal Medicine*. 2013;158(10):741-54.
46. Mind. Supporting someone who feels suicidal <https://www.mind.org.uk/media/5452271/how-to-support-someone-who-feels-suicidal-2017.pdf> (accessed 30.01.19)
47. Broadbent M, Moxham L, et al. The development and use of mental health triage scales in Australia. *International Journal of Mental Health Nursing*. 2007;16(6):413-21.
48. Beck AT, Kovacs M, et al. Assessment of suicidal intention: the Scale for Suicide Ideation. *Journal of Consulting and Clinical Psychology*. 1979;47(2):343-52.
49. Nimeus A, Alsen M, et al. The Suicide Assessment Scale: an instrument assessing suicide risk of suicide attempters. *European Psychiatry*. 2000;15(7):416-23.
50. Stanley B, Brown GK. Safety planning intervention: a brief intervention to mitigate suicide risk. *Cognitive and Behavioral Practice*. 2012;19(2):256-64.
51. Hegel MT, Oxman TE, et al. Watchful waiting for minor depression in primary care: remission rates and predictors of improvement. *General Hospital Psychiatry*. 2006;28(3):205-12.
52. Petrak F, Baumeister H, et al. Depression and diabetes: treatment and health-care delivery. *The Lancet Diabetes & Endocrinology*. 2015;3(6):472-85.
53. Hermanns N, Caputo S, et al. Screening, evaluation and management of depression in people with diabetes in primary care. *Primary Care Diabetes*. 2013;7(1):1-10.
54. Atlantis E, Fahey P, et al. Collaborative care for comorbid depression and diabetes: a systematic review and meta-analysis. *BMJ Open*. 2014;4(4):e004706.
55. Informed Health Online [Internet]. Cologne, Germany: Institute for Quality and Efficiency in Health Care (IQWiG); 2006-. Depression: How effective are antidepressants? 2015 Jan 28 [Updated 2017 Jan 12]. <https://www.ncbi.nlm.nih.gov/books/NBK361016/>
56. Van der Feltz-Cornelis CM, Nuyen J, et al. Effect of interventions for major depressive disorder and significant depressive symptoms in patients with diabetes mellitus: a systematic review and meta-analysis. *General Hospital Psychiatry*. 2010;32(4):380-95.
57. Bystritsky A, Danial J, et al. Interactions between diabetes and anxiety and depression: implications for treatment. *Endocrinology and Metabolism Clinics of North America*. 2014;43(1):269-83.
58. Diabetes UK. Minding the Gap: The provision of psychological support and care for people with diabetes in the UK. Diabetes UK, 2008. https://diabetes-resources-production.s3-eu-west-1.amazonaws.com/diabetes-storage/migration/pdf/Minding_the_Gap_psychological_report.pdf
59. Pfizer. Patient Health Questionnaire (PHQ) Screeners, [cited 15 May 2014]. Available from: www.phqscreeners.com.
60. van Steenberg-Weijnenburg KM, de Vroeg L, et al. Validation of the PHQ-9 as a screening instrument for depression in diabetes patients in specialized outpatient clinics. *BioMed Central Health Devices Research*. 2010;10(1):235.
61. Spitzer RL, Williams JBW, et al. Instruction manual: instructions for Patient Health Questionnaire (PHQ) and GAD-7 measures, ND [cited 5 February 2015]. Available from: www.phqscreeners.com.
62. Lamers F, Jonkers C, et al. Summed score of the Patient Health Questionnaire-9 was a reliable and valid method for depression screening in chronically ill elderly patients. *Journal of Clinical Epidemiology*. 2008;61(7):679-87.

63. Kroenke K, Spitzer RL, et al. An ultra-brief screening scale for anxiety and depression: the PHQ-4. *Psychosomatics*. 2009;50(6):613-21.
- 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-10 criteria. The term 'depressive symptoms' is used where self-report is not yet confirmed by a clinical interview.
 - b. 22%, 35% and 23% respectively have moderate-to-severe depressive symptoms (PHQ-9 total score ≥ 10).
 - c. Severe diabetes distress (PAID total score ≥ 40)
 - d. Moderate-to-severe depressive symptoms (PHQ-9 total score ≥ 10)
 - e. PAID total score < 40 and PHQ-9 total score < 10
 - g. Diabetes-specific references have been cited where available.

Anxiety disorders



Key messages

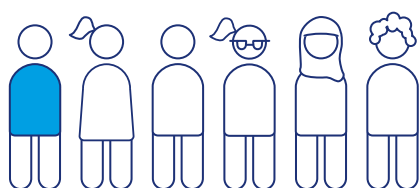
- An anxiety disorder^a is a psychological condition indicated by frequent, intense and excessive worry, occurring for at least six months, and substantially affecting daily functioning and causing significant distress. It includes feeling nervous, anxious or on edge, and not being able to stop or control these feelings.
- Moderate-to-severe anxiety symptoms, an indication of an anxiety disorder, affect one in five people with insulin-treated Type 2 diabetes, and one in six with Type 1 diabetes or non-insulin-treated Type 2 diabetes; this is within the range of general population estimates.
- Elevated anxiety symptoms in people with diabetes:
 - are associated with sub-optimal diabetes self-management and metabolic outcomes, diabetes complications, depressive symptoms, and impaired quality of life
 - can be difficult to recognise, as severe anxiety and panic attacks share some similar physical symptoms to hypoglycaemia (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).



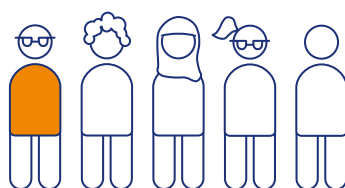
Practice points

- 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 GP.
- Remain mindful that elevated anxiety symptoms also need attention, as they can develop into an anxiety disorder.

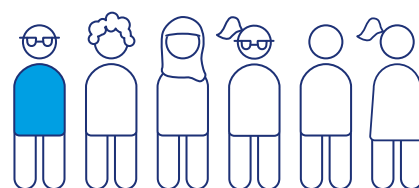
How common are elevated symptoms of anxiety?



Type 1 diabetes^{b,1}



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 characterised by persistent and excessive anxiety and worry.² This is also known as clinical anxiety. The worry is accompanied by a variety of symptoms³

- emotional (feeling uneasy, worried, irritable or panicked, including experiencing panic attacks)
- cognitive (thinking that one cannot cope, or having difficulty concentrating)
- behavioural (aggression, restlessness, fidgeting or avoidance)
- 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:^{2,3}

- generalised anxiety disorder: intense excessive and daily worries about multiple situations
- social anxiety disorder: intense excessive fear of being scrutinised by other people, resulting in avoidance of social situations
- panic disorder: recurrent, unpredictable, and severe panic attacks
- 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 standardised clinical diagnostic interview, for example the Structured Clinical Interview for DSM Disorders (SCID; 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)³ and the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10).² For example, generalised 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:³

- restlessness or feeling 'on edge'
- being easily fatigued
- difficulty concentrating or mind going blank
- irritability
- muscle tension
- 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, derealisation (feelings of detachment from one's surroundings), depersonalisation (feeling detached from oneself), and fear of 'going crazy', 'losing control', fainting, or dying.^{2,3}

A subthreshold anxiety disorder is characterised 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,⁴ and deserve attention in clinical practice.

Anxiety disorders in people with diabetes

Diabetes is associated with both elevated anxiety symptoms and anxiety disorders.⁵ This relationship may be bi-directional but this has not been confirmed, as most studies have been cross-sectional.⁵ 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.⁵ Further research is needed regarding the specific types of anxiety disorders associated with Type 1 and Type 2 diabetes.⁵

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.⁴ 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.⁴

In people with diabetes, elevated anxiety symptoms are associated with adverse medical and psychological outcomes, including:

- sub-optimal self-management and unhealthy behaviours (e.g. reduced physical activity, smoking, or heavy use of alcohol)⁶⁻¹²
- elevated HbA1c^{6,13-15} and other sub-optimal metabolic indicators (e.g. higher BMI, waist-hip ratio, waist circumference, triglycerides, or blood pressure; lower HDL cholesterol)^{6,7,9,16}
- increased prevalence of diabetes-related complications and co-morbidities^{8,12,17,18}
- the presence of depressive symptoms^{6,12,15} and impaired quality of life.^{15,19,20}



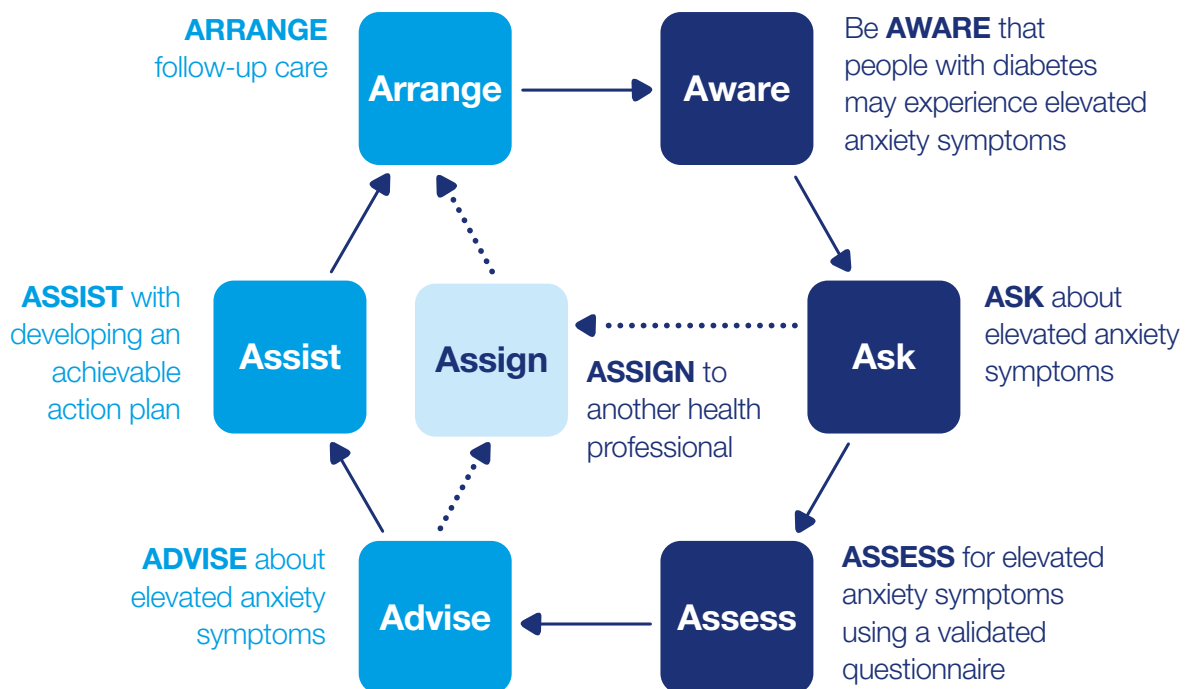
People with a co-existing anxiety disorder and depressive symptoms are likely to experience greater emotional impairment and take longer to recover.²¹

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

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



How can I identify elevated anxiety symptoms?

Be AWARE

Anxiety disorders have emotional, cognitive, behavioural 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-5³ and ICD-10.² 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 hypoglycaemia (and vice versa). For example, pounding heart, confusion, shaking, sweating, dizziness, headache, and nausea are symptoms of both hypoglycaemia and panic attacks.²²

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.²²

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/ behaviours)
- 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, hospitalisation, or severe hypoglycaemia with loss of consciousness)
- if the individual has a history of anxiety disorder(s) or other mental health problems
- in line with clinical practice guidelines



Take the time to **ASK** about well-being at every consultation. 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 impacting on 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.²³ They are the core symptoms required for a diagnosis of generalised 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.

Sum the responses to the two questions to form a total score. A total score of 3 or more indicates elevated anxiety symptoms,²³ 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 **Chapter 1**.

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)²⁴ was designed to identify symptoms of generalised anxiety disorder. It is also a helpful indicator of panic attack and social anxiety.^{23,25} 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 summed to form a total score ranging 0-21.

In the general population, GAD-7 scores are interpreted as follows:²⁶

- 0-4 indicates no anxiety symptoms (or a minimal level)

- 5-9 indicates mild anxiety symptoms
- 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 hypoglycaemia 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-5³ or ICD-10² 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 generalised anxiety disorder, social anxiety disorder, or panic disorder?²⁷ It is important to consider whether the person has multiple co-morbid anxiety disorders.²⁸

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 hypoglycaemia, see **Chapter 4**)?

Are there any factors (psychological, physiological, or behavioural) that are co-existing 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.²⁷ 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? How long it took them to recover?).
- Is there an underlying medical cause for the symptoms? For example, hypoglycaemia; hyperthyroidism or hypothyroidism; an inner ear, cardiac, or respiratory condition; vitamin B deficiency; or medication side-effects.²⁷
- 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?²⁸ 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
- 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
 - 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.
- Recognise 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 needs and preferences of the person with diabetes
 - your qualifications, knowledge, skills and confidence to address elevated anxiety symptoms
 - the severity of the anxiety symptoms, and the context of the problem(s)
 - whether other psychological problems are also present, such as diabetes distress (see Chapter 3) or depression (see Chapter 6)
 - 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
 - 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 spontaneously²⁹, so intervention is important. The stepped care approach provides guidance on how to address elevated anxiety symptoms and anxiety disorders in clinical practice.³⁰⁻³²

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)
 - 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. At the end of this chapter, there are several resources that may be helpful for a person with diabetes who is experiencing an anxiety disorder. 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 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 remit 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 generalised anxiety disorder, social anxiety disorder and panic disorder is usually selective serotonin re-uptake inhibitors (SSRIs).^{21,33} Pharmacological treatment is not standard first-line treatment for specific phobias.²¹
- First-line psychological intervention for generalised anxiety disorder, social phobia, panic disorder and specific phobia is usually cognitive behavioural therapy (CBT).^{21,33} Where avoidance behaviour is present, CBT should be combined with exposure.³³
- The current evidence base does not support combining pharmacological and psychological approaches for generalised anxiety disorder or social anxiety disorder.^{21,33} Combined psychological intervention and pharmacological treatments can be beneficial for panic disorder.^{21,33}
- Some medications used to treat mental health problems (e.g. antidepressants, anxiolytics, neuroleptics) can have adverse side effects, such as weight gain and metabolic abnormalities, and are associated with insulin resistance.³⁴ Benzodiazepines are generally not recommended as a first-line treatment due to the risk of addiction.²⁴ 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.^{30,31,35,36,39} A recent trial found a stepped care approach to be effective for reducing anxiety symptoms in people with diabetes.³²
- Early intervention is likely to benefit people with subthreshold anxiety disorder.⁹ Little research has been conducted into the effectiveness of psychological and pharmacological interventions.⁹ A stepwise approach has been proposed, beginning with watchful waiting and gradually increasing the intensity of intervention as symptoms persist or increase.^{9,40}

ASSIGN

The vast majority of specialist diabetes services in the UK do not have an integrated mental health professional, such as a clinical psychologist, to refer to. Therefore, the majority of referrals will be made to professionals outside the diabetes service. These might include: ^{39,40}

A general practitioner to undertake a clinical interview and diagnose major depression, and/or 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. cognitive behavioural therapy or interpersonal therapy).

- **A psychiatrist** to undertake a clinical interview and prescribe and monitor medications. A GP referral is usually required to access a psychiatrist. Referral to a psychiatrist is likely to 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).
- Community Mental Health Teams can help the person find ways to effectively manage situations that are contributing to their anxiety or inhibiting their treatment (e.g. trauma or life stresses), using psychologically-based therapies and skills training (e.g. problem solving and stress management).

- **Improving Access to Psychological Therapies – Long Term Conditions (IAPT-LTC)** are accessible in some areas in England. These services focus on people with long term conditions, including diabetes. Local contact details can be found online (see ‘Resources’ section).

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 with a GP or diabetes specialist (e.g. an endocrinologist, diabetes specialist nurse, and/or diabetes specialist 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
- 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 more frequent follow-up visits or extended consultations are required until the person feels stronger emotionally. Encourage them 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 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 agreed that I would refer you to see a psychologist. Have you had an appointment with the psychologist? How has this worked out for you?’

Case Study



Deepa

37-year-old woman living with her partner, George

Type 1 diabetes, (diagnosed 21 years ago)

Health professional: Dr Ariadne Pappas (Diabetologist)

Be AWARE

Deepa has not been feeling 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 hypoglycaemia). She likes things in her life to be in order, so this change from the ordinary concerns her. Deepa 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 Deepa's concerns and acknowledges that some of the symptoms may be related to Deepa'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 Deepa's symptoms: sometimes Deepa sweats or shakes, and when this happens her heart beats faster than usual. This has happened to Deepa a few times on

the train to work in the city. It is physically and mentally draining for Deepa; 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 Deepa to complete two screening questionnaires: for anxiety (GAD-7) and depression (PHQ-9). Deepa 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 HbA1c and asks to look at Deepa'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 Deepa and asks her if this fits with how she has been feeling lately. She also explains to Deepa 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. Deepa appears interested in seeking treatment and support. Dr Pappas advises Deepa to make an appointment for an extended consultation with her GP as soon as possible to discuss the best treatment options for her. She explains that a GP can diagnose the anxiety and, if necessary, organise psychological treatment and prescribe medication. She offers Deepa plenty of opportunity to ask questions, and Deepa agrees to see her GP. Dr Pappas gives Deepa a copy of the 'Diabetes and Anxiety' Fact Sheet ([see resources section](#)).

ASSIGN

With Deepa's permission, Dr Pappas writes a letter to Deepa's GP and includes the scores and interpretation of the GAD-7 and PHQ-9 questionnaires.

ARRANGE

Dr Pappas and Deepa agree that Dr Pappas will write a letter to Deepa's GP, with the agreed plan that Deepa will make an appointment for an extended consultation with her GP for the following week. Dr Pappas and Deepa arrange a follow-up appointment once she has seen her GP. With agreement from Deepa Dr Pappas telephones Deepa's GP to check that they will make an appointment available to her in a timely manner. Dr Pappas encourages Deepa to contact her via telephone if she has any difficulty getting an appointment with the GP.

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: Mai Nguyen (and dietitian)

Be AWARE

Ned was recently diagnosed with Type 2 diabetes, and his dyslexia is causing him some challenges with self-management. His GP has referred him to Mai for diabetes education. Mai and Ned have met twice and have begun to build a good rapport. Mai 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. Mai has observed Ned to be quite an anxious person, as he:

- fidgets during consultations
- gets visibly nervous (shaky hands, sweaty palms), particularly when practising reading food labels; his nervousness seems to be related to reading and interpreting written information
- expresses worries about whether he is getting his diabetes management 'right'.

Mai 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

Mai enquires about why Ned has not been sleeping. He tells her that 'I can't switch my brain off... I worry 'bout my dad – he's not been well, and how the kids are going at school, and now there's this diabetes thing... and the little things worry me too – noises at night, whether I locked the car... Faye says I'm a "worry wart". She won't say it, but it annoys her... I can't help it'. Mai 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

Mai 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 Mai:

- opens a copy of the GAD-7 on her computer screen
- reads the GAD -7 questions and response options aloud to Ned and asks him to respond to each question.

Ned scores 17, indicating severe anxiety symptoms.

ADVISE

Mai explains that Ned's score is high – that this is more than just worry – it indicates a possible diagnosis of anxiety. 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 GP. If you do have an anxiety disorder, then he will confirm it and he can help you to treat it, too, with medication or a referral for psychological support, 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. Mai tells him that anxiety is very common, with one in five men experiencing an anxiety disorder at some stage in their life.⁸ Mai 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 GP.

ASSIGN

Mai explains that Ned can continue to see her for diabetes education but he will also need to see his GP to address the anxiety, as this is outside her expertise. She proposes that she write a referral to his GP, including his questionnaire responses and scores. Ned agrees to make an appointment with the GP. Mai suggests that he sees the GP as soon as possible, and that he requests an extended consultation so that they have plenty of time.

ARRANGE

They agree that Ned will return to see Mai in one week. They would like to continue with the diabetes education, and Mai would like to check Ned’s progress with his GP regarding his anxiety symptoms. Due to the severity of Ned’s symptoms, Mai calls his GP to check that the referral was 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 below, please tick the box 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 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 = _____

	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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

Background

The GAD-7^{27,29} is a seven-item questionnaire for assessing anxiety symptoms and their severity. It has satisfactory psychometric properties for screening for generalised anxiety disorder, panic disorder and social anxiety disorder.^{27,29}

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.³⁰

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 generalised anxiety disorder).^{28,30} Items are scored on a scale from 0 (not at all) and 3 (nearly every day).³⁰

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 publication²⁴ but not in the version on the website, and has been included in the questionnaire.



For tips about using questionnaires, see 'Using questionnaires to inform consultations' (see Chapter 1).

Interpretation of scores

The scores for each item are summed to generate a total score (range: 0-21).³⁰ Anxiety symptom severity is indicated by the GAD-7 total score.³⁰ Generally, a GAD-7 total score of 10 or more is an indicator of likely anxiety disorder,^{29,30} and needs to be followed up with a clinical interview.

GAD-7 total score	Anxiety symptom severity
0-4	None – minimal
5-9	Mild
10-14	Moderate
15-21	Severe

Short form – GAD-2

- The GAD-2^{27,29} 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.^{27,29}

Resources

For health professionals

Peer-reviewed literature

- **Association of diabetes with anxiety: a systematic review and meta-analysis**

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.

- **Anxiety disorders: assessment and management in general practice**

Describes the diagnosis, assessment and management of anxiety disorders in general practice.

Source: Kyrios M, Moulding R, et al. Australian Family Physician. 2011;40(6):370-374.

Finding Specialist Services

- **Find a psychologist:**

<https://www.bps.org.uk/public/find-psychologist> This directory of Chartered Psychologists is provided by the British Psychological Society. Chartered psychologist are listed by locality and specialist area of interest.

- **Improving access to psychological therapies (IAPT) :**

Find a service: [https://www.nhs.uk/Service-Search/Psychological-therapies-\(IAPT\)/LocationSearch/10008](https://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008)

Guidelines

- **National Institute for Health and Care Excellence Guidelines (NICE): Anxiety**

Clinical guidelines for the care and treatment of anxiety

Source: National Institute for Health and Care Excellence guidelines (NICE) (2014). Anxiety Disorders. Accessed online September 2018:

<https://www.nice.org.uk/guidance/qs53>

Books

- **Management of mental disorders (5th edition)**

A book that provides practical guidance for clinicians in recognising and treating mental health problems, including generalised 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. CreateSpace. 2014.

Additional information: Sections of this book (e.g. treatment manuals and worksheets) are freely available to download from the 'Support for clinicians' section of the Clinical Research Unit for Anxiety and Depression (CRUfAD) website at www.crufad.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.

Information

- **Mind:**

Mental health charity offering information (and telephone and online support), including discussion forums.

Tel: 03001233393

Email: info@mind.org.uk

Website: www.mind.org.uk

- **Mind's specific anxiety information**

Information about anxiety, including possible causes and how to access treatment and support.

Website: www.mind.org.uk/information-support/types-of-mental-health-problems/anxiety-and-panic-attacks/anxiety-disorders/#.W5O2XOhKjIU

- **Anxiety and Diabetes Fact Sheet:**

Description: A factsheet specifically to accompany this guide, giving information about anxiety and how to manage it

Website: www.diabetes.org.uk/emotional-health-professionals-guide

- **Rethink Mental Illness, Guide to Anxiety:**
Description: A factsheet from the charity Rethink Mental Illness, with sections including types of anxiety, causes and ways to get treatments
Website: <https://www.rethink.org/resources/a/anxiety-disorders-factsheet>
- **NHS Apps Library (Mental Health):**
Description: Apps for mental health support, from the NHS digital website –
Website: https://apps.beta.nhs.uk/category/mental_health/
- **NHS Apps Library: (Diabetes)**
Description: Apps for health and wellbeing with diabetes, including emotional help, from the NHS digital website
Website: <https://apps.beta.nhs.uk/category/diabetes/>
- **Anxiety. An NHS Self-Help Guide:**
Description: A 20-page booklet from the Northumberland Tyne and Wear NHS Trust containing information and practical ways to manage anxiety
Website: <https://web.ntw.nhs.uk/selfhelp/>

Books

- **Mind Over Mood: Change How You Feel by Changing the Way You Think (1995, Greenberger, D. and Padesky, C. Guilford).**
A self-help book to learn how to change unhelpful thoughts and solve problems, with a chapter specially focusing on anxiety.
Website: https://www.amazon.co.uk/Mind-Over-Mood-Second-Changing/dp/1462520421/ref=pd_lpo_sbs_14_img_0/261-8472430-1202157?encoding=UTF8&psc=1&refRID=92NW5NSGVYNGP145B6HX
- **Overcoming Anxiety: A Self-Help Guide Using Cognitive Behavioral Techniques (2009, Kennerley, H., Robinson Books).**
A self-help book to learn how to overcome a range of anxieties, in a step-by-step format.
Website: https://www.amazon.co.uk/Overcoming-Anxiety-Self-help-Bahvioural-Techniques/dp/1459643410/ref=sr_1_3?s=books&ie=UTF8&qid=1548510570&sr=1-3&keywords=overcoming+anxiety

- **Diabetes and Wellbeing: Managing psychological and Emotional Challenges in Type 1 and Type 2 Diabetes (2013, Nash, J., John Wiley and Sons).**
A book written by Dr Jen Nash, Clinical Psychologist who lives with Type 1 diabetes, with a chapter on managing the anxiety of living with both type 1 and type 2 diabetes
Website: <https://www.wiley.com/engb/Diabetes+and+Wellbeing:+Managing+the+Psychological+and+Emotional+Challenges+of+Diabetes+Types+1+and+2-p-9781119967187>

Support

- **Diabetes UK Online Support Forum**
An online discussion forum for people living with diabetes to access information and support, with many different topics being discussed. The Welcome page explains more about it and where to find support for specific aspects of your diabetes, including anxiety
Website: <https://forum.diabetes.org.uk/boards/forums/welcome-and-getting-started.37/>
- **Diabetes UK information on emotional wellbeing and support**
A website page giving information and ideas of ways to access emotional support
Website: www.diabetes.org.uk/guide-to-diabetes/life-with-diabetes/emotional-issues
- **Type 1 Resources:**
A collection of useful websites and resources to help manage life with type 1 diabetes:
Website: www.t1resources.uk/resources/managing-life/
- **Find a psychologist:**
This directory of Chartered Psychologists is provided by the British Psychological Society. Chartered psychologist are listed by locality and specialist area of interest.
Website: www.bps.org.uk/public/find-psychologist
- **Improving access to psychological therapies (IAPT) :**
IAPT is an NHS service providing treatment for anxiety and depression. There is a search function to find local IAPT services on the NHS website:
Website: [https://www.nhs.uk/Service-Search/Psychological-therapies-\(IAPT\)/LocationSearch/10008](https://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008)

References

1. Speight J, Browne JL, et al. Diabetes MILES – Australia 2011 Survey Report. Diabetes Australia – Vic, Melbourne: 2011.
2. World Health Organization (WHO). International Statistical Classification of Diseases and Related Health Problems (ICD-10). 10th Revision: Version 2015 ed. Geneva: WHO; 2015.
3. American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders (DSM-5). 5th ed. Arlington, VA: American Psychiatric Association; 2013.
4. Haller H, Cramer H, et al. The prevalence and burden of subthreshold generalized anxiety disorder: a systematic review. *BioMed Central Psychiatry*. 2014;14(1):128.
5. Smith KJ, Béland M, et al. Association of diabetes with anxiety: a systematic review and meta-analysis. *Journal of Psychosomatic Research*. 2013;74(2):89-99.
6. Balhara YPS, Sagar R. Correlates of anxiety and depression among patients with type 2 diabetes mellitus. *Indian Journal of Endocrinology and Metabolism*. 2011;15(Suppl 1):S50-4.
7. Engum A, Mykletun A, et al. Depression and diabetes: A large population-based study of sociodemographic, lifestyle, and clinical factors associated with depression in type 1 and type 2 diabetes. *Diabetes Care*. 2005;28(8):1904-9.
8. Collins M, Corcoran P, et al. Anxiety and depression symptoms in patients with diabetes. *Diabetic Medicine*. 2009;26(2):153-61.
9. Bener A, Al-Hamaq A, et al. High prevalence of depression, anxiety and stress symptoms among diabetes mellitus patients. *Open Psychiatry Journal*. 2011;5:5-12.
10. Lipscombe C, Smith KJ, et al. Gender differences in the relationship between anxiety symptoms and physical inactivity in a community-based sample of adults with type 2 diabetes. *Canadian Journal of Diabetes*. 2014;38(6):444-50.
11. Lloyd C, Dyer P, et al. Prevalence of symptoms of depression and anxiety in a diabetes clinic population. *Diabetic Medicine*. 2000;17(3):198-202.
12. Wu S-FV, Huang Y-C, et al. Relationships among depression, anxiety, self-care behaviour and diabetes education difficulties in patients with type-2 diabetes: a cross-sectional questionnaire survey. *International Journal of Nursing Studies*. 2011;48(11):1376-83.
13. Ludman E, Katon W, et al. Panic episodes among patients with diabetes. *General Hospital Psychiatry*. 2006;28(6):475-81.
14. Anderson RJ, de Groot M, et al. Anxiety and poor glycemic control: a meta-analytic review of the literature. *The International Journal of Psychiatry in Medicine*. 2002;32(3):235-47.
15. Labad J, Price J, et al. Symptoms of depression but not anxiety are associated with central obesity and cardiovascular disease in people with type 2 diabetes: the Edinburgh type 2 diabetes study. *Diabetologia*. 2010;53(3):467-71.
16. Khuwaja AK, Lalani S, et al. Anxiety and depression among outpatients with type 2 diabetes: A multi-centre study of prevalence and associated factors. *Diabetology & Metabolic Syndrome*. 2010;2:72.
17. Fisher L, Skaff MM, et al. A longitudinal study of affective and anxiety disorders, depressive affect and diabetes distress in adults with type 2 diabetes. *Diabetic Medicine*. 2008;25:1096-101.
18. Peyrot M, Rubin RR. Levels and risks of depression and anxiety symptomatology among diabetic adults. *Diabetes Care*. 1997;20(4):585-90.
19. de Ornelas Maia ACC, de Azevedo Braga A, et al. Comorbidity of depression and anxiety: association with poor quality of life in type 1 and 2 diabetic patients. *Clinical Practice and Epidemiology in Mental Health*. 2013;9:136-41.

20. Kohen D, Burgess A, et al. The role of anxiety and depression in quality of life and symptom reporting in people with diabetes mellitus. *Quality of Life Research*. 1998;7(3):197-204.
21. Baldwin DS, Anderson IM, et al. Evidence-based pharmacological treatment of anxiety disorders, post-traumatic stress disorder and obsessive-compulsive disorder: a revision of the 2005 guidelines from the British Association for Psychopharmacology. *Journal of Psychopharmacology*. 2014;28(5):403-39.
22. McDade-Montez EA, Watson D. Examining the potential influence of diabetes on depression and anxiety symptoms via multiple sample confirmatory factor analysis. *Annals of Behavioral Medicine*. 2011;42(3):341-51.
23. Kroenke K, Spitzer RL, et al. Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection. *Annals of Internal Medicine*. 2007;146(5):317-25.
24. Spitzer RL, Kroenke K, et al. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*. 2006;166(10):1092-7.
25. Kroenke K, Spitzer RL, et al. The patient health questionnaire somatic, anxiety, and depressive symptom scales: a systematic review. *General Hospital Psychiatry*. 2010;32(4):345-59.
26. Spitzer RL, Williams JBW, et al. Instruction manual: instructions for Patient Health Questionnaire (PHQ) and GAD-7 measures, [cited 5 February 2015]. Available from: www.phqscreeners.com.
27. Kyrios M, Mouding R, et al. Anxiety disorders: assessment and management in general practice. *Australian Family Physician*. 2011;40(6):370-4.
28. Katzman MA, Bleau P, et al. Canadian clinical practice guidelines for the management of anxiety, posttraumatic stress and obsessive-compulsive disorders. *BioMed Central Psychiatry*. 2014;14(Suppl 1):S1.
29. Dixon A, Kozłowska K. Distinct developmental presentations. In: Boyce P, Harris A, et al., editors. *The Sydney Handbook of Anxiety Disorders: a guide to the symptoms, causes and treatments of anxiety disorders*. Sydney: Sydney Medical School, The University of Sydney; 2015.
30. National Institute for Health and Care Excellence (NICE). *Common mental health disorders: Identification and pathways to care*. London: 2011.
31. Muntin A, van der Feltz-Cornelis C, et al. Effectiveness of collaborative stepped care for anxiety disorders in primary care: a pragmatic cluster randomised controlled trial. *Psychotherapy and Psychosomatics*. 2014;83(1):37-44.
32. Stoop C, Nefs G, et al. Effectiveness of a stepped care intervention for anxiety and depression in people with diabetes, asthma or COPD in primary care: A randomized controlled trial. *Journal of Affective Disorders*. 2015;184:269-76.
33. Bandelow B, Lichte T, et al. The diagnosis of and treatment recommendations for anxiety disorders. *Deutsches Ärzteblatt International*. 2014;111(27-28):473-80.
34. Bystritsky A, Danial J, et al. Interactions between diabetes and anxiety and depression: implications for treatment. *Endocrinology and Metabolism Clinics of North America*. 2014;43(1):269-83.
35. Archer J, Bower P, et al. Collaborative care for depression and anxiety problems. *Cochrane Database of Systematic Reviews*. 2012;10:CD006525.
36. Goorden M, Muntin A, et al. Cost utility analysis of a collaborative stepped care intervention for panic and generalized anxiety disorders in primary care. *Journal of Psychosomatic Research*. 2014;77(1):57-63.
37. Helmchen H, Linden M. Subthreshold disorders in psychiatry: clinical reality, methodological artifact, and the double-threshold problem. *Comprehensive Psychiatry*. 2000;41(2):1-7.
38. Pfizer. Patient Health Questionnaire (PHQ) Screeners [cited 15 May 2014]. Available from: www.phqscreeners.com.
39. Diabetes UK Report. *Minding the Gap: The provision of psychological support and care for people with diabetes in the UK*. Diabetes UK, 2009b

40. National Institute for Health and Care Excellence guidelines (2014). Anxiety Disorders. Accessed online September 2018: <https://www.nice.org.uk/guidance/qs53>
- a. In this chapter, the term ‘anxiety disorder’ is used when diagnosis is confirmed by a clinical interview according to DSM-5 or ICD-10 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 hypoglycaemia, hyperglycaemia, injections, or complications), which are discussed in Chapter 4.
 - b. 15%, 19%, and 14% respectively have moderate-to-severe anxiety symptoms (GAD-7 total score ≥ 10).
 - c. Evidence is currently only available for type 2 diabetes.
 - d. Diabetes-specific references have been cited where available.

Eating problems



Key messages

- The term 'eating problems' encompasses both 'sub-clinical' disordered eating behaviours and full syndrome eating disorders.
- **Disordered eating behaviours** 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, binge eating disorder), which are characterised by preoccupation with food and body weight, disordered eating behaviour, with or without compensatory weight control behaviours.
- Among people with diabetes, the full syndrome eating disorders are rare. The most common disordered eating behaviours are binge eating and insulin restriction/omission but prevalence is not well established.
- Eating problems in people with diabetes are associated with sub-optimal 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 the diabetes management in parallel.

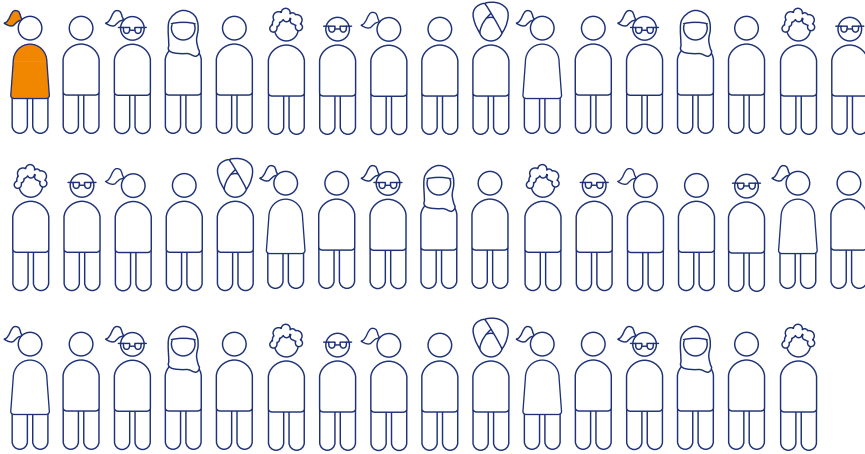


Practice points

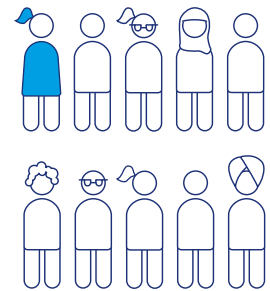
- Ask the person directly, in a sensitive/non-judgemental way, about eating behaviours and attitudes towards food, insulin restriction/omission, and concerns about body weight/shape/ size.
- Be aware not to positively reinforce weight loss or low HbA1c when eating problems are (likely) present.
- Be aware that acute changes in HbA1c 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, binge eating disorder)

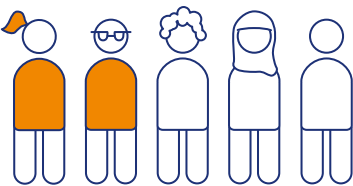


Type 1 diabetes^{a,1-3}

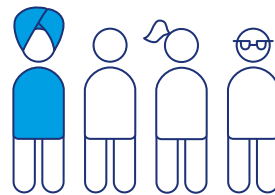


Type 2 diabetes^{2,4,5}

Disordered eating behaviours



Type 1 diabetes⁶⁻⁹



Type 2 diabetes^{4,10-12}

See Box 8.1 for background about this section.

What are eating problems?

Eating disorders

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

- **Anorexia nervosa:** characterised 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 behaviour interfering with weight gain; and disturbance in self-perceived weight or shape. There are two subtypes:

- restricting subtype with severe restriction of energy intake
- binge eating/purging subtype with restriction of food intake and occasional binge eating and/or purging (e.g. self-induced vomiting, misuse of laxatives).

- **Bulimia nervosa:** characterised by recurrent episodes of binge eating, at least once a week for three months, and compensatory weight control behaviours. 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:** characterised 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 behaviours and are often overweight or obese.
- **Other specified or unspecified feeding or eating disorders:** characterised 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.

The complete diagnostic criteria for the abovementioned eating disorders can be found in the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10)¹³ and Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5).¹⁴ The criteria for eating disorders were revised in the fifth edition of the DSM.¹⁴

Although eating disorders develop typically during adolescence, they can develop during childhood or develop/continue in adulthood; they occur in both sexes.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.³

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 behaviours in people with diabetes.^{1,3} Dietary behaviours used to manage Type 1 diabetes could be considered problematic or disordered for people without 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 behaviours, such as insulin restriction/omission.¹⁸

In addition, most studies have included predominantly female adolescents or young adult women and sample sizes are small.¹⁶

Due to such limitations, the evidence of eating problems in adults with diabetes is limited and findings should be interpreted and generalised 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 population¹
- people with diabetes are more likely to present with periodic overeating, binge eating and compensatory weight control behaviours,¹⁹ with more frequent and severe behaviours likely to meet criteria for a full syndrome eating disorder such as bulimia nervosa or binge eating disorder.

Future studies about eating behaviours 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 behaviours

These are characterised 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 behaviours can develop into a full syndrome eating disorder. The following disordered eating behaviours can present in isolation or as part of an eating disorder:¹⁴

- **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 behaviours:** 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, 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 inappropriate compensatory weight control behaviour.¹⁶ Intentional insulin restriction or omission induces hyperglycaemia and loss of glucose (and calories) in the urine, enabling a person to eat with reduced concerns about gaining weight. It is sometimes referred to as 'diabulimia' by the media and those who are struggling, although insulin restriction is the preferred clinical term.
- Estimates of insulin omission have been reported in up to 40% of people with Type 1

diabetes.² However, people omit or restrict insulin for other reasons than weight loss (e.g. fear of hypoglycaemia).

- 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 in other more typical eating disorder ways.

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.²⁶ For example:²⁷

- 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 time²⁸ and tends to be more common in people who are overweight or obese.²⁹
- 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.³⁰

Emotional and external eating may increase the likelihood of snacking on high fat or high sugar foods,³⁰ higher energy intake,³¹ overeating and binge eating,³² and night-time snacking.³³

- 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 sub-optimal HbA1c.³⁴

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.

- Both general negative affect and diabetes distress substantially increase the odds of insulin restrictions.¹⁷

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:

- **Behavioural 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.^{21, 22}
- **Physical changes:** people with Type 1 diabetes commonly experience weight loss prior to diagnosis, and weight gain following insulin treatment,¹⁶ whilst overweight and obesity is associated with the diagnosis of Type 2 diabetes.²³ Increasing body weight is associated with body dissatisfaction and concerns about body shape,¹⁶ which in turn increases the risk of developing disordered eating.²⁴
- **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.²⁵
- **Physiological changes:** in Type 1 diabetes, beta cells are destroyed and unable to secrete insulin and amylin,¹⁶ whilst beta cell functioning declines and insulin resistance worsens over time in people with Type 2 diabetes.²⁵ 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.¹⁶

It may be difficult to distinguish disordered eating behaviours from self-care behaviours required for diabetes management, both include weighing foods, counting calories and carbohydrates, and avoiding certain foods. Signs of disordered eating behaviours may remain undetected if mistaken for 'normal' diabetes management behaviours.^{16,19}

Diabetes self-management behaviours 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 behaviours can interfere with activities of daily living, pose a significant health risk, and impair the person's emotional well-being.¹⁶

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 targets³⁵
- impaired mental health.³⁵

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

- earlier onset of¹⁶ and increased risk of microvascular complications^{8,36} (e.g. retinopathy, neuropathy)
- more frequent episodes of diabetic ketoacidosis and diabetes-related hospital admissions^{6,37,38}
- up to three times greater risk of mortality over a 6-10 year period.^{18,39}

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

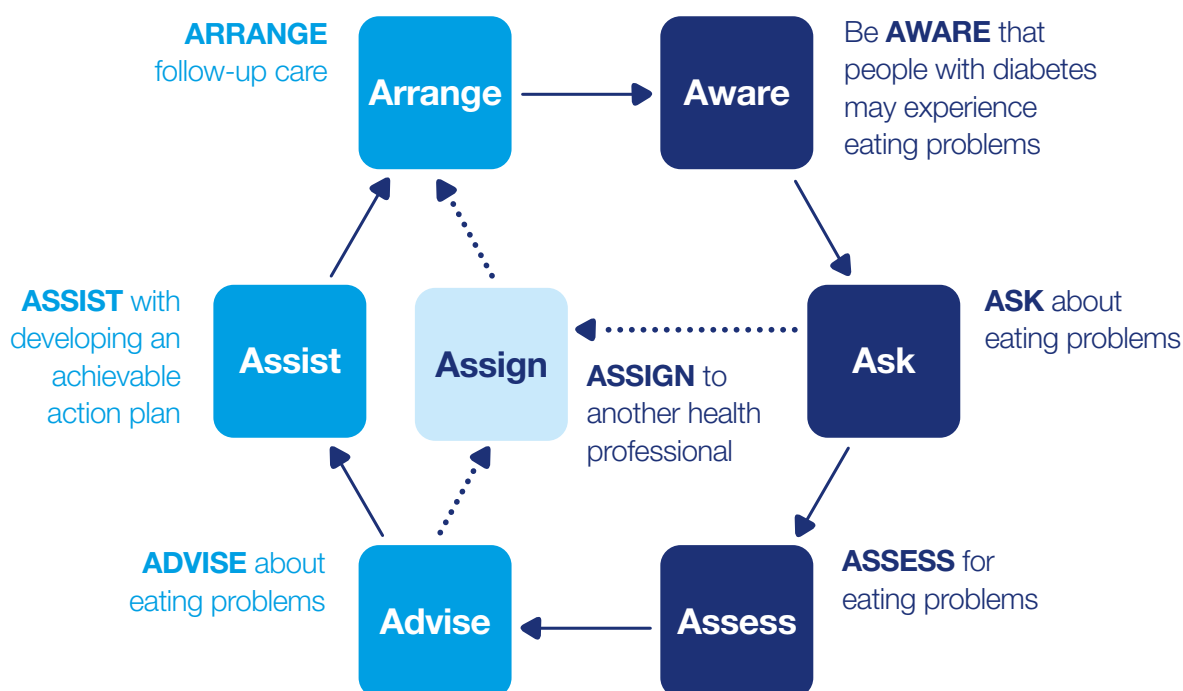
- overweight and obesity^{40,41}
- lower self-efficacy for diet and exercise self-management¹²
- sub-optimal dietary and glucose levels, but not HbA1c⁴²
- not taking medications as recommended⁴³
- impaired mental health⁴⁴ and quality of life.^{4,12,45}

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

Apply the model flexibly as part of a person-centred 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 behaviour: ^{2,18,19}

- 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 be: reluctance having their weight taken, negative self-statements about weight and/or shape)
- unexplained weight loss or gain
- sub-optimal 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), missed clinical appointments
- sub-optimal diabetes outcomes, including: unexplained high or low HbA1c (a sign of

food restriction without insulin omission); acute change in HbA1c (a sign of the onset of an acute eating disorder, often with insulin omission); erratic fluctuating blood glucose levels; recurrent hypoglycaemia (with binge eating and self-induced vomiting); recurrent diabetic ketoacidosis and diabetes-related hospitalisations; and early development of microvascular complications

- depression, distress, 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
- physical signs as a consequence of an eating disorder (e.g. calluses on the hands, oedema, dental problems).

Not all of the abovementioned 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-5¹⁴ and ICD-10.¹³ 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 behaviours 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 enquiry 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-judgemental way, about eating and weight management behaviours, as well as concerns about body weight/shape/size.

Option 1: Ask open-ended questions

You may find it helpful to lead in to 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 behaviours, 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, behaviours, 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 changes/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’ or ‘Do you ever adjust your insulin to influence your weight?’ Explore how often this occurs, and the person’s beliefs and feelings about medication restriction/omission.
- ‘Your HbA1c 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 behaviours in people with Type 1 or 2 diabetes who use insulin therapy. Health professionals may feel uncomfortable to ask about insulin omission/restriction for the same reason. Whether or not this conversation can take place comes back to the respectful and non-judgemental 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' in [Chapter 1](#)). Maladaptive behaviours such as insulin omission often go unrecognised 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 behaviours (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 hypoglycaemic episode. You might like to use following questions¹⁷ related to hypoglycaemia:

- '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 behaviours/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)
- deny the seriousness of their symptoms and condition.

Therefore, creating a respectful, non-judgemental, 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 giving them an information leaflet about disordered eating with reference to online or telephone support (see '[Resources](#)' section).



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 behaviour. 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.

However, the SCOFF (a screening questionnaire for eating disorders)⁴⁶ was recently modified for people with diabetes (mSCOFF) and trialled with a small sample of adolescent girls with Type 1 diabetes.⁴⁷

The mSCOFF consists of five questions:

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

© American Diabetes Association 2014.⁴⁷ Reproduced with permission. Permission conveyed through Copyright Clearance Centre, Inc.

For information about using questionnaires in clinical practice, see [Chapter 1](#).



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

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 be related to weight loss purposes.



The Diabetes Eating Problem Survey – Revised (DEPS-R) is a 16-item diabetes-specific questionnaire, which has been validated, but only in youth and adolescents with Type 1 diabetes.⁴⁸

If disordered eating behaviours 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?'). From a clinical perspective, any problematic eating behaviour 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 behaviours/ 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 NICE Clinical Guidelines NG69¹⁵ and recommendations specifically for type 1 diabetes in Goebel-Fabbri.⁴⁹

Clinical interview

A clinical interview assesses:

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

Also see [AWARE](#) and the abovementioned 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 blood tests (e.g. HbA1c, ketones, potassium, sodium).¹⁵ The clinical examination is also able to exclude any other conditions that could cause changes in weight or appetite.⁵⁰

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



Blood tests and/or physical symptoms do not always confirm an eating disorder even when one is present.⁵⁰



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 behaviours: consider assessing their eating styles (see [Box 8.2](#)) or body dissatisfaction. Referral to a diabetes specialist 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 behaviours and eating disorders. Depression (see [Chapter 6](#)) and disordered eating behaviours commonly occur together,² 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 behaviours 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, 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.
- Recognise 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 consultation, 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 blood test results, I wonder if you might be struggling with disordered eating or 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 (behaviours): The general practitioner (GP) involved in the person’s diabetes management has a key role in the early detection of disordered eating behaviours and/or body dissatisfaction. If the person is experiencing disordered eating, GPs are best placed to coordinate collaborative care with other health professionals, such as a dietitian and a psychologist (see Box 8.3). Because diabetes adds to the complexity of an eating problem, input/support from a diabetes health professional (e.g. diabetologist or credentialed diabetes nurse educator with diabetes specialist) for adjusting the diabetes treatment plan may also be required. Thus, if you are not the person’s GP, you will need to **ASSIGN** the person to their GP, 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 (see Box 8.3).¹⁵ Inclusion of a specialist in diabetes

in the team is also essential.⁵⁰ 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 according to geography and include outpatient, day programme and inpatient treatment in severe cases.¹⁵ Where to **ASSIGN** will depend on multiple factors (e.g. availability of services, type and severity of the eating disorder, geography).
- The Australian and New Zealand guidelines recommend treatment in the least restrictive context possible, utilising a stepped care approach.¹⁵ 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.¹⁵

Box 8.3

The collaborative care team

The multidisciplinary collaborative care team for eating problems must include:^{49,50}

- **A medical practitioner (either a GP or diabetologist)** to obtain the person's medical history and arrange the medical checks required to diagnose/treat eating problems. They can also assist with the general medical and diabetes-specific aspects of care during the treatment/therapy of the eating problem. The GP is often also well placed to co-ordinate the collaborative care team and to take on long-term follow-up of the person.
- **A mental health professional, preferably with expertise in eating disorders and diabetes** (either a diabetes specialist **psychologist** or **psychiatrist**) to provide psychotherapy and address the psychological and social aspects of the eating disorder, as well as any co-existing mental health problems (e.g. mood or anxiety disorders).
- **A diabetes specialist dietitian**, to assist with developing flexible and structured eating plans appropriate for people with

diabetes⁴⁹ and medical nutrition therapy goals appropriate for people with both diabetes and an eating disorder. Also, a dietitian can support people with diabetes to have strategies in place to effectively deal with cues to overeating (e.g. negative emotions, low blood glucose) when they arise.

- **A diabetes specialist nurse to provide diabetes-specific care throughout treatment.**

Ideally, all members of the collaborative care team will have knowledge, skills, and experience in both eating disorders and diabetes; however, it may be unlikely everyone in the team will have this combined expertise. A health professional with experience in eating disorders only, can be trained by and collaborate closely with diabetes experts.

Keep consistency in messages and treatment goals, philosophy, and delivery by facilitating regular communication between all team members. This will also help to ensure smooth transitions between services.

ASSIST

Evidence for the management of eating disorders in combination with diabetes is very limited.⁵¹ Thus, in practice, general eating disorder treatments are applied to address the needs of people who are living with both conditions.

Once disordered eating behaviour(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 (see Box 8.3):

- Provide information about the specific eating problem that was identified during the comprehensive clinical assessment, and its likely impact on diabetes management/outcomes and general health.
- Explain and discuss treatment options with the person to enable them to make a well-informed decision. This will help them to engage with the treatment/therapy, which will likely be a combination of:
 - an adapted diabetes management and dietary plan: with more flexible and realistic blood glucose targets, and with less focus on weight loss or strict dietary plans
 - psychological therapies: for example, family-based therapy (if the person is still living with family), enhanced cognitive behaviour therapy (CBT-E) or interpersonal therapy (IPT). These aim to address -unhelpful thoughts, emotions, and behaviours (CBT-E) or problems in relationships (IPT)^{52,53}
 - pharmacological treatments.¹⁵

- Assist the person to access appropriate support and treatment (e.g. if you are a GP: establish a collaborative care team, including referral to a relevant health professional who can provide psychological therapy).
- Explain that a collaborative approach is needed, and which health professionals will be part of the team (see Box 8.3).
- 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. At the end of this chapter, there are several resources that may be helpful for a person with diabetes who is experiencing eating problems.

Select **one** or **two** of these that are most relevant for the person; it is best not to overwhelm them with too much information.



There may be a need to work with the family and to liaise with schools and other agencies if the person with diabetes is still living at home or attending school.¹⁵



Eating disorder treatment recommendations specific to Type 1 diabetes can be found in the NICE guidelines (15) and Goebel-Fabbi.⁴⁹

ASSIGN

If the person is at immediate risk: they will need to go to hospital. For example, people with recurrent episodes of diabetes ketoacidosis, cardiac arrhythmias, hypothermia, hypotension, electrolyte abnormalities, or if the person has stopped taking insulin,^{19,49} should be referred to specialist inpatient services or taken to the nearest hospital for treatment.

If the person is not at immediate risk: refer them to specialist eating disorder outpatient services or day programmes.

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. blood test assessments, 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 consultation about the person's progress (e.g. have they engaged with the planned 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 (GP)

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 five kilograms over the past few months
- feels down about her weight and embarrassed about her body.

ASK

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

- 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 (specialising 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). Lydia refers Sarah to a psychologist and a dietitian (preferably with an understanding of diabetes).

ARRANGE

Despite her concerns, Lydia is satisfied that Sarah is not at immediate risk. She asks 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.

“My relationship with food now... it’s hard... sometimes I just feel like I don’t enjoy my food, because I’ve got to think so hard about what goes into my mouth, and then I’ve got everyone around me telling me what to do.

Like today I haven’t eaten... and I’ve been trying to keep on top of my insulin which I haven’t been doing the best...”

(Person with Type 2 diabetes)

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 (Diabetologist)

Be AWARE

Mark has been seeing Eliza 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 hospitalised twice for diabetic ketoacidosis. Additionally, her most recent HbA1c was 116 mmol/mol (12.8%), while previously it ranged between 53 and 64 mmol/mol (7-8%). 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. Eliza has her next appointment with Mark.

ASK

Mark informs Eliza about her most recent HbA1c result. He asks how she feels about this result, whether she expected it, and about her recent hospitalisations.

Mark notices that Eliza's appearance and demeanour 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
- answers his questions with few words.

Mark asks Eliza what she thinks may be causing the higher HbA1c. 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 hospitalisations, 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 behaviour and body image. Eliza indicates that she:

- has lost about around 6kg 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
- misses insulin when she feels like she has eaten too much
- started missing insulin eight months ago, at first sporadically, but now on most days
- continues to inject long-acting insulin at night
- 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 missing 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
- it is important to address eating problems as early as possible, to prevent them 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.

ASSIGN

Given Eliza's recent hospitalisations for diabetic ketoacidosis and her ongoing insulin omission, Mark suggests that Eliza attends a specialist outpatient clinic for eating disorders to see a psychologist and a dietitian (preferably with an understanding of diabetes). Although initially Eliza is hesitant to be referred to other health professionals, she understands that her future health is at risk. She agrees for Mark to contact the outpatient clinic to arrange for and make a referral.

ARRANGE

Mark and Eliza agree to see each other again in two weeks. 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 behaviour in individuals with diabetes: Importance of context, evaluation, and classification**

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**

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**

This overview paper describes procedures for assessment and interventions for people with Type 1 and Type 2 diabetes,

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

Websites (not diabetes specific)

- **Centre for Eating and Dieting Disorders**

This website contains information for health professionals including links to guidelines, information on prevention, assessment and treatment, factsheets, and case studies. Look for the 'Health Professionals' section of the website.

Source: www.cedd.org.au

- **Anorexia & Bulimia Care (In partnership with the Royal College of General Practitioners).**

Online training course in Eating Disorders for GPs and primary healthcare professionals.

Source: <http://www.anorexiabulimiacare.org.uk/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.

Support

- **Diabetes UK**

Facts and further information about insulin omission ('diabulimia') and how to access the Helpline, with dedicated, trained counsellors to help.

Phone: 0345 123 2399

Website: <https://www.diabetes.org.uk/guide-to-diabetes/life-with-diabetes/diabulimia>

- **Diabetics With Eating Disorders**

Diabetics With Eating Disorders (DWED) is a UK based charity that supports and advocates for people who struggle with both Type 1 diabetes and any kind of eating disorder. Provides online support and resources along with training for health professionals.

Website: <http://dwed.org.uk/>

- **BEAT Eating Disorders**

Provides support for people (with or without diabetes) struggling with any type of eating disorder. Support groups, helplines and information leaflets.

Phone Helpline: 0808 801 0677

Website: <https://www.beateatingdisorders.org.uk/>

- **Anorexia and Bulimia Care**

Providing information and support for non-diabetes specific eating disorders. Support for family and carers.

Helpline: 03000 11 12 13

Website: <http://www.anorexiabulimiacare.org.uk>

- **The Eating Blueprint**

Information and support for individuals struggling with external/non-hunger/binge eating difficulties. Offers psychological strategies to support weight management. Free online Starter Pack available from the website.

Website: www.EatingBlueprint.com

Information

- **Eating Disorders: An NHS Self-Help Guide**

A booklet on 'Eating Disorders' that can be freely downloaded from Northumberland Tyne and Wear NHS Foundation Trust.

Website: <https://web.ntw.nhs.uk/selfhelp/>

- **Disordered eating /diabulimia and diabetes**

An area of the T1 Resources website with information and video

Source: T1 Resources

Website: <https://www.t1resources.uk/resources/item/disordered-eating-diabulimia-and-diabetes-infographic/>

Books

- **Getting Better Bit(e) by Bit(e)**

(2007, Ulrike Schmidt and Janet Treasure, Routledge, UK).

A self-help 'Survival Kit' for people struggling with bulimia and binge eating disorders.

- **Diabetes and Wellbeing: Managing psychological and Emotional Challenges in Type 1 and Type 2 Diabetes**

(2013, Dr Jen Nash, John Wiley and Sons, UK).

Written by Dr Jen Nash, Clinical Psychologist who lives with Type 1 diabetes, with a chapter titled 'Managing Food, Weight and Emotions'.

References

1. Mannucci E, Rotella F, et al. Eating disorders in patients with type 1 diabetes: a meta-analysis. *Journal of Endocrinological Investigation*. 2005;28(5):417-9.
2. Pinhas-Hamiel O, Levy-Shraga Y. Eating disorders in adolescents with type 2 and type 1 diabetes. *Current Diabetes Reports*. 2013;13(2):289-97.
3. Young V, Eiser C, et al. Eating problems in adolescents with type 1 diabetes: a systematic review with meta-analysis. *Diabetic Medicine*. 2013;30(2):189-98.
4. Wilfley D, Berkowitz R, et al. Binge eating, mood, and quality of life in youth with type 2 diabetes: Baseline data from the TODAY study. *Diabetes Care*. 2011;34(4):858-60.
5. Herpertz S, Albus C, et al. Relationship of weight and eating disorders in type 2 diabetic patients: a multicenter study. *International Journal of Eating Disorders*. 2000;28(1):68-77.
6. Colton P, Olmsted M, et al. Disturbed eating behavior and eating disorders in preteen and early teenage girls with type 1 diabetes: a case-controlled study. *Diabetes Care*. 2004;27(7):1654-9.
7. Jones JM, Lawson ML, et al. Eating disorders in adolescent females with and without type 1 diabetes: cross sectional study. *British Medical Journal*. 2000;320(7249):1563-6.
8. Rydall AC, Rodin GM, et al. Disordered eating behavior and microvascular complications in young women with insulin- dependent diabetes mellitus. *New England Journal of Medicine*. 1997;336(26):1849-54.
9. Stancin T, Link DL. Binge eating and purging in young women with IDDM. *Diabetes Care*. 1989;12(9):601-3.
10. Lawrence JM, Liese AD, et al. Weight-loss practices and weight-related issues among youth with type 1 or type 2 diabetes. *Diabetes Care*. 2008;31(12):2251-7.
11. Herpertz S, Albus C, et al. Comorbidity of diabetes mellitus and eating disorders: A follow-up study. *Journal of Psychosomatic Research*. 2001;51(5):673-8.
12. Kenardy J, Mensch M, et al. Disordered eating behaviours in women with type 2 diabetes mellitus. *Eating behaviors*. 2001;2(2):183-92.
13. World Health Organization. *International statistical classification of diseases and related health problems (ICD-10)*. 10th Revision: Version 2015 ed. Geneva: WHO; 2015.
14. American Psychiatric Association. *Diagnostic and statistical manual of mental health disorders (DSM-5)*. 5th ed. Washington DC. 2013. Hay P,.
15. National Institute for Health and Care Excellence Guidelines (NICE (2017) *Eating disorders, recognition and treatment*. NG69: National Institute for Health and Care Excellence.
16. Young-Hyman DL, Davis CL. Disordered eating behavior in individuals with diabetes: Importance of context, evaluation, and classification. *Diabetes Care*. 2010;33(3): 683-9.
17. Merwin RM, Moskovich AA, et al. Disinhibited eating and weight-related insulin mismanagement among individuals with type 1 diabetes. *Appetite*. 2014;81:123-30.
18. Criego A, Crow S, et al. Eating disorders and diabetes: screening and detection. *Diabetes Spectrum*. 2009;22(3):143-6.
19. Gagnon C, Aimé A, et al. Comorbid diabetes and eating disorders in adult patients assessment and considerations for treatment. *The Diabetes Educator*. 2012;38(4):537-42.
20. Striegel RH, Bedrosian R, et al. Why men should be included in research on binge eating: results from a comparison of psychosocial impairment in men and women. *International Journal of Eating Disorders*. 2012;45(2): 233-40.
21. Stice E, Marti CN, et al. Risk factors for onset of eating disorders: evidence of multiple risk pathways from an 8-year prospective study. *Behaviour research and therapy*. 2011;49(10):622-7.

22. Jacobi C, Hayward C, et al. Coming to terms with risk factors for eating disorders: application of risk terminology and suggestions for a general taxonomy. *Psychological Bulletin*. 2004;130(1):19.
23. Wang Y, Rimm EB, et al. Comparison of abdominal adiposity and overall obesity in predicting risk of type 2 diabetes among men. *The American Journal of Clinical Nutrition*. 2005;81(3):555-63.
24. Wertheim EH, Koerner J, et al. Longitudinal predictors of restrictive eating and bulimic tendencies in three different age groups of adolescent girls. *Journal of Youth and Adolescence*. 2001;30(1): 69-81.
25. Blinder BJ, Cumella EJ, et al. Psychiatric comorbidities of female inpatients with eating disorders. *Psychosomatic Medicine*. 2006;68(3):454-62.
26. Braet C, Claus L, et al. Differences in eating style between overweight and normal-weight youngsters. *Journal of Health Psychology*. 2008;13(6):733-43.
27. van Strien T, Frijters JE, et al. The Dutch Eating Behavior Questionnaire (DEBQ) for assessment of restrained, emotional, and external eating behavior. *International Journal of Eating Disorders*. 1986;5(2):295-315.
28. van Strien T, Herman CP, et al. Eating style, overeating and weight gain. A prospective 2-year follow-up study in a representative Dutch sample. *Appetite*. 2012;59(3):782-9.
29. Geliebter A, Aversa A. Emotional eating in overweight, normal weight, and underweight individuals. *Eating Behaviors*. 2003;3(4):341-7.
30. Cleobury L, Tapper K. Reasons for eating 'unhealthy' snacks in overweight and obese males and females. *Journal of Human Nutrition and Dietetics*. 2014;27(4):333-41.
31. van de Laar F, van de Lisdonk E, et al. Eating behaviour and adherence to diet in patients with Type 2 diabetes mellitus. *Diabetic Medicine*. 2006;23(7):788-94.
32. Wardle J. Compulsive eating and dietary restraint. *British Journal of Clinical Psychology*. 1987;26(1):47-55.
33. Nolan LJ, Geliebter A. Night eating is associated with emotional and external eating in college students. *Eating Behaviors*. 2012;13(3):202-6.
34. Martyn-Nemeth P, Quinn L, et al. Diabetes distress may adversely affect the eating styles of women with type 1 diabetes. *Acta diabetologica*. 2014;51(4):683-6.
35. Bernstein CM, Stockwell MS, et al. Mental health issues in adolescents and young adults with type 1 diabetes prevalence and impact on glycemic control. *Clinical Pediatrics*. 2013;52(1):10-5.
36. Steel JM, Young RJ, et al. Clinically apparent eating disorders in young diabetic women: associations with painful neuropathy and other complications. *British Medical Journal (Clinical Research Edition)*. 1987;294:859-62.
37. Nielsen S, Emborg C, et al. Mortality in concurrent type 1 diabetes and anorexia nervosa. *Diabetes Care*. 2002;25(2):309-12.
38. Larrañaga A, Docet MF, et al. Disordered eating behaviors in type 1 diabetic patients. *World Journal of Diabetes*. 2011;2(11):189.
39. Goebel-Fabbri AE, Fikkan J, et al. Insulin restriction and associated morbidity and mortality in women with type 1 diabetes. *Diabetes Care*. 2008;31(3):415-9.
40. Meneghini LF, Spadola J, et al. Prevalence and associations of binge eating disorder in a multiethnic population with type 2 diabetes. *Diabetes Care*. 2006;29(12):2760.
41. Crow S, Kendall D, et al. Binge eating and other psychopathology in patients with Type II diabetes mellitus. *International Journal of Eating Disorders*. 2001;30(2):222-6.
42. Rotella F, Cresci B, et al. Are psychopathological features relevant predictors of glucose control in patients with type 2 diabetes? A prospective study. *Acta Diabetologica*. 2012;49(Supplement 1):S179-S84.
43. Goebel-Fabbri AE, Uplinger N, et al. Outpatient management of eating disorders in type 1 diabetes. *Diabetes Spectrum*. 2009;22(3): 147-52.

44. Ali S, Stone M, et al. The prevalence of comorbid depression in adults with type 2 diabetes: a systematic review and meta-analysis. *Diabetic Medicine*. 2006;23(11): 1165-73.
 45. Cerrelli F, Manini R, et al. Eating behavior affects quality of life in type 2 diabetes mellitus. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*. 2005;10(4): 251-7.
 46. Morgan JF, Reid F, et al. The SCOFF questionnaire: assessment of a new screening tool for eating disorders. *BMJ*. 1999;319(7223):1467-8.
 47. Zuijdwijk C, Pardy S, et al. The mSCOFF for screening disordered eating in pediatric type 1 diabetes. *Diabetes Care*. 2014;37(2):e26-7.
 48. Markowitz JT, Butler DA, et al. Brief screening tool for disordered eating in diabetes internal consistency and external validity in a contemporary sample of pediatric patients with type 1 diabetes. *Diabetes Care*. 2010;33(3):495-500.
 49. Goebel-Fabbri AE. Disturbed eating behaviors and eating disorders in type 1 diabetes: Clinical significance and treatment recommendations. *Current Diabetes Reports*. 2009;9(2):133-9.
 50. Colton P, Rodin G, et al. Eating disorders and diabetes: introduction and overview. *Diabetes Spectrum*. 2009;22(3):138-42.
 51. Fairburn CG, Bailey-Straebler S, et al. A transdiagnostic comparison of enhanced cognitive behaviour therapy (CBT-E) and interpersonal psychotherapy in the treatment of eating disorders. *Behaviour Research and Therapy*. 2015;70:64-71.
 52. Watson H, Bulik CM. Update on the treatment of anorexia nervosa: review of clinical trials, practice guidelines and emerging interventions. *Psychological Medicine*. 2013;43(12): 2477-500.
- a. Based on young women only.
 - b. The original item refers to one stone (14 pounds).
 - c. 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).
 - d. Call charges may apply.

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 hypoglycaemia).
- If the person is experiencing a mental health problem (e.g. eating disorder or depression) and you do not have the expertise to assist, a referral to a general practitioner (GP) or mental health professional will be necessary.
- Some mental health problems require immediate attention and referral to a specialised service or admission to hospital (e.g. an eating disorder with direct risk for the person, or acute suicide risk).



Practice points

- Talk with the person with diabetes about the reasons for the referral and ask them about their thoughts and feelings about 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-centred approach to diabetes care and which problems need referral to a mental health professional.

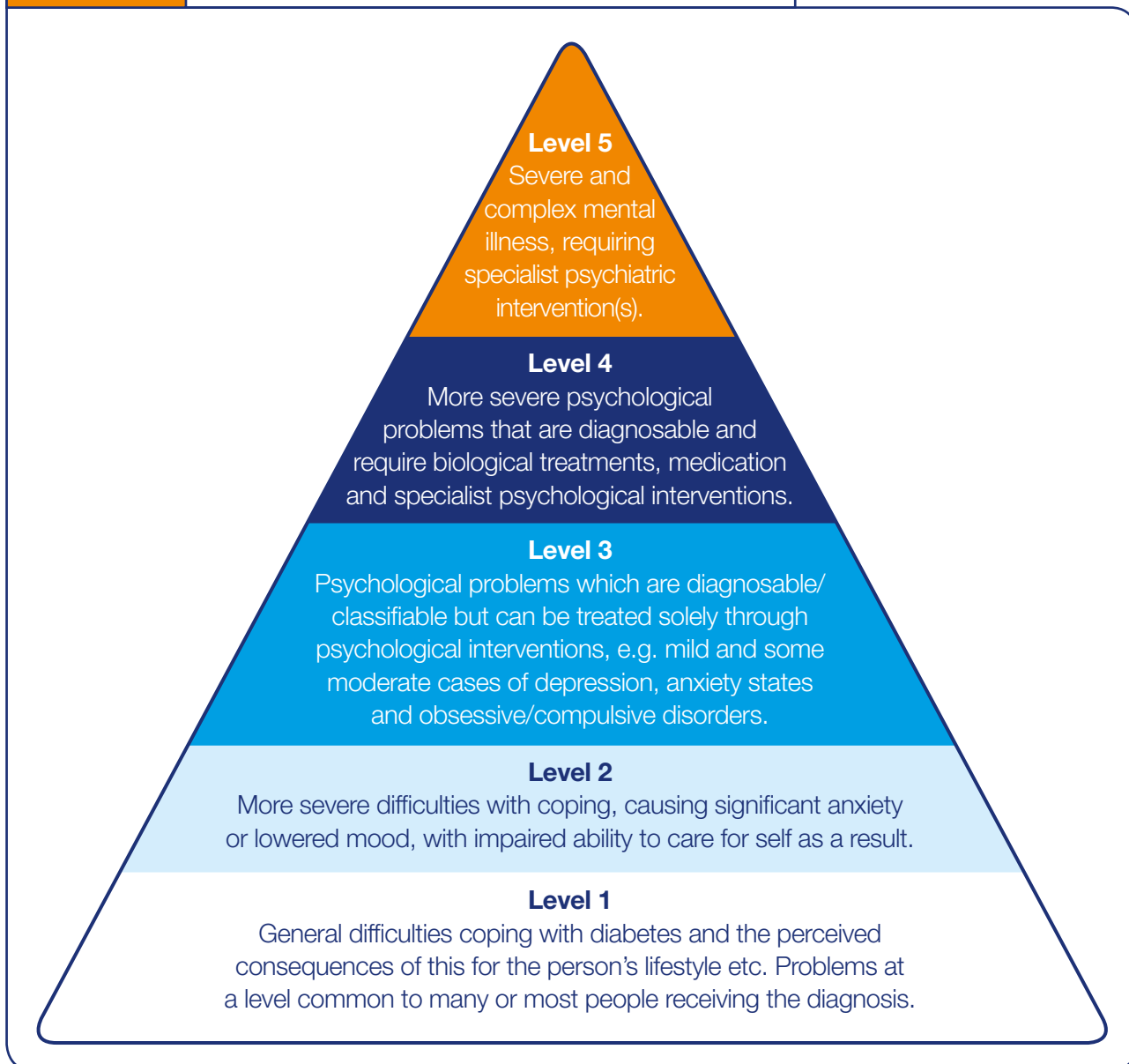
Most people with diabetes (Level 1 of the pyramid in [Box 9.1](#)) experience only general or mild difficulties in coping with their diabetes and will benefit largely from the support and counselling that their usual diabetes health professionals can offer. Moving up the pyramid, the more severe and 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 co-exist 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



©Diabetes UK/NHS 2010. Reproduced with permission.¹

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).

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.

- **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, normalise 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. It is helpful to be familiar with local referral pathways and to develop professional networks with appropriately trained individuals and services both inside and outside the NHS who provide psychological support and intervention to people 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.
- **Prepare the person for what to expect at the mental health consultation.**^{2,3,4} 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 consultation (e.g. 45-60 minutes) and subsequent consultations; the duration of the therapy will be decided together with the mental health professional. There may also be tasks they need to complete between consultations (e.g. keeping a record of their mood).

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 • NHS record number
<input type="checkbox"/>	Purpose of the referral	Your reason for writing the referral (e.g. to establish a diagnosis, or to treat major depression).
<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	Where available, include validated questionnaire scores (and/or a copy of the completed questionnaire), and interpretation of the results of any suicide risk assessment.
<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	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.
<input type="checkbox"/>	Consent	Document that the person has provided consent for the referral.
<input type="checkbox"/>	Your contact details	<p>For example, your:</p> <ul style="list-style-type: none"> • name • practice name • address • telephone • email address.
<input type="checkbox"/>	Your signature and the date	Complete the referral with your signature and the date.

- **Explain waiting times and service limitations.**⁴ 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). Monitor the person and make a plan to revisit the option of a mental health referral at another time, as needed.
- Talk about their experience of the mental health intervention. For example, ‘You had a few sessions with the psychologist. How is that working out for you? How have things been since you’ve been talking about things?’ 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. 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’.

Writing the referral

After agreeing with the person with diabetes that referral is the best option, you can then write a referral letter. In addition, you may also choose to have a telephone or Skype conversation about the presenting problem with the mental health professional to whom you are referring the person. Retain a copy of the letter in the person’s file and send a copy of the letter to the GP and, if appropriate, the person with diabetes themselves.

You may already have a standardised template for the referral letter. If not, a general guide about what to include is offered in [Box 9.3](#).

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.⁴ 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:

- 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 impact on 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

A crisis referral must be considered⁵ when:

- someone feels they are no longer able to cope
- someone is fearful they might lose control
- someone is expressing strong suicidal feelings or are experiencing visual or auditory hallucinations.

If you feel someone is at risk to themselves, or to someone else, you must refer them to a mental health service. Check whether the person is already known to mental health services. If so, contact that particular service.

In England, you can call NHS 111 if someone requires urgent, but not life threatening, care. For example:

- if they have an existing mental health problem and symptoms are getting worse
- if they are experiencing a mental health problem for the first time
- if someone has self-harmed but it does not appear to be life-threatening, or is talking about wanting to self-harm
- if a person shows signs of onset dementia
- if a person is experiencing domestic violence or physical, sexual or emotional abuse

Alternatively, contact their GP practice and ask for an emergency appointment with the first available doctor.

A mental health emergency needs to be taken as seriously as a medical emergency. Call 999 (from anywhere in the UK) if someone is experiencing an acute life-threatening mental health emergency. People in crisis can be directed to the nearest Accident and Emergency (A&E) department if immediate help is needed or if you are worried about their ability to keep themselves safe.

Many hospitals now have a liaison psychiatry team to address mental health issues that present to Accident and Emergency. If this service is not available, the A&E team will contact the local on-call mental health services, such as the Crisis Resolution and Home Treatment Team (CRHTs).

When to contact social services?

Beyond a crisis situation, it may be more appropriate to call social services if you have urgent concerns about someone's social or domestic circumstances, such as vulnerable children and young people, vulnerable adults or people with learning disabilities⁶. Social services can be contacted out-of-hours. Social services may also be involved in the assessment of people in crisis through the legislation of the Mental Health Act.

Resources

Resources for Health Professionals

Making a referral

NHS E-referrals: https://digital.nhs.uk/binaries/content/assets/legacy/pdf/14/nhs_e-referral_service_mental_health_services.pdf

MENTAL HEALTH CRISIS RESPONSE: <https://www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Pages/mental-health-emergencies.aspx>

MANAGING RISK: SAFEGUARDING POLICY: <https://www.england.nhs.uk/wp-content/uploads/2015/07/safeguard-policy.pdf>

Increasing Access to Psychological Therapies (IAPT): <https://www.england.nhs.uk/mental-health/adults/iapt/>

Guidelines

NICE Guidance on Common Mental health Problems: Identification and pathways to care (CG123): <https://www.nice.org.uk/guidance/cg123>

NICE Guidance on Depression (CG90): <https://www.nice.org.uk/guidance/cg90>

Resources for people with diabetes

Information

Patient information: <https://www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Pages/accessing%20services.aspx>

Patient rights: <https://www.england.nhs.uk/wp-content/uploads/2018/02/choice-in-mental-health-care-v2.pdf>

Support

NHS Moodzone, including self help, how to get help urgently and a listing of mental health helplines: <https://www.nhs.uk/conditions/stress-anxiety-depression/>

Finding IAPT Services locally: [https://www.nhs.uk/service-search/Psychological-therapies-\(IAPT\)/LocationSearch/10008](https://www.nhs.uk/service-search/Psychological-therapies-(IAPT)/LocationSearch/10008)

References

1. Emotional and Psychological Support Working Group of NHS Diabetes and Diabetes UK. Emotional and Psychological Support and Care in Diabetes. NHS Diabetes and Diabetes UK, London: 2010 [accessed 28 January 2019]. Available from: www.diabetes.org.uk/About_us/What-we-say/Diagnosis-ongoing-management-monitoring/Emotional-and-Psychological-Support-and-Care-in-Diabetes
2. How to access NHS mental health services. (accessed 28 January 2019) <https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/how-to-access-mental-health-services/>
3. Information about mental health services (accessed 28 January 2019) <https://www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Pages/accessing%20services.aspx>
4. Information about patient rights (accessed 28 January 2019) <https://www.england.nhs.uk/wp-content/uploads/2018/02/choice-in-mental-health-care-v2.pdf>
5. Crisis mental health referrals (accessed 28 January 2019) <https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/dealing-with-a-mental-health-crisis-or-emergency/>
6. NHS England Safeguarding policy (accessed 28 January 2019) <https://www.england.nhs.uk/wp-content/uploads/2015/07/safeguard-policy.pdf>

Appendix A: 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 organisations.

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, coping with negative emotions
- linkages to formal healthcare or community resources – help with navigating the health system
- ongoing support reflecting the long-term nature of the condition – encouraging and engaging with proactive follow-up.

Diabetes peer support programmes can lead to improvements in:²⁻⁸

- behavioural outcomes (e.g. self-monitoring, medication-taking, healthy eating, physical activity)
- psychosocial outcomes (e.g. diabetes knowledge, self-efficacy, emotional distress, quality of life)
- health outcomes (e.g. reductions in blood glucose, blood pressure, body mass index).

Ultimately, this may lead to reduced healthcare utilisation and reduced healthcare costs.

Peer support takes many forms, including one-to-one mentoring, support groups, and online forums. The table below lists some examples of UK diabetes peer support initiatives.

Many of these organisations also hold references to other forms of peer support not mentioned in this listing.

Organisation/Initiative	Details	Contact
Diabetes UK	Diabetes UK is a British-based healthcare charity aiming to create a world where diabetes can do no harm. It funds research, campaigns for better care, raises awareness to prevent Type 2 diabetes and supports people living with and affected by the condition, to make sure that everyone can live well with diabetes. And eventually find a cure. It also provides face to face local support groups, an online support forum and a helpline of trained counsellors.	www.diabetes.org.uk 0345 123 2399
Juvenile Diabetes Research Foundation (JDRF) (merged with INPUT Diabetes in 2018)	JDRF are committed to eradicating Type 1 diabetes and its effects for everyone in the UK with Type 1, and at risk of developing it.	https://jdrf.org.uk/ 020 7713 2030 info@jdrf.org.uk
T1 Diabetes Resources	A collection of resources for Type 1 Diabetes, including blogs, experiences and discussions between people living with it.	www.t1resources.uk/resources/all-resources/

My Diabetes My Way	NHS Scotland-wide interactive website to help support people with who have diabetes and their family and friends.	https://www.mydiabetesmyway.scot.nhs.uk
Circle D	Facebook and Twitter support group for (mainly) 18-30s with diabetes of any type. Kent local meet ups, 'rant room' & other places where Circle D groups have developed. 'You are not alone' is their motto	www.facebook.com/circledrocks/ Twitter: @circled
Diabetics With Eating Disorders (DWED)	Online support via Facebook and other social media platforms, for those dealing with eating disorders and (mainly) Type 1 diabetes.	http://dwed.org.uk
InDependent Diabetes Trust (IDDT)	A charity run by people living with diabetes to support people living with diabetes, including a telephone helpline and a conference for people to meet and discuss living with diabetes	https://www.iddt.org Telephone: 01604 622837 Email: enquiries@iddtinternational.org
Great Britain Diabetes Online Community (The GBDOC)	24/7 discussions, conversations and support. Weekly 'tweetchat' focussing on a particular topic; Facebook groups; blogs; occasional conferences	Twitter: @thegebdoc #gebdoc #ourD
Talking About Diabetes (TAD)	Website and annual conference for people living with diabetes aimed at showcasing peoples' inspiring stories to generate discussion about innovation and new technologies through shared experiences	http://talkingaboutdiabetes.co.uk/about-us/ Twitter: #tadtalk2018
Diabetes self-management education courses (offered locally as part of diabetes care)	Group programmes to give information about living well with diabetes, also giving the chance to meet and share experiences with others with diabetes.	X-PERT (Type 2) www.xperthealth.org.uk DESMOND: (Type 2) www.desmond-project.org.uk DAFNE: (Type 1) www.dafne.uk.com Find local diabetes services provision at www.nhs.uk and following the relevant country and then your local area
NHS England Type 1 Resource	A collection of resources for Type 1 diabetes, including a get support section, detailing many ways people living with diabetes can access support	www.nhs.uk/conditions/type-1-diabetes/get-support/

References

1. Fisher EB, Ayala GX, et al. Contributions of peer support to health, health care, and prevention: papers from Peers for Progress. *The Annals of Family Medicine*. 2015;13 (Suppl 1):S2-S8.
2. Glasgow RE, Boles SM, et al. The D-Net diabetes self-management program: long-term implementation, outcomes, and generalization results. *Preventive Medicine*. 2003;36(4):410-9.
3. Baksi A, Al-Mrayat M, et al. Peer advisers compared with specialist health professionals in delivering a training programme on self-management to people with diabetes: a randomized controlled trial. *Diabetic Medicine*. 2008;25(9):1076-82.
4. Heisler M, Vijan S, et al. Diabetes control with reciprocal peer support versus nurse care management: a randomized trial. *Annals of Internal Medicine*. 2010;153(8):507-15.
5. Pratt C, Wilson W, et al. Peer support and nutrition education for older adults with diabetes. *Journal of Nutrition for the Elderly*. 1987;6(4):31-43.
6. Keyserling TC, Samuel-Hodge CD, et al. A randomized trial of an intervention to improve self-care behaviors of African-American women with type 2 diabetes: impact on physical activity. *Diabetes Care*. 2002;25(9):1576-83.
7. Lorig K, Ritter PL, et al. Community-based peer-led diabetes self-management: a randomized trial. *The Diabetes Educator*. 2009;35(4):641-51.
8. Lorig K, Ritter PL, et al. Online diabetes self-management program: a randomized study. *Diabetes Care*. 2010;33(6):1275-81.

Appendix B: 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 categorised 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.

Source of distress: negative emotions		
Explore how negative feelings could be reduced:	Explore ways of coping with stress:	Explore worries related to diabetes complications (acute and chronic):
<ul style="list-style-type: none"> • Ask ‘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, reading a book). • How could the person incorporate ‘their quality time’ into their daily schedule? <p>Explore whether – and how – social support could help in reducing diabetes distress:</p> <ul style="list-style-type: none"> • Is there someone they can talk to? • Would they like to join a support group or online forum? (see Appendix A for Peer Support Opportunities) 	<ul style="list-style-type: none"> • Identify whether the person’s perceptions of their risks are realistic. • 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 ◦ how can they live a long and healthy life with 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"> • Ask the person whether they would like to be informed 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. 	<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 diabetes specialist nurse. • Ask whether the person would like to receive information about structured diabetes education programs like DAFNE, DESMOND or X-PerT (find out more at www.diabetes.org.uk/education) 	<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) their 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 A).

Source of distress: interpersonal relationships

<p>Ask the person if it would be helpful to invite their partner or family/friends to join them at the next consultation:</p>	<p>Support the person to become more assertive in their interactions with their partner or family/friends:</p>	<p>Promote peer support:</p>
<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 ○ what help they would appreciate from their partner or family/friends. • Explore what resources might support them to have such conversations with their family members or friends • Be alert to the possible need for specialist therapy for interpersonal relationships 	<ul style="list-style-type: none"> • Describe what peer support is, and the benefits. • Provide details of peer support initiatives (see Appendix A).

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, at the start of the consultation, ask what they would like to discuss today. • 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 or what information they need. • Suggest the type of support from HCPs that would work best for them, eg text, email, face to face, between formal appointments

At the end of the conversation about diabetes distress:

- Ask the person how they are feeling now 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, perhaps from the list of resources at the end of [Chapter 3](#), 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.

Appendix C: 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.

Barrier: myths and misunderstandings about insulin (e.g. insulin causes diabetes to worsen, insulin causes complications, 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 hyperglycaemia could be a motivator to change). • Ask whether: <ul style="list-style-type: none"> ○ they know other people with Type 2 diabetes using insulin ○ 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). • Emphasise that Type 2 diabetes can be a progressive condition, insulin use is very commonly needed. • Counterbalance their concerns with benefits (e.g. insulin helps to improve glycaemic 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 in Chapter 5), 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, 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 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 in Chapter 5.</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, less sensitive sites) • the reason for the treatment regimen (type of insulin and number of injections) 	<ul style="list-style-type: none"> • Show them needles or pens and demonstrate insulin injection. • Have a conversation about injecting (e.g. sites, needles, technique) and insulin use (e.g. storage). • If the person is experiencing pain while injecting: <ul style="list-style-type: none"> ◦ encourage them to make an appointment for a time when they would normally inject, so you can observe/talk about the technique ◦ check insulin sites. • If the person is new to insulin: <ul style="list-style-type: none"> ◦ invite them to do their first injection at the consultation 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. • Assist in referring them to a diabetes specialist nurse to learn or improve injection techniques and work through the barriers. • Suggest a short ‘trial’ period of insulin use (see ASSIST section of Chapter 5). <p>NB: Consider new technologies and treatment advances (e.g. finer needles, insulin pump, longer-acting insulins).</p>

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. • Emphasise that most people feel better physically once they begin insulin use. • Explain that a collaborative approach (involving their GP/diabetologist, dietitian and/or diabetes specialist nurse) can help in minimising the impact. 	<ul style="list-style-type: none"> • Assist in developing an action plan to minimise the impact of insulin on weight (e.g. optimising 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: Optimise their insulin dose to avoid over-treating.</p> <p>NB: Explore weight-neutral or weight-reducing diabetes therapies (e.g. incretin-based therapies, 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 or accept and discuss feelings of failure, blame, shame, etc. • Emphasise that: <ul style="list-style-type: none"> ○ Type 2 diabetes can be a progressive condition ○ many people with Type 2 diabetes need insulin ○ 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. • Discuss if peer support might help and how to access this.

Barrier: impact on lifestyle (e.g. reduced flexibility or spontaneity, time consuming, having to give up other activities, effect on work, 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 what they eat; 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 Diabetes UK on 0345 123 2399 for advocacy support. • Provide information about insulin prescriptions and how to obtain them, + free prescriptions 	<ul style="list-style-type: none"> • Problem-solve situations in which they would feel uncomfortable to inject (e.g. with colleagues, 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 section of Chapter 5). <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 stigma, embarrassment, 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 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 consultation or to attend a diabetes information session (if available). 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 A.</p>

Barrier: risk of hypoglycaemia

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 hypoglycaemia their concerns about the risk of hypoglycaemia what they fear most about hypoglycaemia (see Chapter 4). 	<p>Explain that:</p> <ul style="list-style-type: none"> hypoglycaemia 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 hypoglycaemia (very low blood glucose) is low in people with Type 2 diabetes training in hypoglycaemia prevention/ management is available. 	<ul style="list-style-type: none"> Assist the person in accessing appropriate hypoglycaemia 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, 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 • the experienced challenges (for those already using insulin). 	<ul style="list-style-type: none"> • Recognise 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 section of Chapter 5).

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 • impacts 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, flexibility in when and what they eat) and be able to live a 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 hypoglycaemia), with specific attention to the aspects of their regimen that they find most challenging. • Suggest a short 'trial' period of insulin use (see ASSIST section of Chapter 5)

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.
- 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. There is a list of resources in [Chapter 5](#) 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, along with them,; it is best not to overwhelm them with too much information.

References

1. Peyrot M, Barnett A, et al. Factors associated with injection omission/non-adherence in the Global Attitudes of Patients and Physicians in Insulin Therapy study. *Diabetes, Obesity and Metabolism*. 2012;14(12):1081-7.
2. Brunton SA, Davis SN, et al. Overcoming psychological barriers to insulin use in type 2 diabetes. *Clinical Cornerstone*. 2006;8 (Suppl 2):S19-26.
3. Funnell MM. Quality of life and insulin therapy in type 2 diabetes mellitus. *Insulin*. 2008;3(1):31-6.
4. Marrero DG. Overcoming patient barriers to initiating insulin therapy in type 2 diabetes mellitus. *Clinical Cornerstone*. 2007;8(2):33-43.
5. Korytkowski M. When oral agents fail: practical barriers to starting insulin. *International Journal of Obesity and Related Metabolic Disorders*. 2002;26:S18-24.
6. Barag SH. Insulin therapy for management of type 2 diabetes mellitus: strategies for initiation and long-term patient adherence. *Journal of the American Osteopathic Association*. 2011;111 (7 suppl 5):S13-6.
7. Hajos TRS, Pouwer F, et al. The longitudinal association between glycaemic control and health-related quality of life following insulin therapy optimisation in type 2 diabetes patients. A prospective observational study in secondary care. *Quality of Life Research*. 2012;21(8):1359-65.
8. Wilson M, Moore MP, et al. Treatment satisfaction after commencement of insulin in type 2 diabetes. *Diabetes Research and Clinical Practice*. 2004;66(3):263-7.
9. Polonsky WH, Jackson RA. What's so tough about taking insulin? Addressing the problem of psychological insulin resistance in type 2 diabetes. *Clinical Diabetes*. 2004;22(3):147-50
10. Polonsky et al (2017) Initiating insulin: How to help people with type 2 diabetes start and continue insulin successfully *International Journal of Clinical Practice* 71(8): e12973
11. Russell-Jones, Pouwer, Khunti (2018) Identification of barriers to insulin therapy and approaches to overcoming them *Diabetes Obes Metab* 20 (3) 488-496

