ENHANCING YOUR CONSULTING SKILLS

Supporting self-management and optimising mental health in people with type 1 diabetes

An education resource for trainees in adult endocrinology and other interested health professionals

The National Diabetes Services Scheme (NDSS) is an initiative of the Australian Government administered by Diabetes Australia. If you require further information about this resource, please contact the Australian Diabetes Society on 02 9256 5462. Please refer people with type 1 diabetes to the NDSS Infoline 1300 136 588 for information, self-management support or products.

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foreword

> *"The effort of diabetes care is great, but the reward is also great, for the prize is life itself"*
>
> Elliott Joslin, American diabetologist, 1928

On January 11th 1922, Leonard Thompson (1908-1935) became the first person to receive insulin for the treatment of type 1 diabetes. He had come close to falling into a coma from diabetic ketoacidosis, but recovered and went on to live for another 13 years. Prior to the availability of insulin, type 1 diabetes was invariably a fatal condition, with most people living only a few months after diagnosis. The miracle of insulin was that it saved lives. And it remains a miracle today.

Over the years, however, we have come to expect much more of diabetes care. Research in partnership with adults and children with type 1 diabetes has led to a range of technological developments that have substantially improved clinical outcomes. There are now better insulins and delivery devices, as well as increasingly sophisticated ways of measuring blood glucose levels. Clinical and laboratory tests are readily available for monitoring long-term diabetes control, and for assessing the status of chronic diabetes complications and their risk factors. Furthermore, with new medications and treatments, diabetes-related vascular damage can be prevented, slowed or even reversed. Most people with type 1 diabetes can now expect to live a long and full life.

But the physical and medical aspects of diabetes care are only part of the story. Living with type 1 diabetes is extraordinarily challenging, requiring the acquisition and maintenance of a complex set of practical skills, and the ability to manage the behavioural and psychological impacts of having a chronic medical condition. As a result, health care systems have evolved to help people live well with diabetes, including multi-disciplinary care clinics and telemedicine, in addition to a range of consumer organisations, including peer support groups.

As well as teams and systems, individual health professionals play an important role in helping to optimise the well-being and outcomes of people with type 1 diabetes. Engaging with, supporting and learning with and from people with type 1 diabetes are, as they were in Joslin's time, central to delivering quality care. The skills required to effectively consult with people who have type 1 diabetes, however, are complex and not necessarily intuitive. There is evidence, however, that they can be defined and acquired, but to date there have not been specific structured education programs available for this purpose for advanced trainees in adult endocrinology within Australia. This resource aims to meet this educational need not only for trainees, but also for other interested health professionals.

We wish to thank the many people who have contributed to the development of this resource (see Appendix 1), particularly its lead author, Dr Jennifer Conn, an endocrinologist and medical educator from The Royal Melbourne Hospital. Other major contributors have been Dr Carol Silberberg, a psychiatrist from St Vincent's Hospital, Fitzroy, and Dr Christel Hendrieckx, a clinical psychologist from the Australian Centre for Behavioural Research in Diabetes. We also thank the members of the Local Working Party and the National Advisory Group who provided oversight for the project, as well as the many other diabetes health professionals, mental health experts, communication specialists, advanced trainees, medical illustration and design professionals, and people with type 1 diabetes who were involved in the production of the resource.

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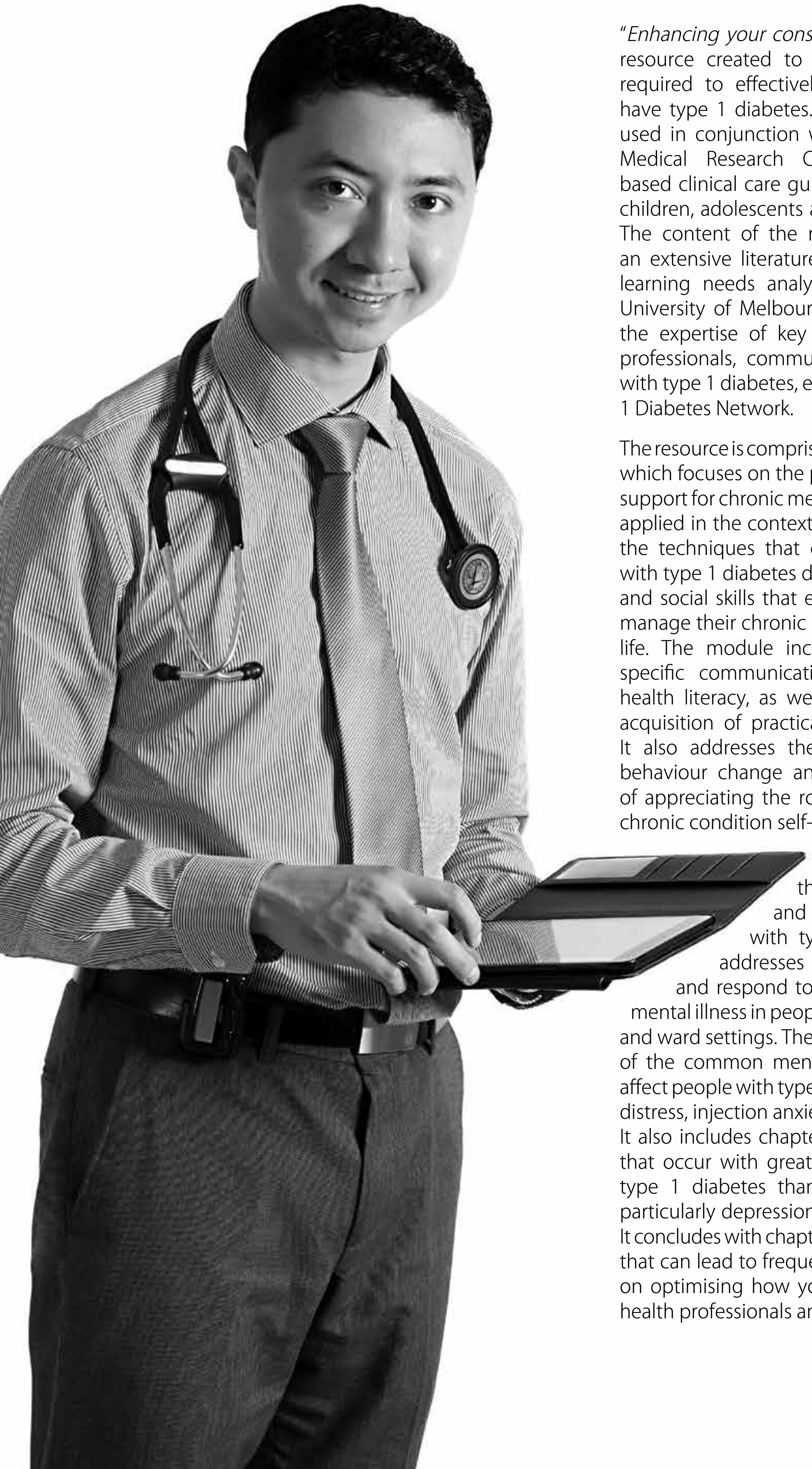
introduction



"*Enhancing your consulting skills*" is an educational resource created to help you develop the skills required to effectively consult with people who have type 1 diabetes.[1] It has been designed to be used in conjunction with the National Health and Medical Research Council's national evidence-based clinical care guidelines for type 1 diabetes in children, adolescents and adults produced in 2011.[2] The content of the resource has been based on an extensive literature search, as well as a trainee learning needs analysis carried out through The University of Melbourne.[3] It has been informed by the expertise of key diabetes and mental health professionals, communication experts and people with type 1 diabetes, especially members of the Type 1 Diabetes Network.

The resource is comprised of three modules, the first of which focuses on the principles of self-management support for chronic medical conditions, as specifically applied in the context of type 1 diabetes. It outlines the techniques that can be used to help people with type 1 diabetes develop the cognitive, practical and social skills that enable them to optimally self-manage their chronic medical condition in everyday life. The module includes chapters on diabetes-specific communication, information giving and health literacy, as well as on how to support the acquisition of practical and problem-solving skills. It also addresses the skills required to promote behaviour change and highlights the importance of appreciating the role that peer support plays in chronic condition self-management.

The second module explores the emotional, psychological and psychiatric aspects of living with type 1 diabetes. It specifically addresses the skills required to identify and respond to mental health problems and mental illness in people with type 1 diabetes in clinic and ward settings. The module provides an overview of the common mental health problems that can affect people with type 1 diabetes, including diabetes distress, injection anxiety and fear of hypoglycaemia. It also includes chapters about the mental illnesses that occur with greater prevalence in people with type 1 diabetes than in the general population, particularly depression, anxiety and eating disorders. It concludes with chapters on the mental health issues that can lead to frequent medical presentations and on optimising how you communicate with mental health professionals and teams.

introduction

The final module brings together many of the themes addressed in the first two modules by exploring the advanced skills required to problem solve around challenging consultations with people who have type 1 diabetes. It provides a framework for identifying and responding to difficulties with engagement, including those related to the communication skills and perceptions of the clinician. It places emphasis on being able to recognise the emotional, psychological and psychiatric factors that can impact on the quality of clinical interactions. The module also includes material about preventing and managing conflict, including being able to respond to expressions of anger and to set limits around disruptive behaviour. It closes with a chapter that outlines the importance of maintaining your own well-being so you can optimise the quality of the care you provide to people with type 1 diabetes.

Each chapter in the resource is based on a set of learning outcomes and key readings to guide your study. The body of each chapter includes text outlining the evidence base underpinning its subject matter and the clinical applications of the concepts discussed. A range of tools are included to support your learning, including screening instruments, diagnostic criteria for common mental illnesses and case studies to illustrate common scenarios. Also included are examples of dialogue that can be used for specific clinical situations, although it is recommended that you develop a repertoire of responses that reflect your own consulting style rather than using the suggestions verbatim. At the end of the skills-based chapters are clinical tasks that can be used to guide your practice in clinic or ward settings.

You may feel there is very little time to focus on the behavioural and psychological aspects of diabetes care at the beginning of your training, since you have other knowledge and skills to acquire within your discipline. As you develop more experience, however, you will be able to more readily incorporate the required skills into your consultations. It is suggested that you initially focus on aspects of the resource that are helpful for specific situations that arise in your clinical practice. Ongoing development of your consulting skills will be optimised by purposefully applying the principles of deliberate and reflective practice,[4,5] as well as taking time to learn from and with people who have type 1 diabetes.

I hope you enjoy developing your consulting skills using this resource. Being able to address the behavioural and psychological aspects of diabetes care is more efficient and satisfying in the long term than just focusing on the biomedical aspects. Most importantly, it will enable you to better meet the needs of the people with type 1 diabetes you meet throughout your career.

Jennifer Conn.

Dr Jennifer Conn
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Australian Diabetes Society

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Disclaimer

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list of abbreviations

ADEA	Australian Diabetes Educators Association
ADS	Australian Diabetes Society
AIHW	Australian Institute of Health and Welfare
BGAT	Blood Glucose Awareness Training
BGL	Blood Glucose Level
CABGs	Coronary Artery Bypass Grafts
CBT	Cognitive Behaviour Therapy
CHO	Carbohydrate
DA	Diabetes Australia
DAFNE	Dose Adjustment for Normal Eating
DAWN	Diabetes Attitudes, Wishes and Needs study
DCCT	Diabetes Control and Complications Trial
DDS	Diabetes Distress Scale
DNT	Diabetes Numeracy Test
DSM	Diagnostic and Statistical Manual
HbA1c	Glycated Haemoglobin
HON	Health On the Net
IAH	Impaired Awareness of Hypoglycaemia
ICT	Information and Communication Technology
JDRF	Juvenile Diabetes Research Foundation
MDI	Multiple Daily Injections
NDSS	National Diabetes Services Scheme
PAID	Problem Areas in Diabetes
PHQ-2	2-item Patient Health Questionnaire
PHQ-9	9-item Patient Health Questionnaire
QOL	Quality Of Life
REALM	Rapid Estimate of Adult Literacy in Medicine
SDE	Structured Diabetes Education
SPD	Severe Psychological Distress
TOFHLA	Test of Functional Health Literacy in Adults
WHO	World Health Organization

1

supporting self-management

1.1 chronic condition support

learning outcomes

to be able to:

- describe the tasks of self-management in type 1 diabetes
- outline the principles of self-management support in type 1 diabetes
- discuss the evidence for effectiveness of interventions designed to enhance self-management

key reading

1 Zwar N, Harris M, Griffiths R, *et al.* A systematic review of chronic disease management. Sydney: Australian Primary Health Care Research Institute; 2006.

2 Politi MC, Street RL Jr. The importance of communication in collaborative decision making: facilitating shared mind and the management of uncertainty. *J Eval Clin Pract* 2011; 17: 579-584.

3 Audulv A, Asplund K, Norbergh K-G. Who's in charge? The role of responsibility attribution in self-management among people with chronic illness. *Patient Educ Couns* 2010; 81: 94-100.

Introduction

Type 1 diabetes is arguably one of the most challenging chronic medical conditions for a person to self-manage. It requires vigilant and relentless juggling of insulin doses, dietary intake and physical activity to achieve glycaemic targets so the onset of its debilitating acute and chronic complications can be prevented or delayed.[1,2]

For effective self-management, a person with type 1 diabetes needs to have a sound understanding of the nature of their condition and its treatment. They also need to be proficient in a comprehensive and complex set of cognitive, practical and social skills that enable them to engage in collaborative partnerships with their health professionals, make informed decisions about their health care and develop successful diabetes management plans.[3,4] Importantly, they require the ability to adopt the behaviour changes required to apply their management plans, overcome barriers to implementation, and find a balance between the tasks of self-management and the activities of daily life.[5]

The knowledge and skills required to effectively self-manage type 1 diabetes are not necessarily intuitive, nor are the associated behaviours easy to sustain in the long term. Furthermore, even with diligent self-care, outcomes are not always as expected. Health professionals can play a vital role in providing support and facilitating acquisition of the required expertise. Type 1 diabetes is an exemplar of a condition where clinical practice and health care systems have been strategically developed to provide quality self-management support. There is increasing recognition, however, that health professional skill sets need to be extended to more effectively meet the needs of people with type 1 diabetes, especially in the behavioural and psychological domains of diabetes management.[6]

Principles of self-management support

A number of generic models exist that define the principles of self-management support in the setting of chronic medical conditions.[3,5,7-11] While many of these models have been developed for primary care settings, the principles apply equally in specialist practice for supporting people with type 1 diabetes. All models recognise that supporting the self-management of chronic conditions requires a different approach from delivering care in the acute illness context.[10,12] Chronic condition support is multi-faceted, involving not only the medical aspects of management, but also the application of techniques to promote the development of cognitive, practical and social skills, support behaviour change and address the emotional, psychological and psychiatric challenges of living with a chronic medical condition.[13] Specifically, it involves the following principles: [9,14]

A. A collaborative approach to management

Effective self-management support is based on collaboration between the person with the chronic medical condition and their health professional or health care team.[5,15] This reflects the reality that the person is ideally placed to know how management options can best be applied within their own life context. Additionally, it acknowledges that health professionals are experts in the clinical aspects of chronic medical conditions and can contribute by providing specialist information, including updates about new pharmacological agents, technological developments and the results of relevant medical research. Importantly, a collaborative approach to management is characterised by shared decision making and joint responsibility for outcomes between the person with the chronic condition and their health professional or health care team.[15]

B. An individualised approach to care

Support for self-management needs to be tailored to suit the individual requirements and preferences of the person with the chronic medical condition. In type 1 diabetes, this comprises not only individualising the medical aspects of management, such as deciding on glycaemic targets[16] or helping the person develop an insulin regimen that suits their lifestyle, but also actively addressing the cognitive, practical, social and cultural factors that can impact on self-management.[5,17,18] Individualised care involves establishing a person's priorities and helping them to identify goals that are realistic in their own life context. It also involves establishing the type of extra support the person prefers in order to achieve their goals. This may be in group or individual format, in person or by remote consulting, or by a mixture of methods. Importantly, it means having respect for the values and beliefs of the person with type 1 diabetes.

C. A focus on empowerment

A key goal of self-management support is the empowerment of people living with chronic medical conditions.[18] It is often quoted that over 95% of diabetes care is carried out by the person living with

the condition.[19] This means health professionals need to focus on providing access to relevant evidence-based knowledge and activities to facilitate the development of the skills required for a lifetime of self-management.[20] A health professional cannot and will not always be available to help the person manage their routine diabetes care.

D. A longitudinal approach to care

Effective self-management support for people with chronic medical conditions requires a longitudinal approach to care.[5] This involves strategic planning to ensure continual enhancement of self-management skills and anticipation of needs that will arise over time. Modification of goals and therapies may be required when life circumstances change, new evidence emerges or novel technologies become available.

For type 1 diabetes, having a longitudinal approach to care specifically involves co-ordinated service provision around critical transition points, such as transfer from paediatric to adult care or preparation for pregnancy. It also recognises that a person's level of engagement in collaborative care and the effectiveness of interventions will vary across the life cycle.

Components of self-management support

As a trainee, you need to develop expertise in a range of specific skills so you can support people who have type 1 diabetes with their self-management. These skills include:[9,21,22]

A. Communication skills

Being able to develop rapport and communicate effectively is the cornerstone of chronic condition self-management support in type 1 diabetes. This requires the application of generic communication skills, such as active listening, effective questioning techniques, reflecting and summarising.[23] It also encompasses acquiring an understanding of the experience of living with type 1 diabetes,[24] using language that is motivational and non-judgemental,[25] and being able to elicit and respond to a person's concerns about their diabetes.[26] Furthermore, it involves being able to tailor communication to meet a person's individual needs. For example, it is critical to take into account developmental level when interacting with an adolescent or to use an interpreter when consulting with a person whose language you do not speak.[27-29]

B. Information-giving skills

Possessing high quality evidence-based information is important for people with type 1 diabetes so they can participate in informed decision making about their management. As a health professional, you can assist through providing information in a clinic setting or by facilitating access to written or electronic sources of knowledge. This involves helping people with type 1 diabetes to integrate new information into their existing knowledge bases and apply it in their own life situations. It also involves being able to identify and support those who have specific learning needs, such as people with low health literacy. Importantly, it comprises being able to appreciate that most people with type 1 diabetes are very knowledgeable about their condition and will usually need information to be provided at quite sophisticated levels. As a trainee, this can be challenging, especially when your own knowledge base in the area of type 1 diabetes is in its early stages of development.

C. Facilitation of skills acquisition

People with type 1 diabetes need to be able to monitor and interpret their blood glucose levels (BGLs), estimate carbohydrate (CHO) intake and flexibly administer insulin doses to achieve desired glycaemic outcomes. They also need to develop problem-solving skills for making decisions about their blood glucose management and for overcoming barriers to implementing lifestyle interventions. Supporting self-management involves being able to facilitate the acquisition of these skills and to assess pre-existing proficiency so areas requiring further development can be identified.[30] Crucially, this involves being able to work collaboratively with other members of the diabetes team.

D. Behaviour change support

An essential component of working with people who have type 1 diabetes is being able to support behaviour change.[31,32] This involves helping them to adopt complex routines and adjust or replace pre-existing behavioural patterns.[33] On your part, behaviour change support requires being able to assess the attitudes, preferences and confidence of people with type 1 diabetes with respect to their self-care, as well as to work collaboratively on goal setting and the development of management plans. It also involves addressing any cognitive, psychological and social factors that may present barriers to implementing these plans. Providing ongoing review, guidance and constructive feedback is important for ensuring the maintenance of successful behaviour change and the ongoing development of adaptive behaviours.

E. Emotional, psychological and social support

The emotional, psychological and social demands of chronic condition self-management can have a considerable influence on the health outcomes and the quality of life (QOL) of a person who has type 1 diabetes.[34] Addressing the negative impacts of such demands is likely to be beyond the scope of any one health professional. As an individual, however, you can identify and respond to emotional, psychological and social issues as they arise, facilitate access to mental health professionals and services, and liaise with other members of the diabetes team as required.[6] This may involve working with partners, families or carers of people with type 1 diabetes, especially when self-management is compromised by co-morbidities, such as mental illness, cognitive impairment or drug and alcohol addiction. It also comprises facilitating access to financial and community services through organisations such as the NDSS and DA,[35,36] and to peer support through local or online organisations, such as the Type 1 Diabetes Network.[37]

What is the evidence for the effectiveness of self-management support?

There is growing evidence for the effectiveness of interventions designed to support the self-management of chronic medical conditions.[12] This evidence applies to generic approaches as well as those for specific conditions, such as type 1 diabetes. Overall, the evidence suggests that self-management support enhances well-being and confidence, increases participation in health care, reduces emergency department presentations and is cost-effective.[38,39]

In a systematic review by Zwar *et al*, the specific elements found to improve outcomes included patient education, provision of educational materials and motivational interviewing.[12] It was also found that group formats enhance effectiveness,[12] as does delivery by multi-disciplinary health care teams or peers with the same medical condition.[12,40] Self-management support has been shown to produce positive health outcomes across diverse populations,[41-42] although ethnic minorities, those with mental or physical disabilities and other vulnerable groups are often under-represented in research programs.[43]

1.1 chronic condition support

A range of condition-specific interventions for self-management support have been shown to enhance QOL and improve surrogate measures of health outcomes.[42] In type 1 diabetes, a large body of evidence is accumulating on the positive impacts of short-term structured education programs for skills acquisition, especially the Dose Adjustment for Normal Eating (DAFNE) program.[44-48] There is also a growing evidence base for the effectiveness of behavioural interventions and psychological therapies to enhance self-management by people with type 1 diabetes.[33,49-56]

Being able to critique studies of chronic condition self-management support requires an appreciation of the difficulties involved in designing and evaluating complex health care interventions. The development of study protocols can raise significant methodological challenges as multiple interactions and influences need to be taken into consideration.[14,58,59] Identifying the specific ingredients that produce positive outcomes can be especially challenging when there is a long time interval between the intervention and follow-up.[58] Furthermore, often only one intervention can be investigated in a particular study, whereas multiple changes may be required for a particular outcome to be achieved, especially in the setting of complex medical conditions, such as in type 1 diabetes.

Substantial effort has been made over the past decade to ensure that studies of complex health care interventions are conducted with similar rigour to other types of interventions, such as those involving pharmacological agents.[58-62] Advances have included specifying the need for detailed descriptions of interventions in academic papers, the development of a taxonomy for defining individual techniques and, increasingly, the publication of study protocols.[57,62] These allow for comparisons to be made between studies and for sources of variability to be explained, especially when adaptations of standard approaches have been used.[58,63]

As a trainee, you do not need to know the details of the research methodology used for evaluating complex health care interventions. It is important, however, that you are aware of the key evidence for the behavioural, psychological and clinical benefits of self-management support, particularly in the setting of type 1 diabetes. The results of relevant studies will be highlighted throughout this resource and placed into context so you can apply the key principles within your consultations.

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1.2 communication skills

learning outcomes

to be able to:

- describe the critical role of effective communication in supporting the self-management of type 1 diabetes
- apply effective communication skills in diabetes-specific contexts
- tailor your communication to meet the individual needs of a person with type 1 diabetes

key reading

1 Lloyd M, Bor R. Communication skills for medicine. 3rd Edn. London: Elsevier; 2009.

2 Anderson RM, Funnell MM. Patient empowerment: myths and misconceptions. *Patient Educ Couns* 2010: 79: 277-282.

3 Bensing JM, Deveugele M, Moretti F, *et al.* How to make the medical consultation more successful from a patient's perspective? Tips for doctors and patients from lay people in the United Kingdom, Italy, Belgium and the Netherlands. *Patient Educ Couns* 2011; 84: 287-293.

Introduction

Effective communication skills are critical for developing rapport with people who have type 1 diabetes and for helping them feel supported in the self-management of their condition.[1-7] This involves being able to gather and synthesise information using a range of basic techniques, such as active listening, clarifying, signposting, paraphrasing and summarising.[6] It also involves being able to provide clear, accurate and specific information to encourage active participation in consultations and to ensure that the person can make informed decisions about their diabetes care. Importantly, it comprises using motivational and non-judgemental language, being empathic, attending to the affective dimensions of clinical interactions and tailoring communication to individual needs.

Effective communication has been shown to lead to greater satisfaction for patients and health professionals alike.[8-11] It can also improve health-related outcomes, with research showing that checking on patient concerns, expectations and understanding of medical problems, asking about feelings and showing empathy are associated with faster resolution of symptoms and reduction in psychological distress.[8] Conversely, insufficient information giving by health professionals and low levels of patient input into consultations have been shown to be associated with poorer health outcomes.[12]

Developing generic and discipline-specific communication skills

As a trainee, you bring considerable experience in communication to your clinical encounters. This will have been acquired not only as a medical student and a junior doctor, but also through your interactions with people in your life outside work. Your communication skills will continue to develop, since these are acquired over a lifetime of practice. There is no simple formula to ensure success, but there is strong evidence that skills can be enhanced by having a sound understanding of the core principles and techniques of effective communication, and through deliberate and reflective practice.[13-18]

There is increasing recognition in the literature that discipline-specific as well as generic communication skills are important in health care settings.[19,20] For instance, a doctor working in an emergency department needs to hone their skills of rapidly acquiring critical information from patients with acute undifferentiated presentations.[19] Similarly, you need to develop specific communication skills for your discipline of endocrinology, including those required to support a person who has type 1 diabetes with their self-management.

Applying basic communication techniques in the diabetes context

During your medical training, you will have learned about the basic techniques that facilitate effective communication in a health care context. Many of these techniques will by now be instinctive, but it can be helpful to reflect on how you explicitly incorporate them into your interactions with people who have type 1 diabetes.

A. Active listening

Active listening is one of the most fundamental communication techniques. It involves paying full attention to the linguistic and paralinguistic elements of what a person is saying.[6] This means listening to *what* the person says and *how* they are saying it, including taking note of fluency, volume and timing. It also means observing the non-verbal components of communication, particularly body language and facial expression. Importantly, it requires taking note of any inconsistencies between verbal and non-verbal communication, as these can be signs of underlying psychological or social issues.

A key component of active listening is *demonstrating* you are paying attention.[21] Non-verbal facilitators, such as head nodding or adopting a forward leaning posture, and verbal facilitators, such as *"Uh huh ..."* or *"Go on ..."*, are useful techniques for this purpose. Be careful not to overuse these facilitators or your communication style may be perceived as being artificial.

Maintain an appropriate level of eye contact while listening to a person's narrative.[6] This is especially important if you are writing notes or entering information into a computer during a consultation.

B. Using questions effectively

Start the body of a consultation with an open-ended question so you can determine the person's priorities.[22-24] You are more likely to build rapport if you start with a question about the person rather than their diabetes.

> *"How are things with you right now?"*
>
> rather than:
>
> *"How is your diabetes going?"*

Focused questions are more suitable for later in the consultation when you need to find out specific information. In general, questions requiring a *"Yes"* or *"No"* answer are not very helpful for eliciting information.

When gathering information around complex, sensitive or emotional issues, try using the "behavioural incident" technique. First described by Pascal, this technique involves asking about concrete facts or trains of thought and behaviours rather than interpretations, so you can establish the exact sequence of events surrounding an incident.[25] This can be an effective way of re-creating and analysing scenarios, such as a severe hypoglycaemic episode or an attempt at self-harm in the setting of psychological distress.

> *"You injected your lunchtime insulin and then ate a sandwich ... what happened after that?"*

C. Clarifying information

Always clarify information if you are not sure about what the person has said or meant. Do this in a way that places the onus for understanding on you rather than the person. Saying:

> *"So I can be sure I've got this right, could you please tell me exactly how ..."*
>
> is likely to be more encouraging than:
>
> *"I didn't understand what you meant when you said ..."*

D. Reflecting and paraphrasing

Reflecting and paraphrasing are techniques for acknowledging that you are listening to a person and have understood what they have said.[6,26]

> *"I was at a party and I had to guess the amount of carbs that I ate. I injected what I thought would be a reasonable dose just before I started eating, but my BGL shot up to 19 ... so I gave myself a correction ... but then I ended up having a big hypo in front of everyone. I was REALLY embarrassed ..."*

Reflecting involves restating a selection of the person's dialogue in their own words. This encourages them to continue their narrative:

> *"... you ended up having big hypo in front of everyone and were really embarrassed ..."*

Paraphrasing involves capturing the meaning of the person's dialogue with your own words. As well as showing that you are listening, it can encourage the person to conceptualise their thoughts, feelings and experiences, which is an important strategy for problem solving in the context of diabetes self-management.

> *"... so there was an insulin to carbohydrate mismatch ... and then the correction lead to an embarrassing hypo ..."*

E. Signposting

Signposting lets a person know that you would like to move to a new segment of the consultation and what this might involve. It can help to reduce uncertainty and encourage more active participation if the person understands the clinical tasks that need to be completed:

> *"... so that sounds like a good plan for working on your BGLs ... I'd now like to perform a physical examination as your complications screening is due today ..."*

F. Strategic use of silence

Silence can be an effective way of leaving a person space to put their thoughts together and decide how they wish to express themselves. Likewise, silence can give you time to synthesise what the person has told you and to think about what else needs to be addressed during the consultation.

Use silence judiciously as a technique for your interactions with people who have type 1 diabetes. If pauses are too prolonged or too frequent, a person may become uncomfortable and lose confidence in you. If the person is silent and you are unsure whether they are thinking about what to say next or whether they have finished their narrative, ask directly. Be sure to maintain eye contact through periods of silence.

G. Summarising

Summarise the main issues at the conclusion of the consultation. This allows both you and the person with type 1 diabetes to be sure there is a common understanding of what has been discussed and what actions are planned.

> *"So just to summarise what we decided on today ... you're keen to go onto an insulin pump. I'll arrange a referral to the diabetes educator ... and you would like to see your dietitian again so you can brush up on your carbohydrate counting skills. We'll catch up again in about six weeks' time to see where it's all at. Does all that sound right to you?"*

Develop an understanding of what it's like to have type 1 diabetes

To effectively communicate with a person who has type 1 diabetes, it is vital that you have an understanding of what it is like to live with a chronic medical condition. One simple way of doing this is to talk with people you meet in clinics and on the wards about how they feel about having diabetes and the impact it has on their lives.

Another way of learning about the experience of living with type 1 diabetes is to access online forums, such as Reality Check and Munted Pancreas on the Type 1 Diabetes Network site.[27] This can help you to develop an awareness of the issues currently being discussed within the type 1 diabetes community. Other online forums and websites include *diabetogenic* by blogger and consumer advocate Renza Scibilia[28] and *Insulin Pumps Need Tetris* by Matt Cameron, who blogs about his experiences with type 1 diabetes, especially with new technologies.[29]

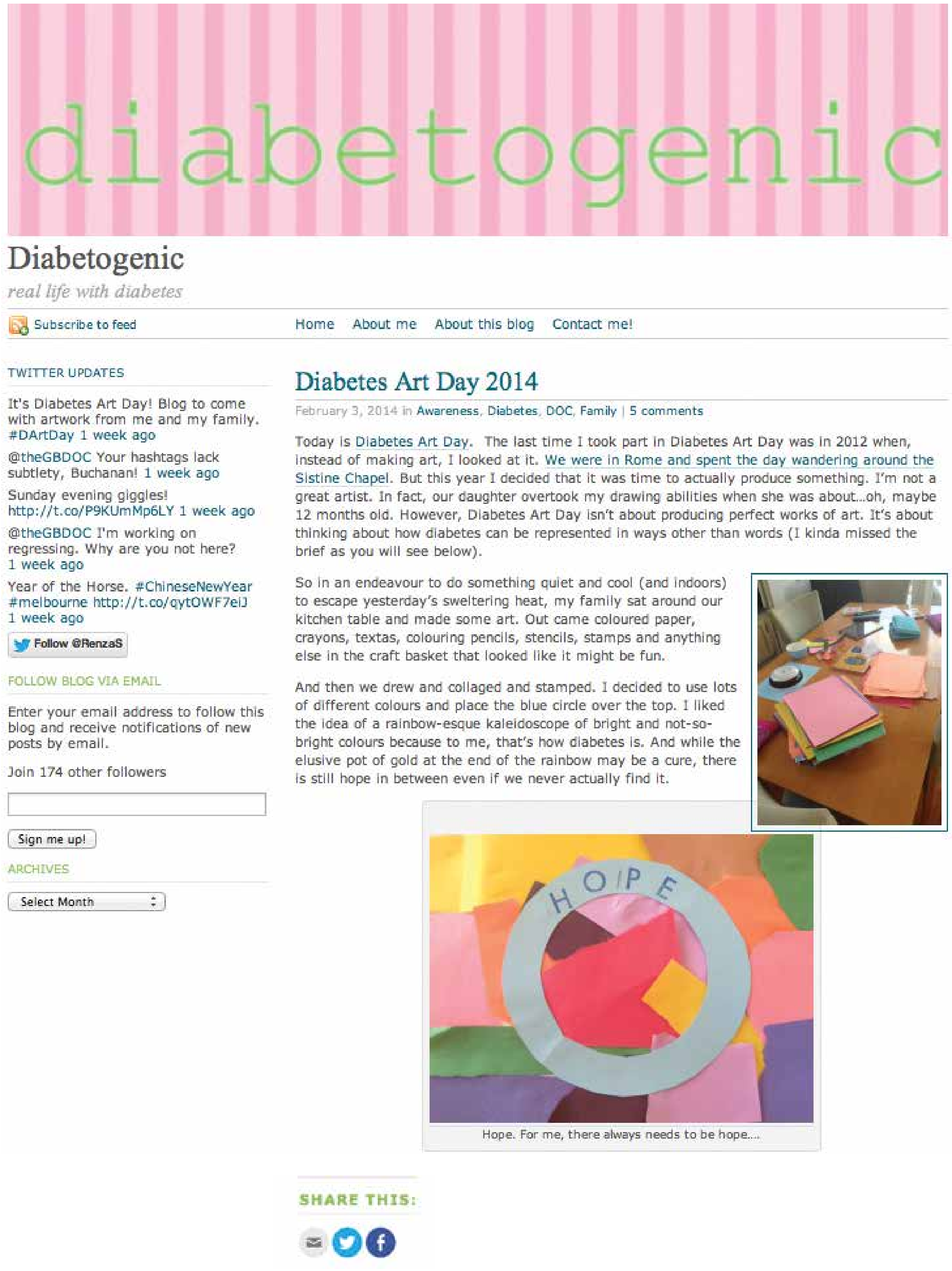
One highly recommended method of learning about living with type 1 diabetes is to work through the online resource *Living with Type 1 Diabetes,* which has been developed for health professionals by the Type 1 Diabetes Network.[30] This resource follows the lives of three characters with type 1 diabetes using stories drawn from experiences described on the Reality Check, Munted Pancreas and the Type 1 Diabetes Network websites.

There are a number of experiential ways you can learn about life with type 1 diabetes. Volunteering to assist at a diabetes camp for children or adolescents, for example, can provide unique insights into the multiple influences on BGLs and the complexities of diabetes self-management. Trying out activities such as blood glucose monitoring or CHO counting in your own daily life is also a valuable way of building empathy with people who have type 1 diabetes.

Normalise thoughts, feelings and behaviours

People with type 1 diabetes can at times be anxious or embarrassed about their thoughts, feelings or behaviours in relation to their diabetes. They may believe that they are alone in struggling with the challenges of daily blood glucose management or the fears surrounding adverse outcomes, such as severe hypoglycaemia or long-term microvascular complications.

Be proactive in raising issues that commonly concern people with type 1 diabetes. Not only can this be



Diabetogenic

real life with diabetes

TWITTER UPDATES

It's Diabetes Art Day! Blog to come with artwork from me and my family. #DArtDay 1 week ago

@theGBDOC Your hashtags lack subtlety, Buchanan! 1 week ago

Sunday evening giggles! http://t.co/P9KUmMp6LY 1 week ago

@theGBDOC I'm working on regressing. Why are you not here? 1 week ago

Year of the Horse. #ChineseNewYear #melbourne http://t.co/qytOWF7eiJ 1 week ago

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Diabetes Art Day 2014

February 3, 2014 in Awareness, Diabetes, DOC, Family | 5 comments

Today is Diabetes Art Day. The last time I took part in Diabetes Art Day was in 2012 when, instead of making art, I looked at it. We were in Rome and spent the day wandering around the Sistine Chapel. But this year I decided that it was time to actually produce something. I'm not a great artist. In fact, our daughter overtook my drawing abilities when she was about…oh, maybe 12 months old. However, Diabetes Art Day isn't about producing perfect works of art. It's about thinking about how diabetes can be represented in ways other than words (I kinda missed the brief as you will see below).

So in an endeavour to do something quiet and cool (and indoors) to escape yesterday's sweltering heat, my family sat around our kitchen table and made some art. Out came coloured paper, crayons, textas, colouring pencils, stencils, stamps and anything else in the craft basket that looked like it might be fun.

And then we drew and collaged and stamped. I decided to use lots of different colours and place the blue circle over the top. I liked the idea of a rainbow-esque kaleidoscope of bright and not-so-bright colours because to me, that's how diabetes is. And while the elusive pot of gold at the end of the rainbow may be a cure, there is still hope in between even if we never actually find it.

Hope. For me, there always needs to be hope….

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1.2 communication skills

reassuring, but it can also provide a entry point into useful discussions about barriers to effective self-management.

> *"A lot of people with type 1 diabetes who live alone sometimes feel frightened about having overnight hypos. Is that something that you have experienced?"*

Normalise but do not condone risky behaviour, such as insulin omission or self-medication with alcohol or drugs.

> *"Quite a few young people with type 1 diabetes I know binge drink at weekends, but this can be risky because having a hypo can be confused with being affected by alcohol ... so together we need to think about ways of helping you to stay safe when you're out with your friends ..."*

Use motivational and collaborative language

A fundamental element of effective communication is the careful choice of language. It is recommended that you read the DA Language Position Statement (see Appendix 2), and reflect on how verbal and written language can impact either positively or negatively on the development of rapport as well as diabetes outcomes.[31]

The position statement highlights the importance of avoiding words that label people or create and perpetuate negative stereotypes. The word "diabetic", for example, defines a person who has type 1 diabetes by their medical condition rather than acknowledging that having diabetes is only one facet of their identity. Likewise, using the word "patient" when the person is outside an acute health care setting can imply illness or dependency, even though they are successfully functioning in their work or home environment.

Try to avoid using words that are judgemental and demotivating. Many people with type 1 diabetes report being subject to frequent criticism of their attempts to manage their diabetes, especially when they do not meet treatment targets.[32] Such criticism does not acknowledge the challenges of balancing BGLs and other aspects of diabetes management with the responsibilities and stresses of daily life. Phrases like "poor control", "poorly managed" or "failing to manage" can leave people with type 1 diabetes feeling demoralised. As a result, they may become wary of confiding in their health professionals about the difficulties they are experiencing or provide misleading accounts of their diabetes self-management. Of even more concern, they may stop attending their medical appointments altogether.

Be mindful that the language you use can send powerful messages about approaches to self-management. Using words like "non-compliant" or "non-adherent" can imply that diabetes management needs to fit with the priorities of the health professional, rather than those of the person with type 1 diabetes. Words like "non-compliant" or "non-adherent" are often used as adjectives to describe a person rather than their behaviour. They can infer fixed attributes, despite there being little evidence at present to link medication behaviours with personality traits.[33]

Most people with type 1 diabetes go through times when their diabetes management is not the main focus of their lives. One of the main problems with using words like "non-compliant" or "non-adherent" is that it can lead to missed opportunities for conversations about why a person is not achieving their diabetes targets or is requiring frequent hospital admissions. For example, a person who has type 1 diabetes may have made a conscious decision to run their BGLs high because of fear of having a severe hypoglycaemic episode. Alternatively, unrecognised mental health issues may account for harmful health behaviours and adverse outcomes, as may factors relating to health professional communication, such as not providing sufficient information or not adequately supporting skills development.

When talking with people who have type 1 diabetes, use words that provide encouragement and reflect a collaborative approach to management. Focus on behaviours and outcomes rather than the person.[31] When discussing BGLs, use neutral terms such as "in" or "out" of target or "elevated HbA1c" (glycated haemoglobin), rather than "good control" or "bad control" which may be seen as being judgemental. In general, use words like "choices" and "options", which respect the person's autonomy, rather than directives such as "you must" or "you should".

Be sure to use these principles when you are talking *about* as well as *with* people with type 1 diabetes. This includes when you are dictating letters to referring doctors or other health professionals, making presentations at unit meetings and conferences, or writing journal articles. Remember that adopting and maintaining positive language requires deliberate practice, as with any other clinical skill.[34] It also needs to take into account the reality that language is constantly changing, as novel words and new meanings emerge.

Tailoring your communication for individual needs

When working with people who have type 1 diabetes, you need to be able to tailor your communication to meet individual needs. This includes being able to take into account physical barriers to communication, such as speech, visual or hearing impairment, or cognitive issues, such as dementia or acquired brain injury. It also involves adapting how you interact with people to cater for different personality styles and understanding how emotional, psychological and psychiatric issues can impact on engagement.

Recognise and respect any socio-cultural differences there may be between you and the person with type 1 diabetes.[35] Familiarise yourself with common cultural traditions that can influence how a person self-manages their diabetes, especially dietary rules and practices.[36] Make sure you use correct names and titles, and understand the meaning of gestures and other communication rituals.[35] But also appreciate the wide variability that exists within cultural groups and try to avoid stereotyping people. Apply effective communication skills to explore a person's individual cultural identity and how it might impact on their interactions with the health care system. Be careful of the language you choose when working with people who have different cultural or linguistic backgrounds from your own. For example, try to avoid using idiomatic speech, such as saying: *"Learning to carb count is a piece of cake"*, which has the potential to cause confusion.

Use a trained interpreter if you do not speak the same language as a person with type 1 diabetes. This not only facilitates communication, but is also a means of identifying cultural issues that may be influencing self-management or interactions within consultations. Having an interpreter present is necessary for quality and safety purposes, especially in situations where medication adjustment is required, such as when discussing insulin dose regimens or when obtaining consent for a procedure.[6,37] When working with interpreters in clinical settings, remember that they are there to facilitate communication between you and the person attending for medical care.[38] You need to keep eye contact with the person and not the interpreter. It is the interpreter's responsibility to keep all three participants involved in the interview. Always indicate if an interpreter is required when you make referrals to other health professionals.

Be mindful that people with type 1 diabetes will have different communication needs at different phases of the life cycle. For example, when consulting with a young person who has transitioned to an adult diabetes clinic from a paediatric hospital, you will need to adapt your approach to match their developmental level, especially with regard to their increasing need for autonomy from their parents. This will require respecting their confidentiality, arranging for them to be seen alone for part or all of the consultation and being aware of the special issues that concern young people.[39-42] To build your skills in this area, it is suggested you access the educational resource *Working with Young People,* which is available to physician trainees through the Royal Australasian College of Physicians website.[43] Elderly people with type 1 diabetes typify another age group where specific communication skills may be required. Apart from being aware of age-related physical and cognitive impairments that can impact on communication, you may need to take into account their increasing dependence on family members or carers.

clinical tasks

1 Undertake an activity that enhances your understanding of what it is like to live with type 1 diabetes. This could involve measuring your BGLs at least four times a day for a week, applying CHO counting to your meals or working through the Type 1 Diabetes Network resource *Living with Type 1 Diabetes.*

2 Select a letter that you have written to another health professional or a presentation you have given at a unit meeting about a person with type 1 diabetes. Review the language you used in the context of the recommendations set out in the DA Language Position Statement.

1.2 communication skills

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1.3 information giving

learning outcomes

to be able to:

- apply the core principles of effective information giving with a person who has type 1 diabetes
- provide information to a person with type 1 diabetes who is highly informed about their condition
- discuss online-sourced information with a person who has type 1 diabetes

key reading

1. Maly RC, Bourque LB, Engelhardt RF. A randomized controlled trial facilitating information giving to patients with chronic medical conditions: effects on outcomes of care. *J Fam Pract* 1999; 48: 356-563.
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Introduction

To effectively engage in self-management, people with type 1 diabetes need a sound understanding of the pathogenesis and natural history of their condition. They also need to know about the basis of investigations and therapies, the potential side-effects of medications and the principles of preventing acute and chronic diabetes complications. In addition, they require information about specific situations, such as pregnancy planning, sick day management and travel,[1-4] as well as about their social obligations and rights, such as driving certification and financial support through NDSS or other sources.[5,6] A sound knowledge base can help people with type 1 diabetes to make informed decisions about their care, feel more confident about self-management and optimise their health outcomes.[7,8]

Up-to-date and relevant information is important for *all* people with type 1 diabetes, regardless of whether they have just received the diagnosis or have had diabetes for many years.[9] A person's information needs will change according to their stage of life and health status. In addition, they will expect to be kept informed of emerging scientific and technological developments.

As a health professional, you are responsible for providing information to people with type 1 diabetes on a one-to-one basis within consultations on wards and in clinics. This includes providing specific facts, such as details of investigation results, prognostic markers or medication dosing instructions. It also includes being able to enhance the work of diabetes educators in providing general information about diabetes and its self-management, in individual as well as in group formats.[10] In addition, it increasingly comprises being able to effectively discuss online-sourced information and to help people with type 1 diabetes evaluate the information they source using information and communication technologies (ICTs).

Principles of effective information giving

Information needs to be provided in an interactive manner and in a way that maximises understanding and retention. This process involves a number of key steps:

A. Check preparedness

Make an assessment of how prepared a person with type 1 diabetes is to receive and process information. If they are acutely unwell, such as during hospitalisation with diabetic ketoacidosis, details may not be easily retained. In this situation, provide basic information and ensure that it is expanded upon after recovery. A person's mental status will also need to be taken into account. They may not understand or remember important information if they are depressed or highly anxious.

Ask whether a person would like a family member or friend to be present during an information-giving session, especially in the setting of breaking bad news or when discussing complex information. Arrange for an interpreter to be present if the person does not speak the same language as you.

B. Establish a person's information needs

Identifying what a person with type 1 diabetes needs and wants to know is a collaborative process. You have a responsibility to ensure that they have the information required for safe and effective self-management of their diabetes, but they will also have specific learning needs that are a priority.

Rather than making assumptions, find out what is important for a person at a particular point in time. In an Australian study by Gilbert and Millard, 70 adults with type 1 diabetes were asked to retrospectively rank their information needs at diagnosis.[11] Major themes identified included food choices, insulin dose adjustment and physical activity, as well as having access to on-line and peer support, and to personal narratives of other people with type 1 diabetes.

In contrast, the 49 diabetes health professionals surveyed thought that people with newly diagnosed type 1 diabetes would primarily want to know about mental health care, drugs and alcohol, employment and legal issues, and pre-pregnancy care.

In some circumstances, a person may not want to receive information about their medical status. Decide what information is necessary to keep them safe and revisit the issue at a later time.

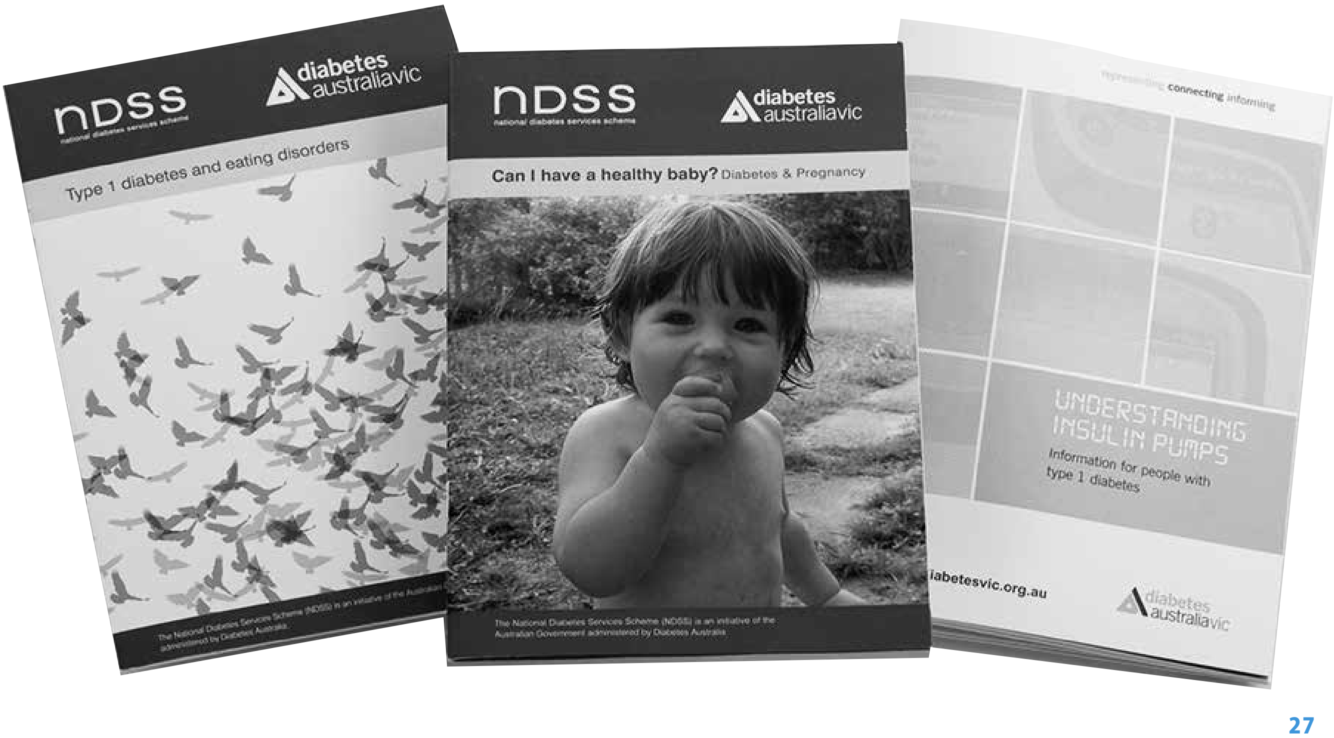
C. Provide accurate and tailored information

Find out what a person already knows about a particular topic and try to build on their knowledge.

> *"If your blood glucose is less than 4, what do you usually do?"*

Take note of the words they use as this can help you to tailor your message to their experience and level of education. The specific skills required to provide information to people with type 1 diabetes who have low health literacy will be addressed in the next chapter.

Make sure that the information you provide is accurate, evidence-based and specific. Break it down into small chunks and deliver the most important parts first.[12] If time is limited, prioritise the content according to the person's immediate needs and circumstances.



1.3 information giving

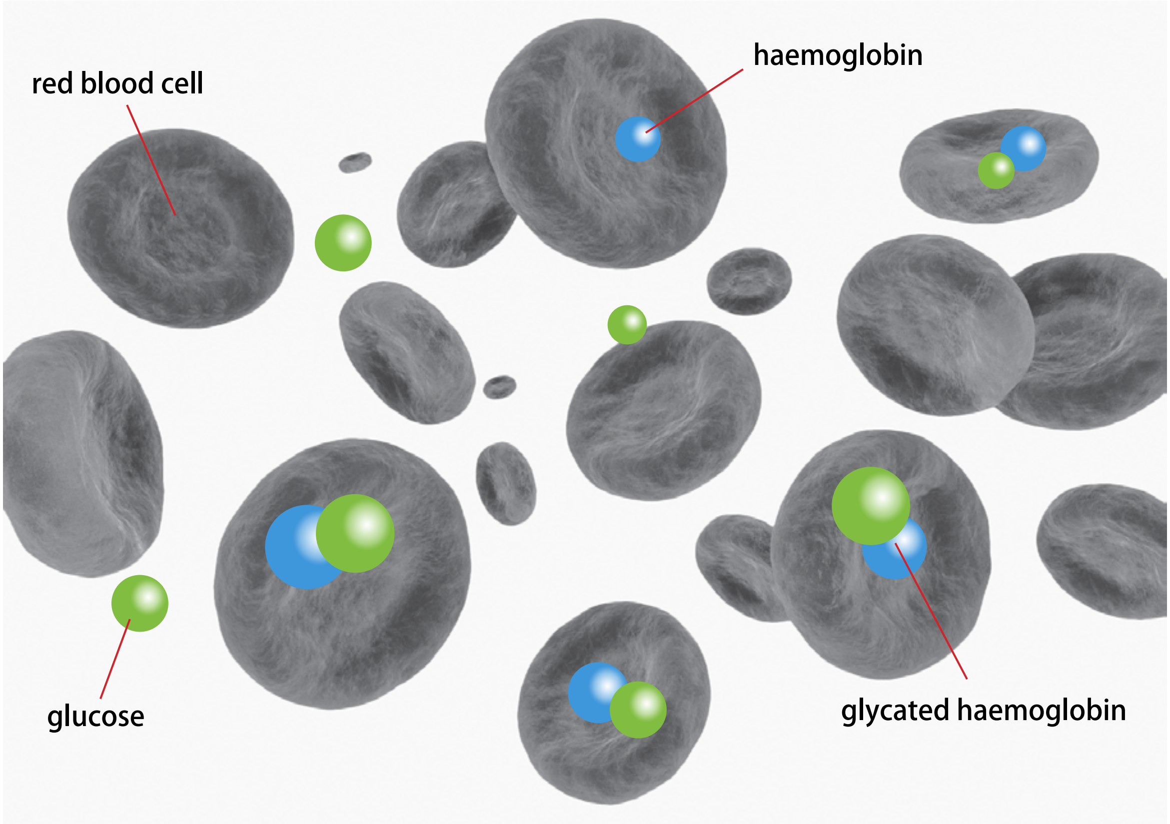


Figure 1.3.1: DIAGRAM SHOWING GLYCATION OF HAEMOGLOBIN

D. Use plain language rather than jargon or highly technical terms

Use everyday language when talking with people who are unfamiliar with medical concepts and terminology.[13] Even terms that might seem straightforward to you may be interpreted the wrong way. For example, saying:

> *"The result of your urine microalbumin collection was negative ..."*

may be interpreted as being bad news by a person who is unfamiliar with the use of the word "*negative*" in a medical context. Likewise, the term "*diet*" may mean a weight loss strategy to a person with diabetes, whereas to a health professional it may mean a food plan for a specific purpose (such as a gluten-free diet). Use such terms in your conversations if you know that a person with type 1 diabetes is familiar with them in a medical context, but clarify the information to ensure comprehension:

> *"The result of your urine microalbumin collection was negative, which is good news ..."*

Remember that acronyms well-known to you may not be readily understood by people with type 1 diabetes, especially those who have recently received the diagnosis. For example, if you are using the terms "LDL-" and "HDL"-cholesterol", make sure the person understands what the acronyms mean. This principle applies to other commonly used acronyms, such as MDI (for multiple daily injections) or CABGs (for coronary artery bypass grafts).

E. Use pictorial representations of concepts

Using pictorial representations can be an effective way of ensuring comprehension. Many people are visual learners and will grasp concepts more easily through the use of drawings, pictures or diagrams than by the spoken word alone.[14] For instance, the diagram above can be used to help explain what an HbA1c represents.

F. Use analogies to explain concepts

The use of analogy can be an effective technique for explaining difficult concepts to people with type 1 diabetes, especially if they do not have a science or heath-care background. For example, a sieve can be used as an analogy for the filtering mechanism of the kidneys when describing to a person what microalbuminuria means (see example). Make sure that they understand the limitations of the analogy and move them towards a more exact understanding of the concept. Build up a set of useful analogies that relate to type 1 diabetes for use in your clinical practice (see the following page for further examples).

Example

Soluble bodily waste is removed from the body through the kidneys, which act like a sieve. Normally albumin and other proteins are too large to go through the sieve. When there is damage to the kidneys due to diabetes, the holes of the sieve become larger and allow albumin to spill into the urine. This albumin can be measured with a urine sample, providing early warning of diabetic kidney disease. This enables the right treatment to be prescribed to help prevent progression and, potentially, heal or reverse some of the damage to the kidneys.

Figure 1.3.2: EXPLAINING MICROALBUMINURIA USING ANALOGY

Concept	Analogy	Description
Glucose	Petrol	Cells metabolise glucose to produce energy in the same way that a car engine uses petrol as fuel.
Immune system	Police or defence force	The immune system keeps out "invaders" from the body, like an army or police force protects people in a community. In an autoimmune disease, the immune system mistakenly turns on a body part.
Hormone and receptor	Key and lock	A hormone links with a receptor to start a biological process within a cell, just like a key fits in a lock to open a door.
Cells	Building blocks	Cells are the building blocks of the body. Different combinations of cells make different body parts. This is similar to how a set of building blocks can be used to make objects.
Blood vessels	Plumbing	Blood vessels are like pipes in the body's plumbing system. A blockage in a vessel means that less blood flows to the body part it normally supplies.
Nerves	Electricity	Nerves transmit messages to and from the brain like electricity. Numbness occurs when nerves are damaged by diabetes and messages do not get to the brain. Over-activity of impulses in nerves can cause abnormal sensations, including pain.
Brain	Computer	The brain is like a computer. It processes, stores and transmits information, and is involved in decision making about bodily processes.
Heart	Pump	The heart operates as a pump that moves blood around the body to the tissues, delivering oxygen and nutrients to cells.

Figure 1.3.3: ANALOGIES FOR EXPLAINING CONCEPTS TO PEOPLE WITH TYPE 1 DIABETES

G. Check understanding

Check understanding by asking the person to explain in their own words the key points that have been covered. Approach this by inviting the person to comment on how well you explained the information rather than asking how well they understood it.[12]

> *"I'd like to check that I've explained this to you clearly enough. Could you please say it back to me in your own words so I can be certain?"*

This provides you with an opportunity to identify any information that requires further clarification. The person is more likely to be open about what they do not understand if they realise the onus is on *you* to provide clear and comprehensible information. Checking learning in this way is a commonly applied educational technique.[17] One variation, called "Teach Back", has been studied in a diabetes context. This technique has been shown to promote an active role for the person with diabetes and lead to improved diabetes outcomes.[12]

H. Provide supplementary written information

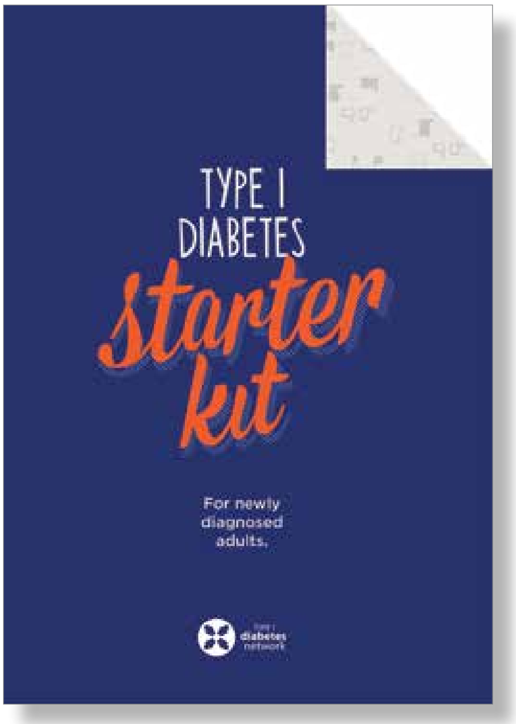
Oral information giving is usually more effective if it is supplemented by written materials. These materials may comprise fact sheets, links to reliable web-based resources or information that is specific to an individual, such as a print-out of their latest laboratory results. Do not under-estimate the value of providing hand-written notes to reinforce what has been discussed within a consultation.

Build up a bank of your favourite resources to use in your consultations.[1,15,16] One comprehensive and highly recommended resource for adolescents and adults with newly diagnosed type 1 diabetes is the Type 1 Diabetes Network's *"Starter Kit"*.[15] This resource has been written by people living with type 1 diabetes and specifically focuses on what they think is important, based on their own experiences. It can be downloaded from www.d1.org.au. Hard copies can be ordered from this site free of charge, although your local diabetes centre will probably have a supply. Another useful resource is the Juvenile Diabetes Research Foundation (JDRF) guidebook, *"Straight to the Point"*.[16]

I. Explore the person's reaction to information

Explore the person's *cognitive* reaction to the information discussed:

> *"We've spent some time today talking about the benefits as well as the downsides of using an insulin pump. What are your thoughts at this stage?"*



In many circumstances, it will also be important to explore a person's *emotional* reaction to information. This is especially relevant in the setting of bad news, such as when informing a person of the onset of microvascular complications:

> *"Finding out that you have developed diabetic retinopathy can be very upsetting ... would you like to talk about how you are feeling about what we have just discussed?"*

J. Ask if further information is required

Ask the person if you have provided sufficient information. What extra questions would they like answered? Would their partner, family or carer like any specific information? Offer to repeat the information at the next appointment:

> *"This has probably been a lot to take in all at once. We can go over it again next time we meet if you like."*
>
> OR
>
> *"You might find that you think of more questions after you leave here today. Write them down and we can discuss them at your next visit."*

If the person will be seen by another clinician at the next appointment, make sure there is a mechanism for follow-up.

K. Document the key information provided

Briefly record the key elements of the information discussed. This is a particularly important step if you are providing information with medico-legal implications, such as when discussing obligations around driving certification, obtaining consent for a procedure or outlining the potential side-effects of a new medication.

Information giving as a team

A person with type 1 diabetes will receive information about their condition and its management from a range of health professionals within and beyond the diabetes team. Work with other members of your team to ensure that the information you provide is as consistent as possible. This is particularly important when discussing treatment targets, especially for HbA1c results and BGLs.[18]

It is best, however, to prepare a person for the reality that they will sometimes receive conflicting advice from their health professionals. Treatment targets, for example, are often not clear-cut and can be open to individual interpretation. Encourage the person to be proactive in asking for clarification in these circumstances.

> *"We've talked about some targets for your blood glucoses today. I'll let your diabetes educator know what we've decided. But targets are not always black and white, and you might receive different advice from other people. Also, sometimes targets can change, such as if you become pregnant. If there ever seems to be any confusion, just let me know and I will try to clarify things for you."*

The highly informed person with type 1 diabetes

Many people with type 1 diabetes are highly informed about their condition through wider reading and membership of advocacy and peer support groups. As a trainee, it can be daunting if the person with whom you are interacting knows more about diabetes and its management than you do. For example, a person may ask you for information about the factors that can influence their blood glucose levels at a time when you have little experience in the area.

> *"I want to ask a question. I was having a lot of problems with my blood glucoses … they kept changing all the time and I couldn't figure out a pattern. Then a friend of mine with type 1 said that sometimes your period can affect the levels. I started to look out for that and found that my levels actually went up for the week before … each time pretty much in the same way. So I've adjusted my basal rates … I use an extra 20% for that week and it seems to be working out really well. But I think I need to change the carb ratios too, especially at breakfast time … but I was wondering if you could explain why all this happens in the first place?"*

Be honest about what you know and what you don't know, rather than becoming defensive or trying to bluff your way through.[19] Adopt a professional and confident approach in the way that you respond. Acknowledge that the person is being proactive about their health care and that the questions they are asking provide you with an opportunity to build your own knowledge. This demonstrates a collaborative approach to diabetes care. Say that you will follow up their questions by asking a senior colleague or by consulting the literature. Be sure to respond in a timely manner.

> *"I'm still building my knowledge about the factors that can influence blood glucose levels, so I'm probably not the best person to give you information about this. What I need to do is talk with Professor Jenkins and to see what she says. She's not here right now but I can follow this up with her and get back to you as soon as I can. Would that be OK with you? I'm really interested in finding out about this too … "*

Working with online-sourced information

A. Appreciate the benefits of discussing online-sourced information in consultations

Advances in technology have transformed how people with type 1 diabetes access information about their condition and its management.[20-22] Generic research has demonstrated benefits for patients and health professionals alike when discussions about online-sourced information are encouraged within consultations.[2,20,21,23] These benefits include enhanced development of rapport, strengthening of collaborative approaches to making decisions about management and more efficient use of the clinical time available.

People with type 1 diabetes may also source information through social media, such as Twitter and Facebook, but as yet very few studies have addressed their particular impacts. A recent systematic review by Jones *et al* documented the use of social networking sites as a tool for sourcing information about the risks associated with using alcohol in people who have type 1 diabetes.[24] Talking about such information may enhance the quality of communication within consultations.

B. Apply effective communication strategies for discussing online information

A number of strategies have been described in the literature for optimally managing discussions about online-sourced information: [20,25,26]

1. Demonstrate a positive attitude towards online-sourced information

When a person with type 1 diabetes wants to talk with you about information they have found online, show that you are interested in what they have found. Appreciate that online-sourced information supports rather than challenges or replaces the doctor-patient relationship.[20,25,27,28] Provide the person with positive feedback for the efforts they have made to develop their knowledge base and to take responsibility for their diabetes self-management:

> *"You have done a lot of research about exercise and type 1 diabetes. And you are obtaining much smoother blood glucose results with the pump rate adjustments you have made as a result of your new knowledge. Is there anything I can do to help you build on this?"*

2. Help the person to prioritise information for discussion

If a person has brought in a large amount of printed online-sourced information to discuss, help them to prioritise the topics of interest to them:

> *"There is a lot of information here that you have printed off. To make the most of the time that we have today, I wonder if you could show me the section that is most interesting to you and we can talk about that ..."*

3. Directly address expectations and anxieties

Discussions in consultations about online-sourced information can help to address expectations about diabetes outcomes or therapies, especially if these are unlikely to be met at the present time:

1.3 information giving

> *"I can see how it is encouraging to think that stem cells could cure your diabetes, but research is still quite new in this area. It's probably going to be quite a while before scientists know if this treatment can be used successfully outside clinical trials ..."*

Talking about online-sourced information with a person who has type 1 diabetes is important for alleviating any anxieties that may have been generated. This is particularly important if the material has focused on the more severe end of the spectrum of a diabetes complication or co-morbidity.

4. Challenge and clarify online-sourced information where necessary

Be confident about challenging or clarifying online-sourced information that is incorrect, incomplete or does not apply to a person's specific situation.[29]

> *"Having an angiogram sounds like a good way of checking whether or not you have heart disease, but it's not something that would be recommended as a routine screening test. There are some risks involved, so there are usually other tests we would consider first."*

Bylund *et al* have found that patient satisfaction is not compromised when a health professional contests such information, as it demonstrates they are taking the discussion seriously.[26]

C. Promote critical appraisal of health-related websites

Encourage people with type 1 diabetes to develop and maintain the skills required to critically and independently evaluate the information that they access online.[20,30] One useful tip is to suggest they check if a website displays the Health On the Net (HON) logo.[31]

HON is a non-government organisation founded to encourage dissemination of quality health information through the internet to the general public, as well as to health professionals. It has developed a code of ethics to guide those setting up websites for this purpose.

The HON logo on an accredited website signifies the intention of the site to contribute objective and transparent information, although it does not guarantee the accuracy of the content. To see an example of the use of the HON logo, visit the Type 1 Diabetes Network website.[15]

To obtain HON accreditation, a website must fulfil the following criteria:

1. **Authority**
   The qualifications of authors must be provided
2. **Complementarity**
   The intention of the information should be to support, not replace, interactions with health professionals
3. **Confidentiality**
   The privacy of site users must be respected
4. **Attribution**
   The source of medical information and the date it was published must be cited
5. **Justifiability**
   Claims being made in the site must be objective and balanced
6. **Transparency**
   The website must be accessible and valid contact details must be provided
7. **Financial disclosure**
   Details of funding need to be provided
8. **Advertising**
   Advertising must be clearly distinguished from editorial content

The HON logo and criteria have been reprinted with the permission of Health On the Net, Geneva, Switzerland.

D. Recommend reliable websites

Be proactive in recommending reliable websites to people with type 1 diabetes.[20,32] Research from generic settings suggests that patients welcome such advice.[32] Build up a bank of useful diabetes-specific sites, including those of the NDSS, Diabetes UK, the American Diabetes Association, the national, state and territory divisions of DA, and other major diabetes organisations (see Appendix 3).[6,33-42] Websites that are helpful for facilitating peer support will be discussed in Chapter 1.8.

General resources that are helpful for accessing online-sourced health information include:

HealthInsite website – How to Assess Health Information Online at: http://www.healthinsite.gov.au/topics/How_to_Assess_Health_Information_Online (accessed Oct 2013).

The Cochrane Collaboration – Working together to provide the best evidence for health care at: http://www.cochrane.org/ (accessed Oct 2013).

Media Doctor Australia – Providing quality ratings of current news items about medical treatments at: http://www.mediadoctor.org.au (accessed Oct 2013).

National Health Service (NHS) News – Providing unbiased analysis of the facts behind health stories at: http://www.nhs.uk/news/Pages/NewsIndex.aspx (accessed Oct 2013).

clinical tasks

1. Explain what an HbA1c measurement means to a person who has newly diagnosed type 1 diabetes.
2. Identify a person with type 1 diabetes who accesses information online about their condition. Find out how they decide if the information on a website is credible.

1.3 information giving

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39. Diabetes Australia-Tasmania website. http://www.diabetestas.com.au (accessed Oct 2013).
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41. Australian Diabetes Council website. http://www.australiandiabetescouncil.com (accessed Oct 2013).
42. Juvenile Diabetes Research Foundation website. http://www.jdrf.org.au (accessed Oct 2013).

1.4 health literacy

learning outcomes

to be able to:

- describe the prevalence and the impact of low health literacy
- identify and respond to the presence of low health literacy in a person with type 1 diabetes
- develop accessible written information for people with type 1 diabetes

key reading

1. Powers BJ, Trinh JV, Bosworth HB. Can this patient read and understand written health information? *JAMA* 2010; 304: 76-84.
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What is health literacy?

Health literacy is the global term used to describe the cognitive and social skills that enable a person to access, understand and apply information to achieve optimal health outcomes.[1,2] As well as referring to the general literacy and numeracy required to understand basic oral, written or digital health information,[3,4] health literacy also comprises the ability to know when and how to seek such information. Furthermore, it involves being able to evaluate the quality of the information obtained and to translate it into practice.

There is increasing awareness of the importance of health literacy and its impact on the ability of people to make decisions about their health care in the context of their daily lives.[3,5,6] Health literacy is of particular importance in the self-management of chronic medical conditions where participation in collaborative approaches to care is vital. The focus of this chapter is on identifying and responding to the presence of *low* health literacy in people with type 1 diabetes. As a trainee, you need to be able to acquire these skills so you can adapt the delivery of your care to meet individual needs.

How prevalent is low health literacy?

According to the Adult Literacy and Life Skills survey conducted in 2006, up to 60% of Australians have sub-optimal health literacy.[7] In many situations, learning difficulties play a role, but social and cultural influences are also important factors. People from culturally and linguistically diverse backgrounds are over-represented in statistics about low health literacy. Within these populations, 45% have low general literacy, with 25% also having low literacy in their first language.[8] Other over-represented groups include:

- native speakers with low proficiency in English
- individuals from low socio-economic groups
- those with limited education
- people who are unemployed
- those with chronic medical conditions
- the elderly

Studies suggest that low health literacy is more prevalent in people who have diabetes than in the general population.[9,10] Most of this research, however, has focused on people with type 2 diabetes. There are no robust data specifically addressing the prevalence of health literacy in people with type 1 diabetes, although pilot studies suggest that numeracy, as a specific component of health literacy, may be suboptimal in up to 50% of this population.[11,12]

What is the impact of low health literacy?

Research has demonstrated that people with low health literacy have poorer health outcomes than those who can more readily access, understand and apply health information, especially in the context of chronic medical conditions.[13] A recent systematic review by Berkman *et al* identified that low health literacy is associated with:[14]

- a two-fold hospitalisation rate
- greater use of emergency care
- lower uptake of the influenza vaccine
- poorer access to and use of health services
- poorer overall health status and higher mortality rates, especially amongst older people

For people with diabetes, sub-optimal health literacy correlates with low levels of knowledge about their condition, limited medication understanding and elevated HbA1c levels.[6,10,12,15-18] There are few data specifically concerning adults with type 1 diabetes, although research has demonstrated that low carer health literacy can impact negatively on glycaemic control in children and adolescents.[11,19] There is some evidence to suggest that numeracy can influence outcomes in type 1 diabetes, with Marden *et al* recently reporting an association between numeracy and HbA1c levels, independent of socio-economic factors. Further studies are required to confirm this relationship.[20]

Identifying the presence of low health literacy

A. Be aware of the prevalence of low health literacy

Just being aware that low health literacy is prevalent is the vital first step in being able to identify its presence. Research suggests that health professionals routinely over-estimate the ability of their patients to access, interpret and apply health information.[4,21] In addition, people generally do not volunteer their difficulties, especially with respect to reading or writing, for fear of embarrassment.[4] Those who have low health literacy can be quite adept at hiding their situation, often compensating by relying on family, carers or other patients for assistance.

B. Use educational attainment as a surrogate marker

Educational attainment can be used as a surrogate marker for health literacy, although it is important to be aware it can sometimes be misleading. It has been shown that up to 20% of high-school educated patients have limited health literacy.[4] In one Australian study, it was found that using educational level alone as a marker of health literacy led to a misclassification in 10% of individuals.[22]

1.4 health literacy

C. Recognise signs of low health literacy

Be aware of the signs that indicate a person may be struggling to understand and apply health information. These signs include:

- providing incorrect answers to your questions about written material
- avoiding or being nervous about situations that require complex learning
- "forgetting" to bring BGL record books to appointments or seeming reluctant to record other numerical data, such as CHO estimations and insulin doses
- making medication errors, especially with insulin dose adjustments or other complex dosing schedules
- submitting incomplete medical forms, such as NDSS or hospital admission forms
- missing appointments or attending without adequate preparation, especially for investigations or procedures that require reading detailed instructions, such as nuclear medicine cardiac scans, colonoscopies or insulin pump starts

D. Recognise compensatory behaviours

People with low health literacy often develop a range of compensatory behaviours to manage or conceal their situation, especially with respect to reading proficiency.[4] These behaviours include:

- lifting written material closer to their eyes and following the text with their fingers
- saying they forgot their glasses and will read the information provided when they get home
- handing forms or written instructions to an accompanying person

E. Use direct enquiry

Studies have shown that certain questions can be helpful in identifying the presence of low health literacy. Asking *"How confident are you in filling in forms by yourself?"* has been found to be a particularly effective strategy.[23] Another approach is to ask the person how often they need help to access and read health information or how they rate their own reading and mathematical abilities.[4]

It is important to be sensitive and tactful when you are talking about health literacy. Embed your enquiry within conversations rather than raise it as a separate issue. If possible, build up a picture across time, rather than during just one consultation.

Instruments for assessing health literacy

A range of instruments have been created to measure health literacy in individuals and across populations.[24-27] Most of these instruments focus on reading proficiency and numeracy, rather than on the wider aspects of health literacy, such as being able to seek, evaluate and apply health information. A recent systematic review examined the validity, reliability and feasibility of existing instruments,[25] and found that those with the strongest psychometric properties were TOFHLA (Test of Functional Health Literacy in Adults), which measures comprehension of written instructions and numerical information,[4,24,25] and REALM (Rapid Estimate of Adult Literacy in Medicine), which focuses on the pronunciation of medical words.[28]

Specific instruments have been developed to measure health literacy in diabetes populations.[17,18] One example is the Diabetes Numeracy Test (DNT), which includes items such as nutrition-label reading, using a diagram to correlate HbA1c with average BGLs, interpreting medication schedules and applying insulin to CHO ratios.[17] The DNT has been found to correlate with level of education, reading proficiency and general mathematical skills.

Formal measurement of health literacy has generally been confined to research settings. Most instruments are too long and time-consuming to administer in routine clinical practice. Brief instruments have been developed to overcome this limitation, for example, the Newest Vital Sign, which involves a person answering questions about a nutrition label from an ice-cream container.[26] It has been argued, however, that formally measuring a person's health literacy, especially within a consultation, is confronting and only adds to the embarrassment people feel about not being able to understand information relating to their health care.[4]

Enhancing health literacy in type 1 diabetes

If you identify that a person with type 1 diabetes has low health literacy, there are a number of strategies you can use to enhance their ability to understand health information:

A. Individualise communication

Tailor information to the person's literacy level. This has been shown to improve health outcomes, especially in the context of complex medical interventions.[29] Ensure that you spend time providing clear verbal information, as people with low health

case study

Jim

Jim is a 66-year old retired brick-layer who has had type 1 diabetes for 45 years. He is attending Diabetes Clinic for review and is talking with Sarah, a second-year trainee. At his last visit, it was noted his haemoglobin level had fallen from 132 to 110 g/L (reference range 130-170 g/L). Subsequently, he was found to have iron deficiency, so an upper gastro-intestinal endoscopy and a colonoscopy were requested.

Sarah sees from Jim's medical records that the colonoscopy was not completed due to insufficient bowel preparation and has been rescheduled for next month. Jim hesitantly admits to Sarah that he couldn't read the instructions provided by the staff at the day centre and was too embarrassed to say anything. He tells Sarah his wife died eight months ago and she used to help him with reading documents. Since then he has been relying on his daughter Debra for help, but she and her family are away on holidays.

A copy of the bowel preparation instructions is obtained from the gastroenterology registrar and Sarah talks Jim through the content, checking carefully that he understands each step. She then notes that his HbA1c has risen from 62 mmol/mol (7.8%) to 77 mmol/mol (9.2%) over the past six months.

On further discussion, Sarah learns that Jim has been struggling with his diabetes self-management since his wife died. He says she used to help him check his BGLs and calculate insulin doses for his carbohydrate intake because he was "never good with numbers". Sarah asks Jim how she can best help him with his diabetes. Together, they decide to engage the assistance of a diabetes educator for extra support. Jim says he will ask his daughter to come to his next appointment so she can become more involved in his diabetes care.

1.4 health literacy

literacy tend to rely on this type of delivery rather than on written information.[30]

Apply the basic principles of effective information giving, as outlined in the previous chapter, especially chunking and "Teach Back". Focus on the main parts of the message, particularly those relating to actions or health behaviours. Encourage the person to ask a family member to accompany them to consultations.

B. Select appropriate written materials

Studies have shown that much of the health education information available is too complex for the average person to comprehend.[3] Select appropriate educational material and underline the key points. Where possible, use models, DVDs, CDs, internet links or other interactive media to reinforce information.[31]

C. Provide assistance and practical suggestions within consultations:

- help fill in forms in a confidential manner
- explain the maps on the back of referral forms
- ask for a list or bag of medications for review and check that the person knows what each is used for
- use colours to differentiate between medications and devices, especially insulin pens
- explain recent test results or medical reports and provide copies for the person to take home
- encourage the use of bolus calculators or smart phone applications for estimating CHO intake and determining insulin doses[32]
- involve other members of the diabetes team to help reinforce information

D. Formal interventions

Formal interventions have been developed to help people with diabetes enhance their health literacy, but data about their effectiveness in improving glycaemic control and other diabetes outcomes are inconclusive.[33]

Producing accessible written health information

As a trainee, you may be involved in producing written information for people with type 1 diabetes. This may include developing information brochures or writing plain language statements for research projects.[34] There are a number of basic principles that you can apply to help make this information accessible, especially to people with low health literacy:[35]

A. Clarity of purpose

Make sure the purpose of the material is clear. State for whom it has been written and what it designed to convey.

B. Layout

Use easy-to-follow layouts with simple pictures or diagrams. Include white spaces to break up the text to enhance user-friendliness. Use headings as much as possible and highlight important points in bold, in colour or by placing them within a box. In general, use *sans serif* fonts and ensure the font size is large enough for the text to be easily read.

C. Content

Use repetition of content, with rephrasing of the key information in a variety of ways to facilitate comprehension.

In general, it is more effective to focus on behaviours rather than just medical facts. For example, it is better to write:

> *"Eating low fat food can help to lower cholesterol"*
>
> rather than:
>
> *"A low fat content diet can improve cholesterol levels."*

D. Use of language

1. Ensure that your language is clear and simple. Use non-medical and jargon-free wording. For example, write *"high blood pressure"* rather than *"hypertension"*.
2. Make the text personally relevant by using second rather than third person language.

   "You might find it easier to keep your insulin prescriptions with your local chemist than at home."

   is more engaging than saying:

   "People who have type 1 diabetes might find it easier to …"

3. Write in the active voice, as it is usually a more concise form of expression than the passive voice. It is also usually less confusing for the reader. For example:

   "Medical researchers have found that …"

   will usually be easier to read than:

   "It has been found by medical researchers that …"

4. Frame the information in a positive rather than a negative style.[36]

   "If you can keep your HbA1c within or near target, you are more likely to stay healthy with your diabetes."

   will be more favourably received than:

   "If you have an elevated HbA1c, you will be more likely to develop diabetes complications."

E. Check readability

Readability reflects features such as the number of words per sentence, the number of complex words (usually defined as being those of three or more syllables) and the average length of sentences in a sample.[37-38] In general, it is recommended that the readability of written materials is targeted at Year 8 standard, although it has been suggested that an even lower level may be required for general health information.[39]

EXAMPLE OF TEXT AT TERTIARY LEVEL OF READABILITY:

If you have persistent hyperglycaemia, measure your serum ketone concentration and consult your physician immediately if the level is elevated.

EXAMPLE OF TEXT AT PRIMARY SCHOOL LEVEL OF READABILITY:

If your glucose levels stay up, check the ketones in your blood. Call your doctor right away if the ketones are high.

Numerous readability instruments are available to check the reading level of written materials. The Fry readability formula and the Simple Measure of Gobbledygook readability calculator are amongst the most commonly applied in health care settings.[40-42] These instruments use small sample sizes, are relatively quick to use and are freely available online.

Be aware that readability instruments have their limitations. They are based on the assumption that longer sentences and longer words are more difficult to read, but do not take into account whether or not the words used are familiar to the target audience. They also do not take into account the consistency and layout of the writing or supporting materials, such as diagrams and graphs.

1.4 health literacy

clinical tasks

1. Identify a person with type 1 diabetes you suspect has low health literacy. Ask how confident they are about filling in forms by themselves. Be sure to introduce the question in a sensitive manner and within an appropriate context.
2. Rewrite the following text about sick day management so it is accessible for people with type 1 diabetes, especially those with low health literacy. If required, adapt the details to match your local sick day management policy. Use a readability formula to check the reading level of your rewritten text. Format your final version to maximise its visual appeal.

SICK DAY MANAGEMENT FOR PEOPLE WITH TYPE 1 DIABETES

Intercurrent illnesses, especially those of an infective aetiology, can result in a state of relative insulin deficiency in people with type 1 diabetes. This state is mediated though a range of pathophysiological responses, including elevated secretion of counter-regulatory stress hormones (glucagon, catecholamines, cortisol and growth hormone) which produces loss of insulin-dependent suppression of hepatic glucose production and diminished glucose utilisation as a consequence of impaired glucose transfer across cellular membranes. The resultant hyperglycaemia generates polyuria and dehydration through osmotic diuresis, and compensatory thirst and polydipsia can supervene. In addition, alternate energy sources are utilised by the body, predominantly though lipolysis of triglycerides to free fatty acids and glycerol as substrate for ketone body formation and gluconeogenesis respectively. Some illnesses, such as those associated with emesis, diarrhoea or reduced nutritional intake, may lead to hypoglycaemia rather than hyperglycaemia. Irrespective, additional precautions are required for optimum glycaemic management during episodes of illness. Primarily, the intensity of blood glucose monitoring must be escalated, with concentrations being initially measured every 2 - 4 hours from the onset of symptoms. More frequent BGL monitoring is indicated if there are persistently elevated BGLs or if BGLs are < 4 mmol/L. There should be contemporaneous measurement of serum or urine ketones. Heightened surveillance of BGLs will be necessary if there is ketonaemia or ketonuria. Regular insulin administration is essential, although dose modification may be indicated. Supplemental doses of rapid or short-acting insulin will be necessary for the treatment of hyperglycaemia. For BGLs > 15 mmol/L with elevated ketones, administer 10-20% of the total daily insulin dose every 2 – 4 hours until BGL < 15 mmol/L. Adequate fluid intake is essential to prevent dehydration. Fluids should be carbohydrate-free if BGLs are > 15 mmol/L. Carbohydrate-containing fluids should be consumed if BGLs are ≤ 15 mmol/L. If there is vomiting and diarrhoea, saline rather than pure aqueous fluids are required. Management of the underlying illness is indicated and does not differ from that necessitated for a non-diabetic person. A medical practitioner must be consulted if the underlying aetiology of the illness is not evident. Paracetamol can be administered for symptomatic relief of hyperpyrexia and myalgias, unless contraindicated. Prompt assistance should be obtained if the person is pregnant, elderly, unable to follow sick day instructions or does not have a support person in the domiciliary environment. Other indications for expeditious presentation are: persistent hyperglycaemia (BGL >15 mmol/L) despite two sequential doses of supplemental insulin, persistent hypoglycaemia (BGL < 4 mmol/L), ketonaemia (> 1.5 mmol/L) or heavy ketonuria. Urgent hospitalisation and specialist management is mandatory if features of diabetic ketoacidosis (DKA) develop. The symptoms and signs of DKA include severe abdominal pain, persistent emesis, Kussmaul respiration, dehydration, ketotic breath and neurological decompensation. It is advised that a contingency strategy be developed for acute episodes of illness with type 1 diabetes and be retained in a readily accessible location. It should document the particulars of the nearest health care facility or a health care provider who can be promptly contacted in the event of an emergency.

Adapted from:

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1.4 health literacy

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1.5 practical skills

learning outcomes

to be able to:

- describe the principles of practical skills acquisition
- facilitate the acquisition of a practical skill by a person who has type 1 diabetes
- check the pre-existing proficiency in a practical skill of a person with type 1 diabetes

key reading

1. Ericsson KA. Deliberate practice and the acquisition and maintenance of expert performance in medicine and related domains. *Acad Med* 2004; 79: S70-S81.
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Introduction

For effective self-management, a person with type 1 diabetes needs to develop and maintain a core set of practical skills. This skill set includes technical skills, such as BGL measurement, insulin self-injection and ketone checking, as well as cognitive skills, such as CHO estimation and insulin dose adjustment.[1,2] Additionally, a person may wish to develop more advanced skills, such as using an insulin pump or a real-time continuous glucose monitor.[3,4] Family members or carers may need to acquire practical skills, such as being able to administer glucagon in the event of severe hypoglycaemia.[5]

The responsibility for helping people with type 1 diabetes to acquire practical skills generally lies with diabetes educators and dietitians. As a trainee, however, you need to have an understanding of the principles and practice of facilitating practical skills acquisition so you can build an appreciation of the roles and skills of other members of the diabetes team.[6] This can help you to build strong professional relationships and to optimise the quality of your referrals within the team.

In addition to promoting successful teamwork, being able to facilitate the acquisition of practical skills is a key way of enhancing your own consultations with people who have type 1 diabetes. It enables you to check their practical skills as a part of routine care and to trouble-shoot if a person seems to be struggling with their self-management or is not reaching their glycaemic targets. You will be more able to accurately identify skills needing further development if you have a thorough knowledge of how they are performed. You are also more likely to instil confidence in a person with type 1 diabetes if you can demonstrate that you have a sound grasp of the breadth and depth of the practical aspects of diabetes management. Importantly, you will be able to teach survival skills if a diabetes educator or a dietitian is not available, such as if a person with newly diagnosed type 1 diabetes is admitted to hospital outside routine working hours.

Principles of practical skills acquisition

To effectively acquire a practical skill, a learner needs to work through a number of defined levels of competence with increasing complexity. These levels are often represented in the medical education literature using a configuration known as “Miller’s triangle” (see Figure 1.5.1).[7] Originally developed for use in the context of clinical assessment, Miller’s

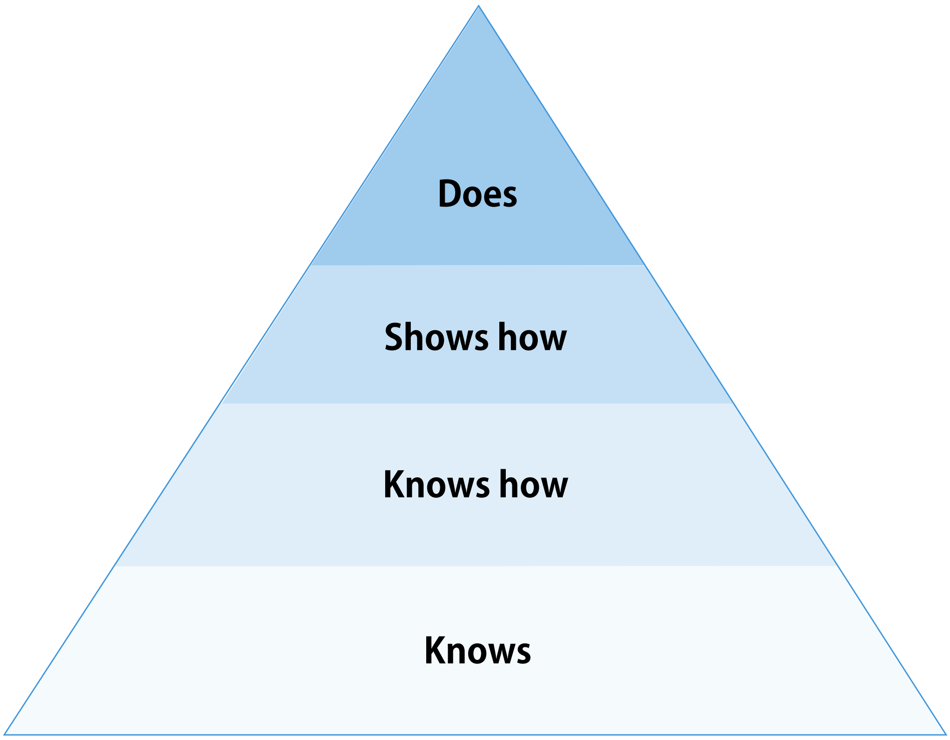


Fig 1.5.1: MILLER'S TRIANGLE: LEVELS OF PERFORMANCE

Adapted from Miller GE. The assessment of clinical skills/competence/ performance. *Acad Med* 1990; 65: S63-S67.

triangle also provides a useful conceptual framework when approaching the facilitation of skills acquisition.

Based on Miller's triangle, the first level of skills acquisition involves the learner *knowing about* the skill. This includes being able to say broadly what the skill involves and how it is relevant to their own life context. At the next level, they need to know *how* to carry out the skill. This forms the basis for the next level, which is being able to *demonstrate* proficiency in the skill. During this stage, dexterity is developed through targeted feedback from the person who is facilitating the acquisition of the practical skill. The highest level of competence involves the learner being able to *apply* the skill effectively in a real world context.[8-10]

Facilitating the acquisition of a practical skill

The acquisition of a practical skill is an interactive process, with both teacher and learner playing an active role. It comprises the following steps:

A. Preparation

Make sure that you know how to perform the skill correctly yourself. You need to be able to clearly delineate its component parts, a process known as "deconstruction" or "task analysis".[11,12] Specifically, you need to be aware of the steps that are more difficult than others so you can spend more time on these during the teaching and learning process. For example, a person with type 1 diabetes who is learning how to use an insulin pump will probably find it more difficult to set a temporary basal rate

1.5 practical skills

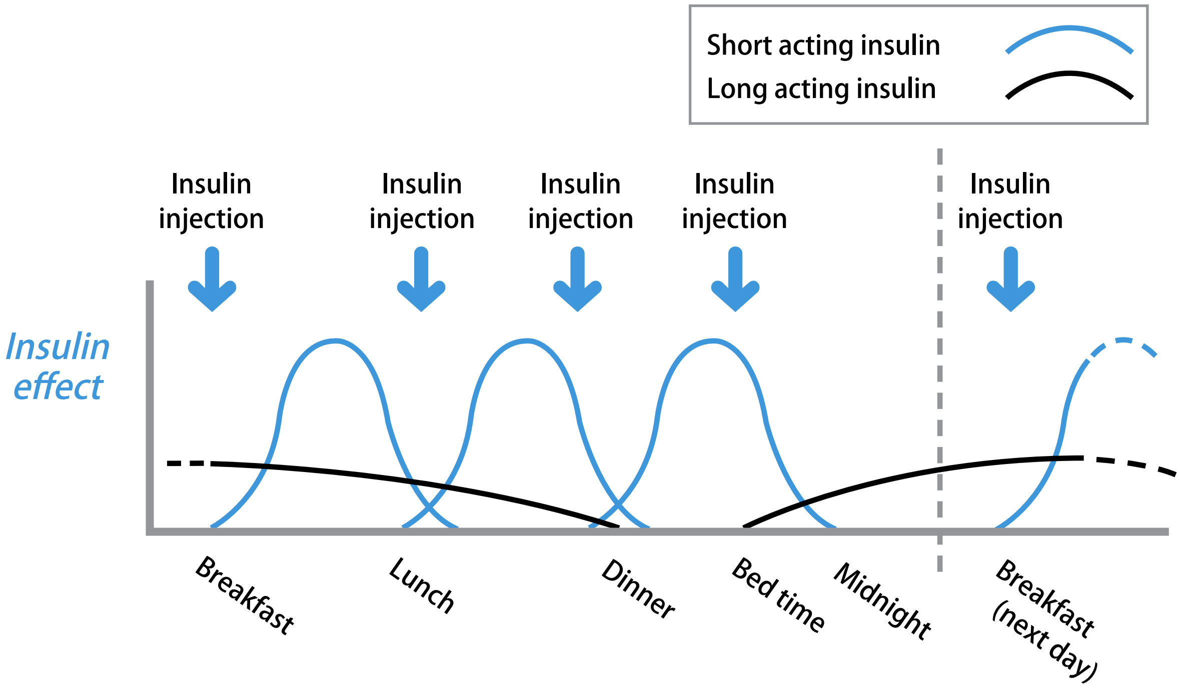


Figure 1.5.2: BASAL-BOLUS INSULIN PROFILE

Diagram reproduced with the permission of Diabetes UK.

than a routine basal rate, so more time may need to be allocated to teaching this particular aspect of the skill.

B. Establish a person's learning needs

Determine if a person with type 1 diabetes has the prerequisite knowledge for acquiring a new skill for self-management. For instance, if you are going to teach someone with newly diagnosed type 1 diabetes about insulin dose adjustment, you will need to make sure that they have an understanding of the typical profiles for prandial and basal insulin (see Figure 1.5.2).

Determine the skills a person needs to develop at the present time. For example, when a person has just been diagnosed with type 1 diabetes, there will be a set of survival skills that need to be acquired as a matter of urgency. This means that some skills will need to be left until a later time. In the longer term, the person will play a more active role in setting the agenda with respect to identifying when and how they wish to learn new skills or build on pre-existing skills.

In some circumstances, a person may know about a skill if they have a family member with diabetes or are a health professional themselves. Ask them to tell you what they know and build on this information, rather than just assuming they know everything about the skill.

C. Identify any potential barriers and check preparedness

Identify potential barriers that might impact on the acquisition of a practical skill. These might be physical, such as visual impairment or arthritis in the small joints of the hands, or cognitive, such as delirium or acquired brain injury. In some situations, there may be issues with reading proficiency that limit the person's ability to understand supplementary handouts. Establish if a third person, such as a carer or an interpreter, needs to be present during a consultation.

Be alert to emotional, psychological or psychiatric factors that can act as barriers to learning. When a person is depressed, anxious or overwhelmed by other life priorities, their ability to learn a new practical skill may be limited. There may also be specific psychological barriers, such as fear of injecting or severe hypoglycaemia, that can negatively impact on learning and will need to be addressed.[13]

Be sure that adequate time is allowed for the person to learn the skill. Inform them how long the session will take before you start. Ensure that the environment is not noisy and that there are no distractions, such as non-urgent telephone calls.

D. Outline the steps of the practical skill

Talk the person through the practical skill step-by-step. It is recommended that you provide written or pictorial materials to support this process, taking into account the person's level of literacy. These may be in the form of pamphlets, DVDs or web-based instructional materials.

E. Demonstrate the practical skill

Go through the steps again as you demonstrate the skill to the person. Refer to the supplementary written or pictorial materials as you do this. Sitting next to the person may convey a more collaborative approach than sitting opposite them. You may need to take into account any difference in handedness between you and the person.

F. Ask the person to try out the practical skill while you observe them

After you have demonstrated the practical skill, ask the person to show you step-by-step how they can perform it. Encourage them to refer to the supplementary materials for reinforcement. Depending on the complexity of the skill or the person's level of confidence, it may be easier for them to talk through the steps of the skill with you before they try it out.

Simulation can be effective as a technique to support skills acquisition.[14] For example, using an injection pad can be a helpful way of teaching and learning about injection technique, especially when a family member or a carer is learning how to administer glucagon.

G. Provide constructive feedback

Provide constructive feedback to the person about how they performed the skill.[15,16] Unlike praise or criticism, feedback involves providing specific information that can help to guide future performance. It therefore needs to be objective and focused on the elements of the performance rather than on the person. Importantly, the feedback process needs to be interactive and conversational, rather than didactic.

Start by asking the person how well they felt that they performed the skill. This encourages effective self-evaluation and provides a useful starting point for discussion. Focus initially on the positive aspects of the person's performance by reinforcing what they did well and why. Then focus on the aspects of the skill they have identified as needing more attention. After this, comment on any remaining aspects of the skill requiring feedback.

Be sure to use collaborative and non-judgemental language.[17] Use "*and*" rather than "*but*" or "*however*" when moving from the initial positive feedback to a discussion about aspects of a skill that need further development. This can help to validate rather than negate the value of the positive feedback.[16] Using personal ("*I*") statements can be a non-threatening way of delivering information about ways to improve how a skill is performed:

> *"I think the angle of the needle could be moved a little this way so it's closer to 90 degrees. This will help the insulin get to the best spot ..."*

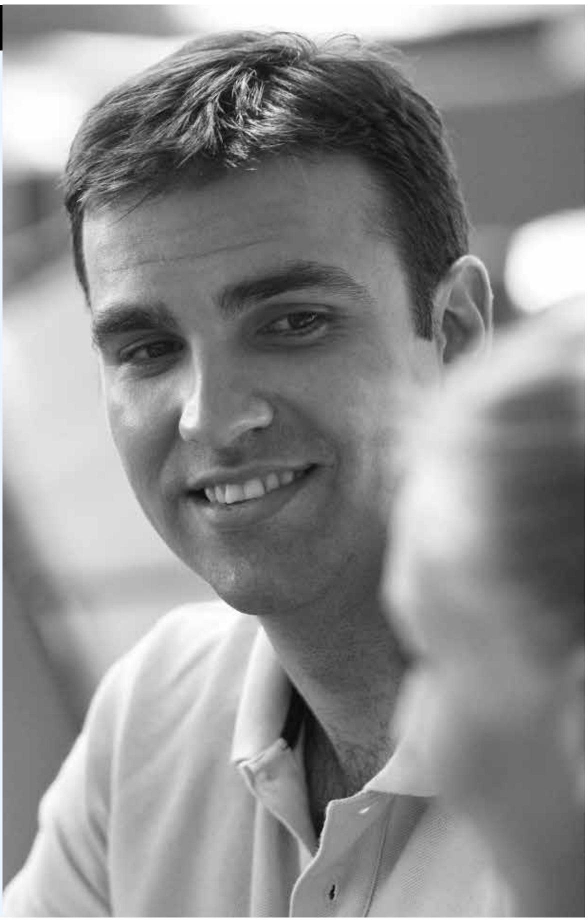
Check that you have adequately conveyed the meaning of your feedback. It is also important to find out how the person feels about doing the skill. Their

case study

Alex

Alex is a 28-year old man who presented to the emergency department at the weekend with four days of increasing thirst, polydipsia and polyuria. Mild diabetic ketoacidosis was noted on initial biochemical testing and a diagnosis of type 1 diabetes was made. The acidosis was treated according to the hospital protocol and Alex was admitted to a medical ward for ongoing management, including initiation of a basal-bolus insulin regimen.

David, a third-year trainee, has reviewed Alex's medical status and is now helping him to acquire the skill of self-injecting short-acting insulin using a disposable injector device. He has explained the steps of the skill using supplementary written instructions and followed this with a demonstration using an injection pad. He then watches as Alex gives an injection into his abdomen. David is now giving feedback to Alex.



DAVID: *Alex, how do you think that went?*

ALEX: *OK, I think. I felt OK about putting on the needle, doing the air shot and dialling up the dose ... and the needle didn't hurt as much as I thought it would. I hardly felt it go in at all ... but I'm not sure if I actually injected it properly ...*

DAVID: *I think you did really well for your first injection. Yes, you put on the needle, did the air shot and dialled up OK ... that all was fine ... Alex, I also noticed that you looked away as you actually gave the injection ...*

ALEX: *Yes, I was really scared it might hurt. That's why I did that ... and that's why I'm not sure if I did it the right way ...*

DAVID: *Uh huh ... I'm wondering now that you know that it doesn't hurt much, perhaps you could try looking while you are injecting? That way you can check if you are holding it at a 90 degree angle ...*

ALEX: *Sure ...*

DAVID: *Would you like to use an injection pad to have another go at this? That way we can also see what sites feel most comfortable for you.*

ALEX: *Sounds good ... (tries again with the injection pad) ...*

DAVID: *That's great, Alex. Your technique is fine. How confident do you feel about doing this on your own?*

ALEX: *I think I'll be OK, but I wouldn't mind if someone could watch me when I give my injection for dinner tonight. I don't feel 100% confident yet.*

DAVID: *Not a problem. I'll ask one of the nursing staff to help you with that. Perhaps you could have the instruction sheet in front of you while you do the injection. That way you can talk them through what you are doing ...*

attitude and emotional reaction to performing it are important in determining how well they will be able to implement it in their real life context. Always end with an encouraging remark.

H. Provide contextual information

Determine the contextual information required to support acquisition of the skill. For instance, when a person is learning to self-inject with insulin, they will need information about how to rotate injection sites, store their insulin and dispose of the needles.[2] They will also need assistance to complete an NDSS form to state that they are using insulin injections, so that they can obtain subsidised supplies of consumables.[18] Importantly, they will need to learn how to effectively recognise and manage hypoglycaemia.[5]

I. The practice phase

Encourage the person to consolidate their newly acquired skill through deliberate practice.[9] This involves attention, concentration and repetition until they become fluent in the skill. This phase is particularly important for complex skills, such as flexible insulin dose adjustment and adjustment of insulin pump settings. Provide contact details so the person can ring for support between appointments as required.

J. Documentation

Document that the person has acquired proficiency in the practical skill. If only part of the skill has been covered during a session, ensure that this information is recorded and a plan is made for building upon it at the next appointment.

K. Review

Plan an early follow-up appointment to promote consolidation of the practical skill. Make sure the next stage is not forgotten if a step-wise approach to skills acquisition has been initiated.

Checking pre-existing proficiency in a practical skill

A. When to check pre-existing proficiency

Periodically review the self-management skills of a person with type 1 diabetes. This not only supports maintenance of proficiency, but also provides an opportunity for the person to be kept up to date with new technological developments, such as upgrades in blood glucose meters, injector devices or insulin pumps.

The International Society for Pediatric and Adolescent Diabetes has recommended that all children and adolescents with type 1 diabetes have access to a diabetes multi-disciplinary team to review their skills at least once a year, in addition to their routine medical checks.[19] Currently, there are no specific recommendations about the frequency of this type of review for adults with type 1 diabetes in Australia. As a minimum, however, review is recommended if there are changed circumstances, such as when a pregnancy is being planned or if diabetes-related complications have developed.[20]

B. How to check pre-existing proficiency

Checking pre-existing proficiency of a practical skill requires a sensitive approach. If a person has had diabetes for a long time, they may feel embarrassed to admit that they don't know how to perform a skill properly. They may also find it confronting if they find out they have been performing a skill incorrectly over a long period of time.

Start with a general enquiry about the practical aspects of the person's diabetes self-management. Comment on what you know the person can do and ask what they think about the results they are achieving with their diabetes.

> *"You know a lot about using your pump. How do you feel that using it has made a difference to your diabetes management?"*

If the person is not achieving their desired diabetes outcomes, ask:

> *"Are there any aspects of your diabetes practical skills you would like to review?"*

It can be easier to broach the subject of checking proficiency if it is accepted as being a routine part of long term management or if you have not met the person before. As a trainee, you are well placed to say:

> *"I haven't met you before so would you mind showing me how you adjust the basal rates on your pump?"*

One effective strategy is to ask about a person's confidence rather than their competence. Most people find that admitting they are not confident in a skill is far less confronting than saying they cannot perform it correctly.

1.5 practical skills

> *"Are there any aspects of carbohydrate counting you don't feel confident about?"*
>
> rather than:
>
> *"Can you carbohydrate count properly?"*

Be aware that a person may not be able to perform a skill fluently because it has not been demonstrated to them correctly. Take responsibility for how a person acquires proficiency in a practical skill.

> *"Have I taught you well enough how to adjust your insulin sensitivity factors?"*

Use review of practical skills as an opportunity to assess for physical complications that may have arisen over time. For example, when checking a person's insulin injection technique, look for the development of lipohypertrophy or atrophy at their injection sites.[21] Make sure they understand the nature of these conditions and avoid these sites when injecting.

Structured Diabetes Education

Structured diabetes education (SDE) is a widely used technique for helping people with type 1 diabetes to build their practical skills.[22-26] It is designed around skills such as CHO estimation and flexible insulin therapy, and is generally conducted in a group format.[25] SDE is based on a set of defined learning outcomes and is conducted by specially trained educators.

It is recommended that you learn about the content of commonly-accessed local SDE programs. It is also recommended that you learn about DAFNE, which is one of the most widely recognised SDE programs in Australia and internationally.[27-38] This information will help you to support people with type 1 diabetes who have participated in such programs as they apply and consolidate the skills they have acquired.

In addition to enhancing your clinical care of people with type 1 diabetes, knowing about the content and delivery of SDE programs will allow you to effectively critique research in this area. There is now robust evidence that SDE can improve a range of metabolic and psychological outcomes in type 1 diabetes. Specifically, SDE programs can lead to improved glycaemic control and QOL, as well as reduced rates of hypoglycaemia.[27,30-33] There is also growing evidence for the cost-effectiveness of such programs.[34] Further research is required, however, to establish the optimal way of providing ongoing support and to determine why some people benefit more than others from SDE.[35]

Resources for facilitation of practical skills

The ADEA website contains a number of guidelines, standards and position statements regarding practical skills acquisition in diabetes.[1] It is recommended that you access the following documents:

ADEA Clinical Recommendations – Subcutaneous Injection Technique for Insulin and Glucagon-like Peptide-1

Use of Blood Glucose Meters

Minimum Standards for Capillary Blood Glucose Sampling Devices in Health Care Settings

Risk of Using Incorrect Needle Length

Use of Subcutaneous (S/C) Insulin Delivery Devices

clinical tasks

1. Attend a structured diabetes education course, such as a DAFNE course for people with type 1 diabetes
2. Ask a diabetes educator to supervise while you facilitate the acquisition of insulin self-injection by a person with diabetes using rapid-acting insulin in a disposable pen.[2, 34] Work through the steps on the following page using the principles outlined in the chapter.

A. Remove the end cover of the insulin pen

B. Attach a new needle

C. Dial up 2 – 4 units for an air shot

D. Remove the outer and inner needle caps

E. Hold the pen upright and expel the insulin into the air

F. Dial the recommended dose

G. Insert the needle at a 90 degree angle, inject the insulin into the skin, count to 10 and then remove the needle (the person may need to pinch up an area of fat for this step)

H. Place the large outer needle cap firmly on the needle and unscrew it to remove the needle

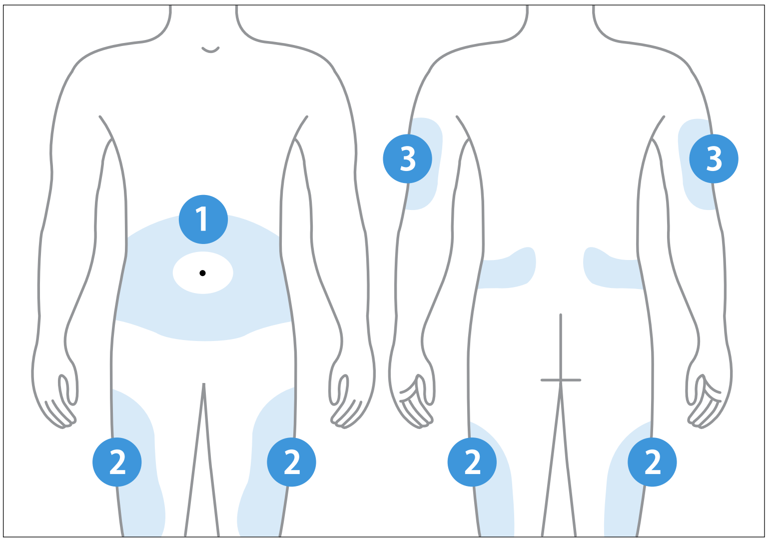
I. Discard the needle and the cap into a sharps container

J. Replace the end cover on the insulin pen

K. Provide the following supporting information:

- Storing insulin safely
- Changing and disposing of needles, including using sharps containers
- Changing and disposing of pens
- Obtaining supplies of consumables through NDSS
- Selecting and rotating injection sites

Figure 1.5.3: RECOMMENDED INSULIN INJECTION SITES



① **The abdomen**
Except for a 2-inch circle around the navel

② **The top and outer thighs**
Avoid injecting too close to the bony area above the knee

③ **The outer, upper arms**
Use the outer back area of the upper arm where there is fatty tissue

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1.6 problem-solving skills

learning outcomes

to be able to:

- discuss the role of problem solving in the self-management of diabetes
- describe the key principles of effective problem solving
- engage in a problem-solving exercise with a person who has type 1 diabetes

key reading

1. Hill-Briggs F. Problem solving in diabetes self-management: a model of chronic illness self-management behaviour. *Ann Behav Med* 2003; 25: 182–193.
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Introduction

A person with type 1 diabetes needs to effectively apply their knowledge and skills in their daily lives to achieve optimal health outcomes.[1-4] They will, however, encounter many challenges along the way. The development and application of diabetes-specific problem-solving skills is critical for decision making around BGLs and for overcoming barriers to the implementation of lifestyle interventions.

There are two broad types of problem solving. One type is *quantitative* problem solving, which for people with type 1 diabetes principally involves the application of numeracy skills to the interpretation of BGL data, CHO counting and decision making around insulin dose adjustment.[5,6] Quantitative problem solving also includes the ability to interpret numerical depictions of risks and benefits for decision making around treatment options.[4] The other type of problem solving is known as *qualitative* problem solving. In general, this relates to the behavioural and psychological domains of self-management, such as being able to seek appropriate support from health professionals for sick day management or applying strategies for coping with the emotional demands of diabetes. In reality, effective self-management in type 1 diabetes involves applying a combination of quantitative and qualitative problem-solving techniques at any one time.

As a health professional, you need to be able to work in an interactive manner with people who have type 1 diabetes to help them optimise their problem-solving skills. This requires having a sound knowledge of the principles and practice of problem solving.[1,4,7,8] In this chapter, the focus will predominantly be on the *quantitative* aspects of problem solving in type 1 diabetes. The application of problem-solving skills in the behavioural and psychological domains of diabetes self-management will be explored in subsequent chapters.

Principles of problem solving in a health care context

Problem solving encompasses a range of cognitive abilities, such as verbal reasoning, causal analysis, consequential thinking and reflective skills.[9] The problem-solving process itself consists of a set of specific steps that need to be worked through sequentially to achieve successful outcomes. These steps include problem identification, analysis of potential underlying causes, strategy generation, implementation and evaluation of outcomes.[1] The steps that people with type 1 diabetes work through for problem solving have much in common with those that you apply during diagnostic reasoning in clinical practice.[10-12]

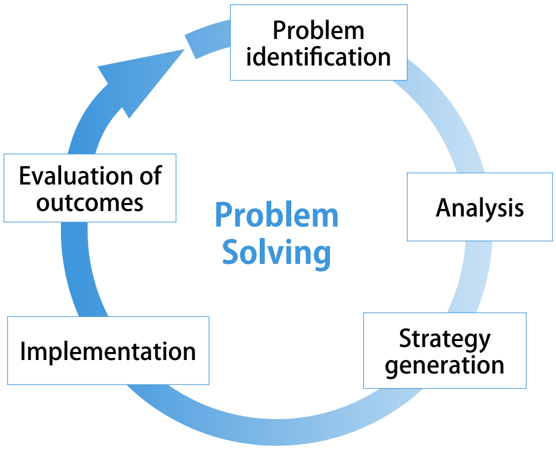

Fig 1.6.1: THE STEPS OF PROBLEM SOLVING

The outcomes of problem solving are influenced not only by cognitive ability, but also by a complex mix of contextual and attitudinal factors. Hill-Briggs has proposed a framework for thinking about the broader aspects of problem solving in diabetes self-management that draws upon cognitive psychology, educational theory and social problem-solving theories.[1] This framework acknowledges that successful problem solving is dependent on having specific knowledge for the task at hand and the capacity to transfer learning from past experiences to new situations.[13] It also involves being able to store knowledge in a way that can be readily accessed, a process facilitated by having good organisational skills. Furthermore, successful problem solving involves accepting problems as being a part of normal life and being motivated to tackle rather than avoid them. Specifically, it requires having the flexibility to try out new strategies and not be discouraged by negative past experiences.

Facilitating problem solving in the clinical context

Problem-solving skills in diabetes are much harder to acquire than knowledge or practical skills.[14] There are often multiple variables to be considered at any one time and higher-order cognitive skills are required. Helping people with type 1 diabetes to enhance their problem-solving abilities requires providing regular access to skill-building activities in this domain of self-management.[14] Within consultations, you can provide support by modelling and articulating the steps of problem solving.

A. Philosophical approach

Recognise that problem solving is a core component of diabetes self-management.[15] Your role is to facilitate the acquisition of problem-solving skills in people with type 1 diabetes, rather than to solve problems for them. Just after diagnosis, a person who has developed type 1 diabetes will need a great deal of support with problem solving, but there should be a plan towards graduated independence. You may encounter people who have had diabetes for many years and who have expectations that health professionals will fix their diabetes-related problems for them. They may become frustrated if this does not occur, so it is important to openly discuss the rationale for building their problem solving skills and to provide them with scaffolded opportunities for becoming more competent in this area.

B. Apply individual approaches to problem solving

Certain contexts will need specific approaches, such as when working with adolescents, if there are baseline learning difficulties or other cognitive issues, or when there are mental health issues that are impacting on the ability of a person to self-manage their diabetes.[14] These situations will usually require the additional support of partners, family or carers, as well as close collaboration with other members of the diabetes team.

C. Articulate the steps of the problem-solving process

1. Problem identification

A person with type 1 diabetes may come to a consultation with a specific problem they would like to be addressed. Alternatively, you may need to work with them to identify problems with their diabetes self-management. Over time, you will develop specific strategies for promoting problem identification, depending on the nature of the person's presentation. If working on quantitative problem solving around BGLs, for example, encourage the person to record their data in formats that enhance pattern recognition, so they do not rely just on responding to prevailing BGLs. Such formats include spread sheets with rows and columns, logbook downloads from smart meters and continuous glucose monitoring profiles, rather than just linear meter printouts. Recognise that other formats may be suitable for additional purposes, such as pie charts that can motivate by showing improvements in the percentage of readings in target over time, although these do not supply information in a way that facilitates problem solving.

1.6 problem-solving skills

case study

Emily

Emily is a 32-year old woman who is currently 29 weeks' pregnant (G1P0). She is attending the antenatal diabetes clinic at her local maternity hospital and is talking with Paul, a third-year trainee. She tells Paul she developed type 1 diabetes when she was 17 years of age. Her diabetes has been complicated by diabetic retinopathy, for which she has required laser treatment, and necrobiosis lipoidica affecting her right shin.

Emily's HbA1c has fluctuated over the years, peaking at 10.1% about 18 months ago. After attending a DAFNE course last year, however, she became more confident about carbohydrate counting and insulin dose adjustment. When she and her partner decided they were ready to start a family, she was referred by her endocrinologist to the maternity hospital for pre-pregnancy planning. Just prior to conceiving, her HbA1c was down to 47.5 mmol/mol (6.5%).

During the first trimester of her pregnancy, Emily experienced moderately-severe morning sickness and frequent mild hypoglycaemia, but she managed this well by using the problem-solving skills she had developed leading up to her pregnancy. By the end of the first trimester, her HbA1c had fallen further to 41 mmol/mol (5.9%).

Emily says that her BGLs were easy to manage during her second trimester, but now she is entering the third trimester, her BGLs are elevated after breakfast. She is currently taking10 units of rapid-acting (RA) insulin at this time of day, with 14 and 18 units respectively for lunch and dinner, and 28 units of long-acting insulin at night. Emily has tried increasing her pre-breakfast insulin to 14 units and exercising in the mornings, but these strategies resulted in hypoglycaemia prior to lunch. She is not sure what to do next and would like help with problem solving.

Day 1

Time			0700		0900		1100		1300		1500				1900		2100			
BGL			5.0		**11.1**		6.3		6.1		7.0				5.0		7.5			
RA insulin			10						14						18					
CHO (gm)			60						60						75					

Day 2

Time			0700		0900		1100		1300		1500				1900		2100			
BGL			4.9		**10.6**		6.5		6.4		7.3				5.5		7.2			
RA insulin			10						14						18					
CHO (gm)			60						60						75					

Day 3

Time			0700		0900		1100		1300		1500				1900		2100			
BGL			5.3		**11.5**		6.9		6.1		6.9				4.9		6.6			
RA insulin			10						14						14					
CHO (gm)			60						60						60					

Figure 1.6.2: EMILY'S BGL DATA PRIOR TO PROBLEM SOLVING

2. Explore potential underlying causes

Encourage the person to think about whether lifestyle changes, sickness, stress or technical issues may be playing a role. Can they think of anything that is different? What have they tried in order to fix the problem and how well did it work?

Help the person to build up a tool kit of strategies for diabetes trouble shooting, such as using new batches of test strips or insulin and checking for ketones if BGLs are elevated. Provide specific input if there is an underlying biological or medical explanation for changes in BGLs, for example, hormonal changes related to pregnancy or the effects of glucocorticoids. Acknowledge that sometimes a specific underlying cause may not be identified.

3. Generate strategies to solve problems

Encourage the person to think about strategies for finding solutions to problems, but try not to push the issue or you risk undermining their confidence. If they have come to you for help, they may have already tried everything they can think of doing. Ask what they have already attempted and why they think it did not work, so you do not offer unhelpful advice. Together, build a list of alternative options. For problem solving around BGLs, use the four basic pillars of diabetes management (BGL monitoring, food, exercise and insulin) as a framework. Depending on the problem, having more than one strategy can be preferable so that if one doesn't work, then others can be tried. The risks and benefits of each option need to be weighed up before a selection is made.

Emily (continued)

Paul reassures Emily that the pattern she has identified is common with the increasing insulin resistance of pregnancy. He discusses other options, including administering her insulin at a longer time interval before breakfast or using CHO splitting. Emily tries giving her insulin earlier, but finds this difficult to remember to do. She then decides to try CHO splitting. Using this technique, Emily takes her usual insulin dose with breakfast, but only eats half *of her usual CHO intake (30 gms = 1/2 x 60 gms). She has the other 30 gms of CHO 1½–2 hours later.*

4. Implement an intervention

Implementation may require a planning phase, depending on the nature of the problem. It may, for example, involve further skills development, such as revision of CHO counting or insulin to CHO ratio calculations. Work with the person to identify the potential flow-on effects of a particular intervention. For example, if they have decided to increase an insulin dose at a certain time of day, they will need to consider whether the dose for the next segment of the day needs to be decreased to prevent hypoglycaemia.

5. Evaluation of outcomes

Make a plan to evaluate the outcome of an intervention. This may be through review in clinic or a telephone call with you or the diabetes educator. How did the strategy work? If there were multiple components, did one part work more effectively than another? Is further refinement required? Can the intervention be sustained? Are there any downsides to it? If the strategy didn't work, what other options could be tried? Be sure to provide effective feedback to the person about their efforts.

Emily (continued)

Emily returns to clinic with her BGL records. She has tried CHO splitting and, for the most part, the strategy has been successful. One day, however, she was unable to have the second 30 gm serving of CHO due to being called to an urgent meeting at her workplace. As a consequence, she had a mild hypoglycaemic episode before lunch. She has spoken with her manager and he has agreed that Emily can be briefly excused from meetings so she can have her snacks.

Day 1

Time			0700		0900		1100		1300		1500				1900		2100			
BGL			5.0		7.0		6.3		5.9		7.7				5.4		6.8			
RA insulin			10						14						18					
CHO (gm)			30		30				60						75					

Day 2

Time			0700		0900		1100		1300		1500				1900		2100			
BGL			4.9		6.5		**3.1**		11.0		9.0				6.2		7.5			
RA insulin			10						16						18					
CHO (gm)			30		---		Jelly beans		60						75					

Day 3

Time			0700		0900		1100		1300		1500				1900		2100			
BGL			5.3		6.8		6.9		6.5		7.2				4.9		6.8			
RA insulin			10						14						18					
CHO (gm)			30		30				60						75					

Figure 1.6.3: EMILY'S BGL DATA AFTER PROBLEM SOLVING

D. Contextual elements of problem solving

Encourage transfer of the problem-solving skill. Are there any other situations where the person could apply it? Does it need to be adapted so it can be applied in other situations?

E. Attitudinal and affective dimensions of problem solving

If the person seems to be having difficulties with diabetes-related problem solving, explore the attitudinal and affective dimensions of the process. They may have unrealistic expectations of the outcomes of their problem-solving efforts and easily become frustrated when these expectations are not met. In other situations, a person may have other life priorities and not be interested in working on their diabetes. In this setting, highlight problem solving as an issue to be revisited at a later time.

If you think that mental health issues are impacting on a person's ability to apply their problem-solving skills, make an assessment of their emotional, psychological and psychiatric status. Approaches to assessment of mental health in people with type 1 diabetes will be addressed in the second module of this resource.

How does problem-solving ability relate to diabetes outcomes?

Although it seems intuitive that problem-solving is important for effective self-management of type 1 diabetes, there has been remarkably little research in this area. Early evidence derived from the Diabetes Control and Complications Trial (DCCT) suggested that people with type 1 diabetes who have well-developed problem-solving skills enjoy more flexible lifestyles and better quality of life (QOL) than those who do not, but this was largely anecdotal.[16] Since then, problem solving has been the focus of a number of cross-sectional and intervention studies, though most have been either not specific for type 1 diabetes or have included children and adolescents as participants rather than adults.

A. Measuring problem-solving skills

In 2007, Hill-Briggs and Gemmill published a systematic review of problem solving in diabetes. They identified six instruments with satisfactory internal consistency and validity for analysis,[4] but only one of these was studied in adults with type 1 diabetes. This instrument, the Diabetes Numeracy Assessment Tool, was found to correlate well with interpretation of BGL data, reading of food labels and insulin dose adjustment.[17] The other five instruments measured analytical and verbal reasoning, generally using responses to hypothetical scenarios, such as applying sick day guidelines and decision making around BGLs,[4] but were applied in children and adolescents with type 1 diabetes or adults with type 2 diabetes.[8,18,19] Subsequent publications in the area of problem solving have also largely focused on adolescents rather than adults.[20]

One of the limitations of many of the instruments described in the literature for measuring problem solving is that they use recall of fact rather than assessment of higher level cognitive skills, such as analysis, synthesis and evaluation.[21] Others have used generic measures of problem solving that do not correlate well with diabetes self-management behaviours or other diabetes-specific measures.[4] In addition, the generalisability of the various instruments has not been established and they are therefore not suitable as yet for use in clinical settings.[4]

B. Correlation between problem-solving skills and clinical outcomes

Overall, research shows an association between problem-solving skills and a range of generic and diabetes-related outcomes. Studies have supported the benefits of problem-solving ability in reducing the mental and physical health problems that can impact on QOL and self-care.[22] Data also support a relationship between problem-solving ability and various self-management behaviours, including healthy eating, exercise participation and blood glucose monitoring.[4]

A number of studies have particularly explored the relationship between problem solving and metabolic outcomes, such as HbA1c, management of glycaemic emergencies and presentations to the emergency department.[4] In their systematic review, Hill-Briggs and Gemmill reported consistent evidence for an association between ineffective problem solving and poorer metabolic outcomes from studies involving both type 1 and type 2 diabetes.[4]

C. Effectiveness of formal problem-solving interventions

There is little research to date that has addressed the impact of formal programs designed to facilitate the development of condition-specific problem-solving skills in adults with type 1 diabetes. There are, however, some studies that have examined problem solving itself as an outcome and found a positive

1.6 problem-solving skills

impact,[4] while others have shown that interventions can have an influence on specific behaviours, such as dietary management.[23]

There is some evidence to suggest that problem-solving programs can positively impact on HbA1c.[4] One difficulty, however, is that they are often part of wider diabetes self-management interventions and their specific contribution can be difficult to establish.[4]

Emerging topics of research in the area of problem solving include establishing the optimal balance between algorithmic and principle-based approaches, the effectiveness of health professional training and the role of internet-based interventions.[4,24]

clinical tasks

1. Using the principles outlined in this chapter, work with a person who has type 1 diabetes on a quantitative problem-solving task related to their BGLs.
2. Talk with a person who has type 1 diabetes about the attitudinal and affective factors that influence how they problem solve with respect to their diabetes.

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1.7 behaviour change

learning outcomes

to be able to:

- describe the components of successful behaviour change
- discuss the evidence for the effectiveness of behaviour change interventions
- effectively support a person who has type 1 diabetes with behaviour change

key reading

1. Armitage CJ, Conner M. Social cognition models and health behaviour: a structured review. *Psychol Health* 2000; 15: 173-189.
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Introduction

For effective self-management, people with type 1 diabetes need to adopt a complex set of behaviours, including strategic monitoring of BGLs, making healthy food choices, engaging in regular physical activity and being able to administer insulin in a flexible manner. Making and sustaining the behaviour changes required to meet desired outcomes can be enormously challenging.[1] This is reflected in studies that suggest up to 50% of people with type 1 diabetes have HbA1c levels above recommended targets.[2,3] It is easy for a person with diabetes to become de-motivated, especially when their BGLs are influenced by factors outside their control and if they don't see rewards for their efforts.[4] In turn, being de-motivated can lead to glucose instability or chronically elevated BGLs, resulting in an increased risk of adverse health consequences.[2]

As a trainee, it is important that you develop the skills to help people with type 1 diabetes make behaviour changes and support them so they can sustain these changes. It is evident from research that simply telling someone what to do or warning them of the consequences of inaction are not effective approaches for supporting behaviour change.[5,6] Instead, you need to apply techniques that recognise the responsibility for daily management primarily lies with the person who has type 1 diabetes and that only *they* know what is important to them or what is feasible within their own life context.[4,7,8]

Theories, interventions and techniques

Numerous theoretical models have been developed to explore the nature of behaviour change in the health care setting.[9] Although it is difficult to capture the real world by using a theoretical model, such an approach contributes to our understanding of how people develop and maintain adaptive health-related behaviours. Insight can also be gained into why some people do not change unhelpful behaviours, even when they are aware of the adverse consequences.

One of the most widely known theoretical models is Prochaska and DiClemente's Stages of Change Model.[10,11] This model provides a framework for conceptualising readiness for change by defining the processes people work through as they develop adaptive behaviours. It incorporates strategies for implementation based on individual decision making and recognises that progress through the stages is not always linear. Relapse is regarded as being a normal part of the process, providing an opportunity for learning how to maintain change. The Stages of Change Model has been criticised, however, for being too simplistic and for ignoring the situational determinants of behaviour change.[12] Other models include The Theory of Reasoned Action, Social Cognitive Theory and the Health Action Process Approach.[13] Each of these models places a different emphasis on the psychological, cognitive and social domains of behaviour change.

As a trainee, you do not need to know the details of the various theoretical models, but it is important to be familiar with the common interventions and techniques that derive from them.[14] One of the most extensively applied behaviour change interventions is motivational interviewing. This intervention was first described in 1983 as a tool for helping people overcome alcohol addiction and has since been used in a wide variety of contexts, including diabetes self-management.[15-17] Motivational interviewing is based on a number of theories of behaviour change, including the Stages of Change Model, as well as several models of psychotherapy.[17] Other behaviour change interventions include cognitive behaviour therapy (CBT), the Medication Interest Model and brief solution-focused therapy.[18-20]

All behaviour change interventions consist of a combination of specific techniques.[21] Michie and Johnston have defined these techniques as the “observable and replicable components of behaviour change interventions”.[21] Techniques used to support intention formation include providing information about links between behaviour and health outcomes, defining the desired change in behaviour and assessing motivation.[13,22] Implementation of change is facilitated by goal and task setting, enhancing self-efficacy and identifying barriers, as well as monitoring and evaluating progress, providing effective feedback and preventing relapse.[5,22] Techniques can be applied within formal intervention programs in individual or group formats, either face-to-face or online.[23] They also form the basis of skills that can be used within consultations to support behaviour change.

Evidence for effectiveness of behaviour change interventions

A large body of research has demonstrated the effectiveness of behaviour change interventions in the management of a range of chronic medical conditions, and for modifying lifestyle factors that contribute to the risk of disease and disability.[14] The

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National Institute for Health and Clinical Excellence in the United Kingdom has stated there is no clear evidence for the superiority of any one model or intervention over another,[14] but in general those explicitly based on theory have been the most successful.[24]

Motivational interviewing is one of the most intensively studied behaviour change interventions. Several meta-analyses have found evidence for its effectiveness in modifying problem behaviours, including those related to drug and alcohol use or low participation in physical activities.[25-27] There is also evidence for its usefulness in the self-management of chronic medical conditions where complex treatment regimens are required.[28] Other interventions have been found to be effective for a similar range of health-related behaviours.[14,18,28,29] Additional research has explored the impact of individual techniques, such as establishing intentions, facilitating goal and task setting, and giving feedback.[5,7]

The specific role of behaviour change interventions in the management of diabetes was reviewed by Plack *et al* in 2010.[30] The authors reported on the results of randomised trials using a range of interventions and techniques, including motivational interviewing, goal setting, self-efficacy skills, behavioural action plans and coping skills training. They cited evidence for positive impacts on behaviour, including engagement in physical activity and making healthy dietary choices, as well as on outcomes resulting from behaviour change, such as weight reduction and improved glycaemic control. In one robust study by Ismail *et al*, participants with type 1 diabetes were randomised to motivational enhancement therapy with or without CBT.[31] The results of the study showed that combination therapy was more effective than motivational therapy alone in improving glycaemic control through behaviour change. Few studies, however, have focused on behaviour change in people with type 1 diabetes, with most research to date exploring interventions in people with type 2 diabetes or mixed populations.

The critical appraisal of studies of behaviour change interventions, either for diabetes self-management or other health-related behaviours, requires an appreciation of the methodological difficulties of developing protocols for research in this area.[32] Most behaviour change interventions consist of multiple interacting components, with outcomes often influenced by local contextual factors. Long-term follow up is usually required, which increases the complexity of identifying the ingredients of the intervention that are responsible for behavioural change.[32] Moreover, it can be difficult to compare outcomes and account for variability if adaptations of standard techniques are used or if individual components are not described in sufficient detail in academic papers.[21,33] Over the past decade, considerable effort has been made to increase the rigour of the design and the evaluation of complex behavioural interventions,[32,34] including the development of a taxonomy for defining individual techniques.[22]

Supporting behaviour change in type 1 diabetes

The core techniques of behaviour change interventions can be applied within clinical consultations to support self-management. Making the steps of behaviour change explicit to people with type 1 diabetes can be an effective method of developing rapport.[20,35]

A. Establish baseline status

Explore existing behaviours and establish why these behaviours work or do not work for the person. Ask an open question to initiate discussion around this theme:

> *"How do you feel your diabetes is going for you right now?"*
>
> OR
>
> *"Is there anything you would like to be different about your diabetes right now?"*

A person may identify behaviours that are having a negative impact on their diabetes outcomes and that are amenable to change. In other circumstances, a person may be meeting their targets and be successfully achieving a balance between their diabetes self-management and other aspects of their life. In this context, there may be no need for behaviour change at the present time and positive reinforcement can be provided about the outcomes they are achieving.

B. Assess motivation

When a need for behaviour change has been identified, assess the person's degree of motivation so you can tailor the type of support that you offer.[13] There are two key features that help to predict a person's intentions to change:

1. Value

Establish what is important to the person right now. The extent to which they are motivated to change will, in part, depend on the value they place on the potential advantages of a new behaviour. If a person seems ambivalent about change, explore the reasons behind their hesitation. One strategy is to ask how much they think they are at risk of an adverse health outcome if change does not take place and if they believe an intervention would reduce this risk.

2. Confidence

A person's confidence in being able to succeed in adopting or maintaining a behaviour, also known as self-efficacy, is an important factor in the development of motivation to change.[36] Self-efficacy is not the same as possessing knowledge, practical skills or problem-solving ability. Rather, it is the degree to which the person feels they can successfully apply their expertise in their daily lives.

> *"Now that you have learned how to carbohydrate count, how confident do you feel about putting it into practice on a day-to-day basis?"*

C. Facilitate collaborative goal and task setting

While intentions are important, studies suggest they account for only 25-50% of variance in behaviour change.[37-40] A person also needs to have specific goals to work towards in order to be successful in adopting and maintaining new behaviours.[5,7,8] Behaviour change is more likely to take place and be sustained if the person develops their own goals based on their own values rather than if goals are chosen for them by their health professionals.[8,41]

To be effective, goals need to be specific and well-defined.[7] For example, if a person has decided to put their CHO counting skills into practice, they may be more successful if they first apply them at a particular time of day, such as breakfast where they may have a smaller range of food choices, rather than for every meal. They may also decide to start with a particular type of CHO counting skill, such as label reading, rather than attempt the full range of techniques. Choosing goals that are easily measurable facilitates monitoring and evaluation of progress.

Goals need to be challenging, but achievable within realistic timelines. If they are too ambitious, such as planning to go to the gym *every* day, they may not be met and the person may lose confidence. Conversely, if goals are too easy, they do not help to build self-efficacy.[5] Help the person to set priorities if they have multiple goals. Behaviour change may not

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case study

Andrew

Andrew is a 32-year old man who has had type 1 diabetes for 16 years. He has returned to Diabetes Clinic for review and is talking with Mervyn, a first year trainee. His most recent HbA1c was 75 mmol/mol (9.0%). He had an episode of mild diabetic ketoacidosis two weeks ago in the context of an episode of gastroenteritis. Andrew's knowledge of sick day management was reviewed while he was an inpatient.

After a general conversation, Mervyn asks Andrew how he feels his diabetes is going in general right now. Andrew admits he is demotivated and is tired of looking after his diabetes on a long-term basis. He says he has stopped checking his BGLs because he finds it a hassle in the context of his busy lifestyle, especially during the day when he is at work. He is still giving himself his insulin regularly, but is using the same doses all the time as he doesn't have BGLs to guide dose adjustment.

Andrew wants to resume checking his BGLs because he is concerned about his HbA1c and wants to lower his risk of long-term diabetes complications. He says that he is not sure how to find the motivation to get started so Mervyn encourages him to set a specific and achievable goal.

Andrew decides to start by checking his BGLs pre- and post-lunch, as he often feels tired and thirsty in the afternoons and thinks his BGLs are probably high at that time of day. He says he will use the results to work on adjusting his lunch-time insulin dose. He also says he will obtain an extra blood glucose meter to keep at work to see if this helps him to remember to check. If he finds it too hard to check at lunchtime, he will try to monitor before breakfast as a way of "gettings back into things".

be successful if too much is attempted at once, such as trying to simultaneously quit smoking and lose weight, or if there are conflicting goals.[4] Encourage the person to develop a menu of options so that if one strategy doesn't work, then there are alternatives to try. Funnell and Anderson have proposed that framing goal and task setting in terms of trial and error helps to lessen the sense of failure that can follow if an intervention does not bring the desired results.[4]

Work with the person to determine the particular tasks that will help them to achieve their goals.[5,8] For example, a person who wants to start applying CHO counting may decide to update their label reading skills with their dietitian or download a software application to facilitate the process.

Be aware that the person may not be used to thinking about managing type 1 diabetes in terms of goal and task setting. You may need to introduce the concept in a graduated manner, especially if they have only recently developed type 1 diabetes.

D. Help to identify the potential barriers to implementation

Ask the person to identify what barriers they think they might face in implementing their plan.[42] These barriers might include social factors, such as lack of privacy, time constraints or financial pressures, or personal factors, such as motivational or psychological issues.

If a barrier is identified, work with the person to identify a solution or find a way of modifying the goal or task. For instance, they might plan to measure their BGLs at lunchtime, but lack of privacy in their workplace is a barrier.[43] Instead, they might decide to start by only measuring their BGLs at lunchtime at the weekends until they can find an effective solution for work days.

Often the rewards from modified goals or tasks provide extra motivation for overcoming barriers. For example, if a person starts measuring their BGLs regularly at lunchtime at weekends, they may be able to better estimate the amount of insulin required at that time of day. As a result, they might feel better later in the day because their BGLs are within the target range. This may motivate them to find ways of checking their BGLs on the other days of the week.

Where psychological barriers are present, additional strategies may be required.[1] Many behaviour change interventions use combined behavioural and psychological approaches.[31] The psychological aspects of diabetes self-management in type 1 diabetes are addressed in Module 2.

E. Establish what support the person needs from you.

Find out what support the person needs from you to implement their plan. What extra knowledge do they need? Do they need opportunities to review or build practical or problem solving skills? Are any referrals required? Does the person need any new equipment, such as a new meter or a pen with an insulin dose memory?

F. Encourage monitoring

Encourage monitoring during the change process. This could be as simple as recording BGLs, but it might also involve more complex documentation. For example, a person may use a diary to record how often a particular behaviour is applied, what motivated them to carry out the behaviour and what impact it had on their diabetes or other aspects of their life.[13,44]

G. Review and provide feedback

Plan regular followup to see how the person is managing their tasks and whether they are progressing towards their goals. Start by enquiring about processes rather than outcomes. This reinforces that learning can occur whether an intervention has worked or not.

> *"What is working well for you with your blood glucose monitoring?"*
>
> OR
>
> *"What did you learn from checking your blood glucose levels at lunchtime?"*

Focusing on the person's feelings and attitudes is just as important as asking about the new behaviour itself. Even if the person has been successful in implementing a change in behaviour, they are unlikely to maintain it if they do not feel comfortable about doing it.

> *"How do you feel about checking your blood glucose levels at lunchtime every day?"*

Explore what did not go so well. Certain aspects might not have been effective or there may have been unanticipated barriers. See if the person can identify what could be changed with respect to their tasks.

> *"What could you do differently based on what you have tried?"*

After you have discussed the process of behaviour change, provide feedback about the outcomes. Start by discussing the positive aspects. For example, when discussing BGL data, focus on the levels that are in target first and ask what the person did to achieve these results. This will be far more motivating than if you go straight to the levels that are not in range.

Be alert to unintended consequences, such as if an intervention results in the replacement of one problem behaviour with another. A typical scenario is when a person successfully quits smoking, but starts to overeat instead, with resultant weight gain.[45]

Make it clear that not being able to implement a change of behaviour doesn't invalidate the intervention nor does it mean that the person has "failed". If a goal has been too ambitious, help the person to reset it at a lower level of difficulty.[5,46-48]

Andrew (continued)

Andrew returns to clinic six weeks later. Mervyn asks how his blood glucose monitoring is coming along. Andrew says he managed to check his BGLs at lunchtime on most days, except when he had unexpected work commitments. He found checking before lunch fairly easy to do, but needed to use a phone alarm to remember the after-meal checks. Mervyn asks what he found from monitoring his BGLs. Andrew said it confirmed that his levels were high after lunch, sometimes up to 18 mmol/L, so he increased his insulin doses for lunch. He says he feels much better as a result. Specifically, he has a lot more energy in the late afternoon. Andrew then shows Mervyn his results for the past week.

Mervyn starts with a positive comment by noting that Andrew's BGLs on Tuesday and Wednesday were within his target range. Andrew says he was happy about that as he used a CHO calculator on his smart phone to estimate his intake on those days. Mervyn then enquires about the elevated reading after lunch on Friday. Andrew says he was out for a business lunch and miscalculated his CHO intake. He says: "I probably need to focus on my carbs when I eat out, but one change at a time …" He wants to stay with his current pattern of monitoring until his next review, when he will be keen to see if his HbA1c has fallen.

H. Challenges in supporting behaviour change

1. What if a person does not *value* behaviour change?

A person may not be achieving their diabetes targets, but not feel that their diabetes is a priority in their life at the present time. Or they may be reluctant to make changes to their diabetes self-management for reasons that are important to them, such as fear of hypoglycaemia. Significant behaviour change is unlikely to occur in these contexts.

Challenge the person to outline to you the benefits for them of not making any changes to their diabetes

				0700		0900		1100		1300		1500			1900		2100			
Mon										7.0		10.0								
Tues				5.0						5.9		7.7			6.4					
Wed										5.4		7.6								
Thurs				6.0						–		–			10.0		11.3			
Fri										5.6		**15.2**								
Sat				7.3						6.0		11.0			8.1					
Sun										7.1		10.5								

Figure 1.7.1: ANDREW'S BGL DATA

self-management. Check that they understand the potential health risks. Ensure that they are medically safe and see if you can encourage them to move at least a little towards healthier outcomes:

> *"Checking your BGLs regularly is very stressful for you ... but I am wondering how you would feel about doing some readings for, say, just three days before your next appointment so that you and I can see how well your insulin doses are matching your carbohydrate intake right now. How would that work for you?"*

Emphasise that the issue of behaviour change can be revisited at any time when the person feels ready. Arrange for regular review.

Events, such as pregnancy, or threats, such as the onset of vascular complications, can provide extrinsic motivation. When a person returns to seek help in these circumstances, be supportive of their renewed motivation rather than dwelling on any adverse outcomes or past unhelpful attitudes and behaviours.

2. What if the person lacks the *confidence* to make changes?

A person may be interested in making behaviour changes to optimise their diabetes self-management, but lack the confidence to do so. Ask them if they can identify the aspects of behaviour change that make them feel particularly apprehensive.

Be aware that sometimes a person may express their lack of confidence indirectly by blocking discussion about behaviour change:

> *"I could go back to carbohydrate counting, but I know it won't work because I've tried it before and it didn't make any difference to my blood glucose levels."*

If a person lacks confidence because of unsuccessful attempts in the past, ask them to be specific about why they think things did not work out. This may inform the development of a modified or alternative plan of action.

Try to motivate the person to make changes by building on past successes. Ask them to identify the strategies they were using when things were working well.

> *"Last year in May, your HbA1c was 50 mmol/mol (6.7%) ... what were you doing then to achieve that result?"*

Review the level of support that the person needs from you and the diabetes team. They may need more frequent review than usual as they start to work towards their goals.

I. Taking a longitudinal approach ("the big picture")

Make a plan to review diabetes-related behaviours on a regular basis. Encourage the person who has type 1 diabetes to re-evaluate their goals and tasks as they build skills and confidence or to modify them if their personal or medical circumstances change. Be aware that a person's level of engagement with their diabetes self-care will fluctuate over time, depending on their motivation and life circumstances. Be alert to early signs of relapse. Normalise this scenario and help the person to re-focus on their goals.

As a trainee, it may be difficult to apply the techniques of supporting behaviour change over the long term in a clinical setting. Nevertheless, individual steps can be covered within single consultations. Document what has been planned so the next clinician who sees the person can build on what has been initiated.

Above all, appreciate that while supporting a person with behaviour change may seem time-consuming, it is far more effective, efficient and satisfying in the long term than merely providing directives.[20,48,49]

clinical tasks

1. Identify a person with type 1 diabetes in clinic or on the wards who has an HbA1c that is > 75 mmol/mol (9.0%). Explore their diabetes self-management behaviours and assess their motivation for making the changes required to lower their HbA1c.
2. Identify a person with type 1 diabetes in clinic or on the wards who has been making changes to behaviours related to their diabetes self-management. Review their progress. Provide feedback about the process and outcomes of their efforts.

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1.8 peer support

learning outcomes

to be able to:

- discuss the definition and function of peer support for chronic condition self-management
- describe the methods by which peer support is delivered
- discuss the evidence for effectiveness of peer support in type 1 diabetes

key reading

1. World Health Organization (WHO). Peer Support Programmes in Diabetes: Report of a WHO Consultation: 5–7 November 2007. Geneva: WHO; 2008.
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Definition of peer support

Having supportive relationships is integral for effective self-management of type 1 diabetes, particularly for implementing treatment plans and achieving sustained behaviour change. Generic research has shown a positive association between supportive social relationships and a range of health outcomes, including physical status, psychological morbidity and adjustment to living with a chronic medical condition.[1] Dennis has described how such relationships may be part of either embedded social networks (family, friends and other sources of support, such as sporting or community groups) or created social networks, such as condition-specific support groups (see Figure 1.8.1).[1] An important example of a created social network is peer support, which for type 1 diabetes is increasingly being recognised as a vital component of effective self-management.[2]

A key characteristic of peer support is that it is provided by volunteers with the same chronic medical condition as the person and not by health professionals or other members of their social network. It has been formally defined as "the provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population ..."[1] This generic definition was developed by Dennis in 2003 and subsequently endorsed in the context of diabetes self-management by the World Health Organization (WHO).[3]

As a health professional, it is important that you know about the role that peer support plays in the management of type 1 diabetes. Using this knowledge, you can help to facilitate access to peer support groups, as well as contribute to the development of resources for people with type 1 diabetes through these organisations.

Functions of peer support

Boothroyd and Fisher have described four core functions of peer support.[4] Although these functions apply to chronic medical conditions in general, much of the research from which they are derived comes from the diabetes self-management literature.[4]

A. Information for implementation of management plans

Through peer support, people with type 1 diabetes can obtain practical information about their condition and its management to complement that

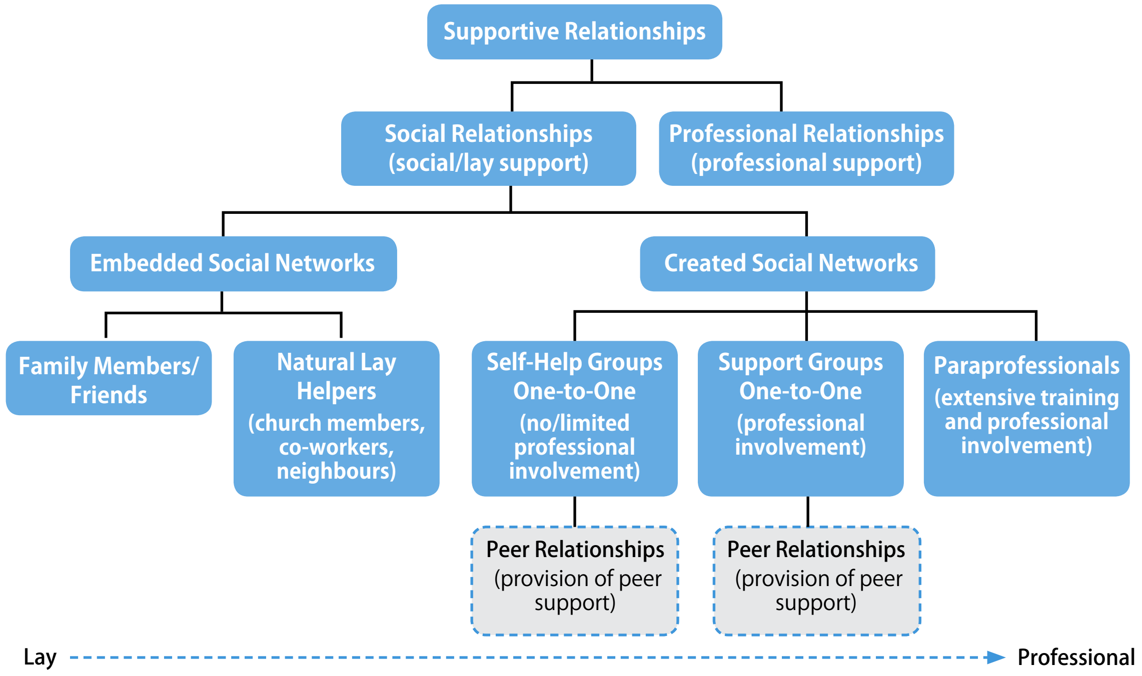

Figure 1.8.1: SOCIAL RELATIONSHIP CLASSIFICATION

Reprinted from *Int J Nurs Stud*, 40, Dennis C-L. Peer support within a healthcare context: a concept analysis (pages 321-332), Copyright (2003), with permission from Elsevier.

provided by health professionals.[5] In type 1 diabetes, this might include information about transitioning to a new pump, using mobile phone applications for carbohydrate counting or finding programs for pre-pregnancy planning. It might also include tips such as where to find a good local gym or buy gluten-free foods if there is co-existent coeliac disease. Peers can also play a valuable role in helping people adapt their management plans to fit in with their social and geographical contexts. Specifically, they can help others to integrate the burden of diabetes management into their daily lives, the complexities of which, according to May *et al*, are under-estimated by many health professionals.[6]

> *"I just log in to see what is happening, who has posted, any exciting news … ie A CURE lol & just lurk around and read whatever interests me. I generally feel satisfied that I have learned something or contributed my 2c worth whenever I visit."*
>
> Comment by person with type 1 diabetes on Reality Check website, quoted from Gilbert *et al*, Diabetes Spectrum (2012).

B. Emotional and social support

Although supportive relationships with family, friends and other members of a person's social network are vital, only peers can truly understand the experience of living with type 1 diabetes. They can help other people with this condition to overcome the isolation they may experience within their embedded social networks.[1] A person who has experienced the ups and downs of type 1 diabetes can also provide more credible role modelling than someone who has not. Through their experiences with diabetes, peer supporters can inspire others, especially those with newly diagnosed type 1 diabetes. They can also help to promote positive changes in diabetes-related behaviours.

> *"I don't know anyone else who has type 1 so the forums are really useful for information, to vent our frustrations, to make you feel like your (sic) not alone."*
>
> *"It is not there to tell me off for not doing the expected diabetic management but it sometimes motivates me to improve how I care for myself."*

1.8 peer support

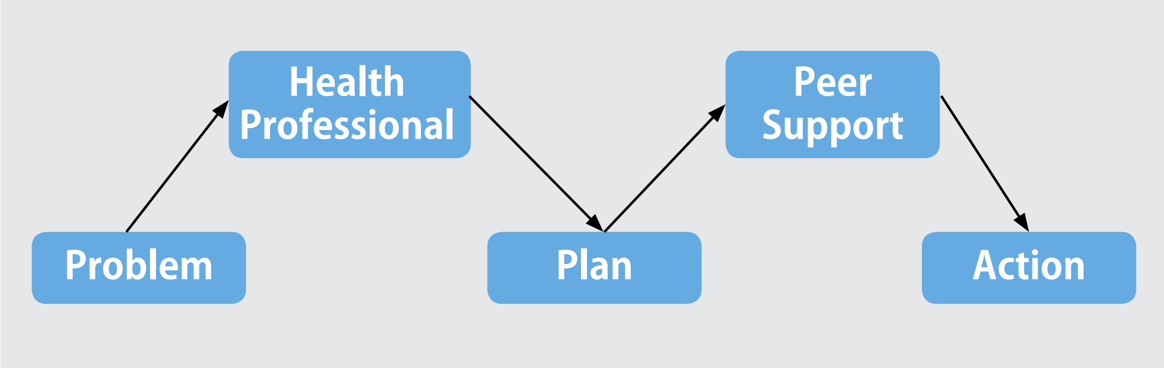

Figure 1.8.2: RELATIONSHIP BETWEEN HEALTH PROFESSIONAL AND PEER SUPPORT

Reprinted from Fisher E: Establishing sustainable and effective peer support programs for people with chronic conditions. Paper presented at the Peers for Progress Peer Support Forum, Melbourne, Copyright 2010, reproduced with the permission of Edwin Fisher PhD, Peers for Progress (peersforprogress.org) and University of North Carolina-Chapel Hill.

> Comments by people with type 1 diabetes on Reality Check website, quoted from Gilbert *et al*, Diabetes Spectrum (2012).[5]

C. Linkage to clinical care

Peers can encourage people to seek timely and appropriate clinical care. For example, a woman with type 1 diabetes may provide the cue for a peer to attend a pre-pregnancy planning seminar or program. Peers can also provide specific advice about what to ask their health professionals within consultations, such as information about new technologies or how to initiate conversations about specific aspects of their care, especially about topics of a sensitive nature.

D. Ongoing flexible and accessible support

Peer support can provide ongoing assistance in a flexible and easily accessible manner. It is always available, unlike the episodic care provided by health professionals in clinics and hospitals.

> *“I see my endo (doctor) ... every 4 months or so. This site is there all the times in between and especially when I don’t need a medical opinion ...”*

Comment by person with type 1 diabetes on Reality Check website, quoted from Gilbert *et al*, Diabetes Spectrum (2012).[5]

How is peer support achieved?

Peer support is achieved through a variety of modalities.[5] These include:

A. Face-to-face group programs

Face-to-face programs usually involve a volunteer or team of peers supporting diabetes self-management in a group-based setting.[9] They often focus on skills development, such as problem-solving and networking, as well as goal and task setting.

B. Peer coaches

Peer coaching involves individuals working with people with chronic conditions to provide emotional support and role modelling. Coaches are usually trained by the managing organisation or by mentors who are psychologists.

C. Telephone-based peer support

Telephone support provides a flexible method of peer support, especially for people who are isolated by geography or physical immobility. Calls generally take place at predetermined times and are usually initiated by the volunteer calling the peer. Most organisations set a limit on the number of calls that can occur between any given pair of volunteer and peer, although the limit varies widely between support groups.[10]

D. Internet or email-based peer support

New ICTs are becoming increasingly popular for providing and receiving peer support. These include blogs, email circulars, online communities and other social media, such as Twitter and Facebook. ICTs are convenient for volunteers and peers alike, can overcome geographical isolation and provide anonymity if desired.[11,12] They can involve interactions between individuals or the formation of large online communities.

The benefits and disadvantages of the various types of peer support have been outlined in detail by the Melbourne-based Chronic Illness Alliance,[10] an organisation that has developed a framework to inform best practice for the development and evaluation of peer support programs.

Evidence for effectiveness of peer support

Over the past decade, there has been rapid growth in research output about the effectiveness of peer support in the management of chronic medical conditions. Much of this research activity has specifically focused on diabetes, including type 1 diabetes.[9,13] The outcome measures have included behavioural, psychosocial and metabolic parameters.[14]

A. Behavioural and psychosocial outcomes

The most favourable research outcomes of peer support relate to behavioural and psychosocial domains.[9,15,16] Specifically, peer support has been found to reduce the frequency of missed medical appointments, lead to improved self-efficacy and promote more positive behaviours surrounding management plans, particularly with respect to exercise participation.[9,15]

B. Biological outcomes

There is limited research to date on the impact of peer support on metabolic outcomes, but the emerging data are promising.[9,14] A recent study by Dale *et al* involved a systematic review of the effect of peer support on diabetes outcomes in adults, although it was not specific to type 1 diabetes.[17] It noted associations with improved glycaemic control, blood pressure and cholesterol in some, but not all, studies, and concluded the evidence is too limited and inconsistent at present to inform policy and practice.[17]

Challenges in accessing and sustaining peer support programs

Some people, such as the elderly, those from minority ethnic groups or individuals with mental health or cognitive issues, may find it more challenging than others to engage with peer support organisations. It is important, however, not to make assumptions about who may or may not benefit before deciding whether to recommend peer support. Partners, family members or carers can also benefit from being involved in peer support organisations.

Issues may arise if people with significant medical, psychological or psychiatric issues turn to peers for support rather than to their health professionals. Organisations are expected to provide mentoring and debriefing support for volunteers so they can effectively deal with such situations.

Peer support groups or programs, especially those involving face-to-face contact, can be challenged by issues surrounding long-term viability, especially in geographic areas where there are small numbers of people with type 1 diabetes. Online support programs are emerging as more viable options, but can have their own drawbacks, especially for people who have financial constraints or low ICT literacy.

The role of the clinician in peer support

As a health professional, you can play a vital role in promoting the concept of peer support.[5] Discuss the benefits with people who have type 1 diabetes and help to facilitate contact, especially to well-established, high quality groups and programs. An endorsement by a health professional can be very powerful in helping a person overcome perceived barriers to initiating contact. You can also help by forming partnerships with peer support programs and offering specific professional services, such as providing medical input into resource development and evaluation.

1.8 peer support

Peer support groups for type 1 diabetes

One of the largest peer support groups in Australia for people with type 1 diabetes is the Type 1 Diabetes Network.[18] This organisation manages the online communities Reality Check for adults and the Munted Pancreas for parents of children with type 1 diabetes. It produces the Yada Yada newsletter, and co-ordinates seminars and informal get-togethers for the purpose of facilitating peer support.[19] It also has a Facebook page and a Twitter account to help meet the broader needs of its community. Other examples of peer support groups include HypoActive, Young Western Australian Insulin Takers and those of the JDRF.[20-22] Many of the state and territory-based organisations of DA have local peer support groups. For example, DA-Vic currently has 21 type 1 diabetes-specific groups in local areas throughout Victoria.[23] There also a number of international online organisations out of the United States and Europe, such as Diabetic Rockstar,[24] Juvenation[25] and Tu Diabetes,[26] which are accessed from Australia by people with type 1 diabetes.

clinical tasks

1 Visit an online peer support website, such as the Reality Check online community at www.realitycheck.org.au. Identify three issues currently being discussed by people with type 1 diabetes.

2 Identify a person with type 1 diabetes who participates in a peer support program. Ask them what they gain from the experience and how this differs from what they obtain from consultations with their diabetes health professionals.

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26. Tu Diabetes. http://www.tudiabetes.org (accessed Oct 2013).

2

optimising mental health

2.1 overview

learning outcomes

to be able to:

- describe the relationship between mental health and type 1 diabetes
- outline the range and the prevalence of mental health problems and mental illnesses that can affect people with type 1 diabetes
- discuss the principles of identifying and managing mental health problems and mental illnesses in people with type 1 diabetes

key reading

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Introduction

Mental health is the term used to refer to a person's psychological well-being and functioning. More than just the absence of mental illness, it has been defined by the WHO as:

> *"… a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community."* [1]

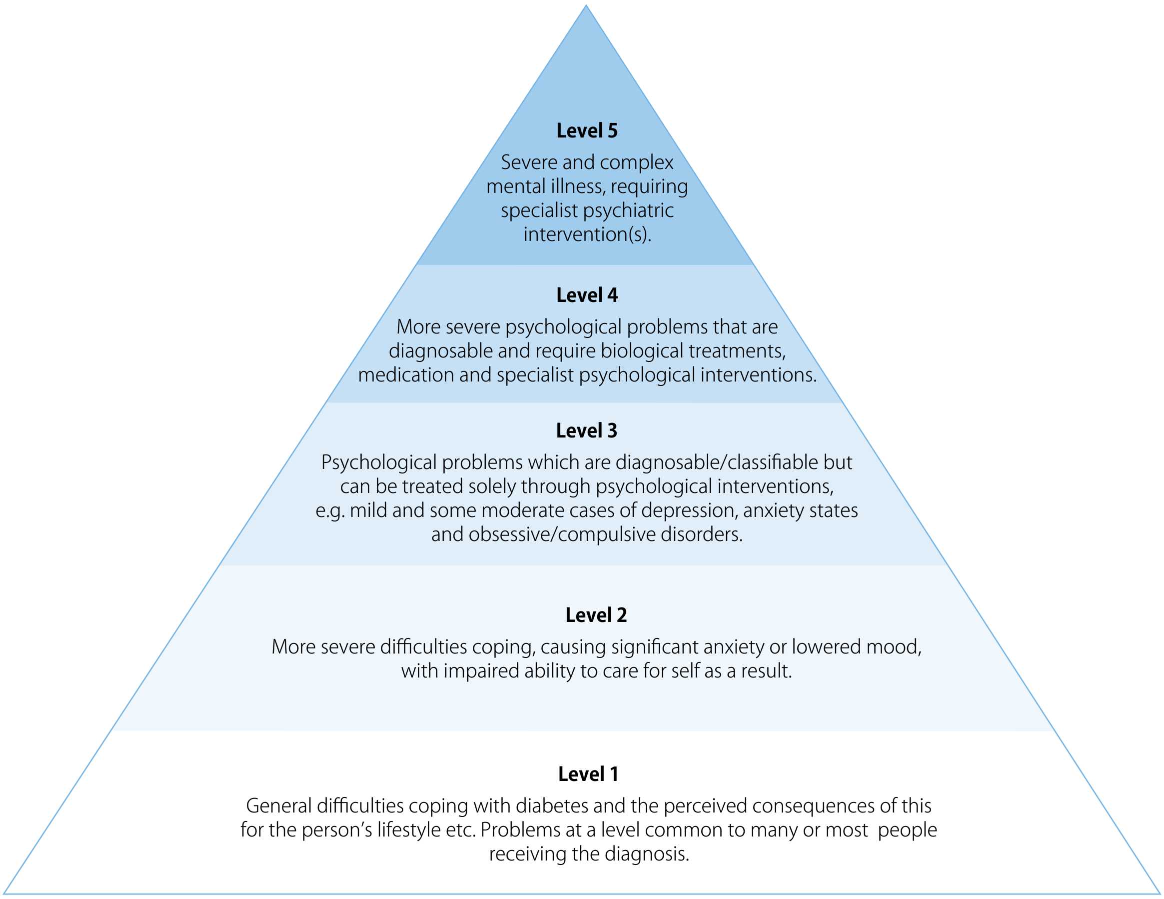
People living with type 1 diabetes face a range of challenges that can compromise their mental health.[2-5] These challenges include adjusting to the diagnosis, adopting and maintaining the complex routines required to achieve blood glucose stability, and dealing with acute and chronic diabetes-related complications.[6] The demands of diabetes and its self-management can also add to the burden of co-morbid emotional, psychological and psychiatric conditions.[7]

Conversely, mental health issues can have a significant impact on a person's diabetes outcomes.[8-11] Poor emotional and psychological wellbeing has been shown to correlate with elevated HbA1c levels and hence an increased risk of developing chronic diabetes complications.[5,12,13] Although the causal relationships are not completely understood, they are thought to be mediated through biological mechanisms involving the immune, endocrine and nervous systems, as well as behavioural factors, such as distraction from the tasks of diabetes self-management.

There is growing evidence to show that providing psychological support to people with type 1 diabetes reduces distress and can lead to better physical outcomes.[14,15] While it has been identified that more needs to be achieved at a policy level to provide wider access to appropriate mental health services,[2,3,5,16,17] there is much that can be done within individual clinical consultations to help people with type 1 diabetes optimise their psychological functioning.[18]

Spectrum of mental health issues in type 1 diabetes

A range of emotional, psychological and psychiatric conditions exist that can impact negatively on the wellbeing, coping and productivity of people with type 1 diabetes. Trigwell *et al* have developed a pyramidal model to help conceptualise the spectrum



Level 5

Severe and complex mental illness, requiring specialist psychiatric intervention(s).

Level 4

More severe psychological problems that are diagnosable and require biological treatments, medication and specialist psychological interventions.

Level 3

Psychological problems which are diagnosable/classifiable but can be treated solely through psychological interventions, e.g. mild and some moderate cases of depression, anxiety states and obsessive/compulsive disorders.

Level 2

More severe difficulties coping, causing significant anxiety or lowered mood, with impaired ability to care for self as a result.

Level 1

General difficulties coping with diabetes and the perceived consequences of this for the person's lifestyle etc. Problems at a level common to many or most people receiving the diagnosis.

Figure 2.1.1: THE PYRAMID OF PSYCHOLOGICAL PROBLEMS

Reprinted with the permission of Diabetes UK from "The provision of psychological support and care for people with diabetes in the UK" (Copyright © 2010)

of these conditions and to guide management in clinical practice (see Figure 2.1.1).[5,19]

At the lower levels of the pyramid are the common mental health problems, such as coping difficulties, distress, adjustment disorders and mild anxiety, that generally arise in response to transient life stresses. For people with type 1 diabetes, these problems can occur at diagnosis or be triggered by life events, for example, pregnancy and motherhood, transition from paediatric to adult care or the onset of diabetes-related complications.[5,10] Other diabetes-related mental health problems include diabetes distress, injection anxiety and fear of hypoglycaemia.[5] Mental health problems from the lower levels of the pyramid can usually be managed within the diabetes clinic setting in conjunction with the person's general practitioner, although referral to a psychologist may also be required. Peer support can play a vital role in this context.

Higher up the pyramid are the mental illnesses, which are less common, but of greater severity and complexity than mental health problems. Mental illnesses (also known as "mental disorders") are defined using standardised psychiatric diagnostic criteria.[20] Examples include depression, anxiety disorders and full syndrome eating disorders. A mental illness may not necessarily be related in aetiology to a person's diabetes, but its presence can significantly complicate self-management. The diabetes team still plays a vital supportive role in this context, but specialist psychiatric intervention and pharmacological therapies will generally be required.[5] It is important to be mindful that mental health problems and mental illnesses can co-exist, requiring separate yet co-ordinated management strategies.

What is the prevalence of mental health issues in people with type 1 diabetes?

In 2011, the Australian Institute of Health and Welfare (AIHW) reported on the prevalence of mental health and wellbeing issues in people with diabetes, including those with type 1 diabetes.[3] The report drew upon data from a range of sources, including Medicare Benefits Schedule (MBS) claims and hospitalisation records. Overall, it was found that the age-adjusted prevalence of poor mental health and wellbeing in people with type 1 and type 2 diabetes combined was appreciably higher than that of the general population (43.4% versus 32.2%).

Specific data from the AIHW report showed that people with diabetes were twice as likely as the general population to have claimed for mental health-related services (13% versus 6%) during 2008.[3] The difference was even more pronounced in the subset between 0-29 years of age. In this group, of which the majority were likely to have type 1 diabetes, 16.0% had made a claim related to their mental health during the study period, a three-fold increase over the general population. Hospitalisation records from 2007-08 showed that inpatients with diabetes were more likely to have a coexistent mental health problem than those without diabetes, particularly males when compared with females (8.2% versus 7.1%). The most common comorbid mental health conditions in inpatients with type 1 diabetes were substance abuse and depression.[3]

The results of international and other local studies are consistent with the findings of the AIHW report, especially for the lower levels of the pyramid of psychological problems. In 2008, Hislop *et al* found that about one third of adults with type 1 diabetes in Australia had experienced psychological distress of some type to some degree.[21] The Diabetes Attitudes Wishes and Needs (DAWN) study, which was conducted across 13 countries from Asia, Australia, Europe and North America, found that 41% of people with type 1 diabetes reported less than optimal psychological wellbeing,[17] although only 9% of this group had received psychological treatment in the previous five years. A significant proportion of health professionals in the DAWN study reported that they perceived their patients had psychological problems of sufficient severity to impact on diabetes self-management.

Rates of diabetes-related distress, anxiety and depression were outlined in the Diabetes MILES-Australia 2011 Survey Report.[2] The survey found that 28% of adults with type 1 diabetes had severe distress resulting from their diabetes and its management. The most commonly reported concerns related to anxieties about the future and the development of diabetes-related complications, findings which are consistent with international research in this area.[2,22] It was also found that moderate-to-severe depressive symptoms were experienced by 27% of adults with type 1 diabetes, while moderate-to-severe anxiety symptoms were experienced by 15% of this population.

In a paper by Li *et al,* the prevalence of nonspecific severe psychological distress (SPD) was examined in adults with diabetes in the United States using the Kessler-6 scale, a brief self-report instrument which has robust predictive power in screening for mood and anxiety disorders.[23] A sub-group analysis of 713 adults with type 1 diabetes showed an 11% prevalence of SPD compared with 3.6% in those without diabetes. Those more likely to have SPD included young people and those with diabetes complications, disability or low socio-economic status.

The co-occurrence of type 1 diabetes with mental illnesses at the more severe end of the spectrum has been studied in a range of international settings. There is evidence for an increased prevalence of depression, anxiety disorders and bulimia nervosa in people with type 1 diabetes.[24,25] Other mental illnesses, such as anorexia nervosa, schizophrenia and bipolar affective disorder, have not been shown to be more prevalent in people with type 1 diabetes than in the general population, but can significantly complicate its management when they are present.[24]

Overall, the prevalence of mental health conditions in diabetes is probably under-estimated, particularly at the milder end of the spectrum.[3] The collection of accurate data can be a difficult and inexact process, often relying on self-report and small sample sizes. The need for better psychometric instruments has also been acknowledged.[3]

Identifying and responding to mental health issues in type 1 diabetes

Many mental health problems and mental illnesses in people with type 1 diabetes go undiagnosed and therefore untreated.[26,27] This may in part be due to lack of awareness of the prevalence and impact of these conditions, but may also be a consequence of limited opportunities for health professionals to receive formal training in this area. In the DAWN study, it was found that only 42% of health professionals felt able to adequately evaluate and meet the psychological needs of people with diabetes.[17] Specialist physicians were less likely than primary care physicians to report confidence in their ability to provide the appropriate psychological support.[17]

Like any other clinical skill, the ability to identify and respond to mental health issues in people with type 1 diabetes can be developed through formal educational opportunities, as well as deliberate practice in simulated and clinical settings.[28,29] This process needs to be underpinned by a sound knowledge of the emotional, psychological and psychiatric impacts of living with type 1 diabetes. It also needs to be guided by an attitude that addressing mental health issues is a core component of delivering high quality care to people who have type 1 diabetes and not just a distraction from the management of its biological aspects.

Early identification of mental health problems in people with type 1 diabetes can help to alleviate psychological distress, improve QOL and prevent progression to full-blown mental illness. In some circumstances, the presence of emotional, psychological or psychiatric conditions may be difficult to establish. A person with type 1 diabetes may not recognise the symptoms of these conditions for what they are or not know how to talk about them with their diabetes team. They may feel reluctant to admit that they are struggling emotionally with their diabetes or other areas of their life due to a perception that there is a social stigma about mental illness. Furthermore, they may perceive that their health professionals are not interested in this domain of diabetes.

It is essential you create an atmosphere within your consultations whereby people with type 1 diabetes feel comfortable raising issues of concern about their mental health with you. Be alert to the clinical markers of underlying emotional, psychological or psychiatric conditions, such as when HbA1c

levels are deteriorating or there are frequent admissions for diabetes-related complications. Also be mindful that a person with type 1 diabetes who is reaching their glycaemic targets may be expending considerable psychological energy in doing so. It is therefore necessary to enquire proactively about mental health in *all* people with type 1 diabetes. A range of screening instruments are available that can help to facilitate clinical interactions in this domain.[30-33] It is also good practice to be familiar with the criteria for the diagnosable psychiatric disorders that are prevalent in people who have type 1 diabetes and that can impact on self-management.[20]

When an emotional, psychological or psychiatric condition is identified in a person with type 1 diabetes, you need to be able to respond in a sensitive manner and offer practical help. There are a number of simple interventions that you can offer in a clinic or a ward setting. It is specifically recommended that you become familiar with interventions that target diabetes distress, disordered eating and mild forms of anxiety or depression. These interventions are outlined in the relevant sections of this module.

In addition to being able to apply basic interventions in your clinical practice, it is also recommended that you are aware of the principles and evidence for effectiveness of formal interventions that are available, either in individual or group format, for the management of psychological conditions in people with type 1 diabetes.[14,15,34,35] Most of all, it is essential that you take into account comorbid mental health conditions when interacting with people who have type 1 diabetes, especially when supporting skills acquisition and behaviour change.

Finally, a key skill to develop as a trainee is being able to distinguish between the mental health problems that can be managed within the diabetes team and those that require referral to a mental health professional or a mental health service.[19] Decision making around the referral process will be, to a certain degree, influenced by the preferences of the person with diabetes and the local availability of resources. Make sure you keep the person's general practitioner informed, as they will usually the best person to coordinate the management of common mental health problems, including the facilitation of access to government-funded mental health care plans.[36] For mental illnesses at the more severe end of the spectrum, psychiatry input will be necessary.

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2.2 emotional health

learning outcomes

to be able to:

- outline the emotional impact of living with type 1 diabetes
- identify and respond to emotions that are expressed within consultations
- discuss the principles and effectiveness of psychological interventions that can enhance emotional wellbeing in people with type 1 diabetes

key reading

1. Robertson SM, Stanley MA, Cully JA, Naik AD. Positive emotional health and diabetes care: concepts, measurement and clinical implications. *Psychosomatics* 2012; 53: 1-12.
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Introduction

People with type 1 diabetes need to manage not only the normal mood swings of daily life, but also the emotional demands of living with a chronic medical condition.[1] Despite life's ups and downs, they have to be able to maintain the momentum of diabetes self-management to prevent or delay the onset of diabetes complications. The degree to which diabetes and its management can be successfully integrated into everyday life is a major factor in determining psychological and metabolic outcomes.[2,3]

As a health professional, you can play an important role in supporting people with type 1 diabetes to optimise their emotional health. To do this effectively, you need to have an appreciation of the variety of ways people cope with adversity and how emotions can impact on diabetes self-care activities, QOL and psychological well-being.[4,5] This will enable you to take into account a person's emotional status and resilience when helping them to develop diabetes management plans and implement behaviour change.[6,7] Being aware of the emotional dimensions of type 1 diabetes is particularly important at times of heightened vulnerability, such as when a person is not achieving their targets despite best efforts or when microvascular complications begin to appear.

The emotional aspects of living with type 1 diabetes

A person with type 1 diabetes can experience a range of negative emotions as a result of living with a chronic medical condition. These emotions, which include anger, frustration, hopelessness, fear and guilt, can be particularly pronounced at diagnosis and have been likened to those associated with bereavement.[8] A person can grieve for the life that they had before diabetes, as well as experience feelings of loss of control and uncertainty about the future. Denial is another typical emotion at diagnosis, when a person can feel overwhelmed by the demands of learning to self-manage their diabetes.[9]

On a daily basis, maintaining blood glucose stability can be a significant source of stress. For many people with type 1 diabetes, the degree to which extremes of blood glucose can be easily prevented or corrected is a key influence on their emotional well-being.[4] Other factors, such as the pain and embarrassment that can be associated with checking BGLs and administering insulin, may have a negative impact on emotions, as can the side-effects of medications used to treat co-morbidities, such as β-blockers for ischaemic heart disease or hypertension. A variety of social factors can also play a role. Examples include lack of understanding or support from partners, family and friends, and stress caused by unhelpful, if well-intentioned, comments and behaviours. Negative emotions can also be evoked if limitations are imposed on activities, such as driving and occupation, because of diabetes.

For a person with type 1 diabetes, being able to regulate their emotions is central to being able to sustain healthy coping and well-being.[10-12] This helps to build resilience, which in turn enables the maintenance of effective self-management in the face of adversity.[11] Research has shown that people with type 1 diabetes who have a positive emotional affect are more likely to participate in healthy behaviours, particularly regular exercise.[13] There is also a growing body of evidence to support the hypothesis that positive emotional health is linked to improved metabolic outcomes and a lower risk of mortality.[5,14] Furthermore, effective emotional regulation can help to attenuate the severity of psychological and psychiatric conditions, such as diabetes distress, anxiety and depression.[5]

Identifying and responding to emotions

A. Be comfortable discussing emotional issues

There is a duty of care to respond to emotional distress expressed by a person with type 1 diabetes in an empathetic manner and to assess whether this distress is a sign of an underlying mental health issue.[4,15] You may feel apprehensive about discussing emotional concerns because of low comfort levels about such conversations or a perceived lack of ability in this area, but there is evidence that the requisite expertise can be acquired using the same principles as for any other clinical skill.[16]

B. Enquire about the emotional aspects of type 1 diabetes on a regular basis

Conversations about emotional well-being need to be a core component of interactions with people who have type 1 diabetes. These need not unduly prolong consultations. For many people with type 1 diabetes, just knowing that their clinician acknowledges the emotional demands of living with a chronic medical condition will be sufficient. Furthermore, talking about the emotional impact of diabetes is efficient in the long term, as it can help to uncover issues that are negatively influencing their metabolic outcomes. Without such discussions, there is a risk that time and resources will be wasted on unnecessary interventions, such as changes in insulin regimens or inappropriate referrals to other health professionals.[17, 18]

In the DAWN study, the following questions were found to be useful for eliciting responses about emotional issues:[19]

> *"What are your greatest concerns about your diabetes?"*
>
> AND
>
> *"What is the most difficult part of living with diabetes?"*

In replying to one of these questions, a person with type 1 diabetes may choose to discuss their emotional concerns, but they also have the option to raise medical or practical issues if they do not have any relevant emotional issues or they do not feel comfortable talking about their feelings at the present time. Recognise it as a positive sign if a person with type 1 diabetes trusts you enough to share their difficulties with you. You may wish to acknowledge this during the consultation.

C. Responding to overt expressions of emotions in consultations

If a person with type 1 diabetes expresses emotions during a consultation, respond in a way that gives them space to elaborate on what they are feeling.[20] If you disregard what they are trying to tell you, you may miss a valuable opportunity to identify issues that are influencing their diabetes self-management or mental health.

Start by acknowledging the person's distress, but follow this by exploring the reasons that underlie it. An emotion is a symptom that requires a structured diagnostic approach, just like a physical symptom, such as chest pain or sensory loss. For example, if a person says they hate giving their injections, invite them to be specific about what part of injecting is of concern to them:

> *"You hate having to inject all the time. What part of it bothers you the most?"*

The person may be experiencing physical pain or bruising from injections, be embarrassed if they need to inject in front of peers, have anxieties about hypoglycaemia or be using injecting as a symbol of broader fears about having type 1 diabetes. Their response will help you to decide the best way of offering support.

Appreciate that no one can fully understand what another person is experiencing. Staying with a person's emotions is more likely to be effective than offering your own interpretation of the situation. Saying *"I know how you feel"* may be well-intentioned, but it can leave the person feeling they haven't been listened to and may even worsen their distress.

Offer reassurance, but only when it is appropriate for the person's situation. Saying *"I am sure it will all turn out OK"* when this might not be the case is unlikely to be of comfort.[20] Rather, ask about the person's fears and offer practical support as required.

If a person becomes tearful during a consultation, it does not necessarily mean that they have a mental health problem or that referral to a mental health professional is required. Suggesting there is an underlying psychological diagnosis or referring too early can be counter-productive. Establish if the level of the person's distress is proportionate to their current life difficulties. For example, if a person has recently been bereaved or has had a significant medical setback, then a degree of emotional distress is to be expected. If you are concerned that an expression of emotion is disproportionate to a person's situation, be empathetic and ask them to tell you why they are so distressed at the present time. Try to establish how they normally respond to stressful situations.

D. Be alert to subtle expressions of emotions

A person with type 1 diabetes may be experiencing strong emotions, but not be able to express them overtly.[21] Be alert to cues, such as flat affect or a change in diabetes self-care behaviours. Respond by stating what you observe and asking the person to verify your understanding of how they might be feeling.

> *"I can see that you're not measuring your BGLs as often as before ... and you don't look as cheerful as usual. How are things going with you?"*

Be proactive in making enquiries about emotions in situations that are likely to evoke distress in a person with type 1 diabetes. If a person has had a setback with their diabetes or is experiencing a difficult life situation, ask about their emotional reactions to it.

E. Respect the privacy of a person with type 1 diabetes

Appreciate that a person with type 1 diabetes may not wish to discuss their emotions with you. They may not feel ready to share their feelings or they may have other people, such as family, friends or other health professionals, with whom they would prefer to discuss their emotional issues. Let them know that you are open to discussions about emotions at a later stage if they wish.

The relationship between emotions, cognition and behaviours

To help a person with type 1 diabetes to optimise their emotional health, it important to have an awareness of the complex and dynamic interactions that occur between emotions, cognitions and behaviours.[22] This awareness can help you to understand the processes that underlie both adaptive and maladaptive responses to stressful situations, such as extreme BGLs, the development of chronic diabetes complications or other difficult life events not related to diabetes. It can also help you to appreciate the rationale behind the techniques and formal interventions that can be used to optimise psychological and metabolic outcomes in people who have type 1 diabetes.[7, 23]

A. Adaptive responses to stressful situations

Emotions are a normal part of the human experience, but they generally do not provide effective solutions to life's challenges. Rather, positive cognitions are needed to provide perspective, attenuate unpleasant emotions and enable effective problem solving. These positive cognitions can promote adaptive behaviours that, in turn, can help to sustain psychological well-being and, in people with type 1 diabetes, optimise metabolic outcomes. A diagrammatic representation of this process is shown in Figure 2.2.1. In reality, a person's reaction to a stressful event is usually quite complex and the sequence is not necessarily linear.[22]

Figure 2.2.1: ADAPTIVE COGNITIVE AND BEHAVIOURAL RESPONSES TO A TRIGGER

case study

Tim

Tim, 24, has had type 1 diabetes for three years and manages his BGLs using a multi-dose insulin regimen. Last year, he attended a DAFNE course to learn how to carbohydrate count and to adjust his insulin according to his food intake. He is now at his local diabetes clinic for review and is talking with Fiona, a second-year trainee.

During review of his blood glucose data, Tim mentions an elevated reading of 18 mmol/L that he recorded a week ago. He tells Fiona that he became angry and frustrated when he saw the result, but accepted that this was a natural response. "I figured that my level might've been high because I didn't accurately estimate the carbohydrate content of the pasta I had at the restaurant where we ate. I reminded myself that most of the time my BGLs are fine and my last HbA1c was pretty much in target, so I didn't criticise myself about it. I know I'm doing OK overall with my diabetes right now compared with how I did at the beginning."

Fiona asks Tim what he did to manage the elevated BGL. He says, "I gave myself an extra shot of insulin and my BGL came down to 12.2 mmol/L two hours later. I thought that was a reasonable result. I knew I could give you or my educator a call if it became a pattern and I couldn't sort it out by myself. But I also think it's time I got around to doing that DAFNE refresher course so I can get a better grip on my carbohydrate counting, especially for when I'm eating out."

Tim was able to place his elevated BGL into perspective using positive cognitions. He then responded with an adaptive behaviour so he could lower the BGL closer to his target range. Fiona provides feedback to Tim about how effectively he reacted to the situation.

Cognitive distortion	Sample dialogue
Categorical ("all or nothing") thinking	"I never get things right with my diabetes."
Catastrophic thinking or exaggerating the likelihood of a poor outcome	"My BGL is 18 mmol/L. I'm going to get complications of my diabetes for sure."
Biased interpretation of evidence	"My BGLs were terrible today so I'm not doing well overall with my diabetes."
Attributing blame to events that are beyond one's control	"It's my fault that my BGLs are always so hard to get right."
Faulty labelling	"I'm a bad diabetic."
Using feelings as evidence	"I feel bad about my diabetes. That means it can't be going all that well."

Table 2.2.1: EXAMPLES OF COGNITIVE DISTORTIONS WITH SAMPLE DIALOGUE

Figure 2.2.2: MALADAPTIVE COGNITIVE AND BEHAVIOURAL RESPONSES TO A TRIGGER

B. Maladaptive responses to stressful events

Maladaptive responses to stressful events generally involve negative cognitions. Such thoughts are typically inaccurate, exaggerated or illogical. In a psychotherapeutic context, they are often known as "cognitive distortions". Examples of cognitive distortions are shown in Table 2.2.1.[24,25] Cognitive distortions can serve to reinforce unpleasant emotions and may promote maladaptive behaviours. In people with type 1 diabetes, cognitive distortions and maladaptive behaviours in response to stressful events can be associated with adverse psychological and metabolic outcomes (see Figure 2.2.2).

Be aware that a person may use denial as a strategy for responding to stressful aspects of their diabetes.[26] A degree of denial can be a way of dealing with strong emotions, especially just after diagnosis or when dealing with overwhelming life events, such as needing to start renal dialysis. It becomes maladaptive, however, when it is used as a long-term coping mechanism.

case study

Nick

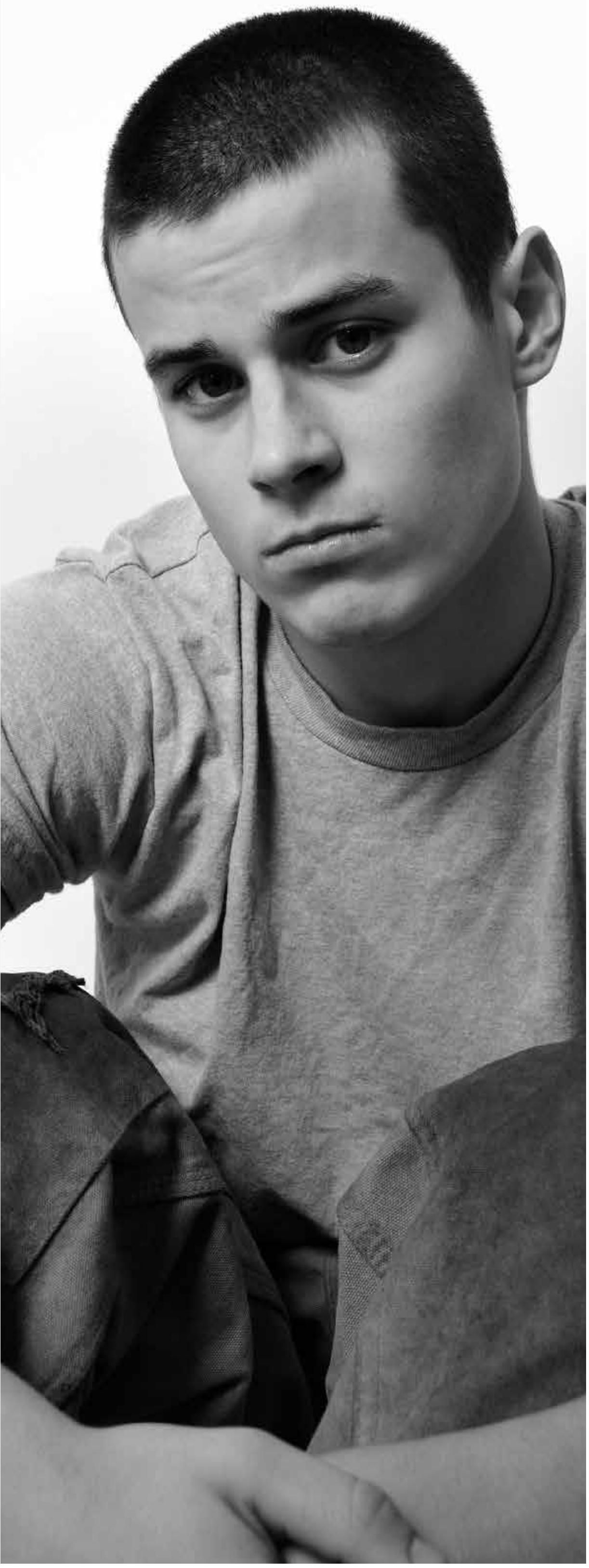
Nick, 24, has had type 1 diabetes for three years and manages his BGLs using a multi-dose insulin regimen. Last year, he attended a DAFNE course to learn how to carbohydrate count and to adjust his insulin according to his food intake. He is now at his local diabetes clinic for review and is talking with Hanh, a second-year trainee.

During review of his blood glucose data, Nick mentions an elevated reading of 18 mmol/L that he recorded a week ago. He tells Hanh he became angry and frustrated when he saw the result. "I've been trying so hard … I never seem to get things right with my diabetes. I must be a bad diabetic. Anyhow, I've decided to give up monitoring for a while because I figure that if I don't know what's happening with my BGLs then I can't get upset …"

The frustration Nick felt about his elevated BGL was understandable, but he compounded the situation by his distorted cognitions in response to it. He demonstrated categorical thinking ("I never get things right with my diabetes") and generated a negative self-evaluation by labelling himself as a "bad diabetic" in response to an event that may not have been within his control.

Nick subsequently reacted by stopping his blood glucose monitoring, a maladaptive behaviour that will probably lead to a worsening of his blood glucose instability. In turn, this is likely to perpetuate the sense of anger and frustration that he feels about his diabetes.

Hanh responds by challenging Nick's negative beliefs about himself and his diabetes. She encourages him to build on his strengths and apply strategies that will lead to more adaptive responses to negative events that he experiences in the context of his diabetes.



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Thurs				9.0				2.6		14.0		11.0								
Fri				**5.2**		**7.7**				**5.6**		**6.9**			**5.0**		**7.8**			
Sat				5.1						6.0		15.3			2.9		13.8			
Sun				8.5						5.6		10.5								

Figure 2.2.3: NICK'S BLOOD GLUCOSE DATA

Techniques to enhance emotional well-being

Simple techniques can be used within consultations to help people with type 1 diabetes to optimise their emotional wellbeing. These techniques, which are drawn from a range of formal psychotherapeutic interventions, require you to have an understanding of how individuals feel, think and act in response to setbacks with their diabetes or other challenging life events.[7,23,27] As a trainee, you may not have the opportunity to learn about the resilience and coping styles of all the people you meet in clinics and on the wards, but later on this will be an important part of your clinical practice.

A. Encourage goal setting

If a person with type 1 diabetes is struggling with their emotions, ask what would need to change for them to feel better about themselves and their diabetes. They are more likely to work on changing aspects of their emotional life if they identify their own goals. Help them to identify their strengths and build on these to make the desired changes. Find out what help they need from you.

B. Use cognitive restructuring to encourage adaptive responses to stressful events

Use cognitive restructuring to challenge any negative beliefs that a person with type 1 diabetes holds about their condition, its management or other aspects of their life.[28] This involves identifying cognitive distortions and asking the person to test their propositions against the evidence.[24,29] This technique can be readily integrated into conversations within routine consultations:

> *"Nick, you said you never get things right with your diabetes … but I note that last Friday most of your BGLs were within target …"*

Ask the person to explain to you why they hold particular thoughts about themselves and encourage them to focus on behaviours rather than labels:

> *"Nick, you called yourself a 'bad diabetic' because you had a high BGL. What made you say that?"*

Work with the person to identify specific events or contexts that tend to trigger negative emotions and thoughts:

> *"Why do you feel that way about yourself sometimes and not at other times?"*

If a person can describe adaptive cognitive responses to certain situations, ask how they might use insights from these to change the way they respond in other circumstances.

When BGL instability is a specific source of emotional distress for a person with type 1 diabetes, help them to set realistic expectations by explaining that there are many influences on BGLs, such as illness, medications and stress, that are not under their direct control. Highlight that emotional reactions can be difficult to interpret and manage in the setting of extreme BGLs.[30]

C. Apply behaviour change techniques to encourage adaptive responses to stressful events

A maladaptive behaviour may help a person deal with the emotions surrounding a stressful situation in the short term, but it may merely serve to substitute one negative emotion for another. To help a person move towards more adaptive functioning, start by exploring decision making surrounding their behavioural responses to stressful events.

> *"Nick, you said you have stopped monitoring your BGLs. How do you feel about that decision?"*

Nick may feel less angry about his elevated BGLs, but instead feel guilty that he is no longer monitoring. Help people with type 1 diabetes to articulate their emotions and encourage them to adopt adaptive behaviours using the techniques outlined in Chapter 1.7 (see Figure 2.2.4).

Formal interventions for optimising emotional health

Formal psychological interventions are available if measures instituted in a clinic or ward setting are not effective in helping a person with type 1 diabetes to optimise their emotional health. One of the most commonly used of these interventions is cognitive behaviour therapy (CBT), a psychotherapeutic method that makes use of cognitive restructuring and behaviour change techniques in a systematic manner to improve psychological functioning.[24] CBT can be offered in either individual or group format, depending on availability and patient preference.[23,27] In a study by Amsberg *et al*, it was found that a CBT-based intervention for people with type 1 diabetes and sub-optimal glycaemic control at baseline led to an improvement in psychological outcomes, as well as diabetes self-management behaviours.[23] A recent randomised study showed that mindfulness-based cognitive therapy, as group therapy in a mixed population of people with type 1 and type 2 diabetes, was effective in reducing emotional distress and increasing QOL compared with usual care in those with lower levels of emotional well-being at baseline.[31]

The impact of formal psychological interventions on metabolic parameters in people with type 1 diabetes has been examined by Winkley *et al* in a systematic review. A small although non-significant association was found between the use of psychological therapies and improved glycaemic control.[7] Psychological therapies may be particularly helpful in augmenting the effects of behavioural interventions. In a randomised trial, Ismail *et al* observed a greater benefit with respect to lowering HbA1c when motivational enhancement therapy was delivered in combination with cognitive behavioural therapy (CBT) than when it was used as a single intervention.[6] The methodological limitations of studies in this area have been acknowledged and further research is required.

Monitoring progress

Appreciate that it can take time for a person with type 1 diabetes to develop adaptive cognitions and behaviours in response to stressful events and negative emotions relating to their diabetes or other aspects of their life. Monitor progress over time and support the person through any setbacks they may have. Help them to understand that not every day will be the same and on some days it will be more difficult to react in a positive way than on others. Also help them to understand that no one, whether they have type 1 diabetes or not, always has perfect responses to stressful events and negative emotions.

If you have concerns about the emotional wellbeing of a person with type 1 diabetes, arrange to see them again within a short time frame. Talk with your

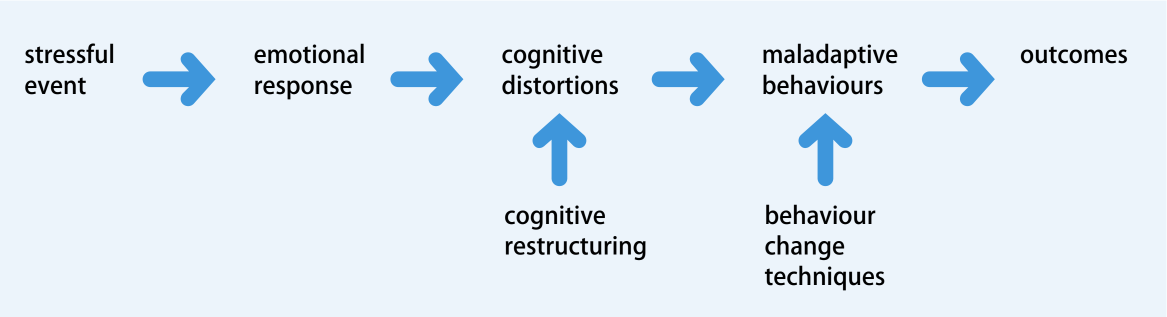

Figure 2.2.4: POINTS OF INTERVENTION FOR OPTIMISING EMOTIONAL WELL-BEING

consultant or a mental health professional if you suspect that the person has an undiagnosed mental health problem. It is best to involve the person's general practitioner, but ask for permission before you do this.

clinical tasks

1. Identify a person who developed type 1 diabetes as an adolescent or as an adult. Ask them to describe their emotional reactions to receiving the diagnosis.
2. Ask a person with type 1 diabetes to describe how they feel, think and react if they have a BGL of > 15 mmol/L, especially if they cannot explain why it happened. If they expresses negative thoughts, engage them in a cognitive restructuring exercise and then explore their decision making around any associated maladaptive behaviours.

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2.3 diabetes distress

learning outcomes

to be able to:

- describe the features of diabetes distress
- identify the presence of diabetes distress in a person with type 1 diabetes
- respond to the presence of diabetes distress in a person with type 1 diabetes

key reading

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Introduction

Diabetes distress refers to the psychological morbidity that results if the emotional reactions to the demands of living with diabetes are intense and sustained.[1,2] It is distinct from mental health problems that arise from other causes, such as traumatic life events or unrelated chronic medical conditions. It is also a discrete entity from depression, which has different diagnostic criteria and clinical correlates.[3] Diabetes distress is common and it is thought that it probably occurs in most people with diabetes to some degree at some stage of their condition.[1,3] It can be especially pronounced at diagnosis.

The presence of diabetes distress can have a significant impact on metabolic and psychosocial outcomes. It can distract from the tasks of self-management, leading to elevated or unstable BGLs and, therefore, an increased risk of diabetes complications.[3,4] Diabetes distress conveys an increased risk of psychiatric morbidity, particularly depression,[5] and can place a significant strain on relationships with family, friends and health professionals.[2,3] A number of validated psychometric instruments have been developed to identify and monitor the presence of diabetes distress in research and clinical settings. In most situations, diabetes distress can be managed within the diabetes team.

What causes diabetes distress?

The causes of diabetes distress tend to cluster into four main domains:[2,6]

A. THE EMOTIONAL BURDEN OF LIVING WITH DIABETES

B. THE BURDEN OF SELF-MANAGEMENT

C. INTERACTIONS WITH PARTNER, FAMILY OR FRIENDS

D. INTERACTIONS WITH HEALTH PROFESSIONALS AND THE HEALTH CARE SYSTEM

A. The emotional burden of living with diabetes

A person with diabetes can readily come to resent the load and limitations diabetes places on their life. They may feel overwhelmed by the physical and emotional energy they need to expend to keep up with the activities and responsibilities of daily life.[7-11] The fear of developing acute and chronic diabetes complications adds to this emotional burden.[1]

> *"… when you are presented with a person who really truly seriously yearns for a holiday from T1D and laments their ability to keep on with the constant decision-making, consider whether they need some psychological support and help them get it. Yes, it's tiring and everyone gets sick of it sometimes, but PLEASE recognise the mental toll of this disease and don't expect that it will just come good on its own."*
>
> Quote from: "What would you like health professionals to know about living with type 1 diabetes?" www.d1.org.au (March 2011). Reproduced with the permission of the Type 1 Diabetes Network.

B. The burden of self-management

For a person with type 1 diabetes, the relentless demands of highly complex treatment regimens, including blood glucose monitoring, CHO estimation and insulin self-injection, can readily create distress. They may struggle to maintain the motivation that is required to keep up with their diabetes self-care on a day-to-day basis over the long term, especially when the tasks of self-management start to lose their novelty. As a result, they may feel guilty or discouraged when they are unable to implement and sustain their management plans as well as they would like. Self-doubt can easily arise, particularly if desired diabetes targets are not met, despite best efforts.

> *"The more complicated it gets, the more room for errors and anxiety around control. Counting every carb is like counting every step on a 10km run, it's just not going to happen. Having BSLs at 6.5 all day every day is a nice thought, kinda like patting a unicorn. Yes, it's an unrealistic fantasy. Bear in mind though, targets to aim at are required or there is no control. It's all about BALANCE …"*
>
> Quote from: "What would you like health professionals to know about living with type 1 diabetes?" www.d1.org.au (March 2011). Reproduced with the permission of the Type 1 Diabetes Network.

C. Interactions with partner, family or friends

A person with diabetes may become distressed if they feel that their partner, family or friends do not understand the challenges of living with a chronic medical condition or do not provide the expected emotional support. They may also resent attempts by members of their social network to be protective of them or to offer misguided help, such as urging them to eat or avoid certain foods.[9] The term "diabetes police" has been used to describe family and friends who are overly forthcoming in offering advice and surveillance of a person's self-care.[7] Conflict can readily arise as a result of a person's efforts to negotiate relationships around their diabetes in such situations.

> *"My partner tries his best to be strong and supportive, but to be honest I think he worries about the future much more than I do. I had to ask him to sort of back off and stop worrying after the first few weeks because the constant attention was annoying. My first hypo of 2.3 he was calling 000, I was laughing because he was being so ridiculous, I was obviously still completely coherent and feeding myself. He leaves me alone most of the time now to deal with it, it gets a bit lonely, but I think it's a bit less stressful for him at least."*
>
> Quote from: The Type 1 Diabetes Network, Reality Check online discussion forum, www.reality check.org.au (accessed June 2013). Reproduced with the permission of the Type 1 Diabetes Network.

D. Interactions with health professionals and the health care system

A person with diabetes can become distressed if they feel that their health professionals do not fully appreciate the load of diabetes care or are unsympathetic about the associated emotional demands. They may also feel that too much focus is placed on biological outcomes within consultations, particularly with respect to HbA1c levels, rather than on the efforts required to achieve these outcomes or on more general issues surrounding QOL. Feelings of being detached or rejected may develop if the intensity of support a person receives from their health professionals diminishes over time from diagnosis, as often occurs. Financial or geographical barriers to accessing timely and appropriate health care, such as new technologies and structured education programs, may further add to a person's diabetes-related distress.

2.3 diabetes distress

> *" ... my endocrinologist has an excellent knowledge of the chemistry and biology of type 1, but doesn't seem to recognise the impact of this on lifestyle and the psychology that comes with that – I often feel that she can't understand that my whole life can't revolve around diabetes – there are other important things in my life as well."*
>
> Quote from: "What would you like health professionals to know about living with type 1 diabetes?" www.d1.org.au (March 2011). Reproduced with the permission of the Type 1 Diabetes Network.

The term *diabetes burnout* is sometimes used to describe the state of physical, cognitive and emotional exhaustion that can accompany long-term efforts of trying to self-manage diabetes.[7] It is included as a feature of diabetes distress, but has also been described as a separate entity.[7] Diabetes burnout, however, is not yet a well-defined construct. The symptoms and signs are non-specific and can occur with other mood disorders or burnout from another cause.

How prevalent is diabetes distress?

In the Diabetes MILES-Australia 2011 Survey, 28% of respondents with type 1 diabetes reported high levels of diabetes distress,[1] consistent with results from international studies.[12,13] Younger adults and those from rural areas were more likely to be affected than those from other demographic groups. There was a higher prevalence of diabetes distress amongst those with type 1 diabetes than those with type 2 diabetes.

When should diabetes distress be suspected?

A. In an asymptomatic individual

There are currently no formal recommendations in Australia that screening for diabetes distress be conducted on a regular basis.[14] A number of authors, however, have argued for the benefits of screening, particularly in young people with type 1 diabetes.[15,16] Various international guidelines and position statements have also highlighted the potential benefits of monitoring the emotional and psychological wellbeing of people with diabetes.[17-19]

B. If a person has metabolic, behavioural or psychosocial risk factors

- an elevated HbA1c, unexplained by other factors
- being stressed by the demands of diabetes care, even if metabolic markers are within target
- evidence of reduction in the level of diabetes self-care, such as less frequent BGL monitoring or missed appointments
- multiple presentations with the same physical symptoms
- problems with not coping in other areas of their life
- poorly-developed strategies for dealing with stress, including self-medication with alcohol or recreational drugs
- multiple co-morbid psychosocial stressors

How is diabetes distress measured?

A number of self-report instruments have been developed for measuring diabetes distress. The most commonly used of these instruments are:

- Problem Areas in Diabetes (PAID), a 20-item questionnaire using a 5-point Likert scale from 0 to 4, with the result being adjusted to a score out of 100[6]
- Diabetes Distress Scale (DDS), a 17-item questionnaire with four sub-scales using a 6-point Likert scale[9]

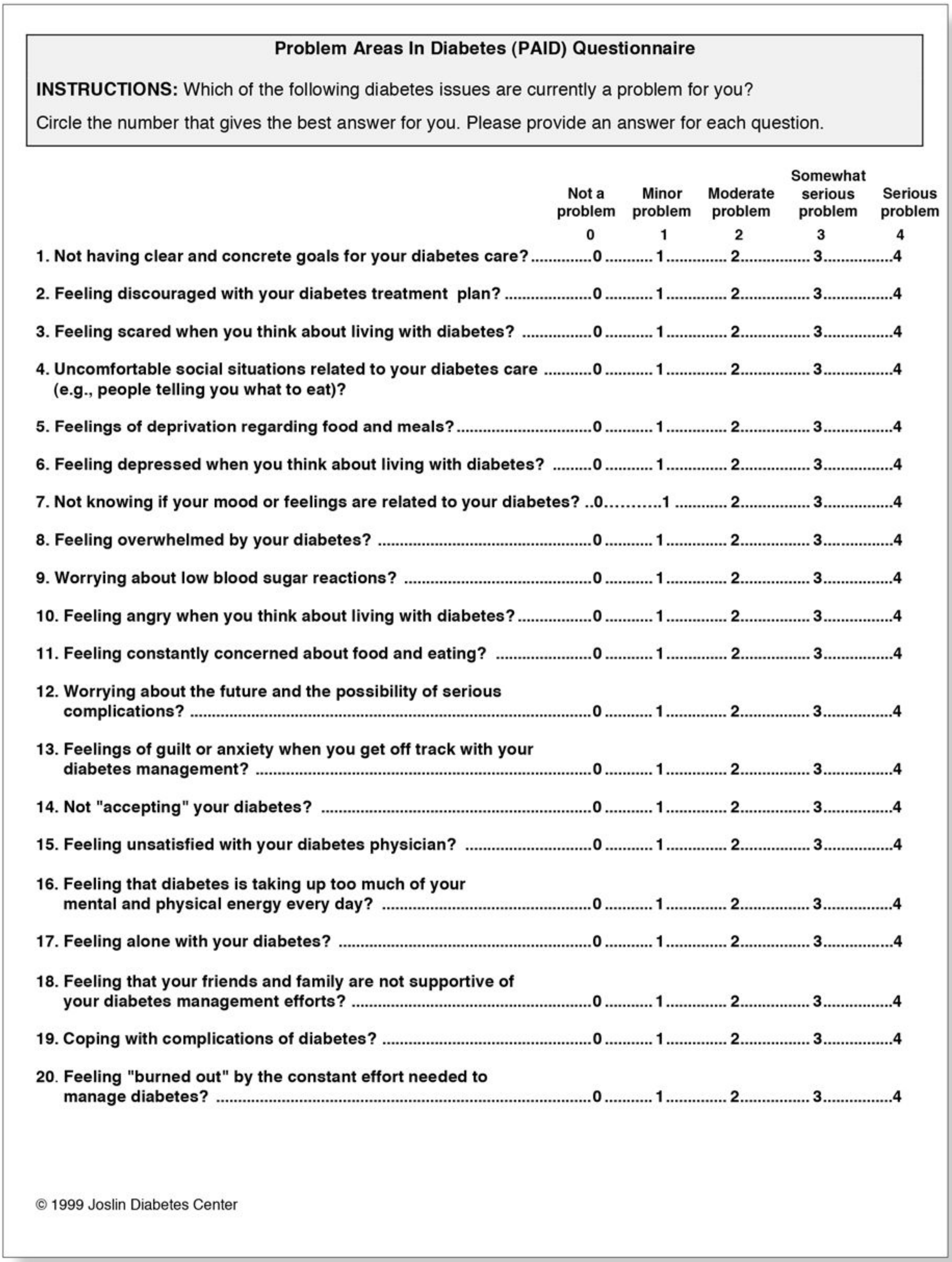
These instruments can be used for screening, diagnosis and monitoring of diabetes distress. At present, there are no head-to-head studies comparing the two instruments, but both have robust psychometric properties and demonstrated validity.[12,20] Copies of these instruments are included in the following pages.

Instruments for measuring diabetes distress are most frequently applied in research contexts, but are increasingly being used in clinical settings. Feedback about results needs to be provided in a timely manner, especially if the instrument has not been completed at the same time as a consultation.

If you are using an instrument to measure diabetes distress in a clinical setting, first explain the purpose of the exercise:

> *"It sounds like you are quite distressed about your diabetes right now. Many people experience some level of distress like this at times. I often find it helpful to use a questionnaire that outlines some of the issues that can cause distress so I can get a better idea of how a person is feeling about their diabetes ... and what I might be able to suggest to help. Does this sound like something you might be interested in doing?"*

PROBLEM AREAS IN DIABETES (PAID) QUESTIONNAIRE



Problem Areas In Diabetes (PAID) Questionnaire

INSTRUCTIONS: Which of the following diabetes issues are currently a problem for you?

Circle the number that gives the best answer for you. Please provide an answer for each question.

	Not a problem 0	Minor problem 1	Moderate problem 2	Somewhat serious problem 3	Serious problem 4
1. Not having clear and concrete goals for your diabetes care?	0	1	2	3	4
2. Feeling discouraged with your diabetes treatment plan?	0	1	2	3	4
3. Feeling scared when you think about living with diabetes?	0	1	2	3	4
4. Uncomfortable social situations related to your diabetes care (e.g., people telling you what to eat)?	0	1	2	3	4
5. Feelings of deprivation regarding food and meals?	0	1	2	3	4
6. Feeling depressed when you think about living with diabetes?	0	1	2	3	4
7. Not knowing if your mood or feelings are related to your diabetes?	0	1	2	3	4
8. Feeling overwhelmed by your diabetes?	0	1	2	3	4
9. Worrying about low blood sugar reactions?	0	1	2	3	4
10. Feeling angry when you think about living with diabetes?	0	1	2	3	4
11. Feeling constantly concerned about food and eating?	0	1	2	3	4
12. Worrying about the future and the possibility of serious complications?	0	1	2	3	4
13. Feelings of guilt or anxiety when you get off track with your diabetes management?	0	1	2	3	4
14. Not "accepting" your diabetes?	0	1	2	3	4
15. Feeling unsatisfied with your diabetes physician?	0	1	2	3	4
16. Feeling that diabetes is taking up too much of your mental and physical energy every day?	0	1	2	3	4
17. Feeling alone with your diabetes?	0	1	2	3	4
18. Feeling that your friends and family are not supportive of your diabetes management efforts?	0	1	2	3	4
19. Coping with complications of diabetes?	0	1	2	3	4
20. Feeling "burned out" by the constant effort needed to manage diabetes?	0	1	2	3	4

2.3 diabetes distress

DIABETES DISTRESS SCALE (DDS)

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

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

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

2.3 diabetes distress

DDS17 SCORING SHEET

INSTRUCTIONS FOR SCORING:

The DDS17 yields a total diabetes distress score plus 4 subscale scores, each addressing a different kind of distress.[1] To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale.

Current research[2] suggests that a mean item score 2.0 – 2.9 should be considered 'moderate distress,' and a mean item score > 3.0 should be considered 'high distress.' Current research also indicates that associations between DDS scores and behavioral management and biological variables (e.g., A1C) occur with DDS scores of > 2.0. Clinicians may consider moderate or high distress worthy of clinical attention, depending on the clinical context.

We also suggest reviewing the patient's responses across all items, regardless of mean item scores. It may be helpful to inquire further or to begin a conversation about any single item scored > 3.

Total DDS Score: a. Sum of 17 item scores. ________________
b. Divide by: ______17________
c. Mean item score: ________________
Moderate distress or greater? (mean item score > 2) yes___ no___

A. Emotional Burden: a. Sum of 5 items (2, 4, 7, 10, 14) ________________
b. Divide by: ________5________
c. Mean item score: ________________
Moderate distress or greater? (mean item score > 2) yes___ no___

B. Physician Distress: a. Sum of 4 items (1, 5, 11, 15) ________________
b. Divide by: ________4_______
c. Mean item score: ________________
Moderate distress or greater? (mean item score > 2) yes___ no___

C. Regimen Distress: a. Sum of 5 items (6, 8, 3, 12, 16) ________________
b. Divide by: ________5_______
c. Mean item score: ________________
Moderate distress or greater? (mean item score > 2) yes___ no___

D. Interpersonal Distress: a. Sum of 3 items (9, 13, 17) ________________
b. Divide by: ________3_______
c. Mean item score: ________________
Moderate distress or greater? (mean item score > 2) yes___ no___

References:

1. Polonsky WH, Fisher L, Esarle J, *et al.* Assessing psychosocial distress in diabetes: Development of the Diabetes Distress Scale. *Diabetes Care* 2005; 28: 626-631.
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In research settings, a score of ≥ 40 out of 100 for PAID is regarded as representing severe distress.[21] For DDS, a mean item score of ≥ 3 across its four subscales reflects a degree of distress warranting prompt intervention.[2] In the clinical context, ratings on individual items can provide useful starting points for conversations about specific sources of distress, regardless of the total score.

> *"On the questionnaire, you recorded a high score on the item about feeling alone with your diabetes. Can you please tell me something about what makes you feel that way?"*

Be aware that a low score does not necessarily mean there is no diabetes distress. Rather, it may mean that a person is reluctant to talk about their emotional issues at the present time.

Shortened forms of instruments for measuring diabetes distress have been developed to reflect the time demands of clinical practice.[9, 22] These brief instruments take only a few minutes to administer and they can be readily incorporated into an annual diabetes review. If there are positive findings on a brief instrument, then a longer instrument can be used or a focused clinical interview can be conducted.

The PAID instrument has a 5-item short instrument (PAID-5) that includes questions about fears relating to diabetes, depressed mood and the demands of living with diabetes. It has been shown to have a sensitivity of 95% and a specificity of 89%.[22] An even shorter scale, known as PAID-1, has a concurrent sensitivity and specificity of about 80%.[22] It involves asking the following question:

> *"Do you worry about the future and getting complications?"*

The DDS instrument has a two-item short instrument (known as DDS-2).[9] This instrument comprises the following two questions:

> *"Do you ever feel overwhelmed with the demands of looking after your diabetes?"*
>
> AND
>
> *"Do you often feel that you are failing with your diabetes regimen?"*

The specificity and sensitivity of DDS-2 are 95% and 85% respectively.[9] Of note, as Fisher *et al* have observed, the questions in DDS-2 derive from the two domains that relate to internal features of distress rather than to those concerning relationships with other people.[9] Neither the short-form DDS instrument nor PAID-1 or -5 has as yet been validated in an Australian context.

USING THE PAID OR DDS INSTRUMENTS, EITHER IN THEIR SHORT OR LONG FORMS, IS NOT A SUBSTITUTE FOR SCREENING FOR DEPRESSION[9]

Correlates of diabetes distress

Numerous studies have explored the relationship between diabetes distress, as measured by the PAID and DDS instruments, and a range of behavioural, psychological and metabolic outcomes. Most of these studies have been conducted in populations with type 2 diabetes, but some have examined mixed populations or specifically those with people who have type 1 diabetes. The presence of diabetes distress has been linked with self-management behaviours, such as physical activity, diet, blood glucose monitoring and use of medications,[13] and with metabolic indicators, particularly HbA1c levels and rates of hypoglycaemia.[2,4,13,23-26] Gonzales *et al* have found that diabetes distress correlates more closely with behavioural and clinical measures of diabetes management than does depression.[27] Emotional and psychological outcomes associated with high total PAID and DDS scores include perceived burden of diabetes,[6,11] general emotional distress,[6] relationship adjustment, anxiety and depression.[11] PAID and DDS have also been found to be useful measures of several aspects of diabetes-related QOL.[28,29]

Responding to the presence of diabetes distress

A. Anticipatory guidance

Discuss the concept of diabetes distress early after diagnosis. Make sure a person with type 1 diabetes is able to recognise the symptoms and understands that it is normal to sometimes feel distressed or burnt out from their diabetes.

B. Name the problem

If a person has diabetes distress, just naming the problem can be therapeutic.[30] It helps to validate what the person is experiencing and this can provide an effective "entry point" into further discussion about emotional issues.

C. Basic interventions within the diabetes team

If a person's diabetes distress is not particularly severe, problems can generally be managed within the diabetes team. In a national survey of people with type 1 diabetes, most reported they were more likely to gain benefit from talking about emotional concerns with their endocrinologists or diabetes educators than with other health professionals.[31] This means that you need to be equipped to respond to issues such as diabetes distress in the clinic setting. This involves identifying whether a person needs extra help with the practical aspects of their diabetes and associated self-management behaviours, general stress management or interpersonal issues. The results of instruments designed to measure diabetes distress can be helpful to guide you in how best to offer support.

1. Practical strategies for optimising diabetes management

Review basic diabetes skills, including practical and problem solving skills. Facilitate access to structured education programs, such as DAFNE, which can help people with type 1 diabetes to achieve greater understanding of how to manage their blood glucose fluctuations and, in turn, improve their confidence and QOL.[32-34] Offer access to new technologies and other innovations if they are available, financially feasible and likely to benefit the individual.

Recommend that a reward system be implemented for diabetes self-management tasks that are unpleasant to perform. For example, a person with type 1 diabetes might decide to treat themselves to a movie if they check their BGLs four times a day for a whole week.

Modifications to diabetes regimens can lighten the burden of self-management or provide a change of routine.[7] A person with type 1 diabetes, for example, may decide to take a rest from using their insulin pump and try twice daily injections of pre-mix insulin in its place. If a person chooses to check their BGLs less often for a while, suggest ways of doing this safely by reinforcing the principles of strategic blood glucose monitoring.

2. Simple behavioural techniques

Encourage adaptive behavioural responses to diabetes distress or other life events.[35-37] Mood charting is one simple technique that can be recommended to facilitate this process. This involves a person recording their mood on a daily basis for a fixed period of time and using the results to identify triggers for their negative emotions. If specific issues surrounding diabetes self-management are contributing to distress, suggest that mood charting be combined with BGL data recording. Apply basic cognitive reframing and behaviour change techniques to support the person towards healthier psychological functioning.

3. Generic stress management strategies

- encourage simple lifestyle measures, such as regular exercise, healthy eating and consistent sleep patterns
- recommend techniques such as meditation, yoga or Pilates, regular breaks from technologies and learning to say *"No"*
- suggest timetabling of regular pleasurable activities, such as going out for coffee with friends or joining an adult education class
- provide advice about time management and support "time out", including short-term leave from employment
- suggest that the person seek support from partners, family, friends and peers

4. Strategies for enhancing interactions with partner, family and friends

If a person's distress relates to the reactions of family or friends, suggest that they access *"Diabetes etiquette for people who DON'T have diabetes"* (see next page).[38] This resource provides techniques for helping people negotiate relationships with significant others about their diabetes and its management. It also provides advice for people who *do not* have diabetes about how to support those who *do*. A similar resource called *"Type 1 Essentials: Common Questions Made Easy"* has been developed by DA–Vic.[39]

5. Strategies for enhancing interactions with health professionals

If you are using effective consulting skills, people with type 1 diabetes are likely to be satisfied by their interactions with you. One way of checking if this is the situation is to ask for suggestions about ways of improving delivery of care:

> *"I see that when you filled out the PAID questionnaire, you recorded that you were satisfied with your diabetes doctor. But do you have any suggestions for what the diabetes team or I could do to improve the way we support you with your diabetes?"*

case study

Kim

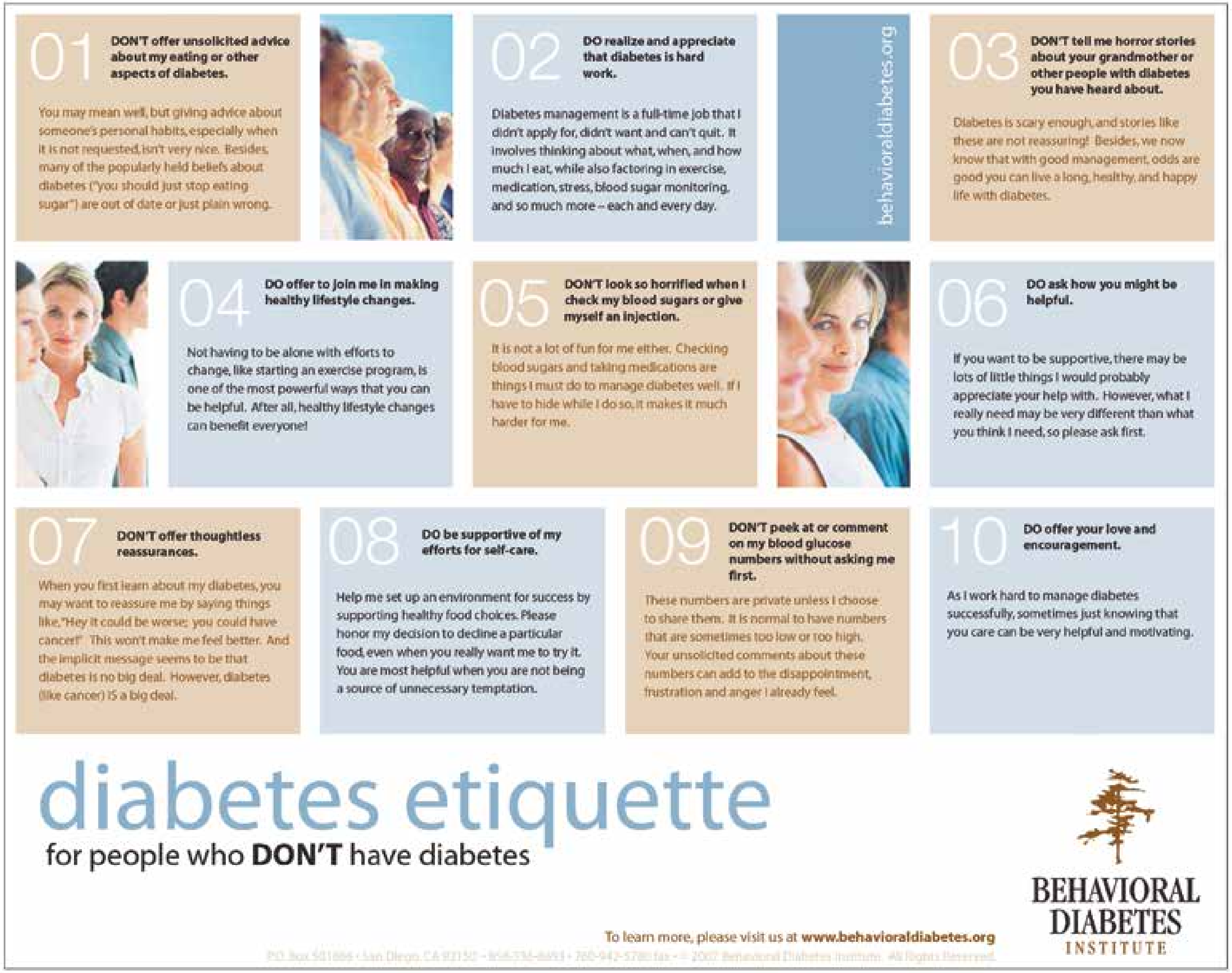
Kim is a 23-year old woman who has had type 1 diabetes for 12 months. She lives in a rural community and is attending for routine review at a diabetes clinic in her nearest regional centre, which is about 80 kilometres from her home. As part of her review, Kim has been given the DDS instrument to complete, which she does prior to her consultation with Michelle, a second-year trainee.

Michelle notes that Kim has a low score in all domains of the DDS, except for the subscale relating to interpersonal distress (mean score = 3). She asks Kim if she would like to talk about the issues that have been causing her distress in this area. Kim says she doesn't know anyone else with type 1 diabetes and, because of this, feels isolated in her community. She says her family members are well-meaning, but don't seem to understand how difficult it is to live with diabetes on a daily basis. They often tell her things could be worse and it is "only a touch of diabetes."

Michelle talks with Kim about some strategies that might help with addressing some of these issues. She asks Kim if she has heard about online peer support groups, such as the Type 1 Diabetes Network. Kim says that she hadn't thought of looking online, but it might be a good option for her. Michelle also mentions the resource "Diabetes etiquette for people who DON'T have diabetes" and says that it might be a useful way for Kim to learn about strategies to help optimise interactions with her family about her diabetes.

Michelle arranges to see Kim again in three months' time to see how she is doing from a medical point of view and also whether the isolation she has been experiencing due to her diabetes has abated.

2.3 diabetes distress



01 DON'T offer unsolicited advice about my eating or other aspects of diabetes.

You may mean well, but giving advice about someone's personal habits, especially when it is not requested, isn't very nice. Besides, many of the popularly held beliefs about diabetes ("you should just stop eating sugar") are out of date or just plain wrong.

02 DO realize and appreciate that diabetes is hard work.

Diabetes management is a full-time job that I didn't apply for, didn't want and can't quit. It involves thinking about what, when, and how much I eat, while also factoring in exercise, medication, stress, blood sugar monitoring, and so much more – each and every day.

behavioraldiabetes.org

03 DON'T tell me horror stories about your grandmother or other people with diabetes you have heard about.

Diabetes is scary enough, and stories like these are not reassuring! Besides, we now know that with good management, odds are good you can live a long, healthy, and happy life with diabetes.

04 DO offer to join me in making healthy lifestyle changes.

Not having to be alone with efforts to change, like starting an exercise program, is one of the most powerful ways that you can be helpful. After all, healthy lifestyle changes can benefit everyone!

05 DON'T look so horrified when I check my blood sugars or give myself an injection.

It is not a lot of fun for me either. Checking blood sugars and taking medications are things I must do to manage diabetes well. If I have to hide while I do so, it makes it much harder for me.

06 DO ask how you might be helpful.

If you want to be supportive, there may be lots of little things I would probably appreciate your help with. However, what I really need may be very different than what you think I need, so please ask first.

07 DON'T offer thoughtless reassurances.

When you first learn about my diabetes, you may want to reassure me by saying things like, "Hey it could be worse; you could have cancer!" This won't make me feel better. And the implicit message seems to be that diabetes is no big deal. However, diabetes (like cancer) IS a big deal.

08 DO be supportive of my efforts for self-care.

Help me set up an environment for success by supporting healthy food choices. Please honor my decision to decline a particular food, even when you really want me to try it. You are most helpful when you are not being a source of unnecessary temptation.

09 DON'T peek at or comment on my blood glucose numbers without asking me first.

These numbers are private unless I choose to share them. It is normal to have numbers that are sometimes too low or too high. Your unsolicited comments about these numbers can add to the disappointment, frustration and anger I already feel.

10 DO offer your love and encouragement.

As I work hard to manage diabetes successfully, sometimes just knowing that you care can be very helpful and motivating.

diabetes etiquette

for people who **DON'T** have diabetes

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Check whether the people who have type 1 diabetes that you see in clinic or on the wards are having difficuties with accessing services, such as after-hours support, or interacting with the health care system in other ways, such as making clinic appointments or accessing subsidies for diabetes-related supplies and services.

D. Monitoring and referral

Increase the frequency of appointments if you have any concerns about a person's psychological health. Referral to a mental health professional or mental health service will usually be indicated if you suspect the person is depressed, if the problem is persistent and severe, or if there are biological markers of concern. With the person's permission, engage the support of their general practitioner when making referrals.

E. Formal psychological interventions

Research has demonstrated that distress in people who have type 1 diabetes can be reduced through formal psychological interventions.[35,40] Interventions that may be helpful include CBT, coping skills training, interpersonal therapy and stress management programs.[40,41] Relationships counselling or family therapy may be beneficial in specific circumstances.

F. Secondary prevention

If a person with type 1 diabetes has had an episode of diabetes distress, ensure that they can identify the early signs of relapse. Provide an action plan that includes the person's general practitioner and the diabetes team, as well as any mental health professional involved in their care. Monitor the person's emotional welfare periodically rather than just responding to crises or relapses.

2.3 diabetes distress

case study

Ahmad

Ahmad is a 28-year old man who has had type 1 diabetes for three years. He uses a pump for insulin delivery and his most recent HbA1c was 50 mmol/mol (6.7%). He is attending Diabetes Clinic for his annual review. David, a first-year endocrinology trainee, uses PAID-1 as a brief screening instrument for diabetes distress as part of Ahmad's assessment.

When Ahmad admits he worries about his future with diabetes, David suggests he complete the long-form PAID instrument so broader issues about living with diabetes can be explored. A score of 56 is recorded, indicating Ahmad has significant diabetes distress. On further questioning, Ahmad says he feels angry that he has diabetes and is burnt out by the constant demands it places on him. He wants to take a break from his insulin pump and go back to injections using a twice daily insulin regimen.

David prescribes pre-mix insulin in a disposable pen and assists Ahmad with dose calculations based on his daily insulin requirements on the pump. He asks Ahmad if he would like to see a diabetes educator to facilitate the changeover to pens and for extra support with his diabetes. Ahmad says he would appreciate a referral to the educator and this is arranged for him.

Ahmad does not have a general practitioner so David discusses the benefits of identifying one for his primary medical care. He also asks Ahmad whether he thinks it would be helpful to see a psychologist to talk through the issues that are contributing to his diabetes distress. Ahmad says he will find a general practitioner, but is not interested in seeing a psychologist. David arranges to see Ahmad in clinic in four weeks' time and provides his contact number should Ahmad have any concerns in the meantime.

clinical tasks

1 Practise using either PAID or DDS in your clinical setting with a range of people who have type 1 diabetes.

  (i) Ask each person how they felt about completing the instrument and whether it was helpful for them to think about potential causes of distress related to their diabetes.

  (ii) For each person, review their total score and compare this with your initial impression of their emotional wellbeing. Reflect on whether using a formal instrument helped you to more effectively identify the person's specific diabetes-related psychological issues.

2 Identify a person with type 1 diabetes who recorded a high score for an item on either PAID or DDS. Ask about what they think might help to reduce their distress and if they would like any support from you. Arrange further evaluation and referral if you suspect the person is suffering from severe diabetes distress and requires more than the simple interventions that you can offer in diabetes clinic.

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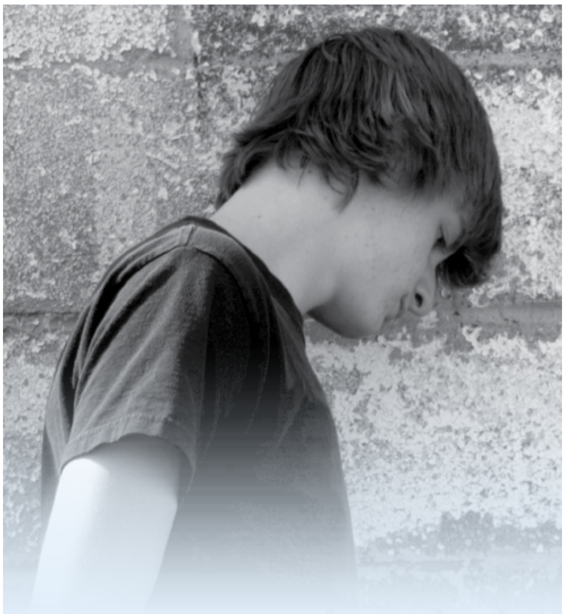
2.4 depression



learning outcomes

to be able to:

- describe the relationship between type 1 diabetes and depression
- screen for the presence of depression in a person with type 1 diabetes using a brief validated instrument
- make a diagnosis of depression in a person with type 1 diabetes and institute appropriate initial management

key reading

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Introduction

Living with type 1 diabetes brings an increased risk of developing depressive symptoms and major depressive disorder.[1] Important aetiological factors include the psychosocial stresses of managing a chronic medical condition and fears surrounding the development of diabetes complications. There is also emerging evidence that diabetes itself can increase susceptibility to depression by causing structural and functional changes in the brain.[2,3] When depression is present, it can impact adversely on diabetes outcomes through reduced focus on the tasks of self-management, although complex neuroendocrine mechanisms are also thought to play a role.[4]

In people with type 1 diabetes, depression can go undiagnosed, and therefore untreated, so a high index of suspicion is required.[5] Validated screening instruments are available to identify those requiring further assessment. It is important to be aware that the somatic symptoms of depression, such as fatigue, are less diagnostically useful in people with chronic medical conditions than in the general population. This is especially relevant in people with type 1 diabetes who have elevated HbA1c levels or complications, such as significant renal impairment or chronic foot wounds. Depression in people with type 1 diabetes can be successfully managed with standard pharmacological and talking therapies.[1]

The prevalence of depression in type 1 diabetes

Although there are persuasive reasons why people with type 1 diabetes might have a higher risk of developing depression, Gonzalez *et al* have recently suggested that the increase in prevalence may be overstated.[6] They have proposed that many people with diabetes are classified as being depressed when in fact they have diabetes distress.[6] Studies investigating the prevalence of depression in people with type 1 diabetes have also been criticised for lacking methodological rigour, as they often rely on self-report or use screening instruments that do not take into account the diagnostic unreliability of somatic symptoms in the context of chronic illness.[7] Small sample sizes and selection bias have also limited the validity of research in this area.

One robust study by Petrak *et al* applied structured interviews using Diagnostic and Statistical Manual (DSM)-IV criteria for the diagnosis of depression in a cohort of German inpatients with type 1 diabetes.[8] A higher prevalence of major depressive episode was found in women (9.3% in the diabetes group versus

3.2% in the control group) but not in men. The study included only people with newly diagnosed type 1 diabetes and the findings may not be generalisable to the wider diabetes population. In a recent study, participants with type 1 diabetes reported higher use of anti-depressant medication than the general population, although this may represent a detection bias due to closer contact with the medical profession, rather than a true increased prevalence.[9]

When to suspect a person with type 1 diabetes has depression

Suspect the co-occurrence of depression and type 1 diabetes in the following situations:

A. If a person with type 1 diabetes describes symptoms of depression or a third party expresses concern

A person with type 1 diabetes may describe symptoms of depression or a third party (family member, friend or carer) may be concerned that the person has exhibited changes in mood or behaviour, such as tearfulness, social withdrawal or reduced focus on diabetes self-management.

B. If a person has diabetes distress

Diabetes distress can be a precursor to depression. It can also co-exist with depression and there is considerable overlap in presentation, which can create a diagnostic challenge. Common features include feeling overwhelmed, anxious or fearful, and lacking motivation. When depression and diabetes distress co-exist, separate interventions may be required.[5]

C. If a person has risk factors for depression

Risk factors for depression in people with diabetes have been identified and, in general, mirror those for the general population.[8] Demographic factors include female gender, younger age and membership of a minority ethnic group.[10-13] Low socio-economic status, divorce and separation, social isolation and stressful life events are also predisposing factors. People who exhibit perfectionism or have low self-esteem are particularly vulnerable. Be alert to the possible increased risk of depression in women with newly diagnosed type 1 diabetes.[8] There should always be a heightened index of suspicion if a person has a past history of depression.

D. If there are unexplained diabetes presentations

Depression needs to be suspected in the setting of unexplained diabetes presentations, such as elevated HbA1c levels despite attention to the behavioural elements of self-management and interventions to alleviate diabetes distress.[14] The relationship between depression and HbA1c is complex but is thought to be mediated through self-efficacy.[15] Sacco *et al* have suggested that a perception of lack of control over one's health may be a risk factor for the development of depression.[15] Of note, their research has found that when depression is present, its severity correlates more strongly with HbA1c in type 1 diabetes than it does in type 2 diabetes (see Figure 2.4.1).[15] Depression can also be an underlying factor in recurrent hospital admissions for acute and chronic diabetes complications.[4]

Identifying depression in a person who has type 1 diabetes

A. Using screening instruments

At present, there are no formal recommendations in national Australian guidelines that screening for depression in people with type 1 diabetes take place on a regular basis.[7] Validated instruments, however, are available if a clinician would like to check for the presence of depression in an asymptomatic individual. The Patient Health Questionnaire 9 (PHQ-9) is commonly used as it mirrors the DSM-5 criteria for major depressive episode. A PHQ-9 score of ≥ 10 has a sensitivity of 88% and a specificity of 88% for major depression.[16]

The Beck Depression Inventory II (BDI-II) is another frequently used instrument but, like the PHQ-9, is generic and not specifically designed for use in people with chronic medical conditions.[17] Other instruments have been developed that place more emphasis on the cognitive rather than the somatic symptoms of depression, including the Hospital Anxiety and Depression Scale (HAD) and the Geriatric Depression Scale (GDS).[18,19]

At present, screening instruments for depression are largely used for research purposes and are generally not practical for use in clinical settings. Shorter versions, however, have been developed that can be readily incorporated into routine consultations. One useful brief instrument is PHQ-2, which is based on the first two questions of PHQ-9.[16] It involves asking the person if they have experienced the following symptoms in the past two weeks:

- feeling down, depressed or hopeless
- having little interest or pleasure in doing things

2.4 depression

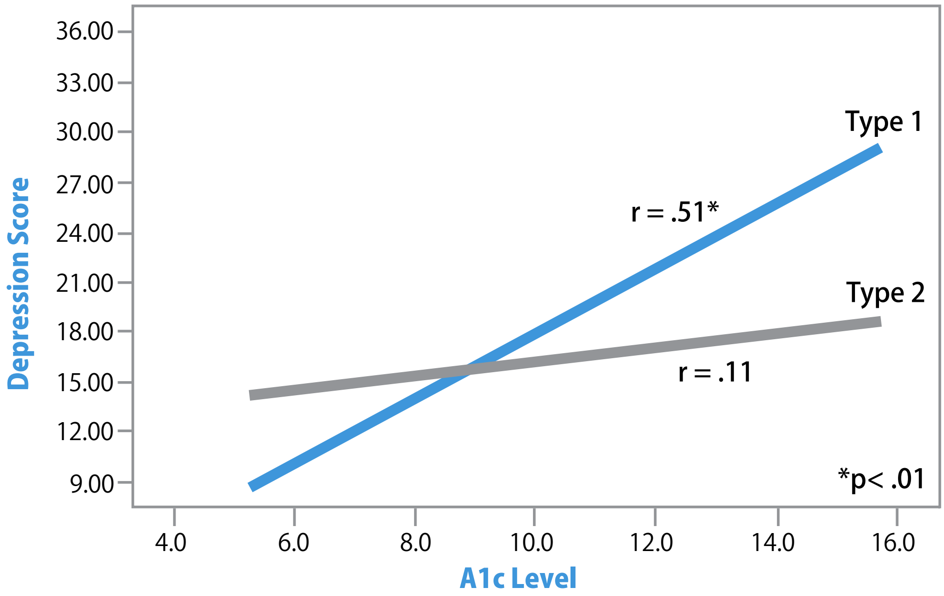

Figure 2.4.1: THE RELATIONSHIP BETWEEN DEPRESSION AND HBA1C IN TYPE 1 AND TYPE 2 DIABETES.

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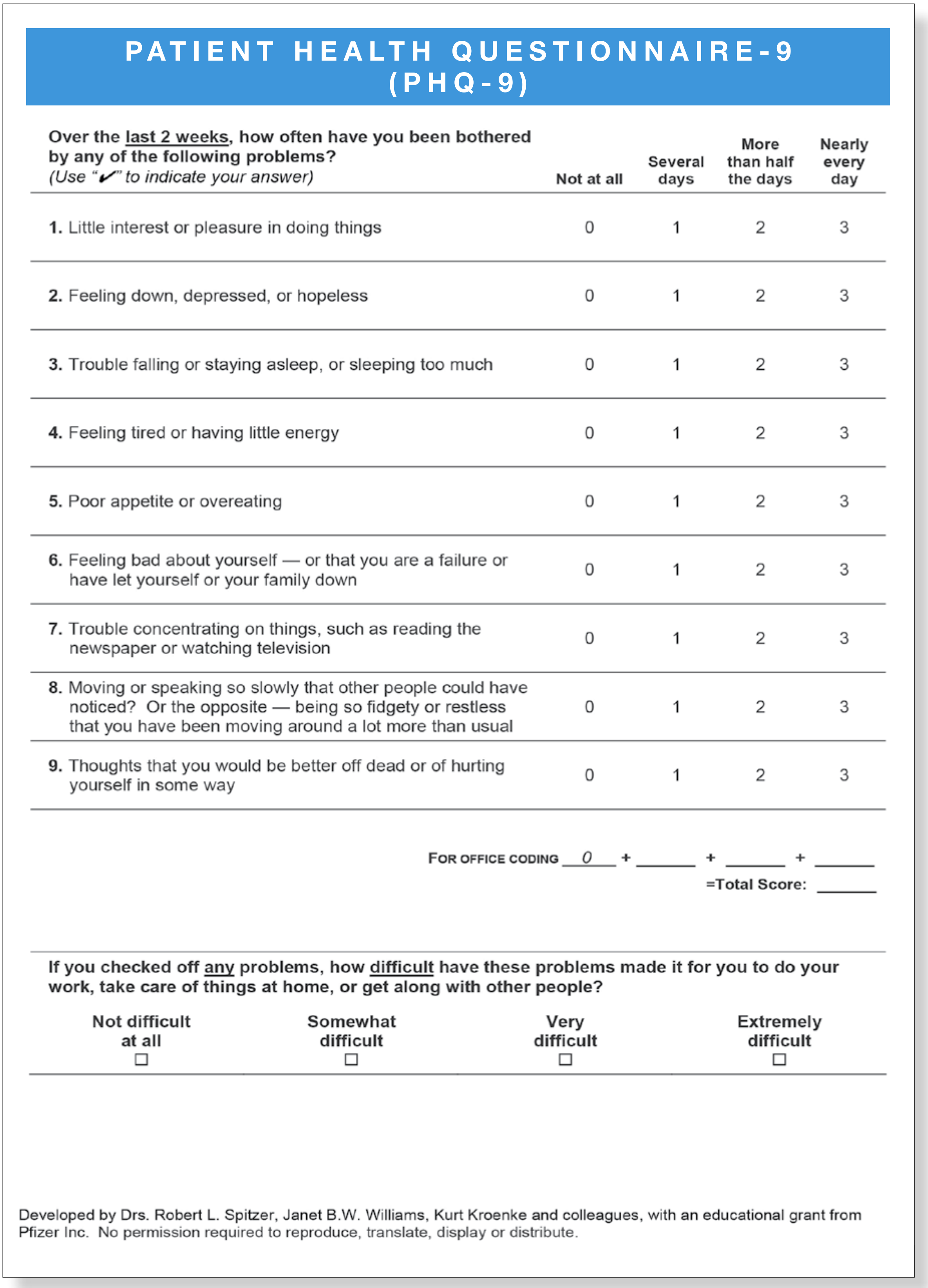
The PHQ-2 instrument can be used if an individual has been identified as being at risk of having a mood disorder during a consultation, especially if there is evidence of diabetes distress. It is best, however, to incorporate the questions from the instrument into your conversation with the person, rather than asking the questions directly.

> *"You mentioned that you've been feeling a bit burnt out with your diabetes. Sometimes this can be a symptom of depression … so it's important that I follow this up. So, I'm wondering if over the past few weeks you have been feeling down at all?"*
>
> AND
>
> *"I'm also wondering if you have been feeling recently that you have lost interest in doing the things you usually enjoy?"*

Each item of PHQ-2 is rated on a scale from 0 (not at all) to 3 (nearly every day). A total score of ≥ 2 has a sensitivity of 86% and a specificity of 78% for a diagnosis of depression.[20] If a person screens positive for an increased risk of depression on PHQ-2, then a full screening instrument, such as PHQ-9, needs to be administered or a formal diagnostic interview conducted.

B. Conducting a diagnostic interview

A diagnostic interview is required if a person with type 1 diabetes obtains a high score on a screening instrument, has symptoms suggestive of depression or is clinically deemed to be at high risk. In Australia, the WHO's International Classification of Diseases (ICD) is used for case-mix funding, but the American Psychiatric Association DSM-5 criteria for major depressive episode are generally used for diagnostic purposes in the clinical setting.[21]



PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✓" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	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	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING ___0___ + ______ + ______ + ______

=Total Score: ______

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	**Somewhat difficult**	**Very difficult**	**Extremely difficult**
☐	☐	☐	☐

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2.4 depression

DSM-5 Criteria for Major Depressive Disorder

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

Note: Do not include symptoms that are clearly attributable to another medical condition.

1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, hopeless) or observation made by others (e.g., appears tearful). (**Note:** In children and adolescents, can be irritable mood.)
2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).
3. Significant weight loss when not dieting or weight gain (e.g., change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day. (**Note:** In children, consider failure to make expected weight gain.)
4. Insomnia or hypersomnia nearly every day.
5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
6. Fatigue or loss of energy nearly every day.
7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or suicide attempt or a specific plan for committing suicide.

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The episode is not attributable to the physiological effects of a substance or to another medical condition.

Note: Criteria A-C represent a major depressive episode.

Note: Reponses to significant loss (e.g., bereavement, financial ruin, losses from a natural disaster, a serious medical illness or disability) may include the feelings of intense sadness, rumination about the loss, insomnia, poor appetite, and weight loss noted in Criterion A, which may resemble a depressive episode. Although such symptoms may be understandable or considered appropriate to the loss, the presence of a major depressive episode in addition to the normal response to a significant loss should also be carefully considered. This decision inevitably requires the exercise of clinical judgment based on the individual's history and the cultural norms for the expression of distress in the context of loss.

D. The occurrence of the major depressive episode is not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified and unspecified schizophrenia spectrum and other psychotic disorders.

E. There has never been a manic episode or a hypomanic episode.

Note: This exclusion does not apply if all of the manic-like or hypomanic-like episodes are substance-induced or are attributable to the physiological effects of another medical condition.

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Responding to a person with type 1 diabetes who has depression

A. Frame a response to the person

If a person with type 1 diabetes has described symptoms of depression, provide a synthesis of their narrative and offer them hope:

> *"You said that you're feeling overwhelmed by what's going on in your life right now and that you can't imagine you'll ever be happy again. You also mentioned that you've been having trouble sleeping. It sounds like you have depression, which can be a normal reaction to finding out that you have type 1 diabetes. It's important that we find out for sure whether you have depression or not. The good news is that there are effective treatments available if you do."*

B. Perform a suicide risk assessment

A suicide risk assessment is essential if a person with type 1 diabetes is deemed to be depressed on clinical assessment or if they have indicated on a screening instrument, such as PHQ-9, that they have thoughts of self-harm.[22,23] You may be reluctant to broach the subject of suicide, but there is no evidence that talking about it will prompt a person to act.[22] Instead, addressing the issue is far more likely to prevent an attempt. Most people will be relieved to have the opportunity to talk about their distressing thoughts and emotions. Reflect on whether any reluctance you may have about discussing suicide is due to your own beliefs, experiences or level of comfort, rather than your concerns about the person's reaction.

1. Create a safe environment within the consultation

Being supportive and non-judgemental can help to create a safe environment so the person feels comfortable about speaking freely to you. If they are emotionally engaged in the consultation, they are more likely to spontaneously share any suicidal thoughts.

2. Identify risk factors for suicide

Unfortunately, there are no reliable instruments that can be used to predict if a person is at risk of suicide. There are a number of risk factors, however, that should raise your level of suspicion (see Table 2.4.1).[22,24] Be particularly alert to self-medication with alcohol or recreational drugs.

Chronic illness is known to be an independent risk factor for suicide. The specific risk for type 1 diabetes has not been established,[25] although Goldston *et al* have observed that severely compromised self-management strongly predicts the presence of suicidal ideation in young people with type 1 diabetes.[26]

3. Respond to hints

A person who is depressed may not spontaneously volunteer suicidal ideation, but instead may provide hints as to their mental status. Such hints often involve themes of emptiness or not being able to visualise a future. Use this information to direct the conversation towards a discussion about suicidal ideation.

- **social isolation**
- **relationship difficulties**
- **impulse control issues**
- **other mental illness**
- **past history of suicide attempt or self-harm**
- **history of childhood physical or sexual abuse**
- **history of domestic violence**
- **unemployment or recent loss**
- **substance abuse**
- **hopelessness**
- **low self-esteem**
- **poorly developed problem solving skills**
- **family history of suicide or mental illness**
- **recent discharge from acute psychiatric care**

Table 2.4.1: FACTORS ASSOCIATED WITH AN INCREASED RISK OF SUICIDE

2.4 depression

case study

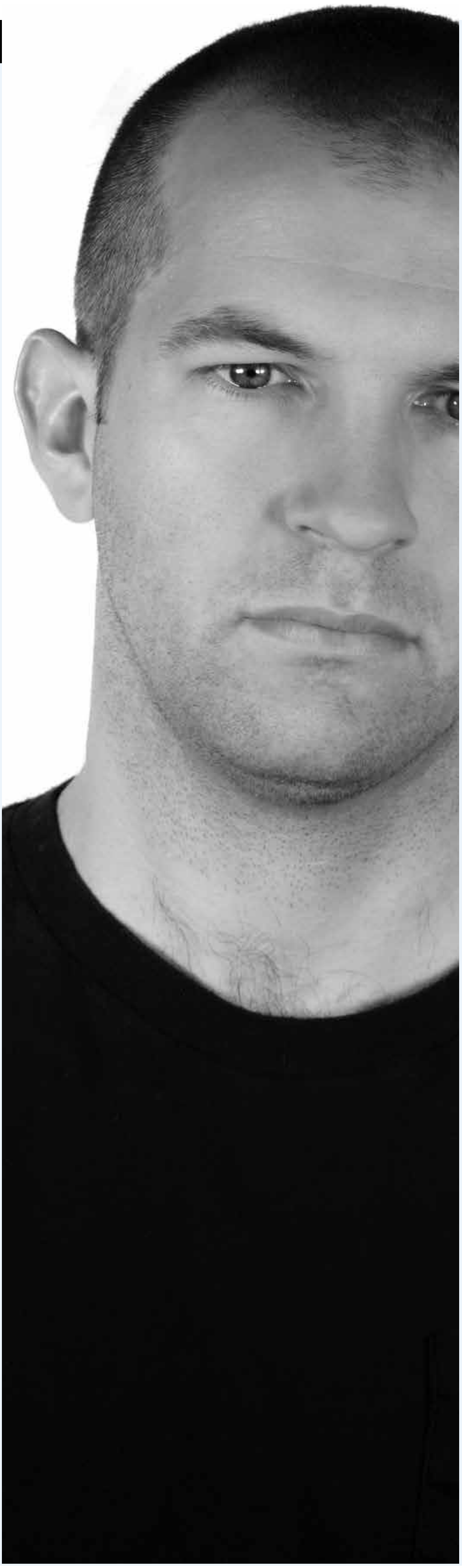
Scott

Scott is a 38-year old aircraft mechanic who has had type 1 diabetes since he was 19 years of age. His last HbA1c was 80 mmol/mol (9.5%). He recently had a retinal haemorrhage requiring laser treatment, but there are no other diabetes complications. Scott also has episodic asthma and gastro-oesophageal reflux disease. There is a family history of depression, with both his father and paternal uncle having been affected by this condition. Scott is married, but he separated from his wife six months ago. He has two children, aged 9 and 6, who live with his wife in a rural town.

Sarah, a second-year endocrinology trainee, is talking with Scott during a routine diabetes review. As the conversation progresses, Scott tells Sarah he is feeling burnt out with his diabetes and is anxious about having developed retinopathy. Sarah acknowledges his concerns and invites him to say more about how he has been feeling. She then further explores his emotional state by integrating the items from the PHQ-2 instrument into the conversation.

Scott reveals that he has been experiencing feelings of hopelessness about both his diabetes and his home life. He says he seems to have lost interest in doing the things he usually enjoys, such as going to the football at weekends and playing tennis with friends. He says he has been feeling like this most days over the past few weeks.

Sarah decides that Scott is at high risk of having depression so she conducts a diagnostic interview using the DSM–5 criteria for major depressive episode. She establishes that Scott has not been sleeping well and has been feeling guilty about the breakdown in his family relationships. He has been feeling more tired than usual, but doesn't feel that this is due to his BGLs, as these have been at about the same levels for some time now. He is finding it difficult to concentrate at work and even the most routine of tasks is taking longer than usual for him to complete. Based on Scott's responses, Sarah identifies that he meets the criteria for having a major depressive episode. She then proceeds to perform a suicide risk assessment.



SARAH: *We've been talking about how you've been feeling really down lately and seem to be depressed. I wonder if you could say a bit more about what's been making you feel this way ...*

SCOTT: *Well, my wife and I broke up about six months ago. Things hadn't been great for quite a while, but I must admit that I was surprised when she left. She took the kids and went to live with her father up country. I don't get to see my kids much with them being so far away and I really miss having them around ... (stops) ...*

SARAH: *It sounds like it's been a pretty tough time for you ...*

SCOTT: *... yep, and work's not going all that well either right now ... there're redundancies looming and I'm worried that I'm going to be a part of that ... and now there's this trouble I'm having with my eyes and having to have the laser treatment ... I know I haven't been great at looking after my diabetes over the years and it seems like it's finally catching up with me ...*

SARAH: *... (silence) ...*

SCOTT: *... (long pause) ... well, I guess I'm feeling a bit empty right now. It seems like I'm at risk of losing everything that's important to me ... (stops) ...*

SARAH: *Do you ever feel so empty that you don't want to go on?*

SCOTT: *Well, sometimes when I'm going off to sleep, I hope that I won't wake up in the morning ... (expression of passive suicidal ideation) ...*

SARAH: *Do you ever think about actively doing something to end your life?*

4. Make a direct enquiry

If a person who is significantly depressed has not provided hints that they are planning to take their own life, you will need to ask directly. Approach this in a highly sensitive manner. It is best to build up to asking within a discussion about the person's general mental state, rather than raising the subject without warning.

Observe for hesitancies, vehement denials or ambivalent responses. Be aware that leading questions, such as: "*You're not thinking of ending your life, are you?*", may bias the person against disclosure.

Recognise that a person may be resistant to discussing suicidal ideation because they believe that it is shameful or they are afraid what might happen to them if they reveal their thoughts. Alternatively, they may be so suicidal that they are committed to carrying out their plans and do not want anyone to know.

SARAH: *We've talked a lot about everything that is happening in your life right now. Sometimes when people have a lot of stress like you have, they think of ending their life. Have you had any thoughts like this?*

SCOTT: *... (quickly) ... no, absolutely not ...*

SARAH: *You seem quite definite about that ... sometimes when people feel down and that they can't go on ... well, often they're reluctant to talk about it ...*

SCOTT: *... (long pause) ... well, yes, I guess I have thought like that occasionally ...*

5. Explore the extent of lethality

Ask about the frequency and intensity of suicidal ideation. If the person mentions a specific method, ask explicit questions to help establish the degree to which they have advanced their plans.[27] For example, if a person has considered taking a drug overdose, ask about what type of medication they have thought of using, their ease of access to it and whether they have been stock-piling supplies. Find out if there have been any practice attempts.

Intentional insulin overdose is a readily accessible option to people with type 1 diabetes, but its true prevalence is not known.[24,28,29] It is probably under-recognised and thus under-reported as insulin has a narrow therapeutic index and intentions are often concealed. Prompt identification can help to ensure optimal outcomes. In one retrospective study, it was found that full recovery from intentional insulin overdose was the most likely result, with cerebral injury and death occurring in a small percentage (5.4%) of cases.[28]

SARAH: *When you've been really down and thought about ending your life ... what do you think about doing?*

SCOTT: *... nothing really ...*

SARAH: *... (silence) ...*

SCOTT: *... well, sometimes I think about ... (pauses) ... well, there are times when I think about overdosing on insulin ...*

SARAH: *How often do you think like this?*

SCOTT: *... (long pause) ... well, I often think about it when I'm holding my pen ready to inject ...*

SARAH: *Have you ever dialled up a higher dose than you would normally use?*

SCOTT: *... (hesitates) ... a few times, maybe ... (stops) ...*

SARAH: *Do you have a specific dose in mind that you think might work?*

SCOTT: *... I don't know ... maybe 100 units ...*

SARAH: *Have you ever injected more than your routine dose on purpose?*

SCOTT: *Yes, once...*

SARAH: *What happened?*

SCOTT: *I took an extra 20 units and had a really bad hypo ... I was at work and someone found me and took me to hospital ... I didn't say I had done it on purpose ... no one asked ... they just thought it was an accidental hypo .*

SARAH: *I'm glad that you're telling me this ... given how bad you're feeling, I think it's important that you and I plan to get some help for you from a mental health professional ...*

6. Information from a third person

Information from a third person, such as a partner, a family member or a friend, may be helpful in determining the person's risk of suicide. For example, a third person may have observed the person placing their financial affairs in order or making a will for no particular reason.

INFORM YOUR CONSULTANT IMMEDIATELY IF YOU SUSPECT A PERSON WITH TYPE 1 DIABETES HAS SIGNIFICANT DEPRESSION

C. Arrange appropriate referral

If a person has mild depression, their general practitioner is usually best placed to offer care. More severe depression will require the involvement of a mental health service. The urgency of referral will depend on whether or not suicidal ideation is present. If a person is actively suicidal, they must NOT be left alone.

Management of depression in a person with type 1 diabetes

Therapies used for depression in people with type 1 diabetes are the same as those for the general population.[30-32] A meta-analysis of 14 RCTs conducted by van der Feltz-Cornelis *et al* showed that treatment for people with type 1 or type 2 diabetes is effective in terms of reduction in depressive symptoms.[1] In this study, anti-depressants were found to have a moderate impact on symptoms, with psychotherapy being most effective when combined with diabetes self-management education.[1] A recent pilot study has specifically shown evidence for the feasibility and potential utility of CBT in people with type 1 diabetes who have depression.[33]

While standard treatments are helpful for reducing depressive symptoms, there is less evidence at present to show that they have a positive influence on diabetes outcomes. Markovitz *et al,* however, have emphasised that this does not diminish the importance of treating depression as an endpoint in itself in people with diabetes.[32] It also highlights the complex and incompletely defined relationship between diabetes and depression, as well as the importance of enhancing self-efficacy in diabetes self-care and addressing comorbid mental health conditions, such as diabetes distress.[34,35]

At present, there is little evidence to guide specific selection of anti-depressant therapy for a person with comorbid depression and type 1 diabetes. Effects on metabolic status are variable,[36,37] although there is some evidence that serotonergic agents may have a more favourable metabolic profile than noradrenergic agents.[30,31,38] One small study by Lustman *et al* found an improvement in HBA1c with sertraline compared with placebo in the treatment of depression in type 1 diabetes, but the generalisability of this finding has not been established.[38] Overall, optimal treatment of depression needs to take precedence in decision making. If an anti-psychotic agent is to be included in a treatment plan, as might be the case in severe depression, its impact on weight and glycaemic control needs to be anticipated.[39]

In the inpatient setting, the co-occurrence of depression and type 1 diabetes can raise specific management issues. Where there is a high risk of suicide, insulin injections need to be either very closely supervised or administered by health professionals. This situation needs to be managed sensitively, as a person with type 1 diabetes may find it confronting to relinquish control over their self-management. The issue is best addressed in advance in a sensitive yet explicit manner. Be aware of the risk of hypoglycaemia if a person has had reduced focus on self-care prior to hospitalisation and then resumes their regular insulin regimen in a ward setting.

clinical tasks

1. Practise using the brief screening instrument PHQ-2 in your clinical consultations.
2. Identify a person with type 1 diabetes who has scored ≥ 2 on PHQ-2. Conduct a diagnostic interview using the DSM–5 criteria for major depressive episode. Institute appropriate initial management if you find that the person is depressed.

2.4 depression

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2.5 anxiety

learning outcomes

to be able to:

- describe the prevalence and the impact of anxiety and anxiety disorders in people with type 1 diabetes
- identify the presence of anxiety or anxiety disorder in a person with type 1 diabetes
- respond to the presence of anxiety or anxiety disorder in a person with type 1 diabetes

key reading

1. Grigsby AB, Anderson RJ, Freedland KE, Clouse RE, Lustman PJ. Prevalence of anxiety in adults with diabetes. A systematic review. *J Psychosom Res* 2002; 53: 1053-1060.
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Introduction

Anxiety is one of the most common mental health problems in people with type 1 diabetes. Specific anxieties related to diabetes are well-described, and include injection anxiety,[1] fear of hypoglycaemia[2] and worries about developing long-term complications.[3] The presence of anxiety can have a significant impact on diabetes outcomes, partly through neuroendocrine-mediated mechanisms and partly through behaviours, such as avoidance of stressful situations associated with the tasks of diabetes self-management.[4 5]

When anxiety impacts significantly on functioning, it is classified as an anxiety disorder. A range of anxiety disorders exist that can affect people with type 1 diabetes, including generalised anxiety disorder and panic disorder.[4,5] Common symptoms of these disorders include fear and apprehension, as well as adrenergic symptoms, such as sweating, palpitations and tremor. These features overlap with the symptoms of hypoglycaemia, which can make diagnosis and management challenging. Simple interventions can be instituted in a diabetes clinic if anxiety is mild. For more severe anxiety or full-syndrome anxiety disorders, referral to a mental health professional will generally be required. Standard psychological and pharmacological therapies for anxiety are effective in people with type 1 diabetes.

Adaptive versus pathological anxiety

A certain degree of anxiety is a normal part of life. Anxiety is adaptive when it provides motivation, such as during preparation for university examinations, or if it increases vigilance in potentially dangerous situations. Too much anxiety, however, can interfere significantly with functioning and well-being.[6] The relationship between arousal and performance (shown graphically in Figure 2.5.1) was first described by Yerkes and Dodson in 1908.[7]

Two categories of anxiety are described.[8] The first is *state* anxiety, which refers to the emotional response to a specific trigger, such as a high-stakes examination or a medical emergency. The second is *trait* anxiety, which refers to a person's constitutional set-point. People with high trait anxiety tend to worry more than the general population, experiencing anxious feelings regularly, often on a daily basis. State and trait anxiety can co-exist, and those who have trait anxiety often have more intense reactions to specific anxiety-provoking situations than those who do not have this condition.

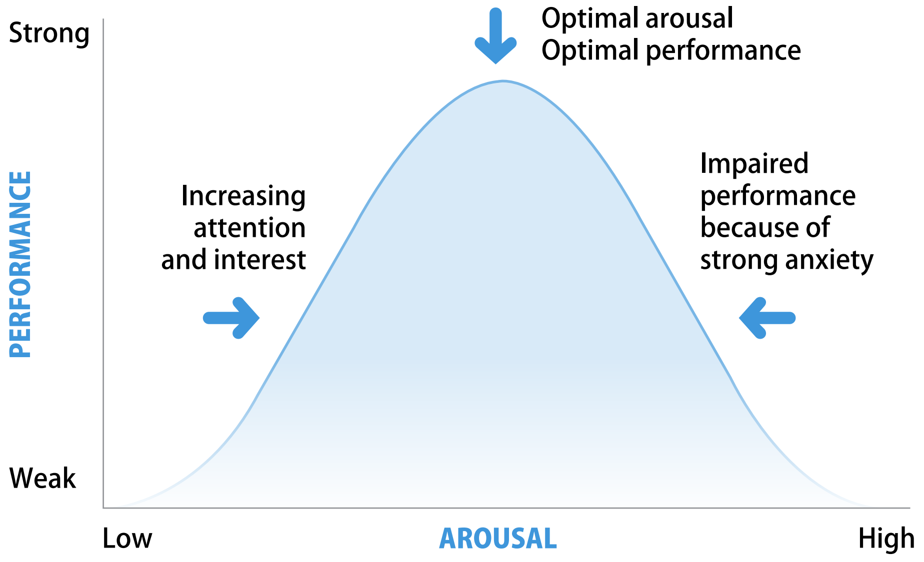


Figure 2.5.1: THE RELATIONSHIP BETWEEN AROUSAL AND PERFORMANCE

When anxiety becomes pathological by impacting significantly on how a person functions in daily life, it is usually classified as being a mental illness. Anxiety disorders are among the most common of the mental illnesses and can lead to significant morbidity, often being as disabling as major depression. There are a range of anxiety disorders, including generalised anxiety disorder, panic disorder, social phobia, obsessive-compulsive disorder and specific phobias, such as needle phobia.

Prevalence of anxiety disorders in people with type 1 diabetes

There is evidence that clinically significant anxiety is more common in adults with type 1 diabetes than in the general population.[4,9,10] In a high quality controlled French study, the lifetime prevalence of Anxiety Disorders (Not Otherwise Specified) was 44%, simple phobia 27%, social phobia 25% and agoraphobia 15%, as defined by DSM-III-R criteria.[10] Data from uncontrolled prospective studies have also shown high rates of anxiety in people with type 1 diabetes.[9] Kovacs *et al* found that 20% of young people with type 1 diabetes developed some form of anxiety disorder with time, predominantly generalised anxiety disorder,[11] while Northam *et al* identified 17% of participants with anxiety according to DSM-IV criteria after 10 years of diabetes.[12]

The prevalence of diabetes-specific anxiety has been studied in a range of settings. Zambanini *et al* measured injection anxiety in a cohort of people with type 1 and type 2 diabetes using the Injection Anxiety Score and the General Anxiety score.[1] They found that approximately 25% of the cohort had a psychological problem related to injecting insulin, with 14% reporting they had omitted insulin doses due to anxiety about injections. A significant association was found between injection-related anxiety and generalised anxiety, but gender, type of diabetes and duration were not predictive factors. Needle phobia is a more extreme form of injection-related anxiety, but is less commonly reported.[13] Anxieties surrounding the development of chronic diabetes complications are common, as found in the Diabetes MILES-Australia 2011 Survey.[3] Fear of hypoglycaemia is also an important source of anxiety for people with type 1 diabetes.[2] This issue is addressed in the following chapter.

The impact of anxiety disorders in type 1 diabetes

Anxiety is known to have an adverse effect on metabolic outcomes in people who have type 1 diabetes.[14-17] This effect is mediated partly through biological mechanisms, specifically activation of the adrenergic nervous system, and partly through

2.5 anxiety

psychological factors impacting on self-management. In a study by Berlin *et al*, anxiety symptoms were found to be associated with less frequent BGL monitoring and elevated HbA1c levels.[14] Research has also demonstrated that people with type 1 diabetes who suffer from panic disorder have higher HbA1c levels, more complications, greater disability and lower self-rated health than those who do not have this anxiety disorder.[5] Zambanini *et al* found a trend towards elevated HbA1c levels in those with injection anxiety and higher associated generalised anxiety, but the association did not reach statistical significance.[1]

When to suspect the presence of anxiety in a person with type 1 diabetes

A. If the person with type 1 diabetes reports symptoms of anxiety or a third party expresses concern

A person with type 1 diabetes may describe cognitive symptoms of anxiety, such as being "stressed" or "worried", or a third party (family, friend or carer) may report that the person appears overly anxious. In some situations, somatic symptoms, especially those mediated through the autonomic nervous system, can be presenting features. Any report of either cognitive or somatic symptoms of anxiety requires further assessment.

B. If the person has a risk factor for an anxiety disorder

The risk factors for anxiety disorder in people with type 1 diabetes are similar to those for the general population and include:[18]

- female gender
- family history of mental illness
- childhood trauma
- significant current life stressors
- personality style, such as perfectionism
- substance abuse

C. If there are signs of autonomic nervous system over-activity

Signs of autonomic nervous system over-activity, such as tachycardia, sweating and tremor, may be noted on physical examination and provide a clue to the presence of an underlying anxiety state.

D. If there are unexplained diabetes presentations

Consider the presence of an anxiety disorder if a person with type 1 diabetes has an unexplained elevated HbA1c or exhibits behavioural changes with respect to diabetes self-management, such as reduced frequency of BGL monitoring or insulin administration. Be aware that a person with a normal HbA1c may have a high degree of anxiety associated with their efforts to maintain euglycaemia. In this context, there may be associated obsessive behaviours, such as excessively frequent blood glucose monitoring.

Identifying anxiety in a person with type 1 diabetes

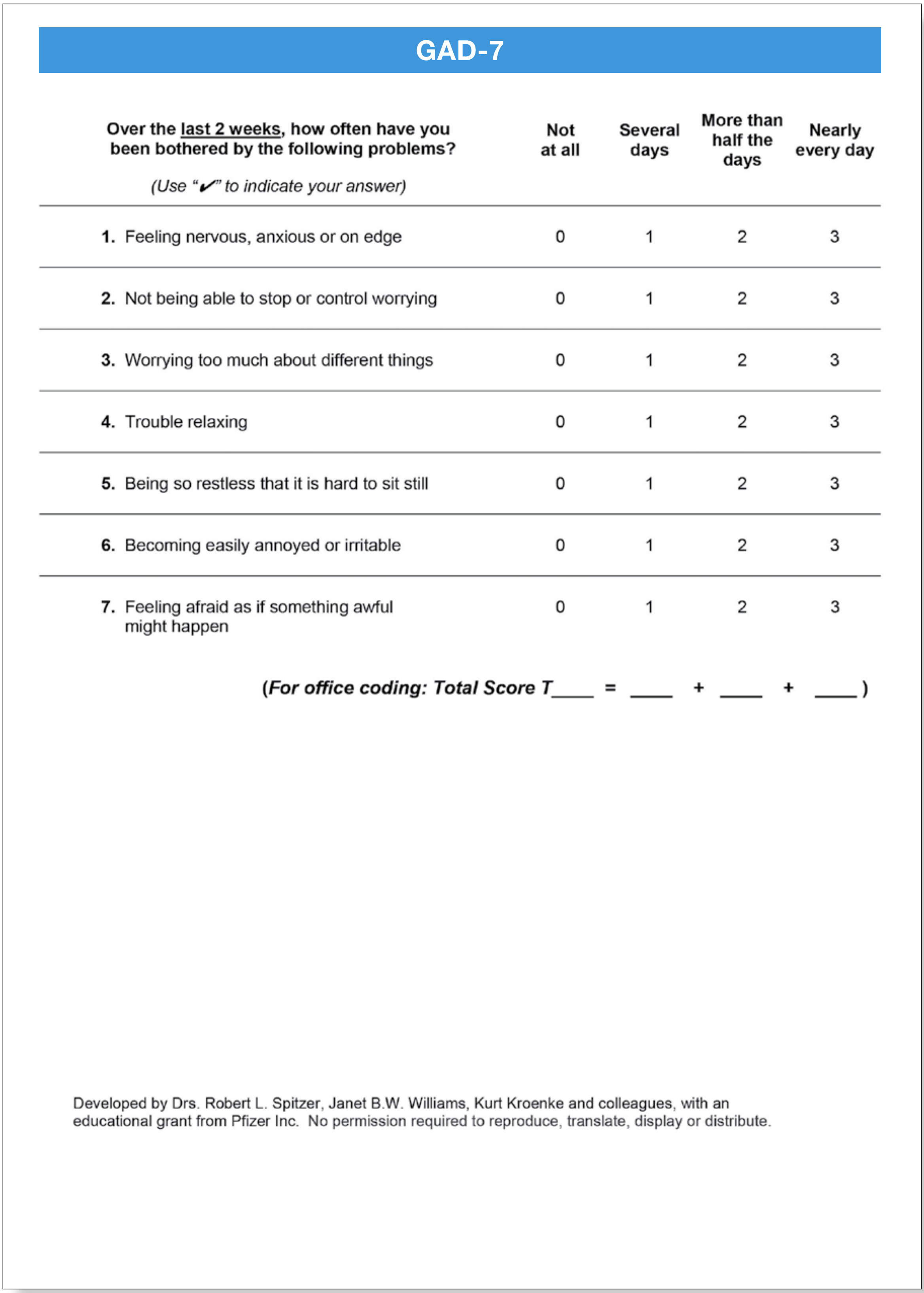
A. Screening instruments

In Australia, there are currently no formal recommendations that screening for anxiety or anxiety disorders in people with type 1 diabetes take place on a regular basis.[9] There are a number of validated instruments available, however, to check for the presence of anxiety in an asymptomatic individual. One brief instrument commonly used to screen for the presence of generalised anxiety disorder is the GAD-7 scale.[19] GAD-7 has also been shown to be helpful for screening for panic attack, social anxiety and post-traumatic stress disorder.[20] The HADS inventory is also often used and has the advantage that it is designed to detect the presence of anxiety in people with comorbid medical conditions.[21] Furthermore, it screens for both anxiety and depression, conditions which often co-exist in people who have type 1 diabetes. Other screening instruments include the BECK Anxiety Inventory and Depression, Anxiety and Stress-21,[22,23] as well as scales that are specific for sub-types of anxiety, such as obsessive-compulsive disorder.[24]

A score of ≥ 10 on GAD-7 should be a trigger for further evaluation, and a score of ≥ 15 indicates that treatment is likely to be warranted. The first two questions of GAD-7 can be used as a brief screening tool, known as GAD-2. A score of ≥ 3 on GAD-2 indicates the need for further assessment with a full screening instrument or a diagnostic interview.

B. Conducting a diagnostic interview

A diagnostic interview is indicated if a person with type 1 diabetes reports symptoms of an anxiety disorder, has a high score on a screening instrument or is clinically deemed to be at high risk. DSM-5 criteria for anxiety disorders are most commonly used for diagnostic purposes in clinical practice.[25] The criteria for generalised anxiety disorder and panic disorder, and the features of panic attack, are listed in the following pages. For other anxiety disorders, consult DSM-5 for details of diagnostic criteria.[25]



GAD-7

Over the last 2 weeks, how often have you been bothered by the following problems? *(Use "✓" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

(*For office coding: Total Score T____* = ____ + ____ + ____)

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2.5 anxiety

DSM-5 Diagnostic criteria for Generalized Anxiety Disorder

A. Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities (such as work or school performance).

B. The person finds it difficult to control the worry.

C. The anxiety and worry are associated with three (or more) of the following six symptoms (with at least some symptoms having been present for more days than not for the past 6 months).

Note: Only one item is required in children.

1. Restlessness or feeling keyed up or on edge.
2. Being easily fatigued.
3. Difficulty concentrating or mind going blank.
4. Irritability.
5. Muscle tension.
6. Sleep disturbance (difficulty falling or staying asleep, or restless unsatisfying sleep).

D. The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

E. The disturbance is not attributable to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition (e.g., hyperthyroidism).

F. The disturbance is not better explained by another mental disorder (e.g., anxiety or worry about having panic attacks in panic disorder, negative evaluation in social anxiety disorder (social phobia), contamination or other obsessions in obsessive-compulsive disorder, separation from attachment figures in separation anxiety disorder, reminder of traumatic events in post-traumatic stress disorder, gaining weight in anorexia nervosa, physical complaints in somatic symptom disorder, perceived appearance flaws in body dysmorphic disorder, having a serious illness in illness anxiety disorder, or the content of delusional beliefs in schizophrenia or delusional disorder).

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DSM-5 Diagnostic Criteria for Panic Disorder

A. Recurrent unexpected panic attacks. A panic attack is an abrupt surge of intense fear or intense discomfort that reaches a peak within minutes, and during which time four (or more) of the following symptoms occur:

   Note: The abrupt surge can occur from a calm or an anxious state

   1. Palpitations, pounding heart or accelerated heart rate.
   2. Sweating.
   3. Trembling or shaking.
   4. Sensations of shortness of breath or smothering.
   5. Feelings of choking.
   6. Chest pain or discomfort.
   7. Nausea or abdominal distress.
   8. Feeling dizzy, unsteady, light-headed, or faint.
   9. Chills or heat sensations.
   10. Paraesthesias (numbness or tingling sensations).
   11. Derealization (feelings of unreality) or depersonalization (being detached from oneself).
   12. Fear of losing control or "going crazy".
   13. Fear of dying.

   Note: Culture-specific symptoms (e.g., tinnitus, neck soreness, headache, uncontrollable screaming or crying) may be seen. Such symptoms should not count as one of the four required symptoms.

B. At least one of the attacks has been followed by 1 month (or more) of one or both of the following:

   1. Persistent concern or worry about additional panic attacks or their consequences (e.g., losing control, having a heart attack, "going crazy").
   2. A significant maladaptive change in behaviour related to the attacks (e.g., behaviours designed to avoid having panic attacks, such as avoidance of exercise or unfamiliar situations).

C. The disturbance is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition (e.g., hyperthyroidism, cardiopulmonary disorders).

D. The disturbance is not better explained by another mental disorder (e.g., the panic attacks do not occur only in response to feared social situations, as in social anxiety disorder; in response to circumscribed phobic objects or situations, as in specific phobia; in response to obsessions, as in obsessive-compulsive disorder; in response to reminder of traumatic events, as in post-traumatic stress disorder; or in response to separation from attachment figures, as in separation anxiety disorder).

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2.5 anxiety

Panic attack symptoms (DSM-5)	Symptoms of hypoglycaemia
palpitations, pounding heart, or accelerated heart rate	palpitations, pounding heart, or accelerated heart rate
sweating	sweating
trembling or shaking	trembling or shaking
sensations of shortness of breath or smothering	
feeling of choking	
chest pain or discomfort	
nausea or abdominal distress	nausea
feeling dizzy, unsteady, light-headed or faint	dizziness or light headedness
chills or heat sensations	coldness
paraesthesias (numbness or tingling sensations)	paraesthesias (numbness or tingling sensations)
derealisation (feelings of unreality) or depersonalisation (being detached from oneself)	depersonalisation
fear of losing control or "going crazy"	weakness
fear of dying	confusion

A panic attack is an abrupt surge of intense fear or intense discomfort that reaches a peak within minutes and during which time four (or more) of the above symptoms occur.

Note: The abrupt surge can occur from a calm state or an anxious state.

Criteria for Panic Attack reprinted with permission from the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. (Copyright ©2013). American Psychiatric Association.

Panic attack by itself is not a mental disorder and is not codable. Panic attacks can occur in the context of any anxiety disorder, as well as other mental disorders (for example, depressive disorders, post-traumatic stress disorder, substance use disorders) and certain medical conditions (for example, cardiac, respiratory, vestibular and gastrointestinal conditions).

When a panic attack is identified, it should be noted as a specifier (for example, post-traumatic stress disorder with panic attacks). For panic disorder, the presence of panic attack is contained within the criteria for the disorder and panic attack is not used as a specifier.

The diagnosis of a panic attack in a person with type 1 diabetes can be challenging, especially in the context of frequent hypoglycaemia, as there is considerable overlap in symptoms (see previous page).

Responding to a person with type 1 diabetes who has anxiety

A. Exclude a physical cause for the presentation

Exclude thyrotoxicosis and other medical or psychiatric conditions that can mimic anxiety, such as supra-ventricular tachycardia, medication side-effects or hypomania.

B. Frame a response to the person

If a person with type 1 diabetes has described symptoms of anxiety, acknowledge their distress and provide a summary of their presentation.

C. Offer simple interventions in diabetes clinic

1. Provide brief psycho-education by explaining the nature of anxiety and its impact.
2. Recommend online self-help interventions, for example, “Panic Stations” – an initiative of the Western Australian Government.[26]
3. Address mild diabetes-specific anxieties, such as injection anxiety or fear of chronic complications, with further education or skills development and by using a supportive approach.

INFORM YOUR CONSULTANT IMMEDIATELY IF YOU SUSPECT A PERSON WITH TYPE 1 DIABETES HAS SIGNIFICANT ANXIETY THAT IS IMPACTING ON THEIR FUNCTIONING.

D. Arrange appropriate referral

If a person has mild anxiety, involve their general practitioner, who will usually be best placed to offer care. A referral to a psychologist through a mental health care plan may be arranged. More severe anxiety will require the involvement of the psychiatry team, but be sure to keep the person’s general practitioner closely involved.

Therapies for management of anxiety

Generic talking therapies, such as CBT, are effective in the management of anxiety and are generally recommended as first-line treatment.[27] These therapies have been shown to reduce the risk of relapse compared with the use of pharmacological therapy alone.[28] There are a number of reports in the literature of CBT being used explicitly for the management of anxiety in people with type 1 diabetes.[29,30] Specific interventions may be indicated for diabetes-related anxiety, such as injection anxiety and needle phobia. Pharmacological therapies, specifically the SSRIs and SNRIs, may be helpful if there is co-morbid depression. Benzodiazepines generally should be avoided because of the risk of dependence. The specific choice of therapy is often guided by patient preference and the local availability of resources.

clinical tasks

1 Use the GAD-7 instrument to practise screening for anxiety in people with type 1 diabetes. Conduct a formal diagnostic interview if a person has a score of ≥ 10. Arrange appropriate follow-up if you find that a person has significant anxiety or a full-syndrome anxiety disorder.

2 Identify a person with type 1 diabetes in clinic who has an HbA1c > 75 mmol/mol (9.0%). Ask if they have anxiety about injecting insulin. If so, explore their thoughts and behaviours surrounding this anxiety.

2.5 anxiety

case study

Stavros

Stavros is a 29-year old man who developed type 1 diabetes nine months ago. He is attending Diabetes Clinic for review and is talking with Dev, a first-year trainee. Dev notes that Stavros' recent HbA1c was 75 mmol/mol (9.0%), compared with 51 mmol/mol (6.8%) three months ago. He asks Stavros how he is doing with his diabetes self-management. Stavros admits that he is finding it difficult to incorporate the load of type 1 diabetes management into his life.

When Dev asks what is most challenging for him, Stavros says he hates giving his insulin injections, as these are a constant reminder that he now has a chronic medical condition. He also feels embarrassed when he needs to give his injection in front of others. Most of all, though, he feels very anxious when he pierces his skin with the needle, even though it hurts a lot less than he expected when he first found out that he had diabetes.

Stavros admits to Dev that on average he misses two out of four injections each day at present because of his anxieties around injecting. He also says he has always hated having injections, and remembers that as a child he was distressed when having immunisations. Stavros tells Dev that he has probably always been a rather anxious person, especially in social situations.

Dev talks through these issues with Stavros and asks how he can best help. Stavros decides that closer contact with the diabetes education team for extra support would be beneficial. Dev suggests that CBT might be a useful adjunct treatment. He recommends that Stavros see his general practitioner to obtain a mental health care plan and a referral to a clinical psychologist. Dev arranges to see Stavros in six weeks' time to ensure that all plans are in place.

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2.6 fear of hypoglycaemia

learning outcomes

to be able to:

- discuss the physical, psychological and behavioural effects of hypoglycaemia in type 1 diabetes
- identify the fear of hypoglycaemia in a person with type 1 diabetes
- respond to the presence of fear of hypoglycaemia in a person with type 1 diabetes

key reading

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Introduction

Hypoglycaemia is caused by a discrepancy between the amount of insulin administered and that required to match food intake, energy expenditure and prevailing biological influences.[1] It is usually defined by Whipple's triad: (i) the presence of symptoms, (ii) a documented low BGL, and (iii) symptom resolution with appropriate CHO intake.[2] There is no universally agreed numerical cut off, but hypoglycaemia is typically denoted by a laboratory BGL of ≤ 3.9 mmol/L.[3,4]

Hypoglycaemia leads to unpleasant symptoms, including tremor, palpitations, sweating and, less commonly, impaired consciousness. By definition, mild hypoglycaemia can be treated by a person with type 1 diabetes themselves, whereas severe hypoglycaemia requires external assistance. Severe hypoglycaemia can result in physical injury, motor vehicle accidents, cardiac events and, rarely, death.[2,4]

The unpleasant symptoms and associated risks of hypoglycaemia can create significant anxiety for people with type 1 diabetes. Although the benefits of tight glycaemic control for preventing or delaying the onset of diabetes complications are well established,[5] worries surrounding hypoglycaemia present a major barrier to achieving desired outcomes.[6] Most people with type 1 diabetes face the risk of hypoglycaemia on a daily basis, with the DCCT trial finding that mild hypoglycaemia occurred twice a week on average in the intensive management group.[5] Chronic complications, such as neuropathy or nephropathy, however, can take many decades to develop, if at all.[7] Therefore, avoiding hypoglycaemia is usually a greater priority than the prevention of long-term complications, especially if there is co-existent impaired awareness of hypoglycaemia (IAH).[8]

Psychological, behavioural and social effects of hypoglycaemia

The psychological effects of hypoglycaemia for people with type 1 diabetes are often underestimated by health professionals.[9] Even mild hypoglycaemia can lead to reduced QOL, particularly when it is frequent or there are attenuated symptoms. Severe hypoglycaemia leading to reduced conscious state can create embarrassment when it occurs in public and can also provoke considerable anxiety about safety. With almost 50% of all hypoglycaemic episodes occurring at night, issues surrounding safety can be especially acute for those who live alone.[10]

Many people with type 1 diabetes who have anxieties about hypoglycaemia develop compensatory behaviours, such as reducing or omitting insulin, eating extra amounts of food and avoiding physical activities.[11] These behaviours can be associated with acceptance of persistently elevated BGLs, with a consequent increased risk of developing long-term diabetes complications.

Hypoglycaemia can place a significant burden on relationships with partners, families or carers.[12] Over-involvement or over-concern of a partner or family member can create conflict, as can the situation where a person who has type 1 diabetes relies on a significant other for recognition and intervention. Personal or family distress may also result from issues surrounding hypoglycaemia that limit work and lifestyle opportunities for the person with type 1 diabetes.[13]

By addressing fear of hypoglycaemia, health professionals have the potential to minimise associated morbidity, identify related psychological conditions and improve long-term metabolic outcomes.

Risk factors for fear of hypoglycaemia

A number of risk factors for fear of hypoglycaemia have been identified. These risk factors broadly fall into two groups, one relating to diabetes-specific features and the other relating to the psychosocial characteristics of the person with type 1 diabetes. To a certain degree, the risk factors for severe hypoglycaemia overlap with those for fear of hypoglycaemia.[7]

A. Diabetes-specific risk factors:[9,14-16]

- frequent minor hypoglycaemic episodes disrupting daily life
- a history of severe episodes, especially involving loss of consciousness
- low mean BGLs
- high mean BGL variability
- nocturnal hypoglycaemia
- IAH

B. Psychosocial risk factors:[9,17,18]

- trait anxiety and general fearfulness
- obsessive tendencies
- panic attacks, including phobic-type panic attacks
- living alone

The underlying mechanisms that mediate the link between fear of hypoglycaemia and trait anxiety have not been definitively established. Being anxious, however, can make it difficult for a person with type 1 diabetes to focus on their BGLs and can distract them from the routine tasks of diabetes self-management.[19] This can increase the risk of hypoglycaemia, which in turn can escalate anxiety. In addition, it is known that fear of hypoglycaemia is associated with difficulties in distinguishing between the symptoms of anxiety and those of hypoglycaemia.[20]

Identifying fear of hypoglycaemia

A. In a routine clinical setting

1. Ask about frequency and symptoms of hypoglycaemia

Ask about hypoglycaemia on a regular basis. This involves establishing the frequency of both mild and severe hypoglycaemia in conjunction with review of BGL monitoring data. It also involves asking about warning symptoms of hypoglycaemia. Enquiring about the type of symptoms is likely to yield more information than just asking if the person experiences symptoms.

> *"Can you please tell me what sort of symptoms you have when your blood glucose level goes low?"*

Ask about the level at which symptoms appear, as this can be helpful for identifying IAH. Autonomic symptoms should generally commence at a capillary BGL of between 3.0 and 4.0 mmol/L, but with IAH they may not start until the BGL is < 3.0 mmol/L, the level at which neuroglycopenia develops. IAH is relatively common in type 1 diabetes, with a study by Geddes *et al* finding a prevalence of approximately 20% in a hospital-based clinic population.[21]

Be aware that IAH is not an "all or nothing" process, as it can vary with time and context. Also be aware that some people with type 1 diabetes believe that they are only "having a hypo" if they experience symptoms. It may be more helpful to ask a person how often their BGLs are < 4 mmol/L, rather than how often they are having hypoglycaemic episodes.

2. Ask directly about fear of hypoglycaemia

Ask about the person's emotions surrounding the risk of hypoglycaemia and how these impact on their diabetes management and QOL. For example, a person may be purposefully running their HbA1c at an elevated level for fear of hypoglycaemia.

2.6 fear of hypoglycaemia

case study

Rebecca

Rebecca, 32, has type 1 diabetes which was diagnosed when she was 16 years of age. She manages her BGLs with an insulin pump and has no diabetes complications. She also has a history of anxiety and depression, which are usually well controlled with medication and counselling. Rebecca has two children, a four-month old baby, Hugo, and 3-year old Harper. She is currently breastfeeding Hugo and plans to do so until he is 12 months of age.

In the first trimester of her recent pregnancy, Rebecca had an episode of severe hypoglycaemia with loss of consciousness. She was at her local shopping centre with Harper when it occurred. Fortunately, a shop owner called an ambulance and took care of Harper until the episode was treated by the paramedics. Rebecca was quite shaken emotionally by the episode and was particularly anxious about what might have happened to Harper if there had been no one around to help. She has had no further episodes of severe hypoglycaemia, but had frequent mild episodes in the first few weeks after Hugo was born.

Rebecca is now attending Diabetes Clinic for routine review and is talking with David, a third-year trainee. Her HbA1c is normally between 50 and 55 mmol/mol (6.7% and 7.2%), but was 70 mmol/mol (8.5%) when checked one week prior to the consultation. David is concerned that Rebecca's BGLs are higher than usual and spends time exploring the underlying causes. After a long conversation, Rebecca admits to David that she has made a deliberate decision to run her BGLs higher at present because she is fearful of having a severe hypoglycaemic episode while she is alone with her children. She says she plans to continue running her levels high for now, at least until she has finished breastfeeding.

> *"A lot of people I see who have type 1 diabetes feel anxious about having hypos. Is that something that you have experienced?"*

If the reply is in the affirmative, explore the impact of hypoglycaemia on the person:

> *"How does this affect the way you manage your diabetes?"*
>
> OR
>
> *"How does this impact on your everyday life?"*

Be aware that some people who are achieving their glycaemic targets may be living in constant fear of having a severe hypoglycaemic episode.

3. Check for co-existing anxiety disorders

If you suspect the presence of a co-existing anxiety disorder in a person with type 1 diabetes, administer a screening instrument or conduct a diagnostic interview. Ask about their ability to distinguish between hypoglycaemia and symptoms of anxiety.

> *"Do you sometimes find yourself thinking you are having a hypo ... and then find out you weren't?"*

4. Ask about the social impacts of hypoglycaemia

Explore how hypoglycaemia affects the person's relationship with their partner, family, friends or carers.

> *"Do you rely on your partner for picking up your hypos?"*
>
> OR
>
> *"How do you respond if your mother asks you to check your BGL when she is worried that you might be having a hypo?"*

Ask about how hypoglycaemia impacts on other people in the person's social network. For example, partners, family or carers can develop considerable anxiety around the risk of hypoglycaemia in a person with type 1 diabetes. Partners can also develop sleep disturbance if there is frequent nocturnal hypoglycaemia.[22]

B. Formal screening instruments

The Hypoglycaemia Fear Scale (HFS), developed by Cox *et al*, has been used in research settings to explore behavioural and emotional responses to hypoglycaemia.[23] With 33 items, the HFS is quite time-consuming, which limits its use in the clinical context. Furthermore, a well-defined or clinically relevant cut-off score has not yet been established.[24]

Responding to fear of hypoglycaemia

A. Implement strategies for reducing the incidence of hypoglycaemia

- review BGL monitoring skills
- review CHO counting, insulin dose adjustment and problem-solving skills
- recommend structured education programs, such as DAFNE, which have been shown to reduce rates of hypoglycaemia[25,26]

B. Review hypoglycaemia management

- check the person's knowledge of hypoglycaemia and its management[27]
- encourage involvement of the person's partner, family members or carers
- recommend that the person identify a significant other who can learn to administer glucagon as a backup in the event of severe hypoglycaemia[28]

C. Consider formal interventions to enhance blood glucose awareness

Formal interventions have been developed to help people with type 1 diabetes enhance their awareness of hypoglycaemia.[29,30] This heightened awareness can be harnessed to improve blood glucose stability, which in turn can help to reduce fear of hypoglycaemia. For a person with type 1 diabetes, developing reliable blood glucose awareness involves having an appreciation of the physical, cognitive and emotional symptoms that occur with hypoglycaemia, especially those that reliably predict its onset. It also requires an understanding of the pathophysiological basis of hypoglycaemia, as well as the factors that usually lead to low BGLs. Critically, blood glucose awareness involves identifying the psychological factors that can distract from paying attention to symptoms of hypoglycaemia and from responding to it in a timely manner.

One of the most widely known formal interventions for improving blood glucose awareness is Blood Glucose Awareness Training (BGAT). Developed by Cox *et al*, this structured education program focuses on enhancing identification of both high and low BGLs. Typically conducted in a group format, BGAT is delivered in sessions of two hours duration over an eight-week period.[29] It is based on a diary in which information is documented about estimated and actual BGLs.[29] When a person feels their BGL is out of range, the value is estimated on perception of symptoms or cues and is compared with the result of a simultaneous blood glucose meter measurement.

2.6 fear of hypoglycaemia

case study

Richard

Richard, 35, has had type 1 diabetes for 14 years and is attending Diabetes Clinic for review. He is speaking with Mervyn, a first-year trainee. Richard's most recent HbA1c was 42 mmol/mol (6.0%). He has been running his BGLs fairly tight since retinopathy was diagnosed 12 months ago, as he is worried about progression and also about the prospect of developing other chronic diabetes complications.

About six months ago, Richard had a severe hypoglycaemic episode as he was about to get into his car to drive home. He had to stop driving for six weeks afterwards and this had a significant impact on his work and social life. Richard says he is quite fearful of having another severe episode, but also remains anxious about developing long-term complications. He tells Mervyn he feels he is always "walking a tightrope" and that his anxiety is interfering with how he recognises low BGLs.

Mervyn reviews Richard's knowledge of hypoglycaemia management and also suggests that he keep a diary to document the physical symptoms he experiences when his BGLs are < 4 mmol/L. He discusses with Richard how it might also be helpful to document his stress levels at the time of hypoglycaemic episodes and to identify why they might have occurred. Richard has never attended a DAFNE course so Mervyn outlines what the benefits might be for him for his diabetes management in general, but also for helping to prevent hypoglycaemia.

Richard returns for review three weeks later and reports that he has found that numbness around his lips is quite a reliable symptom of hypoglycaemia. He has also realised that anxiety in general is an issue for him and says he has made an appointment with his general practitioner to discuss this. He has also booked in to do a DAFNE course in three months' time, when he will be able to schedule a week off work.

In addition, symptoms experienced at the time of the episode are logged. The exercise usually focuses on one type of symptom at a time. For instance, a person may start by recording physical symptoms of hypoglycaemia and correlating these with their BGLs, before focusing on emotional and cognitive symptoms.

A number of studies have explored the effectiveness of BGAT.[29,31,32] Most have confirmed its efficacy in improving recognition of low and high BGLs, especially in people with type 1 diabetes who have reduced hypoglycaemia awareness at baseline, and have demonstrated a significant reduction in the frequency of severe hypoglycaemia. Additional positive outcomes include improved decision-making around BGLs, especially with respect to driving, better overall diabetes knowledge and QOL, and enhanced psychological functioning.[29]

The HyPOS structured education program is another intervention that can help people with type 1 diabetes to enhance their blood glucose awareness, specifically in the setting of hypoglycaemia. Developed in Germany, it is delivered across five 90-minute sessions using diaries and blood glucose estimations.[30] A randomised study of HyPOS by Hermanns *et al* showed a significant improvement in recognition of hypoglycaemia at six months in the intervention arm, as well as a higher threshold for detection and treatment of low BGLs, and a reduced rate of mild hypoglycaemia.[30] At follow up after 31 months, there was a lower incidence of severe hypoglycaemia in the intervention group compared with the control group (12.5% vs 26.5%), as well as greater intensity of autonomic warning symptoms.[33]

One major disadvantage of formal interventions for enhancing blood glucose awareness is that they are only effective if the person with type 1 diabetes is motivated to work on their blood glucose management. They are also labour-intensive for people with type 1 diabetes, as well as for health professionals. At present, BGAT and HyPOS programs are not generally available in Australia. An internet-based version of BGAT has been developed, but is not currently accessible.[34]

D. Specific psychological interventions

Targeted psychological therapies are indicated if there is a co-existent anxiety disorder.[35] These will require referral to either a psychologist or a psychiatrist, depending on severity. Ideally, this will be co-ordinated through the person's general practitioner.

Lack of concern about hypoglycaemia

While the focus of this chapter has been on fear of hypoglycaemia, lack of concern about hypoglycaemia can also be an issue in people with type 1 diabetes. In a recent paper by Rogers *et al*, four distinct sub-groups of people who lack concern about hypoglycaemia were identified:[36]

- those who have normalised their IAH and feel that there is no concern because they do not have symptoms
- those who underestimate their IAH and risk of hypoglycaemia, feel they can function with a BGL < 3.0 mmol/L, and have confidence that family and friends will respond if hypoglycaemia is severe
- those who want to avoid the "sick role" and see absence of worry about hypoglycaemia as being a sign of having control
- those who tend to over-estimate the effects of hyperglycaemia and the risks of developing diabetes-related complications

Neuroimaging studies have found a relationship between lack of concern about hypoglycaemia and decreased activation of the amygdala and brain stem areas.[37] This research may help to shed light on why structured educational interventions do not work for all people with type 1 diabetes. For example, one study on the effectiveness of DAFNE showed that 48% of participants reported fewer hypoglycaemic episodes, meaning that many participants did not achieve this outcome.[38] Behavioural and psychological therapies to supplement such interventions may be required to increase awareness of the consequences of severe hypoglycaemia and IAH.[39]

clinical tasks

1. Talk with people who have type 1 diabetes about their knowledge, behaviours and emotions surrounding hypoglycaemia:
   - (i) Identify a person who has an HbA1c of > 75 mmol/mol (9.0%). Ask them whether fear of hypoglycaemia is a barrier to achieving their metabolic targets.
   - (ii) Identify a person who has an HbA1c of < 48 mmol/mol (6.5%). Ask them if anxieties about hypoglycaemia impact on their QOL.
2. Identify a person with type 1 diabetes who is having frequent hypoglycaemia. Ask them to identify the physical, behavioural and emotional symptoms they experience when their BGLs are low. Suggest they keep a diary of their hypoglycaemic episodes by recording estimated and measured BGLs, with associated symptoms. Review the results and see if the exercise has helped them to improve their recognition of and response to hypoglycaemia.

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2.7 eating disorders

learning outcomes

to be able to:

- discuss the impact and the prevalence of eating disorders in type 1 diabetes
- identify and respond to disordered eating in a person with type 1 diabetes
- identify and respond to a full syndrome eating disorder in a person with type 1 diabetes

key reading

1. Warren MP. Endocrine manifestations of eating disorders. *JCEM* 2011; 96; 333-343.
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Introduction

Eating disorders encompass a spectrum of conditions characterised by faulty cognitions with respect to body image, a preoccupation with food and eating, and excessive energy expenditure.[1] At the more severe end of the spectrum are the full syndrome eating disorders, the most recognised of these being anorexia nervosa, which is characterised by food restriction and a fear of gaining weight, and bulimia nervosa, in which binge eating and purging behaviours predominate. At the milder end of the spectrum are behaviours that come under the classification of disordered eating. These behaviours include food restriction, compulsive eating and irregular eating patterns that do not qualify for a diagnosis of a full syndrome eating disorder, yet can have a significant impact on physical, psychological and social functioning.

At present, the aetiology of eating disorders is incompletely understood.[2-4] A mix of biological, psychological and social factors is thought to contribute to their expression. Biological factors can have an influence through genetic predisposition, epigenetic processes and by dysregulation of complex neuroendocrine feeding mechanisms.[5] Psychological, emotional and personality factors can play a significant role, with regulation of food intake serving as a mechanism for coping in those who have depression, anxiety or low self-esteem. Individuals who feel they lack control over life events, are perfectionists or who have difficulty expressing emotions are particularly vulnerable. Sexual and physical abuse or troubled family and personal relationships may act as triggers.

Research suggests that social context can have an impact on the development of eating disorders,[2] with individuals from high socio-economic levels being over-represented in prevalence statistics. Certain professional groups, such as ballet dancers, are especially prone.[6] A higher prevalence of eating disorders has been found in Western countries, especially those where obesity is widespread, although there is evidence that rates are increasing in non-Western nations.[7]

Cultural norms where physical appearance is valued over personal qualities are also thought to play a part in the manifestation of eating disorders. The media, in particular, have been criticised for promoting ideals of body shape that are unattainable by most of the population.[8] In addition, advances in ICT have enabled the proliferation of pro-eating disorder websites designed to inspire readers to lose weight, and to provide information about controlling hunger, as well as escaping detection by health professionals.[9]

Eating disorders can lead to significant morbidity and mortality.[10] In type 1 diabetes, they are associated with increased rates of microvascular complications and sub-optimal metabolic control, including ketoacidosis.[11-14]

Prevalence of eating disorders in type 1 diabetes

Studies show that eating disorders are more common in people with type 1 diabetes than in the general population.[15,16] They occur most frequently in females in the adolescent and young adult age groups, although they can affect males and older women.[17,18] A meta-analysis by Nielsen in 2002 found an odds ratio of 2.9 for bulimia nervosa and approximately 2 for Eating Disorders Not Otherwise Specified (using DSM IV-R criteria) and other sub-threshold eating disorders in females with type 1 diabetes.[19] A subsequent systematic review found an increased prevalence of bulimia nervosa in females with type 1 diabetes (1.7%) compared with controls (0.7%).[14] There does not, however, seem to be an increased prevalence of anorexia nervosa in adolescent and adult females with type 1 diabetes, although its impact is significantly greater when it is present.[20]

Why is type 1 diabetes a risk factor for eating disorders?

The relentless quest for blood glucose stability in type 1 diabetes requires an intense focus on food intake, especially through CHO counting and limits on overall consumption. This focus has the potential to generate considerable anxiety about weight and food intake. The metabolic monitoring that forms a routine part of diabetes self-management can exacerbate the situation, as can the weight gain that can be associated with extra intake of CHO for the management of recurrent hypoglycaemia.

For those who have concerns about body image and regulation of food intake, type 1 diabetes provides a unique opportunity for achieving weight loss through insulin omission or restriction.[20,21] In a study by Bryden *et al*, 30% of older adolescents and adult females reported having omitted or restricted insulin specifically for the purpose of weight control.[22] Insulin omission or restriction is associated with poorer health outcomes, with one study showing a 3.2-fold increased mortality after 11 years of follow up.[21]

The period after the onset of type 1 diabetes can be a particularly vulnerable time with respect to the development of eating disorders. The loss of weight that usually occurs prior to diagnosis can result in favourable comments about appearance, setting the scene for considerable disappointment with the return to pre-morbid weight when exogenous insulin is initiated. This can be an important trigger for use of insulin omission as a tool for weight loss. In addition, the onerous burden of self-management in type 1 diabetes can lead to issues of control, anxiety and depression, which in turn can drive the expression of eating disorders.

Disordered eating

A. What is healthy eating?

Having an understanding of the principles of healthy eating is the first step in being able to identify and respond to the presence of disordered eating. Primarily, healthy eating involves having a flexible and balanced approach to selection and consumption of food. Importantly, it means choosing food types that help to meet daily nutritional requirements and eating adequate quantities of these foods, with intake spread out over the day. More food may be eaten on some days than on others, as long as it balances out over time.

Healthy eating is also characterised by a set of adaptive biopsychosocial attitudes and behaviours, including being able to go to a meal hungry and physically recognise satiety. It also involves acknowledging that appetite will fluctuate over time and that it is normal to eat in response to triggers other than appetite, such as boredom, frustration or happiness, as long as it is kept in perspective. Ultimately, healthy eating means taking enjoyment from food, being comfortable about eating in the presence of others and appreciating the important role that food plays in facilitating social interactions.

B. What is disordered eating?

In contrast with healthy eating, disordered eating involves an abnormal focus on food. It encompasses a wide range of practices, including restriction of food intake, binging or rigid dietary rules. Weight control behaviours, such as purging, diuretic and laxative abuse or excessive exercise, are also considered to be part of disordered eating, as long as they are not of a degree that meets the diagnostic criteria for a full syndrome eating disorder.

2.7 eating disorders

Distinguishing healthy eating from disordered eating at the milder end of the spectrum can be challenging as the boundary is difficult to define. There can also be considerable flux over time, in that a person who routinely follows the principles of healthy eating can cross over into disordered eating in periods of stress as part of a maladaptive coping style. The situation is even more complex in the presence of type 1 diabetes since behaviours that are a routine part of self-management, such as weighing foods and CHO counting, would be classified as being dysfunctional in the general population.[25]

The presence of disordered eating can compromise daily functioning or be a precursor to a full syndrome eating disorder, so early identification is critical. In type 1 diabetes, disordered eating is associated with increased morbidity and mortality, generally mediated through insulin omission.[21]

C. When to suspect someone with type 1 diabetes has disordered eating

The presence of disordered eating in a person with type 1 diabetes needs to be suspected if any of the following factors are present:[11,14,26-28]

- an elevated HbA1c
- unexplained BGL variability
- frequent changes of baseline insulin regimen
- pump downloads that are suggestive of insulin omission or bolusing for binge eating
- weight loss without a healthy eating plan or exercise program
- early development of microvascular complications
- psychological risk factors for disordered eating, such as perfectionism or problems with self-esteem
- concern expressed by a third party, such as a parent or a partner

D. Broaching the topic of disordered eating

1. Promote open and honest communication

Ensure there is an atmosphere of open and honest communication within your consultations. Many people with type 1 diabetes do not confide in their health professionals about their disordered eating because of shame or the fear of being judged.[29] Appreciate that it may take time for a person to feel comfortable talking about the issues that underlie their disordered eating.

2. Start with non-threatening questions

Ask about the person's general well-being before broaching the topic of eating behaviours. Make a specific comment if you observe that the person is anxious or in any other way exhibiting signs of an emotional or psychological problem.

> *"You seem to be a bit anxious today. Am I correct in saying this?"*

3. Ask about weight or body image concerns

Initiate a discussion about weight and body image at a suitable point in the consultation. Normalise the concerns that many people with type 1 diabetes have about these issues:

> *"A lot of young women your age worry about their weight. Have you had any concerns yourself?"*

Markowitz *et al* have found that an affirmative answer to the question: *"Have you ever been overweight?"* is a marker for disordered eating in adolescent females with type 1 diabetes.[30] This question, which applies whether the history of being overweight is real or perceived, has a sensitivity of 83% and a negative predictive value of 94%.[30]

4. Comment on the presence of a biological marker of disordered eating

A biological marker of disordered eating, such as an elevated HbA1c or early microvascular complications, may be present. Comment on the marker as a way of broaching weight and body image issues.

> *"When someone has an elevated HbA1c, it can sometimes mean that they are struggling with weight issues. Is this something that might be happening with you?"*

5. Ask about insulin omission

Asking about insulin omission can be an effective and efficient way of screening for the presence of disordered eating. In a survey by DA-Vic, it was found that 85% of females with type 1 diabetes had never been asked about insulin omission by a health professional.[29] Of these women, about 50% were withholding insulin specifically for the purposes of weight loss. While the survey had a high risk of ascertainment bias, the results nevertheless highlight the importance of exploring this issue in clinical practice.

Weight control, however, is just one of the many complex reasons why someone with type 1 diabetes might be omitting or restricting insulin. Start with a broad exploration of the issue and then ask more directly about the underlying reasons.

> *"A lot of people with type 1 diabetes find it hard to keep up with taking their insulin all the time. Do you find that you sometimes miss your insulin injections?"*

If the person says yes, then ask:

> *"Tell me about some of the reasons why you miss your insulin."*
>
> then be more direct:
>
> *"Do you ever do this to try to lose weight?"*

You may have concerns that broaching this topic will act as a trigger for insulin omission as a weight loss strategy. Most people with type 1 diabetes, however, are well aware of the effects of insulin omission on weight. Moreover, you have a duty of care to identify and respond to behaviours associated with disordered eating, as well as the emotional and psychological issues that drive them.

The Golden Rule is:
IF YOU DON'T ASK, YOU WON'T BE TOLD

E. Use a formal screening instrument

Formal screening instruments can be used to detect the presence of disordered eating. Many generic instruments are available, but most are not suitable for type 1 diabetes because of the inclusion of eating behaviours that are part of normal diabetes self-management and the absence of items addressing insulin omission. In addition, many instruments have been developed for the adolescent age group and have not been validated in adult populations.

The Disordered Eating Problem Survey (DEPS) was developed to overcome the limitations of generic instruments in type 1 diabetes.[31] More recently, Markowitz *et al* have produced a revised form of DEPS, known as DEPS-R, which they have validated for use in adolescents.[32] DEPS-R is a 16-item instrument scored on a 5-item Likert scale and has been shown to have robust internal consistency and construct validity (see Figure 2.7.1 on the following page). Experience with this instrument has shown that more than 50% of participants scoring > 20 were restricting or omitting insulin.

While DEPS-R is primarily a research instrument for use with adolescents, specific items may be helpful for clinical interviews with adults who have type 1 diabetes. DEPS-R has been criticised, however, for not including measurements of body dissatisfaction or shape concerns and for lacking definition of psychological traits using subscales that could be used to guide clinical management.[33] Instruments that include these items are currently being validated in populations with type 1 diabetes.[33]

F. Responding to disordered eating in a person with type 1 diabetes

1. Use a sensitive approach

Be empathic and non-judgemental. Normalise the focus that type 1 diabetes brings on food and weight.

> *"It sounds like you are struggling with your eating and weight at present ... this is quite common when people have type 1 diabetes. Sometimes all the focus on carb counting and balancing glucose levels can be really difficult ... I'm a bit worried, though, that all the really good strategies that you have developed to help with your diabetes might not be working well for you right now ..."*

2. Explore the underlying reasons for disordered eating.

Ask the person if they can identify the factors that impact on their body image and eating behaviours.

DEPS-R (DISORDERED EATING PROBLEM SURVEY - REVISED VERSION)

Each item is scored on a 6-point Likert scale where 0= Never and 5 = Always

Item	0 Never	1 Rarely	2 Sometimes	3 Often	4 Usually	5 Always
Losing weight is an important goal for me						
I skip meals and/or snacks						
Other people have told me my eating is out of control						
When I eat, I don’t take enough insulin to cover the food						
I eat more when I am alone than when I am with others						
I feel that it’s difficult to lose weight and control my diabetes at the same time						
I avoid checking my blood sugar when I feel it is out of range						
I make myself vomit						
I try to keep my blood sugar high so that I will lose weight						
I try to eat to the point of spilling ketones in my urine						
I feel fat when I take all of my insulin						
Other people tell me to take better care of my diabetes						
After I overeat, I skip my next insulin dose						
I feel that my eating is out of control						
I alternate between eating very little and eating huge amounts						
I would rather be thin than have good control of my diabetes						

Figure 2.7.1

Reprinted from *Diabetes Care*, Vol 33, Markowitz JT, Butler DA, Volening LK, Antisdel JE, Anderson BJ, Laffel LMB. Brief Screening Tool for Disordered Eating in Diabetes, page 497: Adapted from Table 1 with DEPS-R items formatted as a Likert scale, Copyright (2010), with permission from American Diabetes Association.

These will usually be complex, but sometimes there are clear precipitants. The treatment of frequent hypoglycaemia, for example, may have led to weight gain, which in turn has triggered disordered eating.

> *"Can you think back to when you first noticed that your eating patterns changed?" ... "What was happening in your life at that time?"*

3. Identify risk factors for progression to a full syndrome eating disorder

The factors that lead to progression from disordered eating to a full syndrome eating disorder are, as yet, poorly understood. In a recent study of high risk college-age women, Jacobi *et al* found that a history of depression and critical comments about weight by a teacher, a coach or a sibling were the most powerful predictors.[34]

> *"Sometimes when people have eating patterns like what you have told me about ... well, they can get worse and start to affect the person's health ... they can sometimes even develop into an eating disorder ... I don't think that is what is happening with you but I am still concerned ... I'd like to ask you some more questions. First of all, has anyone been saying anything to you about your weight?"*

4. Discuss the risks of disordered eating

Ensure that the person is aware of the associated risks of disordered eating. It is best to start by asking how they feel about their weight-related behaviours and if they think these might be having an impact on their health.

> *"Sometimes when people are struggling with their eating, they become worried about what effect it might have on their health. Have you had any concerns like this?"*

If the person is not forthcoming about any health concerns, comment on any relevant biological markers of risk. Indicate that you are willing to help them work towards a healthier way of coping with any underlying psychological issues.

> *"I'm concerned that your HbA1c is a little higher than it was last year and that may be because of the eating patterns you have told me about ... I'm also concerned that stress may be making things worse for you ... It would be good if you and I could work on a plan to help with your stress and to get you back to healthier eating patterns before it starts to affect your health ... "*

5. Offer suitable and timely intervention

The type of intervention offered will depend on the nature of the precipitating factors and the local availability of resources. If weight gain due to frequent hypoglycaemia is an issue, then input from the diabetes team can help the person optimise the practical skills that promote glycaemic stability.

In general, disordered eating is best managed by the person's general practitioner in conjunction with a dietitian who can reinforce the principles of healthy eating. A referral to a psychologist with an interest in eating disorders may also be arranged to help the person explore issues surrounding body image, self-esteem and emotional regulation.

Referral to a psychiatrist may be indicated for diagnostic clarification or if there are co-morbid psychiatric conditions. Frequent review will be required initially to ensure that all management plans are in place and to monitor for progression.

G. Prevention

Use anticipatory guidance by discussing issues surrounding weight before problems arise, especially in high risk groups such as young women and those with newly diagnosed type 1 diabetes.

> *"Type 1 diabetes is a chronic condition that can often be difficult to manage. It can sometimes have an impact on weight. If this becomes a problem for you, please let me know so we can work together to find a solution."*

Full syndrome eating disorders

A When does disordered eating become a full syndrome eating disorder?

Disordered eating becomes a full syndrome eating disorder when it leads to significant distress or impacts on the person's ability to function in any aspect of their daily life. At times, it can be difficult to distinguish disordered eating in its more extreme forms from a full syndrome eating disorder. Furthermore, just as individuals can move between healthy eating and disordered eating at times of stress, so too can there be flux between disordered eating and a full syndrome eating disorder.[35]

B. DSM-5 diagnostic criteria for full syndrome eating disorders

DSM-5 provides criteria for the diagnosis of full syndrome eating disorders. The criteria for Anorexia Nervosa, Bulimia Nervosa and "Other Specified Feeding or Eating Disorder" are in the following pages:

2.7 eating disorders

case study

Taylor

Taylor, 19, has had type 1 diabetes for seven years and uses an insulin pump to manage her BGLs. She is attending Young Adults Diabetes Clinic for review and is talking with Daniel, a third-year endocrinology trainee. Taylor says she is not having any problems with her diabetes at present, but Daniel notes her most recent HbA1c was 88 mmol/mol (10.2%) and that she has new onset retinopathy on recent retinal photographs. He discusses these results with Taylor, as well as the data from her pump download.

As the conversation progresses, Daniel starts to wonder if Taylor has an issue with disordered eating, especially as there seem to be missed boluses in her pump data. He carefully broaches the subject by asking questions about her general wellbeing, but she says everything is fine with her right now. When he asks specifically about weight and body image, Taylor admits that she feels overweight. Daniel, however, is aware that her BMI is normal at 22.9 kg/m^2*.*

After exploring Taylor's perceptions of her weight, Daniel sensitively asks if she ever skips her insulin doses. She reveals that she occasionally does. When Daniel asks her to say more about this, Taylor says her main motivation is to lose weight, especially leading up to special social events. She says she also omits insulin when she binges on food to reduce stress and that she started doing this after her parents separated when she was in Year 12 at school.

Daniel is confident that Taylor is at low risk of progressing to a full syndrome eating disorder at present, but discusses the risks of insulin omission with her in a non-judgemental way. With Taylor's permission, he contacts her general practitioner and recommends referral to a dietitian and a psychologist. He also offers a review appointment in clinic for six weeks' time.

DSM-5 Diagnostic Criteria for Anorexia Nervosa

A. Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. *Significantly low weight* is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.

B. Intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.

C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Coding Note: The ICD-9-CM code for anorexia nervosa is 307.1, which is assigned regardless of the subtype. The ICD-10-CM code depends on the subtype (see below).

Specify whether:

(F50.01) Restricting type: During the last 3 months, the individual has not engaged in recurrent episodes of binge-eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics or enemas). This subtype describes presentations in which weight loss is accomplished primarily through dieting, fasting, and/or excessive exercise.

(F50.02) Binge-eating/purging type: During the last 3 months, the individual has engaged in recurrent episodes of binge-eating or purging behaviour (eg. self-induced vomiting or the misuse of laxatives, diuretics or enemas).

Specify if:

In partial remission: After full criteria for anorexia nervosa were previously met, Criterion A (low body weight) has not been met for a sustained period, but either Criterion B (intense fear of gaining weight or becoming fat or behaviour that interferes with weight gain) or Criterion C (disturbances in self-perception of weight and shape) is still met.

In full remission: After full criteria for anorexia nervosa were previously met, none of the criteria have been met for a sustained period of time.

Specify current severity:

The minimal level of severity is based, for adults, on current body mass index (BMI) (see below) or, for children and adolescents, on BMI percentile. The ranges below are derived from World Health Organization categories for thinness in adults; for children and adolescents, corresponding BMI percentiles should be used. The level of severity may be increased to reflect clinical symptoms, the degree of functional disability, and the need for supervision.

Mild: BMI $\geq$ 17 kg/m^2

Moderate: BMI $\geq$ 16-16.99 kg/m^2

Severe: BMI $\geq$ 15-15.99 kg/m^2

Extreme: BMI $<$ 15 kg/m^2

2.7 eating disorders

DSM-5 Diagnostic Criteria for Bulimia Nervosa

A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:

   1) Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances

   2) A sense of lack of control over eating during the episode (e.g, a feeling that one cannot stop eating or control what or how much one is eating)

B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; or excessive exercise.

C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least twice a week for 3 months.

D. Self-evaluation is unduly influenced by body shape and weight.

E. The disturbance does not occur exclusively during episodes of anorexia nervosa.

Specify if:

In partial remission: After full criteria for bulimia nervosa were previously met, some, but not all, of the criteria have been met for a sustained period of time.

In full remission: After full criteria for bulimia nervosa were previously met, none of the criteria have been met for a sustained period of time.

Specify current severity:

The minimal level of severity is based on the frequency of inappropriate compensatory behaviours (see below). The level of severity may be increased to reflect other symptoms and the degree of functional disability.

Mild: An average of 1-3 episodes of inappropriate compensatory behaviours per week.

Moderate: An average of 4-7 episodes of inappropriate compensatory behaviours per week.

Severe: An average of 8-13 episodes of inappropriate compensatory behaviours per week.

Extreme: An average of 14 or more episodes of inappropriate compensatory behaviours per week

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DSM-5 Diagnostic Criteria for Other Specified Feeding or Eating Disorder

The category applies to presentations in which symptoms characteristic of a feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the feeding or eating disorders class. The other specified feeding or eating disorder category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for any specific feeding and eating disorder. This is done by recording "other specified feeding or eating disorder" followed by the specific reason (e.g., "bulimia nervosa of low frequency").

Examples of presentation that can be specified using the "other specified" designation include the following:

1. **Atypical anorexia nervosa:** All of the criteria for anorexia nervosa are met, except that despite significant weight loss, the individual's weight is within or above the normal range.
2. **Bulimia Nervosa (of low frequency and/or limited duration):** All of the criteria for bulimia nervosa are met, except that binge eating and inappropriate compensatory behaviours occur, on average, less than once a week and/or for less than 3 months.
3. **Binge-eating disorder (of low frequency and/or limited duration):** All of the criteria for binge-eating disorder are met, except that binge eating occurs, on average, less than once a week and/or for less than 3 months.
4. **Purging disorder:** Recurrent purging behaviour to influence weight or shape (e.g., self-induced vomiting; misuse of laxatives, diuretics, or other medications) in the absence of binge eating.
5. **Night eating syndrome:** Recurrent episodes of night eating, as manifested by eating after awakening from sleep or by excessive food consumption after the evening meal. There is an awareness and recall of the eating. The night eating is not better explained by external influences such as changes in the individual's sleep-wake cycle or by local social norms. The night eating causes significant distress and/or impairment in functioning. The disordered pattern of eating is not better explained by binge-eating disorder or another mental disorder, including substance use, and is not attributable to another medical disorder or to an effect of medication.

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2.7 eating disorders

C. Features that should alert you to the presence of a full syndrome eating disorder

1. Features on medical interview

Physical symptoms of eating disorders include gastrointestinal symptoms, such as abdominal pain or constipation, cognitive problems, sleep disturbance and menstrual disturbance, specifically oligo- or amenorrhoea. Be aware that a person with an eating disorder may not divulge these symptoms. In this setting, a clue to the presence of an eating disorder may come from a third party.

Be alert to the presence of a full syndrome eating disorder in the setting of mental health issues, particularly depression, anxiety and psychosocial stressors. There may also be features to suggest the presence of personality traits that predispose to eating disorders, such as perfectionism, dependence and obsessiveness.[36] All young women with type 1 diabetes who have low self-esteem need to have food and body image issues explored.

The presence of dysfunctional family dynamics or a family history of mental health issues should raise the index of suspicion for an eating disorder. A history of childhood sexual abuse is also a marker of risk.

2. Signs on physical examination[37,38]

The features of full syndrome eating disorders, specifically anorexia nervosa and bulimia nervosa, are shown in Figure 2.7.2.

> "GENERALLY CLINICIANS SHOULD ASSUME THAT ANYONE WHO IS UNDERWEIGHT OR EXHIBITS RAPID WEIGHT LOSS HAS A DIETING DISORDER UNLESS PROVEN OTHERWISE." [39]

3. Behavioural features

Certain behaviours should alert you to the presence of an eating disorder. A person may seem uncomfortable when you ask to weigh them or may wear loose fitting clothing to disguise weight loss or evidence of self-harm. Examples of diabetes-specific behaviours that should raise concern include a preoccupation with food when discussing blood glucose management and a reduction in the frequency of requests for insulin prescriptions.

4. Laboratory results

- an unexplained elevated HbA1c (although do not rule out an eating disorder if it is within the target range)
- anaemia
- hypokalaemia or hypomagnesaemia on routine electrolytes assay
- hyponatraemia (< 125 mmol/L) due to purposeful water loading in order to increase weight for clinical assessment
- metabolic alkalosis secondary to loss of stomach acid through vomiting or secondary to diarrhoea from use of laxatives
- ECG abnormalities

D. Explore further if you suspect a full syndrome eating disorder

1. Exclude other causes of weight loss

Ensure that the person does not have a medical condition, such as thyrotoxicosis, malabsorption or substance abuse. It may be difficult to detect the presence of a superimposed eating disorder when a person with type 1 diabetes has gastroparesis or hyperemesis gravidarum, but, as with other mental health disorders in the context of chronic medical conditions, emphasis needs to be placed on cognitive rather than somatic symptoms for diagnostic purposes.

2. Use a sensitive and non-threatening interview style

The same principles apply as for disordered eating. Start with non-threatening questions and build up to more direct inquiry. Asking about insulin omission is a powerful way of detecting the presence of a full syndrome eating disorder. Be aware that the person may need time to feel comfortable divulging information about their weight loss behaviours with you.

3. Elicit a weight history

If the person's responses suggest an underlying full syndrome eating disorder, take a careful weight history. Specifically, establish how the person's weight fluctuates with life events.

"What was your highest weight since you were at school?"

"Does your weight fluctuate over time?" "What are the factors that influence this?"

"Have you ever had a time when you weighed a lot less than others thought you should?"

4. Take a brief dietary history

"What did you eat yesterday?", "How did you feel about it?", "Did you keep the food down?"

Physical effects of full syndrome eating disorders

Figure 2.7.2

5. Check for physical and cognitive features of starvation syndrome.[40]

6. Explore behaviours that are characteristic of a full syndrome eating disorder[41]

- avoiding meals
- slowly eating or picking at food
- eating in secret
- denying being on a diet
- hoarding food
- cooking for family, but not for self
- raiding the fridge
- leaving the table early
- social phobia about eating
- excessive school work
- excessive exercise
- eating low calorie foods

E. How to respond if there is evidence of a full syndrome eating disorder

1. Comment on what you observe

> *"I've noted that your weight has fallen quite a bit since I last saw you in clinic. Also, your potassium level is below the normal range and your HbA1c has gone up to 12.3%. I'm concerned that you are putting your health at risk and am wondering whether you might have an eating disorder."*

2. Highlight the links between behaviours, health and risks in an explicit manner

> *"All the purging you've told me about has lowered your potassium levels. This can make your heart rate irregular and even lead to death if your heart stops."*

3. Conduct a suicide risk assessment

A suicide risk assessment is essential if you identify that a person has a full syndrome eating disorder. A meta-analysis from 2004 showed that suicide is the major cause of mortality in individuals with anorexia nervosa, with rates exceeding those of starvation.[42] This may be due to co-existent affective disorders, but may also be a consequence of the cognitive and psychological changes that accompany full syndrome eating disorders.

NOTIFY YOUR CONSULTANT AS A MATTER OF URGENCY IF YOU SUSPECT THAT A PERSON WITH TYPE 1 DIABETES HAS A FULL SYNDROME EATING DISORDER

F. Referral

Management of a full syndrome eating disorder will involve referral to a psychiatrist or a specialist eating disorders unit. The nature of the referral will depend on the severity of the person's presentation and the services available in your local area. Involuntary treatment under the Mental Health Act may be required.

G. Management of eating disorders in the context of type 1 diabetes

The management of a full syndrome eating disorder is complex and requires a multi-disciplinary approach.[43,44] It will generally be co-ordinated by a mental health care team, but you will need to stay closely involved to assist with the treatment of general and diabetes-related aspects of the person's physical health. Be aware that you may have strong emotional responses when assisting in the management of a person with a full syndrome eating disorder. Discuss this with your consultant if you feel it is a significant issue for you.

1. Weight restoration in anorexia nervosa

Support staged recovery goals. Take the focus off weight when you are interacting with the person. Instead, concentrate on biological parameters, such as potassium levels and HbA1c. Acknowledge the person's fears regarding weight gain:

> *"Weight gain can be frightening … you can feel like things are out of control …"*

2. General medical management

- assist with interpretation of fluid balance charts
- correct metabolic disturbances, such as hypokalaemia and hyponatraemia
- be aware of the risk of re-feeding syndrome[45]
- determine if nasogastric feeding is indicated

3. Diabetes-related management

Recommend an insulin regimen that ensures BGLs are kept within a safe range. This can be difficult when food intake is unpredictable. The administration of insulin *after* rather than *before* meals may be helpful where there are purging behaviours. This helps to fit diabetes around the disordered eating and allows the eating disorder therapists to follow their usual program without compromise due to fear of hypoglycaemia. Insulin pump therapy may be beneficial for this purpose. Ensure that screening for diabetes complications is kept up-to-date.

clinical tasks

1. Find a pro-eating disorder website and read about the perspectives of people who have eating disorders.
2. Ask about insulin omission for weight loss in people with type 1 diabetes, especially in young women who have an elevated HbA1c or early onset microvascular complications.

2.7 eating disorders

case study

Hannah

Hannah, 23, has had type 1 diabetes since the age of 11. Her diabetes has been complicated by retinopathy, microalbuminuria and gastroparesis. This year, Hannah moved from the city to a large regional centre to start work as a primary school teacher. She uses an insulin pump to manage her BGLs and her last HbA1c was 65 mmol/mol (8.1%). Her previous endocrinologist suspected disordered eating when Hannah's HbA1c was consistently elevated with unexplained blood glucose variability. Hannah denied having any issues with eating or body image at the time as she did not feel ready to talk about her emotions.

Hannah's issues around eating were exacerbated by the stresses of entering the workforce, as well as the loneliness of being away from family and friends. She started binge eating daily with episodic self-induced vomiting. She also started doing a gym workout every second day, sometimes for up to two hours.

David, the endocrinology trainee at the regional diabetes clinic Hannah now attends, wonders if she might have an eating disorder after he notices calluses on her knuckles, a potassium concentration of 3.1 mmol/L (reference range 3.6 – 5.0 mmol/L) on routine biochemistry and her reluctance to have a pump download. He explores the issue of an eating disorder with her over a number of consultations using a sensitive and non-judgemental approach. He diagnoses bulimia nervosa by DSM-5 criteria. Hannah is relieved that she can finally talk about her psychological distress and agrees to see the mental health team at the hospital.

David liaises carefully with Hannah's therapists as she embarks on her treatment program. He helps her to modify her pump settings so she can manage her BGLs around binge eating and exercise. He arranges for frequent review in clinic so her pump settings can be adjusted as she returns to more adaptive eating and exercise behaviours. He also refers Hannah to a dentist to check for dental erosions and to a gastroenterologist for advice about managing the gastroparesis.

David’s suggestions

If I’m having a binge, use square wave bolus and stop if I vomit food.
If I eat high GI food for binge, use dual wave and stop if vomit food.
Check BGLs hourly after binge to see the pattern, record my carbs.

Drop the basal rate to 50% an hour before starting exercise.
If I want to exercise for a long time, I need to check my BGLs every 30-60 mins and eat food if I’m going to exercise for more than an hour.

THURSDAY 20 FEBRUARY

	12am	2am	5am	7am	8am	9am	10am	11am	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	10pm	11pm
Blood Glucose				5.0	7.5	**3.4**	6.8		7.0	8.9	8.6			6.0	6.3	**2.9**	7.5	10.3	
Basal Rates (U)	1.10		1.20			0.65			0.5						1.0				
Bolus (food) (U)																			
Correction (U)																			
Carbohydrate				60g					45g								75g		
Notes			Used square wave for breakfast, vomited, stopped bolus but still went low, had jelly beans					Had ham and cheese sandwich for lunch but didn’t vomit					Dropped basal rate at 4 pm and went to gym an hour later. I didn’t feel like eating while exercising. I had a hypo (not good). Ate dinner and felt OK about that						

FRIDAY 21 FEBRUARY

	12am	2am	5am	7am	8am	9am	10am	11am	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	10pm	11pm
Blood Glucose	8.4			6.2		9.0			6.5		11.1	7.1			6.0	11.2	13.0	10.7	9.6
Basal Rates (U)	1.10		1.20			0.65			0.5						1.0				
Bolus (food) (U)																			
Correction (U)																			
Carbohydrate				60g					50g						90g	30g	75g		
Notes			Ate breakfast – no problems, felt OK					Chicken salad sandwich with mayo, plus apple and muesli bar – under-estimated carbs				2 biscuits for afternoon tea		Felt really stressed after work today. Binged on snake lollies, rice crackers and honey sandwiches, used dual wave, vomited and stopped insulin for 2 hours					

Figure 2.7.3: HANNAH’S BLOOD GLUCOSE CHART

2.7 eating disorders

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2.8 somatisation

learning outcomes

to be able to:

- discuss the aetiology of somatisation
- identify the presence of somatisation in a person with type 1 diabetes
- respond to somatisation by a person who has type 1 diabetes

key reading

1. Singh BS. Managing somatoform disorders. *Med J Aust* 1998; 168: 572-577.
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Introduction

> ***"Grief that finds no vent in tears may make other organs weep"***
>
> Henry Maudsley 1835-1918

Somatisation is a process by which psychological distress is expressed as a physical symptom or an altered bodily function.[1,2] It involves: (i) the experience of stress as a somatic symptom, (ii) the conceptualisation of the symptom as a physical illness, and (iii) medical help-seeking behaviour.[1,3] Somatisation is estimated to be the underlying reason for up to 20% of primary care consultations, but is also prevalent in specialist practice.[3,4] In people who have type 1 diabetes, somatisation can be superimposed on diabetes-related presentations and be the basis of recurrent hospitalisations.

Although usually mild and transient, somatisation can be associated with significant functional impairment and is often linked with abnormal illness behaviour.[5] It is a feature of a spectrum of psychiatric disorders, including somatic symptom disorder, conversion disorder, illness anxiety disorder and chronic pain syndromes.[6] Because the features of these disorders tend to overlap and because the same approach to management applies across the spectrum, it is probably more useful to focus on the process of somatisation itself rather than any specific diagnosis.

What is the aetiology of somatisation?

A range of factors can predispose to, precipitate and perpetuate somatisation. Predisposing factors include genetic susceptibility to stress and anxiety, childhood adversity, female gender and a family history of chronic illness.[1,7] Stressful life events or minor illness can serve as precipitating factors, while a complex interplay of physical, cognitive and behavioural elements is thought to perpetuate the experience of somatic symptoms. The perceived social stigma of mental illness may be a contributing factor for some people. Of note, the expression of psychological distress through physical symptoms is accepted in many cultures as being part of a normal process. Examples include "brain fag" in West Africa, "susto" in Latin America and "hwa-byung" in Korea.[1]

A cognitive-behavioural model is often used to explain the mechanism of somatisation and as a basis for therapeutic interventions.[7,8] Within the framework

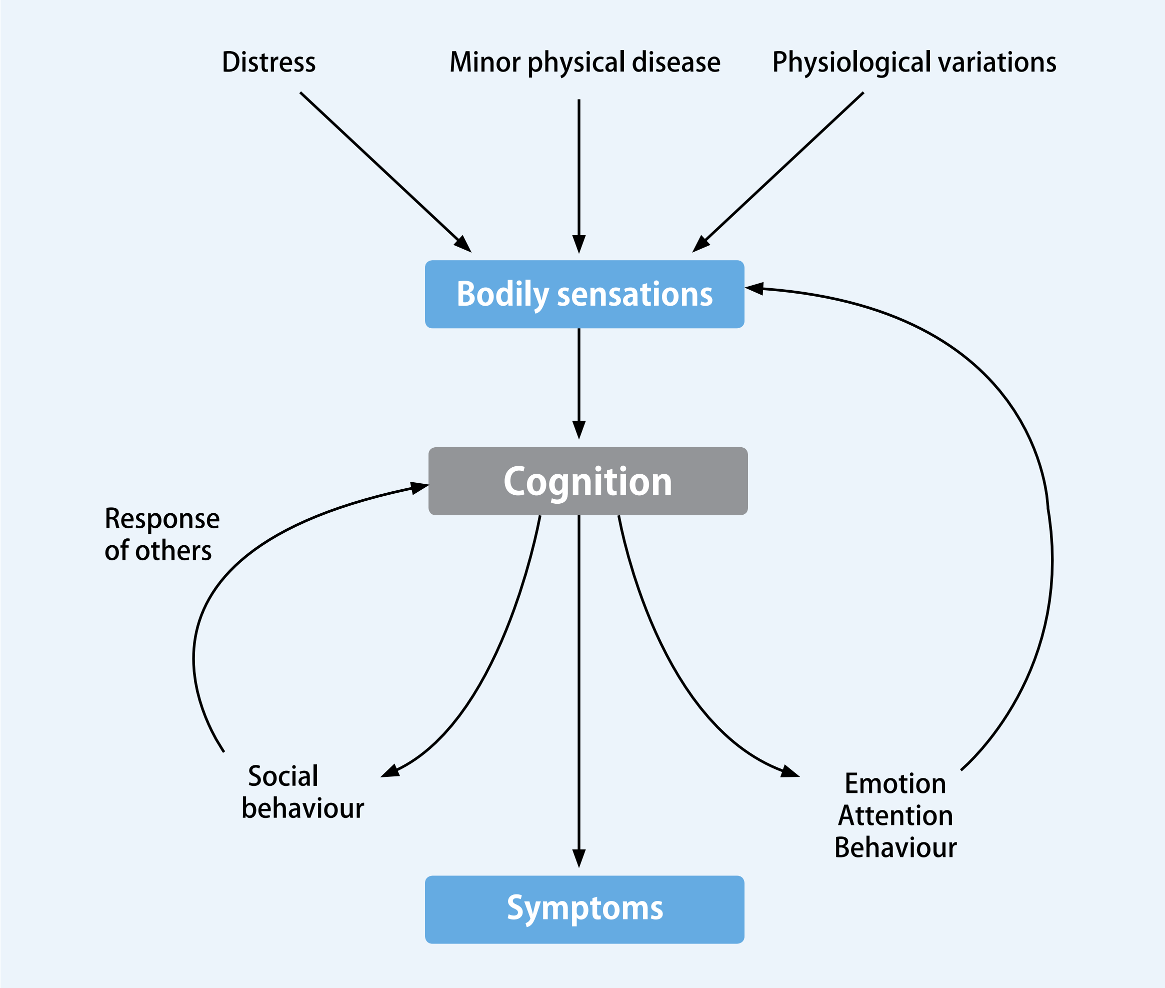

Figure 2.8.1: COGNITIVE-BEHAVIOURAL MODEL OF FUNCTIONAL SOMATIC SYMPTOMS

Reprinted from: *J Psychosomatic Research*, Vol 36, Sharpe M, Peveler R, Mayou R. The Psychological Treatment of Patients with Functional Somatic Symptoms: A Practical Guide, pages 515-529, Copyright (1992), with permission from Elsevier.

of this model, somatisation is described as involving a heightened sensitivity and attention to normal bodily sensations caused by physiological variations or sympathetic nervous system activation (see Figure 2.8.1). Through cognitive distortions, these sensations are interpreted as being due to a disease process. This can generate significant anxiety, which may be amplified by ongoing stressful life events. In turn, this anxiety can produce further physiological changes, thereby setting up a vicious circle.

Physical, psychological and social influences may reinforce the process of somatisation. A person can, for example, become deconditioned due to reduced mobility related to frequent hospitalisations, which strenghtens the perception of an organic basis for their bodily sensations. The attention of others can inadvertently reinforce the sick role. In some situations, a family member may have their own psychological needs fulfilled by adopting the role of a carer. Furthermore, health professionals can compound the problem if there is lack of clarity and consistency in their response to abnormal illness behaviour.

Identifying the presence of somatisation

Somatisation needs to be suspected if a person presents with ill-defined physical symptoms that, after appropriate evaluation, cannot be explained by a known medical condition.[1,2,9] The person will characteristically play down any psychosocial links to their presentation, which they will be convinced is due to a physical illness. They will typically have difficulty expressing emotions in words, a condition known as alexithymia.[10,11]

Somatisation may be difficult to identify when it is superimposed on a pre-existing medical condition, such as type 1 diabetes. It is also important to distinguish somatisation from the physical symptoms that accompany psychiatric conditions, for example, fatigue and sleep disturbance in depression, or sweating and palpitations in anxiety.

A. Carry out a careful clinical assessment

Make a list of the person's symptoms and establish the degree of functional impairment they are causing. Be sure to assess the symptoms fully from an organic point of view. Ask about past history of physical and psychiatric illness, as well as substance abuse. Review the person's past medical notes if these are readily available.

B. Identify developmental risk factors:[12,13]

- a family member with a chronic illness
- modelling of abnormal illness behaviour in formative years
- a history of emotional, physical or sexual abuse, especially domestic violence

C. Explore the link between physical symptoms and emotions

Attempt to establish the psychosocial precipitants of the presentation.[14] You will need to ask directly, as the person will probably not volunteer that they are experiencing emotional problems. Approach this using a sensitive manner. Be non-judgemental and recognise that the person is probably expressing their emotional distress in the only way they know how. In general, it is more effective to focus on how psychological factors might be exacerbating symptoms rather than causing them.

Circle around the problem rather than going straight to what you think are the main issues. Ask about general, non-threatening psychosocial issues before probing deeper:

> *"How are things going for you at present?"*

Ask the person to say what they think might be contributing to the presentation:

> *"Is there anything you can think of that might be making your stomach pain worse?"*

Use a menu if the person seems unsure about what to say:

> *"Sometimes gastroparesis can be made worse by high blood glucose levels, being stressed about something or by eating certain foods. Do you think any of these might be the situation with you right now?"*

Be aware that you may not able to easily identify a specific psychosocial precipitant for a presentation and that underlying issues may take time to emerge. You may need to sit with the idea that the person is not able to, is not ready to or doesn't want to acknowledge what is happening. If you press the issue, you risk losing their trust.

D. Physical examination and investigations

- perform a thorough physical examination and be unequivocal in the feedback about your findings[1]
- request the investigations that are necessary to rule out an underlying medical condition, but resist the temptation to over-investigate

E. Always keep an open mind

Check for an underlying organic basis of symptoms at each new presentation. A person with a history of somatisation will have the same risk of developing an organic illness as the general population.[15] Be alert for the presence of medical conditions, such as multiple sclerosis or systemic lupus erythematosus, that can develop slowly and present with non-specific symptoms early in their course.

Responding to the presence of somatisation

A. Provide the person with a formulation of the presenting problem

Start by legitimising the person's symptoms and their functional impact.[16,17] Make it clear that you understand what they are experiencing is real. If you say: *"I can't find anything wrong with you"*, you negate the person's subjective experience and may imply that another clinician could find the answer, thereby compounding the situation. Pejorative phrases, such as *"It's all in your head",* are likely to offend.[18]

Be clear and unambiguous about what is happening. Reassure the person that they do not have a serious underlying physical illness and say what they don't have.

> *"If your stomach pain was due to cancer, then the gastroscopy and the CT scan would have shown up something. Fortunately, these tests were normal . . . so it means there is no cancer and that it is not the cause of the pain. The gastroparesis is probably causing some of the pain that you are feeling."*

It can be useful to focus on the functional aspects of the person's presentation and emphasise the potential reversibility of their symptoms:

> *"The good news is that you don't have any damage to your stomach . . . but it's not working properly at present. There are some things that I can recommend that may help you to manage your symptoms and get some relief."*

Provide psycho-education about how emotional factors can cause or aggravate physical symptoms.[17] Also provide the person with specific illustrations, such as how anxiety can cause hyperventilation, which in turn can produce paraesthesias. Inventing a false diagnosis to explain a presentation of somatisation is never appropriate.

B. Be clear about the goal of management

Frame the goal of management to the person as being functional improvement rather than achieving a cure. Explain that it is unlikely that there will be a "quick fix".

C. Engage the liaison psychiatry team

For minor degrees of somatising, management by the person's general practitioner will usually be the preferred option. For more severe presentations or if there are frequent hospitalisations or attendances to diabetes clinic, referral to the liaison psychiatry team will generally be indicated. This can be a difficult process to negotiate if the person does not recognise there is a psychological component to their symptoms.

It is usually best to speak with a member of the psychiatry team before arranging a referral. They can help you to decide on the optimal time to broach the subject of referral. They can also provide advice about the most effective way to raise the issue. In general, this will involve normalising the process, picking up on cues and reflecting the person's own words in your response:

> *"You mentioned before that you were upset when you missed your university placement last week. In my experience, being anxious about things like that can make problems like gastroparesis worse. When this is happening, I usually ask the psychiatry team to help me work this out. They are the best people to advise whether stress might be involved in any way."*

If there has been no mention of stress or worry, carefully broach the subject, but be prepared for a defensive reaction. Do not force the issue of referral if the person does not want to engage with the psychiatry team. Continue to provide care within the diabetes team and ask the psychiatry team to support you by providing strategies for management. Revisit the option of referral at a later time. The person themselves may raise the subject after a period of reflection.

D. Work as a team and maintain consistency

Find out what is acceptable to the person with respect to who else can be involved in their care, especially from their family. Ideally, the person's general practitioner will coordinate their overall medical care, but a contact person within the diabetes team will also be required. As a trainee, you may be asked to assume this role under the supervision of your consultant.

Work as a team to provide consistent care. Team consultations and team meetings are key mechanisms for developing care plans and ensuring clarity, especially with respect to boundaries. Care plans usually include items, such as indications for hospital admission, governance of insulin therapy, guidelines for communication and organisation of discharge planning.

Mutual support within the diabetes team is important for dealing with 'splitting' and for addressing the insecurity that can be generated by setting limits on investigations and referrals. It is also important for dealing with the negative attitudes that can easily develop towards people with recurrent unexplained presentations.[19,20] While it is inevitable that such attitudes will arise, it is important that they do not adversely influence your interactions and delivery of care.

2.8 somatisation

case study

Caitlin

Caitlin is a 23-year old woman who has had type 1 diabetes mellitus for 12 years. She uses a multi-dose insulin regimen to manage her BGLs and her most recent HbA1c was 100 mmol/mol (11.3%). Caitlin has a number of chronic diabetes complications, including non-proliferative diabetic retinopathy, microalbuminuria and gastroparesis. In addition, she has had recurrent episodes of vomiting that cannot be explained by delayed gastric emptying. There have also been multiple admissions to hospital with abdominal pain, the underlying cause of which has not been found, despite extensive investigation by the Gastroenterology Unit.

In addition to her medical issues, Caitlin has a history of disordered eating, depression and self-harm in the context of quite complex social issues. In her adolescent years, she helped to care for her mother who had multiple sclerosis and died when Caitlin was 19 years of age. She is estranged from her father and a history of abuse has been suspected, although never established. After Caitlin left school, she undertook an apprenticeship to become a hair-dresser, but is currently unable to maintain employment because of her multiple health issues. She has been with her most recent boyfriend for the past nine months, but their relationship has been marked by frequent arguments and break-ups.

Caitlin's hospital admissions usually appear to be triggered by specific psychosocial stressors and are often complicated by mild diabetic ketoacidosis. Interactions between Caitlin and ward staff can be fraught, as she seems to play one staff member off against another and often discharges herself against medical advice. During a diabetes team meeting, it was decided that a care plan was required to provide consistency of care, limit the number of unnecessary investigations requested and optimise Caitlin's health outcomes. Natalie, a third-year trainee, volunteers to prepare the plan.

CARE PLAN

Aim

The aim is to support Caitlin in her long term efforts to achieve optimal physical and psychological quality of life and to minimise admissions to hospital.

Initial Assessment

1. When Caitlin presents to the Emergency Department, the assessment needs to be based on the presenting problem. A careful history needs to be recorded and a thorough problem-orientated physical examination performed.
2. Investigations should be requested as indicated by the presenting problem but any plans for non-urgent invasive investigations MUST be discussed with the Endocrinology Unit.
3. Admissions should be limited to the Emergency Department or the Short Stay Unit where possible. Admission to a ward MUST be approved by the Endocrinology Unit.

Intravenous access

1. Establishing intravenous access can be difficult and anaesthetic assistance may be required.
2. A firm approach is needed as Caitlin may initially resist. Provide her with information about the indication for intravenous therapy and its likely duration.

Insulin therapy

1. Insulin therapy is to be supervised by the Endocrinology Unit.
2. Insulin should NOT be withheld by general staff without consultation with the Endocrinology Registrar or the On Call Endocrinology Consultant.
3. An insulin infusion should in general ONLY be used in the setting of diabetic ketoacidosis.

Pain relief

1. Opiate analgesia should be avoided unless absolutely necessary.
2. Use heat packs and simple analgesia as first line pain relief.

Vomiting

1. Encourage oral fluid intake and avoid intravenous hydration where possible.
2. Anti-emetics may be prescribed as required.
3. For oral hydration, use cups not jugs of fluid as Caitlin sometimes “over-drinks” to precipitate vomiting.

2.8 somatisation

Ward

1. If possible, Caitlin should be admitted to Ward 4 West where she is known to the nursing staff.
2. Allocate a bed as near as possible to the nurses' station.
3. Keep the curtains open as much as possible, but balance this against her dignity.

Psychiatry assessment

1. Assessment needs to focus on current psychosocial issues.
2. Do not revisit Caitlin's past psychiatric history.

Communication

1. Use a warm but firm approach.
2. Maintain compassion regardless of how frustrated you feel.
3. Be consistent and don't make promises you can't keep.
4. Explain all decisions about management.
5. Major decisions need to be discussed in the presence of the team and her primary carer to ensure consistency and reduce splitting.

Team

1. Ensure consistency of care with effective communication within and across medical and psychiatry units.
2. Arrange regular team meetings to discuss management. These should include the Endocrinology Unit, the liaison psychiatry registrar and the Nursing Unit Manager.

Discharge Planning

1. Ring Caitlin's general practitioner, who will arrange weekly review.
2. Notify Caitlin's Community Liaison Worker.
3. Arrange fortnightly review in Diabetes Clinic.

Care Plan prepared by:	Dr Natalie Banting
Designation	Endocrinology Registrar
Signature	Natalie Banting
Contact number	9999 1000 Pager 2478
Date:	February 22nd 2014
Date of review:	August 25th 2014

This care plan is based on a framework developed by Ms Julie Sharrock, Consultant Liaison Nurse and Co-ordinator of Consultant Liaison Psychiatry Services, St Vincent's Hospital, Fitzroy, Victoria. Adapted with permission.

E. Ensure regular review

Increase the frequency of review in diabetes clinic or by the person's general practitioner as a preventative measure. Place an emphasis on maintenance rather than just responding to acute presentations or crises. Seeing the person when they are well can help to reduce the link between their somatic symptoms and receiving care from health professionals. Titrate appointments to the longest interval that prevents acute presentations, but be realistic that relapses are likely.

F. Specific therapies for somatisation

Psychotherapeutic options may be offered for management of somatisation, especially cognitive behavioural therapy with an emphasis on problem-solving.[8,16,21] RCTs have shown that highly structured short-term interventions can provide significant physical and mental health benefits.[22] Pharmacological therapies, such as anti-depressants, have also been shown to be effective,[23] but there is limited research comparing them against psychological therapies. The choice of therapy is often guided by patient preference.

clinical tasks

1. Identify a person with type 1 diabetes who has a chronic symptom related to their diabetes, such as neuropathic pain, or a symptom related to a co-morbid condition, such as joint pain due to rheumatoid arthritis. Explore the emotional aspects of their experience of the symptom. How do they convey their experience of the symptom to others? How do they expect others to respond?
2. Make a care plan for a person with type 1 diabetes who has had recurrent admissions with acute diabetes-related presentations and where psychosocial factors are thought to play a significant role. Discuss your plan with your consultant and, if possible, apply it in your clinical setting.

2.8 somatisation

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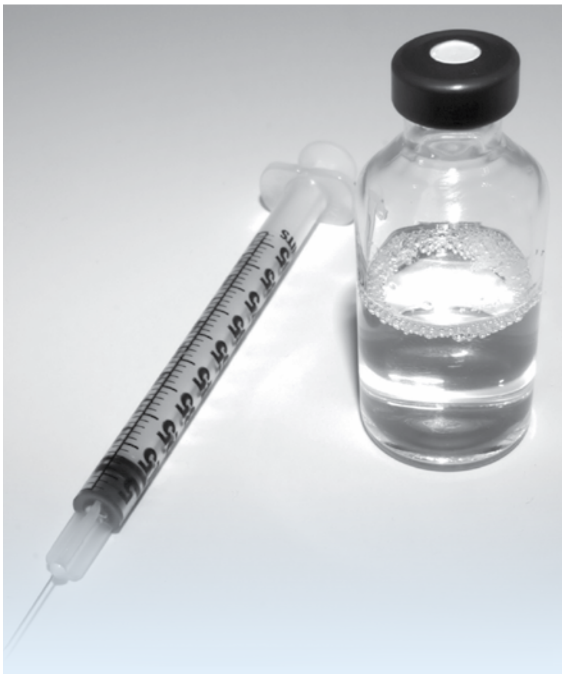
The Royal Melbourne Hospital

2.9 factitious presentations



learning outcomes

to be able to:

- discuss the key aetiological factors for factitious presentations
- identify the presence of a factitious presentation in a person with type 1 diabetes
- respond to the presence of a factitious presentation in a person with type 1 diabetes

key reading

1. Alinejad NA, Oettel DJ. Factitious disorder as repeated diabetic ketoacidosis. *Innov Clin Neurosci* 2011; 8: 41-47.
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Introduction

A factitious presentation comprises a person feigning, exaggerating or intentionally producing a physical or psychological condition in order to adopt a sick role.[1-4] It can involve manufacturing an illness, exaggerating a real illness, tampering with specimens or deliberately sabotaging management. Factitious presentations can be associated with mortality, significant morbidity and excessive health care expenditure.[5] People with factitious presentations are generally unaware of the relationship between their emotions and behaviours.Their motivations are therefore usually unconscious, although the process of falsification is not. This differs from somatisation where a person's presentation is an expression of emotional conflict, but is not produced by voluntary behaviour.[4]

In the setting of type 1 diabetes, factitious presentations can account for otherwise unexplained glycaemic instability, as well as recurrent hospital admissions for severe hypoglycaemia or diabetic ketoacidosis.[2,5-9] There are several recent reports in the literature of individuals with type 1 diabetes using their insulin pumps to create factitious hypo- or hyper-glycaemia.[10,11] There are also descriptions of fabrication of chronic diabetes complications, including simulation of proteinuria by contamination of a urine specimen,[12] and sepsis caused by self-injection of pathogens.[13] Deliberate interference with wound healing is known to be a common presentation of factitious illness,[14] which has implications for the management of diabetic foot wounds.

The incidence of factitious presentations in people with type 1 diabetes may be under-estimated, especially at the milder end of the spectrum. In one study, it was found that deliberate interference with therapy was established or admitted in up to 40% of a cohort of people with glycaemic instability.[7] A factitious presentation is usually challenging to diagnose, especially if it is superimposed on an underlying medical condition, as is often the case.[5] Management is generally guided by case reports as robust evidence in this area is lacking.[15]

Diagnostic criteria for factitious disorder

Factitious presentations can range in severity from minor exaggeration of symptoms through to accurate simulation of medical or psychological conditions.[3] The formal criteria for Factitious Disorder Imposed on Self, as outlined in DSM-5, are:[16]

A. Falsification of physical or psychological signs or symptoms, or induction of injury or disease associated with identified deception.

B. The individual presents himself or herself to others as ill, impaired, or injured.

C. The deceptive behavior is evident even in the absence of obvious external rewards.

D. The behavior is not better explained by another mental disorder, such as delusional disorder or another psychiatric disorder.

Specify:

Single episode

Recurrent episodes (two or more events of falsification of illness and/or induction of injury)

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Munchausen syndrome is an extreme form of factitious disorder, usually involving impersonation, with presentations to multiple health care facilities.

Aetiological factors for factitious presentations

A wide range of developmental, cognitive and psychodynamic theories have been proposed to explain the aetiology of factitious presentations, although they do not fully explain why people seek to fabricate physical or psychiatric illnesses.[1,4]

From a developmental perspective, creating an illness may be a way of attempting to gain mastery over past traumas, for example, having been a child living with a seriously ill parent. Other developmental risk factors include serious illness in childhood, such as frequent admissions with diabetic ketoacidosis, or disturbed emotional attachments due to neglect, abuse or loss.

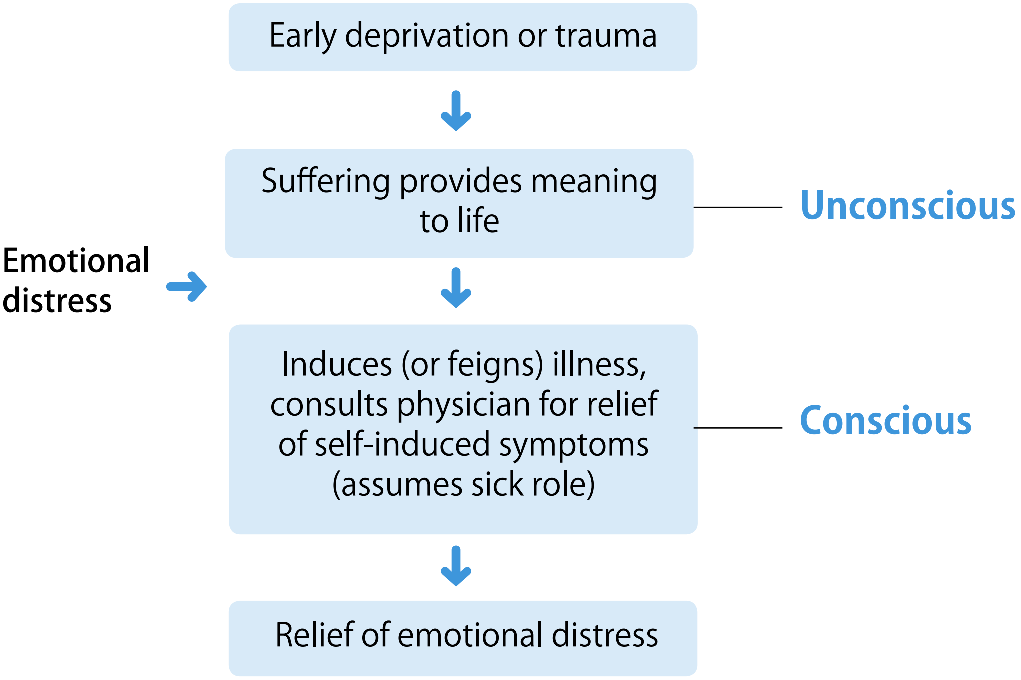

Figure 2.9.1: PROPOSED PATHOGENESIS OF FACTITIOUS DISEASE

Reprinted from *Proc (Bayl Univ Med Cent),* 19, Savino AC, Fordtran JS. Factitious disease: clinical lessons from case studies at Baylor University Medical Center (pages 195-208), Copyright (2006), with permission from *Bayl Univ Med Cent.*

2.9 factitious presentations

For some people with factitious disorder, fabricating an illness may be a means of satisfying unmet psychological needs.[4] They may seek nurturing from health professionals to compensate for an inability to develop or sustain meaningful and supportive relationships in other domains of their life. Other secondary gains that accompany the sick role, such as being excused from social obligations, may also be motivating factors. In addition, adopting a sick role can provide a mechanism to avoid dealing with painful emotions, a premise supported by the observation that factitious presentations are often triggered by stressful life events.[4]

Personality factors may play a part in the development of factitious disorders. Adopting a sick role may provide a sense of identity that a person feels they cannot achieve in their everyday life. It may also provide an excuse for perceived failures, thereby serving to protect against low self-esteem.[1] Borderline Personality Disorder is a common association with factitious disorder,[17] but other Cluster B personality traits can co-exist, particularly those associated with narcissistic or anti-social personality disorders.[1] Factitious disorder can cluster within families, although no genetic or biological basis has yet been identified.[1]

Identifying the presence of a factitious presentation

A. When should a factitious presentation be suspected?

A factitious presentation needs to be suspected if the history sounds too perfect or descriptions of symptoms seem exaggerated, vague or inconsistent. Suspicion should also be raised if the person fits the typical demographic risk profile of being female, aged between 20-40 years and engaged in a health care occupation,[5,14] or if developmental risk factors and co-morbid personality disorders are present.[4,5] The presence of an eating disorder, depression or substance abuse should also lead to a raised index of suspicion.[3,18]

A person with a factitious presentation may exhibit masochistic themes, such as requesting or too readily agreeing to invasive and potentially painful medical

Ethical issues:

- The patient has a right to self-determination.
- The patient has the right to be informed and to approve or disapprove of any diagnostic procedure.
- Ordering unnecessary tests as a ruse to get the patient out of the hospital room is repugnant.

Legal issues:

- The patient's right to control their destiny supersedes society's interest in preserving his or her life.
- A search is beyond the bounds of the implied contract between the doctor and the patient.

Privacy issues:

- A purse or suitcase is something meant to be private. It might be acceptable to search a hospital nightstand, but not the patient's purse.

Figure 2.9.2: ETHICAL AND LEGAL ARGUMENTS AGAINST A SECRET SEARCH OF PATIENTS' POSSESSIONS TO LOOK FOR EVIDENCE OF FACTITIOUS DISEASE

Reprinted from Proc *(Bayl Univ Med Cent)*, 19, Savino AC, Fordtran JS. Factitious disease: clinical lessons from case studies at Baylor University Medical Center (pages 195-208), Copyright (2006), with permission from *Bayl Univ Med Cent* (adapted from Plumeri PA. The room search. *J Clin Gastroenterol* 1984; 6: 181-185).

procedures. In some circumstances, there may be unusual or inconsistent laboratory results, such as poly-microbial bacteraemia or atypical pathogens identified at a specific bodily site.[19] For example, if *E Coli* is cultured from a skin abscess on a person's thigh, then deliberate self-injection of feculent material should be suspected.[20] Evidence of fabrication may be observed incidentally, such as empty insulin pens in the setting of unexplained hypoglycaemia. Be aware, however, that searching a person's belongings for evidence of fabrication without their consent raises significant ethical and legal issues. These issues have been discussed by a number of authors [4,21,22] and are listed in Figure 2.9.2.

Certain features relating to a person's behaviours and interpersonal relationships may alert you to the possibility of a factitious presentation. A person who has fabricated their medical or surgical presentation may appear isolated and rarely receive visitors as an inpatient. There may be a history of difficult interactions with health professionals. The person will usually decline consent for medical information to be supplied by other health care facilities. In this context, privacy laws may create a barrier to gathering information, especially if the person has presented to multiple health care facilities for medical treatment.[23]

B. Confirming the diagnosis

Although the diagnostic criteria for factitious disorder are well-defined,[16] it may be difficult to determine if a presentation has been falsified. It is essential to rule out underlying medical and surgical problems first, while resisting the urge to over-investigate. This needs to be done at every new presentation. Somatisation needs to be considered, but it can be challenging to establish whether a presentation has been consciously falsified or not. In practice, it is probably not necessary to make this distinction, as the approach to management is similar for both conditions.[1,5,24] People with mental illness, such as psychosis, may inflict self-injury, but this is generally not intentional and is not categorised as factitious disorder.

Responding to the presence of a factitious presentation

A. Protect the person from harm as a priority

You have a duty of care to treat the presenting medical or surgical problem, but do not submit a person to risk of iatrogenic harm from unnecessary medical procedures.[15] Your priority needs to be their welfare.

B. Maintain empathy with the person

A major component of managing a factitious presentation is being able to address your own feelings towards the person.[13,25] It is very easy to feel frustrated and angry, but expressing this will usually be counter-productive.[13,25] Appreciate that the medical or surgical presentation is not the person's underlying problem. Rather, it signifies a psychological condition that requires skilful management. You will be better placed to provide optimal care if you understand that the person does not have well developed mechanisms for coping with psychological distress.

C. Use confrontation judiciously

The primary goal of treatment is to address the person's underlying psychological needs rather than to press them to admit they have been fabricating their presentation. The issue of whether or not to

2.9 factitious presentations

case study

Danielle

Danielle is an 18-year old student who has had type 1 diabetes since the age of five. She recently moved to the city from a rural town to study hospitality. She has been living in a hostel and has obtained part-time employment as a doctor's receptionist to support her studies.

Just over a month ago, Danielle was admitted to hospital with gangrenous appendicitis. Her HBA1c was 99 mmol/mol (11.2%) and she reported she had not had specialist review for many years. Apart from mild retinopathy, there are no chronic diabetes complications, but she reported having multiple admissions with diabetic ketoacidosis as a child.

On the morning of planned discharge, Danielle had an episode of hypoglycaemia due to late delivery of breakfast and stayed until the following day. She was re-admitted one week later with mild diabetic ketoacidosis and wound breakdown, attributed to delayed healing in the setting of hyperglycaemia. At 9 am on the day of discharge, a member of the nursing staff found Danielle drowsy with a BGL of 1.3 mmol/L. No apparent cause for the episode was identified, but she stayed in hospital for stabilisation for a further two days.

Two weeks later, Danielle presented again, this time with lower abdominal pain. Her wound had healed, all investigations were within normal limits, and analgesia and laxatives were prescribed. Again, severe hypoglycaemia delayed discharge. The nursing staff commented that Danielle had had no visitors, apart from a cousin who came once during the first admission. They also thought that she seemed unduly pleased to be in hospital. The possibility of factitious hypoglycaemia was raised. During a team meeting, it was decided the focus needed to be on her psychological wellbeing and that a search of her belongings for insulin was inappropriate. Michelle, a second-year trainee, feels she has good rapport with Danielle and volunteers to speak with her.

MICHELLE: *Danielle, you have had a difficult time over the last few weeks since you had appendicitis …*

DANIELLE: *… (looks down) … I guess so …*

MICHELLE: *The hypos that you have had must have been scary …*

DANIELLE: *… maybe …*

MICHELLE: *Most people who have to be in hospital like you have … well, they find it quite tough …*

DANIELLE: *I'm OK …*

MICHELLE: *… you've just moved from the country and are a long way from home so that might make it harder for you.*

DANIELLE: *… maybe…*

MICHELLE: *… [pauses] … often it can be helpful to talk with someone about these sorts of feelings … [pauses] …*

DANIELLE: *… [silence] …*

MICHELLE: *I usually recommend that someone from our psychiatry team come along to have a chat when I'm wondering if someone might be having some stress in their life.*

DANIELLE: *… uh huh …*

MICHELLE: *How would you feel about that?*

DANIELLE: *… [appears reluctant] …*

MICHELLE: *… [silence as waits for a response] …*

DANIELLE: *… I guess I could …*

Michelle arranges a referral to the liaison psychiatry service. The psychiatrist elicits a history of complex family dynamics and wonders about a diagnosis of borderline personality disorder. Further assessment is deemed necessary to establish this diagnosis so follow up is arranged.

An appointment is also arranged for Danielle in Diabetes Clinic for two week's time. She does not attend this appointment, nor her follow-up with the liaison psychiatry service. She hasn't left the name of a general practitioner to contact and doesn't respond to telephone messages. A management plan is recorded in Danielle's medical file should she present to the hospital again for medical care.

confront a person with evidence or suspicion of fabrication is complex and controversial. While it is important to aim for an open and honest doctor-patient relationship, confrontation may only serve to increase the person's sense of alienation and neediness. It may even precipitate a breakdown in their psychological defence mechanisms before you have had an opportunity to help them develop a more adaptive coping style. There is a risk that confrontation will result in denial, aggression, threats of suicide or discharge against medical advice.[5,23]

There have been no randomised trials examining the risks and benefits of confrontation in the setting of factitious presentations. In one retrospective study by Krahn *et al,* 71 out of 93 people with factitious disorder were confronted with the diagnosis, but only 16 admitted they had falsified their presentation. Eighteen discharged themselves against medical advice.[23] In a systematic review by Eastwood and Bisson, 32 case reports and 13 case series of factitious disorder were examined. No advantages were found in challenging individuals about the underlying cause of their presentation.[15] Other studies have reported very low rates of acknowledgement after confrontation, but no adverse outcomes.[14,15]

A role for confrontation has been proposed where it occurs within an established doctor-patient relationship and with the support of a liaison psychiatry service.[4,26] Such an approach needs to be non-judgemental, non-punitive and based on facts not suppositions. There should always be a face-saving mechanism for the person that places their emotional needs at the forefront, along with reassurance that on-going care will be provided regardless of any disclosure.[14]

D. Engage the psychiatry team

To approach the issue of referral to the psychiatry team, use the same technique that you would in the setting of somatisation:

> *"Most people with diabetes who come to hospital a lot with diabetic ketoacidosis find it very stressful. It can be very helpful to have someone to talk to about that. I'm not an expert in that area so I usually ask someone from our psychiatry unit to help me out. Do you think that's something that might be helpful for you?"*

E. Maintain consistency and work as a team

Try to keep the person's management within one hospital or health care facility. Develop a consistent approach within the team for management of admissions. Educate ward staff to help reduce splitting, and to optimally manage transference and counter-transference.[25] Support within the team is important to discuss details of management and to be able to sit with the anxiety that may be created by limiting investigations. Input from the psychiatry team to support staff can be a very helpful strategy.

F. Ensure regular review

Arrange regular contact in diabetes clinic or with the person's general practitioner to remove the link between providing care and acute medical presentations. Be aware of the risk of relapse in times of stress.

G. Specific therapies

At present, there are no commonly accepted evidence-based treatments available for factitious disorder.[4] Behavioural and psychotherapeutic techniques have been used with mixed success.[27] Most strategies are aimed at helping the person to adopt more constructive ways of meeting their emotional needs.[5,27] Comorbid conditions, such as depression or an eating disorder, need to be optimally treated.

clinical tasks

1. Use Danielle's case study for a role play to rehearse your response to a person who has type 1 diabetes and a suspected factitious diabetes-related presentation. Ask a colleague to provide you with feedback. Think about how you might apply your skills in your own clinical setting.
2. Identify a situation where you suspected that a person with type 1 diabetes purposefully intervened to produce a negative clinical outcome. Examine your emotional reactions to the situation. How did these emotions impact on how you related to the person? Is there anything you would do differently when next confronted with a situation like this?

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2.10 making a mental health referral

learning outcomes

to be able to:

- decide when and how to discuss a referral to a mental health professional with a person who has type 1 diabetes
- describe a psychological or psychiatric intervention to person who has type 1 diabetes
- craft an effective referral to a mental health professional for a person who has type 1 diabetes

key reading

1 Peyrot M, Rubin RR. Behavioral and psychological interventions in diabetes. *Diabetes Care* 2007; 30: 2433-2440.

2 Marshall S, Harrison J, Flanagan B. The teaching of a structured tool improves the clarity and content of interprofessional clinical communication. *Qual Saf Health Care* 2009; 18: 137-140.

3 Tattersall MHN, Butow PN, Brown JE, Thompson JF. Improving doctors' letters. *Med J Aust* 2002; 177: 516-520.

Introduction

During your training, you will develop the skills required to effectively support the self-management and optimise the mental health of people with type 1 diabetes.[1] This will include being able to help people make and sustain the behaviour changes required to meet their desired diabetes outcomes, as well as to manage common mental health problems, such as diabetes distress and mild generalised anxiety.[2] There will be times, however, when the skills required exceed your expertise or that of the diabetes team. In such situations, you may need to raise the issue of a referral to a mental health professional. This will involve knowing when and how to broach the subject with a person who has type 1 diabetes, being able to explain what the proposed mental health intervention will involve and providing realistic expectations of the likely outcomes. Making an effective referral to a mental health professional or service also involves knowing your local referral pathways and being able to write concise yet informative referral letters.

When and how to discuss a mental health referral

If a person with type 1 diabetes is manifesting signs of severe mental illness or is at high risk of suicide, a mental health referral will be urgent and mandatory. In most other situations, the subject of referral is usually best raised after you have built up a picture over time of the person's emotional, psychological or psychiatric state. By adopting such an approach, you can more effectively gauge whether a mental health intervention is indicated at the present time and, if so, how ready the person might be to take up the suggestion.[3] If you raise the issue of referral too early, you risk alienating the person if they do not require a formal intervention or if they are not ready to recognise or disclose that they are experiencing difficulties with their mental health. As a trainee, you may only meet a person with type 1 diabetes once or twice in a clinical setting. In such situations, it is important that you raise any concerns you might have about the person with your consultant so that appropriate follow up can be arranged.

Make sure the person who has type 1 diabetes understands exactly why you feel a mental health referral would be of benefit to them. For example, you could outline how CBT might be helpful for enhancing their skills of diabetes self-management.[4] In another situtation, you may be recommending an assessment for the purposes of diagnostic clarity, such as when you feel it is necessary to differentiate between disordered eating and a full syndrome eating disorder:

> *"Over the past few consultations, we've talked about how you've been managing with your diabetes. From what you've been saying, it seems like you are still struggling with your eating and emotions … I think it would be a good time now to ask someone from our mental health team to advise on how best to support you with this …"*

Establish how comfortable the person feels about being referred to a mental health professional. In some circumstances, the person's preference may be for you or the diabetes team to provide the required emotional and psychological support, even though specialist mental health expertise is indicated.[5] Unless the situation is urgent, provide basic support and, with the person's permission, engage the assistance of their general practitioner. Explain the limitations of your skills and plan early review to monitor the situation:

> *"I can understand why you might not want to see a psychiatrist right now … as an endocrinology trainee, I can help you with how you manage your diabetes and provide some support for the emotional issues that you have experiencing lately, but I am not an expert in managing mental health issues. It doesn't mean, though, that we can't still talk about the issues you have been having in our consultations and how they are impacting on your diabetes …"*

If you are not sure whether a mental health referral is indicated for a person with type 1 diabetes, talk with your consultant about your concerns. Discussing the person's situation with a member of the liaison psychiatry service can be helpful for deciding when and how to broach the subject of referral. If you are seeking advice outside the diabetes team, maintain the person's anonymity until after you have obtained their permission to make a formal referral.

Discussing the practical aspects of a mental health referral

Make sure a person with type 1 diabetes has a clear understanding of what to expect when they attend a consultation with a mental health professional.[3] For example, if you have recommended a behavioural psychologist, explain that this person will use talking therapy which may also involve tasks outside the consultation, such as keeping a diary. If you have referred the person to a liaison psychiatrist, outline that the initial assessment will involve talking about their mental health problems, as well as their medical history and general aspects of their life. Explain that a psychiatrist is a medical practitioner who can recommend and prescribe medications if they are considered likely to be beneficial. Provide realistic expectations about the likely outcomes of the intervention. Importantly, emphasise that a mental health intervention is usually not a "quick fix" and that ongoing input will often be required.

Provide an estimate of the time commitment that will be required for the proposed intervention. An initial assessment by a mental health professional will usually involve a consultation of 45–60 minutes duration.[3] The duration and frequency of subsequent sessions will depend on the nature of the problem and the type of intervention required.[3] This information will generally be discussed by the mental health professional in the initial consultation.

Ensure that the person is aware of the cost of the proposed intervention. Their general practitioner can facilitate access to subsidised psychology services by writing a mental health care plan under the Access to Allied Psychological Services (ATAPS) scheme.[6] An initial referral covers six sessions, but an additional six sessions can be accessed in any one calendar year if required. In exceptional circumstances, a further six sessions may be approved. Some diabetes services are able to provide access to a psychologist in the hospital setting at no cost. Psychiatry referrals arranged through a liaison psychiatry service will normally be free of charge, but out-of-pocket expenses will usually apply if a referral to a private psychiatrist is arranged.

Unless it is an urgent situation, the person with type 1 diabetes will generally be expected to make their own appointment to see a psychologist or psychiatrist. This enables them to demonstrate a commitment to taking up the intervention.

Crafting a referral to a mental health professional

The general principles of crafting a referral to a psychologist or psychiatrist are the same as for any other medical referral.[7,8] Ensure that your communication is informative yet concise, whether it be in writing, by telephone or through electronic means. The most important details need to appear early on in the referral. Organise the content into themes and, in the case of complex written referrals, consider using headings to promote readability.[8] Make sure your language reflects the principles outlined in the DA Language Statement.[9] The following points are provided as a guide to crafting your referrals.

A. State the purpose of the referral in the first paragraph

Start with a brief vignette of the person's presentation. Clearly state the purpose of the referral in the first paragraph, whether it be for establishing a diagnosis or management of a specific mental health issue. In some situations, you may be requesting a referral to ask for support for staff in managing a challenging situation on the wards.

B. Provide details about the presenting problem

Provide a concise account of the presenting problem. Describe what the person has told you and what you have observed, rather than anticipating the diagnosis or the management plan. For example, it is generally better to start by saying:

> *"Scott reports having a low mood and loss of interest in his usual activities for the past four weeks."*
>
> instead of:
>
> *"He seems to be suffering from depression."*

Include a comment about how you feel the person's mental state is interacting with their diabetes at the present time.

Make sure there is sufficient information so the mental health professional knows how to approach the initial consultation in a problem-orientated manner, but be mindful of confidentiality issues. Ask the person with type 1 diabetes if there are any issues they have mentioned to you that they do not want included in the referral. On one hand, a person may not want to raise a specific personal issue with someone they do not know, at least at first. On the other hand, they may appreciate having a sensitive issue outlined for the mental health professional so it is easier for them to broach the subject.

C. Provide relevant details of the medical history and any history of mental health problems

Provide a synopsis of the person's medical history, particularly the aspects that are of relevance to the presenting problem. List all current medications with any known drug allergies or adverse effects. Include any history of mental health problems and their treatment, including the names and contact details of any other mental health providers. Identify key risk factors for psychological or psychiatric morbidity and include a relevant social history. Provide information about alcohol and recreational drug use, as well as any forensic history.

D. Overall assessment

Summarise the person's presentation and provide a risk assessment, especially with respect to suicide if you suspect the presence of a severe mental illness, such as depression or a full syndrome eating disorder. Document that person has provided consent for the referral.

E. Follow-up plan

Provide an estimate of the projected time span for the person's medical treatment. If the person is an inpatient, indicate whether you would like them to be seen during the current admission or whether you feel an outpatient appointment after discharge would be sufficient. Provide your contact details, especially if the person is going to be transferred to an inpatient psychiatric facility.

Know your referral pathways

Knowing your local referral pathways involves being aware of the type of mental health services that are available in your region and the processes for making contact with them. It can be reassuring to the person involved if you can personally recommend a particular mental health professional or service.

If a person with type 1 diabetes is going to obtain a referral from their general practitioner, you may want to recommend a specific mental health professional, such as a psychologist with an interest in the behavioural aspects of type 1 diabetes or a liaison psychiatrist with a private practice. It is important, however, to respect the general practitioner's role and expertise in holistic patient care. They will probably know the person better than you do and have well-established referral pathways to local mental health professionals.

Access to mental health professionals and services may be limited in rural or remote areas. Nonetheless, there is growing availability of online resources and teleconferencing which may help to fill the gap, especially for high prevalence disorders, such as anxiety and depression.[10-14]

Following up on a referral

If you have made a referral to a mental health professional for a person with type 1 diabetes, don't assume the issue has been dealt with just because you have initiated the arrangement. When you next see the person, make sure they have been able to make contact with the mental health professional or service. Continue to see the person regularly in diabetes clinic while they establish a therapeutic relationship with their mental health professional, especially if you have concerns about their wellbeing.

Enquire about how the intervention is working out for the person and find out what benefits the person is deriving from it. If a behavioural intervention has been recommended, support and reinforce the principles that are being addressed and use the information to enhance your discussions about their diabetes self-management. It is important, however, to respect the person's privacy, especially if highly personal issues are being explored within the context of a mental health intervention. The person may not want to discuss these with anyone other than the psychologist or psychiatrist. If the person has been referred to a psychiatrist, check if any medications have been prescribed, especially those that have the potential to impact on glycaemic control.

Ask the person to provide specific feedback about the intervention. If it is not working out, find out why. Let the person know at the time of the initial referral that their feedback is important and that an alternative option can be arranged if the mental health professional or service does not meet their requirements. Use feedback from people who have type 1 diabetes to optimise how you make mental health referrals.

clinical tasks

1 Using role play, practise explaining what cognitive behaviour therapy involves with one of your peers.

2 Write a de-identified referral to a psychiatrist about a person with type 1 diabetes and ask for feedback.

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2.10 making a mental health referral

The John Turtle District Hospital
Cnr Martin and Taft Streets
JOSLIN Vic 1922

MMc:jc

22nd February 2014

Dr Carol Silberberg
Consultation Liaison Psychiatry Unit
St Vincent's Hospital
FITZROY Vic 3065

Dear Dr Silberberg

Re: Danielle BANTING (DOB: 07.01.1996) 22 Best Street, JOSLIN Vic 1922

Thank you for accepting the referral of Danielle Banting, about whom we spoke by telephone today. She is an 18-year old woman with type 1 diabetes who has had three admissions to The John Turtle District Hospital in the past five weeks. The possibility of a factitious disorder has been raised and your diagnostic input would be appreciated.

Presenting problem

Danielle was initially admitted for management of a ruptured appendix for which she underwent surgery without any complications. Her discharge from hospital was delayed by one day due to an episode of severe hypoglycaemia in the context of a delayed meal. She was readmitted one week later in mild diabetic ketoacidosis with a wound breakdown, attributed to a delay in healing in the setting of hyperglycaemia.

The wound was treated with antibiotics and optimisation of blood glucose management. Danielle's discharge was again delayed by an episode of severe hypoglycaemia, this time unexplained. She was readmitted two days ago with lower abdominal pain. Her wound has healed, all investigations are within normal limits and she has been treated with analgesia and laxatives. Again, there has been a severe hypoglycaemic episode that remains unexplained.

The nursing staff has reported that Danielle seems isolated. She has had no family or friends come to visit, apart from a cousin on one occasion during the first admission. It has been noted that she seems pleased to be in hospital and has reacted angrily with tears when discharge has been discussed. A diagnosis of factitious hypoglycaemia been considered, but this has not been confirmed and Danielle has not been confronted with this diagnosis.

Background history

Danielle has had type 1 diabetes since the age of five. Her most recent HBA1c was elevated at 99 mmol/mol (11.2%). She has not had specialist review for many years. Apart from mild retinopathy, she has no chronic diabetes complications, but she reported having multiple admissions with diabetic ketoacidosis as a child. No other medical history has been elicited and, apart from the insulin, she is not taking any other medications. There are no known drug allergies.

There is no reported psychological or psychiatric history, although Danielle has not been forthcoming about her history overall. She has recently moved to the city from a rural town to study hospitality. She has been living in a hostel and working part-time as a medical receptionist to support herself financially. Danielle says she does not drink alcohol or smoke, and does not use recreational drugs.

Overall assessment

In summary, Danielle is an 18-year old woman with unexplained severe hypoglycaemia who seems isolated and emotionally labile, and for whom the possibility of a factitious disorder has been raised.

She has provided consent for this referral although was initially reluctant. She does not seem suicidal on assessment, but her severe hypoglycaemic episodes are exposing her to physical risk.

Follow-up plan

Danielle's abdominal pain has settled and discharge is planned for the day after tomorrow. An assessment while she is an inpatient would be appreciated. She will be followed up in Diabetes Clinic two weeks after discharge. Danielle does not have a nominated general practitioner, but has been encouraged to make contact with one for ongoing support.

I can be contacted through the hospital switchboard on pager number 1055.

Yours sincerely

Michelle McLean

Dr Michelle McLean
Endocrinology Registrar

Note: Emeritus Professor John Turtle has kindly agreed to his name being used in this referral letter.

3

challenging consultations

3.1 difficult engagement

learning outcomes

to be able to:

- recognise when there are difficulties engaging with a person who has type 1 diabetes
- identify causes of difficulties engaging with a person who has type 1 diabetes
- prevent difficulties with engagement through focused enhancement of your consulting skills

key reading

1 Fortin AH, Dwamena FC, Smith RC. The difficult patient encounter. In: *UpToDate*, Basow DS (ed). Waltham, MA: UpToDate; 2013.

2 Breen KJ, Greenberg PB. Difficult physician-patient encounters. *Int Med J* 2010: 40: 682-688.

3 Goldberg PE. The physician-patient relationship: three psychodynamic concepts that can be applied to primary care. *Arch Fam Med* 2000; 9: 1164-1168.

Introduction

As an endocrinology trainee, you will sometimes encounter difficulties with engagement when you are consulting with people who have type 1 diabetes. You may sense that they are not very communicative, are reluctant to adopt your recommendations about their diabetes self-management or are making you feel frustrated for no apparent reason.[1] Historically, the generic medical literature framed such scenarios in terms of the "the difficult patient", but it is now recognised this label should be avoided as difficulties with engagement are rarely due to fixed personality traits.[1-7]

It is more constructive to focus on the physician-patient interaction itself and identify the factors that might be having a negative influence on it.[1] In some situations, systems issues, such as work load and interruptions, or environmental issues, such as lack of privacy and background noise, can interfere with the quality of communication.[2] In other circumstances, unrecognised medical, psychological or psychiatric conditions in the patient play a role. Often, difficulties with engagement reflect the communication skills of the health professional, an observation that is borne out by the reality that a situation that is challenging for one clinician may be quite straightforward for another.[1,2,7,8]

Recognising when there are difficulties with engagement

Being able to effectively respond to difficulties engaging with a person who has type 1 diabetes foremost requires being able to recognise the early warning signs that a consultation is not going as well as it should.[9] There are two key skills that are important for this process:

A. Being able to recognise changes in yourself that might indicate you are having difficulties engaging with a person:

- realising you are the one doing most of the talking
- finding that you are taking too much control over the direction of the consultation
- recognising that you are developing a negative attitude towards the person, such as being frustrated with them if your suggestions are not perceived as being helpful
- sensing there is a "brick wall" between you and the person

B. Being able to recognise the signs in a person with type 1 diabetes that indicate there may be difficulties with engagement:

- changes in body language, such as when a person becomes fidgety or averts their gaze while talking with you
- variations in tone, speed or fluency of speech, especially hesitation
- one-word answers, such as *"Yes", "No"* or *"Never";* responses that seem evasive; or silence when the person had previously been taking an active part in the consultation
- repeating questions or showing resistance to your suggestions, especially during conversations about diabetes self-management

Identifying the causes of difficult engagement

If you are having difficulties engaging with a person who has type 1 diabetes, take a step back and reflect on what you think might be happening within the consultation. Asking yourself the following questions may provide a starting point for identifying the underlying cause:

A. IS THE PERSON HAVING A HYPOGLYCAEMIC EPISODE?

B. AM I COMMUNICATING ON THE RIGHT LEVEL?

C. AM I MISSING AN UNDIAGNOSED PSYCHOLOGICAL OR PSYCHIATRIC PROBLEM?

D. DO I HAVE A NEGATIVE ATTITUDE TOWARDS THE PERSON?

A. Is the person having a hypoglycaemic episode?

If a person who has type 1 diabetes seems to be uncommunicative or distracted, consider whether they are having a hypoglycaemic episode. Hypoglycaemia is not uncommon in the clinic setting, especially if there have been delays or the person has been rushing to make their appointment. In a ward setting, disrupted routines can easily play havoc with BGLs.

The person may not recognise that their BGL is low if they have attenuated warning symptoms or if they confuse their autonomic symptoms with those of anxiety relating to their health care. On your part, a hypoglycaemic episode can be easy to miss if the physical signs are not obvious and you don't know how a person normally interacts in a clinical environment.

The subject of hypoglycaemia as a cause of difficulties with engagement needs to be broached with great tact. While picking up a low BGL early is a priority to ensure the person's safety, you also do not want to offend them if there is another cause for their level of engagement in the consultation.

> *"You seem very quiet right now. I'm not sure if it's because of what we've been talking about, but I'm worried you might be having a hypo. I wonder if you could you check your BGL so I can be sure everything's OK before we continue our conversation?"*

You may need to assist the person if they do not have the dexterity to use their blood glucose meter. If hypoglycaemia is confirmed, ensure that it is adequately treated. Appreciate that the person may have difficulties absorbing information while recovering from a significant episode of hypoglycaemia. Depending on the urgency of the consultation, it may be best to reschedule for another time. Make sure that you take the opportunity to ask about the person's warning symptoms and review their knowledge of hypoglycaemia management at their next appointment.

B. Am I communicating on the right level?

Reflect on how you are communicating within the consultation with the person who has type 1 diabetes. Have you adequately elicited, understood and addressed their main agenda? Have you correctly judged their baseline level of knowledge? Are there any physical, linguistic or cultural communication barriers that you have not taken into account? Do you have time pressures and are rushing the consultation? Are you tired and not able to focus fully on what the person is saying? Are you "present" in the consultation or is your mind elsewhere?

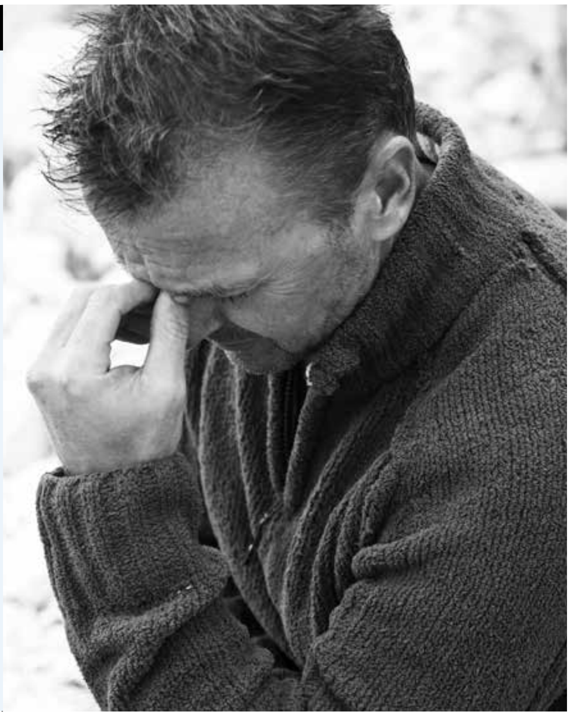
Consider whether you might be unintentionally using language that is judgemental or does not reflect a collaborative approach.[10] A person with type 1 diabetes who is frequently repeating themselves or seems resistant to what you are saying may be trying to tell you they are not being given adequate opportunity to participate in the consultation.[11] Effectively applying the techniques of behaviour change as outlined in Chapter 1.7 will generally help to prevent such a situation from arising.

3.1 difficult engagement

case study

Tony

Tony, 35, has had type 1 diabetes for 10 years. He is attending Diabetes Clinic for review and is talking with Fiona, a third-year trainee. Fiona has started the consultation by asking Tony how he is doing at present. He says he is unhappy with his most recent HbA1c result, which was 75 mmol/mol (9.1%), but he doesn't know what to do to improve it. He says he can't find any patterns with his BGLs to work on. Fiona suggests that they look at his record book together. She notices that Tony is checking his BGLs about once a day and that the levels have been ranging between 3.1 and 17.8 mmol/L. His BGL just prior to the consultation was 11.7 mmol/L.



FIONA: *... in terms of working on your diabetes, do you think it would be a good idea to see one of the diabetes educators to review your injection technique and perhaps have a look at some of the new meters that are now available?*

TONY: *... well, I saw a diabetes educator a few years ago ... I don't feel I need to do that again for a while ... and I only got a new meter last year ...*

FIONA: *OK. Do you think it would be useful to see a dietitian to brush up on your carbohydrate counting?*

TONY: *I tried that in the past and ... well ... it didn't really make much difference to my BGLs. So I can't see how that would help ...*

FIONA: *One option might be to do a DAFNE program. It's a week long course where you can find out more about carb counting and insulin dose adjustment ... I think it's good because you get to learn with other people who have type 1 diabetes ...*

TONY: *... I know about it ... the doctor I saw last time told me what it involves. But I can't afford to take a week off work to do it right now ...*

Fiona feels that Tony is blocking everything she suggests. She starts to become frustrated, but quickly recognises that this is not a constructive response. Instead, she tries to identify what is going wrong with the consultation. She realises that she has been trying to provide solutions for Tony rather than trying to find out about what he thinks might work best for him.

FIONA: *... yes, I can understand that doing a week-long course right now would be hard with your work commitments ... [pauses] ...What do you think might help with getting your diabetes back on track?*

TONY: *... um, I don't really know ...*

FIONA: *... [pauses to think] ... Tony, two years ago, your HbA1c was 7.3%. That's a lot lower than it is now. What was happening then to make your diabetes go so well?*

TONY: *... [looks surprised, but pauses for a while to think] ... well ... I was going to the gym back then ...*

FIONA: *Tell me why that worked well for your diabetes ...*

TONY: *... I felt better from the exercise and I was more careful about what I ate ... and I lost some weight ... and I guess I checked my*

BGLs more because I didn't want to hypo when I worked out ...

FIONA: *... so, checking your BGLs more often was helpful in keeping your diabetes on track?*

TONY: *... yep ...*

FIONA: *OK ... (pauses) ... and you stopped going to the gym?*

TONY: *Well, my gym closed for renovation ... and the one in the next suburb was too hard to get to after work ...*

FIONA: *Is the gym open again?*

TONY: *I haven't checked, but it probably would be by now. I guess I could look into that ...*

FIONA: *Sounds like a plan. Is there any help you need from me at this stage?*

TONY: *No, but thanks ... I think I'll see how the gym thing works out first ...*

Ask yourself if you are *really* listening to what the person is saying. Are you missing important verbal or non-verbal clues? The literature in this area suggests that such clues often are emotional in nature.[4,9,11] A person who does not seem engaged in a consultation may be reacting to feelings of helplessness, sadness or anger. They may, for example, be distressed about the result of an investigation, such as the first appearance of retinopathy on fundus photography, or be concerned about broader issues relating to the demands of living with type 1 diabetes. You are less likely to miss such clues if you are in tune with the emotional dimensions of living with type 1 diabetes. Use the approaches outlined in Chapters 2.2 and 2.3 to enhance your skills in this area.

C. Am I missing an undiagnosed psychological or psychiatric problem?

Psychological and psychiatric problems, particularly depression, can go undiagnosed in people with type 1 diabetes and can manifest as a lack of engagement during a consultation.[12] There needs to be heightened suspicion in the context of other warning signs, such as missed appointments, recent frequent hospitalisations, unexplained weight loss or evidence of self-medication with recreational drugs and alcohol.[13]

If you suspect the presence of a psychological or psychiatric problem, enquiring about the person's general wellbeing can be a non-threatening way of initiating a conversation about the topic. If they are not forthcoming, try asking if they have any concerns about their diabetes.[14] It is important not to imply too soon that you think there is a mental health problem as you risk alienating the person. Take your cues from the person's manner and by the words they use. Comment on what you observe, such as changes in communication style, body language or metabolic outcomes, rather than offering your own interpretation of the situation:

> *"You paused for a while when I asked just then about how you are doing with your diabetes. Is everything OK with you right now?"*
>
> OR
>
> *"When I see that someone whose HbA1c has gone up, it makes me wonder if they are having some stress or worry in their life. Is this something that might be happening with you right now?"*

If you already know the person, you may be able to adopt a more direct approach.

> *"I know that in the past when your HbA1c has gone up, it means that things are not going so well emotionally for you. Is there anything going on that I can help with?" "*

Listen carefully to the person's response and try to pick up on clues that point to a specific psychological or psychiatric diagnosis. As outlined in Module 2, there are a range of brief screening instruments available that can help you with this process, such as DDS-1, PAID-2, PHQ2 and GAD-2. Incorporate questions from these instruments into your conversation with the person. If you elicit a positive response to any of these questions, administer a full instrument or conduct a diagnostic interview. Arrange further management as required.

D. Do I have a negative attitude towards the person?

You may notice that you are becoming frustrated, anxious or irritable in the presence of a person with type 1 diabetes, or are finding that their requests, however reasonable, seem quite burdensome.[1,15] It is natural such feelings, known as countertransference, will arise in clinical practice from time to time, but the reasons underlying them need to be recognised.[15,16] If not, you may find yourself taking excessive control over the consultation, being unable to show empathy, offering differential medical treatment or even trying to avoid the person altogether.[4,9,17] If the person senses your negative attitude, either consciously or unconsciously, they are likely to be

3.1 difficult engagement

case study

Julie

Julie is a 51-year old woman who has had type 1 diabetes for 34 years. She has missed two recent appointments in Diabetes Clinic and her general practitioner has encouraged her to attend for follow-up. He was particularly concerned that her HbA1c was 70.5mmol/mol (8.6%) when it is usually < 58.5 mmol/mol (7.5%).

Justin, a second-year trainee who is talking with Julie in clinic, remembers meeting her briefly when she was admitted for spinal surgery earlier in the year. He initiates a conversation by asking how she is doing at present, but she is not very forthcoming and he feels he is "talking to a brick wall." He can't remember having difficulty engaging with Julie during her hospital admission. He tactfully asks her if she could check her BGL.

When hypoglycaemia is excluded, Justin asks if Julie has any particular concerns about her diabetes. She says no, nothing. Justin continues: "Julie, your GP is worried about your diabetes because your HbA1c is bit higher than it has been … I'm wondering if everything is really OK?" Julie looks down and fidgets with the cuff of her jumper. Justin wonders if she may be depressed and uses the questions from PHQ-2 to further explore the issue. Julie says the she has been feeling very down and that nothing seems to make her feel good any more.

Justin conducts a formal diagnostic interview and finds Julie meets the DSM-5 criteria for major depressive disorder. He also establishes that she has a history of post-natal depression. Furthermore, he finds she is having difficulties recovering from her surgery and is disappointed she is still experiencing quite a lot of pain. Justin performs a suicide risk assessment and establishes that she is at moderate risk. With Julie's permission, Justin rings her general practitioner who supports the plan of referral to the liaison psychiatry unit at the hospital. An intake interview is arranged for later in the day with the consultant liaison nurse.

left unsatisfied with their health care and even stop attending appointments.

Research has shown that health professionals are particularly susceptible to developing negative attitudes towards people who have psychological or psychiatric issues.[2-4,18,19] In a study by Hahn *et al,* patients rated as being "difficult" by a cohort of primary care physicians were more likely to have a mental illness than those who were not thought to be "difficult" (67% versus 25%, $p < 0.0001$).[18] The clinicians in the study rated people with somatoform disorders, panic disorder or suspected substance abuse as being particularly challenging.[18] Other research suggests that individuals who do not seem motivated to implement adaptive self-care behaviours or who take risks with their health are also more likely to be regarded as being "difficult".[2] For example, adolescents with type 1 diabetes who withhold insulin or place themselves in situations where hypoglycaemia may be confused with intoxication are likely to evoke considerable anxiety in their health professionals.[20,21]

Other "at-risk" groups are those with frequent hospitalisations or who are otherwise high users of the health system,[22] as well as those who fabricate presentations and are perceived as having breached the mutual trust expected in a doctor-patient relationship.[23] Several authors have highlighted the risk of developing a negative attitude towards those who seem entitled, unsatisfied with their medical care or excessively dependent.[2,4,24] Positive perceptions of a person may also be clouded if they have a partner, family member or carer who appears overly dominant or protective.[1]

Ensure that you have the self-awareness to recognise when you are at risk of developing a negative attitude towards a person with type 1 diabetes.[15,25] A study by Smith *et al* demonstrated that structured training of junior doctors increased self-awareness of previously unrecognised negative attitudes and led to improved communication skills.[26] Other authors have described methods that can help health professionals gain insight into how factors such as family background, temperament and personal values influence their encounters in the clinical setting.[1,2,9,15]

If you find that your attitude towards a particular person is interfering with your ability to provide unbiased care, discuss the situation with your consultant or another senior member of the diabetes team. The advantage of working in a multidisciplinary team is that you can draw upon the support and experience of others to ensure optimal outcomes for people with type 1 diabetes.

Preventing and minimising difficulties with engagement

As you develop your expertise, you are likely to find it easier to problem solve when you encounter difficulties engaging with people in the clinical setting. You are also likely to experience fewer challenging consultations overall as your communication skills mature and you acquire greater insights into the factors that can negatively influence physician-patient encounters, a premise that is supported by clinical communications research.[2,3,9,27]

Use deliberate and reflective practice to enhance your skills in preventing, identifying and resolving difficulties with engagement.[28,29] Analyse your own communication style and be aware of how you react in challenging situations. Focus on developing your skills in chronic condition self-management support so you consistently apply a collaborative approach to your consultations. Be open to learning from people with type 1 diabetes by asking about their expectations with respect to communication. Make sure that you attend to the psychosocial aspects of living with type 1 diabetes.[2,29,30] Knowing about a person's life experiences will help you to understand how they interact in a clinical setting and will enable you to tailor your consulting to meet their individual needs.[31] Significantly, research suggests clinicians who take a broader view of patient care report fewer difficult consultations than those who adopt a purely biomedical focus.[32]

In addition to enhancing your communication skills, develop an awareness of the factors that can negatively impact on the physician-patient encounter. Try to limit the effects of environmental and systems issues, such as noise, workload or competing responsibilities.[2] Recognise and take into account physical or medical conditions that can affect how a person with type 1 diabetes is able to engage with you in a clinical setting. Similarly, be alert to the presence of emotional, psychological or psychiatric conditions that can impact on communication.

Ultimately, being able to prevent, identify and resolve difficulties with engagement will lead to more productive and satisfying consultations, as well as resulting in better outcomes for people who have type 1 diabetes.

3.1 difficult engagement

clinical tasks

1. Reflect on a consultation with a person who has type 1 diabetes where you felt a discussion about their diabetes self-management did not go as well as it could have. How did you recognise there was a problem? What factors do you think contributed to the situation? What would you do differently next time?
2. Identify a consultation where you developed a negative attitude towards a person with type 1 diabetes. Why do you think this happened? What signs did you recognise in yourself? How did your attitude impact on the consultation and on the medical care you provided? Are there any skills you need to work on to prevent the situation happening again?

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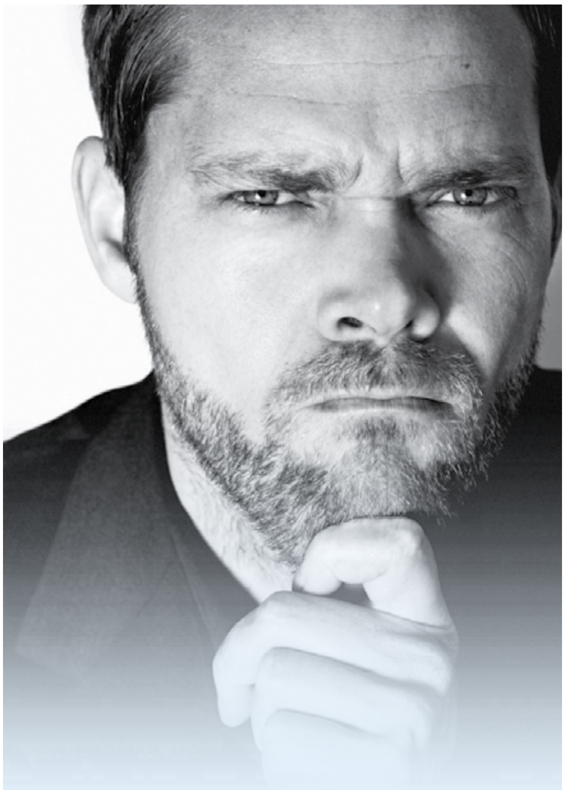
3.2 conflict



learning outcomes

to be able to:

- decline an inappropriate request from a person with type 1 diabetes
- respond to anger expressed by a person with type 1 diabetes
- set limits around disruptive behaviour in the clinical environment

key reading

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Introduction

Sometimes you will encounter situations where you come into overt conflict with a person who has type 1 diabetes. Examples of such situations include having to decline an inappropriate request, respond to anger or set limits around disruptive behaviour in a clinic or the ward setting.[1-3] As a health professional, you need to be able to respond in a way that prevents escalation, is respectful and produces optimal outcomes for all persons involved. You also need to be able to recognise situations where there is the potential for conflict and implement suitable preventative strategies.

Declining an inappropriate request

At times you will be asked by people who have type 1 diabetes for unnecessary or inappropriate investigations, treatment or certification.[4,5] For example, you may be asked to write a prescription for a medication that is not directly related to a person's diabetes care, such as a sleeping pill or an opiate analgesic, or a medical certificate when you have not been personally involved in the management of the illness. In other contexts, there may be problems with the timing of requests, such as asking that forms be completed at extremely short notice.

Rather than simply declining a request, take time to understand the reasons that underlie it.[6] For example, by asking you to initiate a sleeping pill, a person may be trying to tell you that their diabetes is currently having a negative impact on their mental health. Untimely requests may reflect disorganisation due to psychosocial stressors or difficulties integrating the load of diabetes self-management into everyday life. In some situations, a person may not understand how the health care system works or feel powerless when trying to negotiate it. Furthermore, they may not understand why their various health professionals have different roles and responsibilities.

Criticising a person for making an inappropriate request will rarely be constructive and may provoke conflict. Rather, respond by saying what you will and won't be able to offer.[6] Remain respectful, but be firm, clear and unambiguous to prevent misunderstandings. Using *"I"* statements and third person language can be useful face-saving techniques:

> *"Unfortunately, I won't be able to do that for you. A medical certificate needs to be written out by the doctor who looked after the person during their illness ..."*

Explain how a request may not lead to the optimal outcome for the person's medical problem. If possible, offer to facilitate a more suitable plan of action for them:

> *"The best option for you is to see your general practitioner as he will have a better idea of how to help you with the problems you have had getting to sleep. If you like, I can let him know that this has been an issue for you …"*

A study by Paterniti *et al* confirmed, not surprisingly, that patients were more likely to be satisfied with a consultation in which a request had been declined if they had been provided with a clear explanation for why it could not be granted, than if they were given an outright refusal.[6] This was particularly so if they felt they had been able to be an active participant in the consultation.

Conversations around inappropriate requests will generally be easier if there are guidelines in place that are consistently applied, especially around providing prescriptions and certificates. In addition to providing guidelines, offer practical tips to help with the logistical aspects of diabetes self-management. For example, you might suggest that a prescription be kept with a local pharmacist so it won't be misplaced and require last minute replacement. In the setting of illness, you might suggest that a person asks their treating doctor for a medical certificate at the time of discharge from hospital if one has not already been offered.

Responding to anger

Anger is a common emotion encountered in the health care setting.[7] For a person with type 1 diabetes, this emotion may be experienced as a response to long waiting times in diabetes clinic or to losing control over their diabetes self-management in a ward setting, particularly if there has been sub-optimal management by medical or nursing staff.

In many circumstances, anger is a "surface emotion". That is, it is a feature of another emotional state, such as anxiety or grief, rather than a primary emotion. In other contexts, a person's anger in response to a legitimate concern may be disproportionate, suggesting that they have underlying issues with emotional regulation.

Being able to respond in a professional manner to a person who is angry is a skill that can be developed, just like any other clinical skill.

A. Stay calm when you encounter expressions of anger

When confronted with a person who is angry, keep at a safe distance. Do not try to placate the person by touching them.[7] Avoid becoming defensive or taking personal offence. Above all, stay calm and try not to respond on an emotional level yourself. According to Halpern, being able to empathise with the other person in a situation of conflict is an effective way of optimising the outcomes for all concerned.[8] Specifically, she has proposed that it is just as important for a patient who is angry to know that you are trying to understand their perspective as it is when they are displaying a benevolent emotion, such as sadness or grief.[8]

B. Responding to specific situations

1. Responding to anger about long waiting times in clinic

Long waiting times are a common source of anger in the health care setting. Delays can be particularly frustrating for people with type 1 diabetes where there is a risk of hypoglycaemia if snacks or meals are delayed. Young adults, who are trying to interact with a health care system that may not be structured in a way that meets their needs, may be especially vulnerable.[9]

Ensure that you have effective strategies in place for responding effectively when people are angry about being kept waiting. In a study by McCord *et al*, participants from a general practice population in the USA were shown video trigger tapes of a range of physician responses to a patient who was angry about being kept waiting and asked to rate their satisfaction with the various approaches.[10] The results showed participants preferred an apology using the words *"I apologise that …"* rather than *"I'm sorry that …"*, the former being seen to convey a greater sense of responsibility than the latter. They then preferred a brief explanation of reasons for the delay and a prompt segue into the consultation:[10]

> *"I apologise that you have had to wait so long today. Unfortunately one of the doctors is away unwell. But let's get started … how I can help you today?"*

Of interest, the study showed acknowledging anger *"I can see that you are upset"* produced the lowest satisfaction with participants. The results of this study may not be generalisable to other health care settings or to other cultural contexts, but they provide a general guide to responding to a person who is angry about being kept waiting. Above all, be flexible and adjust your approach if your initial response has not been successful.

2. Responding to anger about a health care incident

In some circumstances, you may need to respond to a person who is angry about a health care incident, whether or not you may have been personally involved. Apologise if you have contributed to the situation, but do not do this if events have been beyond your control.[7]

Listen carefully to the person without interrupting while they ventilate their anger.[7,11] Do not challenge what they have said, even if you feel they have misinterpreted what has happened. Appreciate that their anger is real, regardless of the facts. The priority is to produce a satisfactory resolution for the person and the facts of a situation may remain a matter of opinion.

When the person's anger has diffused, try to problem solve with them. To do this, you may need to gather more information about the events surrounding the episode. You may find using the behavioural incident technique helpful:[12]

> *"After the cast was applied to your leg, you noticed that the top was digging into your skin and causing you a lot of pain. You said that you told the resident, but you felt they didn't seem to listen to you. What happened after that?"*

Find out what the person thinks might work best for them and explore the range of options that are available to resolve the situation:[7]

> *"I understand that your insulin dose was omitted last night. I'll raise the issue with the ward staff to see what can be done to prevent this happening again ... but is there anything in particular you think that we can do to make this work better for you while you are in hospital?"*

Be respectful and genuine in how you respond to the person. If you sound formulaic, they may be left feeling that you are not taking their concerns seriously. In turn, this is likely to further provoke their anger.

Offer to act as an advocate for the person. If relevant, make sure they know how to contact the patient complaints department in your hospital. If a negative health outcome has occurred as a result of an incident, it is essential that you inform your consultant.

C. Differentiate surface anger from other causes of negative emotions

If you feel a person's anger is disproportionate to a situation, consider whether it might be an expression of an underlying mental health problem or a response to a threat, such as loss of physical integrity or independence.[7] For example, a person with type 1 diabetes who is facing an amputation for a diabetic foot complication may present as angry and unreasonable about their blood glucose management on the wards, but underlying this may be a profound anxiety about the implications of surgery for their livelihood, as well as broader fears about living with a disability. Sensitively explore such situations using a general approach, rather than suggesting to the person upfront that you think their anger is due to another cause.[7]

D. Ensure your own safety

Remove yourself from a situation if you sense a person's anger is escalating out of control. Give yourself and the person "time out", and return at a later time so you can have a more rational conversation:[13]

> *"I don't think this conversation is working out. I am going to leave and discuss this with my consultant. I will come back later to see if we can resolve this issue."*

If a person becomes aggressive and you feel threatened, call a security guard as per your hospital protocol.[7] Make sure your consultant is aware of what has happened and that you have an opportunity to debrief after the incident.

E. Preventing conflict

Become skilled at recognising the early signs of anger in a clinical setting so you can take the appropriate action to prevent overt conflict.[7] Be alert to physical signs in a person, such as crescendo speech, changes in body language or features of autonomic nervous system activation, which may indicate a person is angry or upset about an aspect of their health care. Also be alert to changes in yourself, such as feeling uneasy about the direction in which a consultation is heading.

Anticipate situations that can provoke anger. One particular scenario that can lead to conflict with a person who has type 1 diabetes is an adverse finding around driving certification, especially if it is likely to impact on their independence and, potentially, their livelihood. It is beyond the scope of this resource to address processes around driving certification, but it is suggested that you become aware of your obligations in this area of diabetes management.[14] Maximise opportunities to learn from and with your consultants as they negotiate difficult conversations around this topic.

On a broader scale, identify where there are systemic issues that could be addressed to help reduce conflict and to improve the experience of people with type 1 diabetes in your clinical environment. Examples include looking at ways of managing waiting times in clinic or streamlining insulin administration on the wards.

Setting limits around disruptive behaviour

Sometimes a situation will arise where a person with type 1 diabetes is displaying behaviour that is disrupting the smooth functioning of a ward or a clinic.[15-17] Such behaviour may be an expression of anger, but can also be a feature of a range of physical, cognitive or psychiatric conditions.[18] Effectively responding to disruptive behaviour involves defining the behaviour, identifying any predisposing conditions and precipitants, setting limits and helping the person work towards adopting more adaptive behaviour. Not only can this ensure the safety and wellbeing of others, but it can also provide a trigger to address issues that might be impacting on the mental health of the person concerned.

1. Define the behaviour

Start a conversation with the person by defining the behaviour of concern. Explore their perception of the situation rather than reprimanding them.[8,13]

> *"The nursing staff called me to say there have been concerns about the number of times you have been ringing your buzzer overnight. Please tell me what's been happening from your point of view ..."*

2. Identify any predisposing conditions

Try to identify any medical, psychological or psychiatric conditions that might be predisposing to the behaviour. You may already be aware of a predisposing condition from the person's medical history, but in other situations specific assessment will be required. This may involve performing a focused re-examination of the person's medical status, reviewing the person's past history or obtaining information from a family member or carer.

One of the most common causes of disruptive behaviour in a hospital setting is withdrawal from substances such as alcohol, nicotine, recreational

drugs or benzodiazepines.[19] The frequency of the use of such substances by people with type 1 diabetes can be underestimated by clinicians.[20-22] A recent online survey by Lee *et al* showed that 77% of young people with type 1 diabetes had used recreational drugs, although few had informed their health professionals.[21] Alcohol and recreational drug use can lead to serious problems in people with type 1 diabetes and can confer an increased risk of hospitalisation, especially for diabetic ketoacidosis.[23]

If you suspect that substance use underlies a person's disruptive behaviour, carefully explore the topic using effective communication skills.[24] Start with a broad enquiry around amounts and frequency. Be aware that people with type 1 diabetes often use alcohol or recreational drugs to self-medicate mental health problems, such as anxiety or depression, or emotional problems related to the burden of diabetes self-management. Other physical or psychiatric conditions that can predispose to difficulties with setting personal boundaries around behaviour include acute brain syndrome, cognitive impairment and Cluster B personality disorders.[19,25,26]

In some circumstances, disruptive behaviour results from poorly-developed coping skills and difficulties adjusting to the unfamiliar environment of a hospital. This may be particularly pronounced if a person experiences loss of routine and autonomy with their diabetes self-care. "Acting-out" behaviour may be the only way they can communicate their need for structure in a hospital setting. Acknowledging the loss of control that a person may be feeling is an important step in initiating an effective response to their behaviour and working towards a better experience for them as an inpatient.[8,19]

3. Identify any specific precipitants

Identify if there are any specific precipitants to the person's behaviour. There may be issues relating to their medical care, such as episodes of real or perceived lack of attention from medical or nursing staff. In other situations, a person may experience setbacks with their diabetes or frustrations due to difficulties sleeping. In some circumstances, there may be an external trigger, such as conflict with a partner or family member.

4. Talk with the person about why their behaviour is disruptive

Talk with the person about the effect their behaviour is having on other people in the ward or clinic, especially other patients.[19] Focus primarily on the behaviour rather than the person. Use *"I"* statements and third person language to reduce blaming:

> *"I understand how you like to stay up late at night when you are in hospital ... but if a TV is kept up loud overnight, it is very difficult for other patients to sleep ..."*

Reassure the person that any issues arising as a consequence of their behaviour will not compromise their ongoing medical care.

5. Set limits around disruptive behaviour

Setting limits can provide a person with structure and a sense of control within a hospital setting.[19,27] According to Sharrock and Rickard, limit setting is not only a response to disruptive behaviour, but also an important component of patient care.[19]

Hospital policies usually place absolute limits on certain behaviours, such as smoking or taking recreational drugs, but in other circumstances you and the diabetes team may need to develop limits that are tailored for an individual person.

Make sure that the limits you set have a clear purpose and are communicated to the person in an unambiguous manner.[19] Explain that limits are a necessary part of the efficient functioning of a clinic or the wards.

> *"It's important that there are only two visitors at a time. This helps to make sure that other patients aren't inconvenienced and nursing staff can go about their job without interruption ..."*

Discuss the consequences of breaching limits, but make sure these are enforceable. Don't shift the goal posts unless it is absolutely necessary.[19] Provide positive reinforcement when the person observes the limits that have been set.

Having conversations about limit setting can be very daunting, especially if you have had limited experience in doing this in a professional context. You might find it helpful to rehearse your responses beforehand. Advise your consultant if there are particularly challenging or persistent behavioural issues.

6. Encourage adaptive behaviours

Work with the person to help them to adopt more adaptive ways of behaving in the clinical setting.[15] For example, if a person wants to watch television overnight, suggest that they go to a separate room, such as sitting room elsewhere in the ward. If they are receiving calls or text messages over night, recommend that they turn their telephone onto mute and take calls in an area where they will not disrupt other patients. Consider enlisting the assistance of a family member to provide a calming influence if a person is finding being in hospital particularly stressful. Special strategies may be required if the person has cognitive impairment or severe mental illness.

7. Ensure consistency and take a team approach

If a person's disruptive behaviour starts to become an ongoing problem, use team meetings to develop clear management guidelines. Document these guidelines for all staff involved with the person's care so that consistency can be maintained and to prevent splitting.[19] Team meetings can also be a helpful forum for discussing any issues with counter-transference that may arise.[19,28,29] Engage the liaison psychiatry team for support if the situation is particularly problematic and basic measures have not been effective.

8. Prevention and follow-up

Be proactive in addressing situations where behavioural issues may arise in your health care setting. Institute preventative measures if a person has a history of displaying disruptive behaviour during previous admissions. Be alert to conditions that are likely to predispose to disruptive behaviour, such as cognitive impairment or withdrawal from psychoactive substances. If a person is identified as having drug and alcohol issues, talk with them about treatment options and discuss the benefits of referral to local services. Finally, appreciate the frustrations that can arise from long stays in hospital, such as for the management of diabetic foot wounds.

clinical tasks

1 Reflect on a consultation where you were asked to write an inappropriate investigation request, prescription or work certificate. How did you respond? If you fulfilled the request, how did you feel about this afterwards? If you declined the request, how did you do this and how did the person respond? What would you do differently next time?

2 Use Robert's case study (see next page) as a role play to rehearse your response to a person with type 1 diabetes who is displaying disruptive behaviour in a ward setting. Specifically practise how you would set limits around his behaviour. Ask a colleague to provide you with feedback. Think about how might apply these skills in your own clinical setting.

3.2 conflict

case study

Robert

Robert is a 43-year old IT manager who has had type 1 diabetes for 27 years. He has been admitted to hospital for management of a diabetic foot ulcer that has complicated his Charcot's arthropathy. After he has been an inpatient for three days, there are complaints from other patients that he has been disrupting their sleep. He has been turning up his television to a loud volume, as well as constantly making phone calls and receiving text messages. When one of the night staff talked to him about this, he responded by swearing loudly and punching his bedside cabinet.

Jessie, a first-year trainee, makes a time to talk to Robert about the concerns of the nursing staff. She opens the conversation by describing what they have told her. She then invites Robert to talk about his perspective. Initially, he says he is not sure what all the fuss is about as he is normally up at home during the night. Jessie asks Robert to say more about his sleeping patterns and he reveals he can usually only sleep for a couple of hours at a time. He uses alcohol to get to sleep but he can't do this in hospital. He says the trouble sleeping started after he was involved in a car accident three years ago. He was driving a friend home from their football club one night when a truck jack-knifed in front of his car. He and his friend were trapped in the car for two hours while the emergency response team worked to free them. Robert had a severe hypoglycaemic episode while he was trapped, but fortunately the paramedics provided prompt treatment. Since then, he has woken up at night with sweats and having flashbacks to the incident.

Jessie, who suspects that Robert has post-traumatic stress disorder, asks if he has ever told anyone about his symptoms. He says no, as he found the alcohol seemed to work for him. Jessie explains to Robert that there may be more effective options available and discusses a referral to the liaison psychiatry team. He agrees to this, albeit grudgingly. Jessie also explains that it is important that other patients in the ward feel safe and can sleep undisturbed at night. She sets limits around his behaviour and also discusses alternatives, such as watching television and taking telephone calls in the ward sitting room overnight. She also asks that he set his telephone to mute overnight.

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3.3 your own wellbeing

learning outcomes

to be able to:

- effectively regulate your own cognitions, emotions and behaviours in the clinical setting
- set realistic expectations of your clinical performance when working with people who have type 1 diabetes
- maintain healthy boundaries in your clinical setting and during out-of-hours contact

key reading

1. Novack DH, Suchman AL, Clark W, Epstein RM, Najberg E, Kaplan C. Calibrating the physician: personal awareness and effective patient care. *JAMA* 1997; 278: 502-509.
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Introduction

To effectively provide care for people who have type 1 diabetes, you need be able to maintain your own wellbeing. Supporting self-management and optimising the mental health of people with chronic medical conditions, such as type 1 diabetes, can be cognitively and emotionally demanding. This can especially be the case when there are challenges with engagement or when there is conflict in the clinical setting.[1,2] Research suggests that clinicians who maintain their personal wellbeing are less likely to encounter difficulties with communication and are more likely to maintain a high standard of clinical care.[3-11]

Managing your own cognitions, emotions and behaviours

Make sure that you understand and can appropriately regulate your own cognitions, emotions and behaviours in the clinical setting.[12-18] This involves having a keen awareness of how your own family background, life experiences and temperament affect your interactions with patients, their families and other health professionals.[14] Not only will this lead to better outcomes for your patients, but it will also lead to more satisfying clinical experiences for you and your colleagues.[19]

Take measures to manage or prevent the factors that lead to undue stress and burnout. Effective time management is crucial so you can achieve a healthy balance between work and leisure. Time management within your workplace is also important. Allow sufficient time for situations you anticipate will be challenging, such as consultations with people who have complex medical or psychosocial needs in addition to their diabetes. Schedule important meetings, such as family conferences, at times when you are less likely to be tired or rushed.

Your diabetes team will be an important source of support in the clinical setting, especially for debriefing after stressful encounters. Identify a consultant with whom you feel comfortable to talk about difficult clinical issues and who can act as a mentor to you.[14]

Setting realistic expectations

Set realistic expectations about what you can and can't achieve when consulting in diabetes clinic or on the wards. Appreciate that you will not be able to develop rapport with every person who has type 1 diabetes that you encounter.[16,17,20] Try not to take this personally and recognise that it may merely reflect differences in personality styles. Even very experienced health professionals have difficulty engaging with some people at times.

Accept that you can't fix every situation. Diabetes care is a collaborative process, but ultimately the person with type 1 diabetes needs to take responsibility for their health care behaviours and outcomes. Ensure that you have provided them with access to opportunities for building the requisite practical skills and have encouraged adaptive behaviours using effective behaviour change techniques. Make certain that you have checked for underlying mental health issues that might be impacting on their ability to optimally self-manage their diabetes.[21] If, despite your best efforts, a person does not seem to be engaged with their diabetes self-management at the present time, take a long term view and focus on maintaining the relationship you have with them. By doing this, you will be there for them when they "switch back on" with their diabetes. Be prepared for the reality that things won't always work out for the best.

Be realistic about the limits of your own skills. You won't be able to be proficient in all areas of diabetes care, especially as a trainee. Recognise when you need to ask for advice and focus on areas where you need to up-skill.

Maintaining healthy boundaries

Supporting the self-management of someone with a chronic medical condition, such as type 1 diabetes, is a long term undertaking. Over time, you will come to know them well as an individual. It is important that you establish the right balance between objectivity and empathy.[14] Specifically, you need to decide the amount of personal information that you will share about yourself. A degree of self-disclosure can be a valuable way of developing rapport, such as revealing your allegiance to a specific football team or interest in a cultural pursuit, but highly personal information should never be divulged.

Healthy boundaries are especially important when you are providing access to out-of-hours contact for people with type 1 diabetes. Being available to receive telephone calls or other forms of remote contact for insulin dose adjustment, particularly in the setting of intercurrent illness, is an important part of the work of an endocrinologist. Provide clear guidelines for when and how you can be contacted in such circumstances. If you find that a person is contacting you out-of-hours more frequently than seems appropriate, explore the underlying reasons so you can be sure that you aren't missing a psychological issue, such as anxiety or fear of hypoglycaemia, or a social issue that is affecting their diabetes. Make sure you don't use a person's dependence to meet your own emotional needs.

Conclusion

"Life is so short and the craft takes so long to learn."

Hippocrates (circa 460-377 BC)

As a trainee, you will have the privilege of working with people who have type 1 diabetes to help them achieve the best possible health outcomes. To do this, you need to be able not only to attend to the biophysical aspects of diabetes, but also to provide support with self-management and to optimise mental health. Developing these skills is a life-long process, with your training years being only the beginning of the journey. Understanding yourself and how you interact in the clinical setting is a key component of this process. Appreciate your strengths, but also work on identifying skills that require further development. Learn with and from people with type 1 diabetes, and take satisfaction from the support that you can offer them. As Elliott Joslin recognised in 1928, the efforts and rewards of diabetes care are great.

clinical tasks

1 Identify three strategies you apply in your daily life to optimise your own wellbeing as an endocrinology trainee.

2 Identify three areas you need to develop in order to optimise your consulting skills when working with people who have type 1 diabetes. Devise a plan to build your skills in these areas.

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appendices

1 acknowledgements

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Dr Christel Hendrieckx is a clinical psychologist who trained in Belgium and the United Kingdom. She joined the Australian Centre for Behavioural Research in Diabetes (Deakin University and Diabetes-Australia Vic) in 2011. Her key research interests focus on interventions to improve the psychological wellbeing of people living with diabetes and on prevention of severe hypoglycaemia. She contributed to this resource by sharing her clinical experience of supporting people with type 1 diabetes in different aspects of living with their condition, especially coping with emotions, overcoming barriers of behavioural changes and addressing fear of hypoglycaemia.

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2 DA Language Statement

Position Statement

A new language for diabetes

improving communications with and about people with diabetes

Summary

- Diabetes is the fastest growing chronic condition in Australia, affecting 1.7 million Australians. It is a progressive condition, which can reduce both quantity and quality of life, and requires daily self-care. On average, people with diabetes have higher levels of emotional distress than those without diabetes. Distress can continue throughout life with diabetes.
- The way language is used-both verbal and written-reflects and shapes our thoughts, beliefs and behaviours. Language has the power to persuade, change or reinforce beliefs, discourse and stereotypes-for better or for worse. Words do more than reflect people's reality: they create reality.
- Language needs to engage people with diabetes and support their daily self-care efforts. Importantly, language that de-motivates or induces fear, guilt or distress needs to be avoided and countered.
- Diabetes Australia believes optimal communication increases the motivation, health and well-being of people with diabetes; furthermore, that careless or negative language can be de-motivating, is often inaccurate, and can be harmful.
- The aim of this position statement is to encourage greater awareness of the language surrounding diabetes, and identify potential improvements.

The power of language

> *"Words are, of course, the most powerful drug used by mankind"*
>
> Rudyard Kipling

People are sensitive to the implications of the words and phrases used to describe, categorise and label aspects of their identity; language can define them and their health. Language, and the attitudes it reflects, can affect self-confidence and motivation, and influence health and well-being directly or indirectly. Certain words and phrases can be de-motivating, inaccurate or even harmful. So, when communicating with *and* about people with diabetes, it is important to consider how your choice of language could affect their thoughts, feelings and behaviours.

Diabetes Australia recommends using language that encourages positive interactions, and positive outcomes when the person with diabetes leaves the interaction. Careful use of language applies equally to the conduct of health services, health professionals, family, friends and colleagues of people with diabetes, and the media.

Language can be inaccurate and harmful

Health professionals and family members, in particular, are in a position to influence people with diabetes positively or negatively. Sometimes, the language used can be inappropriate. Talking about 'good', 'bad', and 'poor control', people 'failing' to adopt certain self-care activities and/or being 'non-compliant' implies that:

- 'following orders' will result in perfect blood glucose levels all the time;
- the person with diabetes is acting irresponsibly or being 'difficult'.

Use of the terms 'compliant' and 'non-compliant' is particularly problematic. Such terms characterise the individual as cooperative or uncooperative, especially when used as adjectives to describe the person rather than the behaviour. Using these labels can mean opportunities are lost to ask relevant questions, develop collaborative goals, tailor treatment regimens and make referrals that actively support the person to manage his or her diabetes. Attempts to increase 'compliance' and 'adherence' generally involve persuading the person with diabetes to change his or her behaviour to fit the health professional's agenda.

Such attempts at persuasion can disregard the beliefs, priorities, preferences, skills and constraints of the individual or their life situation. Focusing on these issues is often the key to improving management plans and outcomes. For example, individuals labelled as 'non-compliant' may simply be exercising their right to make alternative rational decisions that are consistent with their explanatory models, experience, health capability, outcome goals or lifestyle. For example, people with higher blood glucose levels may be making active (but perhaps, silent) decisions to avoid hypoglycaemia. Conversely, those who experience recurrent severe hypoglycaemia may do so because they believe it will prevent them developing long-term complications. Such actions may well be consistent with the advice they received at diagnosis or over many years.

Language can reveal negative attitudes

The language used when discussing 'compliance' can reveal attitudes that:

- regard the person with diabetes as a passive and submissive recipient of care, who *should* follow the prescriptions of health professionals or services;
- define the person as 'weak-willed' or 'difficult';
- do not take into account the challenges the person with diabetes faces as he or she tries to reconcile conflicting and contradictory information—received from different health professionals, often within the same team or health service;
- disregard valid choices the person may have made or the complexities of emotions that they may be experiencing, such as anxiety about their diabetes or about the health consultation.

Language can reflect unrealistic ideas about diabetes

Much of the language surrounding diabetes is inaccurate when one reflects on the realities of diabetes:

- Despite people's best efforts, diabetes can be unpredictable and very difficult to manage;
- All people with diabetes go through stages when their own health is not their highest priority or their efforts seem less effective in managing their diabetes;
- Diabetes is a progressive condition. In type 2 diabetes, health professionals sometimes use the threat of insulin therapy to try to improve self-care. This threat can create fear and avoidance (psychological insulin resistance) and contribute to a sense of failure when insulin becomes necessary to achieve glycaemic control.

Can language influence outcomes?

Persistent references to 'failing to control' blood glucose levels leaves people with diabetes feeling that those around them do not recognise their efforts or that their diabetes can control them.

For people with diabetes, feelings of failure, frustration and self-blame are common consequences of unrealistic expectations. Many individuals stop confiding in their health professionals or family members to avoid judgmental or negative responses.

An important aspect of diagnosis and continuing care is using language that individuals can relate to, understand and feel comfortable with. Language must not de-motivate. Referring to health outcomes and medical results *without* using concrete terms such as 'control', 'good', 'bad' encourages individuals to think of blood glucose and HbA1c as indicators that continually change in response to many controllable and uncontrollable factors, e.g. hormonal changes, medications, emotions, physical health, food, activity.

Language can also create a power imbalance between the health system and the person with diabetes. Over-use of medical jargon can result in distrust of or over-reliance on health professionals who are assumed to 'know best'.

What kind of language is needed?

Many health professionals and services acknowledge that people with diabetes need to participate actively in their self-care yet continue to use disengaging words and phrases (see Table 1) that can disrespect the individual's autonomy. In many instances, such language is used naively, without full appreciation of its unintended meaning or impact. Rather, we need more careful use of language that:

1) promotes active engagement. Discussing 'diabetes management options' or 'self-management choices' encourages people with diabetes to be actively involved in making decisions about their own health;
2) supports the self-care efforts people make. Health outcomes depend largely on activities and choices people make outside of health consultations. Using respectful and comprehensible language can help individuals realise they are capable of and encouraged to make informed choices about their diabetes, and that their choices are respected;
3) acknowledges the frustrations, anxieties, guilt and distress that many people with diabetes experience.

2

DA Language Statement

Table 1: EXAMPLES OF LANGUAGE TO BE AVOIDED, RATIONALE AND EXAMPLES OF PREFERRED LANGUAGE

Avoid	Use	Rationale
Diabetic, sufferer, patient	Person with diabetes, Person living with diabetes	The term 'diabetic' defines the individual as their health condition. It is better to emphasise the person's ability to live with diabetes. Patients are people, and people are individuals, with their own preferences, priorities and lives beyond diabetes. The term 'patient' also implies the person is a passive recipient of care, rather than an active agent in his or her own self-care.
Disease	Condition	Disease has negative connotations of something that may be contagious and nasty. People with diseases are often avoided or feared. Diabetes is the results of a malfunctioning pancreas, a condition that the person will live with for the rest of their life.
Normal (person, blood glucose levels etc.)	People without diabetes; target, optimal blood glucose	Referring to people who do not have diabetes as 'normal' implies that people with diabetes are 'abnormal'. This is not the case and not the point. Similarly, referring to 'normal blood glucose levels' implies that levels outside this range are 'abnormal'.
Obese, normal weight	Unhealthy, healthy weight	The term 'obese' is frequently used to label a person, e.g., he or she is obese', in a way that frames the excess weight as a trait rather than a state. A trait is something that we have to live with (like personality), a state is something that can change. Furthermore, with excess weight fast becoming the norm in society, the term 'obese' does not convey the message that excess weight puts health at risk. Nor does it suggest to the person that he or she has the power and the means to change this risk factor.
Describing the person (e.g. 'he or she is ··· poorly controlled, cooperative, uncooperative')	Words that describe outcomes or behaviours ('his or her blood glucose is high')	Describing the person rather than the behaviour implies the behaviour will not and cannot change. It has fatalistic connotation. People with diabetes need to think of HbA1c and blood glucose levels as changing indicators that respond to a variety of factors. When health professionals use such labels, it suggests that they may have given up. Furthermore, it is futile to try to 'make' people change their behaviour or self-care activities. Diabetes requires a collaborative approach, not persuasion or coercion.
Poor control, good control, well controlled (referring to HbA1c or blood glucose levels	Stable, optimal, within the optimal range, or within the target range; suboptimal, high/low	Referring to 'poor' or 'good' control infers a moral judgment about the outcome, i.e. the person with diabetes has been good or bad. No one needs criticism when things are not going well. Taking the judgment out of the language acknowledges that a variety of factors affect optimal diabetes management, many of which are beyond the person's control. Furthermore, the individual's efforts need to be acknowledged regardless of outcome.
Should, should not, have to, can't, must, must not	You could consider ···, you could try ···, consider the following options ···, you could choose to ···	The individual is an expert in his or her own diabetes. Giving instructions about whether he or she should (or should not) do implies that: (a) you know better, and (b) not following the instruction renders the person morally deficient or uncooperative. Suggesting treatment options emphasises the individual's choices, acknowledges his or her autonomy and that he or she has ultimate responsibility for his or her own health.
Failed, failing to ···	Did not, has not, does not ···	'Failure' implies that one has aimed and missed the target. It implies lack of achievement, ineffective efforts or lack of effort. It also implies disappointment on the part of the person using the term. It is better in most circumstances to rely on facts and avoid judgments about the facts.
Compliance, compliant; non-compliance, non-compliant	Collaborative goal-setting	The term 'compliance' refers to the extent to which behaviour matches the prescriber's recommendations. It implies a lack of involvement in decision-making by the person with diabetes. It assumes the health professional's guidance was clear, does not conflict with the advice of others, and that the person with diabetes recalls the instruction clearly. It implies that people who do not comply are irresponsible or uncooperative. There is no single, convenient term to replace 'compliance'. Self-management of diabetes requires active, collaborative decision-making, taking into account the individual's preferences and priorities.
Chances (of complications etc.)	Health risks; risk of complications	Complications are not destiny nor are they entirely due to bad luck. Talking about an individual's 'chances' of developing complications suggests the person has no control over his or her future. It dismisses the very real efforts needed to delay of prevent their onset. Focusing on the individual's actual risk and what he or she can do to minimise it is more pro-active.
Blood tests, testing	Checking, monitoring, self-monitoring	'Tests' imply success or failure and an end result. Rather, people with diabetes need to monitor their changing blood glucose levels throughout their lives.
'Treating the patient'	Managing diabetes	Referring to 'treating the patient' implies something done to the person rather than the diabetes and ignores the active role of the person with the diabetes. 'Managing diabetes' enables the person with diabetes to actively engage in decision-making.

Recommendations

In your verbal and written interactions with or about people with diabetes, Diabetes Australia recommends:

1) Be aware of the language you use with each person with diabetes and when referring to people with diabetes.
2) Take your language seriously. Language is personal and so is diabetes. Think carefully about what words might mean to a person with diabetes mellitus and be aware your words may not be interpreted the way you intend.
3) Remember language reflects attitude. Do not use different language just because you are talking or writing about people with diabetes rather than with them.
4) Remember everyone is different. Some people will object to or be irritated by certain language; others may not. Regardless of an individual's immediate reaction (or lack of reaction), your language influences how they think, feel and act. Use language that most people would find helpful and encouraging.
5) Inform by don't judge. Avoid blame and any language that implies moral judgment about behaviours. Accept and respect that (a) the individual has the right to make choices, (b) that he or she has the responsibility for his or her own condition and (c) that diabetes may not always take priority in his or her life. Your language needs to reflect such understanding.
6) Be understood. Try not to use jargon. Listen to the words that person with diabetes uses and reflect that language. Wherever possible, check assumptions, understanding and the effect your language has on individuals.
7) Take a holistic approach. Diabetes is frustrating, challenging and distressing for many people. Focusing on their 'non-adherent' behaviour dismisses the very real efforts they may well be making.
8) Focus on the achievable. Wellness and health involve much more than just gaining 'control'; encourage optimal self-management and behaviour change using appropriate and encouraging language.
9) Appreciate that the meaning and acceptability of words and phrases changes over time. Continually reflect on your language and check your assumptions.
10) Remember language creates reality. People with diabetes need to know that their continual efforts to improve their health and self-care activities are worthwhile and valued. Focusing on the positive changes that people make and can continue to make in the future is more effective than focusing on past behaviours and outcomes.

Conclusions

Diabetes Australia believes communications with and about people with diabetes need to be:

- effective in helping people with diabetes manage an unrelenting and challenging condition
- sensitive to people's health capacity, situation, physical and emotional well-being, which all affect their everyday ability and motivation to manage diabetes effectively

Diabetes Australia recognises communication as a skill that can be improved through conscious efforts. Making subtle but significant changes to the words and phrases we use everyday makes a difference to how people with diabetes think, feel and act.

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Further reading

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Seley JJ (1993). Professional development: Is noncompliance a dirty word? *The Diabetes Educator*, 19(5): 386-391.

Thorne SE, Nyhlin KT & Paterson BL (2000). Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies*, 37(4): 303-311.

3 useful resources

General contacts

Type 1 Diabetes Network
www.t1dn.org.au
PO Box 1293, Kensington, VIC, 3031
0414 281 539
www.t1dn.org.au

National Diabetes Services Scheme
GPO Box 9824 (in your state or territory capital)
1300 136 588
www.ndss.com.au

Australian Diabetes Society
145 Macquarie Street, Sydney, NSW, 2000
02 9256 5462
www.diabetessociety.com.au
suzie@diabetessociety.com.au

Australian Centre for Behavioural Research in Diabetes
570 Elizabeth Street, Melbourne, VIC, 3000
03 8648 1844
www.acbrd.org.au
info@acbrd.org.au

Australian Diabetes Educators Association
PO Box 163,Woden, ACT, 2606
02 6287 4822
www.adea.com.au
inquiries@adea.com.au

Australasian Diabetes in Pregnancy Society
145 Macquarie Street, Sydney, NSW, 2000
02 9256 5462
www.adips.org
admin@adips.org

Australasian Paediatric Endocrine Group
APEG Secretariat, PO Box 180, Morisset, NSW, 2264
02 4973 6573
www.apeg.org.au
apeg@willorganise.com.au

Dietitians Association of Australia
Dietitians Association of Australia,
1/8 Phipps Close, Deakin, ACT, 2600
02 6163 5200
www.daa.asn.au
nationaloffice@daa.asn.au

Diabetes Australia Ltd
GPO Box 3156, Canberra, ACT, 2601
1300 136 588
www.diabetesaustralia.com.au
admin@diabetesaustralia.com.au

Diabetes Australia – Victoria
570 Elizabeth Street, Melbourne, VIC, 3000
1300 136 588
www.diabetesvic.org.au
mail@diabetesvic.org.au

Diabetes WA
Level 3/322 Hay Street,
Subiaco, WA, 6008
1300 136 588
www.diabeteswa.com.au
info@diabeteswa.com.au

Diabetes Tasmania
88 Bathurst Street, Hobart, TAS, 7001
1300 136 588
www.diabetestas.com.au
mail@diabetestas.com.au

Diabetes Australia – Queensland
29 Finchley St, Milton, QLD, 4001
1300 136 588
www.diabetesqld.org.au
info@diabetesqld.org.au

Diabetes SA
159 Sir Donald Bradman Drive,
Hilton, SA, 5033
1300 136 588
www.diabetessa.com.au
info@diabetessa.com.au

Healthy Living NT
Darwin: Shop 1 and 2, Tiwi Place, Tiwi, NT, 0810
Alice Springs: Shop 1, 9 Parsons Street, Alice Springs, NT, 0870
1300 136 588
www.healthylivingnt.org.au
Darwin E-mail: info@healthylivingnt.org.au
Alice Springs E-mail:
alicepsrings@ healthylivingnt.org.au

Australian Diabetes Council
Glebe Resource Centre and Office,
26 Arundel Street, Sydney, NSW, 2037
1300 342 238
www.australiandiabetescouncil.com
info@australiandiabetescouncil.com

Juvenile Diabetes Research Foundation Australia
There are offices in most major
state captials; check the website for contact details
www.jdrf.org.au

Mental Health resources

Beyond Blue
PO Box 6100, Hawthorn West, VIC, 3122
1300 22 4636
www.beyondblue.org.au

Kids Helpline
Kids Helpline Administration,
GPO Box 2469, Brisbane, QLD, 4001
1800 55 1800
www.kidshelp.com.au
admin@boystown.com.au

Lifeline
PO Box 173, Deakin, ACT, 2600
13 11 14
www.lifeline.org.au

Black Dog
Hospital Road, Prince of Wales Hospital,
Randwick, NSW, 2031
02 9382 4530
www.blackdoginstitute.org.au
blackdog@blackdog.org.au

Headspace
www.headspace.org.au/headspace-centres

Suicideline
1300 651 251
www.suicideline.org.au

Eating Disorders Victoria
Cnr Lulie and Abbotsford Streets,
Abbotsford, VIC, 3067
1300 550 236
www.eatingdisorders.org.au
help@eatingdisorders.org.au

The Butterfly Foundation
PO Box 453, Malvern, VIC, 3144, OR
103 Alexander Street, Crows Nest, NSW, 2065
1800 33 4673
www.thebutterflyfoundation.org.au
support@thebutterflyfoundation.org.au

Mental Health Foundation (ACT)
PO Box 78, Woden, ACT, 2606
02 6282 6658
www.mhf.org.au
info@mhf.org.au

The Centre for Eating and Dieting Disorders
Derwent House,
1–3 Derwent St, Glebe, NSW, 2031
02 8587 0200
www.cedd.org.au
info@cedd.org.au

The Eating Disorders Association Inc (Queensland)
12 Chatsworth Rd, Greenslopes, QLD, 4120
07 3394 3661
www.eda.org.au
admin@eda.org.au

Centre for Clinical Interventions
223 James Street, Northbridge, WA, 6003
08 9227 4399
www.cci.health.wa.gov.au
info.cci@health.wa.gov.au

MensLine Australia
1300 789 978
www.mensline.org.au

Diabetes Counselling Online
http://www.diabetescounselling.com.au

Australian Psychological Society
1800 333 497
www.psychology.org.au

SANE
1800 187 263
www.sane.org

Victorian Centre for Excellence in Eating Disorders
C/- PO, Royal Melbourne Hospital, Parkville, VIC, 3052
03 8387 269
www.ceed.org.au
ceed@mh.org.au