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evidence & practice
diabetes

Why you should read this article:

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Emotional well-being in patients with diabetes

Charlotte Gordon

Citation

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Peer review

This article has been subject to external double-blind peer review and has been checked for plagiarism using automated software

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Conflict of interest

None declared [Q can you confirm? Yes]

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Abstract

Diabetes mellitus is a condition characterised by elevated blood glucose levels leading to significant acute metabolic and long-term micro and macro vascular complications. Alongside these physical complications the condition can have substantial effects on people's emotional well-being, potentially resulting in diabetes distress and/or major depressive disorders. Timely assessment and referral of patients with diabetes who display signs and symptoms of diabetes distress or other mental health conditions are essential to limit the negative effects on their well-being. This article gives an overview of type 1 and type 2 diabetes and considers emotional well-being in patients with the condition. The article also examines some diabetes-specific validated assessment tools that can be used in practice and management and onward referral for people with diabetes who require support with emotional well-being.

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Keywords

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Key points

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Living with diabetes not only affects people's overall physical health but can also have a significant effect on emotional well-being. Understanding the complexity of diabetes enables nurses to gain insight into the emotional burden of the condition on patients. Acknowledging the importance of early assessment of emotional well-being and providing appropriate advice and onward referral is central to improving the well-being of people with diabetes and limiting long-term complications.

This article provides an overview of diabetes and the burden of living with the condition and suggests approaches to assessment using relevant tools and strategies for person-centred management.

Diabetes mellitus

Diabetes is a common long-term condition. Incidence in the UK has more than doubled in the last 15 years with around 4.9 million people (1 in 14) living with the condition, a figure predicted to rise to more than 5.5 million by 2030 (Diabetes UK 2021a). [Q? we've changed the wording slightly to reflect the stats in the document referenced. We couldn't find these stats in the WHO ref so we've taken it out - ok with edit? Yes]

Diabetes is characterised by chronically elevated blood glucose levels (hyperglycaemia) arising from relative or absolute deficiency of the hormone insulin, which is produced by the pancreas. Insulin regulates blood glucose levels by facilitating the uptake of glucose by the cells, where it can be utilised for energy. Type 1 and type 2 are the two main diabetes types, **alongside other rarer subtypes of the condition such as gestational diabetes, slower progressing forms of diabetes (latent autoimmune diabetes of adults) and diabetes arising from single gene mutations (monogenetic diabetes)** [Q such as? Could you add a couple of examples? Added] (World Health Organization (WHO) 2019).

Type 1 diabetes arises from an autoimmune attack of the insulin producing cells of the pancreas (beta cells) which are then no longer able to produce insulin. Type 2 diabetes, which is often secondary to obesity, is caused by cellular resistance to the action of insulin in response to which the pancreas produces increasing amounts of insulin to compensate; ultimately insulin secretion by the pancreas will become impaired (Holt and Kumar 2015). Around 90% of people with diabetes have type 2, 8% have type 1 and the remaining 2% have other more rare forms of the condition (Smyth 2020).

Diabetes management is complex, requiring lifestyle modification with regards to diet and physical activity, the cornerstones of optimal diabetes prevention and management (Khaltaev, 2021). In addition, daily medication and/or injections of insulin, alongside close monitoring of blood glucose levels may be required. [Q reviewer comment: 'It is important to consider that not everyone with diabetes will manage it with medication and/or injection. Just following a healthy lifestyle for some people can be as difficult and burdensome as having QDS insulin injections. Also diet and lifestyle are the cornerstones of diabetes management and should not be replaced by medication'. Please can you add some text to reflect this. Agreed, reference added] This places constant, daily demands on the individual for whom self-management is vital to reduce the risk of potentially fatal long-term complications such as cardiovascular disease, amputation, renal failure, neurological impairment, and vision loss (Paptheodorou et al, 2015) leading to ([Q such as? Could you add a couple of examples? Added], reduced quality of life and reduced life expectancy (National Institute of Health and Care Excellence (NICE) 2021a, Smyth 2020). Effective self-management requires constant motivation and changes in behaviours, therefore the effect of diabetes on people's psychological and emotional well-being can be profound (Diabetes UK 2018-2021 [Q there is a 2021 position statement – see query in reference list – please use updated ref]). Interview based research conducted by Kneek et al (2012), explored perceptions of diabetes 3 year post diagnosis, with 13 respondents and ~~who conducted interviews with 13 people who had been diagnosed with diabetes three years previously,~~ [Q addition ok? Yes but wording changed] highlighted how some participants perceived their life as having been 'invaded' by diabetes and acknowledged the significant challenges of managing the condition for the rest of one's life.

Diabetes and emotional well-being

The increasing incidence of diabetes **gives rise to a significant burden for the individual in relation to physical and emotional complications of the condition.** [Q can you clarify what you mean – eg. do you mean a burden in terms of healthcare system resources/costs? Is the increasing incidence means that more people need physical care/emotional support and this places pressure on health services? The text outlines that the burden is physical and emotional –clarified] People with long-term conditions **experience more physical** [Q physical?YES] complications if they also develop mental health problems (NHS England 2016). People with diabetes are twice as likely to experience depression and **are more likely to be depressed more frequently and for longer than the**

general population [Q than the general population? YES], while around 40% of people with diabetes struggle with their well-being due to the constant demands of the condition (Whicher 2020).

Karla et al (2018) posit that psychological factors can increase the risk of diabetes-related complications and mortality [Q is this the Kalra et al ref? Yes] outlining the complex association between diabetes and psychiatric disorders, describing how each affects the other in multiple ways as independent conditions either arising in tandem or contributing to the pathogenesis of each other. In addition, psychiatric conditions are a risk factor for the development of diabetes [Q is this also the Kalra et al 2018 ref? YES]. Despite this evidence, Jones et al (2014) argued that too often person-centred care, which incorporates psychological needs, is not available to many people with diabetes.

Well-being, quality improvement indicators and primary care resources

Diabetes UK (2017a) highlighted the importance of emotional and psychological support in its '15 Healthcare Essentials' package which advocates an annual written plan of care agreed between the patient and their healthcare team [Q addition ok? YES].

The package includes the need for discussion of patients' concerns about their well-being. Box 1 lists the 15 Healthcare Essentials. [Q box redrawn – please check text is accurate. Please revise to more clinical language: point 1 to say HbA1c level, remove '(for blood fats)' from point 3, change 4 to retinal screening. Change 6 to renal function test, change 12 to 'good care during hospital admission', change 14 to 'smoking cessation' change 15 to 'specialist care for those planning pregnancy']

Box 1. 15 Healthcare Essentials

1. Blood glucose test (HbA1c test)
2. Blood pressure check
3. Cholesterol check (for blood fats)
4. Eye screening
5. Foot and leg check
6. Kidney tests
7. Advice on diet
8. Emotional and psychological support
9. Group education course
10. Care from diabetes specialists
11. Free flu jab
12. Good care if you're in hospital
13. Support with any sexual problems
14. Help to stop smoking
15. Specialist care if you're planning to have a baby

Adapted from Diabetes UK (2017a)

Most diabetes management takes place in primary care with an estimated 20 million diabetes contacts annually, and nurses play a significant role in patients' ongoing review and management, predominantly for those living with type 2 diabetes (Dambha-Miller et al 2020; Ali et al 2021). It is notable that emotional and psychological support is not outlined as a Quality Outcome Framework (QOF) indicator for diabetes care (a system now focused on England to remunerate general practices based on specific outcomes) (NHS England, 2020). It is also not a measure definitively considered within the core National Diabetes Audit Programme 8 care processes (NHS digital, 2018, 2021), all measures being focused on morbidity and mortality related to physiological complications. Contention therefore exists between the demonstrable impact of diabetes on well-being and the metrics upon which health indicators are derived and measured within primary care. [Q can you expand on/explain this a bit more? I think the point about quality indicators (which I think is that effective diabetes management is based on physiological measures rather than holistic including emotional well-being?) needs to be made more clearly here to give context to the rest of the section. Perhaps you could also add a bit more on under-resourced nursing staff in primary care? (with references) have added back in in what I was asked to remove so this makes sense, refs added.] In addition, the NICE (2021) guideline for the care and treatment of adults with type 1 diabetes outlines the need identify the development or presence of clinical or subclinical depression or anxiety, particularly in relation to challenges with burden of self-

management and the impact upon it [Q do you mean in terms of how it affects self-management? Revised]. However, the recently revised NICE (2022) [this was updated this week – I have revised references] guideline on care of adults with type 2 diabetes makes no such reference to well-being, representing disparity between the importance placed on well-being for people with type 1 or type 2, when ultimately, the impact on well being is essentially the same.

In contrast, Ali et al (2021) identify the recent restructuring of Clinical Commissioning Groups (CCGs) to Primary Care Networks (PCN's) as an opportunity to strengthen joined up specialist care to address the holistic needs of the person with diabetes and recommend an integrated approach to physical and mental health across PCNs, making no differentiation between types of diabetes.

It has been argued that a reluctant consensus exists between patients, GP's, and nurses that in primary care, only minimum standards can be achieved with aspirations for high quality provision unlikely to be met (Dambha-Miller *et al*, 2020). Limited time, resources, and knowledge of current diabetes management strategies place pressure on primary care to meet treatment targets. This leads to frustration with the compromises to diabetes management, and confusion surrounding roles and responsibilities due to the multi-dimensional nature of diabetes care (Rushforth *et al*, 2016).

Maxwell *et al* (2013) noted that nurses described difficulty in incorporating assessments into routine review, the contention of replacing individualised care with mechanistic assessment, a disconnect between physical and mental health and uncertainties regarding onward referral or care provision. Higher levels of nursing staff have been significantly associated with better QOF performance in relation to DM with particular reference to blood glucose control, suggesting better intermediate clinical outcomes and real benefit associated with the nurse's role in improved patient outcome (Griffiths *et al*, 2010).

Only 30% of general practitioners, from a 1000 surveyed across the UK, felt that there was enough emotional and psychological support for patients with diabetes (DUK 2019a). Given the workload pressure of nurses in primary care, magnified during the COVID-19 pandemic, the focus on physiological measures of successful treatment and a lack of knowledge regarding DM management, it is not surprising that well-being related to DM may often be missed as a pivotal component of care. For the person living with DM, issues related to well-being are often more real and tangible than improvement in blood glucose levels (Jones, 2014).

Looking beyond the COVID-19 pandemic, PCN's will be supported to develop care delivery, addressing current gaps via 5 key priorities:

- Early referral and intensive treatment for people newly diagnosed with diabetes including attendance at structured education
- The focus for diabetes management should not solely reside in glycaemic management. Proposed care processes address the need for a holistic approach and the need to address long-term disease burden.
- PCNs will work within their new structures to deliver focussed care to certain groups and underserved populations in their localities e.g.: people with frailty, young adults, people of Black and Minority Ethnic (BAME) background, people with type 1 diabetes, people with learning difficulties.
- In order to deliver the above key priorities, the formation of a DiaST (Diabetes Support Team) within the PCNs is essential. Supporting structures for governance and training needs to be present within each PCN to enable this.
- Ensuring high-quality diabetes care across the board requires healthcare professionals delivering diabetes care are appropriately educated and upskilled in diabetes management, which will be supported by the PCN DiaST.

(Ali et al 2021)

A systematic review of the barriers to effective management of type 2 diabetes in primary care (Rushforth et al 2016) reported that limited time, resources and lack of confidence in knowledge of guidelines and skills make it challenging for primary care clinicians to meet treatment targets. [Q correct as edited? YES] This leads to frustration about the subsequent compromises in diabetes management and confusion about roles and responsibilities due to the multi-dimensional nature of diabetes care (Rushforth et al 2016). **Higher levels of nursing staff have been significantly associated with better outcomes in relation to optimal blood glucose control, suggesting real benefit associated with the nurse's role in care delivery (Griffiths et al 2010).** [Q I'm not quite clear what you mean or how this links to the rest of the paragraph—please can you reword/clarify? This was removed.....Again, I have put back in what I was asked to remove....and revised the paragraph—see above.]

Given the workload pressure of nurses in primary care, particularly during the coronavirus disease 2019 pandemic, the focus on physiological measures of treatment success, and the apparent lack of knowledge about diabetes management, it is not surprising that

addressing well-being in relation to diabetes as a vital component of care may often be missed [Q please add a ref]. For the person with diabetes, issues related to their well-being are often more tangible than improvements in blood glucose levels (Jones 2014).

Diabetes distress and major depressive disorder

People with all types of diabetes commonly experience psychological distress, including diabetes-related distress and more generalised distress which may develop into a major depressive disorder (Jones 2014). Early screening, prevention and treatment of diabetes distress or depression can result in improved diabetes self-management and quality of life for people with type 2 diabetes (Owens-Gary et al 2019).

Diabetes distress is a recognised emotional state in which people with diabetes experience guilt, fear, stress and denial arising from the burden of living with and managing their condition and its social effects (Young-Hyman et al 2016, Hardy 2021). The condition identifies people with diabetes with sub-clinical depression who do not meet the criteria for diagnosis of major depressive disorder (Kreider 2017). Diabetes distress is particularly associated with women and comorbid depressive symptoms (Perrin et al 2017).

Increasing diabetes distress correlates with elevated blood glucose levels and decreased efficacy of self-management, impaired quality of life and more frequent, severe hypoglycaemia (Hendrieckx et al 2019) (Fisher et al 2010) and affects up to 36% of people with type 2 diabetes (Perrin et al 2017) [Q Is there a more up to date reference/figure? Eg Diabetes UK stats? I was told I was relying too much on DUK stats! Have added a ref].

Diabetes and major depressive disorder frequently coexist and may be bi-directional, encompassing psychological and physiological factors [Q is this the Kreider 2017 ref? YES]. Major depressive disorder has an inverse relationship with optimal diabetes outcomes [Q does this mean they affect outcomes negatively? YES] (Kreider 2017). Significant depressive symptoms are seen in one in four people living with diabetes [Q with type 2 diabetes? Amended – all types] and more frequently affect women, while people with early diagnosis, a high body mass index, poor glycaemic control, associated complications [Q such as? An overview of this is discussed in the intro – is this needed again? Seems repetitive] and lower levels of education are more at risk of developing these symptoms (Hermans et al 2013). [Q correct as edited? YES]

Diabetes distress and major depressive disorder are closely associated and there is significant overlap of symptoms between the two conditions (Perrin et al 2017), although Gonzalez et al (2008) noted that although the symptoms of the conditions are related they are independent constructs. Symptom presentation may enable **clinicians to differentiate between the diabetes distress and major depressive disorder and support** [Q correct as edited? YES] appropriate assessment and management. Table 1 lists the main symptoms of diabetes distress and major depressive disorder (Kreider 2017).

Table 1. Main symptoms of diabetic distress and major depressive disorder (Kreider 2017)

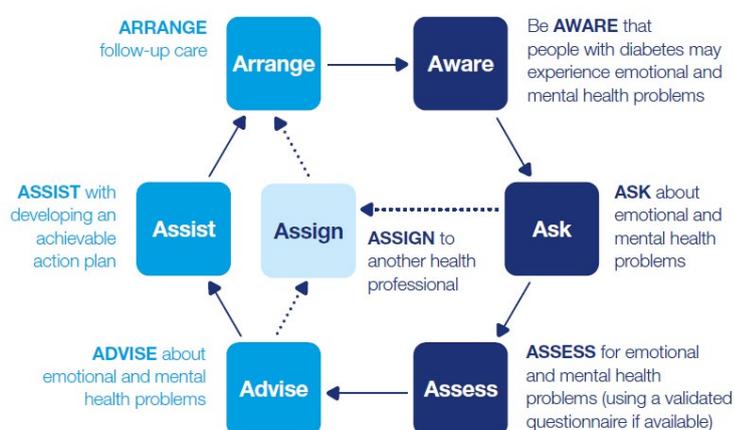
Symptoms of diabetes distress	Symptoms of major depressive disorder (five or more must be present and show significant change from baseline)
Unmotivated	Anhedonia (inability to feel pleasure in normally pleasurable activities) or depressed mood
Burned out	Diminished interest/pleasure in daily activities
Overwhelmed	Appetite changes (weight gain/loss)
Frustrated	Insomnia or hypersomnia
Defeated	Psychomotor agitation or retardation
Angry	Fatigue
Guilt	Feelings of worthlessness or guilt
Denial	Diminished concentration
Fear (for example, of hypoglycaemia/complications/needles)	
Loneliness	
Poor self-care behaviours	
Lack of concordance with diabetes treatment	

Assessment and management of well-being – the ‘7As’ model

The dynamic ‘7As’ model (Hendrieck et al 2019) (Figure 1) is a seven-step process that can be used by nurses in clinical practice. The model has been shown to have clinical utility and provides a memorable, consistent and logical pathway for screening and monitoring of issues related to emotional health as part of a person-centred approach [Q to the management of patients with diabetes? See amend] (Halliday et al 2020). The model provides prompts to assist healthcare professionals to identify diabetes distress (aware, ask, assess) and to initiate support (advise, assist, assign, arrange) and can be used to provide a summary of an issue related to well-being (Hendrieck et al 2019) [Q We’ve added some detail from the model – ok with edit? YES]

Figure 1. 7A’s model (Hendrieck et al 2019) [Q please provide evidence of permission to reproduce image – Dr Hatchett says you can assist with this?]

7As Model



Ask

Diabetes UK (2019b) provides guidance of how to have a ‘quality conversation’ about patients’ well-being using open-ended questions such as ‘how are you feeling?’ In any nursing consultation, it is vital to use appropriate language. **Poor communication can be hurtful, stigmatising and detrimental to clinical outcomes** [Q is this from NHS England 2018? YES]. Good use of language can build [Q patients? YES] confidence, reduce their anxiety and improve self-management (NHS England 2018).

Quality conversations should consider the following (Diabetes UK 2019, NHS England 2018):

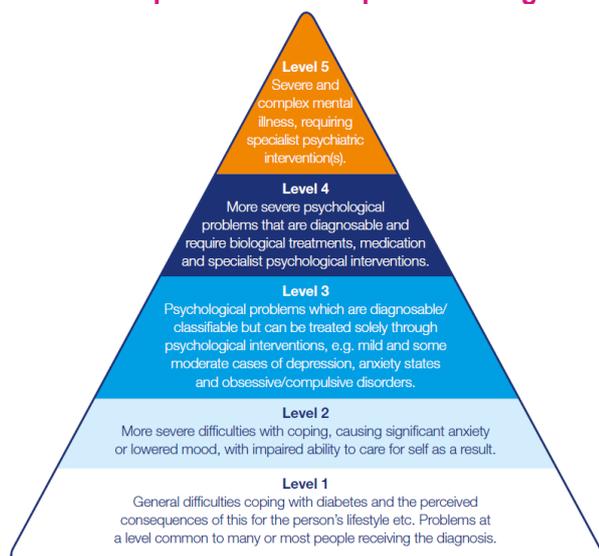
- » Step 1: Opening up a conversation: for example, by asking ‘How are you feeling?’
- » Step 2: Making the most of the conversation: **gain insight before the appointment through validated tools**, [Q do you mean ask patients to undertake a validated self-assessment before the consultation then use the responses as a prompt for exploring the issues raised during the consultation? YES] use open questioning, demonstrate active listening, reflection and positive verbal and non-verbal language, reflecting that of the person.
- » Step 3: Safely closing a conversation: for example, by agreeing actions at the person’s pace, asking them to summarise the discussion, offering them an opportunity to ask questions, ending on a positive, emphasising the importance of well-being and arranging another appointment to explore well-being or referring to a specific service or organisation as necessary.

Assess

Well-being in relation to diabetes may be considered a continuum from healthy coping, through diabetes distress, to mental health conditions such as major depressive disorder (NHS Diabetes and Diabetes UK 2010). The challenge for nurses is to support early identification of issues that can then be addressed as part of a person-centred approach. The pyramid of psychological problems (Figure 2) (Trigwell et al 2008, NHS Diabetes and Diabetes UK 2010) conceptualises this increasing complexity. Individuals may

move between levels over time and identification of which level a patient may be at can be supported by using validated assessment tools and open questioning.

Figure 2. Pyramid of psychological problems (NHS Diabetes and Diabetes UK 2010) [Q Please provide evidence of permission to reproduce image Dr Hatchett says you can assist with this?]



Assessment tools can support exploration, between the nurse and the person with diabetes, of diabetes-specific effects on well-being. They offer a starting point from which to guide conversations, identify issues of particular importance **and inform referral [Q to specialist mental health support when required? YES]** (Hendrieck et al 2019). There are several validated tools for the assessment of patient well-being specific to diabetes. The choice of tool should reflect the clinical purpose and ideally healthcare professionals should use the same tool to ensure consistency in measurement. **Professionals should also have appropriate training in using assessment tools if appropriate (Ali et al, 2021) [Q correct as edited? YES]**. Changes from baseline measures **can help to identify improvements or deterioration in patients' well-being** (Hendrieck et al 2019) [Q correct as edited? YES]. [Can you provide refs for this paragraph?]

The PAID scale (Figure 3) is a **self-reported measure of diabetes distress that [Q correct as edited? YES]** takes the form of a 20-item questionnaire, with each item rated on a 5-point Likert scale from 0 (not a problem) to 4 (a serious problem). Scores are added and multiplied by 1.25 to generate a score out of 100, scores of 40 or more indicate severe diabetes distress (Polonski et al 1995). In addition, an **individual item score of 3 or more indicates a problem area or concern correlating with level 1 of the pyramid of psychological problems (Figure 2) (Trigwell et al 2008, NHS Diabetes and Diabetes UK 2010). [Q changed ref as per reference in previous section for this figure. Please check YES] [Q what is the scale for overall/total score and what do these total scores indicate? Added – Sorry, not sure how that got deleted]**

According to Schmitt et al (2015), the PAID scale is preferable **to other commonly used self-report measures of diabetes distress** such as the diabetes distress scale [Q such as? added] as it ensures all concerns related to a person's diabetes are captured and assesses the effect of their diabetic distress on their quality of life, in line with person-centred care.

if the whole variety of diabetes related concerns is to be sought and if the impact of DD on quality of life is to be appraised aligning effectively to the concept of person-centred care for a diverse range of individuals [Q I'm not clear what you mean – suggest rewording something like this: '... to ensure that all concerns related to a person's diabetes are identified and to assess the effect of their diabetic distress on their quality of life, in line with person-centred care'? Amended]

Reddy et al (2013) noted that the PAID scale has established validity for detecting diabetes distress **in different diabetic populations (type 1 and type 2) [Q such as? Added]** and provides an entry point for discussions, thus overcoming the difficulty some nurses and patients may experience in broaching issues related to well-being.

Chawla et al (2009) conducted a longitudinal pilot study to assess whether providing primary care physicians with the results of the PAID questionnaire completed by their patients immediately before their consultation would improve patients' glycaemic control and satisfaction. [Q correct as added? YES] Findings suggested that this approach supported therapeutic dialogue, led to improved patient satisfaction with the quality of their care and improvements in PAID scores [Q what scores? added]. The authors concluded that the PAID scale has utility in the primary care setting to illuminate critical patient issues. ~~findings implied that conversations about diabetes distress reduced the incidence and/or of the condition.~~ [Q correct as edited?]

Figure 3. The PAID scale (Hendriek et al 2019) [Q please provide evidence of permission to reproduce image Dr Hatchett says you can assist with this?] **The statement on the tool says it can be used for non commercial reproduction – does that apply?**

Questionnaire		Problem Areas In Diabetes (PAID) scale				
Instructions: Which of the following diabetes issues are currently a problem for you? Tick the box that gives the best answer for you. Please provide an answer for each question.						
		Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
1	Not having clear and concrete goals for your diabetes care?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2	Feeling discouraged with your diabetes treatment plan?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3	Feeling scared when you think about living with diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4	Uncomfortable social situations related to your diabetes care (e.g. people telling you what to eat)?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5	Feelings of deprivation regarding food and meals?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6	Feeling depressed when you think about living with diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7	Not knowing if your mood or feelings are related to your diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8	Feeling overwhelmed by your diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9	Worrying about low blood glucose reactions?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10	Feeling angry when you think about living with diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11	Feeling constantly concerned about food and eating?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12	Worrying about the future and the possibility of serious complications?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13	Feelings of guilt or anxiety when you get off track with your diabetes management?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14	Not 'accepting' your diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15	Feeling unsatisfied with your diabetes physician?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16	Feeling that diabetes is taking up too much of your mental and physical energy every day?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17	Feeling alone with your diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18	Feeling that your friends and family are not supportive of your diabetes management efforts?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19	Coping with complications of diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20	Feeling 'burned out' by the constant effort needed to manage diabetes?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
<small>© Joslin Diabetes Center, 1999 (www.joslin.org). All rights reserved. The copyright holder/developer has given permission for the questionnaire to be reproduced in this guide. Readers of the guide are permitted to reproduce the questionnaire for clinical use and non-commercial research purposes. Readers of the guide are not permitted to use the questionnaire for commercial research purposes and must seek permission from the copyright holder/developer to do so.</small>						

[Q I've moved this from the advice section as I think it works better here – are you happy with that? - Yes]

~~Another method of assessment is~~ [Q correct as added? NO it isn't an assessment it is advice and a discussion tool]

Information prescriptions are a personalised single side of A4 which include images, easy to read explanations and individual goals to prevent diabetes related complications; they can be embedded into Primary care IT systems or downloaded for use and can be introduced into the patients care pathway at any time (Diabetes UK, 2017b)

[Q can you add something here about how nurses would use the tool – ie when would they introduce it to patients? Would they support patients to meet the goals they set themselves/signpost them to other services? Signposting is covered in the advise / assign section – moved to the top of the paragraph – OK?]

The Mood Information Prescription (Figure 4), ~~is a one page document that~~ aims to enable people with diabetes to talk about how they feel, manage their diabetes well and find practical ways to feel positive about living with the condition [Q ok with additional information? Yes - great] (Diabetes UK 2021b). The tool can support a structured conversation about well-being with the aim of

breaking down barriers between nurse and patient [Q to what?], acting as an effective conduit through which people can discuss their feelings and can lead to treatment for low mood, often for the first time (Diabetes UK 2021b).

Figure 4. Information prescription – diabetes and mood (Diabetes UK 2021b) [Q please provide evidence of permission to reproduce image Dr Hatchett says you can assist with this?]

Name: _____
Name of Doctor/Nurse: _____

Date: _____



Diabetes and mood

Information prescription

Living with a long-term condition like diabetes has its ups and downs, it not only upsets your body but your mind too. One in five of us feel depressed at some point in our lives, and it's even more likely if you're living with diabetes.

What makes people feel low?

Physical reasons: Some people have lower levels of 'feel good' chemicals in their brain. So if people in your family struggle with mood, you're more likely to.

Emotional reasons: The way we think can impact our mood. The more we listen to and dwell on negative thoughts the lower our mood may become.

Life events: Life can sometimes be difficult to deal with. When you're diagnosed with diabetes, or lose your job, or get divorced it can impact on your mood – which can be made worse if you feel lonely.





When should I seek help?

Whilst it is normal to sometimes feel down, watch out for some of these signs of depression or anxiety if happening daily for two weeks or more:

- not interested in looking after your diabetes
- feeling down or sad and tearful
- not being interested in or enjoying activities
- feeling hungry all the time or going off your food
- trouble sleeping or sleeping more than normal
- feeling restless or tired
- feeling useless, hopeless or guilty
- finding it hard to make decisions
- regular thoughts about hurting yourself.

My next steps

The two most important actions I am going to focus on are:
(Discuss and agree with your doctor or nurse. Think about what, where, when and how?)

1 _____

2 _____

How can I start to feel better?

It's normal for everyone to feel a little down from time to time and it doesn't always mean you're depressed. It's important to remember:

- It's normal to feel scared about having diabetes.
- It's normal to feel stressed about managing your diabetes and experience burnout.
- It's normal to feel nervous when your blood sugar levels are too high or too low.

Talk about your feelings

- Talking to friends or family can be a great help.
- Talking to other people with diabetes can help you learn how others manage when they feel low. Try our Helpline 0345 123 2399*, one of our local support groups or our online forum.diabetes.org.uk
- Talking therapies can help you find positive ways to cope, eg cognitive behavioural therapy, counselling or psychotherapy.

Discuss medication

- Your GP may suggest medication to help improve your mood and help with anxiety.

Make small lifestyle changes

- Looking after your body can improve your mood and your diabetes management. This includes eating a balanced diet, getting plenty of exercise and having enough sleep.
- Make time for yourself.
- Reading a self-help guide, available free online and in libraries.

Advise (assign)/assist/arrange

Patients' responses to tools such as the PAID scale can [Q addition ok? YES] enable the nurse to identify diabetes-specific factors related to well-being arising from emotional burden, management of the condition, the burden of treatment or lack of social support (Martin et al 2018). Using open-ended questions, which can be integrated easily into routine consultations (Hendrick et al 2019), enables **exploration and deeper understanding of an individual's issues highlighted by such an assessment** [Q correct as edited? YES].

For example, a patient's responses to the PAID questionnaire might indicate a lack of social support; this information, combined with open-ended questions used by the nurse in a subsequent consultation, may identify that they would benefit from peer support groups. [Q correct as edited? YES] Alternatively, responses and subsequent discussions that indicate burden of diabetes management may

identify that a patient would benefit from structured education programmes or access to technologies such as wearable glucose monitoring or insulin pumps [Q such as? added] (Martin et al 2018). Nurses could also signpost or refer patients to group-based educational interventions [Q addition ok? YES] which can be effective in improving biopsychosocial outcomes for people with diabetes (Odgers-Jewel et al 2017). Facilitating effective psychological and behavioural change in a supportive environment enables the development of individual and group-based change processes leading to improvements in health outcomes (Borek et al 2019). **Scores of 40 or more on the PAID scale [Q on the PAID scale? See previous query about total PAID scores - Answered]** indicate severe diabetes distress affecting a patient's well-being (Snoek et al 2011) and may suggest level 2-5 issues on the pyramid of psychological problems (Figure 2). The nurse may not have the necessary skills or confidence to address this level of diabetes distress, therefore a referral to a mental health specialist for more in-depth psychological assessment may be required. **PCNs should work in collaboration with mental health practitioners to ensure that appropriate mental and emotional health screening is done for people with diabetes from the first point of contact and regularly thereafter with clear referral processes (Ali, et al 2019). Increasing access to services for adults with common mental health problems with a focus on those with long-term conditions are evolving and it is expected that PCNs will work towards this type of integrated care for all people living with diabetes (Ali, et al 2019).**

However, many patients prefer to continue care with their current practitioner, therefore it is important that the nurse continues to see the person for routine clinical visits following their any referral for specialist care, to demonstrate their commitment to the person's ongoing management (Hendrieck et al 2019).

Conclusion

Diabetes distress is commonly experienced by people living with the condition and is associated **with poorer physical and mental health [Q physical health? Answered]** outcomes. Nurses must be aware of the effects of the condition on patients' well-being and are well placed to complete an initial assessment using open questioning and validated tools such as the PAID scale.

Nurses should act within the limits of their own knowledge and skills and make appropriate **onward** referral **for specialist support or management [Q for specialist support or management]** as necessary, while ensuring continued contact with the person to ensure consistency and effective long-term monitoring and care.

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