Living with diabetes can be challenging and, for some, it can be overwhelming, leading to the psychological condition known as diabetes distress. Dr Mark Davies, Consultant Clinical Psychologist, Belfast City Hospital, describes diabetes distress and its impact, and talks about how healthcare professionals can meet the challenge.
The principal role of all professionals working in diabetes care is to help people diagnosed with diabetes to adjust to living with a complicated, anxiety-provoking, burdensome and, at times, exasperating condition. Everyone diagnosed with diabetes is required to adjust their behaviour, and healthcare professionals are comfortable having conversations about taking tablets, injecting insulin, adapting eating habits, monitoring blood glucose and all the other behavioural tasks inherent in effective self-management. Equally, healthcare professionals understand that everybody diagnosed with diabetes has to make cognitive adjustments, such as learning about, and understanding, diabetes, risk perception, decision-making, and how to think in a crisis.

The majority of diabetes healthcare professionals, particularly those involved with self-management education, are also comfortable discussing, and attempting to influence, how people think about living with and managing their condition. Healthcare professionals also broadly appreciate that – to a greater or lesser degree – a diagnosis of, and living with, diabetes requires an emotional adjustment on the part of the person diagnosed. However, it seems that far fewer of us are comfortable having emotional conversations with the people we care for.

**Defining diabetes distress**

Because people with the condition are themselves in control of the management of Type 1 and Type 2 diabetes, their degree of adjustment (behavioural, cognitive and emotional) is the primary predictor of clinical outcome. Outcome measures, such as HbA1c, are traditionally used to determine whether somebody has made the adjustments required. High HbA1c suggests that a person has not adapted to living with diabetes, whereas low HbA1c is taken as a sign that somebody has made the necessary adjustments. Using HbA1c as a measure of adjustment is not without merit. Much effort and expense is devoted to collecting, collating and auditing HbA1c, blood pressure, cholesterol and so on.

However, the majority of diabetes services in the UK do not routinely undertake psychological measurement of adjustment. A small number of large-scale international studies (such as the Diabetes Attitudes Wishes and Needs study) have found that around 40% of people with diabetes, both Type 1 and Type 2, report measurable levels of poor psychological wellbeing. Until approximately 10 years ago, the diagnostic label most frequently given to people with diabetes who reported psychological distress was depression.

More recently, the assumption that everybody who presents with psychological distress should be considered to be suffering from – and should be treated for – depression has been questioned. In a series of studies, Fisher and colleagues undertook diagnostic interviews with people with both Type 1 and Type 2 diabetes who had self-reported clinically significant scores on depression questionnaires. It was found that up to 70% of those who scored highly on depression questionnaires did not meet diagnostic criteria for depression after a diagnostic interview had been conducted.

The question arises, therefore, if these people are not depressed, then what accounts for their psychological distress? Fisher and colleagues have proposed that these people were reporting genuine psychological distress, but that this distress was centred on living with diabetes. They coined the term ‘diabetes distress’, which has been described as ‘the unique, often hidden emotional burdens and worries that are part of the spectrum of patient experience when managing a severe, demanding, chronic disease like diabetes’.

**Measuring diabetes distress**

The 17-item Diabetes Distress Scale is a psychometrically validated assessment of diabetes distress. Reading through the 17 items that make up the Diabetes Distress Scale (see over), it is clear that around 40% of people with diabetes, both Type 1 and Type 2, report measurable levels of poor psychological wellbeing.

**Need for emotional care**

There has been a significant focus on the clinical significance of diabetes distress in the research literature in the last 10 years, and there is increasing evidence to support the notion that reducing diabetes distress improves HbA1c. Nevertheless, the amount of money spent on psychological research is still very small in comparison with the amount of money spent on biomedical research. Very little research has been undertaken asking people with diabetes themselves what they think might help them to manage the emotional burden of living with diabetes. A small-scale qualitative study undertaken with young adults with Type 1 diabetes in Ireland asked participants this question and found that what young people wanted was more diabetes education, more peer support groups and, crucially, more opportunity to talk to healthcare professionals about living with diabetes.

The young adults who took part in this study identified diabetes healthcare professionals as the people they wanted to talk to. This was because they recognised that diabetes healthcare professionals are in a better position to understand the challenges of living with diabetes, than those who work in services without diabetes experience.

It seems reasonable to suggest that, because everyone who lives with diabetes is impacted emotionally,
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The starting point is to engage with people with diabetes about their emotional and their psychological needs. Barriers raised by healthcare professionals include a perceived lack of time, a sense that healthcare professionals do not have the specific training required to take on this role effectively, anxiety about opening a Pandora’s Box, the absence of referral pathways and a sense that this is an issue that cannot be fixed. These issues must be acknowledged, and asking already overstretched healthcare professionals to take on a task they feel anxious about is likely to result in resistance. We must therefore consider how we can support healthcare professionals to feel more able to engage in emotional conversations. Having worked in diabetes services for nearly 20 years, I know that the vast majority of diabetes healthcare professionals are skilled communicators who are more than able to have emotion-focused conversations (they do so with their colleagues, friends and family every day). It seems there is something about the environment in which they work that makes it difficult for them to do so. Perhaps the emphasis on training healthcare professionals to fix – rather than to simply acknowledge – issues raised by their patients, or the gradual undermining of professional autonomy, have some role to play. Undoubtedly, the lack of referral pathways for issues that emerge and that cannot be contained by diabetes services discourages inquiries about emotional wellbeing, and this issue requires urgent attention both locally and nationally.

Nevertheless, perhaps the most powerful thing we can do as individuals and as services, at this point, is to move away from the search for complex fixes and to embrace the power of emotional acknowledgement. By simply asking ourselves “What would be the hardest thing if I were to be diagnosed with diabetes?”, we can begin to reflect on the emotional challenges that arise.

REFERENCES


5 Gonzales JS, Fisher L and Polonsky WH (2011): Depression in diabetes: have we been missing something important? Diabetes Care 34(1), 236–239


It seems reasonable to suggest that, because everyone who lives with diabetes is impacted emotionally, then emotional care should fall within the clinical bailiwick of every healthcare professional who works in diabetes services.
CHARLOTTE’S JOURNEY WITH DIABETES

I work at a national health charity as a Patient Involvement Manager. Most of my spare time involves playing some kind of sport or doing various activities including softball, strongman training and CrossFit. Three years ago, I started training to be a professional wrestler.

Unfortunately, a seizure at the end of last year (due to low blood glucose at night) and some issues with my joints, have forced me to take a bit of a break, but my heart still belongs in a wrestling ring.

Between my trusted insulin pump and Dexcom CGM, they manage to keep me safe and healthy. They’re a vital part of my diabetes management, particularly around training and physical activity. Sport and exercise are also a huge component of my diabetes management – physically and mentally. Throwing around grown men or flipping 100kg tyres come easy to me but the fact that my diabetes can make me vulnerable at any given time is infuriating.

I don’t remember diagnosis and much of my coping mechanisms were learnt ‘on the job’. Having been diagnosed in 1992, when psychological support wasn’t even a consideration for those living with Type 1 diabetes, I internalised so much of the emotional impact. Over the last five to 10 years, I’ve learned to talk about it a bit more openly, particularly with others with diabetes. It’s difficult, as you almost have to let go of your resilient guard in order to address the underlying issues.

After my most recent seizure, I resorted to joking about nearly dying... that’s just my coping mechanism but it’s fascinating to see reactions from other people.

I keep much of it on my own shoulders as I don’t want to be a burden. But I’ve learned it’s OK to share the load. A few days before my nephew, Charlie’s, 6th birthday, I had a seizure during the night and woke to my mum and brother putting me in the recovery position.

They’ve seen it all before. But the next day I was determined not to let diabetes ruin Charlie’s birthday, so I gritted my teeth and we went horse riding in the rain, followed by afternoon tea.

Type 1 diabetes is hard. It’s relentless and has zero respect for any other aspects of life. One of the biggest challenges for me is around ‘all’ the things you have to remember when living with Type 1. The number of times my insulin pump cannula has sweated off in the gym and I didn’t have a spare in my bag is quite scary. My brain is constantly full with stuff I need to remember for my diabetes, which makes general adulting even more challenging!

What has helped the most?

Fortunately, psychological care is integrated throughout the whole of my local diabetes service. All members of the team (including consultants, DSNs and dietitians) have been trained in identifying those at risk of diabetes distress. If they feel that you need more support, they can refer you to the clinical psychologist (or you can ask to be referred).

My diabetes team uses tools, such as the Type 1 Consultation Tool questionnaire, at every appointment to understand who might be at higher risk of diabetes distress. I’ve been playing this diabetes game for a while, so I don’t get surprised by much (physically or emotionally). But asking for help isn’t easy.

However, after switching to a new pump which didn’t work at all for me, I told my DSN that I couldn’t carry on as I was on the brink of tears after eight weeks of daily pump stress. She took this seriously and actioned another pump to try right away. My biggest reservations would be if I admitted to struggling and nothing practical done – talking is all well and good, but actions speak louder than words.

Another example is the sleep anxiety that I struggled with after having a seizure during the night.

I contacted my DSN and consultant, who then sent me some resources from the clinical psychologist. A couple that work well for me are falling asleep to ‘white noise’ in the background, and mindful breathing during the day (the Breathe app on Apple Watch is great for this).

It’s this multidisciplinary approach that I value so much. The fact that there is a psychologist as part of the service, means ad hoc support can be given when needed.

Diabetes UK and me

One of the biggest turning points for me was getting involved with Diabetes UK, particularly the Young Person’s Programme in Wales, shortly after finishing university. I met others to share experiences and journeys with and, more importantly, making lifelong friends. From that, I’ve gone on to be involved with the Grants Advisory Panel, the Council of People Living with Diabetes and the Young Adults Panel at Diabetes UK. These activities all give me a forum to help shape future diabetes services, but they also give me so much hope. We’re constantly working to make the future better for people with diabetes.

PHOTO: CHARLOTTE AUSTIN