

## Diabetes distress

We already know that living with diabetes affects emotional wellbeing – and the link between depression and the condition is established. But diabetes distress is less well known. Clinical psychologist **Dr Jen Nash**, Director of the education and training company Positive Diabetes, looks at how healthcare professionals can understand and deal with diabetes distress in their patients

Diabetes distress (also known as diabetes burnout) has been defined as the unique, often hidden, emotional burdens and worries that are part of the spectrum of patient experience when managing a severe, demanding chronic condition like diabetes<sup>1</sup>. It may encompass:

- factors relating to the demands of the diabetes regime
- interpersonal issues
- relationships with care givers
- emotional burden.

A large multinational cross-sectional analysis has estimated the point prevalence of high diabetes distress to be 44 per cent<sup>2</sup>, while studies in the United States position prevalence of high levels of diabetes distress at just over 20 per cent<sup>3</sup>.

### Recognising diabetes distress

Possible signs of diabetes distress include:

- a sense of being overwhelmed and defeated by diabetes
- anger about diabetes, feeling frustrated by the self-care regime and/or having strong negative feelings about diabetes
- feeling that diabetes is controlling their life
- worrying about not taking care of diabetes well enough, yet unable, unmotivated or unwilling to change
- avoiding diabetes-related tasks that might give feedback about the consequences of poor control (eg, blood glucose monitoring, attending medical appointments)
- feeling that caregivers and healthcare professionals are unable to truly understand
- feeling alone and isolated with diabetes.

Diabetes distress is conceptually different from depression. It is a rational, natural response to the demands of living with a long-term condition, and is therefore not a 'disorder'. While depression leads a person to have negative thoughts about themselves and others and hopelessness about the future, diabetes distress centres on feelings focused specifically on diabetes, and the person may not necessarily appear low in mood to the outside observer. Diabetes distress has consistently been demonstrated to be associated with significantly elevated HbA1c. For example, both cross-sectional and longitudinal analyses of people with Type 2 diabetes have found that diabetes distress, but not depression, is associated with higher HbA1c<sup>4,5</sup>.

There are two formal assessment measures for diabetes distress – the Problem Areas in Diabetes Scale (PAID)<sup>6</sup>, which is freely available for download from the Diabetes

Attitudes, Wishes and Needs (DAWN) website (see Resources box) and the Diabetes Distress Scale (DDS-17)<sup>7</sup>. In time-limited practice, the short form of the DDS-17 can be used – the DDS-2<sup>3</sup>.

### The DDS-2 measure of diabetes distress

Thinking over the past month –

- 1** Do you feel overwhelmed by the demands of living with diabetes?
- 2** Do you feel that you are often failing with your diabetes regime?

Answer each question on a scale of 1–6, where 1 is not a problem, and 6 is a serious problem. Mean scores of > 3 have been suggested to be an indication for further investigation for diabetes distress<sup>3</sup>.

### Support for diabetes distress

National Institute for Health and Care Excellence guidelines advise access to psychological support for people with Type 1 and Type 2 diabetes but, despite this, current provision for psychologists is limited. In time-limited settings, it can be challenging for the healthcare professional to broach these themes but, with willingness, a sense of support can actually be conveyed in a very short time, as follows:

- Acknowledge that it is usual to experience these feelings. Emphasise that diabetes distress is not a mental health condition, but rather a natural and common aspect of living with the demands of diabetes. Given that interactions with healthcare professionals can actually be one source of diabetes distress, simply acknowledging the fact that diabetes is difficult to live with may relieve some of the stress experienced by the person with diabetes.
- Show empathy and offer support. Reassure the person that many people with diabetes experience diabetes distress and that there is support available (see resources box).
- Offer referral to self-management education. Self-efficacy and a sense of mastery over diabetes may be important in reducing regime-related distress<sup>8</sup>. Referral for structured diabetes education can enhance a person's confidence in their ability to manage their diabetes and peer support can also be gained. The

acceptability of any such referral to the person must be assessed, however, and great care must be taken that they understand this is not an indication that they are a 'bad patient'.

- Adopt a different paradigm. Discussing emotional distress with people with diabetes can be a daunting prospect. Time pressures placed on healthcare professionals are a significant barrier, as are worries about opening a 'can of worms' or concerns about a perceived lack of training. Conversations about emotional themes may be challenging for healthcare professionals, because they do not adhere to the medical model approach of 'fixing' with a prescription. Healthcare professionals are reminded that, although it may not feel like much has been achieved in these normalising conversations, simply allowing the person to voice their feelings and having them heard and normalised is very therapeutic. As diabetes distress impacts HbA1c, conversations about it are potentially as clinically meaningful as offering glucocentric medical advice<sup>9</sup>.

## Diabetes UK resources to recommend for people with diabetes

- **Diabetes UK Support groups:** Diabetes UK voluntary groups provide a useful social forum for discussion and can be helpful in dealing with feelings of isolation or marginalisation.
- **Peer Support:** This service offers an opportunity for people with diabetes, their parents, partners or carers to talk to someone in a similar situation. The service can be contacted on 0843 353 8600, by email at [talktosomeone@diabetes.org.uk](mailto:talktosomeone@diabetes.org.uk) or online at [www.diabetes.org.uk/peersupport](http://www.diabetes.org.uk/peersupport) or at Google+ Hangouts.
- **Careline:** This is a telephone counselling service run by Diabetes UK. It is free and can be reached Monday to Friday 9am–7pm via telephone on 0345 123 2399\* or e-mail at [careline@diabetes.org.uk](mailto:careline@diabetes.org.uk) or [carelinescotland@diabetes.org.uk](mailto:carelinescotland@diabetes.org.uk)

## Further reading and resources

- Polonsky W (1999). *Diabetes Burnout: What to do when you can't take any more*. American Diabetes Association
- Nash J. *Diabetes and Wellbeing: Managing the Emotional and Psychological Challenges of Type 1 and Type 2 Diabetes* (Chichester, Wiley-Blackwell, 2013)
- Positive Diabetes ([www.PositiveDiabetes.com](http://www.PositiveDiabetes.com)) is a website dedicated to helping people to cope with the emotional impact of diabetes, facilitated by Dr Jen Nash, clinical psychologist living with Type 1 diabetes
- Problem Areas in Diabetes Scale (PAID) can be accessed for free at [www.dawnstudy.com](http://www.dawnstudy.com) (search on Tools and Resources and select Dialogue Tools to find the PAID questionnaire).

## References

- 1 Fisher, L., Hessler, M., Polonsky, W.H et al (2012). When is diabetes distress clinically meaningful?: establishing cut points for the Diabetes Distress Scale. *Diabetes Care* 35 (2); 259–264
- 2 Nicolucci A Kovacs Burns K Holt RI et al (2013). Diabetes Attitudes, Wishes and Needs second study (DAWN2™): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabetic Medicine* 30 (7); 767–777
- 3 Fisher L, Skaff MM, Mullan JT et al (2008). A longitudinal study of affective and anxiety disorders, depressive affect and diabetes distress in adults with type 2 diabetes. *Diabetic Medicine* 25 (9); 1096–1101
- 4 Fisher L, Mullan JT, Areal P et al (2010). Diabetes distress but not clinical depression or depressive symptoms is associated with glycemic control in both cross-sectional and longitudinal analyses. *Diabetes Care* 33 (1); 23–28
- 5 Polonsky WH, Anderson BJ, Lohrer PA et al (1995). Assessment of diabetes-related distress. *Diabetes Care* 18 (6); 754–760
- 6 Polonsky WH, Fisher L, Earles J et al (2005). Assessing psychosocial distress in diabetes: development of the diabetes distress scale. *Diabetes Care* 28 (3); 626–631
- 7 Fisher L, Glasgow RE, Mullan JT et al (2008). Development of a brief diabetes distress screening instrument. *Annals of Family Medicine* 6 (3); 246–252
- 8 Zagarins S, Allen N, Garb J et al (2012). Improvement in glycemic control following a diabetes education intervention is associated with change in diabetes distress but not change in depressive symptoms. *Journal of Behavioural Medicine* 35 (3); 299–304
- 9 Berry E, Lockhart S, Davies M et al (2015). Diabetes distress: understanding the hidden struggles of living with diabetes and exploring intervention strategies. *Postgraduate Medical Journal* 91 (1075); 278–283