

EMOTIONAL SUPPORT AND PSYCHOLOGICAL CARE FOR PEOPLE WITH DIABETES

Position Statement - Updated: August 2021

Why have we produced this position statement?

Diabetes is a complex and demanding condition with potentially debilitating complications. Effective management is largely dependent on how people are able to care for themselves; this requires constant personal motivation and changes in behaviour and routine. Not surprisingly, the impact of diabetes on emotional and psychological wellbeing can be profound. The increased risk people with diabetes have faced during the pandemic has further exacerbated this impact, 35% of respondents with diabetes have experienced poor mental health during the pandemic, largely driven by a lack of healthcare support and increased anxiety.¹ The Mental Health Recovery Plan makes no mention of people with long term conditions, despite the poorer mental health outcomes they face. The insight we have gathered on the topic from people affected by diabetes has told us that the emotional and psychological impacts of the condition should be recognised and addressed throughout their diabetes care. Furthermore, type 2 diabetes is more common in people with a serious mental illness (SMI), which supports the need for mental health care services to implement approaches that consider and support physical health.

How did we develop this position?

We developed this through our knowledge and insight gained from:

- An online survey of people affected by diabetes, which collected 2,667 responses from people with diabetes and 351 from parents and carers.
- An online survey of psychological services for people living with diabetes, which collected responses from 155 healthcare professionals involved in diabetes services.
- 32 in-depth face-to-face interviews were carried out with people living with or caring for (including parents of) someone living with diabetes. Conducted by research agency Magenta.
- GP poll, conducted by research agency ComRes, collected responses from over 1,000 GPs across the UK.
- In-depth discussions with services providing emotional and psychological support for people living with diabetes.

¹ Diabetes UK (2021), 'Diabetes can't wait – The importance of diabetes care and prevention in building back a better health system' Available at: [Diabetes is Serious Report Final.pdf \(amazonaws.com\)](#)

- Insights from an expert group of diabetes and mental health specialists convened by NHS England and Diabetes UK.
- Reviewing the current literature around diabetes and emotional and mental health
- Reviewing national guidance around diabetes and emotional and mental health

What we say about this issue

Difficulties with emotional health and psychological wellbeing in people with diabetes can affect quality of life², ability to self-manage³, glycaemic control⁴, and can increase healthcare costs⁵. The psychological and emotional wellbeing of people with diabetes must be an integral part of diabetes care and, to an appropriate degree, the responsibility of commissioners and care providers alike. Support should be available at all levels of need, from emotional support around the time of diagnosis, through to specialist support from a mental health professional who has an understanding of diabetes. Specialist support must not be limited to people with ‘diagnosable/classifiable’ mental health conditions, as common problems such as diabetes distress or ‘sub-threshold’ depressive symptoms also have a negative impact on diabetes self-management, quality of life and health outcomes. Furthermore, type 2 diabetes is two to three times more common among people with SMI than the general population. People with SMI die 10 to 20 years earlier than those without and it is thought that long term conditions such as diabetes contribute to this mortality gap. Therefore, diabetes action planning and access to self-management support is critical for those being cared for in mental health services⁶.

Diabetes UK has developed UK-wide recommendations for the healthcare system to further enable emotional and psychological support for people with diabetes, based on the insight detailed above.

Diabetes UK Recommendations:

- The emotional and psychological impact of diabetes should be recognised in all diabetes care through systematic care and support planning and better conversations.
- The NHS and the third sector at a national and local level should work together to provide services such as peer support, community groups, education and self-help resources for people affected by diabetes.
- Services providing diabetes care should be supported by specialist mental health professionals, including psychologists and liaison psychiatrists, to ensure effective provision across all levels of need.

² Goldney R, Phillips P, Fisher L et al (2004). Diabetes, depression, and quality of life: a population study. *Diabetes Care* 27; 1066–70

³ Gonzalez JS, Peyrot M, McCarl LA et al (2008). Depression and diabetes treatment nonadherence: A Meta-Analysis. *Diabetes Care* 31 (12); 2398–2403

⁴ Lustman P, Anderson R, Freedland K et al (2000). Depression and poor glycaemic control: a meta-analytic review of the literature. *Diabetes Care* 23; 934–942

⁵ Mental Health Taskforce (2016). *The Five Year Forward View for Mental Health: A report from the independent Mental Health Taskforce to the NHS in England*

⁶ Ashworth M, Askey A, Cohen A, Ismail K, (2018). Diabetes outcomes in people with severe mental illness; *British Journal of General Practice*. DOI: <https://doi.org/10.3399/bjgp18X695381>

- An integrated care pathway for diabetes and emotional and psychological wellbeing should be developed and implemented in and across each UK nation.
- All healthcare professionals providing general diabetes care should have the training and skills to identify and support the emotional and psychological wellbeing of people affected by diabetes.⁷
- Mental health professionals providing care for people affected by diabetes should have knowledge of diabetes and an understanding of the impact the condition can have on physical, emotional, and psychological wellbeing.
- Lessons learnt from pilot schemes such as diabulimia pilots and the rollout of Improving Access to Psychological Therapies (IAPT) for adults with Long Term Conditions (LTC) service in England need to be reviewed and implemented wider across the UK.

For recommendations specific to decision makers and stakeholders in each of the UK nations, please refer to:

[Emotional and psychological support - England recommendations](#)

[Emotional and psychological support – Northern Ireland recommendations](#)

[Emotional and psychological support – Scotland recommendations](#)

[Emotional and psychological support – Wales recommendations](#)

Evidence and analysis

7 out of 10 people with diabetes who completed a survey in 2019 on the emotional and psychological impact of diabetes said they felt overwhelmed by the demands of their condition⁸. It is estimated from further research that around 40 per cent of people with diabetes experience poor psychological wellbeing at any one time⁹. Depression is twice as common in people with diabetes as in the general population^{10,11}, and people who experience depressive symptoms tend to have difficulties with self-management, even if they do not meet the diagnostic criteria for clinical depression¹². Depression and anxiety can be directly related to a person's struggles with their condition. The pandemic has further added to these strains with 35% of people

⁷ Reference the range of resources found here [Diabetes and psychological care | Diabetes UK?](#)

⁸ Diabetes UK (2019) 'Too often missing: making emotional and psychological support routine in diabetes care' Available at: https://www.diabetes.org.uk/resources-s3/2019-05/Full%20Report_Too%20Often%20Missing_Diabetes%20UK_May%202019.pdf

⁹ Peyrot M et al (2005) Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitude, Wishes and Needs (DAWN) Study. *Diabetic Medicine* 22: 1379-1385.

¹⁰ Mommersteeg PM, Herr R, Pouwer F et al (2013). The association between diabetes and an episode of depressive symptoms in the 2002 World Health Survey: an analysis of 231,797 individuals from 47 countries. *Diabetic Medicine* 30 (6); 208–214

¹¹ Roy, Tapash & Lloyd, Catherine. (2012). Epidemiology of depression and diabetes: A systematic review. *Journal of affective disorders*. 142 Suppl. S8-S21. 10.1016/S0165-0327(12)70004-6.

¹² Gonzalez JS, Peyrot M, McCarl LA et al (2008). Depression and diabetes treatment nonadherence: A Meta-Analysis. *Diabetes Care* 31 (12); 2398–2403

reporting experiencing poor mental health during the pandemic due to their diabetes.¹³

There are also specific emotional and psychological problems relating directly to diabetes. Diabetes distress involves feelings of frustration and defeat due to the demands of diabetes. Evidence from 50 studies undertaken across the world tells us that one in four people with Type 1 and one in five people with Type 2 diabetes have high levels of diabetes distress that is likely to be negatively affecting how they manage their diabetes. Research has also shown that around one in fifty people with type 1 diabetes and around one in ten people with type 2 diabetes have an eating disorder. Eating disorders include binge eating disorders and the restriction of insulin in order to lose weight, termed 'Type 1 disordered eating or 'diabulimia'. Other problems experienced by people with diabetes include diabetes specific fears, such as fear of hypoglycaemia, and psychological barriers to insulin use¹⁴.

Insight from Diabetes UK has found that adequate specialist support for diabetes-related psychological problems is lacking. Of those people with diabetes who responded to a 2018 survey on emotional and psychological support, three quarters were not able to access the specialist emotional support they felt they needed. The research found that the current provision of psychological care is inadequate and extremely variable. While there are pockets of good practice, there is a need for systemic change to break down the divide between physical and mental health in diabetes care¹⁵. These findings were echoed by an enquiry held by the All Party Parliamentary Group for Diabetes in 2018, which heard from a number of people living with both Type 1 and Type 2 diabetes and their carers, as well as healthcare professionals and researchers¹⁶.

The importance of emotional and psychological support for people with diabetes is recognised at a national level, although NICE guidance for managing Type 1 and Type 2 diabetes in adults could recognise further the psychological impact of diabetes. NICE sets out a stepped care model for managing depressive symptoms in adults with chronic physical health problems¹⁷. For children and young people, the Paediatric Best Practice Tariff¹⁸, NHS England's Diabetes Transition Service Specification¹⁹, and the All- Wales Standards for People with Diabetes Moving from Paediatric to Adult Services within NHS Wales²⁰ stipulate that access to psychological support should be integral to the diabetes multi-disciplinary team.

¹³ Diabetes UK (2021), 'Diabetes can't wait – The importance of diabetes care and prevention in building back a better health system' Available at: [Diabetes is Serious Report Final.pdf \(amazonaws.com\)](#)

¹⁴ Diabetes UK (2019) 'Diabetes and emotional health - a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes'. Available at: <https://www.diabetes.org.uk/professionals/resources/shared-practice/psychological-care/emotional-health-professionals-guide>

¹⁵ Diabetes UK (2019) 'Too often missing: making emotional and psychological support routine in diabetes care' Available at: https://www.diabetes.org.uk/resources-s3/2019-05/Full%20Report_Too%20Often%20Missing_Diabetes%20UK_May%202019.pdf

¹⁶ All Party Parliamentary Group for Diabetes (2018) Emotional and Psychological Support for People Living with Diabetes <https://diabetesappg.wordpress.com/author/matthewlower/>

¹⁷ NICE (2009). NICE guideline CG91: Depression in adults with a chronic physical health problem

¹⁸ Paediatric diabetes best practice tariff. Available at: www.diabetes.org.uk/Documents/nhs-diabetes/paediatrics/Paediatric%20Diabetes%20Best%20Practice%20Tariff%20Criteria.pdf

¹⁹ NHS England (2016) Diabetes Transition Service Specification <https://www.england.nhs.uk/wp-content/uploads/2016/01/diabetes-transition-service-specification.pdf>

²⁰ http://www.cypdiabetesnetwork.nhs.uk/files/4015/2631/0959/Transition_Standard_ReportV8.pdf

Research has also shown that people with SMI and diabetes do not always have adequate support to help them manage their diabetes, and suggests that integrating diabetes action plans into care planning is needed, as well as providing psychological support²¹. Healthcare professionals in diabetes services, primary care and mental health services also have a responsibility in ensuring that people with SMI and diabetes are not disadvantaged²². Furthermore, it is important for clinicians to be aware of the increased risk of the development of type 2 diabetes in those with SMI, as SMI is a risk factor for the condition, and some psychiatric medication is diabetogenic²³.

Diabetes UK worked with an expert working group in England, to set out what best practice should look like in local areas to support the emotional and mental health needs of people with diabetes across all levels of need. This includes a person centred approach with psychological and emotional health supported at diagnosis and beyond, ensuring that people have their needs identified and acted on. That people with diabetes have access to care from diabetes specialist mental health professionals. That people with diabetes are effectively signposted to information and peer support, and referred to structured education programmes. Also that all people with, or at risk of, diabetes who are accessing mental health support in a specialist or primary care setting should have diabetes considered within their care.

Diabetes UK recently worked with National Voices to look at how to support the emotional and mental health needs of people with long-term conditions, including diabetes.. The report of this work makes 10 recommendations for healthcare leaders to ensure that conversations about mental health are taking place and support is being offered where needed²⁴.

Overall, evidence suggests that emotional and psychological support should be included as part of ongoing comprehensive care for all patients with diabetes and not addressed as a separate co-morbid 'condition' that is diagnosed and treated only when detected^{25, 26}. A collaborative care approach can improve physical outcomes, as well as wellbeing and overall quality of life^{27, 28}.

²¹ Mulligan, K., McBain, H., Lamontagne-Godwin, F. *et al.* Barriers to effective diabetes management – a survey of people with severe mental illness. *BMC Psychiatry* **18**, 165 (2018) doi:10.1186/s12888-018-1744-5

²² [Holt RI, Mitchell AJ](#) (2015) Diabetes mellitus and severe mental illness: mechanisms and clinical implications.

²³ Cohen, A. (2018). Diabetes and Severe Mental Illness

²⁴ [Ask How I Am: Supporting emotional health among people living with long-term conditions | National Voices](#)

²⁵ Diabetes UK (2019) 'Too often missing: making emotional and psychological support routine in diabetes care' Available at: https://www.diabetes.org.uk/resources-s3/2019-05/Full%20Report_Too%20Often%20Missing_Diabetes%20UK_May%202019.pdf

²⁶ Fisher L, Gonzalez JS, Polonsky WH (2014). The confusing tale of depression and distress in patients with diabetes a call for greater precision and clarity. *Diabetic Medicine* **31**; 764–772

²⁷ Katon WJ, Lin EHB, Von Korff M *et al* (2010). Collaborative care for patients with depression and chronic illnesses. *New England Journal of Medicine* **363**; 2611–20

²⁸ Diabetes UK (2019) 'Diabetes and emotional health - a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes'. Available at: <https://www.diabetes.org.uk/professionals/resources/shared-practice/psychological-care/emotional-health-professionals-guide>