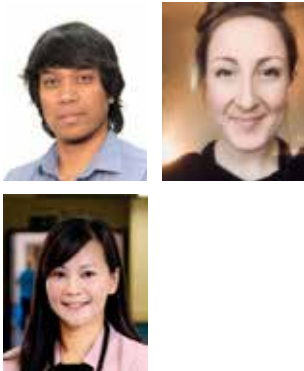


Delivering the NHS Long Term Plan to ensure young people with diabetes have the care they need for their mental health



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Living with diabetes is not easy. It can be a daily struggle, both for children and young people (CYP) with the condition and those close to them. It is essential that CYP with diabetes are supported to manage their diabetes effectively to prevent the development of early complications as diabetes and emotional wellbeing form a two-way street: the condition can affect mental wellbeing, and mental health difficulties make managing the condition more challenging.

How diabetes impacts the paediatric and transition populations

Education and self-management are key aspects aimed towards maintaining good glycaemic control. Research has shown significant associations between psychosocial factors and metabolic control in a large international cohort of children and adolescents with type 1 diabetes (Hoey, 2009). This is reflected in NICE guidance (2016a), which highlights that psychological issues, such as anxiety, depression and eating disorders, have a significant and adverse impact on the management of diabetes and the wellbeing of CYP and their family members and carers (NICE, 2016a). The Hvidøre Study Group on Childhood Diabetes reports that assessment of mental health should be an integral part of a paediatric diabetes care pathway for this population (Hoey, 2009). In a systematic review of psychological interventions for improving diabetes management, psychological interventions led to significant improvement in metabolic health outcomes for children and adolescents compared to adult populations (Winkley et al, 2006).

As transition services cater for young people with diabetes up to the age of 25, the mental health needs of young people and adults (YPA) also have to be catered for (NHS England, 2016). Emotional and psychological problems related to diabetes are common; over two-thirds of adults who responded to Diabetes UK's 2017 Future of Diabetes survey

said that they sometimes or often feel down because of their diabetes. YPA have known diabetes-related physiological and sociological needs and low levels of engagement with health services (NICE, 2019; Raffles, 2019). *NICEimpact diabetes* acknowledges that a greater focus is needed to target young adults with diabetes, as this group has poorer diabetes outcomes than CYP and older adults (NICE, 2019). This group may benefit from behavioural therapies – such as Improving Access to Psychological Therapies (IAPT), psychology support or liaison psychiatrists – or peer support that links them to other young people with the condition.

CYP and mental health

Research tells us that diabetes-tailored mental health support can help improve an individual's quality of life and also their physical health, particularly in reducing HbA_{1c} (Schmidt et al, 2018). Studies in children with type 1 diabetes have demonstrated that as well as patient and family education about intensive diabetes management, psychological interventions are equally important and are associated with improved metabolic control, reduced hospitalisations, fewer emergency room visits, and lower overall costs to the payer and patient (Urbachn et al, 2005). A systematic review of the evidence suggests that the effectiveness of emotional support and solution-focused brief therapy improves behaviour, motivation and academic results, especially in children with long-term conditions (LTCs) (Wood et al, 2011). Despite this, the effect of diabetes on a CYP's mental health is not core to how we think about the impact of the condition in paediatric and transition care. This means mental health support is not an integral part of diabetes care for CYP across England – yet.

Many of us who work in diabetes care understand that mental health and diabetes are interconnected, but integrating mental health support into paediatric and transition diabetes

care can be a challenge. The NHS structures are often not conducive to confidently referring to sources of support or specialist expertise, and in places it is unclear where the right support is to be found. We need to ensure that in implementing the NHS Long Term Plan across sustainability and transformation partnerships and integrated care systems in England, we (and commissioners and decision-makers), are making the most of the new commitments and ways of working to best support CYP affected by diabetes and their families.

What should happen?

NICE guidance states that the diabetes care teams should offer CYP with type 1 diabetes and their family members or carers (as appropriate) timely and ongoing access to mental health professionals with an understanding of diabetes because they may experience psychological problems, such as anxiety, depression, behavioural and conduct disorders and family conflict, or psychosocial difficulties that can have an impact on the management of diabetes and wellbeing (NICE, 2016b). The national Paediatric Diabetes Best Practice Tariff states that “Each patient must have an annual assessment by their multidisciplinary team as to whether input to their care by a clinical psychologist is needed, and access to psychological support, which should be integral to the team, as appropriate” (Department of Health, 2014). Studies have shown that using psychosocial strategies in empowerment-based diabetes education leads to improved metabolic and health outcomes (Davis et al, 1999). The findings stress that assessment of psychosocial factors should be an integral part of diabetes care in this population.

In children with type 1 diabetes, parents are ultimately responsible for daily diabetes management, and this has a significant impact on family life. Caring for their child with type 1 diabetes has been described as an overwhelming experience and screening of parental psychological distress and referral of parents to mental health services should be evaluated (Whittemore et al, 2012).

Transition into adolescence is often associated with poorer diabetes management and greater risk

of psychological disorders in people with type 1 diabetes (Jaser, 2010). Research following CYP with type 1 diabetes into young adulthood reported that 42% experienced at least one episode of a psychiatric disorder, the most common being disorders associated with depression, anxiety and behaviour (Kovacs et al, 1997). Young people may struggle to take increasing responsibility for their self-care and their parents can experience high levels of anxiety over adolescents’ metabolic control, leading to diabetes-specific family conflict (Jaser, 2010). The transition to secondary school and moving away from home for the first time, for instance when taking up a place at university, can place additional stresses on the young person. Diabetes education and regular mental health assessment with appropriate referral pathways are therefore essential in this patient group.

How can this be achieved?

There are two main elements that must be improved. The first is ensuring we are skilled and knowledgeable to support the emotional wellbeing of our young patients within routine diabetes care. The second is ensuring that access to specialist mental health services is there if needed, and that professionals within those mental health services understand the unique way in which diabetes impacts emotional and psychological wellbeing in CYP.

We need to properly integrate physical and mental health services and focus on both upskilling diabetes professionals (including primary care) in mental health and mental health professionals in diabetes. We must also boost the number of mental health professionals working in diabetes care.

How can the Long Term Plan help?

Two commitments from the Long Term Plan are likely to be particularly helpful in moving forward the integration of physical and mental diabetes care. The first is the rollout of personalised care, supported by social prescribing, which will benefit CYP and adults with diabetes. The second is the commitment to increase the provision of IAPT programmes for adults with LTCs, which will benefit YPA with diabetes.

“Ultimately, we need to be looking at diabetes and mental health together to get a solid understanding of how each can affect the other, and help children and young people to feel better.”

- Diabetes UK (2017) The future of diabetes. <https://bit.ly/2iV6Nub> (accessed 24 April 2019)
- Hoey H (2009) Psychosocial factors are associated with metabolic control in adolescents: research from the Hvidoere Study Group on Childhood Diabetes. *Pediatr Diabetes* **10**(Suppl 13): 9–14
- Schmidt CB et al (2018) Systematic review and meta-analysis of psychological interventions in people with diabetes and elevated diabetes-distress. *Diabet Med* **35**: 1157–72
- Davis ED et al (1999) Using solution-focused therapy strategies in empowerment-based diabetes education. *Diabetes Educ* **25**: 249–52
- Department of Health (2014) Paediatric best practice tariff. <https://bit.ly/2PwsbWH> (accessed 25 April 2019)
- Diabetes UK (2019) Improving Access to Psychological Therapies (IAPT): Now supporting people with diabetes through integrated pathways. <https://bit.ly/2PyKavS> (accessed 23 April 2019)
- Jaser SS (2010) Psychological problems in adolescents with diabetes. *Adolesc Med State Art Rev* **21**: 138–xi
- Kovacs M et al (1997) Psychiatric disorders in youth with IDDM: Rates and risk factors. *Diabetes Care* **20**: 36–44
- NHS England (2016) Diabetes Transition Service Specification. <https://bit.ly/1PbcOry> (accessed 23 April 2019)
- NHS (2019) NHS Long Term Plan. www.longtermplan.nhs.uk (accessed 23 April 2019)
- NICE (2016a) Quality standard 125: Diabetes in children and young people. www.nice.org.uk/guidance/qs125 (accessed 23 April 2019)
- NICE (2016b) NICE Guideline 18: Diabetes in children and young people. www.nice.org.uk/guidance/ng18 (accessed 23 April 2019)
- Raffles A (2019) Are we having a NICE impact on young adults with diabetes? *Diabetes Care for Children & Young People* **8**: DCCYP016
- Soni A, Ng SM (2014) Intensive diabetes management and goal setting are key aspects of improving glycaemic control in children and young people with type 1 diabetes mellitus. *World J Diabetes* **5**: 877–81
- Urbach SL et al (2005) Predictors of glucose control in children and adolescents with type 1 diabetes mellitus. *Pediatr Diabetes* **6**: 69–74
- Whittemore R et al (2012) Psychological experience of parents of children with type 1 diabetes: a systematic mixed-studies review. *Diabetes Educ* **38**: 562–79
- Winkley K et al (2006) Psychological interventions to improve glycaemic control in patients with type 1 diabetes: systematic review and meta-analysis of randomised controlled trials. *BMJ* **333**: 65
- Wood K et al (2011) Systematic review of solution focused brief therapy in children and families. Department for Education and University of Manchester: Manchester. <https://bit.ly/2iV6Nub> (accessed 25 April 2019)
- Zaidi R (2018) Young adult diabetes: Engaging to improve; outcomes of the young adult clinic restructure. NICE. <https://bit.ly/2KpSZYy> (accessed 23 April 2019)

Personalised care in diabetes

Psychosocial and behavioural interventions aimed at specific areas of management and supporting emotional well-being have shown significant improvement in the quality of life and diabetes management of CYP with diabetes (Soni and Ng, 2014). With the rollout of personalised care, the Long Term Plan commits to ensuring CYP and, where appropriate, their families or carers are more actively engaged in their own healthcare. Personalised care describes a model where CYP, YPA and their families have choice and control over the way care is planned and delivered, based on their individual needs and preferences and on what matters to them in relation to their health. This model also recognises the importance of families and communities in supporting our health. In diabetes a personalised approach to care is critical in supporting the mental and physical health of CYP. Shifting the focus of consultations to what matters most to the child or young person with diabetes opens up an opportunity to discuss emotional as well as physical aspects of wellbeing.

Social prescribing could help to make connections between CYP with diabetes and their parents or carers. Many CYP affected by diabetes find peer support incredibly valuable (Zaidi, 2018). Peer support could also provide links to local community-based emotional and social support.

Overall, the implementation of personalised care under the Long Term Plan – with its focus on ensuring healthcare professionals are trained to have better conversations and have confidence in addressing both mental and physical health in their consultations – could have a significant positive impact for CYP with diabetes across the country.

Young people and adults: IAPT–LTC programmes and diabetes

One of the fundamentals of any LTC, such as diabetes, is self-management. Making sure that YPA with diabetes have access to a mental health professionals who understand diabetes is critical if we are to improve care. We therefore welcomed the commitment in the Long Term Plan to focus on those with a LTC.

For diabetes, IAPT will be critically important, particularly for those who have transitioned from

children diabetes service and those whose diabetes care is usually managed in primary care settings, to ensure that psychological screening and support is part of a diabetes service.

IAPT–LTC practitioners should be accessible to all YPA with diabetes when needed, particularly for treating common mental health problems, such as anxiety and depression, by using techniques such as cognitive behavioural therapy. It is imperative that training is in place to support these practitioners to develop this knowledge. One way to do this is by increasing the integration of mental and physical health teams.

There have been some positive results from the IAPT–LTC early implementer sites that have developed diabetes pathways for adult care. Local evaluations have shown reductions in levels of diabetes distress in patients, A&E attendances, hospital admissions and ambulance call-outs, resulting in considerable cost savings. IAPT–LTC sites have also benefited from improved knowledge among healthcare staff on diabetes and mental health.

Conclusion

Ultimately, we need to be looking at diabetes and mental health together to get a solid understanding of how each can affect the other, and help CYP and YPA to feel better. It is also important to note that we still need more paediatric diabetes specialist psychologists and psychiatrists to help CYP who might have more complicated problems and that children's diabetes teams have clinical psychologists that are integral to the team.

Although the commitments highlighted in the Long Term Plan are very important, there is a bigger and broader piece of work to be done to ensure that CYP and YPA with diabetes have the right mental health care across all levels of need. NHS England and Diabetes UK have brought together an expert working group to set out what the gold standard care pathway might look like for people with diabetes and to ensure a seamless transition of care that is equitable. We hope that all these pieces of work will come together to ensure more support and prioritisation of the mental wellbeing of CYP and adults with diabetes to make their lives better. ■