Too often missing.

Emotional wellbeing and diabetes: A way forward
How many life or death decisions do you make in a day?
How would you feel going to bed if you thought there was a chance you might not wake up?
How would you feel if you were trying really hard to manage your health condition but were told at every doctor appointment you aren’t doing well enough?
How would you feel about being frequently reminded that you were at risk of losing your sight, losing a limb, having a stroke or heart attack?

This is the reality for people living with diabetes. It’s no wonder that when we asked people living with diabetes how they feel about the condition, seven out of ten said they felt overwhelmed by the demands it puts on them and their families.

Strong evidence already exists to show that when people living with diabetes are given routine emotional and psychological support, it helps improve both physical and mental health. This, in turn, helps people better manage their diabetes and reduces risk of serious and life threatening complications.

So, we know it works and we know what good practice looks like. Yet, provision of emotional, psychological and mental health services is extremely patchy across Scotland. When asked, three quarters of people who said they sought support could not access it. This is nowhere near good enough.

Let us learn from the good practice that is out there and work together to ensure a genuine Once for Scotland approach that sees everyone being able to access the person-centred support to help them manage their condition well and thrive.

Angela Mitchell
National Director
Diabetes Scotland

A survey of more than 2,000 people living with diabetes and more than 300 parents and carers across the UK
What do you wish doctors, nurses and healthcare professionals knew about the emotional toll of living with diabetes?

I wish healthcare professionals acknowledged and recognised that treating diabetes is not just about physical health. In my 20+ years of attending diabetes clinics, healthcare professionals have always been fastidious about checking my feet, looking at my injection and pump sites, testing reflexes, and of course discussing the results of bloodwork. Mental health and the emotional toll of diabetes has never been assessed or discussed with as much rigour, and I absolutely think it needs to be. And a HADS questionnaire to measure clinical levels of depression isn’t enough. It doesn’t help start a conversation around difficulties someone might be having and it certainly doesn’t address diabetes distress, which is quite different from clinical depression. In my opinion, it’s not just knowing about the emotional toll of diabetes but acknowledging it and changing clinical best practice to support people more holistically in living with diabetes.

What does it feel like if you’re struggling to cope and you can’t access mental health support?

Taking care of my mental health is crucial for my diabetes management. Living with diabetes can be lonely because it’s ultimately up to you to keep yourself healthy and alive. But not having support when you’re struggling to cope with managing your diabetes or life in general makes that loneliness even stronger. It feels like there’s absolutely no one who could understand what you’re going through or do anything to help. Even looking at a blood glucose meter feels like a reminder that you’re broken and unfixable. It seems like you will always feel this way and nothing will get better. It’s at these times that I have considered taking my own life in the past because I felt I had no one to turn to for support. I’m so glad that I didn’t act on those thoughts and did speak to my GP and, much later, my diabetes team about what was going on.

What does it feel like when you get access to a psychologist and mental health support?

I am very grateful to have received counselling through the NHS on two separate occasions in the past after being referred by my diabetes team. It was truly amazing to be able to discuss my diabetes and mental health in the same conversation with someone and start to work on what was causing me distress in my day-to-day life. Counselling is not a one-time fix so it definitely takes continued effort to work on your physical and mental wellbeing. I still have to put conscious effort in every day to not let diabetes control my life. But it’s so much easier to do this when you are able to get a starting point or continued support from a professional.

“Having someone to talk to about what I found tough took such a weight off my shoulders and helped me get perspective on many things in my life, including my diabetes.”

Emma’s story

Emma, 27, has lived with Type 1 diabetes for over two decades after her diagnosis at just six years old. It was during the transition to adulthood and moving out of home that anxiety, stress and ultimately a period of depression started. Emma benefited from psychological services. She says having a streamlined system where diabetes teams and mental health teams work together to look at the whole person would help those struggling with the day-to-day self-management and long-term implications of this relentless condition.
“The role of psychologists in diabetes services should be to support the wider team, across both primary and secondary care, in delivering the best possible health and quality of life outcomes.”
Dr Kirsty McLennan, Aberdeen

We’re calling for a national standard to ensure that every person living with diabetes can access the emotional, psychological and mental health support they need to live well.

People may need different levels of support at different times of their lives. The pyramid of psychological problems in diabetes, co-produced by healthcare professionals and Diabetes UK, is a useful tool that should be used by healthcare professionals.

Examples of Best Practice in Scotland

There are some excellent examples of good practice to support emotional wellbeing for people living with diabetes across Scotland. Let’s spread this innovation and create a Once for Scotland approach to make sure there is no longer a postcode lottery of care.

Aberdeen

In Aberdeen Royal Infirmary the diabetes service has been redesigned with emotional wellbeing at its heart. Psychologists routinely work with people to understand how diabetes is affecting them emotionally and provide tailored support.

A specialist nurse and clinical psychologist provide a series of pre-transition groups for parents and young people aged 16 to 22. These focus on teaching problem-solving skills, which is a recommended intervention in SIGN 116.

A DKA protocol in Aberdeen ensures that young people and adults with diabetes who are admitted twice during a 12-month period are seen during admission by a psychologist with follow-up care as needed.

Annual screening for anxiety and depression using a brief inventory called the Hospital Anxiety and Depression Scale. These results are also included in the medical letter to GPs.

Integrating routine mental health and emotional wellbeing support in this way means that problems can be identified before they become too difficult. One specific study for people with Type 2 diabetes showed that this can lead to a 15% reduction in HbA1c and delivering substantial cash savings (£129 per Quality Adjusted Life Year gained).

ADAPT

NHS Education for Scotland (NES) is supporting the Accessible Depression and Anxiety Psychological Therapies for Long Term Conditions (ADAPT for LTCs) project which aims to increase access to quality, local and effective treatments.

Over 200 people in NHS Lanarkshire and NHS Grampian with conditions such as diabetes have been seen as part of the ADAPT service between 2017-2019. Data for 86 people indicate significant change in the severity of depression and anxiety, and substantial improvements in quality of life following an average of six sessions of Cognitive Behavioural Therapy with an ADAPT clinician.

Patients have reported high satisfaction with the service.

“Feeling in control of my own future, I know I can get back to the old me.”

Sandra, living with diabetes and depression

Psychological therapists working in primary care report more knowledge and confidence in helping people who have LTCs following training and coaching in practice. The NES Psychology Directorate have training materials to help all staff support the emotional needs of people with diabetes on their website.

One staff member reports “this is crucial to my role and developing my overall understanding of the impact of LTCs.”

Beating the Blues

Beating the Blues was designed at the Institute of Psychiatry, Kings College, London and is being piloted in NHS Lothian. It helps people suffering with mild and moderate depression to get better and stay better. It is an online course based on Cognitive Behavioural Therapy (CBT) which aims to make changes in unhelpful thinking patterns and behaviour.

It is a proven and effective source of treatment for patients suffering from mild to moderate depression or anxiety that can be accessed quickly.

People using Beating the Blues reported benefiting from 30 additional depression-free days in the six months after treatment.

NHS Education for Scotland offers training for healthcare professionals working in diabetes in health boards across Scotland, providing a route map to behaviour change. The programme develops specific skills that professionals can use to support people to make successful changes to their diabetes management and their lifestyle, and to maintain these over time.

The MAP model is generic enough to be relevant for all behaviours, conditions and types of consultations and interactions (long, short, planned, opportunistic) so the training is suitable for a wide variety of practitioners in both health and social care. Using this approach helps professionals to help people with diabetes to feel better about themselves, develop self-confidence, and promote good mental health and wellbeing.

“Cognitive Behavioural Therapy is probably the most research evidence based treatment in the world today.”

Simon Vearnals, Psychologist Primary Care – Psychology Services

“You go to clinic and the focus is on physical health. You’ve got to get your eyes checked for retinopathy and your feet checked by a podiatrist. They look at your blood sugar levels and you see a dietician to check you’re eating properly. But there’s no focus on the mental or psychological impact of diabetes; you don’t get to see or speak to a counsellor.”

Ron, living with Type 2 diabetes, Fife
Now is the time for action.

There are elements of great practice across Scotland but not every person with diabetes is able to access the emotional and mental health support they need. We must work together to deliver a diabetes service with emotional wellbeing and mental health care integrated as a routine part of diabetes care.

No matter if a person lives in Shetland or Borders, or anywhere in between, we want everybody to be able to access emotional and psychological support that will empower people with diabetes to live well.

We are asking for improved and more consistent care across Scotland over the next twelve months. If you would like to work with us to make this a reality we want to hear from you.

What next?

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We need:

- A Once for Scotland approach to emotional and mental health support for people living with diabetes. This will include self-management support, wellbeing and emotional support and mental health treatment based on best practice.
- Healthcare professionals delivering diabetes care to ask about emotional wellbeing during appointments.
- Ring-fenced funding for emotional, psychological and mental health support within diabetes care.
- Provision of psychological support and mental health treatment for people with diabetes to be included in the strategic plans of all the Integrated Joint Boards.
- Access to training in self-management and behaviour change skills for health and social care professionals working in diabetes.
- GP or diabetes team to ask patients how they feel in every appointment, and also to look out for those close to them.

Almost 2 out of every 3 parents and carers ‘always’ or ‘often’ feel overwhelmed by diabetes.

Providing mental health support as part of everyday care should be seen as essential and not just nice to have. Helping people living with diabetes to manage their condition and prevent complications will mean a longer term cost saving to health and social care and the NHS.

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We know that talking to people with diabetes about their emotional health isn’t easy. Our ‘Diabetes and emotional health’ guide for front line staff offers strategies and tools to help recognise and have conversations about emotional problems, as well as providing appropriate support.

We can help you:
• practically support emotional health
• use consultation time productively
• know when and where to refer.

We’ve got chapters with the latest information on depression, barriers to insulin use, diabetes distress, fear of hypoglycaemia, eating with diabetes, anxiety and adjusting to diagnosis.

Don’t forget that a simple question like ‘how are you feeling today?’ can make a massive difference to people living with diabetes by allowing them to open up about their emotions.

Go to www.diabetes.org.uk/emotional-health-professionals-guide