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Making emotional and psychological support routine in diabetes care.

Contents

Foreword	4
Why did we write this report?	5
Executive summary	7
What have people affected by diabetes told us?	10
What support is in place and what is missing?	17
What more needs to be done: our UK wide recommendations	29

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Endorsed by

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- DISN UK (Diabetes Inpatient Specialist Nurse UK Group)
- National Network of Psychologists in Diabetes
- PCDS (Primary Care Diabetes Society)
- RC Psych (Royal College of Psychiatrists)
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National Network of
Psychologists in Diabetes



Note on terminology

Choosing the best language and terminology to describe these issues can be tricky. We won't always get it right. In this report we've tried to use language that is preferred by people with diabetes, and have followed the guidance in NHS England's **Language Matters: Language and diabetes**¹.

Below are definitions of phrases used throughout this report.

Emotional and psychological wellbeing

People's emotional, mental and psychological wellbeing and health, from day-to-day frustration and low mood, to specific psychological and mental health difficulties such as clinical depression, anxiety, disordered eating and diagnosed eating disorders, and severe mental illness.

Healthcare professional/staff

A person working in healthcare, many of whom provide care for people with diabetes. This includes, but is not limited to, specialist doctors, GPs, nurses, healthcare assistants, dietitians, podiatrists, and physiotherapists, as well as mental health professionals.

Mental health professional

A person with training in mental health who provides care for people with diabetes. This includes, but is not limited to, psychiatrists, psychologists, psychotherapists, occupational therapists, counsellors, and wellbeing practitioners.

Specialist support

Support for people with diabetes from mental health professionals who also have training or specialist knowledge in diabetes.

Person living with diabetes

A person with diagnosed Type 1, Type 2, or other types of diabetes.

Parent. Carer.

A parent of, or carer for, someone living with diabetes.

Those who care for people with diabetes

People, other than healthcare professionals, who provide care for those with diabetes, such as parents of children with diabetes, or carers.

Person affected by diabetes

Someone whose life is affected by diabetes because they are diagnosed with diabetes or because they love and/or provide care for someone with diabetes.

Self-help

This refers to any techniques, resources or materials that might help a person overcome emotional difficulties relating to diabetes. Examples include online resources, our print resources and helpline, information on emotional wellbeing improvement techniques, and so on. Self-help resources relating to diabetes more broadly can often also help improve emotional wellbeing.

Self-management

This refers to the actions and steps taken by people living with diabetes, and those close to them, in order to respond to the physical and emotional demands of living with diabetes.

This includes the management of physical symptoms – for instance by reading blood glucose levels, or managing diet – in order to reduce the likelihood of short and long-term complications.

¹ NHS England (2018) *Language Matters: Language and Diabetes*. Accessed at: www.england.nhs.uk/wp-content/uploads/2018/06/language-matters.pdf

Foreword



Chris Askew
CEO, Diabetes UK



Dr Luke Solomons
Consultant in Psychological Medicine, Oxford University Hospitals NHS Foundation Trust and Faculty of Liaison Psychiatry, Royal College of Psychiatrists

We know that diabetes is much more than a physical condition. It can be tough to live with, and the day-to-day demands of diabetes can be a constant struggle.

People living with different types of diabetes have told us that the condition can have a serious impact on their emotional and psychological wellbeing, which in turn can affect not only their quality of life, but also their diabetes self-management. Emotional and psychological health can be a challenging thing to talk about. So we appreciate the courage it's taken for people to speak out about how they feel.

We have learned, through the new insight presented in this report, that there is a substantial unmet need for more, and better, support for people affected by diabetes – and it is vital that urgent action is taken. Of those we spoke to living with diabetes, 7 in 10 had felt overwhelmed by the demands of the condition.

That is why we're calling on government, the NHS, local decision makers, healthcare professionals, and people affected by diabetes, to work with us now to make sure this need is met.

It is critical that all diabetes care sees and supports the whole person, and explores what matters most to them. Everyone affected by diabetes must have access to the support they need when they need it – whether that's a conversation about emotional wellbeing with their diabetes healthcare professionals, peer support, education and information, or help from a mental health specialist who understands diabetes.

We need to find new ways of working to bridge the divide between physical and mental health services to ensure those with emotional and psychological difficulties related to their condition do not have their needs overlooked.

We promise to work hard to catalyse more action on this issue – but collaboration is needed. By working together in partnership, we will make sure everyone affected by diabetes has support for their emotional and psychological wellbeing as an integral part of their diabetes care.

**Chris Askew
and Dr Luke Solomons**

Why did we write this report?

In 2017, more than 9,000 people living with different types of diabetes shared their experiences with Diabetes UK to shape our [Future of Diabetes](#) report. It revealed that one of the biggest areas of UK diabetes care that needs to improve is support for emotional and psychological wellbeing.

Diabetes is much more than just physical. Living with the condition can be tough, and keeping on top of it can be a struggle. Surveys carried out for this report show that 7 in 10 people living with different types of diabetes feel overwhelmed by the demands it puts on them. It can also affect the emotional and psychological wellbeing of those close to them.

In diabetes, psychological wellbeing and physical health have a two-way relationship. While the demands of living with the condition can affect how people feel; struggling emotionally can make it even more difficult to keep on top of self-management. And when diabetes cannot be well managed, the risk of dangerous complications increases.

Evidence already exists to show that diabetes services that incorporate emotional and psychological support can help people improve both their physical and mental health, reduce pressure on services, and save money. But provision of such services is extremely patchy across the UK.

Alongside this, there are still some aspects we don't yet fully understand about how diabetes impacts on emotional and psychological wellbeing, how to spot people with diabetes who are experiencing these difficulties, and how to best support them. To address this, we have brought together international experts to identify research gaps and opportunities, to help us tackle what we don't yet fully understand. We'll publish a second report setting out priorities for the research community later this year.

There is a real and urgent need for recognition of the impact diabetes has on people's mental health – and action must be taken now.

Who have we reached and how?

We collected extensive insights from people affected by diabetes, and those working with them, to inform this report. Our research comprised:

- a survey of more than 2,000 people living with diabetes and more than 300 parents and carers across the length and breadth of the UK
- 32 in-depth interviews with people affected by diabetes, carried out by a research agency
- an online survey of over 1,000 GPs across the UK, carried out by a research agency
- a survey of over 150 NHS healthcare professionals from primary care, mental health, and diabetes specialist teams
- shared practice work to find out about the good practice that currently exists.

“I have no one I can talk to about my diabetes.”

Person with Type 2 diabetes

² NCVIN (2016), Diabetes Prevalence Model for England + estimated growth between 2015–2020 from APHO (2010) Prevalence Models for Scotland and Wales.

Executive summary

Methodology

The detailed methodology is published on our website at www.diabetes.org.uk/emotional-wellbeing

Scope

For this report, our insight work focussed on adults with diabetes, adult carers, and parents of people with diabetes, as well as healthcare professionals providing adult services. As such, this report does not contain specific recommendations for improving children's services. However, we know that the challenges faced by children and their families in paediatric services are similar to those in adult services, and recognise that some of our calls will apply to both.

Our insight work focussed on understanding the impact diabetes has on emotional and psychological wellbeing, and how we can improve care for diabetes-specific problems. We recognise, however, that there is a need for mental health professionals in all settings to have awareness of the emotional and psychological impact of diabetes. This includes better care for those with a diagnosed co-existing mental health condition that is considered unrelated to their diabetes. We also recognise that social care professionals play an important role in providing support for people affected by diabetes, however we didn't gather insight from social care professionals for this report.

This report concentrates on NHS services. We didn't gather insights from private providers, although some people with diabetes told us that they paid for private services when they weren't available through the NHS.

“It's a bit of a taboo area, people need support and won't or can't talk.”

Person with Type 1 diabetes

“Diabetes affects all aspects of health and wellbeing so emotional support would be very welcome to complement physical support.”

Person with Type 2 diabetes

We know that diabetes is more than just physical. Living with diabetes can be tough, and keeping on top of it can be a struggle. It can affect those who live with it, and those close to them, emotionally and psychologically.

7 in 10 people we spoke to living with diabetes feel overwhelmed by the demands of their condition. Of these, three quarters said their self-management was affected by their emotional struggle.

People with all types of diabetes can experience problems including diabetes distress, depression, anxiety and eating disorders, all of which need diabetes-specific mental health support.

Of those we spoke to, three quarters of people with diabetes who felt they needed specialist support couldn't access it.

Evidence shows that diabetes-tailored emotional and psychological support and treatment improves the emotional wellbeing of the person, and has a positive impact on their diabetes outcomes, most specifically in reducing average blood sugar levels – called HbA1c³. This reduces the risk of serious complications, and cuts the risk of associated ill-health.

While there are some pockets of good practice, too often this support is missing. There is a UK-wide deficit in recognition of the emotional and psychological needs of people with diabetes, and specialist support to meet them.

Our research has drawn out key themes for the improvements that are required.

“Emotional support ought to be a core part of diabetes care.”

Person with Type 1 diabetes

Emotional and psychological support must be a part of all diabetes care, and should include information, education, and peer support.

People affected by diabetes want emotional wellbeing to be a **routine part of care**, so that their healthcare professionals recognise its importance, and regularly ask them how they're feeling. Healthcare professionals should make sure they adopt a person-centred approach to diabetes consultations, so that care and support is planned jointly with the person affected by diabetes.

With better information and support, people with diabetes said they would feel more able to talk about how they feel. They felt that information and education resources about diabetes should highlight the significance of emotional wellbeing too.

People told us **peer support** was often a helpful source of support for them. Services must also be able to signpost or refer people to the nature of support that they need, including peer support, self-help, and community-based services.

Greater access to specialist psychosocial care and support services that understand diabetes.

Of those we surveyed, three quarters of people with diabetes who felt they needed specialist support from a mental health professional couldn't access it. Support was also lacking for parents and carers.

Any support that was available was often described as too generic, with therapists not having a good enough understanding of diabetes and the psychological challenges it brings. There's also a clear lack of consistency in systems or services across the UK.

³ Schmidt CB, van Loon BJP, Vergouwen ACM et al (2018) *Systematic review and meta-analysis of psychological interventions in people with diabetes and elevated diabetes-distress*. Diabetic Medicine 35 (9), 1157 to 1172

The healthcare professionals we spoke to suggested that **mental health professionals should be integrated into specialist diabetes services**, and be available to support people affected by diabetes who are seen in primary care. Indeed, there are examples of good practice where this model is being implemented successfully.

Improve knowledge and skills among professionals who provide care for people affected by diabetes

We have identified a clear need for **training and upskilling of diabetes staff** in recognising and providing support for emotional and psychological issues experienced by people affected by diabetes. This applies both to primary care professionals working in diabetes and specialist diabetes services. There is also a pressing need for **diabetes education for mental health professionals** working in this field.

Many healthcare professionals reported that they do not feel comfortable or confident in raising the topic with people with diabetes and so avoid it. They were also unclear on what emotional and psychological support services are available locally or how to refer or signpost to them.

All staff working in diabetes care should be able to recognise emotional and psychological difficulties common for people affected by diabetes. Diabetes UK and partners⁴ have developed a practical guide to help healthcare professionals support the emotional health and wellbeing of people with diabetes: **Diabetes and Emotional Health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes**⁵.

Diabetes care must see and support the whole person, and be based around their own needs, experiences and circumstances. The emotional and psychological impacts of living with diabetes should be recognised in all diabetes care.

Everyone affected by diabetes must have access to the specialist support they need, when they need it.

Our UK-wide recommendations

Diabetes UK calls for:

-  The emotional and psychological impact of diabetes to 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 to 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 to be supported by specialist mental health professionals, including psychologists and liaison psychiatrists, to ensure effective provision across all levels of need.
-  An integrated care pathway for diabetes and emotional and psychological wellbeing to be developed and implemented in each UK nation.
-  All healthcare professionals providing general diabetes care to have the training and skills to identify and support the emotional and psychological wellbeing of people affected by diabetes.
-  Mental health professionals providing care for people affected by diabetes to have knowledge of diabetes and an understanding of the impact the condition can have on physical, emotional, and psychological wellbeing.

⁴ This resource was adapted from the original *Diabetes and emotional health A handbook for health professionals supporting adults with Type 1 or Type 2 diabetes* which was developed by the Australian Centre for Behavioural Research in Diabetes (ACBRD), the National Diabetes Services Scheme (NDSS) and Diabetes Australia in 2016.

⁵ Diabetes UK (2019) *Diabetes and Emotional Health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes*. Accessed at: www.diabetes.org.uk/emotional-health-professionals-guide



“For me I find living with my condition very worrying and scary as I just don’t know what the future holds for me.”

Person with Type 2 diabetes

Find out more on our calls in each of the four UK nations under the six key areas on our website at: www.diabetes.org.uk/emotional-wellbeing

Join us

We’ve spoken to thousands people affected by diabetes and they told us that when people are struggling, too often the support they need is missing.

Help us make emotional and mental health support a part of everyone’s diabetes care.

Visit our website at:

www.diabetes.org.uk/emotional-wellbeing

What have people affected by diabetes told us?

Diabetes impacts emotional wellbeing, and emotional wellbeing can impact diabetes

Diabetes is not just a physical condition. It can have an emotional impact too, and can affect the psychological wellbeing of those who live with it. Diabetes is present, and requires self-management, 24/7, 365 days a year. It demands constant attention and awareness, which can be a real challenge to cope with.

People with all types of diabetes told us their condition can make them feel frustrated, angry, guilty, fearful and isolated. Sometimes, people can experience anxiety, depression, and other mental health difficulties as a result.

Those we spoke to living with diabetes told us there is a two-way relationship between diabetes and emotional and psychological wellbeing. The relentlessness of managing the condition can affect how people feel, and struggling emotionally can make it even more difficult.

This can mean that those who use insulin stop administering it properly or at all. Others can adopt unhealthy habits, for example with their diet, or neglect their medication. All of which can lead to a rise in average blood sugar levels – also known as HbA1c – putting them at risk of dangerous complications.

Diabetes can lead to specific emotional and psychological problems, which can have physical consequences. Below are some of the more common emotional and psychological problems experienced by people affected by diabetes^{6,7}:

- **Diabetes distress** – can include feelings of being frustrated, defeated, and overwhelmed with the day-to-day demands of diabetes, which can mean that managing the physical aspects can become very difficult. This can lead to elevated diabetes distress, also known as diabetes burnout, where a person can sometimes feel completely unable to manage the physical aspects of the condition. Elevated HbA1c can result⁸, which can potentially lead to very dangerous complications such as diabetic ketoacidosis (DKA), which can require emergency admission to hospital. Diabetes distress can also arise from the social impact of the condition, and worries about the future.
- **Diabetes specific fears** – fears such as needle phobia, or fear of hypoglycaemia. Hypoglycaemia is when blood glucose levels fall, causing a range of distressing and dangerous symptoms. These fears can sometimes require specialist treatment, such as cognitive behavioural therapy.
- **Barriers to insulin use** – the negative thoughts or feelings associated with starting or using insulin. Delaying or reducing insulin can mean that HbA1c is more likely to rise, leading to an increased risk of complications.

- **Depression** – people with diabetes are twice as likely to experience depression^{9,10}, which can be brought on by the relentless nature of the condition. Depression can last years, but with the right treatment it can often be managed and people can get better. Depression can require help from a mental health professional, and it is vital that anyone caring for someone with diabetes-related depression has a comprehensive understanding of the physical and emotional aspects of the condition.
- **Anxiety** – general and specific anxiety relating to the challenges of living with diabetes. For some this can be debilitating, and lead to a fear of leaving the house alone, or going to work. Anxiety problems can, in some cases, require specialist treatment from a mental health professional.
- **Eating problems** – two in five people with Type 1 diabetes have experienced disordered eating behaviours, and one in four people with Type 2 diabetes have also experienced this. Problems can include excessive carbohydrate counting, restricting food, and over and undereating. People can also reduce or omit insulin in order to lose weight, known as diabulimia¹¹. Diabulimia can be very dangerous, and requires specialist help. Effective care requires a comprehensive understanding of diabetes, and while some specialised centres exist in the UK, many eating disorder services are underequipped to care for people with diabulimia.

We have presented some of the more common problems faced, but this is certainly not an exhaustive list. There are many nuanced and individual emotional and psychological wellbeing difficulties faced by people with diabetes, and not all are ‘diagnosable’ mental health conditions. But identifying and supporting those with low mood, lack of motivation or loneliness could help prevent mental health problems, as well as improve diabetes self-management – and most importantly help people feel better.

Those who care for people with diabetes also told us they need support. Caring for someone living with diabetes can feel like a struggle every day, leaving carers and families overwhelmed and anxious. Two thirds of the parents and carers we spoke to ‘always’ or ‘often’ feel overwhelmed by diabetes, and of those 7 in 10 believe this has an impact on the support they can provide to the person with diabetes.

Our insights have revealed that the emotional needs of parents and carers – which can be different from those they care for, and specific to them – are often overlooked.

7 in 10 of those we spoke to living with diabetes felt overwhelmed by the demands of the condition.

Of these, three quarters said it affects how they manage their diabetes.



⁶ Hendrieckx C, Halliday JA, Beeney LJ, Speight J. (2016). *Diabetes and emotional health: a handbook for health professionals supporting adults with Type 1 or Type 2 diabetes*. Canberra: National Diabetes Services Scheme. Accessed at: <https://static.diabetesaustralia.com.au/s/fileassets/diabetes-australia/e8a3bd1a-d785-43c2-804a-b9e27b76f488.pdf>

⁷ Diabetes UK (2019). *Diabetes and Emotional Health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes*. Accessible at: www.diabetes.org.uk/emotional-health-professionals-guide

⁸ Deborah Young-Hyman, Mary de Groot, Felicia Hill-Briggs, Jeffrey S. Gonzalez, Korey Hood, Mark Peyrot (2016). *Psychosocial Care for People With Diabetes: A Position Statement of the American Diabetes Association*. *Diabetes Care* Dec 2016, 39 (12) 2126-2140; DOI: 10.2337/dc16-2053

⁹ Roy T, Lloyd CE (2012). *Epidemiology of depression and diabetes: a systematic review*. *Journal of Affective Disorders* 142, S8 to 21.

¹⁰ Speight J, Browne JL, Holmes-Truscott E et al on behalf of the Diabetes MILES – Australia reference group (2011). *Diabetes MILES – Australia 2011 Survey Report*. Diabetes Australia – Vic, Melbourne.

¹¹ Diabetes UK (2019) *Diabetes and Emotional Health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes*. Accessed at: www.diabetes.org.uk/emotional-health-professionals-guide

Emotional wellbeing can be impacted throughout life with diabetes – but also at specific times

The condition can affect every aspect of day-to-day life, from going shopping to going to work. People with diabetes felt emotional and psychological support should be offered regularly and consistently.

However, it's clear that there are periods during a life lived with diabetes where people might need more emotional or psychological support. Our insights revealed the following to be times of particularly high-risk:

- at diagnosis, and just after
- upon the development of physical complications of diabetes, such as eyesight problems
- around significant life events, such as pregnancy, divorce, or becoming a carer
- when living with other mental or physical conditions
- in transition from children's to adult services

Diagnosis was raised as a critical time when emotional support should be available and emotional impact normalised as a core part of living with diabetes. It can be a time where people are in shock, disbelief, and devastated – and the impact is not only on them, but those close to them too.

Those we spoke to who had transitioned from paediatric to adult diabetes services felt that the system had not adequately supported them through this difficult time. It can often be fraught with worry for parents too.

“I would prefer it if emotional wellbeing was discussed more frequently than at present.”

Person with Type 1 diabetes

“I struggled a bit when I was diagnosed due to a lack of emotional wellbeing and mental health support.”

Person with Type 1 diabetes

“I have other health problems and find it hard to keep on top of everything.”

Person with Type 2 diabetes



There needs to be awareness and acknowledgement of the impact diabetes can have on emotional wellbeing

People with diabetes overwhelmingly acknowledged the impact that diabetes has on their emotional and psychological wellbeing. They felt that others, including their healthcare professionals, are unaware of the connection.

Over half of the people living with diabetes that we spoke to would be comfortable talking to a member of their diabetes team about their emotional wellbeing. Yet of those that feel comfortable, 7 in 10 say they are rarely or never supported to have these conversations.

People frequently told us they were not listened to about the impact of diabetes on their emotional wellbeing, and some felt as though their healthcare professionals didn't care.

There was acknowledgement of the practical limitations of appointments, such as time constraints. But the barriers that people spoke of went beyond these. They included weak relationships with healthcare staff, rapid staff turnover and a lack of confidence in staff competence around managing emotional wellbeing.

Echoing people living with diabetes, parents and carers noted that the focus is often on clinical outcomes and measures. Not only can this add to their feeling of blame when the numbers 'aren't good enough' but also leaves little time for talking about emotional wellbeing. They also reported feeling frustrated when not actively included in consultations with the person they're caring for.

Despite the fact that over half of the parents and carers we spoke to said they feel comfortable discussing their emotional wellbeing with healthcare professionals, many reported that they find it hard to raise the topic. Many feel guilty or selfish for feeling the way they do, and don't want to take attention away from the person with diabetes. They can feel particularly isolated, and even less able to access support, when the person they're caring for is reluctant to engage with the healthcare system.

"I don't feel that my comments regarding my emotional wellbeing is taken very seriously with the diabetes team I see."

Person with Type 1 diabetes

"The stress of being responsible for someone's life is huge and no-one really understands unless they are going through the same."

Carer

Carers and parents told us that stigma and lack of understanding impacts them emotionally too. People do not always realise the seriousness of diabetes. As such, parents and carers can feel that no one else would support their loved one like they do, which places a burden on them.

People with diabetes also highlighted the need to overcome stigma associated with both diabetes and mental health. People felt stigmatised or judged by others due to the role that obesity and lifestyle factors play in the development of Type 2 diabetes, and some people felt as though there was a lack of understanding about the differences and complexities of the different types of diabetes. Some people also felt that their emotional wellbeing was a taboo subject or embarrassing to bring up, meaning they would be less likely to ask for the help they need.

Some people felt if they had better access to diabetes technology and treatments, such as insulin pumps, or better information on appropriate diets, their emotional wellbeing would

4 in 10 of parents and carers we spoke to also reported not being helped by their diabetes teams to talk about how caring for someone affects their emotional wellbeing.



be improved. For some, a major cause of stress and frustration was related to being unable to access the treatment that they felt was right for them. If healthcare staff and commissioners had a greater understanding of the emotional impact of diabetes, it could inform their decisions on prescribing technology and treatments.

People told us they are more often asked how their diabetes is, than how they are feeling. To overcome these challenges, they said the emotional side of diabetes must be normalised; becoming a core part of how we think about the impact of diabetes and diabetes care.

"It's always all about numbers, it sometimes feels like other factors aren't recognised!"

Carer

"I do wish I was not made to feel it was my own fault."

Person with Type 2 diabetes

Case study

Mary's story

Mary's husband was diagnosed with Type 2 diabetes some years ago. She initially felt like the diagnosis was a positive challenge for them both – she sourced information and recipes online and set about helping him try to manage the condition (or even bring about remission if they could). However, as time went on it became obvious he wasn't taking the diagnosis as seriously as she was.

She is now becoming increasingly angry and frustrated with him as he is continuously missing appointments and refusing to change his lifestyle. She feels like she's 'nagging' him all the time and it's having a significant impact on their relationship but she can't help thinking that she doesn't want to be a widow. Sometimes she's unsure if some of his irritability is related to the condition.

She worries that she will be blamed if anything bad happens to him, but fears something terrible has to happen in order to change his attitude towards his diabetes. She thinks his doctor is 'too brutal' with him and that this puts him off going more regularly to his appointments. Her one wish is that they could access emotional and practical support as a couple – acknowledging the fact that she sees this as a team effort and that his inaction is affecting her emotional wellbeing.



Case study

Sara's story

"I was diagnosed with Type 2 in 2015, and overloaded with information about the condition. I was completely overwhelmed and really confused about what I should be doing. Since then I've learned to manage my diabetes through my diet, and my family are really supportive. But the condition is so demanding it can feel exhausting, and I do worry about the future.

With my GP the focus is very much on the physical elements of diabetes. I'd like to talk to the doctor about how it affects me emotionally, but there's no space in my appointments for that, and I feel apprehensive about raising it. Also, the messages from my GP tend to be negative, which can get me down.

It would be a big help just to have someone share a few motivating words. To acknowledge that living with diabetes is hard, but that I'm doing ok. I really feel we need much more awareness across the board about diabetes and emotional wellbeing – from people living with it, the general public, the media, and healthcare workers."

What support is in place and what is missing?

Evidence shows that psychological care for people with diabetes can benefit both mental and physical outcomes, reduce pressure on services, and save money^{12,13,14}. For example, a service in Bath for people with Type 1 diabetes making visits to hospital with recurrent DKA estimated that for every £1 spent on psychotherapist time, £29 was saved¹⁵. Healthcare professionals told us about other pockets of excellent practice across the UK. However, despite the evidence base, these pioneering services have often had to fight for their funding. People affected by diabetes and healthcare professionals have given us their views on the support that is in place, and on the support they feel is too often missing.

"When I needed to see a diabetes psychologist she was very good."

Person with Type 2 diabetes

Emotional and psychological support being 'the norm' in diabetes care

Some people with diabetes told us that they already had a diabetes care professional who was supportive of their emotional and psychological health. This was reported as a hugely positive factor in helping them manage their condition and their lives.

However, others said that their emotional and psychological wellbeing was rarely considered.

One of the strongest calls from people affected by diabetes and healthcare professionals alike was that emotional and psychological support should be embedded as a normal part of all diabetes care. And the importance of mental wellbeing should be recognised throughout the system.

People told us that they would like their diabetes nurse, consultant, GP or other healthcare professional to regularly ask about how they're feeling, in a sensitive and considered way. Then take action to help them get support when necessary, no matter what the context of the appointment was.

It was also stressed that services should identify those who aren't engaging with their diabetes care, and find ways to reach out to them.

Parents and carers told us that better, tailored, emotional and psychological support for them is vital, because their emotional wellbeing has an impact on the care they feel able to provide.

40% of GPs we spoke to said they would not be likely to ask about emotional wellbeing and mental health in a routine diabetes appointment. The majority reported they would be more likely to raise the subject if there were shorter waiting times for local psychological services (84%), access to specialist advice on diabetes and mental health (81%), and relevant self-care and signposting materials on psychological support (82%).

¹² NHS England (2016) *Five Year Forward View for Mental health*. Accessed at: www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf

¹³ Schmidt CB, Potter BJ, van Loon ACM et al (2018). *Systematic review and meta-analysis of psychological interventions in people with diabetes and elevated diabetes-distress*. *Diabetic Medicine* 35 (9), 1157 to 1172.

¹⁴ James U (2019). *Improving access to psychological therapies (IAPT); now supporting people with diabetes through integrated pathways*. *Diabetes Update* Spring 2019 pages 18 to 21.

¹⁵ NHS Southwest Clinical Networks, *Improving Access to Psychological therapies for patients with Diabetes – examples of developments nationally and across the South West*. Accessed at: www.england.nhs.uk/south/wp-content/uploads/sites/6/2018/10/psychological-therapies-factsheet.pdf

Other healthcare professionals reported that low staffing levels and high staff turnover were barriers to provision of psychological support. Both put capacity pressure on teams. The knock-on effect is less time for them to focus on the whole person, including their emotional and psychological health.

Services that are currently offering this support have developed or use tools to encourage patients to talk about emotional wellbeing. They may do this through systematic care and support planning^{16,17}, and by using resources such as:

- Diabetes UK Information Prescription **Your Emotions and Diabetes**¹⁸
- The guide **Diabetes and Emotional Health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes**¹⁹
- questionnaires such as the **Diabetes Distress Scale**²⁰ or **Problem Areas In Diabetes**²¹.

Once the clinician has determined the support the person needs, they can help them access the right services, through signposting or referral.

The insight we've gathered on this good practice – showing what can be done, yet also on the gaps – clearly highlights that emotional and psychological support should be integral to all diabetes care to help people with diabetes live well with the condition, and to make sure those close to them also feel supported.

Best Practice

Diabetes Care for You

Sussex Community NHS Foundation Trust

After staff recognised that emotional wellbeing was affecting people's diabetes self-management, and leading to raised HbA1c, they set up Diabetes Care for You.

This new service integrates comprehensive mental health support into the diabetes service, and supports people with both Type 1 and Type 2 diabetes. Several psychotherapists work within the team, using a technique called cognitive analytic therapy (CAT) with those who need support.

The psychotherapists are embedded at every level of the service and take referrals from all members of the diabetes team. As well as delivering CAT sessions they provide group education, upskill members of the team in psychological skills and provide psychological supervision to team members. They also liaise with secondary and primary care colleagues to support people's emotional journey through the system.

“Diabetes is a 24/7, 365 days a year condition and therefore a job for a carer.”

Carer

¹⁶ National Voices (accessed 2019). *Care and support planning guide at National Voices*. Accessed at: www.nationalvoices.org.uk/sites/default/files/public/publications/guide_to_care_and_support_planning_0.pdf

¹⁷ Year of Care (June 2011). *Report of Findings from the pilot programme*. Accessed at: www.yearofcare.co.uk/sites/default/files/images/YOC_Report%20-%20correct.pdf

¹⁸ Diabetes UK Information Prescription *Your Emotions and Diabetes*. Accessed at: www.diabetes.org.uk/professionals/resources/resources-to-improve-your-clinical-practice/information-prescriptions-qa

¹⁹ Diabetes UK (2019) *Diabetes and Emotional Health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes*. Accessed at: www.diabetes.org.uk/emotional-health-professionals-guide

²⁰ Diabetes Distress Scale. Accessed at: www.diabetesed.net/page/_files/diabetes-distress.pdf

²¹ Problem Areas in Diabetes Scale. Accessed at: <https://static.diabetesaustralia.com.au/s/fileassets/diabetes-australia/e779e421-7621-4c69-8fe5-0fc683e2a86b.pdf>

Case study

Charlotte's story

“My diagnosis of Type 1 in 2015 was a big surprise, and I felt overwhelmed by how demanding my condition is. Quite soon after I started feeling anxious and having panic attacks, often when my blood sugar was low. I was suddenly having to cope with two issues at once – diabetes and anxiety. My work and friends and family were supportive, but I just fell into a ‘black hole’ emotionally.

In the end I decided to tell my diabetes specialist nurse how I was feeling. She was really reassuring, and told me that this kind of anxiety was quite common with diabetes, and that we could try and work through it together. She also told me about the help available through Diabetes UK, like the website and online forum.

By learning more about my diabetes, and how to control my anxiety, I was able to come out the other side. I'm so much happier and more confident now, and I live my life without my diabetes getting in the way.”



Peer support, self-help and education

Peer support was highlighted as a helpful source of emotional support for many of those we spoke to. People living with both Type 1 and Type 2 diabetes felt that meeting other people going through similar challenges was often a very positive experience. For some, peer support from those within a similar demographic and situation was desirable.

But for many, peer support had not been offered, or wasn't available. Over half of the survey respondents with diabetes were not offered peer support as often as they would like.

Over half of parents and carers also told us they are not being helped to meet and talk to others in a similar situation. Yet, of these, almost three quarters would want to.

When support is offered, it must be suited to the individual. For example, some people were offered group therapy, but would have preferred one-to-one support.

Diabetes structured education is the name for clinically-approved education courses for people with diabetes. Some people said it was helpful, but access varied. Of those we spoke to, over one third attended a structured education course, yet only a quarter of those attended a course that included information on emotional wellbeing.

Parents and carers also noted that better access to information and education regarding how to care for someone living with diabetes would help them feel more confident in caring for someone with diabetes and helping them with their management.

“I feel that there should be a more structured support system in place for newly diagnosed diabetics. The DAFNE course is fantastic, but it does not deal with the emotional aspects of living with diabetes day-to-day. I think that there is a lot that can be done.”

Person with Type 1 diabetes

For those that were able to access them, online and telephone resources were also used as an outlet and source of emotional support. Diabetes UK's website, support forums and helpline were highlighted. However, research has found that healthcare professionals don't always suggest online self-help, and so more awareness raising of what is available may be needed²².

It is clear that people affected by diabetes would like to be offered more information and resources, as well as the opportunity to speak to other people with experience of the condition, to be able to mutually support each other. Sometimes, this may be the support that is best suited to a person, and so it should always be in place alongside access to specialist mental health services.

Best Practice

Type 2 Peer Support Groups across the Diabetes UK Midlands and Eastern Region

Diabetes UK peer support groups connect people with Type 2 diabetes across central England in informal sessions. Between six and 12 people, led by a volunteer, chat about the challenges of living with Type 2 diabetes and share their personal experiences and hopes for the future. The sessions aim to offer support and ultimately to help people to live better with diabetes by having a greater understanding of the condition.

The project has been extremely popular, with 500 to 600 people attending associated peer support groups over the past three years. It's proven there is a demand and need for this type of support, which bridges the gap between education and the annual 20 minute visit to the Diabetes Specialist Nurse or GP.

There are now almost 50 Diabetes UK Peer Support groups meeting on a regular basis across the Diabetes UK Midlands and Eastern Region, with new groups joining all the time. If you would like to find out more, please visit www.diabetes.org.uk/emotional-wellbeing

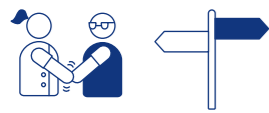
“I have found that meeting others with diabetes and sharing experiences about managing diabetes can be very helpful and emotionally supportive.”

Person with Type 2 diabetes

“I make so many mistakes because I haven't got the knowledge to make the correct decision or treatment choices.”

Carer

²² Primary Care Diabetes Society (2018). *State of the Nations: Diabetes Management in Primary Care*. Accessed at: www.pcdsociety.org/uploads/files/documents/State-of-the-Nation_Full-report_FINAL-web.pdf



Access to specialist psychosocial care and support services which understand diabetes

Although needed, specialist mental health support services for people affected by diabetes are inconsistent across the UK, and within the four UK nations themselves. Consequently, people living with diabetes and healthcare professionals had a range of experiences in accessing and providing support.

Lack of access

Three quarters of people with diabetes who felt they needed specialist support couldn't access it. For people with Type 1, one quarter of people reported having needed emotional support from a mental health professional, but of those, 60% had not been able to access it. 15% of those with Type 2 diabetes reported needing emotional support from a specialist, but three quarters of them had not been able to access it.

“For Type 2 diabetes the support seems very generalised. There needs to be support for those of us who do not fit ‘the norm’.”

Person with Type 2 diabetes

Only 30% of the GPs that we surveyed felt that there was enough emotional and psychological support for people living with diabetes. Recent research by the Primary Care Diabetes Society also shows that clinicians do not always have access to local mental health teams or support from specialists²³. Other healthcare professionals working in diabetes services recognised the physical accessibility of care to be a problem; with a lack of local or community-based provision, patients sometimes have to travel long distances

to hospitals that offered support. This concern was echoed by people with diabetes, who found location and opening times could be a problem, as well as long waiting lists.

Language barriers were also mentioned by healthcare professionals as an access issue.

Lack of diabetes-tailored mental health support

Of those people who had accessed specialist support, some said it was not specific enough to diabetes. They found that often mental health professionals didn't know enough about diabetes to be able to provide the support they needed. Interventions were also reported to have been too short-term. Staff working in diabetes services also told us services were limited, and too generic.

Some healthcare professionals told us that although support is available in their area for more complicated cases, there are gaps at lower levels of need. Whilst other areas offer no support at all for more complicated cases, revealing a complete lack of specialist support. Support offered within children's services becoming limited or non-existent when moving into adult care was also noted as a major challenge.

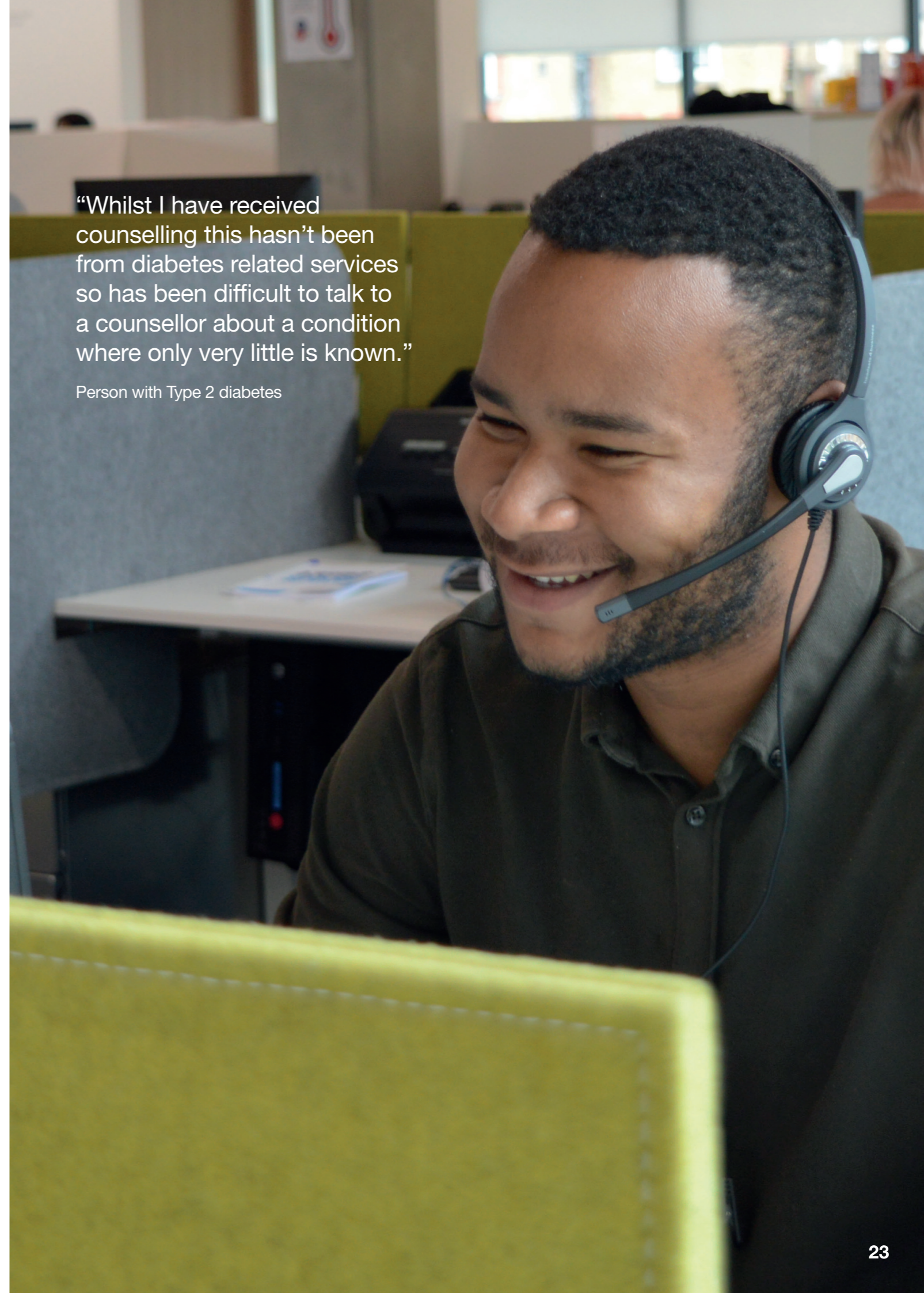
The links between services

The routes to the right emotional and psychological support for people with diabetes are not clear or consistent. Many of the healthcare professionals we spoke to told us that pathways – the links between different levels or types of care – for referring people with diabetes to the right support just didn't exist. This was true for all levels of help, from peer support to specialist mental health services.

Healthcare staff also told us that where these pathways were in place, they were disjointed and confusing. In some cases, people with diabetes were being rejected from the services they were sent to, as they didn't meet the criteria.

“Whilst I have received counselling this hasn't been from diabetes related services so has been difficult to talk to a counsellor about a condition where only very little is known.”

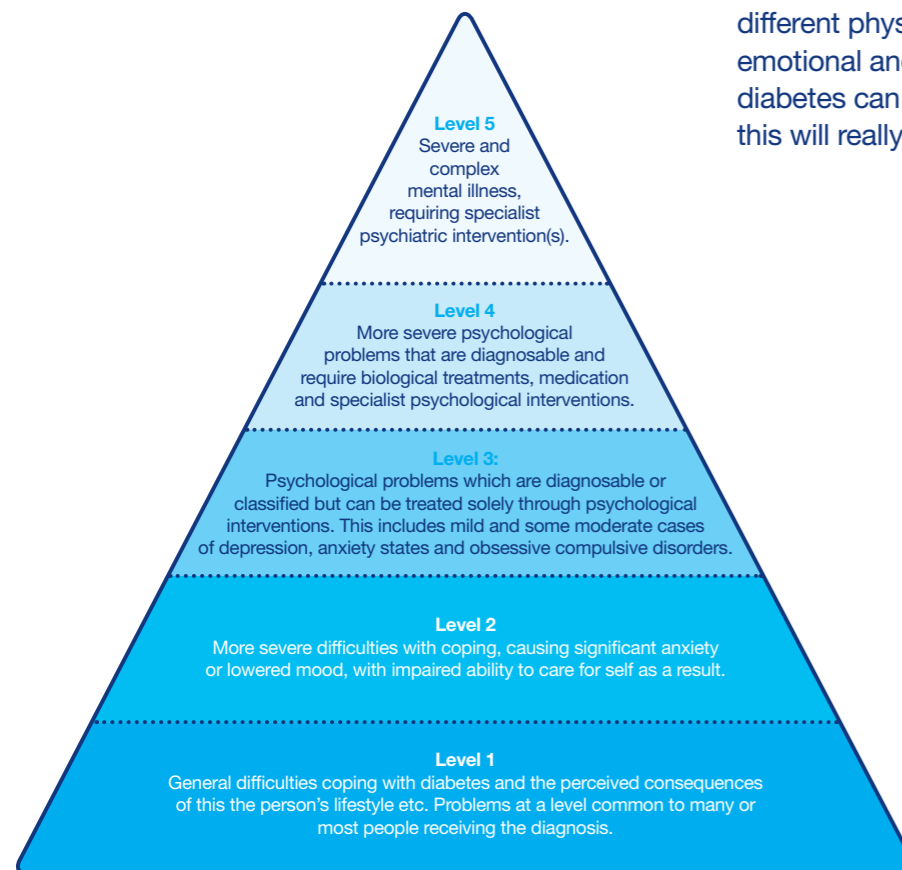
Person with Type 2 diabetes



²³ Primary Care Diabetes Society (2018). *State of the Nations: Diabetes Management in Primary Care*. Accessed at: https://www.pcdsociety.org/uploads/files/documents/State-of-the-Nation_Full-report_FINAL-web.pdf

To determine what level of support a person may need, and to understand if specialist mental health support is needed, the **pyramid of psychological problems in diabetes**²⁴ can be used by healthcare professionals. The base of this pyramid relies on applying a personalised approach to care through conversations that explore what matters most to the person in relation to their diabetes.

Depending on which level a person may be at (and this won't always be neat), those providing diabetes care may be able to help them through general conversations and support around their emotional wellbeing, or more specialist support may be needed. This might range from treatment such as cognitive behavioural therapy for problems such as anxiety, to specialised psychiatry services for complex problems such as severe eating disorders or recurrent DKA.



Integration welcomed

Staff working in diabetes services told us they would welcome more collaboration with specialist mental health professionals. This would help them to incorporate emotional wellbeing into routine diabetes care, and to deliver specialist treatment to people who may have more advanced problems.

Those providing care for people with diabetes recommended that integration of mental health professionals into diabetes teams would enable the most streamlined approach to this aspect of diabetes care.

Our insight has shown that there is some excellent practice in place to provide support for all levels of emotional and psychological need for people affected by diabetes. However, there is still a long way to go.

With increased access to specialist services that understand diabetes, and clearer links between different physical and mental health services – the emotional and physical wellbeing of people with diabetes can be better supported. We know that this will really make a difference to people's lives.

Best Practice

Kingston Diabetes Day Unit & iCope

Recognising the need for emotional support for people with diabetes, the diabetes team at Kingston hospital partnered with the local Improving Access to Psychological Therapies (IAPT) service, and a mental health professional from the IAPT team joined the diabetes team.

The teams collaborated to set criteria for when a person would be referred to see the mental health professional, and continually work together in the decision making around these elements of diabetes care. Sessions are held in the diabetes day unit, so people with diabetes can benefit from emotional and psychological support as part of their routine care.

This also provides an opportunity for a multi-disciplinary team approach to enable discussion and learning.

Case study

Jeff's story

I was diagnosed in 1976 and at that time there wasn't much support or information out there. Diabetes felt like more of a nuisance in the background, than at the forefront of my mind. It was when I started having problems with my eyesight that I began to pay more attention to my diabetes. My diabetes team were encouraging, but I didn't know what questions to ask, and in hindsight, they perhaps could have been more proactive in guiding me and helping me manage it better.

It was several years later that I discovered the diabetes online community. Here I was able to get the information I wanted, for instance about ways to lose weight when you have the condition. It's frustrating though, because I still haven't lost weight even though I think I've done all the right things.

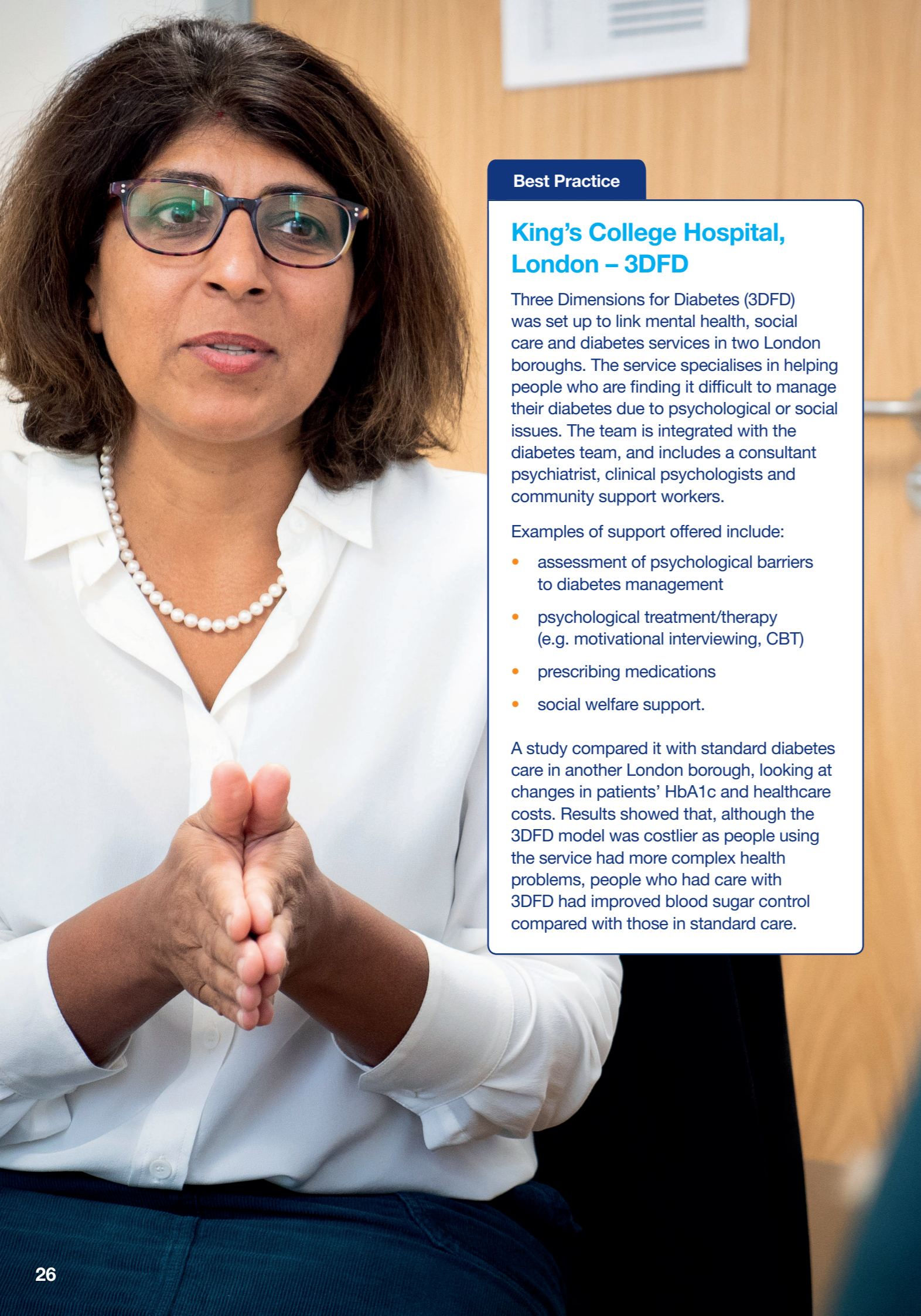
Sometimes I just feel I can't be bothered with looking after myself anymore – it's a feeling that comes to mind quite a lot.

I spoke to my diabetes nurse about how I felt, and I ended up seeing a mindfulness coach working with people with diabetes. They taught me some techniques, which has really helped me cope with my feelings and improve the way I look after myself and my diabetes.

“We really need a psychologist with a special interest in diabetes who can work alongside our community diabetes team. It would be great if they could see patients directly, and also provide support for the other members of the diabetes care team.”

Healthcare Professional

²⁴ Report from the emotional and psychological support working group of NHS Diabetes and Diabetes UK (2010). *Emotional and Psychological Support and Care in Diabetes*. Accessed at: www.diabetes.org.uk/resources-s3/2017-10/Emotional_and_Psychological_Support_and_Care_in_Diabetes_2010%20%28DUK%29.pdf



Best Practice

King's College Hospital, London – 3DFD

Three Dimensions for Diabetes (3DFD) was set up to link mental health, social care and diabetes services in two London boroughs. The service specialises in helping people who are finding it difficult to manage their diabetes due to psychological or social issues. The team is integrated with the diabetes team, and includes a consultant psychiatrist, clinical psychologists and community support workers.

Examples of support offered include:

- assessment of psychological barriers to diabetes management
- psychological treatment/therapy (e.g. motivational interviewing, CBT)
- prescribing medications
- social welfare support.

A study compared it with standard diabetes care in another London borough, looking at changes in patients' HbA1c and healthcare costs. Results showed that, although the 3DFD model was costlier as people using the service had more complex health problems, people who had care with 3DFD had improved blood sugar control compared with those in standard care.



Knowledge and skills of healthcare professionals

There is a clear gap in support and training on emotional and psychological wellbeing for healthcare professionals. It's an issue that's been raised by both healthcare staff and people affected by diabetes. And one that is apparent in both healthcare professionals working in diabetes, focussing on emotional and psychological wellbeing, and mental health professionals working in diabetes.

Nine in 10 of the GPs (91%) we surveyed said they would be confident discussing emotional and psychological wellbeing with their diabetes patients. However, of other healthcare professionals we spoke to, the majority said that more training is needed to help their team recognise symptoms of emotional and mental health difficulties common to those living with diabetes. Some felt it would also be useful for these staff members to have some psychological therapy skills, such as counselling, so they could provide some of this support themselves. Diabetes UK and partners²⁵ have developed a practical guide to help healthcare professionals support the emotional health and wellbeing of people with diabetes: **Diabetes and Emotional Health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes**²⁶.

We also heard that mental health professionals caring for people affected by diabetes require training to understand the specific pressures and characteristics of the condition. This would enable them to provide the right kind of support, treatment, and psychological therapies.

In addition, the need for more mental health professionals who specialise in diabetes was highlighted, as the current demand outweighs the supply.

It is clear that the right training – both for diabetes and mental health staff – is critical. It underpins the calls from people affected by diabetes, and by healthcare professionals themselves. With training in the specific ways that diabetes can affect people's emotional and psychological wellbeing, staff will be better able to respond to the needs of their patients, and help them to live a happier and fuller life with the condition.

“The Mental Health Teams have very limited knowledge of diabetes, its treatment or the impact of the treatment on mental health.”

Healthcare Professional

“I also think that the diabetes team could do with extra training for mental health issues, both recognising concerns and supporting them.”

Healthcare Professional

²⁵ This resource was adapted from the original Diabetes and emotional health A handbook for health professionals supporting adults with Type 1 or Type 2 diabetes which was developed by the Australian Centre for Behavioural Research in Diabetes (ACBRD), the National Diabetes Services Scheme (NDSS) and Diabetes Australia in 2016

²⁶ Diabetes UK (2019) *Diabetes and Emotional Health – a practical guide for healthcare professionals supporting adults with Type 1 and Type 2 diabetes*. Accessed at: www.diabetes.org.uk/emotional-health-professionals-guide

Best Practice

Hackney Diabetes Centre

The Hackney Diabetes Centre Psychology service, part of the diabetes team at Hackney Diabetes Centre, was set up when staff recognised an unmet need when working with people's emotional wellbeing.

The service supports people experiencing diabetes distress, depression or anxiety that is having an impact on their diabetes self-management, and those who are finding it hard to engage with their care. Help is provided through 1:1 therapy and group-based interventions. The service also provides Type 1 support groups one evening a month, involving the psychological therapist, diabetes specialist nurse, and specialist dietitian.

As the psychological therapist sits within the diabetes team, there are joint consultations and joint meetings. Group sessions are held with the wider team providing an opportunity for the team to reflect, discuss concerns and learn from each other.

Links to the wider mental health service now ensures that all people with diabetes related distress have access to support when needed. And the service has helped patients improve their HbA1c, as well as their emotional and psychological wellbeing.

What more needs to be done?

Although there are examples of good practice happening across the country, far too often mental health support is missing from diabetes care.

Our research has shown that the emotional and psychological wellbeing of many people with diabetes, and their parents and carers, is not considered in their care.

We want diabetes care that sees and supports the whole person, based on their personal needs, experiences and circumstances. The emotional and psychological impacts of diabetes should be recognised.

Everyone affected by diabetes must have access to the support they need, when they need it, to help improve both their mental and physical health, and ultimately, their quality of life.

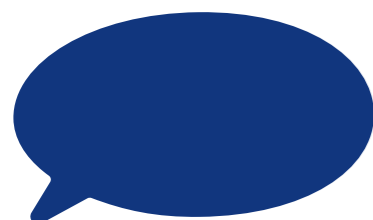


People with diabetes should be able to say

-  I feel comfortable and supported to talk about my emotional wellbeing, if I need to, in my diabetes appointments. My healthcare professionals focus on what matters to me
-  My GP or diabetes team asks me how I feel in every appointment, and also looks out for those close to me
-  When I need information, I am shown where to find resources that are right for me, such as the My Emotions and Diabetes Information Prescription
-  When I need support from other people in a similar situation, I am helped to find it through my diabetes care
-  When I need help from a mental health professional who understands diabetes, I get it quickly
-  If I ever need more support, I know who I can talk to

Our UK-wide recommendations

Diabetes UK calls for:



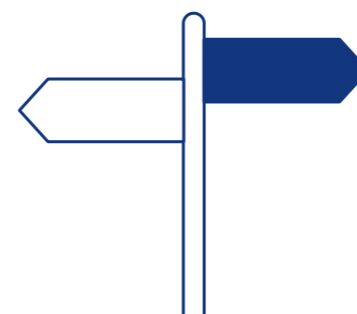
The emotional and psychological impact of diabetes to be recognised in all diabetes care through systematic care and support planning and better conversations.



The NHS and the third sector at a national and local level to 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 to be supported by specialist mental health professionals, including psychologists and liaison psychiatrists, to ensure effective provision across all levels of need.



An integrated care pathway for diabetes and emotional and psychological wellbeing to be developed and implemented in each UK nation.



All healthcare professionals providing general diabetes care to have the training and skills to identify and support the emotional and psychological wellbeing of people affected by diabetes.



Mental health professionals providing care for people affected by diabetes to have knowledge of diabetes and an understanding of the impact the condition can have on physical, emotional, and psychological wellbeing.

Find out more on our calls in each of the four UK nations under these six key areas on our website at: www.diabetes.org.uk/emotional-wellbeing

Join us

We've spoken to thousands people affected by diabetes and they told us that when people are struggling, too often the support they need is missing.

Help us make emotional and mental health support a part of everyone's diabetes care.

Visit our website at:

www.diabetes.org.uk/emotional-wellbeing



**For a world
where diabetes
can do no harm**