DIABETES
All Party Parliamentary Group

Minutes

Mental Health and Wellbeing

Thursday, 13th June 2019

Committee Room 8, Houses of Parliament

2:15 – 4:00pm

Diabetes is a complex and relentless condition. People with diabetes, especially those on insulin, have the responsibility of managing the condition 24/7. Add to that being faced with stigma, balancing other long-term conditions and going through challenging life events; it can be a lot to handle.

7 out of 10 people have said they have felt overwhelmed by the demands of living with diabetes. In the case of Type 2 diabetes, £1.8 billion of additional costs can be attributed to poor mental health. Yet, more than three-quarters of people with diabetes who felt they needed specialist mental health support couldn't access it.

Support for emotional wellbeing and mental health often isn't understood as a vital part of diabetes management, or integrated into care for people affected by diabetes, despite evidence that doing so can improve health, reduce pressure on services, and save money.

- What do people with diabetes need from an integrated mental health and diabetes care?
- What Government and NHS England need to do to ensure every person with diabetes has access to specialist mental health support, if they need to?
- How can we support healthcare professionals to start this conversation with their patients?

The meeting will be chaired by The Rt Hon Keith Vaz MP, Chair of the APPG for Diabetes.

After speeches by the participants listed below, the Chair will open the discussion to the audience.

Participants:

Jackie Fosbury, Diabetes Psychotherapy Lead, Sussex Community NHS Foundation Trust
Zena Innocent, Patient Voice
Dolly Bhaskaran, Patient Voice and Community Champion
Prof Richard Holt, Professor in Diabetes & Endocrinology, University of Southampton

Speeches

Jackie Fosbury, Diabetes Psychotherapy Lead, Sussex Community NHS Foundation Trust

I have worked as a social worker then psychotherapist in diabetes for 28 years and have face to face experience of people's psychological needs as I have heard their emotional health and diabetes stories over this time. I now work for Diabetes Care for You which is a community diabetes service covering East Sussex. We have integrated psychological care and treatment in the diabetes service.

Psychological difficulties are high in people with diabetes with over a third suffering from depression, anxiety and eating disorders such as Diabulimia and BED, plus diabetes burn out and sexual dysfunction. There is a psychological pathway within primary care from depression to binge eating disorder which can lead to the diagnosis of T2 diabetes.

This leads to poor glycaemic control and lowered mood. Sexual dysfunction as a consequence of poor glycaemic control also affects partner wellbeing. So everyone loses.

We need to change our patient's emotional environment, their dietary environment and health care environment. And we need to give equal consideration to female sexual function difficulties in the diabetes consultation room as men have access to a conversation which has until recently excluded female patients. This is prejudicial to care of female patients with diabetes.

Untreated – psychologically - these problems result in costs of distress and disability to the patients in terms of the development of diabetes complications (blindness and amputations for example), and therefore, by definition, high costs to the health service. These difficulties also incur subtle costs to the health service as patients over use diabetes education without any improvement in their diabetes management – unproductive overuse of diabetes education - regularly DNA which is costly to the local health economy and can be admitted to hospital frequently due to DKA.

The NHS Southwest Clinical Networks (2018) state that for every £1 spent on psychotherapy, the NHS saves £29 in admissions. So psychotherapy has to be embedded in all care pathways within diabetes services.

I was employed to lead a team and eventually employed another psychotherapist who had a background as a CPN, and a low intensity CBT therapist and who originally triaged people after the London Bombings and Grenfell Tower. We are not an IAPT team; we are a Cognitive Analytic Therapy team and believe in practice based evidence. We are what they used to call in the old days 'medical psychotherapists' and we are diabetes specialists.

We look at the underlying, sometimes personality factors and early experiences which may lead to depressive self - neglect and the inability to manage diabetes and who self soothe maybe through over eating and drinking. We treat the whole person in Cognitive Analytic Therapy, so we might find that treating problems in the family or with work colleagues lead to less stress and more time to think about taking insulin at the right time and in the right dose for example.

Patients say this:

- Male age 49: It is strange when I think about it, talking to a complete stranger has turned my life around. It is something so simple that seemed so far away at the start. I didn't think my mind-set on comfort eating would ever be changed as it was set in stone for over 35/40 years. You have turned my life around. Hopefully I can continue being positive, and maybe one day diabetic free!
- Female age 42: ….in just 12 sessions, X has helped me identify and address an issue that was quite literally made me make myself ill for my whole life. I didn't know I was doing it. I just felt helpless, exhausted and depressed for so long. Now I can see why. X has quite literally changed my life. She and the Freestyle Libre have freed me and I feel human again.

The impact of integrating psychotherapy has also positively affected male patients. Nationally male mental health is poor with male patients reluctant to ask for help. IAPT have a male access rate of 36% but our percentage 41%. This, we believe reflects the normalisation of psychotherapy provision within the diabetes care pathway

The effectiveness of psychotherapy is shown with drops in anxiety, depression and diabetes distress amongst the cohort. Patients had an average drop in HbA1c of 9mmols from pre therapy to post therapy.

Integrating psychotherapy into our diabetes service also has an impact on the way in which patients use their appointments as we have removed the psychological barriers to diabetes education and good self-management.

And we regularly psychologically upskill member of the diabetes MDT via training, sitting in on consultations and supervision for example. Our colleagues therefore report that this improves the quality of their consultations.

The mind and the body are not separate – there is no health without mental health – WHO. The Kings fund calculated the rising costs of multi comorbidity where the body is split between physical and mental health services and recommend integrated care. Integration prevents communication problems between mental health and physical health teams.

Patients want and benefit from integrated care: Being referred out of a diabetes centre into mental health can be stigmatising and this is particularly true for male patients as although women become more depressed than men, male depression can lead to suicidal ideation. We have to do all we can to normalise emotional care for men with talking cures.

The patient also likes their emotional health being treated with equal validity as their blood checks, and their foot checks for example, this also encourages attendance to appointments and prevents admissions and diabetes complications.

And patients can drop out of mental health services where their therapists do not know or understand the management of diabetes and its demands. They prefer to see psychotherapists who have a comprehensive knowledge of T1 and T2 diabetes so that their psychological issues can be understood within this context.

So emotional and physical care should be integrated. Psychological care is everyone's business - psychological treatment is the psychotherapists business and we should be sitting in the same clinics and drinking in the same bars in Brighton as our physical health colleagues.

Zena Innocent, Patient Voice

I was asked to speak today as the 'patient' voice. I think it would have been more accurate to describe me as the 'frustrated' voice. I can't offer you any expertise on the medical side of diabetes but there are others you have heard from today who can. Or can they?

What do we really know about diabetes? It's true that we have come a long way in the last 50 years. We have better ways of treating it, dealing with complications and monitoring the disease as well complications that we are likely to suffer from but what do we really know? Because no one seems to be able to tell me why my blood sugar is low when I think it's going to be high and high when I expect it to be low?

Why can I eat exactly the same meal every morning, as I do 365 days a year, and sometimes suffer from a hypo but not every time? Why can a target blood sugar reading of 10 before bedtime, mean I will wake with a spot-reading of five in the morning but sometimes it means I wake at 3.30am in a hypo panic. Why did I fall asleep at the table after bunch on last Saturday afternoon (scrambled eggs and baked beans with a slice of toast). My 5k run that morning seemed to have had no effect.

The truth is there are many different reasons, as I am sure the experts alongside me here would agree with. Maybe I ate something that spiked my pre-bedtime reading making it an inaccurate indicator. Maybe I didn't adjust my insulin to allow for exercise I took. Maybe there were more breadcrumbs in my sausages than I thought? Maybe I am too hot or too cold. Maybe I am just stressed out. Who knows? Maybe the reason we don't know is because there is no easy answer. We often think doctors have all the answers but things don't always have a reasonable or logical explanation. Hence the frustration!

I think I could be really good at controlling my diabetes if it were my job and I didn't have to work or care for my children or pay the bills or do the shopping or the school run or remember to send a birthday card to my Aunty Mavis or the hundreds of other things that fill my life. The truth is it feels as if looking after my diabetes is a full time job by itself.

Before I can eat my breakfast, I have to check my blood, calculate my insulin and inject it. Two hours later I check my blood again or deal with a hypo. By the way a hypo is like having a panic attack: heart is racing, palms are clammy, you have a sweaty back and all reasonable thoughts abandon me. In other words I go completely daft and frantically eat jelly babies or glucose tablets to make me feel better. Twenty minutes later I am exhausted.

Now, what am I going to have for lunch? And my mid-morning snack. I have a work meeting and just as I am about to start, I wonder if I am having a hypo or just a little nervous in new surroundings?

Not all these things happen every day but they do occur regularly enough to make me want to press the pause button on diabetes at times. Especially when my diabetes nurse does not have good news for me. Most times!

Leave me alone for a little while, I want to scream. It was at this point while sitting in the Diabetes Clinic one day that I actually did say these words out loud to the nurse. She suggested that I see the psychologist. I didn't even know there was a psychologist within the department. Maybe it was because I was too focussed on the gruesome photos of what could happen to my feet if I didn't get my HBA1C down to single figures!

I was diagnosed with a Type 2 diabetes after two bouts of gestational diabetes. Last week I was told I actually have Type 1 diabetes. I am not overweight and there's no history of it in my family. But I loiter in the biscuit aisle at the supermarket, in the same way others salivate over an expensive bottle of red. I have never smoked, or done recreational drugs or gambled. Chocolate and biscuits give me enough of a thrill. So being told to cut down on the foods I love, is very hard.

I still don't understand how others do it. My best friend's father was diagnosed around four years ago. He's on three tablets a day. My sister's father-in-law lost four stones after his diagnosis and now has annual check-ups. Why am I different? It's not just my frustration, I can feel it when I speak to my doctors and nurses, too. I'm sure they ask the self why can't she just stop eating chocolate?

Maybe it would have been useful to speak to a psychologist when I was first diagnosed. Hearing someone say to me that my feelings of blame and shame are normal and understandable or that there's a reason why I sometimes feel so tired I have to lie down for a few hours, has given me great comfort.

In my work I have a success buddy. We attend events together. We support each other and offer advice. When one of us needs to vent, we know where to go. I would love to have a diabetes buddy, someone who is going through the same experiences as me and understands.

I was lucky to have access to a psychologist when I needed it but I understand this is not a service that is always provided nationwide. I think it should be. Getting a diagnosis of diabetes is life-changing. As well as information, advice and treatment for the physical symptoms, mental well-being should be included as standard.

I would also like to hear more positive stories of diabetes in the media. More about the things we CAN do, rather than the increasing numbers of people diagnosed, the burden on the NHS or the unrealistic diets that can reverse diabetes.

Thank you for listening. I hope it has given you an insight into the day-to-day life of a person with diabetes.

Dolly Bhaskaran, Patient Voice and Community Champion

My name is Dolly Bhaskaran and I am 67 years old. I worked in the NHS for 22 years and now I am retired for the last 13 years. At present, I do voluntary work with local and national charities. I enjoy voluntary work due to the immense happiness I receive from helping others and ultimately it improves my health.

In 2002, I suffered a stroke at the age of 50. As a bonus I also got diagnosed with diabetes, high blood pressure and underactive thyroid.

During this period, I struggled a lot without any support. I had a lot of emotional ups and downs. I was feeling guilty, overwhelmed, frustrated, and angry. While talking to people no one identified my emotional problems, and I continued to struggle alone. I went through anxiety, panic attacks and at the end I went into depression. The main reason I went into depression because I was struggling with my emotions mostly wondering why this is happened to me. I was sitting at home crying without any reason and calling for help which then caused a lot of family issues due to my mood swings. No one could understand what exactly was happening to me. It was a real struggle. And I know many diabetes patients experience the same sort of problems in everyday life.

I was lucky. I came across the local counselling service when I was looking for help online. They provided the best care I could ask for. I also found some tips online that I have used for maintaining my mental wellbeing. These five tips are

1. Connect…with your local community to build a support network Building these connections will support and enrich you every day.
2. Be active means … Go for a walk or run. Step outside of your comfort zone. For e.g. Play a game, Gardening or Dance. Being active will increase your physical and mental wellbeing
3. Take notice… Be curious. Being mindful is the best way to notice your feelings. Take notice of little things and relish those moments to appreciate things around you.
4. Keep learning… New things so you feel you are growing each day. I learned Reiki healing and Reflexology.
5. Give… Do something to yourself and to others. For e.g. Make time for others or show compassion, Smile at others, express gratitude. It will be extremely rewarding

These are the five tips I used to recover and maintain my mental wellbeing. This was the turning point for me to do something in the community so that I can live a healthy and happy life.

Once I recovered from this struggle and understood the importance of emotional support, I wrote to the national charities asking for the support and I noticed a gap. To fill this gap, I set up a group named Living in Harmony in my community for people who live with long term medical conditions to come together and receive the support they needed. My aim was to support the community so that no one needed to suffer alone. The small tips we receive from others makes a big difference in our life. I always believed that prevention is better than cure and I like to see a healthy community where people can manage their own health. My main aim is now to empower people so that they will be able to manage their own health confidently and efficiently. We arrange talks, seminars and workshops for the group. I listen and support them by drop in sessions too. I enjoy doing these sessions.

Another important turning point in my life was joining the community champion program, when I heard about the Diabetes champion program in my community and immediately, I signed up to become a community champion for Diabetes UK.

My main role in the community is to arrange awareness session and engage with people, so that they can get information on what Diabetes is, so they are able to prevent complications. This also gave us a chance to listen to the people about their problems and give them the correct support in the community. While talking to people I understand that people are undergoing a lot of emotional problems along with the diabetes which is makes them stressed day by day. This is not going to help them any way in controlling diabetes. As champions we could give them the right knowledge and information and help them to self-manage their conditions better. This then indirectly help the NHS to reduce the costs and reduces the pressure for the diabetes care.

I have mentioned some of the things I do in my local community. I just would like to add that the Government could help us with structured education for all diabetics in the community .Second thing in my opinion the Diabetes specialist nurses could work in the community, so that the people could get the expert Knowledge and care in the community. The third thing is if Government could provide good transport facilities in our local area, it is a big issue where I live. Good transport enables folks to connect with others, and prevent loneliness and isolation

All these contributes the wellness of the Diabetics. The more they are aware about diabetes they can beat Diabetes by controlling it. From my experience I can say that with more understanding one can control it in a better way and reduce the complications. This could save Ten billion pounds or ten percent of the NHS budget. My vision for the future is “a world without Diabetes”.

Prof Richard Holt, Professor in Diabetes & Endocrinology within Medicine, University of Southampton

Good afternoon, thank you for the invitation. I’m a professor of diabetes and endocrinology at University of Southampton, and for half of my time I work in a diabetes clinic. I have a longstanding clinical and research interest in the links between diabetes and mental illness and well-being. Links between severe mental illness and diabetes lead to studies of depression, then broader psychosocial consequences of diabetes. Mental wellbeing is one of the most significant areas of UK diabetes care in need of improvement.

Diabetes is associated with various mental health problems, from distress to stigma. The prevalence of depression is increased two-fold in people with diabetes compared to the general population. Many people with mental illness have also a higher risk of diabetes. Research has also suggested that there is a complex relationship between depression, the complications of diabetes and long-term health outcomes.

Comorbidity exists and it ultimately leads to worsen outcomes for both diabetes and mental health. Despite immense medical advances on the way diabetes is managed and the way that insulin is delivered, this haven’t been translated to better outcomes for people with diabetes. I would argue that the reason for that are the psychological barriers for those with the condition.

In a survey Future of Diabetes report highlighted the need for more research in this area. There is a strong desire for more research into the consequences of diabetes and mental health. In order to do so, the diabetes Clinical Studies Groups (CSGs), established by Diabetes UK in 2016, have identified a number of research gaps and priority areas under the umbrella of diabetes and mental wellbeing. The CSGs bring together people with diabetes, healthcare professionals and researchers to examine the research landscape, amplify the voice of people living with diabetes, and identify research priorities and practical actions to move forward research in areas of unmet clinical need.

While the group acknowledged the wide range of conditions which affect mental wellbeing, such as severe mental illness and dementia, they recommended focussing this workshop's remit on depression, eating disorders and diabetes distress. This decision was supported by the evidence of the high prevalence of these three conditions in people with diabetes, the need for effective, evidence-based interventions, and the interplay between them.

The workshop aimed to identify key gaps in the evidence base for the links between diabetes and mental health particularly depression, eating disorders and diabetes distress, and how best to address them in order to improve the mental wellbeing of people with diabetes. Eleven key areas in need of increased research investment and focus were identified.

You can read the full report here: https://onlinelibrary.wiley.com/doi/abs/10.1111/dme.14048

The 11 recommendations from the report are:

- Understanding the mechanisms underlying depression
- Understanding the multifactorial impact of social stigma
- Improving the language used by healthcare professionals
- Supporting people who find it difficult to engage with their diabetes
- Supporting significant others
- Supporting people with diabetes and eating disorders
- Improving models of care by learning from best practice
- The potential benefits of screening and managing diabetes distress in routine diabetes care pathways
- Primary prevention of mental health issues at the time of diagnosis of diabetes
- Establishing the effectiveness of diabetes therapies on mood and other mental health issues
- Understanding the impact of current diabetes technologies on mental health

Recommendations for MPs:

- Continue to highlight the need for research into the causes, prevention and management of psychosocial complications with diabetes.
- Advocate for funding for this research, particularly in the light of potential reductions in research funding following the UK's departure from the EU.
- Ensure that research findings are implemented into routine clinical practice through NHS England and Department of Health.

Discussion

The Chair started the discussion asking **Jackie Fosbury** what her area is doing differently. **Jackie** explained that, in her area, the diabetes team will ask people with diabetes about their wellbeing on every single appointment, as standard practice. “If they assess a need, they will be added to a list and receive a triage call within three days. They will be seen by myself or two other colleagues within 6 weeks.”

The Chair asked **Dolly Bhaskaran** if she had attended a Desmond diabetes course. **Dolly** denied it. “I have never been offered an education course in Slough, I would have liked it.”

The Chair also asked **Dr Richard Holt** how many professors of diabetes research mental health and wellbeing. **Dr Holt** answered he does not think there are many others in the UK who have interest in mental health and diabetes. “In terms of mental health and diabetes academic expertise, there is a gap indeed.”

The Chair asked **Zena Innocent** what happened when she told her GP about her emotional struggles. **Zena** clarified that she did not spoke about it with her GP, but with a nurse. “I would not feel comfortable talking about it with my GP. Our conversations are too formulaic, it is all about the numbers. I didn't believe there was time and space to talk about what I was feeling.”

Liz McInnes MP thanked all speakers for the different points of views and mentioned Diabetes UK's Future of Diabetes report. "There were six areas in that report that were not being properly address, including emotional and psychological support. The idea is that it should be integrated through diabetes care, so everyone who works with diabetes is aware of the issue and can ask questions. It will require a change of how we think about diabetes care". **Michael Connellan**, from **JDRF**, agreed with the comment and highlighted the postcode lottery in diabetes care that already exists for all diabetes services.

Dr Holt supported what was said on the difference on access to services across the UK. He explained how CCGs have been trying to breach the gap by referring to IAPT services. "The main issue is the lack of knowledge of diabetes within IAPT." Ideally, **Dr Holt** explains, you would have a psychologist in the community, but there aren't that many psychologists for everyone with diabetes to speak to. "Roles like Jackie are key to upskill the diabetes team to be able to deal with smaller issues and identify when referral is needed. It is something we already do with other complications, such as eyes. We also need to raise awareness with people with diabetes of what they should expect from their appointment". **Dolly Bhaskaran** highlighted how her area, despite having a great diabetes team, is too small to offer a psychological service.

Jackie Fosbury agreed with the comments made and mentioned she and others are working with NHS England to work out the workforce needed to integrate psychological care into diabetes services. "Psychology and Diabetes Network is working on it". **The Chair** mentioned how emotional support seems to not be a priority in diabetes care. "They ask you if you are ok, expecting you to answer yes". **Jackie** agreed and shared how they are trained to not ask people how they are. "Because if they are bad, there is no place to refer them to."

Jonathan asked the panel what role they saw digital on bridging the gap on services providing mental wellbeing for people with diabetes. **Dr Holt** responded that he does see a place for digital. "I do think it is an alternative, but it is complementary. Some people will still need face-to-face support, but it could help others more widely". **Zena Innocent** agreed and highlighted how when you ask for help, you might need help immediately. "You can access a digital service at any time, and would not need to wait six weeks to see a psychologist."

Julia Tyson highlighted the importance of a multi-disciplinary team with a psychologist not only for people who have just been diagnosed, but also for those who have been living with the condition for long. "No one ever asks me about my wellbeing".

Julia also argued that language depends on the patient. "I would like to be called a diabetic and I think my view should be respected". **Zena Innocent** mentioned she would not like to be referred to as a diabetic. "Diabetes is just a part of me, it is not all of me". **Dr Holt** agreed that people with diabetes can describe themselves as they see fit, but explained how research shows how language can affect the attitude of healthcare professionals and diabetes outcomes. "It is interesting which conditions as defined as a noun. You do not call someone with cancer a 'canceric'. But you say 'asthmatic' and 'schizophrenic'. There is stigma associated with naming someone a condition."

The Chair ended the meeting and asked audience members that if they have ideas about what the APPG should discuss in its International Conference to let us know by emailing diabetes-appg@outlook.com