MENTAL HEALTH AND WELLBEING

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APPG
FOR DIABETES

About the All Party Parliamentary Group for Diabetes

The All-Party Parliamentary Group for Diabetes (APPG Diabetes) is a nonpartisan cross-party interest group of UK parliamentarians who have a shared interest in raising the profile of diabetes, its prevention and improving the quality of treatment and care of people living with diabetes.

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Councillor Emma Clayton, Founder, UK Diabetes Network
Duane Mellor, Senior Lecturer in Human Nutrition, Coventry University
Paul McArdle, Lead Clinical Dietitian & Deputy Head of Nutrition, Birmingham

Contact details

Email: diabetes-appg@outlook.com
Website: www.diabetes-appg.co.uk
Twitter: @APPG_Diabetes

Key diabetes facts

- In the UK an estimated 4.6 million people across the UK are living with diabetes.
- An additional 1.1 million people are expected to have diabetes but undiagnosed, this is primarily Type-2 diabetes.
- Since 1996 the number of people diagnosed with diabetes has doubled, from 1.4 million to 3.8 million.
- Of those 4.5 million in the UK diagnosed with Diabetes it is expected that 10% have Type-1 diabetes and 90% have Type-2.
- When looking at genetic predisposition more than 85 per cent of Type 1 diabetes occurs in those with no previous first degree family history, the risk among first degree relatives is about 15 times higher than in the general population.
- The risk of a child developing diabetes if their mother has it is about 2–4 per cent higher than the average, if the father has it is 6–9 per cent higher and if both parents have the condition is up to 30 per cent higher than average.
- Type-2 diabetes can also be affected by genetics have a genetic pre-disposition. Those with diabetes in the family are 2-6 times more likely to develop the condition than those without history in the family.
- Diabetes is a condition which is expected to affect 1 in 10 people globally by 2040, equalling 642 million. This will put diabetes on a par with the number of people being diagnosed with cancer by 2040. There is expected to be 1 in 2 adults across the world undiagnosed with Type-2 Diabetes. The International Diabetes Federation (IDF) has estimated that in 2015 seven countries have more than 10 million people with diabetes; China, India, USA, Russia, Indonesia, Mexico and Brazil.

Reports published by the APPG for Diabetes

- Children with Type 2 diabetes (2019)
- Research into Type 1 diabetes (2019)
- International Diabetes Summit (2019)
- Assessing the Diabetes Transformation Fund (2018)
- Flash Glucose Monitoring: what's next in Diabetes Technology (2018)
- Diabetes and Mental Health (2018)
- Reversing Type 2 Diabetes (2018)
- Diabetes and Podiatry (2018)
- Emotional and Psychological Support for people with Diabetes (2018)
- Next Steps for Childhood Obesity Plan (2018)
- The Future of Inpatient Diabetes Care (2017)
- Safety and Inclusion of Children with Medical Conditions at School (2017)
- Industry Action on Obesity and Type 2 Diabetes (2017)
- Levelling up: Tackling Variation in Diabetes Care (2016)
- Taking Control: Supporting People to Self-Manage their Diabetes (2015)

Mental Health and Wellbeing

A session of the All-Party Parliamentary Group for Diabetes took place on the 13th June 2019 on Mental Health and Wellbeing to talk about how emotional support needs to be a vital part of diabetes management or integrated into care and 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.

Key witnesses;

- **Jackie Fosbury,** *Diabetes Psychotherapy Lead, Sussex Community NHS Foundation Trust*
- **Professor Richard Holt,** *Professor in Diabetes and Endocrinology within Medicine, University of Southampton*
- **Dolly Bhaskaran,** *T2 Patient Voice and Community Champion*
- **Zena Innocent,** *T1 Patient Voice*

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

> ***"We need to change our patient's emotional environment, their dietary environment and health care environment." – Jackie Fosbury***

Jackie Fosbury talked about how psychological difficulties are high in people with diabetes with over a third suffering from depression, anxiety and eating disorders such as Diabulimia and Binge Eating Disorder (BED), plus diabetes burn out and sexual dysfunction. There is a psychological pathway within primary care from depression to BED which can lead to the diagnosis of Type 2 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.

Jackie realized there was a need to change the patient's emotional environment, their dietary environment and health care environment. She also highlights the 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, and is prejudicial to care of female patients with diabetes.

These problems if untreated psychologically result in costs of distress and disability to the patients in terms of the development of diabetes complications (blindness and amputations), 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 due to diabetic ketoacidosis.

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.

Jackie lead a team with another psychotherapist who had a background as a Community Psychiatric Nurse, and a low intensity cognitive behavioural therapist and who originally triaged people after the London Bombings and Grenfell Tower. They are not an IAPT team; but a Cognitive Analytic Therapy team and believe in practice-based evidence. The group is what they used to call in the old days ‘medical psychotherapists’ and diabetes specialists.

They 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. The goal is to treat the whole person in Cognitive Analytic Therapy, so they 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.

Below is some feedback from patients:

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 had 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 as male patients are reluctant to ask for help. IAPT have a male access rate of 36% but **Diabetes Care for You** has a 41% access rate. They believe that this 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 a patient’s diabetes service has an impact on the way in which they use their appointments. Diabetes Care for You has removed the psychological barriers to diabetes education and good self-management.

Why is integration necessary?

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 co-morbidity 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 Type 1 and Type 2 diabetes so that their psychological issues can be understood within this context. So emotional and physical care should be integrated.

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

> ***"A much greater understanding of stigma in diabetes is needed in order to develop strategies to reduce or prevent its impact." – Professor Richard Holt***

Professor Richard Holt talked about how 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 worsening 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 hasn't been translated to better outcomes for people with diabetes. Professor Holt argues that the reasons for this outcome are the psychological barriers for those with the condition.

In a survey *Future of Diabetes* report highlighted a 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.

- 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

Dolly Bhaskaran, Patient Voice and Community Champion

> ***"My aim is to support the community so that no one needs to suffer alone." – Dolly Bhaskaran***

Dolly Bhaskaran is 67 years old and has worked in the NHS for 22 years, now being retired she spends her time doing voluntary work with local and national charities as well as a member of the community champion for Diabetes UK. In 2002, she suffered a stroke and was also diagnosed with diabetes, high blood pressure and underactive thyroid.

During this period, she struggled with emotional ups and downs, anxiety, panic attacks and eventually went into depression. The main reason why she went into depression was due to struggling with emotions and not knowing what she could do. Luckily she came across the local counselling service when looking for help online. They provided the best care she could ask for. She found 5 tips that she uses to maintain her mental wellbeing. These five tips are **Connect with others**, **Be active, Take notice of your feelings**, **Keep learning, and Give to yourself and others.** These were the five tips she used was the turning point in her life to do something in the community so that she can live a healthy and happy life.

In order to help others Dolly set up a group named **Living in Harmony**, where people who live with long term medical conditions can come together and receive the support they need. Her main goal is to empower people so that they will be able to manage their own health confidently and efficiently. She arranges seminars and workshops for the community as well as holding drop in sessions. An integral part of the community is to have awareness sessions so that they can get information on what Diabetes is and that are then able to prevent future complications. This also gave us a chance to listen to the people about their problems and give them the correct support. As a champion, Dolly gives the community the right knowledge and information and helps them to self-manage their conditions better. This results in helping the NHS to reduce the costs and pressure for diabetes care.

Zena Innocent, Patient Voice

> ***"I think I could be really good at controlling my diabetes if I didn't have to work or care for my children or pay the bills or the hundreds of other things that fill my life." – Zena Innocent***

Zena asked, "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?

No one seems to be able to tell her why her blood sugar is low when she thinks it's going to be high and high when she expects it to be low? Eating the exact same meal every morning, why does she sometimes suffer from a hypo but not every time? Why can a target blood sugar reading of 10 before bedtime, mean she will wake with a spot-reading of five in the morning but sometimes she can wake up at 3.30am in a hypo panic.

The truth is there can be many different reasons, maybe she ate something that spiked her pre-bedtime reading making it an inaccurate indicator. Maybe she didn't adjust her insulin to allow for exercise she took. Maybe she is too hot or too cold, or 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.

Zena argues that she could be really good at controlling her diabetes if it were her job, not having to work or care for her children or pay the bills or do the shopping or the school run or the hundreds of other things that fill her busy life schedule. Looking after her diabetes is a full time job by itself.

Before she can eat her breakfast, she has to check her blood, calculate the insulin and inject it. Two hours later, check her blood again or deal with a hypo. Not all these things happen every day but they do occur regularly enough to make her want to press the pause button on diabetes at times. Especially when her diabetes nurse does not have good news.

Zena was diagnosed with a Type 2 diabetes after two bouts of gestational diabetes when previously she was told that she actually has Type 1 diabetes. She is not overweight and there's no history of it in her family. However, she loves to loiter in the biscuit aisle at the supermarket, in the same way others salivate over an expensive bottle of red. So being told to cut down on the foods she loves, was very hard.

She believes that it would have been useful to speak to a psychologist when first diagnosed. Hearing someone say that her feelings of blame and shame are normal and understandable or that there's a reason why she sometimes feel so tired that she has to lie down for a few hours can give great comfort. She was lucky to have access to a psychologist when she needed it, but understands this is not a service that is always provided nationwide. However, she argues that it should be. Getting a diagnosis of diabetes is life-changing. Information, advice, and treatment for the physical symptoms and mental well-being should be included as standard.

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

She hopes that her story can give you an insight into the day-to-day life of a person with diabetes.

Audience discussions:

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 ***Professor Richard Holt*** how many professors of diabetes research mental health and wellbeing. ***Professor 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 speak 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.

Professor 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, ***Professor 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 digitally on bridging the gap on services providing mental wellbeing for people with diabetes. ***Professor 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”. ***Professor 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.”

Recommendations:

- **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.**
- **Integrating psychological treatment within diabetes services (as in cancer services).**
- **Emotional and mental health issues should not be an after-thought in diabetes management.**
- **Psychological screening for Binge Eating Disorders (BED) in depressed patients in primary care as being overweight can lead to T2 (prevention).**
- **Structured education programmes to be offered for all patients with diabetes in the community.**
- **Diabetes Specialists Nurses should meet with the community so people with diabetes could get the expert knowledge and care that they so desperately need.**
- **Provide better transport facilities to enable elderly citizens to connect with others and prevent loneliness and isolation.**