

Notes on Diabetes Group meeting 3rd November 2022

Maxine, Alicia, John, Brad, Jeremy, Nigel, Anne, Penny, Marion and Brian, plus Charlotte Burford and Caroline Walker from Diabetes UK attended. Brad read out John's notes from the previous meeting.

Charlotte began by introducing herself and Caroline. Charlotte is the Engaging communities and volunteering manager for the South East coast and London areas. Caroline is a part-time engaging communities officer, reaching out to communities and vulnerable people who are more at risk of developing type 2 diabetes. Their remit is to let us know what Diabetes UK is and how it can help people with diabetes. Charlotte hoped the group would add their worries and experiences of diabetes in the chat as the session progressed. Caroline started the presentation with a description of what Diabetes UK does. Their job is to tackle the diabetes crisis. They're here to prevent Type 2 diabetes, campaign for and support everyone affected by diabetes, and fund research that will one day lead us to a cure. They run political campaigns, support people with diabetes, fund research, work with communities at high risk of getting type 2 diabetes, engaging with doctors and nurses and the NHS. She introduced the helpline which is available during the working week to give advice and listen to peoples' problems. She moved on to the website, starting with the Learning Zone. This page is a free resource where you enter some personal details and get targeted information relating to your condition. It links you to courses and papers. Next the Forum where you can post queries and get feedback from other users. Another resource is the Shop, where books and literature are available, both free and paid for, and this can be downloaded or in paper format. Also on the website is an interactive tool to help people find out their risk of developing type 2 diabetes in the next 10 years. Charlotte took over to describe the strategic direction of Diabetes UK – essentially to live well and longer with diabetes and to cure or prevent diabetes. She showed us the Diabetes UK team and their roles. She told us the Thanet is one of the areas with the highest diabetes risk in the UK, and they had very few volunteers here. Moving on she told us how we could get involved with Diabetes UK. Caroline introduced the peer support program – a 6 week facilitated course run by trained volunteers aiming to bring people together to share their experiences, with a different theme each week. Other volunteering opportunities included manning stands at events, running events and keeping Diabetes UK aware of events they might benefit from attending.

Charlotte responded to the question 'Did either of you have diabetes?' by saying she did not but her father did reverse his pre-diabetes around 15 years ago with a low-carb diet which was an experimental treatment at the time. Caroline said she had type 1 diabetes. Penny commented in the chat that her GP was very unhelpful and disregarded her issues. Caroline said this was a very common problem, some of which was caused by the Covid lockdown. She said the only way to get help from the NHS was to be very persistent and vocal, and the help courses are only available to pre-diabetics. The low diagnosis rate for pre-diabetes was possibly due to the symptoms being similar to many other conditions. Brian related how GP surgeries were very reluctant to let their patients know about our group, and usually wouldn't even put up our leaflets. Caroline said Diabetes UK often had the same problems with GPs. Penny pointed out the only way she got any help was by implying she would make a complaint if she didn't get her an appointment with either a course of a diabetic nurse. Nigel said he had never seen a doctor about his diabetes, only nurses, and that was only once a year. Alicia said her surgery was excellent and she did get a lot of support. Her consultant was useless and blamed her for her own condition! She said she was envious of type 2 sufferers since their disease was essentially curable. John said he was happy enough with his surgery since they did checks regularly and he saw diabetic nurses when he wanted, Caroline mentioned recent trials in the USA which promised prevention and ultimately a cure for type 1 diabetes. Charlotte said type 2 was mostly reversible but for some people it was impossible.

We moved on to the next agenda item – prescription drugs and pharmacies. Brian asked who of us used prescription drugs and all of us, apart from Brad, said they did. He said he was on a cocktail of drugs and was often over-prescribed so he had boxes of drugs he could only return to a pharmacy for destruction, not re-use. He pointed out that pharmacies were under threat and urged us to sign a

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petition to send to our GPs. We went to the next item which was 'implementing self-care with buddies'. He mentioned he had created self-managed groups in 2003 and some were still active. He asked us to select a buddy from within the group and received approval from some of us. Brian told us about the Keto bread he got in Luxembourg and mentioned he got a good loaf from TK-Max in Westwood Cross. He also recommended the Maqui berry and was looking for a wine made from these berries, since it was supposed to be good for diabetics. He moved onto the topic of 'feet'. He thought we might benefit from a visit from a foot specialist and Brad and others thought this was a good idea for a meeting. He recommended diabetic stockings and had just bought some and was enjoying them. He had a 'doppler' recently which showed his circulation was OK. Brad asked what a doppler was and he was told it was a procedure where the body is wired up to sensors which detect blood flow.

Brad closed the meeting after warning everyone they would be receiving a survey requesting feedback on the group with suggestions for future topics.

Next meeting is 5th January 2023.

Links

Website – <http://diabetesthanet.uk>

Facebook - <https://www.facebook.com/groups/1370586729749214>

Nextdoor - <https://nextdoor.co.uk/events/17592186413264/>

YouTube - <https://www.youtube.com/channel/UCNq8iXg0KgxiGyeEmmz39fQ>