

## **Diabetes education: Experiences within black and minority ethnic communities**

60 people, 55 women and 5 men, from minority ethnic communities in Newcastle took part in discussions about diabetes education. Four of the discussions involved people within family groups.

Language support was needed in nine of eleven separate discussions, for at least one person taking part. This support was provided by bilingual workers and, in family groups, by bilingual relatives.

Just over half (33) of the people who took part in discussions have been diagnosed with type 2 diabetes, 6 within the last five years.

Of those who have been living longer term with diabetes, 6 were diagnosed between five and ten years ago, 14 between ten and twenty years ago, 6 between twenty and thirty years ago, and 1 thirty-five years ago.

6 of the women who took part are from the Chinese community, 10 from the Indian community, 12 from the Bangladeshi community, and 27 from the Pakistani community. 3 men took part from the Bangladeshi community and 2 from the Chinese community.

The age range of participants was: 3 x 25-34; 4 aged 35-44; 4 aged 45-54; 14 aged 55-64; 29 aged 65-74; 6 aged 75-84.

48 participants live in the NE4 postcode area of Newcastle and the remaining 12 are spread across the city. One person currently living in Gateshead was resident in Newcastle at the time of their diabetes diagnosis. Another person, who lives in Newcastle, was diagnosed with diabetes while living in their country of origin.

A person from the Czech Republic was identified as having diabetes by their GP practice and invited by letter to take part in an interview. HAREF arranged language support for a telephone interview, at the beginning of which the person said that they did not think they have diabetes. This confusion illustrates the complexity of providing primary care support in the area of diagnosis of conditions where a lot of explanation and discussion is needed. Practices with a high number of people on their lists with English as a second language have highlighted the practical issue of managing appointments to meet need, in terms of time required for interpreter supported consultations.

### **People diagnosed with diabetes within the last five years**

6 of the women who took part in discussions have been diagnosed within the last five years, one from the Bangladeshi community, two from the Indian community, and three from the Pakistani community. One of the women is aged between 35 and 44, four are in the 65-74 age range, and one is aged 75-84. All live in the NE4 area.

5 women remembered being identified through a health check. The younger woman had gestational diabetes during her pregnancies, and was subsequently monitored. She was identified as being at high risk of developing diabetes, which she initially controlled well through exercise and changes in diet. She was diagnosed with diabetes six months ago.

All of the women talked about the emotional challenge of getting a diagnosis of diabetes, illustrated by the following quotes from three of them:

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“The diagnosis was a big shock. I had no symptoms and when I was told I had diabetes I felt depressed and frightened.”

“I never thought I would get diabetes because I eat healthy food and I walk around a lot. I thought I was just getting old. It is in my family and my husband has had diabetes for about 20 years so I already knew a lot about diabetes and what to do. My husband said he thought I might have diabetes and I went to the doctors and said that my husband had sent me. The doctor laughed and said he'd trust the test more than my husband. The test was positive. I tried managing it by changing my diet but I was already eating healthy food so there wasn't much scope and I felt very bad.”

“When I was first diagnosed I wondered how I would ever control it and it was scary”.

Three of the six women found it difficult to access any information because of their level of English skill.

The information that five women said they needed at the point of diagnosis was:

- how to take care of feet
- how to avoid infection
- what to eat and how to put that information in to practice with the food we cook
- where to go, including information about women-only space, to get in to the habit of exercising

One woman wanted support to make changes in her eating, as she felt she had “fallen in to the bad habit of snacking”.

All six women remember being referred to an education programme by their GP. Five of the women attended the Diabetes Centre Desmond education programme, and one is still taking part in the ‘Living well, taking control’ pilot programme facilitated by HealthWORKS. None of the women could remember having any particular expectations of the programmes to which they were referred.

The women who attended the Desmond programme at the Diabetes Centre could not remember any ongoing support. All highlighted the potential of follow-up sessions with their community-based groups, to top-up messages about how to make changes in diet and where to go to exercise.

The two women who attended the Desmond programme, whose level of English meant that there was no barrier to them getting the information, found it useful:

“I learned a lot of things I hadn't known about what to eat, and felt I got everything I needed at that point.”

“It was a very good programme because they explained everything very well.”

Two women who attended the Diabetes Centre education programme said that it was very difficult to understand the information because the session was long and the language was complicated. There was a language barrier for them.

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The woman who is participating in the 'Living well, taking control' pilot programme, highlighted positive aspects of the support she is receiving:

"I was diagnosed 6 months ago. I had been controlling symptoms of pre-diabetes with diet and then everything I used to do wasn't working. I was having ups and downs in my life and it felt like stress was catalysing everything. My GP looked at the whole picture and referred me to 'Living well, taking control' and I went to the first session in April. It's at a familiar venue and that makes you want to go along. It's a good approach with a lot of visual information. They help you to understand what happens to the thickness of your blood by showing different liquids, water on its own and water with different concentrations of sugar in it, going through a straw. That was such an eye-opener. Joining a group session has had an immediate impact (significant drop in HbA1c reading). The group has been really useful for stress control and for recognising a range of symptoms that other people were describing, because I had been thinking I was going mad. It was so helpful to hear people talking about anxiety and I could think to myself "It's not just me. It does happen to other people". Someone said they felt as though their head was exploding and I recognised that. It was like a picture coming together. It made sense and it was reassuring. It was interesting listening to people from other cultures and hearing about different foods. There is a lot of home cooking in south Asian communities and so people don't always know how to work out what's in the food - there might not be any label. The healthy eating cooking sessions are very good because I've picked up things like using fromage frais and low fat yoghurt. For me, being with people and sharing ideas really helps. There's a group atmosphere. And there's a feel good factor in offering support to others in the group. You go away feeling better. The HealthWORKS professionals are bringing information to you that's hard to find, and what they tell you is accurate and up-to-date. You get all of the information and there's support from your health buddy to make changes. It's motivating. And once you get a few people aware, then the message goes around."

Although three of the five women who attended the Desmond programme at the Diabetes Centre gave positive feedback, they agreed with the other three women that group sessions in familiar community venues are the best option:

"Bringing sessions out to places like here (venue of regular social group supported by the local authority) means it would get to people with a diagnosis of diabetes and their family members, as well as friends who might need to know things because there is diabetes within their families, or to be able to avoid developing diabetes. The group keeps on meeting after we've had the information, and people can encourage each other to exercise and eat different things and not eat as much."

All six women highlighted the value of bilingual workers as language can be a significant barrier to the Desmond programme for some people. Three identified anxiety about getting to an unfamiliar place as a potential barrier to sessions in a hospital setting.

The five older women said that an online education programme would probably not be useful for their peers in south Asian communities, although younger family members might find it useful.

**Health and Race Equality Forum (2014.): Contribution to diabetes education consultation report**