DIABETES EDUCATION AND DEAF ACCESS

Deaflink Responses

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Deaflink Diabetes Education summary

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Methodology

Deaflink invited feedback from our members 3 weeks through July and August. We conducted one to one interviews and also made the questionnaires available through our website.

We had 4 responses (2 D/deaf, 1 hard of hearing and 1 deafblind). All respondents were either living in Newcastle.

We spoke to a further 12 people but they were not in the target group - it was difficult to find members who had been diagnosed in last 5 years.

Summary of Findings

The low number of responses makes it difficult to draw any strong conclusions nevertheless there are some interesting correlations and conflicts

All respondents were diagnosed through routine blood or general health checks.

Only 50% were offered a course. We have no information about whether the other 50% felt that they would have liked to attend a course if it had been offered.

With regard to what the attendees wanted from their course there were common areas – information; advice and answers to questions. There were 2 opposing views of a] peer support and opportunities to share experiences and b] want the facts not chat!

"My experience of the two sessions were people wanting to share their experiences, not that there is anything wrong with that, but I came to learn facts not to hear how someone finds it difficult to eat because of children or how good someone has lost so much weight since diagnosed".

"More explain, personal experiences from others to share, more experiences and more simple information"

"And to meet with other Type 2 diabetics and how they cope".

Due to need for interpreters some BSL users felt this had led to unnecessary delays in their attendance at the course and options offered. One person felt that the delays were discrimination.

"No interpreter in this check-up. Then nurse said have to go back to higher diabetic nurse and she realised need to book an interpreter then went back the next week and told got type 2 diabetes. Was upset and got information how eat well without sugars?"

"With great difficulty!!!! Problems over interpreter bookings/fees delayed my attendance. Once on course everyone was referred to course within 6 weeks whereby I finally attended 8 months later".

Some also expressed concerns about accessible information and support. There is a support group but have no funds for BSL interpreter.

“Searched online but was confused due to personal restrictions of food and foods to avoid/eat according to diabetes. Contacted Diabetes UK, said don't work with deaf people and referred me to Action on Hearing Loss who subsequently said don't do diabetes! “

“Lectures and questions were very good but most people disappointed because no follow up. One can only take so much new information and especially when elderly (60+ years)”.

Half expressed that they would like more support and opportunities to learn. They would have liked the opportunity to follow up with the same group – share what they had learned. They felt the issue of family attitudes, social eating and the guilt of their diabetes affecting family was an area that they could benefit from exploring further.

“WHAT TO EAT and cope with social eating.”

“They find it difficult to help because they don't understand the eating pattern 'you can have a little' or 'I know diabetics who eat this' 'well I won’t have any then' and you feel guilty”.

2 out of the 4 respondents said that community based sessions that were shorter but more of them would help. None of them had issues with a nurse or other healthcare worker delivering the sessions as long as they were trained and had relevant experience. They did however feel strongly that their disability – deafness should be addressed and planned in the delivery e.g. better planned breaks, clearer more visual information, BSL interpreters and much longer sessions with other D/deaf people would be their preferred way to learn about their Diabetes. One person preferred the computer app as it would help them learn better at their own pace. The person who was Deafblind felt that none of those options were appropriate as they would need much more specialist support.

In conclusion, some people have had a relatively positive experience and some had negative experience, some want to share experiences and some don’t – one size does not fit all.

DIAGNOSIS

1 Do you remember when you were diagnosed with diabetes?

3 were within last 12 months and one was in November 2011

2 Do you remember why you were diagnosed?

3 were diagnosed because of routine blood checks (annually or quarterly.
1 said they were diagnosed “When went for a GP check up in a nurse clinic like MOT, weight and urine sample”.

INFORMATION AND EDUCATION AT THE BEGINNING

3 When you were diagnosed, were you given any information?

All respondents were given information – a leaflet or the nurse tried to explain.

“Nurse asked how are you? Said ok but really poor eating. Blood sample and checked weight. No interpreter in this check-up. Then nurse said have to go back to higher diabetic nurse and she realised need to book an interpreter then went back the next week and told got type 2 diabetes. Was upset and got information how eat well without sugars? Another appointment and the nurse booked an interpreter and we went back and more questions about food and leaflet. Need eye test check-up at general hospital? Wife have to contact Newcastle Communication Support to tell who want preferred interpreters.”

3a If yes, was it useful? What else would you have liked?

“More advice on food and a means of measuring my blood sugar. One has no idea what is happening”.

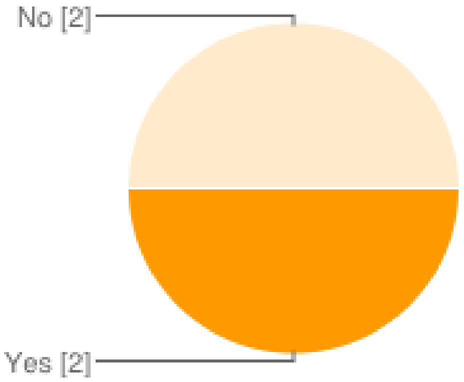
“Simple information about food with pictures, some words hard to understand and I have to ask what they meant. Some words ok understand. Nurse said same food as normal but without sugar. Five fruits a day, amount of each fruits in one day. Interpreter was there”.

“The leaflet was okay but hard to ask about the information and what words means as nurse not available all the time. First time visit to clinic 7 months after diagnosed. For another check-up as well MOT weight”.

To know more about the implications!

Searched online but was confused due to personal restrictions of food and foods to avoid/eat according to diabetes. Contacted Diabetes UK, said don't work with deaf people and referred me to Action on Hearing Loss who subsequently said don't do diabetes!

4 After diagnosis were you offered any educational courses?



4a Did you attend the course offered?

Both people offered the course attended.

EXPERIENCE OF EDUCATION COURSE

5 Do you remember how you were referred to the diabetes course?

"from the practice nurse"

"With great difficulty!!!! Problems over interpreter bookings/fees delayed my attendance. Once on course everyone was referred to course within 6 weeks whereby I finally attended 8 months later".

6 Where did you go for the course?

- Brunton Park
- General Hospital and GP practice at Brunton Park

7 What did you hope to get from the course?

"Why did I have Type 2 diabetes? How should I change my life style? WHAT TO EAT and cope with social eating."

"Clearer understanding of limitations of food types. Understanding of diabetes type 2. Possible peer connection network group. Opportunity to ask questions on overcoming barriers"

8 Did you get this/these from the course?

There were mixed feelings in answer to this question. Both respondents replied Yes and No.

"Yes and No. Learnt there is a group that meet but no funding for deaf to access. They have speakers which supplies information. Anger at being left for so long to attend course compared to hearing. Got more understanding of diabetes but by this time had lost interest and couldn't careless what happens after realising the discrimination and lack of respect. "

"no - more psychological help needed. yes - Lectures and questions were very good but most people disappointed because no follow up. One can only take so much new information and especially when elderly (60+ years)".

9 Did you get any ongoing support after the course had ended? e.g. Booklet

Half were offered further support.

9a If yes, was it useful? What else would you have liked?

A follow up meeting as the diabetic nurses were very good. Men especially found all the food information confusing. And to meet with other Type 2 diabetics and how they cope.

9b If No, would you have like more support? What?

Nutritional support regular check up with nurse every month/months.

No respondent was offered the course but did not attend.

SELF MANAGEMENT

What do you do to self-manage your condition?

Again mixed replies to this question, ranging from demotivated to medicated and monitoring closely.

- No motivation as I'm isolated. No one else to share experience deaf or hearing
- A bit more aware of what I eat and drink

- I manage with difficulty. I have to keep saying 'no' to food and 'I am a diabetic' e.g. no sugar and much less carbohydrates.
- Box of pills from the chemist and monitors all food intake.

If you don't do anything to self manage your condition, what information would help you?

- I would like some more formal information, related specifically to me and my circumstances (DeafBlind)
- Hard to say what information would help as not aware and only diabetes happened for 10 months.
- Nutritional support and regular check ups, contact person to seek support.

Are you and your diabetes helped by anyone at home?

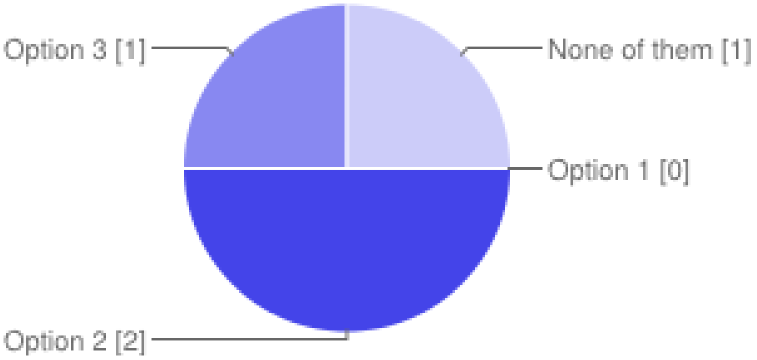
Half of the respondents said they were helped at home.

If yes, what would help them support you?

“Keep an eye on me, bath, and put socks on as can't reach feet. Feed and give tablets at right time in morning, afternoon and night. Get shopping and papers”.
“They find it difficult to help because they don't understand the eating pattern 'you can have a little' or 'I know diabetics who eat this' 'well I won’t have any then' and you feel guilty”.

TESTING THE MENU (FUTURE OPTIONS)

Which of these options would you prefer?



Why do you prefer that option?

- I have done the Desmond course but I would like to do it again, if possible - Option 2.

- Brain freezes after a while! Three sessions gives chance to think things through and bring to next session. If in local community centre, chances are people attending live nearby and potential for peer support

- When learning in a course via BSL, easy forget after the course and prefer on the computer so can read again and again repeat but want BSL on the computer to understand diabetes information better. I have a computer at home.

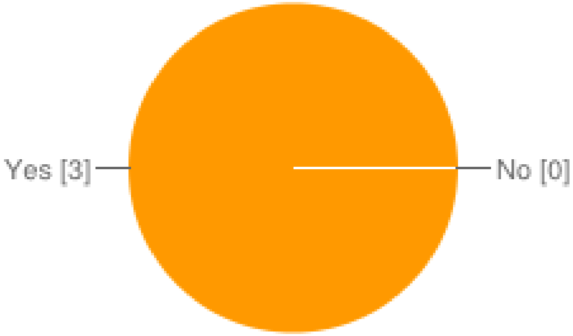
What would you want to learn from this course?

- Food, how manage diabetes, drinks, how much portion can eat, places to go, exercise like chair exercise
- Facts. My experience of the two sessions were people wanting to share their experiences, not that there is anything wrong with that, but I came to learn facts not to

hear how someone finds it difficult to eat because of children or how good someone has lost so much weight since diagnosed. Therefore the facilitator had to rush and omit certain parts of course and over ran but interpreters only booked for 3hrs and had to leave before facilitator had completed their list.

- How to cope with food and how much and what sugar (fruit) carbohydrates I can have.

Would you expect to be given information to support you after the course?



If yes - what would you like? Leaflet? Manual? Helpline?

- Website and leaflet
- Contact groups, "helpline" that was accessible.
- Manual, Helpline and meetings with other Type 2 diabetics

Are there any parts of the course you picked that you would change? If yes, what would you change and why?

BSL interpreter/clips on the course and easier to understand because of English, want simple plain English. Want visual pictures and photos to understand better.
More sessions, less people in group. Too many in small room made it uncomfortable when you also have to account for space for interpreters

Are there any parts of the other options that you thought would be good to include? If yes what and why?

“Follow up support through online would be helpful”
“Like to have the course through the day at Deaflink - easier for me and BSL and easier access to get to Deaflink.”

DETAILS

Where would you prefer to go to attend a diabetes course?

2 people replied to this and both wanted to attend at a Community Building

Why?

Easier for me and BSL, Easier to get to.

The course would be led by a nurse or a healthcare worker, how do you feel about this?

“Fine and nurse more experienced because know about diabetes and from clinic at general hospital”
“I would be delighted especially if they have diabetic experience”
“As long as nurse has deaf awareness training and training materials to reflect that!! i.e. telephone numbers!”

If the course involved you coming to group sessions, would you prefer a specific group?

One person said ‘Any type’ and 2 replied that they would prefer sessions with other deaf people.

In terms of time of the week – 3 respondents did not reply indicating that they did not have any preference. The one respondent who did reply felt late morning on Monday, Thursdays and Fridays would best suit them.

Would you prefer

More sessions but shorter (e.g. 4 x 2 hour)	**3**
Fewer sessions but longer (e.g. 2 x 4 hour)	**0**

What would you prevent you from attending a course?

- “Ignorant/patronising nurses! Need outline of each session sent out prior to course beginning so everyone knows when a certain fact will be discussed. Experienced nurse's phrase was "we will be talking about that later" repeatedly!”
- “Depends on can't be bothered to go, confidence and how well I am on the day. hard to say. Also if no interpreter or BSL”.
- “I am totally Deaf and Blind, I rely on a deafblind manual interpreter. I need a minimum of double the usual time for communication. I would not be able to join in group sessions”.

Do you have any idea's that would encourage people to attend a diabetes course?

“Current Course not suitable. I would need 1 to 1 advice, information and support”.
“More explain, personal experiences from others to share, more experiences and more simple information because hard for deaf people to understand what that mean. I learn a lot from deaf and hearing friends who are diabetic but one friend died”.
“Sorry - some people just bury their heads in the sand”.
“Open course up to another person in that person's life i.e. parent/Sibling/friend/partner as lots of information to take in is too much for one to remember. Supportive person can support accurately and appropriately due to attending course”.

Any other comments?

- I would like to help with any trials to tackle Type 2 diabetes. I would like to be able to measure my blood sugar and know how my body is coping with my diet.
- I would like to learn more about diabetes in the future, family members have diabetes.
- I had a negative experience whereas others may have had positive experiences. Such as on course everyone had had their eye examination within those 6 weeks, I had not. Being a deaf person, eyes are more precious!!

We have not included the personal profiles of the respondents in this report due to the low number of contributors and confidentiality.