Introduction

This was the second meeting of the All Party Parliamentary Group for Diabetes’ investigation into the state of diabetes education and support for diabetes self-management. Focusing on the perspective of people living with diabetes, this session examined the barriers people face in accessing education and sought views about other forms of training and support that would help individuals – and their families – to live with these conditions.

To increase transparency of, and participation in, the Group’s work, Chairman, Adrian Sanders, explained that key themes and thoughts would be tweeted live from the meeting using the hashtag #appgdiabetes. A summary of the social media discussion can be found here: http://www.jdrf.org.uk/campaigns/delivering-research/appg-for-diabetes

1) Speakers

The German model of Diabetes Education – Lara Brockmann

For many years, diabetes education in Germany for both children and adults has been held up as an international example of the benefits of a national programme of holistic diabetes care. Programmes are taught by fully trained, engaged, multidisciplinary healthcare teams who are expert in teaching methodology and techniques which ensure effective delivery of education using age-appropriate tools and language. The outcome of this training and support is that Germany’s mean HbA1c values achieved in both adults and children are lower than corresponding figures in other countries in Europe, including the UK, and progression to long-term diabetes complications is also much slower. Lara Brockmann discussed ten years of diabetes care in Germany.

Lara Brockmann was diagnosed with type 1 at the age of 13 and has lived with the condition for 10 years. She completed a degree in Biomedical Science and is passionate about improving treatment and support for people with type 1. She has just completed a five month internship with JDRF in the UK during which time she represented people with diabetes at a recent NICE Diagnostic Assessment Programme on combined pumps and CGM.

Upon diagnosis, aged 13, Lara and her mother had three consecutive days of training which included all the immediate things they needed to know from a dietician and diabetes specialist nurse (DSN). This included injecting, carb counting, how to cope with Type 1 at school, exercise and going on holiday.

Following the initial induction, a further 10-day overnight course offered more detailed information on living with Type 1, getting greater control of blood glucose, and learning how to calculate insulin doses according to the particular thing being eaten. More specific issues that would crop up in the...
future, such as driving and drinking, were also covered. The course gave Lara an immediate chance to meet other people with Type 1 and to share their experiences.

Two years after diagnosis Lara changed to an insulin pump. Along with 15 other young people, Lara attended the diabetes clinic for another course this time in the school holidays. They had refresher courses on how their blood glucose levels were affected by different experiences, such as exercise, and then on how to deal with hypos. They learned how to use an insulin pump, carb count difficult foods, adjust insulin doses, and there were also specific sessions designed for boys and girls.

The course gave Lara the confidence and knowhow to use a pump, a further chance to meet people with Type 1; it refreshed key skills and provided her with the chance to learn new theory. She was able to repeat the course a year later.

Most recently Lara has received an hour of training each week for two months so her insurance company would fund a continuous blood glucose monitor. Along with covering the basics again, the training offered the chance for people to discuss the issues of particular concern to them. For example, patients raised concerns about the emotional impact of Type 1 and were then provided with additional psychological support by the nurse.

Lara also explained that adults in Germany are entitled to a course each year to refresh and learn new skills; training and support is available for partners for things like work and pregnancy.

Lara concluded by saying she was confident that support and education is available whenever she needs it.

A Case Study in England – June Williams

*Diagnosed with type 2 diabetes in 2010, June Williams felt completely out of her depth, having been given very little information about managing the condition. June discussed the importance of access to education courses from the point of diagnosis to ensure effective self-management in the long term.*

Although June was aware of diabetes as a condition, she knew nothing about Type 2 when she was diagnosed. Instead of education and support, she was given a prescription and told to take tablets. Even though there was a DSN in the GP practice she was told she did not need to see them and that she should just keep taking the tablets.

After a lot of persistence June was able to attend a course but only 10 months after her initial diagnosis. It was with about 20 other people with both Type 1 and Type 2. Having the opportunity to talk and learn from them helped her better control her blood sugar. However, even today, June feels in the dark and the lack of access to testing strips means she would be unable to test her blood if she ate something unusual or found herself in an unexpected situation.

June found the pharmacist was a good source of information, particularly when she found she wasn’t getting on with her drugs. She did not feel that the GP listened to her concerns and in the end, having consulted the pharmacist, she decided to only take metformin. Eventually they worked out the metformin was making her feel ill and after eight and a half months – which June felt was an
unacceptably long time – her prescription was changed. She believes this wouldn’t have happened without the support of her pharmacist.

June has had to buy her own blood glucose monitor, which has helped her control but she still hasn’t been able to see the DSN at her practice.

She feels far more information must be made available from the time of diagnosis so that people can begin to take charge of their blood glucose levels from the start.

**Peer Support and Online Resources – Lis Warren**

In order to increase the transparency of the work of the All Party Parliamentary Group for Diabetes, and to ensure people affected by diabetes are able to input into the APPG’s investigation into the state of diabetes education and support, the APPG hosted the weekly #OurDiabetes tweetchat. Lis Warren reported back on the key themes from the tweetchat and discussed the value of peer support and online resources more widely.

*Lis Warren has had type 1 diabetes for 49 years. She received 2 weeks ‘instruction’ in hospital when diagnosed, and completed a DAFNE course 40 years later. Prompted by her participation in diabetes research, she has recently discovered the diabetes online community (the DOC) and feels she has learned more from peers in the last year than she did in the previous four decades.*

Having purchased a continuous blood glucose monitor, Lis was unable to find any support from her GP so took to the internet and discovered the diabetes online community (the #doc), something few healthcare professionals are aware of. The instant nature of the internet means questions and worries can be answered by people with personal experience of diabetes, whether through social media or online forums.

Lis talked about the online support group, #OurDiabetes, and how it brings together people with diabetes and their families online to share experiences and knowledge. Over the summer, the APPG hosted the weekly #OurDiabetes (#OurD) tweetchat to discuss the experiences of people affected by diabetes of diabetes education and support. Here are the key findings:

Four questions were asked in the Tweet chat:

**Q1. Where do you currently look for support?**

Most people recognised the importance of structured education courses, giving them vital skills and knowledge and the chance to meet other people with diabetes. However, as these courses are not widely available everywhere, online resources are often the ‘go to’ choice for diabetes information. Lis noted that she used Facebook to learn how to use CGM, and watched YouTube videos to learn how to adjust pump settings and insert glucose sensors.

**Q2. What gaps are there in the current provision of education? What other training or support would you or your family find useful?**

People felt strongly that there is a lack of emotional and psychological support to help them live with diabetes. This was something Lis felt particularly strongly about because of her own issues with food, which were never viewed as anything to do with diabetes. Despite raising the problem at the age of 16, it was only five years ago that she was given therapy for an eating disorder. Psychological
support from the point of diagnosis is vital and people felt it would help them to improve their outcomes.

Another key theme that emerged was the lack of training and support available for families, and a real lack of education and support for children and young people with diabetes. Others pointed to the lack of ongoing education for older people with diabetes. As information and good practice changes regularly, it was felt that refresher courses are needed each year to help people top up their knowledge, learn new skills and be re-motivated to manage their condition well.

A very common complaint was the lack of information about diabetes technologies, something rarely discussed in clinics. For example, Lis found that healthcare professionals in both primary and secondary care were unable to understand her CGM data or support her to use the technology. There was a strong concern that the lack of training healthcare professionals receive about technological advancements is holding patients back from accessing, and getting the most out of, new developments.

**Q3. How should education and support best be delivered and by whom?**

Face-to-face peer support was very popular with many taking part in the chat. The feeling that it wasn’t ‘just you’ was very helpful and they were very keen to see people with diabetes take part in the design and content of training courses.

Many were impressed by online resources and the peer support that exists online but felt that signposting to these invaluable resources on diagnosis must improve.

People also felt the structured courses should be marketed and explained more effectively, so that people who are disengaged or in denial about diabetes understood the value of training and would be more likely to attend. Peer support, or local buddying, early after diagnosis was also a key theme.

People with families or in work asked for more flexibility around the courses, suggesting that sessions at weekends and evenings would be welcome.

**Q4. How confident are you that you know what support and education is available to you both locally and nationally?**

Some people mentioned very good centres like Sheffield or the London teaching hospitals, but most people really don’t know what is available or where to look for support. There were many misconceptions with people believing they were not entitled to go on courses while others didn’t know what courses like DAFNE and DESMOND actually offered.

Again, people had little idea where to look for advice on diabetes technologies.

**Addressing Patient Perceptions – John Grumitt**

We know that in the last National Diabetes Audit (2011-12), less than 5 per cent of people with diabetes were offered access to an education course. But the flip side of this is that only 1.4 per cent of people actually chose to attend one. We hear reports of 95 per cent ‘Do Not Attend’ rates in some areas. Drawing on his personal experience as a person with type 1 diabetes, as well as that of introducing patient education into several locations, including South East London, **John Grumitt**
discussed the importance of addressing patient perceptions of education courses and the simple steps that can be taken to increase attendance.

*John Grumitt is Vice President of the International Diabetes Federation and is also Vice President of Diabetes UK. In 2013, John was appointed to the NHS England Commissioning Board Diabetes Clinical Reference Group and is a regular contributor to innovation and policy reviews. He has type 1 diabetes and has completed numerous endurance cycling events, including last year’s mHealth Grand Tour from Brussels to Barcelona.*

**John Grumitt**

John believes the people developing and providing diabetes education have failed to understand and address the needs of people with diabetes. There is a lack of understanding about the perceptions people have over education and going on courses. Currently people do not perceive any value in the existing courses and that must be addressed if people are to start engaging in education.

When introducing diabetes education to South East London, resources meant the team decided to use an existing education programme (X-PERT) but they were determined to tackle the barriers that mean so few people accessed education.

The first thing they discovered was that just over half of local GPs did not believe that education could change the behaviour of their patients. Before anything else, they found they had to address GP perceptions of what education is for because if you don’t convince the person doing the referral, you won’t convince the person being referred to attend the course. Consequently, they set about communicating with GPs intensively to change their minds about the value of education for people with diabetes.

The next stage involved tackling patient perception. When a patient was referred, the team rang them to understand what their expectations of, and beliefs about, the course were. This was a very low cost piece of administration which closed the gaps between people’s perceptions and the reality of what was being offered and, as a result, ‘do not attend’ rates soon became minimal.

They also tailored the approach for different cultures, languages, location and time, something John considered a basic step to increasing attendance rates.

They realised that good healthcare professionals were not necessarily good educators so ensuring good educators delivered the course was vital, with half of them being peers living with diabetes, carers or relatives. There was little difference in outcomes and in many cases outcomes were better from the peer-led courses.

Tracking data was key to monitoring the success of this project. By tracking data they were able to understand each step of the journey through education and how it could be improved. We don’t track data enough in healthcare.

They then built a community amongst the people attending, including both patients and their carers and relatives. The local patient group grew rapidly to become one of the biggest in the country, with over 1000 people signed up and many more involved informally. That on-going peer support, though perhaps difficult in terms of commissioning, was critical in supporting people with diabetes.
To conclude, John and his team looked at the needs of the local diabetes population and how their needs could be met. How do we get the best approaches adopted more widely? We need to look at technology. We need to get the availability of support tools way beyond the classroom, because, although the classroom is important it is just a fraction of the support that should be available to people. If we are going to meet the needs of the wider population, we have to look beyond the 5 per cent who are currently attending education.

2) Questions and Group Discussion

*Kirsty Winkley,* Diabetes nurse and researcher based at Kings College London, has recently completed work on patient explanations for non-attendance on DESMOND courses. Three main themes arising from this work were a lack of explanation or information from healthcare professionals about the course or the benefits; personal issues for not attending including a lack of flexibility due to work, caring responsibilities or other emotional problems around the time the course was offered; and, finally, issues around the stigma of having diabetes. For example, many Nigerian patients interviewed talked about the shame and stigma of diabetes and didn’t want people to know they had the condition. This feedback was echoed by other people in the room.

*Bernie Stribling,* of DESMOND in Leicester, talked about how they have attempted to address the issue of non-attendance in BAME patients by exploring people’s beliefs and behaviours and helping to change them so that they come to see the course as a positive rather than a negative. They are faced with a culture where the belief is often that diabetes doesn’t exist or, if it does, that there is nothing that can be done about it. The course aims to show that diabetes is serious but that it can be properly managed with help.

*Lord Lyndon Harrison* raised concern about the recurring issue of the availability of test strips – is there still a reluctance to provide test strips to people with Type 2, as well as ongoing issues around rationing strips for people with Type 1? This was clearly still a key concern for many people in the room. *Heather Daly* pointed out that historically, test strips were given out without any formal education making it harder for people to know how to interpret and improve on results, whereas in fact monitoring and self-management education need to go hand in hand. *Jonathan Valabhji,* National Clinical Director for Diabetes and Obesity, said people with Type 1 should have limitless access to test strips, but there are a number of cases where people with Type 2 also need test strips. New legislation on driving will mean more people with Type 2 will also need to start to test more. Clear NICE guidelines say that availability should be based around individual needs and patient empowerment. Jonathan is working with Diabetes UK and the patient safety domain on how compliance with guidelines needs to be taken into account in clinical outcomes.

*Baroness Ludford* has lived as the partner of someone with diabetes for over forty years and has never been offered any kind of education or inclusion in diabetes training and support. It has to be key for people with small children with diabetes, but it would also be helpful for family members of older people with diabetes as well.

Referring to John Grumitt’s presentation, *Lord Harrison* asked what reasons GPs gave for their belief that diabetes education cannot change behaviour. John explained that a study by Professor Naveed Satar of Glasgow University found that 56 per cent of GPs felt this way. The reality was that
awareness of education, particularly in primary care clinicians but also among secondary care clinicians, was dismal. John acknowledged that GPs are busy, there is a lot of pressure and noise which makes good referrals difficult. To tackle this they created templates so that GPs could access key information when they were having conversation about education. John felt that one thing he would have changed in the work his team did was communicate even more with GPs to get over the importance of education. Technology offers a huge opportunity to do this much better.

**Trudi Deakin**, of X-PERT Health, also found many GPs are too busy to refer people whereas others were referring lots of people but were not explaining the benefits or the reasoning behind the courses. Recently they asked a GP to send out 408 letters inviting people with Type 2 to an X-PERT course, clearly explaining its benefits. The response has been extremely positive. If the GP shows an interest and recommends a course attendance is much better.

**Sophie Harris**, of the Academic Health Science Network in South London, discussed work they have been doing across South London to increase good referrals, good provision, and good commissioning to try to increase the uptake of structured education. However, what is currently commissioned isn’t always fitted to the people who need it. Some people do not fit into the current care pathway and are not suitable for courses or online support. These people need one-to-one support to promote their self-management.

Paediatrician **Dr Chizo Agwo** pointed out that DAFNE, DESMOND and X-PERT are all adult-focused, so the needs of children and young people should not be forgotten. At diagnosis, parents are often in shock and both parents and children get basic training on diabetes care. Education in the care of children needs to be embedded within the team rather than requiring external programmes of education. Sometimes education needs to be opportunistic or creative in how it is taught. Education needs to be age appropriate and will vary depending on the child’s age and abilities. It needs to be tailored specifically for the child and their family as they develop.

**Bridget Turner** of Diabetes UK pointed out that education for children and their families should be driven by individual need and we need to change the relationships between healthcare professionals and people with diabetes so that healthcare professionals have the knowledge and skills within their team to be able to provide tailored individual support to children, parents, teenagers and their families.

Bridget agreed about the importance of embedding diabetes education within healthcare professional knowledge, but felt that this needs to be broader, so that education is embedded within local communities, online networks, volunteer groups – those who are actually disseminating information.

Should people actually have to be referred to education or should they be able to seek education which fits into their lifestyle at a time to suit them? Bridget acknowledged this could be difficult for the NHS to adopt but online resources and peer support programmes like those offered locally by Diabetes UK can be beneficial in making people with diabetes aware of what’s available to them and the value it can have in terms of their health. A lot of people are scared of the term ‘education’ but they do want to learn and they do want information.
There is a real need to look at all the different forms of diabetes education and support to make people aware of what is out there. Primary care must be a key driver for this dissemination of knowledge.

Rob Gregory, Chair of Association of British Clinical Diabetologists, believes that a legislative solution might be possible if employers are made to release people for educational opportunities. He found a common barrier was people who couldn’t attend because they struggled to get the time off work.

Finally, Adrian asked each speaker to give one final recommendation for change that the APPG could consider for its final report in 2015.

Lara impressed the importance of continuous education to keep up to date with new ideas and developments so advocated refresher courses each year to be tailored to the needs of individuals and their families.

June called for access to education to be provided within a month of diagnosis.

Lis emphasised the importance of peer support in helping GPs to mentor people who are newly diagnosed or who need a little more support and encouragement to attend education courses.

John felt that whilst promoting good practice around courses so that you eliminate variation is good, it can miss the point. The solution lies in building communities, be they virtual through the internet or real in a community setting, and empowering people by providing them with tools to develop their knowledge. This is how we can reach the wider audience. Structured education courses will only ever reach the few.

Actions

MPs and Peers were asked to write to their local CCGs and ask what education and support is available for people with diabetes locally and whether there are any barriers to providing this.

Next Meeting

The next meeting will take place on Wednesday 19 November from 2pm in Committee Room 2. This meeting will examine the role of local clinical commissioning groups and healthcare professionals in the provision of diabetes education and support. Please contact Luke Thorne at luke.thorne@diabetes.org.uk or on 0207 424 1858 for further information.