

Scottish Parliament Cross Party Group on Diabetes

Minute of meeting: Tuesday 13 March 2018

Committee Room 5

Present:

Scott Graham
Ian Sloan
Lorna Frew
Ainsley Duncan
Brian Kennon
Martin Shannon
Caroline Held
Kerry Douglas
David Eadie
Alyson Cumming
Kathryn Noyes
Fiona Mckenzie
Marie McCallum
Susanne Cameron-Nielsen
Vicky Alexander
Carrie Johnson
Catriona Stewart
Karen Hamilton
Isobel Miller
Derek Beatty
Maggie Smith
Kirsty Jarvis
Ellie Kenton
Fiona Howells
Emily Munn
Sarah Strachan
Rupert Pigot

David Stewart
Angela Mitchell
Sara Moran
Justin Warner
Kirsty McKinnon
Scott McKinnon
Euan McKinnon
Oliver McKinnon
Mhairi Macdonald
Shelia Minty
Ann Brooker
Mark Cook
Vicky Masterton
Nicola Zammitt
Iain Smith
Esther Rue
Kathryn Noyes
Damian Crombie
Dave Duff
Anne Duff
Shelia Reith
Marylin Bolland
Cheryl McPhilimy
Grahame Connor
Caroline Connor
Brian Whittle

1. Welcome

David Stewart MSP (DS) opened the meeting and welcomed the group and speakers.

2. Minutes of last meeting:

Isobel Miller (IM) proposed the minutes from 19 September for approval with the amended date. DS seconded.

3. Presentations:

DS introduced Dr Justin Warner (JW) and Sara Moran (SM) to present on their experiences of diabetes care in schools oversight and the push for legislation and implementation.

Kirsty McKinnon (KMK) talked about her family's experiences with her 7 year old son, Evan and how the school approached his diabetes care.

Caroline Connor (CC) is a school assistant and first aider at Peebles High School and talked about the experiences and hurdles that schools can encounter while caring for children with Type 1 diabetes.

4. Discussion

Conn O'Neill (CON) stated that he used to work for National Rheumatoid Arthritis Society (NRAS) and asked about lessons from England. There Diabetes UK study from 2016 found that only 20% of schools had implemented programs, the biggest challenge is oversight. In Scotland, Oliver Mundell MSP, has taken enquiries from constituents.

SM replied that the difference with England legislation, the Children and Families Act 2014, is too broad, the medical conditions amendments were added late in the day. Any child that needs any extra help means that the whole system need reform.

Brian Whittle (BW) added that the reality is about the implementation of the legislation and how to ensure that all children benefit.

SM developed the point with legislation being good for somethings but it is not behaviour change. This can only come from having a framework in place. When schools cannot help it is either won't or can't. The tribunal can work but you have to throw everything at it.

JW added that the legislation is also about protecting the school by having a legal framework.

Dave Duff (DD) drew the parallel with medical training – Healthcare professionals only learn about diabetes in depth if they want to specialise in the area. Is there anything that teacher training can do to support their understanding of diabetes?

JW explained in Cardiff the health board had appointed a school educator who will go in to teach and update schools, it is also a wish that it was available for other conditions.

Brian Kennon stated that he was glad to see that the challenges are similar in Scotland and explained about the partnership working to create Making Connections a care in schools document. It is still a problem in implementation. The health sector was unified, however the department of education and head teachers can be a barrier.

SM replied that she did not go out looking for details but that people came to the charity. In North Wales a local council education administrator had to cut their budget and was making decisions blind. Diabetes UK Cymru facilitated, including Welsh Ofsted, who are supporting the campaign, in addition the teaching union came out in support.

JW advised BK not to give up, Welsh Assembly Government said that there were no complaints but we had to keep at it.

Lorna Frew (LF) declared an interest as she is a teacher and also a mother of a child with Type 1 diabetes. She asked about the process and the involvement of teachers, parents and the child and how to develop that understanding.

SM pointed out that there will always be new staff that need training and that it should be at health board level to co-ordinate with schools.

JW interjected that head teachers are vitally important to develop that understanding. In Cardiff there has been pressure on teachers and schools to help but there are still ones who refuse.

BW talked about educating the educators. There are other conditions that have had to deal with this issue. He is currently involved with a head teacher and a child with dyspraxia but the school is resisting change. Creating a framework with good communication is vital to bringing about change.

CON asked about the role of industry in helping to educate schools and educators in care homes for older people with either Type 1 or Type 2 diabetes?

JW responded that the simple answer is not as most are worried about the pharmaceutical industry giving education to kids.

Ainsley Duncan (AD) retold how she spoke to her class in primary school to explain about Type 1 diabetes. In secondary school, no one knew, she assumed that as it was known in primary school it would be translated into secondary school. She told her new teachers but she was not asked about what she wanted to do about it.

KMK asked if there was much difference in primary and secondary school care?

JW replied that there is an assumption in secondary school that pupils will take responsibility for this where as in primary school the needs are greater. In my own area we run a big transition programme from primary to secondary school.

Vicky Masterton has two children. With the transition to secondary school could have been better, the schools could have done more. She was injecting in S1 but she had not been checking her blood sugar. In addition she has a son who is in P3 but he had to be changed school due to the lack of care.

Scott McKinnon (SMK) there is one child that is dyslexic and dyspraxic and one child that is diabetic. You have to get the right care from the beginning.

LF commented that even with reasonable outcomes in schools complications can arise long after the children have left school. The case for instilling a higher standard of care that will help avoid complications later.

SM added that Diabetes UK's aim is getting the message across that there is a problem. We have had to be teaching people from the start about diabetes. We have some AMs (Welsh Assembly Members) who are now almost experts on the condition.

IM asked SM and JW that now that there is legislation in Wales how are you going about getting people on board? In Scotland we have guidance but is that enough?

SM responded that the guidance in Wales is not being rewritten and is not compatible with the legislation, for instance all decisions finally rest with the head teacher. Welsh Government are doing a lot, Diabetes UK Cymru has given for free resources for Welsh Government to hand out.

DD commended SM and JW for turning guidelines into legislation and commented that as a retired police officer he had spent a lot of time encountering bad legislation.

KMK asked about the long term effects of kids running high blood sugar. A lot of schools think that kids running 14/15 mmol/l is OK (NICE guidance states that children with Type 1 diabetes should target on waking and before meals 4–7mmol/l and after meals: 5–9mmol/l.) Parents know that if children are running or sleeping at this level it is not OK.

Ian Sloan (IS) asked how can Diabetes Local Volunteer Groups further the case for better care?

SM offered in terms of awareness raising with MSPs it is vital. With schools we can give talks and help explain the reasons why good care is needed. Getting trained individual volunteers to go to schools will also help.

JW added that the power is in the collaboration.

Sarah Strachan commented that you can get better care and support from your friends. Throughout her entire time in primary and secondary school there were other people with diabetes but we were never put in touch with them.

Vicky Alexander (VA) pointed out that there are schools where pupils give talks to S1 and S2 pupils on their diabetes.

Susanne Cameron-Nielsen (SCN) asked about raising awareness, looking at what resources to develop with schools and pupils and how to integrate it with something at a national level.

JW responded that one aspect could be about speaking to the whole school on preventing Diabetic Ketoacidosis (DKA).

Derek Beatty (DB) had started to look into these issues 25 years ago and is saddened to hear it is still a problem. He recommended that there needs to be a

much more of a team effort, with all the actors to create a greater awareness of diabetes but also other conditions like Asthma as we owe it to our children to have the best care and support possible.

CON asked CC about glucose monitoring in school.

CC responded that each child has an individual healthcare plan in Peebles High School. Parents, the head teacher and health care professionals come together to talk about how they are going to achieve the level of care required. When their blood glucose is checked they are not allowed to leave until their readings have settled and CC gives a note explaining why they are late back to class. If they are hypo then CC phones the parent(s) and explain where they are so that as a result no child leaves the school if they are hypo or hyper. In addition it is also inputted to the system on transition from primary school to secondary school. It is a relationship that CC and the pupils hold on to.

AD came back with the details that when she was in secondary school there was no care plan, she had just turned 25 and grown in confidence. In addition she detailed how she had recently been to Orkney with other members of the Young Leaders programme in an event organised by a student Joanne Miller to help the members of the secondary school understand Type 1 diabetes. Talking about her condition has helped AD grown in confidence.

DS wrapped up the meeting with an action point to raise discussions with the Association of Directors of Education in Scotland (ADES) to find out how the issue of good care in school can be improved.

RP announced the next meeting of the group will encompass diabetes research, taking place on Tuesday 19th June at 5pm.

DS closed the meeting.