Dorset Health Scrutiny Committee – 17 October 2018

Public Participation

Agenda Item 10 - Glucose Monitoring Device for Individuals with Diabetes

Questions

1. Rosie and Kirsty Edwardes, Bridport Residents

Statements

- Councillor Colin Huckle, Weymouth & Portland Borough Councillor -Weymouth West Ward
- 2. Councillor Keith Day, Dorset County Councillor Bridport Ward

1 Rosey Edwardes and Kirsty Edwardes, Bridport Residents

Rosey: My name is Rosey, I am a 13 year old girl with type 1 diabetes and have had it since I was 17 months old. I've asked the local NHS if you would be able to help to get Flash Glucose Monitoring technology on prescription in Dorset. I've heard they are not planning to make them available to people like me. So I'd like to ask you as my councillors to speak with our local NHS managers and make them understand how important this is.

Flash is available on prescription nearby in Somerset as I know of people who can get them. In fact it's available across almost all of the South West, except Dorset. Why are people with Type 1 diabetes so different in Dorset?

The sensors are so good. My blood sugar control has been much better and it's so much easier to manage when I use them. My parents don't need to wake me up in the night to finger prick me (as that's when lots of diabetics have hypos). And that better control is good for my health long-term as well.

My fingers are not as sore now as I only need to finger prick a few times a day rather than several times (at least 10 times a day as I am very active). These test strips must cost the NHS a lot more than the sensors would, as I get through at least one box of test strips a week.

My mum and dad have to pay £100 per month for the flash monitoring. They work very hard but can't afford one at the moment and a lot of people are missing out as they cannot afford any. Children especially would really benefit from this, especially young children and babies whose fingers (and toes) really hurt from blood tests.

Kirsty: As a mum, I'm asking the council to hold the CCG to account. This technology really is a life changer for us, and could be for hundreds – maybe even thousands – of other people living with diabetes in Dorset. Since Rosey's last check-up, she has been advised by her Doctor to not fingerpick her little fingers as where she has repeatedly testing so much she is damaging the nerve endings in her fingers. Yet she is still not able to be considered for Flash.

The CCG have, almost one year on, said there will be a very small trial for 6 months. But this makes no sense. We're not sure what they are trying to prove. Why do Dorset need a trial when other CCGs have acted? They have not included children in their trial or the majority of people with Type 1. Why not?

Of the groups they have, there is already clear evidence of benefit for pregnant women with diabetes, and then for the other group, national guidance explicitly does *not* recommend Flash at all for those without hypo awareness – they should have CGM instead. This all seems very rushed and not thought through.

The situation nationally

• The device was approved to be put on the NHS Tariff from November 2017.

- It has been made available across Northern Ireland and Wales. It is now available in around half of areas in Scotland and England.
- Almost all other CCGs in the South West have now approved Flash for use on prescription, recognising there's real evidence that it can help people living with diabetes stay healthy.
- Thousands of prescriptions are being issues nationally, however locally
 we face a post code lottery, with our address excluded us from access
 to this life changing technology.

The evidence about benefits

- People living with diabetes are more likely to test regularly if they are using Flash Glucose Monitoring.
- It can be easier for people to test if they have certain types of employment, where finger pricking is more challenging.
- There are particular benefits for parents, and testing can take place without having to wake their children.
- Unlike finger prick blood glucose monitoring, readings from flash monitors show trends and whether glucose levels are rising or falling. This additional information can improve glucose control; increasing the amount of time blood glucose in in a healthy range and reducing hypoglycaemia^[1].

Financial considerations

- If a person living with diabetes is currently using 8 strips daily to currently manage their diabetes, then the use Flash is approximately cost neutral (depending on local strip costs). In the IMACT study SMBG strip use reduced to 0.5 per day on average in those using FSL.^[2]
- FreeStyle Libre is available on the NHS at £35 per sensor, £910 annual acquisition costs
- In addition, people with frequent and severe hypoglycaemia could reduce severe hypoglycaemia incidents – these can lead to expensive ambulance callouts and hospital admissions – this money could be saved in year. There were 27,485 hospital admissions for hypoglycaemia in 2016 in England and Wales.¹
- Finally there is a case to be made for investing to save: the lowering of HbA1c and the reduction of fluctuation in glucose levels are likely to lead to fewer expensive diabetes complications in the long term.
- 80% of NHS diabetes spending is spent on treating complications.
 Early intervention to reduce HbA1c has been shown to reduce microvascular complications such as retinopathy and amputation.

^{[1] (}Haak, T. et al. (2017)Flash glucose-sensing technology as a replacement for blood glucose monitoring for the management of insulin-treated type 2 diabetes: a multicenter, open-label randomized controlled trial. Diabetes Therapy, 8(1), pp.55–73.); McKnight JA and Gibb FW (2017) Diabet Med. 2017 May; 34(5):732; Bolinder J, et al. (2016) Novel glucose-sensing technology and hypoglycaemia in type 1 diabetes: a multicentre, non-masked, randomised controlled trial. The Lancet. Nov 11;388 (10057):2254-63.

^[2] From https://abcd.care/getting-freestyle-libre-your-formulary

¹ (Naser, A.Y. et al. (2018) Hospital Admissions due to Dysglycaemia and Prescriptions of Antidiabetic Medications in England and Wales: An Ecological Study. Diabetes Therapy, 2018 Feb; 9(1): 153–163. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5801235/

It's been close to a year now since the decision was made to put this device on the NHS Tariff, meaning it is in theory available across the country. The latest announcement of a small scale 6 month pilot mean potentially another year of delay before we could get access, and the vast majority of people with diabetes as well.

Since Dorset Clinical Commissioning Group aren't listening, I am asking the Council's Health Committee to look at this issue of unequal access to treatment in our area urgently. People in Dorset aren't being treated fairly. Please can the committee hold the CCG to account and conduct a review into this issue at a future committee meeting?

Statements

 Councillor Colin Huckle, Weymouth and Portland Borough Councillor -Weymouth West Ward

I would like to support one of my Constituents who is concerned that the Dorset CCG is not funding a new treatment to help control Diabetes. The Flash Glucose Monitoring is a new life - changing diabetes technology that helps monitor blood glucose (sugar) levels.

This has been available on prescription since November 2017 and is now available in most of the South West including Somerset and Wiltshire.

Neil, a local man, will be presenting a petition of over 1,200 Dorset residents to the meeting. I would urge the Committee to look into this decision taken by the CCG not to allow this treatment on prescription, to scrutinise that decision and hold them to account.

2. Councillor Keith Day, Dorset County Councillor - Bridport Ward

Members of the Committee, I would like to address you on the subject of Flash Glucose Monitoring – ie the use of the Freestyle Libre.

First, I need to declare an interest – my wife is a type 1 Diabetic and I want her to live to a ripe old age.

My wife is one of a very small number of diabetics that have survived for over 60 years with the condition - and has a gold medal to prove it. It has not been an easy life for her, she has monitored her food carefully and has had to test her glucose levels continuously – initially with urine tests and latterly with blood finger prick testing. This all since the age of 10.

She was offered a 2 week trial of the Libre in July 2016 and found it amazing. She decided that the instant data it provided gave her the ability to control her diabetes as never before. It proved so effective that it was worth every penny of the almost £1200 annual cost.

Her HBA1C (3 month average) has improved enormously and we know of many others that are even better results than hers. The numbers of hypoglycaemic episodes has fallen remarkably.

The Libre enables diabetics to closely monitor their glucose levels and the trend arrows on the device takes the guess-work out of the decision-making, when deciding what action to take with insulin or carbohydrates.

She was amazed that many of the assumptions that had to be made between finger-prick testing were entirely wrong. Being able to see the downward trend enables her to take early action to prevent hypos.

The ability to monitor her glucose levels discretely wherever she is, never possible before, prevents the need for quick, often erroneous just-in-case action. It is also possible for other people to monitor her levels, if needed.

It is clearly not for everyone, for various reasons. Used correctly, it is an incredible aid to diabetic control. As you know the key to preventing diabetic complications is good control, this is a step-change in that process.

If this level of improvement in diabetes control could be replicated throughout Dorset, the incidence of complications, GP visits, hospital admissions etc. would make it a cost-effective investment.

My wife belongs to a number of closed Facebook sites where diabetics swap suggestions and help each other. There are huge numbers of comments on these sites that tell how excited people are about using the device and how proud they are of the improved results they have achieved.

(There is a lot of world-wide evidence that accepts how effective the Libre is in providing accurate diabetic control).

Why then is Dorset so set on delaying the introduction of the Libre? In nearby Somerset and Wiltshire you will have it prescribed. Why is Dorset so arrogant in its belief that they have a better understanding of the device – especially in view of all the mounting evidence?

It is important to note that such is the world-wide success of the Libre that until recently sales were restricted to current users only – and then only two could be purchased within 28 days. Surely this in itself is evidence that the Libre is an effective tool. Diabetics are choosing to buy the device, even at the cost, putting their health above other demands.

Flash glucose monitoring is the future – please embrace it – now! We must give future Dorset generations the best tools to live long and healthy lives. This technology is life transforming, life enhancing and cost-effective. Please consider introducing it for Type 1 diabetics immediately.