

Healthwatch Engagement Diabetes Support Group

Wednesday 4 March, 2015

Number of participants: 10 individuals

Background

Healthwatch Lewisham contacted the leader of Lewisham's Diabetes UK Support Group to find out about the experiences of the group's members using community care services as part of an Inquiry into Community Care Services.

Healthwatch Lewisham initially visited the group on 4 February, 2015 in order to introduce Healthwatch. The group had a visit from Lewisham's Lead Practice Nurse who provided useful information of the support and services that patients with diabetes can access locally, and gave useful tips and information to help patients self-manage. This visit was welcomed by members of the group.

Having briefly introduced the role of Healthwatch, it was agreed that the Community Engagement Officer would come back the following month for an indepth group discussion about their experiences using local services.

The group requested information about their rights as patients with diabetes as they were unsure of what they are entitled to when accessing health services.

Through previous conversations and a planning meeting with the group's leader prior to the visit Healthwatch understand that many patients weren't sure where to go to access support, faced considerable fears around self-management, and couldn't access support when they had concerns. The leader also felt that there was a big disparity of provision for patients with diabetes depending on the area of Lewisham and which surgery they attended. It was agreed that these were some of the topics Healthwatch would explore as part of the discussion.

Providing signposting and information

To respond to the group saying that they were unsure of their rights as diabetes patients and what support they were entitled to, Healthwatch contacted Diabetes UK who provided a '15 essentials in healthcare' which explains what

patients with diabetes should expect from the health service, and what to do if they are not happy with the service they are being given.

Healthwatch provided a pack for all 10 participants which included the summary and more detailed 15 essential guide, and 'what to expect from your doctor' written by the General Medical Council.

Healthwatch recommended taking the guide to show health professionals what they should be receiving if they were experiencing difficulties. They also signposted members to the Diabetes UK Careline who could also provide specialist advice.

Outcome

10 participants have increased awareness including a guide for reference about their 'rights' as patients with diabetes in order to get the best out of their local healthcare services. They also know what to do if they are unsatisfied with their care or have a problem.

Themes arising from the group discussion

Healthwatch asked whether their local doctor's surgery had a specialist diabetes nurse. Not all the participants said that they know if their practice has a specific diabetes nurse. A patient at Baring Rd surgery and St John's Medical centre said that they had a diabetes nurse, a patient from Marvels Lane does not (there are only two doctors at this particular surgery) and a patient from Amersham Vale wasn't clear if they had a specialist Diabetes Nurse or not.

The group reflected that one of the '15 essentials' for patients with diabetes was 'see specialist diabetes healthcare professionals' yet access to this was variable in Lewisham.

Diabetes Foot Specialists

One patient told Healthwatch that they had used the Daughton road foot clinic up until 3 years ago when it closed. Since then they are only able to get their feet checked with the practice nurse at the surgery, who "is not a specialist". They said that they do not feel this is as thorough as the previous chiropodist. The check now takes 1-2 minutes rather than the 20 minutes with the specialist foot clinic. The chiropodist "used to check things that the nurse doesn't check". When asked how this had impacted on their quality of care, they replied that nothing had gone wrong up until now but they would wait and see if something goes go wrong. A few of the group's members stressed the importance of seeing a specialist who was trained in treating diabetics because of the potential severity of foot problems for patients with diabetes.

Another patient said she received a very good service at St John's Medical Centre whose nurse would call her to get an appointment with the foot specialist.

The group felt that overall people were unsure where they could go to get their feet checked by a specialist trained in seeing diabetics and would like more information on this.

“We're told to check our feet but there's nowhere to get them checked”.

Another patient told us that they go privately at the Podiatry Circle because there was a 6-month wait at the chiropodist at the Jenner.

The majority felt it was important to see a specialist because of the particular care required for patients with diabetics.

DECKS programme for Diabetics

Several of the participants said that they go to East Dulwich to get their eyes checked annually. They are usually sent a reminder every year. Fairly soon after their appointment they usually receive a letter to say everything's fine, which is reassuring.

One patient on the other hand said that if there was a problem with their eyes the letter often scared people who were on their own and not sure what to do. They suggested that the letter should advise the patient to book an appointment with a doctor or nurse (who could then have that conversation) and this would ensure that the patient was informed in a supported environment.

A couple of the participants said the letters weren't getting to the surgeries so this part of the communication process was difficult.

Diabetes Nurses

Some of the group expressed to Healthwatch that they had excellent diabetes nurses. When asked what constitutes an 'excellent diabetes nurse' the group said that it would be someone that was easy to talk to, who would chase up patients who haven't be in to see them regularly, and provide follow-up support including a phone call to check up on the patient.

Many of the members of the group in the Grove Park area had noticed a reduction in the number of practicing nurses. The patient at Marvels Lane told Healthwatch that they are currently waiting 6 weeks for their annual check-up.

One participant mentioned that many diabetes nurses had retired recently and it appeared there had been issues in replacing these nurses.

With limited access to diabetes-trained nurses, patients said they were unsure of where to go for support with their self-management.

It was noted by the group that there was a disparity in being able to access diabetes specialist nurses, and specialist foot care depending on which GP surgery the patient attends and where they are in the borough.

Access to support

The group generally felt they were unsure of where to access support around their self-management of diabetes and healthy living lifestyles. They mentioned that you can now self-refer to the DESMOND course but not everyone knows this.

When asked how members had found out about this support group, their responses included: through their GP, through their practice nurse, DESMOND or through Diabetes UK helpline.

One person said the diabetes nurse used to be a great source of information for those that have access to one.

It was highlighted that many people do not know about the group or are unable to access the group.

DESMOND

The group weren't sure that everyone that who was newly diagnosed with diabetes knew about the DESMOND course, and if they did not questioned how did they find out about local support available.

One patient who had been diagnosed out of borough had really struggled to get support in Lewisham where she now lives; Lewisham hospital had told her that she couldn't access DESMOND because she wasn't diagnosed in the borough (this happened three years ago). Since accessing the course it had 'made all the difference'.

Availability of DESMOND varied. Recently, one member had heard that there had been difficulties in recruiting more trainers to run the programmes which was one reason for the varied capacity.

One participant had noted a big improvement on the DESMOND course when she went recently attended for a top-up compared to a few years ago. She told Healthwatch that she felt the action plan was what had made the difference:

patients were asked to choose one aspect of their care that they would like to work on and write actions of how they would go about doing this. This she thought helped to focus and encourage patients.

Another liked that the course wasn't 'preachy' but made suggestions without forcing you to do things.

One member (at Amersham Vale) had been part of project where she received extra support because she had two or more long-term conditions. She felt this scheme was excellent. Through this project they had put her in touch with so much support like JOY who she regularly goes walking with. She felt it was a shame that patients who just have one long-term condition like diabetes won't benefit from the service.

The groups noted that patients with diabetes were encouraged to exercise and live healthily. There was a discussion amongst the group about people not knowing where healthy lifestyle activities were taking part. It was also raised that a lot had been done in Lewisham to provide residents with information, for example wellbeing days however there was a consistent lack of engagement at such events.

A few participants felt that shyness was a barrier for people using local organisations and attending groups, the fear of going on their own or not being accepted. Having support or buddy systems to access these groups would be important.

Self-management

When asked what additional support members would like to help them self-manage, one participant suggested a buddy system would be useful. This could be either a weekly meeting or over the phone to motivate one another to exercise, or talk through issues around diet and blood sugars. Many felt peer support is really important, having someone to talk things through who's been through the same thing.

The group leader felt the link between self-management and support in Lewisham was poor. There was a lack of specialist support for patients with diabetes. Patients are told they must be very careful about their self-management and told how important getting their self-management care right but patients are own their own and not able to access support when they might need it.

"When you're newly diagnosed you're on your own". "You need a number to call or a meeting". Many participants felt there was a lot of fear associated with diabetes and what it means to be diabetic.

“You have to find out yourself”.

“Can’t self-manage if you don’t know how to self-manage”

There was confusion about home testing, some found this a useful way of managing their own diabetes but the leaders suggested that the guidelines were changing, so it was not always recommended for all patients.

The group appreciated the support that the Diabetes UK Support Group offered. Members felt that it gave them an opportunity to share their experiences and learn from others. It is a useful source of ‘honest’ information from people that have been through similar things.

Results from individual survey responses

As part of the Inquiry into community care, participants were asked to complete a spiderdiagram to rate their individual experiences using diabetic-specific services. Looking at the results from the spiderdiagrams, the general trend Healthwatch noted was that for patients whose practice had a diabetes specialist nurse they tended to have a really positive experience and higher quality of care in comparison to those that were experiencing difficulties in accessing diabetes specialist nurses. Specialist diabetes nurse appeared to be a valued source of support, information and advice for patients.

Conclusion

Based on the discussions with participants of the Diabetes UK Support Group, those patients who had access to diabetes specific care generally thought that the quality of care provided was good. The group saw diabetes nurses a valued source of support and medium to access information and further support.

Listening to the experiences of the group there were varying levels of access to diabetes specific services depending on the area of Lewisham and the specific services.

Participants had positive experiences using the DESMOND course in Lewisham. They learnt key skills in self-management, healthy living lifestyles, where to access further support and shared with people going through the same experience as them. Further investigation would need to be done in order to find out whether everyone with diabetes is aware of the course, how to access it, and what the barriers are for people in accessing this support.

Some participants had experienced difficulties accessing specialist foot clinics. They were concerned about the quality of checks provided by non-diabetes specific chiropodists, and some were using private clinics in order to receive the standard of care they felt their condition required.

There is a lot of fear and lack of understanding surrounding diabetes, especially for newly diagnosed patients. Peer support programmes, access and support to access healthy living activities and specialist support when needed were paramount to ensuring people could maintain their self-management successfully and with confidence.

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