

Peer support for parents of children with diabetes: An end to isolation



Lucy Inkster

Peer Support Manager,
Diabetes UK

The peer support service “Talk to Someone with Diabetes” is a phone line staffed by Diabetes UK volunteers. It is open to anyone with diabetes, as well as to parents and relatives of children with diabetes. The volunteers do not offer medical advice, but they do talk about the practical and emotional aspects of living with diabetes. They know this inside out because they also live with the condition or they have children with diabetes, so they understand what it is like to care for a child with the condition.

Diabetes UK created the service after its 2011 Care Survey suggested that 72% of people with diabetes who needed emotional or psychological support had not been offered this from a specialist healthcare service – and parents of children with diabetes were even less likely to receive any support. This is a concern as there is strong evidence that when a child is diagnosed with diabetes, it does not just affect that child, it also has an impact on the whole family, particularly parents and carers who will often be the ones taking primary responsibility for the child’s day-to-day care. What is more, studies show that parents’ anxiety can actually negatively affect a child’s clinical outcomes (Vandagriff et al, 1992), so it is vital that they are given some support.

It can be difficult for parents to talk to friends and family about their child’s condition and sometimes healthcare professionals are unable to really understand what it is like to care for a child with diabetes around the clock. The Diabetes UK peer support service allows people to “match” themselves with a volunteer they feel will be able to help them best. Volunteers have experience of living with type 1 or type 2 diabetes, or caring for a child with type 1.

Beth, who is 43 and has an 11-year-old son with diabetes, explains why she began using the

service:

“I was having a difficult time juggling my new job and getting to grips with a change to Jack’s insulin. I felt I’d exhausted some of my friends’ and family’s time, and I also knew they couldn’t really relate to what I was going through as none of them have a child with diabetes. I don’t normally use phone services or things like that, but I gave it a go. The person I spoke to was great and really helped me at a time when things were all feeling a bit too much – and it was nice to know I wasn’t the only one who had been through it.”

Parents can access the telephone service on 0843 353 8600 from Sunday to Friday, 6 p.m. to 9 p.m., or they can view profiles of all of the volunteers and start a conversation by email with another parent at any time by going to www.diabetes.org.uk/peer-support. In addition, parents can use Google+, the social networking service from Google, where our trained peer support volunteers host conversations and provide support and understanding based on their own personal experiences. The “Hangouts” are free and are available to anyone living with diabetes, as well as their friends and families (visit the Diabetes UK website for details on how to use the service).

Kev’s 13-year-old daughter, Amy, was diagnosed 3 years ago with type 1 diabetes, and he has been volunteering for the Diabetes UK peer support service for the past few months. He feels that it is valuable to connect with people who face the same issues and share a common bond. He says:

“It makes you feel like part of a community and that you are not alone any more.”

He describes a recent Google+ Hangout where a young adult with type 1 diabetes was online to ask questions about managing diabetes. It was the

first time she had ever really spoken to anyone about diabetes, as she lived in a very rural area and her nearest diabetes centre was a 200-mile round trip. Being able to answer all her questions showed Kev the importance of providing peer support.

There is a different topic each week at the Hangout and although some weeks Kev feels that he has little to say, such as during the topic “nights out”, he has found that those Hangouts might be when he learns the most, finding out the issues his daughter will face later in life. Other weeks he has found that he can give a lot of advice, such as when he ended up discussing the features of insulin pumps with two young adults who had a combined diabetes age of 20 or so years and he was able to help them with practical examples.

The volunteers get queries on a variety of subjects, from questions on carbohydrate counting to advice on coping with the impact of diagnosis. Often, it is just that people want to talk to someone who can understand what they are going through and can offer ways to help or view their diabetes-related concerns from a personal perspective.

Kev feels that the peer support scheme is extremely rewarding as it gives him the opportunity to help people who have diabetes and also advise others who, like him, have someone close to them with the condition. He hopes that

he can help people manage their diabetes more effectively by providing advice and support for a condition for which there is currently no known cure.

Kev and his fellow volunteers will not offer medical advice, but can talk about the practical and emotional aspects of living with diabetes or with someone who has the condition.

Living with diabetes can be difficult, as it is a serious lifelong condition but, through this project, Diabetes UK offers the chance to talk to someone who has been there, who knows first-hand what it is like to live with diabetes. Feeling that no-one understands what you are going through can be tough, but sharing experiences with someone who knows is often half the battle in managing diabetes.

People who have used the service have reported that the contact with the volunteers made them feel less isolated and more confident about managing their diabetes. The service has helped more than 1000 people in the past year and is growing as more and more people realise just how effective it is. Whatever is on a parent's mind, there is a good chance they will be able to talk to someone who truly understands, and can give them the time they really deserve. ■

Vandagriff JL, Marrero DG, Ingersoll GM, Fineberg NS (1992) Parents of children with diabetes: what are they worried about? *Diabetes Education* 18: 299–302

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Further information

The “Talk to Someone with Diabetes” service is open from Sunday to Friday, 6 p.m.–9 p.m.

You can call 0843 353 8600 to speak to someone directly.

To view profiles of all the volunteers or start a conversation by email at any time, go to www.diabetes.org.uk/peer-support or email talktosomeone@diabetes.org.uk for a quick reply.

**If you would like to learn more about the service, contact Lucy Inkster,
the Peer Support Manager at Diabetes UK
lucy.inkster@diabetes.org.uk**