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## *What Your Patient is Thinking*

### **“What do you need to make things better?”**

Emma Cartwright

*Emma Cartwright talks about the importance of peer support in self management of chronic diseases*

[emma.j.cartwright@gmail.com](mailto:emma.j.cartwright@gmail.com)

My doctor looked in despair at the blank graph on the computer screen. As a person with type 1 diabetes, I should record my blood sugar five times a day, around 1825 times a year. But I could count, on one hand, the number of tests I’d done in the past year. I knew that I wasn’t managing my diabetes, but every time I took a blood sugar result that wasn’t within range, I felt like I had failed. Ignoring my diabetes meant avoiding those failures, escaping the thoughts of losing my eyesight or my foot, or worrying about what my future might look like.

### **“What do you need to make things better?”**

Then the doctor asked “What do you need to make things better?” and the worst thing was I had no idea. I knew how to stop my diabetes killing me but I didn’t know how to translate that into managing my condition without it controlling my life.

The doctor mentioned an event planned for a couple of weeks later where the connection between mental health and diabetes would be discussed. I agreed to go, largely because I wanted to get out of the room. I felt such despair, but I knew I needed to start facing up to managing my diabetes. Exploring the relationship between diabetes and mental health seemed as good a place as any to start.

At the meeting I met people who also had type 1 diabetes. As we compared blood test meters and hypo stories, I realised this was the first time I had talked about my diabetes outside of a hospital. We all experienced the same difficulties, including not wanting to accept that our lives would be different to those of everyone around us; the constant judgment from doctors, friends, and strangers on our blood sugar results and what we were eating; and managing injections.

### **I wasn’t alone**

I had imagined I was the only person who didn't check their blood sugars constantly, and who didn't always have a perfect result. Talking to my peers helped me accept that a blood sugar out of range was normal and simply provided information that would help me manage my diabetes. They showed me the makeup bags in which they carried their test supplies. As someone who largely "forgot" (as it was the perfect excuse to ignore my diabetes while trying to be the same as everyone around me) to carry any equipment with me, this practical advice made the prospect more attractive.

In a 20-minute conversation, I had learnt more about my condition than I had in the previous 15 years.

Realising there were so many other people who were battling with this condition providing me with motivation. If they could manage it successfully then so could I, I started to explore peer support groups online via social media and through Diabetes charities. I had never wanted an insulin pump and recoiled in horror at the thought of being constantly attached to a machine. But speaking to people who had insulin pumps and who could tell me the pros, cons, and practicalities gave me the confidence to successfully explore the pump as an option.

I have had wonderful doctors, but peer support is vital in supporting me with managing my condition everyday. Knowing there are other people facing the same challenges I am gives me the confidence and motivation to work hard at managing my condition. I feel more engaged and informed about my Diabetes, which means I now know exactly what I need from appointments with my doctors.

## Peer support opens the door to self-management

I've never met anyone who didn't want their diabetes control to be better, but it's hard. Diabetes leaves us constantly open to failure. Every blood test can feel like an exam of the previous couple of hours, or last diabetes equation (meal minus, or sometimes plus, exercise, stress, food type etc. = insulin). Self management is only achieved through trial and error. Peer support allowed me to no longer fear failure but to take it as a learning experience; it is part of my journey. Peer support is as important to my health now as my medication, support from healthcare professionals, and jelly babies.

### box start

#### What you need to know<box-type>1</box-type>

- Peer support can offer a level of knowledge, understanding, and confidence in managing conditions that is impossible to get from doctors
- Social media can be a valuable, free, and accessible source of peer support

- Managing diabetes is difficult, reassure patients that they may not have “perfect” control all the time

**box end**

**box start**

### **Education into practice<box-type>1</box-type>**

- For this patient, the prospect of high blood sugars was a barrier to testing and self management. How could you better explore why patients might not self manage their condition optimally?
- Peer support helped in this case. When and how do you discuss peer support?
- What advice do, and could, you offer on how to access peer support in diabetes, or other conditions? In general terms, how might you discuss the pros and cons of peer support with patients?
- How could you better discuss and distinguish perfect from realistic self management?
- Is there anything else that you might want to do differently having read this article?

**box end**

Competing interests: I have read and understood BMJ policy on declaration of interests and declare the following: . **[Author: Anything to declare?]**