

From the other side of the desk: Patient perspective

I love my CGM: Managing my diabetes is no longer a performance

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About this series

The aim of the “From the other side of the desk” series is to provide a patient perspective and a pause for thought to reflect on the doctor–patient relationship.

Drumming has been my passion since I was 13 – I have an advanced diploma of music and have been teaching as well as playing the drums for nearly 30 years. My career as a drummer was pretty much wiped out, however, when I developed type 1 diabetes.

I was diagnosed with diabetes in June 2010 and the fear and stress of unstable blood sugars made it difficult to focus on the performance. Having lows or highs on stage meant that my brain wasn't functioning properly, so I wasn't performing at the standard I used to in my life before diabetes. The music industry is tough enough without diabetes making it near

impossible. The phone soon stopped ringing. Before I knew it, I was out of work and broke.

Things can only get better

When I was first hooked up to my continuous glucose monitor (CGM), it only took a few hours for me to realise that life was going to be great again. All the stress and fear of managing type 1 diabetes left my mind thanks to a little black box that I kept in my pocket. I was able to sleep all night knowing my new friend would wake me if I was in trouble. Finally I could get back to working full time and living my life to the full.

Before I had my CGM, my average HbA_{1c}



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level was 53 mmol/mol (7%). It's now dropped to 37 mmol/mol (5.5%).

I can mimic the blood sugars of a normal person about 80% of the time. The other 20% of the time I'm only slightly higher than somebody without diabetes. The highest my blood sugars ever get is about 8 mmol/L and most days I don't go above 7. This tight control was unheard of before the CGM. Managing blood glucose levels has become child's play.

The best thing about wearing a CGM is the feeling of safety provided by the alarm. Knowing that I am not going to hypo because an alarm will warn me in advance of low blood glucose becoming a problem is incredibly reassuring.

Testing blood sugar is no performance

Before I got my CGM, I had to do a finger prick test to check my glucose levels – which was a real performance when I was working. I would have to stop drumming, holding up the whole band, and, in front of hundreds of people, sterilise and prick my finger, then wait for the results.

Now I can check my sugars without anyone ever knowing. When I am performing I place my CGM and some jelly beans on the floor behind my drum kit. When there is a gap between songs, I simply poke the CGM button

with the end of my drumstick, glance down and see if I'm OK. All this is done without skipping a beat.

Cost is an issue

As I write this I am not wearing my CGM: with a realistic cost of around \$80–120 per week, saving any respectable amount of money is difficult. For this reason, when work is slow I don't wear it. This is annoying, as I go straight back to having unstable blood sugars and the constant anxiety of having a hypo. I love my CGM. I just wish I could afford it.

It's disappointing that CGMs are not subsidised or covered by insurance for adults. I hope that the subsidy now available to children will be extended to include people of all ages with type 1 diabetes. Clearly the powers that be do not see that CGMs would ease the burden on the healthcare system, as tens of thousands of people with type 1 diabetes would no longer require the same extent of medical attention as their health could potentially improve significantly. They also don't understand that CGMs could get many of these people off income support and back into the workforce, which benefits the whole of society. I hope the doctors I see are as keen as I am to change the system so there is better access to CGMs. ■

"I love my CGM. It's given me back my career and my happy-go-lucky state of mind."