DIABETES RESEARCH AND CLINICAL PRACTICE 154 (2019) 146–147

Contents available at ScienceDirect

Diabetes Research and Clinical Practice

journal homepage: www.elsevier.com/locate/diabres

International Diabetes Federation

The cost of life: Getting the insulin you need ☆

Two advocates discuss their personal experience on accessing and affording insulin.

The cost of life with type 1 diabetes is a serious life-threatening issue. Life with type 1 diabetes doesn't exist without affordable access to insulin plus other expensive medical necessities. Can you imagine if your life depended on a hormone that was unaffordable? It is incomprehensible to many from the hundreds of news reports filed that millions of people with diabetes worldwide are unable to afford the insulin they need. The crisis has resulted in rationing insulin which leads to complications. Tragically, the cost of life with type 1 diabetes has led to preventable and early death.

Riva Greenberg and Bridget McNulty are diabetes advocates. Riva, who lives in the United States has lived with type 1 diabetes for 45years. She has reported on diabetes and written books, helped motivate people to "thrive with diabetes", spoken at global conferences and received awards. Bridget is an advocate from South Africa who has lived with type 1 diabetes for 11years. She is a writer, speaker, and co-founder of Sweet Life Diabetes Community. Both are volunteer members of IDF's Blue Circle Voices Network.

Riva and Bridget live on opposite ends of the globe, so we asked them to give us some idea of their personal experience on accessing and affording insulin. To repeat, each of these amazing people who fight for the rights of people with diabetes, depend on insulin for their lives.

Have you experienced serious concern about getting the insulin you need?

Riva Greenberg (USA): In a general sense, I am worried since I went on Medicare (US assisted healthcare for people >65years) that I could run out of insulin and it would cost a great deal to get more. In terms of serious concern, twice I have run out of insulin and it was frightening. Once, I was traveling out-of-state and my insulin became spoiled and unusable. I went to the pharmacy but they would not sell me insulin without a prescription. On another occasion, I ran out of insulin. I went to a walk-in clinic and they would not give me insulin. I was told to go to the emergency room of the hospital.

Bridget McNulty (South Africa): Yes, absolutely. In South Africa, I am lucky enough to be on medical aid (health insurance). This includes monthly long-acting and short-acting insulin, needles, test strips and lancets. Last year, people with diabetes were told they had to switch to generic alternatives. My endocrinologist wasn't convinced that the generic insulin was right for me. Instead of the five insulin pens I need, I could have just 2/3 pens which is not enough. The 'system' is not geared towards helping patients.

I do need to clarify that I'm in a privileged position in South Africa because I'm able to afford medical aid. Only 17.4% of South Africans can afford private medical aid. For the rest of the population they have to get their insulin and strips from public hospitals or clinics. They are often told that strips "have run out" and then they are turned away. They are also given less advanced insulin. The cost of strips and insulin is prohibitive for anyone but upper middle-class people to afford.

Do you hoard, stockpile or create a reserve of insulin? Do you think this is rational?

☆ This article was originally published in www.diabetesvoice.org, the online magazine of IDF.

https://doi.org/10.1016/j.diabres.2019.107799

Riva Greenberg (USA): On Medicare, insulin is covered under Part D if you take multiple daily injections. After four months, you fall into what's called the "Donut Hole." At this point, insulin costs quite a lot of money as you are paying a good portion of the uninsured price. Because of the high cost of insulin, I have created a temporary solution – hoarding a year's worth of insulin so I do not fall into the Donut Hole. I got samples from my endocrinologist, pre-ordered insulin before my Medicare started and a friend gave me several insulin pens because she had decided to switch to a different type of insulin.

Bridget McNulty (South Africa): It's certainly not rational to hoard but it helps me feel much safer. These days I have only one extra for back-up and it feels risky. Insulin can "go bad" (insulin is fragile and requires refrigeration) in South Africa because the temperatures get very hot in summer. If I'm out for the day and carrying my insulin around, it can stop working. There's no way to know that it's not working except to switch out to a fresh pen (or vial) – you can't do this if you don't have spare insulin.

Other than insulin, what are other concerns, even anger, about living with diabetes?

Riva Greenberg (USA): I am angry about the high cost of insulin and devices. I am frustrated about the never ending constant decision-making and tasks. I am fearful that living with type 1 diabetes in a few decades that I won't be able to see the notches on my syringe. Maybe I'll have dementia. Maybe my partner will have died and I wonder how I will take care of this on my own. I am hopeful that the future will bring more progress, with more life changing impact.

Bridget McNulty (South Africa): I've been running Sweet Life as a diabetes community for 8years, and every November everyone wants to talk to me – magazines, newspapers, websites, radio, TV. For the other 11months, nobody could care less. I think that's what gets to me the most; that we are living with this condition every day and nobody cares. Our governments don't care, our politicians don't care, and our healthcare systems don't care. Nobody chooses diabetes and yet we are ignored as we deal with it every day.

How do you feel about the United States – the wealthiest country in the world – where people are having trouble affording insulin?

Riva Greenberg (USA): It is a travesty, a moral dilemma, shocking, inhumane, embarrassing and most people outside of the US are unaware. That anyone should be denied life-saving medicine is unforgivable. Our healthcare system is broken, and the result of a society that worships money and profit over protecting their citizens. I am somewhat hopeful that the cost of insulin will come down as it has become an extremely highlighted issue and advocates are fighting tooth and nail to keep this in the spotlight and make it happen. When insulin was discovered as a life-saving drug for diabetes in 1922 its patent was sold for $1. Those who gave the world insulin never wanted it to be unaffordable.

Bridget McNulty (South Africa): It's completely ridiculous. I actually don't understand why diabetes isn't more of a hot topic in healthcare and government in general. In South Africa, diabetes kills more people than HIV, Malaria and Tuberculosis combined, and yet there's no attention paid to it at all. I don't understand why.