Interview with Pearl and Raheela about modern diabetes management

This conversation took place at some point between late April and late June 2024.

Pearl is 11 and will be starting secondary school this autumn (2024). She was diagnosed with type 1 diabetes in March 2023 and has been using an Omnipod closed loop system (presumably an Omnipod 5) for the past six months. Raheela, her mother, is keen for Pearl to be as independent and active as ever while managing her diabetes. Both of Pearl's parents have access to her blood glucose readings via an app connected to her continuous glucose monitor (a Dexcom G6), but Pearl is able to manage it on her own and make her own decisions.

On historical glucose management:

Rah: "I remember my dad worrying that he was going toward type 2 diabetes and they used to have these little papers that you'd drop your blood on and they would change colour. That's how they used to do it, rather than you [Pearl] having a little monitor that gives you a number."

Rah: “I remember a friend whose dad was diabetic saying that they had the same foods at the same times every day. That’s how they managed it.”

On being diagnosed with diabetes:

Pearl: “When I was diagnosed, I wanted to meet someone else with it. They do something at the clinic where they choose someone who’s like you. I took part in it and I’ve made a friend with someone who’s got diabetes and is just a bit older than me.”
Rah: “If you’re going through the same thing, it’s just nice to talk to someone else who’s going through it as well.”
Pearl: “Sometimes it’s hard for other people to understand what you’re going through if they’re not going through it themselves.”

On managing diabetes:

Rah: “We went to Costa Rica this year, did ziplining and surfing and kayaking. We were so active and we want to make sure that she knows that she can still do all those things as well. You can manage your diabetes around it.”

Rah: “We try not to restrict diet whatsoever. Pearl eats whatever she wants and then she can manage her diabetes around that.”
Pearl: “But sometimes when you’re having pizza or pasta, food with a lot of fat, you have to input the carbs. Having pizza or pasta or stuff with fat in it is hard because it holds the carbs. So you go hyper a longer amount of time and it's quite hard to get it down."

Rah: "So, if she has pasta or pizza, we'll give her the insulin and she'll be at the right level and then later on she'll go higher for a long period of time. So, we've got to give her a lot of insulin for later on."

Rah: "Over the last year, we've learnt a lot about food and how to manage the different meals that you eat, but we've always said that you can eat whatever you want."

Pearl: "If I'm having dinner, I'm there sorting it out. It's going to be 20 for potatoes or 40 for rice. Add it together and that's 60 for my insulin. I'm more independent working that all out for myself."

Rah: "My husband and I will normally keep an eye on her level before we go to bed and, if she needs a correction, we will give her a correction through this. But, it's fine. You don't go too low at night, really. It's very rare."

Rah: "Pearl went on a residential in January, with school, and were there for a week. You had a pod there and did that all on your own."

Pearl: “On the app you’ve got this thing ‘follower’. So, you press ‘share’ [shows screen]. That’s my mum and that’s my dad, you can see they’re connected right now. They’ve got urgent notes on. On my residential, I could share it with my teacher’s ipad. And then after the residential take them off it.”

Pearl: "I've had a few sleepovers where my mum and dad are in contact on the phone, but I do it all myself."

Pearl: "My friends are very supportive of me. If I have a hypo, I feel a bit weak and can't really move that much and have to sit on the grass. And they'll come over and be with me and chat.”

Rah: "When you're starting out, they're still trying to get the dosage right, you have a lot more hypos. You said: ‘Does anybody else’s legs feel like jelly?’ That’s one of your key things. You feel a bit weak and your legs feel like jelly, so you know that it’s coming on. Then you have sit down, have a jelly baby and wait for it to kick in.”

On glucose tablets:

Pearl: “When we were at the hospital they gave us loads of different choices: stuff like tablets or a drink. But they take about twenty minutes to kick in. They take longer and they’re more expensive. Whereas, if you have jelly babies, you’ve got lots of them and you only need one to keep your levels right. So, I always have jelly babies in my bag for school and then, if I need one, I just eat one.”

Rah: “Sometimes people like that distinction between something mediciney like that [tablets] and sweets or apple juice. But we just want it to be as normal as possible and just have what would be in the house anyway.”

On testing:

Rah: "We've spoken to people who only used to do finger pricks maybe twice a week, whereas now you can see the impact of food."

Pearl: "I have to do a finger prick once every three months when going to the doctor. That's it."

Rah: "It's only if the sensor's not working now that you have to do a finger prick."

Pearl: “Sometimes it hurts your fingers to keep doing it. They say to do it on these two fingers [middle and ring finger] first, because it will make your fingers numb.”

On continuous glucose monitoring:

Pearl: "I started on a Libre and I was using pens. I wasn't using pods or anything. I was only on that for about a month and then onto the Dexcom G7."
Rah: "And then the G6. The G6 is compatible with Omnipod, but the G7 not yet."

Pearl: "They're starting to put the pod onto Dexcom G7, which will be a lot easier because they will communicate better."
Rah: "The G6 is a bit older, so it has tech issues more than the G7."
Pearl: "It takes twenty minutes to warm up. When you put the sensor on, it takes time to get used to what your levels are and reading what it's been before. Dexcom G6 takes two hours where you have no reading. That's when I do finger pricks. That's every seven days. Whereas Dexcom G7 only takes twenty minutes to calibrate and you do it every ten days."

Pearl: "You used to have to scan it, rather than have it go directly to your phone. You would use this [the handset] and scan it [the monitor] and it would tell you your readings."

Pearl: "Sometimes if you lean on it [the Dexcom G6] too much then it starts giving false readings. It will tell you it's a 3, which is really low, but in real life you might be a 6."
Rah: "If you're sleeping on it, sometimes we have to come in and roll you over to get a real reading."

Rah: “You see people who aren’t diabetic with them, like with Zoe. They’re looking more at their lifestyle in general.”

Rah: “I can’t imagine going through it without these now. I guess that’s because we’ve had no other experience of it.”

On insulin pens:

Pearl: “That’s what I used to use. It would already have the insulin in that you put in every thirty days. Then you’d have to dial the number which is how much that you need. You’d have to round it up perfectly, because it only goes by 0.5, 1, 1.5. But now, you can literally have it as, like, 1.85. So, it’s more accurate. Before you had to make it either higher or lower.”
Rah: “That was a problem when Pearl first went on the pen, she would have hypos because the increments weren’t small enough for her. Whereas now, with the Omnipod, it gives it in such small increments that she can get the exact amount she needs.”

On the Omnipod insulin pump (presumably Omnipod 5, as it is a closed loop system):

Rah: "You have to change it every three days. The insulin has to be in the fridge and then you have to inject it into this and then stick it onto your leg. And you don't like that bit. That is the only bit that you don't like: when it goes into your leg. You have to brace yourself for that."
Pearl: "When you open the packet, it already has a needle and a syringe. You attach the needle to the syringe, take the cover off and then get the insulin. You have to separate all the bubbles, because if you have bubbles it will give you less insulin. Then there'll be a small hole and you put the syringe in, press down to put the insulin into the pod. And then when you finish doing that, you press 'continue' on your handset and it will start pumping it down the whole pod. You put it on your arm or leg or wherever you're putting it and then tap that button there. When it's in, you have to do two checks: make sure that you've got the canula in your leg and make sure that there's a red square there. Then it's ready to go."
Rah: "Pearl does it on her own. We're there with her, but she does it all on her own."

Pearl: "It's so much easier, because I used to have to do thirteen injections every day, but now it's just one every three days."

Pearl: “It is a lot easier than having an injection.”
Rah: “You have experienced injections, even if it was only for six months. You kind of know what that’s like, getting out pens whenever you needed. Whereas now it just does it on its own.”

Pearl: "You have to wear it in specific places: inside of your thigh, on your arm, your back or sometimes on your stomach.”
Rah: “Because it talks to the sensor, they have to be inline with each other. They can’t be too far apart.”

Rah: "First of all, we wanted a wireless one. And the second thing was that we wanted it to talk to the sensor, so that it could give automatic corrections, rather than relying on us to give manual corrections. Those were the two key things we were looking for. We read about each of them."

On the closed loop

Rah: “It’s got algorithms in there, so it knows what kind of corrections you might need. It builds a picture the more you use it. But we haven’t always found that so far. You still need to give it manual corrections.”

Pearl: "This is really clever because it's got stuff like Activity Mode where it will change if you're doing an activity. So, you can just say: 'Activity Mode for three hours' if I'm doing tennis for three hours, then it gives you enough insulin to stop you having a hypo."

On representation:

Pearl: “It does make me feel good, seeing other people with them. There’s a girl in Turning Red who’s got a Libre on.”

Pearl: “I like seeing stuff like that here in the museum. It makes me happy that people know what’s going on. People aren’t trying to hide it.”

Pearl: “I’ve recently watched a film called Purple Heart and she’s got diabetes and I’ve watched the Babysitters Club where a girl’s got diabetes. And it makes me happy that they are taking part and people know that kids have got it.”

Pearl: “I got diagnosed the week before I finished watching Babysitters Club, so I was still watching it. When they all found out she had diabetes then the next week I found out I had diabetes.”

Pearl: “Her parents [in Babysitters Club] didn’t really like her being seen with it, so she had to hide her pod when she was out and about.”
Rah: “We’ve watched that episode since and now you think it’s not really a true representation of what it’s like. I guess that’s because things have moved on since then.”

On the future:

Pearl: “I would like it to be a lot easier and more reliable. Sometimes the numbers can be from ten minutes ago and right now it’s not the same number. Even now, it’s not really hard to do. I don’t really mind if it doesn’t get any easier, but I think it will do in the next few years.”

Pearl: “It would be nice if, instead of having it on a separate device, you could have it just go straight to your phone.”

Rah: “If there was a patch you just put on in the morning that was both the sensor and the pod all in one, that would be ideal.”

Pearl: “You could have something that you swallow every day – like a tablet – and then it just makes your pancreas produce insulin that could last 24 hours, instead of having to monitor it.”