

The DigiBete story



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It was 30 October 2015. My husband and I were knee-deep in deadlines for our video production business. It was also the day before Halloween and, personally, I couldn't wait to dress up our little boy, Otis, then 20 months old, as a skeleton and take him to his first Halloween party. The year before, he had only been 8 months old, and he looked so cute dressed as a pumpkin whilst his Dad, Rob, innocently stood behind him dressed as an axe murderer!

This year was different, though. He had changed from a smiley, happy baby to a moody, crying toddler. Looking back, I remember his face had become quite sallow and he seemed to want to be picked up constantly. He hated any noise, always seemed to have infections and had made very little attempt at speech for some time. As the summer progressed, so did his thirst and wetting, often soaking through several outfits a day. He had a toddler's water bottle and would drink four to six of these each day, and he even tried to drink the bath water, often by the jug.

The climax to this period arrived at the Halloween party we were attending. I had changed him just after lunch and he'd been silent all the way there. I carried him, still not wanting to talk, from the car park up the stairs to where my friends and their little boys were all tearing around in their fancy dress costumes and loving the soft play. Just as I was catching up with a couple of the mums, my friend, Lucy, went to pick Otis up as he was crying and said, "He's wet right through, Maddie." Sure enough, his entire skeleton outfit, right up to the neck, was sopping wet.

"I'd only just changed him," I moaned. Lucy, obviously concerned, told me that her boy didn't wet his nappy like that in 12 hours and that she thought I really ought to take him to the doctor. I made an appointment the following Monday.

After a brief consultation, the doctor, who also turned out to be the diabetes specialist, suggested it

was probably a bladder infection, but recommended us to book in with the nurse that week so she could do a urine swab to check his blood glucose levels. In the meantime, he prescribed another course of antibiotics.

We managed to get an appointment with the nurse on the Wednesday, and she was equally reassuring. She eventually managed to get a urine sample from Otis' nappy and, as she did, I watched her face change as she frantically checked her urine sample chart. "I think I had better do a finger-prick test," she added. As the blood glucose machine counted down, I sensed the nurse's anxiety. Having no experience of this test, I was still fairly relaxed. Within minutes though, our lives changed forever.

The diagnosis

It was now 4 November 2015. The nurse went to speak to the diabetes specialist doctor, who broke the news that this was most certainly type 1 diabetes. He explained that our blood glucose levels should normally be regulated by our body at 4–7 mmol/L with no ketones present. Otis had a blood glucose of 37 mmol/L and ketones at 7 mmol/L, indicating that his body was now entering a life-threatening state and burning fatty tissue to survive. We were told he needed to be hospitalised immediately.

The trip to hospital was so scary. Having been crying non-stop for what seemed like hours, Otis was now eerily silent. Both of us were questioning what it all meant. Otis was fast-tracked straight to the Children's Assessment and Treatment Unit at Leeds Hospital. The team immediately began a series of tests to ascertain the level of his diabetic ketoacidosis. The doctors and nursing team were fantastic and confirmed the diagnosis of type 1 diabetes and explained that part of Otis' pancreas had now failed and that he would need to inject a hormone called insulin for the rest of his life. We were propelled into absolute shock. Not our little boy, please no! How could we reverse this?

We spent the next week in hospital slowly nursing Otis back to health. He was hooked up to a drip and monitors, and his blood was taken and tested first hourly and then every 2 hours through the night and day. He just lay there in his metal cot, in a strange ward, with us on a fold-out bed beside him. We attended intensive training sessions to equip us for a lifetime of self-management. We were exhausted and continued to work through our shock and emotions. It was impossible to sleep, as Otis woke and stirred for every test. Alongside this, we had to continue to meet tight work deadlines for fear of losing clients.

For the first 48 hours, Otis was not allowed to eat and just lay there drifting in and out of sleep as we learned how to count every carbohydrate he would eat and match it to an individualised injection of insulin. We were educated on all the complexities of type 1 diabetes and what it meant to have hypoglycaemia and hyperglycaemia. We were assured that this had nothing to do with either his or our lifestyle, or anything we had or hadn't done. It was an autoimmune disease that had no cure, and he would live with it for the rest of his life.

The injections were the most difficult and harrowing part of the training. Prior to every meal, we learned how to test Otis' blood glucose, count his carbohydrates and then inject the correct dose of insulin. Only then could he eat his food. He didn't understand why others around him in the ward were eating but he had to wait. His little body had been literally starving for so long because it was unable to process carbohydrates and we didn't know. If he didn't eat everything on his plate (a likely outcome for a toddler!) we would have to try and make the carbs up with anything he would eat. It was just heartbreaking watching our baby boy going through so much and realising that this would have to become our new normal. We grieved for the baby we had before and reflected on the irony that, before the diagnosis, we hadn't let him have juice or anything sugary for fear he would develop a sweet tooth.

Finally, after a week in hospital, Otis was allowed home under our care. We soon realised that, whilst the training and education in hospital had been excellent, remembering all we had learnt and then teaching our extended family would prove very difficult indeed. The only tool we had available was a 70-page training manual. As visual learners, we really struggled to digest this, especially under all the strain.

The next few weeks and months were extremely hard, with 2-hourly blood checks required night and day, alongside injections in the morning and night, and before every meal. Adjusting to being full-time carers whilst also being in work was very, very difficult. Suddenly, all our focus had to be on managing type 1 diabetes, and keeping clients happy began to become a real worry. But, perhaps even more draining, was the relentless stream of questions from concerned friends, family and strangers, often asking, "Is Otis better now?" This is a question which still plagues us, but I guess we are just getting better and more honest with our answers.

The truth is that Otis will be on insulin and doing blood glucose checks every couple of hours for the rest of his life, unless a cure is found. His need for insulin changes with exercise, the weather, growth, and illness. His dose is not an exact science, and the consequences are a constant worry to all those who understand the condition and look after him. A serious high or low can result in a life-threatening coma, but the scariest time is at night, when he often drifts into hypoglycaemia, and we live with the very real fear that, one day, we might not wake up in time to treat him. The one piece of good news was that, soon after his diagnosis, Otis was funded to receive an insulin pump and continuous glucose monitor. This meant his insulin could be delivered via a small cannula on his lower back (to be changed every 2 days), and we would get alarms when he was going high or low.

The birth of DigiBete

The sheer amount of information we needed to learn and retain was overwhelming, and we were frequently in contact with the clinic or admitted to hospital, at great cost to the NHS. We were constantly googling for help with managing type 1 diabetes, but video tutorials were often hard to come by or not age-appropriate. We were frustrated that the previous NHS website offering self-management help had run out of funding, and our family and friends, who had not attended the hospital training, admitted they were anxious and concerned about looking after Otis. We wanted to be able to reassure them that they could look after Otis and refer them to refresher training websites, but none seemed to be easily accessible.

Before diabetes, we had been passionate about telling stories through our video production

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business. We began to explore how we could create a more sustainable video support model fit for the digital video age. We knew first-hand how critical it was for patients and carers to have access to training and support 24/7. Therefore, since we ran our own video production company, we decided to try and apply our skills to create a sustainable social enterprise: an easy-to-use video training platform to enable more families and carers to access both initial and refresher training without needing to call the NHS. We tentatively emailed the Leeds Children’s Diabetes Hospital team and had an astounding response. Thirty-three emails from diabetes specialist nurses and consultants flooded in and validated the innovation. We quickly partnered with the Leeds team, who recognised not only how much NHS resource we could save but also how long-term outcomes for self-management could improve.

We applied for a place on the NatWest business accelerator programme called Entrepreneurial Spark, and we focused all our frustrations into building a supportive visual solution for newly diagnosed families and young people with type 1 diabetes. DigiBete, our new enterprise, grew with the support of the Entrepreneurial Spark team and my Dad, John, an accountant with many years’ senior commercial experience, who has joined the team and has been able to guide us through the many regulatory, funding and governance issues.

During this initial 6-month period, we received three awards totalling £4000 – two for pitching and one for our “#GoDo attitude”. Our very productive partnership with Leeds Children’s Hospital has gone from strength to strength, thanks to the strategic leadership and energies of Dr Fiona Campbell, who, despite holding several positions nationally, could not have been more collaborative and open to our ideas. Similarly, Caroline Mullier, Diabetes Nurse Specialist, has given so much time, energy and commitment to shaping and steering the management of the platform. It is with their help and support that we launched our first, self-funded website, hosting 10 essential training films, at the Leeds Children’s Hospital Parent and Professionals Diabetes Conference in June this year. This was extremely well received, and feedback has led us to develop and flesh out the importance of not only producing relevant education content for families but also the need to provide better

emotional support for youngsters and families living with type 1 diabetes.

Future plans

Since then, we have continued to build momentum both through developing relationships with key national influencers and by applying for various social enterprise funding schemes for start-up companies. We have now fleshed out a full and robust not-for-profit business model and registered DigiBete as a Community Interest Company. We are very proud of our strong and experienced management team, and we have recently secured a £30 000 social enterprise grant and several other pockets of funding towards our phase 1 platform build.

Being parents of a child with type 1 diabetes and working in collaboration with the NHS has opened up so many possibilities for understanding how we can use our creative skills to extend the brilliant work the Leeds team do, and for the team to gain a deeper, empirical understanding of the experiences families living with diabetes face outside the clinic and hospital environment.

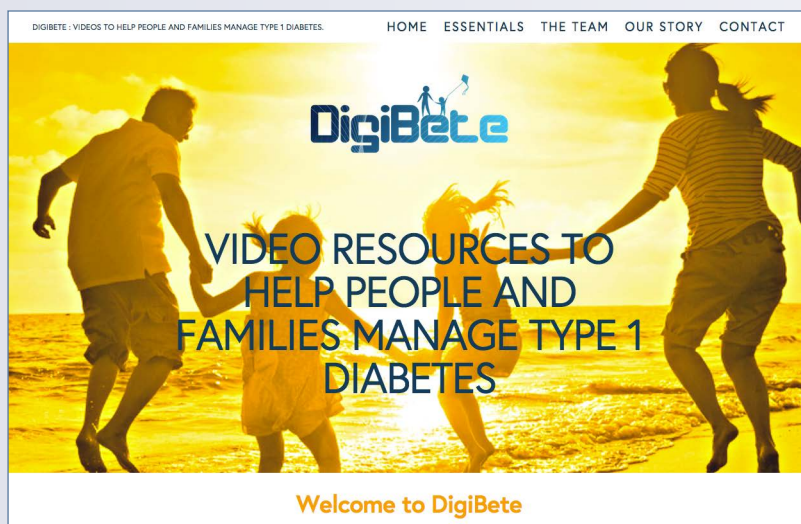
So, whilst type 1 diabetes continues to take its toll on our family, we have surrounded ourselves and Otis with the authentic love and support of the very same community. Our efforts for better awareness and positive social change have enabled our heavy hearts to be somewhat lifted from the frustrations and fears of this condition. For every difficult day or night we experience, we at least wake up the next day feeling we are contributing something positive to an otherwise difficult situation and, in the meantime, we are constantly learning more about the complexities of self-managing this condition.

Otis is now thriving again and continues to bring joy and light into our lives. He is a tenacious and loving toddler who has learnt to say “I can do it.” He loves to ride his balance bike, at considerable speed, though the park and is the first to say “are you okay?” if he sees someone looking sad. He has settled well into his checking routine and is now learning to communicate when he is going high or low. We couldn’t be more proud of him.

We have embraced a problematic and life-changing family issue and, in the process, embarked on a journey with a clear vision of how we can help ourselves, other families and the community to achieve better long-term outcomes for our children and for the wider type 1 community. ■

About DigiBete

DigiBete is a video platform and social enterprise created in partnership with the diabetes team at Leeds Children's Hospital. Our videos are designed to help people and families self-manage their type 1 diabetes. In addition to the 10 videos on the essentials of diabetes self-care below, we will be adding lots more resources shortly. Our videos can be found at: www.DigiBete.org



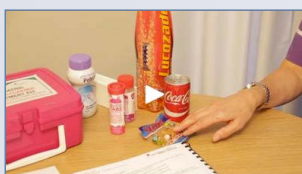
Your first visit to clinic



Equipment you'll need when you leave hospital



How to check blood glucose levels



How to treat low blood glucose levels



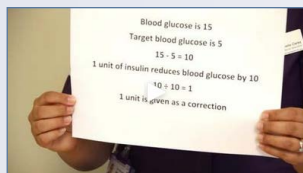
What are ketones and how to check them



How to give an injection of glucagon



How to give an injection of insulin



How to work out a correction dose



A guide to healthy eating



Carbohydrate counting

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