

Dearest Friends

We really wanted to send out a message with a little more information on the experience that Liz and I shared on, and from, 7th August 2017.

Our little girl Coraline triumphantly entered the world. We were told 2 hours later that they strongly believed that she was a baby with Trisomy 21 (Downs Syndrome). In addition to this, Coraline was born with a congenital heart defect called Atrio-Ventricular Septa Defect (AVSD) which means that she has 2 holes in her heart. This is most likely going to require open heart surgery in November. We know there will possibly be other additional responsibilities and challenges in other health areas but at this point none of those are even worth worrying about. We are just getting to know Coraline and all the fun and beauty that entails (plus the endless rounds of nappies and early morning feeds) – we can't stop looking at her as she is just so cute.

This letter is definitely something that I felt would be a really useful process for all of our wide range of friends and family throughout the world. Reading it back I now know that it is also good for me to write it personally so that people understand the immense joy and happiness fatherhood brings, even if it happened not quite as I expected.

I know that some people would prefer to retain their privacy which is totally understandable, but this is a good thing for us to do in order to really explain how we would like our situation to be viewed by one and all. We really want people to come on this journey of discovery with us, and to view this life event as celebratory rather than something which requires sympathy and sadness from people. We prefer to view this news as unexpected rather than unfortunate!

We know that many of you may not sometimes know what to say to us – I'm not sure that we would've initially known what to say to people either, if somebody that we know had received the same news. In the end, just reach out and be interested if you feel like it. We will certainly be posting lots on social media, and doing our bit to raise awareness on the subject of Downs Syndrome.

I know that Liz has been sharing lots of her feelings relating to her individual experience on her Instagram account ([coraline_and_us](#)), which I find really heartwarming and I am immensely supportive of her in this and as a family (that is awesome to say that), we simply want to set the back story and hopefully help to move people along the way.

We had a very happy and uncomplicated pregnancy throughout, and apart from the usual aches and pains, and lack of sleep for Liz in the heat, it was the perfect experience for us both. We had all the usual scans and tests at all the milestones, which were all very standard and normal - and we were so happy and expectant of what we believed would be the arrival of our beautiful baby girl.

Towards 36 weeks, we were told that the baby was still the wrong way up in what is known as the 'Breech' position. Essentially this means that the baby is head up towards Mama's head (their head should do a somersault and be facing down towards the floor by this point). This is not a massively big deal and we went to the hospital to try a process called ECV which is basically where a doctor tries to manually turn the baby. It is not risky at all and we felt that we really wanted to try to deliver the baby naturally so Liz put herself through this process. Alas the baby was not for turning, so we were advised that we should book in a C-Section as delivering babies feet first is not much recommended. We booked the C-section with the caveat that we would return for a second try at turning baby.

We returned 4 days later with renewed confidence as always, but knowing that the most important thing was the baby would be safe if delivered via Caesarian, in the event the turn was unsuccessful again. Alas, baby was not going to budge, so we prepared ourselves for the knowledge that baby would be coming out of the 'sunroof' to paraphrase one of my friends

descriptions of a caesarian. Not only that, but instead of us having a further 11 days until the C-section, we were duly advised that the date would be moved forward, and in fact baby would now be coming out in 2 days time. So much for enjoying my 40th birthday weekend!

Without too much time to dwell on the change in plan or my 40th birthday (sob), we threw ourselves into getting all of the finishing touches completed, and mentally preparing for the huge life changes that would be coming our way.

Monday 7th August arrived in a blink of an eye and so we made our way to Kingston Hospital for our date with destiny. Liz was feeling ok but I could tell that under the surface she was nervous about the upcoming C-section (who wouldn't be), and so I did my best to distract her and make her laugh. I genuinely didn't really know what else I could say or do. I mean what can you say or do in that situation.

Without going into too much detail of the actual delivery of our little baby, I will cut straight to the chase. Everything went according to plan, and at 12.15pm on 7th August 2017 our little girl was born. It was the most surreal and amazing feeling in the world to hear the words "your little girl is out". I remember hearing her cry and looking at her in her wrinkly state and thinking 'wow, that was so intense but I am so glad that it all went ok'. The nurse immediately took our little girl away for all the usual checks and to take her weight etc. I followed her over as Liz and I really wanted our baby to have immediate skin to skin contact which we felt was really important.

The nurse swaddled the baby in a blanket and handed her to me to put her on Liz (lying there whilst they closed the sunroof) and looking back it was at this point that the tone ever so slightly changed. The nurse said that she was going to call the paediatric nurse to check her out – I wasn't really sure why but she did not seem overly concerned so I just went with that. After Liz was patched up we were then moved to the High Dependency Unit (HDU) to start the first stage of recovery.

After an hour or so I asked the nurse if the Paediatrician would be coming to see us - I was not concerned but just wanted to know what she had seen to warrant a visit.

I guess around 2.30pm the Paediatrician arrived with another colleague and introduced herself – she then started to do some checks with her stethoscope and by sight. I asked her what exactly were her concerns at this point. She said that she wanted to do her checks and would then discuss it with us. Even at this point I did not know what could be happening.

The Paediatrician looked at us and in a fairly un-empathetic way said "Do you remember the tests that you took at 12 weeks for Down Syndrome? – they are just a guide you know!"

Both Liz and I looked at each other before the doctor followed up with "there are worse conditions she could have". There is not much that we can say at this point regarding her clumsy words.

Understandably the news came as quite a surprise to us both, especially to Liz who had carried her for 9 months, was in major recovery after surgery, cocktail of drugs and massive levels of hormones. We had been told that the risk of Down Syndrome was low – 1 in 400 was the exact figure to which at the time we both said, well that is fine then – I think we both just thought that was the end of that possible scenario.

Our limited understanding of Down syndrome and what life for our little family could be like initially left us feeling a little overwhelmed – personally I took about 30 seconds of feeling sorry for myself before the stronger feelings of love and positivity kicked back in for me. I really knew that she was still our beautiful girl and it will all be ok, whatever may come.

Despite how this news was delivered, we are glad now that we knew almost from the start of her life on the outside without delay. In retrospect we also both agreed that we are way happier that we did not know before Coraline was born. It would not have changed anything regarding whether we would continue the pregnancy or anything like that, but we feel that we would have had a long period of time to conjure up all of the 'worst case scenarios' and the 'what ifs' without the unbridled joy of Coraline being with us. Unfortunately the vast majority of pre-natal 'information' provided only covers the negative list of things that can be a part of having a child with Downs Syndrome.

We have had to make some adjustments to what we were initially expecting regarding our baby and our 'plans', but we are now just as excited and occasionally worried as any other parent is when they get home with their baby. We spent 6 days in total at Kingston Hospital with Coraline – 2 of which she spent in the Neo Natal ICU. We had the most amazing care from the often maligned NHS – even the Paediatrician who delivered the news to us did amazing work for Coraline in the immediate aftermath, where the heart diagnosis was made and a further complication was noticed, and she was really nice – it is just the way that things happen in hospitals sometimes.

All parenting is a challenge no matter what your child is like. Our little girl will meet all the milestones other children meet, it just may take her a little longer to get there. She'll have a few extra challenges along the way but as she grows up she will be just like any other child. She will be happy, she will be sad, she will laugh, she will get frustrated, she will go to school, and she will fall in and out of love.

Most babies growing up with Down syndrome will lead ordinary lives. Just like you and me, all they need are the right opportunities to reach their full potential. By doing a lot of reading and talking with other parents of children with Down syndrome we have learned that every child is a unique individual and that advances in medicine, education and acceptance mean our little girl will live a very rich and rewarding life – and will enrich the lives of those around her. Nobody knows what will happen in life but we are determined that we will all have a fun time and keep doing all the things we love to do.

To help answer some of the questions you may have and to understand more about Down syndrome, here are a couple of websites we found helpful – whatever happens we will do our best to ensure that Coraline has a fun time with all of our massive group of friends and family to assist us.

<http://www.downs-syndrome.org.uk/>

<https://www.theguardian.com/lifeandstyle/2016/dec/31/my-sons-downs-syndrome-does-not-define-him>

www.nothingdownaboutit.com