



## INSIGHTS

## Family reflections: premature twins

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I found out in November 2018 that I was expecting MCDA twins (monochorionic diamniotic—shared placenta but separate sacs); this was a huge shock because we have no family history of twins and somewhat naively didn't realise twins could happen to anyone. The shock was soon overtaken with fear as the various medical professionals we met with talked about the risks associated with this type of twins. Then in early January 2019 we had a TTTS (twin to twin transfusion syndrome—where the nutrients from the placenta are not shared equally between the two twins) scare but after a referral to the St George's foetal medicine team for a scan they confirmed it wasn't and I finally started to relax and enjoy the pregnancy.

However only a few days later on 21 January 2019 at 21 +5 weeks pregnant I woke up in the middle of the night and my waters had gone, I was suffering from PPRM (preterm premature rupture of the membranes), we were terrified and I was sure I was going to lose the twins. One of the first doctors I was seen by did nothing to alleviate those fears; his exact words were "in the next 48 h you'll get an infection or go into labour and if that happened the twins wouldn't survive." This was understandably devastating; luckily I have a close family member who is a very experienced midwife and she was able to give me a much more balanced view. She was very honest with me in saying that he was correct and the

most likely outcome was an infection or labour, but also explained that it was possible these wouldn't happen, since my cervix hadn't started opening and first pregnancy resulted in an emergency C-section due to failure to progress, there was a real chance my body wouldn't go into labour. This gave me hope, something I desperately needed and then after 48 h when neither of those things had happened everyone started to become more positive.

We were incredibly lucky that our local hospital, East Surrey, had a twin clinic with an incredible consultant, Ms Sharmila Sivarajan; she was very balanced and pragmatic, always honest about the risks but kept us hopeful to. She had experience of PPRM in twin pregnancies and explained that the best thing I could do was to rest to try to remain pregnant for as long as possible, as the weeks went on the twins chances of survival and good quality life would increase.

From this point on I was on strict bed rest, in hospital for the first week and then at home after that; in addition, I had two scans a week to check on the twins and weekly blood test to check my infections markers. The aim was to keep the twins in for as long as it was safe to do so, one of the twins was bigger than the other so the focus was always on the smaller twin, while I was losing fluid around both twins he always had slightly more which was reassuring.

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One of the biggest challenges we faced was that any time I was seen by a doctor other than my consultant, they always wanted to deliver the twins, despite the agreed plan being to keep them in as long as possible. Several even suggested I should be considering a termination or foetal reduction. I had to be very firm on a number of occasions often resulting in an out of hours calls to my consultant. I consider myself very confident, but it's really hard to challenge a professional on something they're trained in and you're not, especially when you can't be sure you're emotions aren't clouding your judgement.

Incredibly I kept the twins in for almost 9 more weeks, until the day I got to 30 weeks, I started having contractions and spiked a temperature so went straight to hospital, initially the team thought I just had an infection and it might be possible to get it under control. However when the smaller twin's heartrate dropped the decision was taken to deliver them immediately (after another out of hours call to my consultant to put my mind at ease that it really was time). I was able to have the magnesium sulfate injections but as I had an infection couldn't have a second set of steroid injections (I did have one set at 24 weeks).

The twins were born on 22 March 19, at to 1 a.m. I officially made it to 30+1 weeks. Arthur, the bigger twin came first, followed by his brother Noah. Incredibly Noah came out crying and required very little support. However this wasn't the case for Arthur he had to be ventilated and, as the hospital only had a level 2 neonatal unit, he was rushed to the nearest tertiary centre, St Peters in Chertsey.



Noah's neonatal journey was uneventful and he came home after 3 months (had he been a single baby I expect he would have come home sooner on oxygen and weaned off at home); Arthur's however was more complicated, but after a long six and a half months at three different hospitals, he finally came home to. Both boys suffer from chronic lung disease, due to when in the pregnancy my waters went, Arthur's is far more severe, as a result he spent time at Royal Brompton, a specialist respiratory hospital before coming home on home CPAP (continuous positive airway pressure) at night and nasal cannula oxygen during the day. He also suffered from severe reflux, which was significantly affecting his growth and causing concern about aspiration to lungs every time he vomited, this was successfully treated by a partial fundoplication procedure.

Despite a very difficult pregnancy and the first year or so of the boys lives being incredibly challenging, we are in no doubt how lucky we are that these are the only complications they suffered. Neither had any brain, heart, hearing or sight issues and both are

meeting their developmental milestones. I have no doubt that this is down to the additional time I was able to stay pregnant for, which wouldn't have happened if it hadn't been for Ms Sivarajan and the twin clinic at East Surrey hospital.



I would welcome more research into why PPROM occurs, why it's more common in twin pregnancies and how it can be prevented.

I would also like more focus on education and research sharing to ensure that other parents don't have to go through some of the challenges we did, how many babies are delivered earlier than they could/should have been after PPROM and what issues do they/their parents face as a result? Even worse how many are terminated when they could have been saved? Foetal reduction wouldn't have been possible for us but if it was we would have been encouraged to terminate the smaller twin when in fact he suffered far less health complications. During our time in neonatal I learned that it is very often the smaller twin who thrives outside of the womb.

Both boys are now doing really well, Noah came home with no ongoing concerns/conditions and has continued to go from strength to strength. Arthur came off oxygen during the day in April 2020 and off home CPAP in September 2020, and hasn't looked back since; in fact, despite his longer stay in hospital is often the one to meet developmental milestones first, he was the first to crawl and to walk. They are now two very cheeky and active toddlers, something I didn't dare dream of during my pregnancy or the first few months of their lives, I'm incredibly grateful to all the medical professionals who cared for them during this crazy journey.

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#### ADDITIONAL INFORMATION

**Competing interests:** The author declares no competing interests.