Submission No 893

INQUIRY INTO BIRTH TRAUMA

Name:Name suppressedDate Received:14 August 2023

Partially Confidential

My name is I am writing this submission after what has been a very ongoing and difficult trauma for myself and my husband after my twin pregnancy in 2016.

In Mid 2016, I had become pregnant with IVF Fraternal Twins. After a difficult start to the pregnancy with Hyperstimulation of the ovaries as well as hyperemesis.

We had a 5, 8, 12 and 16 week scan which showed the two babies were growing lovely and things were looking great.

At 17 weeks while on holiday on themy water broke with twin 2 and I wasrushed tohospital.

It's the treatment in his hospital that has brought me so much trauma, frustration and sadness through my life since.

I was taken to the maternity ward where I was put into a room on my own where a nurse proceeded to tell me I would start to feel my babies coming out. Exact words (maybe a leg or an arm)

She advised they were just waiting for me to go into labour and that I would deliver both of my babies and they would die. (No other information was given and she left the room) This was very distressing for me; I was left in a room on my own while I waited for my husband to travel the 8 hours by car to reach me.

Over the night, nothing happened besides me being in a complete panic as to what was going to happen.

Over the next few days, I hadn't gone into labour, and scans showed both babies were growing and progressing, however Twin 2 had limited fluid around it, just pockets here and there. After my water broke, I continued to lose amniotic fluid daily.

After about two days, a male specialist came in, with a whole team of students, maybe about 9-10 people. He advised with another female doctor my best option was to induce me as my infection risk was too high. Even though the scans showed both babies were progressing, and I had not gone into labour, I was not showing any signs of infection at this time.

I argued that the scans showed the babies were fine, and if I wasn't showing signs of infection at this time and my life wasn't in danger right now, I wouldn't be inducing my twins because he said so especially as both babies were not in distress, if my babies were going to die, it wouldn't be because I induced them. I wanted nature to run its course or until my life at that time was in real danger. I believe this should of be respected.

The female doctor proceeds to tell me; "you have a less then 1% chance to make it to 23 weeks" which is viability week for most. Shaking her head and looking at me as if I was stupid to think this was going to continue.

No other options were given to me, and my refusal was brought with frustration to the doctors and when I asked questions about options, I was never given any. At no point, did the doctors offer me any antibiotics to reduce the risk of infection. I was just left to either have my labour induced or go home and wait to come back extremely unwell with an infection. It was clear to us that we were being pushed into being induced and ending our pregnancy.

I was discharged as I didn't agree to end my pregnancy. When I was leaving. The doctor who was and still is the head of the department, smirked at me, and said. "You can leave; however, I will see you in intensive care in a few days."

I left the hospital.

About a week later, I returned to the hospital thinking I was possibly in labour. (I Wasn't)

On the maternity ward, a locum doctor saw me and said he had worked with many women with complicated twin pregnancies and advised that I should have been referred to the maternal fetal specialist on the straight away to see what my options were to assist the pregnancy to continue, he advised I had options, He also stated I should have been placed on Antibiotics to reduce the risk of infection from the first day.

I am thankful every day I had this locum doctor, as it's from this, I was referred to the maternal fetal medical unit on the . This is where I had an appointment in the following days.

I met with Professor who was lovely who advised me that a case like mine only comes around possibly every 5 to 7 years. The fact I had not gone into labour within the first two days was something not common.

He advised though, that both babies were appearing to do well. However, Twin 2 would likely have serious complications including death if the pregnancy would appear to continue which it was. He advised that due to the critical lung development being between the weeks or 17 and 21 weeks, the baby would need the fluid in the sake for its survival. It would be unlikely after the baby was born that Twin 2 would survive due to this issue.

He agreed that I should have been placed on antibiotics to reduce the risk of infection for the duration of the pregnancy and to continue I would need to rest up, take antibiotics, have weekly scans and be admitted to hospital with a NICU when and if I made it to 23 weeks, I would also need steroid injections at 23 and 24 weeks to hurry the lung development up for the twins in case of early arrival.

We also spoke about the possibility as the pregnancy continued, if twin 2 was in distress or appeared to struggle there were several options to support the life of Twin 1 if something was to arise. However, we could come to that at the time and as the pregnancy continued. At no point did Professor discuss that a termination of the pregnancy at this time was required. He provided options however being gentle about the prospects.

As we were away from home, organised for me to be transferred to the care of Hospital closer to our home on the . We knew if our babies were to be born early after 23 weeks, we would need to be located closer to home to be able to support them.

Care began with the maternal fetal unit where Specialist Dr and her team took care of us.

It was still a difficult time as no one really knew if Twin 2 would survive when born, at one point a Specialist at advised us that it appeared both babies seemed to be doing well and as at times there was build-up of amniotic fluid it wasn't sure what would be the outcome. We still felt supported by and her team however having very challenging conversations and being very traumatised at what could potentially happen to my babies.

I was admitted at 24 weeks and went into spontaneous labour at 26 weeks and 6 days. After I spent 10 weeks on complete bed rest since my water broke, only leaving my bed for a weekly scan and the use of the bathroom. During this time, I didn't even sit up, I continued to lay flat to hopefully have my twins get to a survival week.

Unfortunately, there was another woman who was 25 weeks who went into labour at the same time, so there was a massive rush to open a theatre for the birth of our twins.

While I was having contractions, a midwife at gave me gas, I was extremely distressed at going into early labour and after 10 weeks of not knowing what was going to happen, the day had come.

The nurse took the gas off me, as I was in extreme distress (saying oh' that doesn't appear to be working for you) I still wanted the gas and continued to suck on it, however she just turned if off at the wall and didn't tell me. This midwife also was observed rolling her eyes at me on more than one occasion. (As a young 26 year old giving birth to twins so premature after a long difficult pregnancy. There was no compassion from this woman)

I was given emergency medications while in labour to prevent cerebral palsy which caused my body to have a reaction of extreme heat/burning, it felt like my whole body was on fire, which caused extreme discomfort.

I was also asked while in heavy labour, did I want resuscitation for Twin 2 if it was experiencing complications, Did I want to be a part of trials for delayed cord clamping?

All decisions I wasn't mentally able to make at that point in time, I found these questions in the emergency extremely overwhelming and just wanted to best support for our twins. I didn't know what the best option was.

I was rushed into a theatre where a mask was shoved on my face, and I was put to sleep in a matter of seconds. No one advised me I was going to be put under a general anaesthetic. No information was given to me. (All I can remember is about 20 people running and rushing) I remember thinking as the mask was on my face, I was trying to pull it off to ask was my husband in the room? I have never been so scared in my life and really thought, was I going to die? Or would my twins die before I wake up?

While I was under the general, our Twins were born. Twin 1. A baby girl 800grams and Twin 2 A baby boy 920grams. Both required resuscitation when born and in the beginning both twins were responding to treatments.

I woke up some time later to my husband to tell me that both babies were in the NICU, we had a boy and a girl and our son who was twin 2. Only had a small bend with his ankle but said the doctors said it can be healed by physio.

I remember feeling a wave of relief, thinking, I had done it. I got my babies to a safety point, and they would be ok.

However, after some time, I was wheeled still in bed up to the NICU, where the neonatologist advised us that our daughter was on the left, she's doing great. Your sons on the right, he's not doing so great, and we have some decisions to make.

He advised that he was struggling to keep his oxygen levels up, that they would come up for a period, however he couldn't maintain them. He was being supported heavily and they could keep going with treatment, however it would only get him to the morning. This was about 10pm at night.

While still quite dazed from the general, we made the decision to stop the efforts to support our Son as we didn't want him to have any further trauma to his tiny body. He had fought so hard to make it another 10 weeks after his water breaking and from this had given his sister the gift of life.

He was placed on my chest where we spent some time together before his sister was placed next to him. He passed away with us both with him soon after.

From this point, the hospital was lovely and organised things for us over the coming days including housing at , visits to our son in the morgue and a social worker.

Our daughter had a long and extensive NICU Journey, however now is a thriving and healthy 6-year-old we are truly blessed to have who brings us joy every day.

A few points I would like to make clear from our situation.

I believe the treatment from the Specialists and the staff from Hospital was horrendously wrong. They pressured myself and my husband to move forward with an induction of our twins without offering us any other options, antibiotics to reduce our risk of infection, referrals or options to continue our pregnancy. When we disagreed, we were greeted with Slie comments and threats.

This was so wrong on so many levels and I fear that more woman after me or before me would have potentially taken their advice rather than getting the specialist advice from Maternal Fetal Medicine in complicated pregnancy situations with this, losing children they potentially could have now. One thing I would love to see is that a standard practice is, if a woman comes in the early to mid stages of pregnancy and she presents with her water broken or there is another complication, if labour doesn't happen within the first day on its own then automatically, they are referred to a maternal fetal specialist in a larger hospital to see options rather then automatically advising on termination. I have herd since of single pregnancies continuing after early water breakage also. Let woman explore all options before advising and pushing for an end to the pregnancy.

The next point comes to during the birth. I wish even in a rush that staff would have advised me I would be put to sleep. Not just me screaming in fear and a mask shoved on my face and held down not allowing me to take it off.

I also wish, that when it came to the decision of our son after birth, if to continue treatment or not, That I could have been asked at a time, when I had a clear mind, not just after waking up from a general Anaesthesia.

If I could go back now, I would have preferred my son to be placed on a ventilator to allow myself to have time to come to observe him myself to make an informed decision at the time, hours later perhaps if to end his life. (This is an ongoing trauma for me)

And finally, During the NICU journey, I had a wonderful social worker at , however there wasn't any follow up after I left hospital to how myself and my husband's mental health was going after this ordeal.

Since then, we have had upwards of a hundred Therapy sessions to support us in the Post-Traumatic Stress of these events including still recently almost 7 years later. Perhaps woman who experience extreme birth trauma have follow up by the hospital social worker or at least given priority referral to outside mental health services for appointments right away. In the first two weeks of being home, I was struggling daily, called around my area for an appointment in this acute stage of grief however not one practice could offer me an appointment within the next 3 months.

7 years later, I think of this part of my life daily, it has never left me, it's always there and doesn't seem to leave me. I still experience flash backs, night sweats and nightmares as well as at times struggle with daily tasks depending on the time of year or what happened that week that brought back that memory. I still have days in the year, where I can't get out of bed that day. Mother's day every year, is one of them.

I am however extremely proud of myself for listening to my body and refusing the termination of our Twins from Hospital. It was a tough pregnancy however I now have the most incredible healthy daughter and am glad my son was able to grow with her inside and we were able to have cuddles together after he was born before he passed away. Him holding on and not going into labour and causing both to be delivered early, I am eternally grateful for.

I hope my situation can bring some light into complicated pregnancies and the medical advancements now that are available to woman. Also, importantly that woman in my

situation or other complicated situations are given the correct options and referrals to assist them as they should be.

I would be happy for my submission to be published and happy to talk at a hearing if needed to hopefully have better outcomes for others.