

## **Sarah's story**

My husband and I needed fertility treatment because my husband had a vasectomy 15 years ago. We started to investigate in early 2006 and found out that we could have ICSI treatment and my husband could have Percutaneous Epididymal Sperm Aspiration (PESA) or Testicular Sperm Aspiration (TESA).

### **Fertility treatment**

After only the first cycle, I produced a bumper crop of 29 eggs, and donated half to another couple who were patients at the same clinic. However, after my husband's treatment they recovered only 13 useable sperm. Out of my 15 eggs, 13 developed into embryos – 9 survived to day 3 and we ended up with 3 grade 1 expanded blastocysts.

The day after egg collection I started showing symptoms of OHSS. The clinic confirmed that I had it and told me to rest and drink plenty of fluid. They were concerned about implanting the embryos while I had OHSS as pregnancy can worsen the symptoms.

### **My decision on embryo transfer – lack of information**

We discussed freezing the embryos and agreed that we would see how I felt on day 5 and if I felt better they would implant two embryos. At no time was I told of the risks of premature birth, miscarriage, health problems, etc, for multiple births. All we were told was that they were going to put two blastocysts back, that I had a very high chance of a multiple pregnancy, and we were asked if could we cope with it. We thought 'Twins! Brilliant, all over and done with in one go!'

### **My experience of multiple pregnancy**

Two days after implantation I began to feel extremely ill, my stomach was very distended and I had severe chest pains, so I rang the 24 hour clinic helpline who advised me to go to A&E immediately. My husband rushed me to our local A&E and luckily, I was seen straight away.

A urine pregnancy test showed up negative and I was taken upstairs to a ward. Before they put me into the bed, they tried to put an IV line into the back of my hand but I was so dehydrated that it was difficult and I passed out from the pain.

I had a blood test to confirm that I was indeed pregnant the next morning but was told not to get my hopes up as the count was very low. I had further blood tests every 48 hours and the count was doubling, tripling each time so I had a good idea that it might be a multiple pregnancy.

I ended up staying in hospital for 8 days, and put on 2½ stone overnight from all the fluid that was in my abdomen. All my vital organs were pushed right up into my chest so eating more than two mouthfuls was extremely painful. I actually lost a stone in that week because I just couldn't eat. After 8 days I was allowed home and spent a further 8 weeks at home recovering before feeling able to go back to work. I had a scan at 6 weeks which showed 2 little heartbeats. We were ecstatic and couldn't wait to be parents.

I had my nuchal fold scan done and all was well. I had all day nausea until I was 13 weeks pregnant and then it disappeared overnight and I started to feel great. I really enjoyed being pregnant and loved having a bump. Things started to go wrong at my 20 week scan.

### **Complications in later pregnancy**

The sonographer was quite chatty to begin with and then went quiet. She said she needed a second opinion and needed to take me to another unit and that I wasn't allowed to walk and went to get me a wheelchair. She wouldn't say too much about what was wrong so we were very concerned. It turned out that my cervix had started funnelling (opening up) and there was only 4mm left before it would be open so it was decided that I had to have an emergency shirodkar stitch put in.

The operation seemed to go well and I was allowed home the next day and told to "rest". Realistically I should have never left the hospital and been on strict bedrest. I wasn't told anything else except that I had to rest. I confined myself to the bed with lots of books, magazines, etc, and my husband took over the running of the house. It was a very lonely time as my husband was at work all day. My mum would pop round every day for an hour or so and friends visited at weekends, but I just wanted to have a normal pregnancy and be at work.

### **Further complications**

On the Saturday morning, which was the start of my 23rd week, my husband and I were lying in bed having a chat and a cuddle (I had been saying for two days that something was wrong), when quite a lot of water seeped out of me. I quickly got to the bathroom and lots more came out. I told my husband that we had to go to the hospital NOW and I managed to find some sanitary pads and put them on. By the time I got to the hospital (a 10 minute drive) I had soaked through a pad and put another one on. I took the pads into the maternity unit with me to show them.

At first they were quite nonchalant about things and put me in a room and scanned me with the portable scanner, as the scanning department was closed at weekends! The picture wasn't very clear but they said that there was lots of fluid around both babies. They also said that they were trying to get me a bed in

another hospital that had the facilities to cope with very premature babies born under 24 weeks and that it could be anywhere in the country. Luckily I got transferred to a hospital that was only half an hour from home. Once there I was given steroid jabs to develop the babies' lungs, and put on observation. On Sunday they decided that the stitch had to come out as I had an infection. The stitch was removed without any anaesthetic, which was absolute agony.

### **My experience of multiple birth**

I had started to get back pains and had to call the midwife every time I had one. She put her hands on my stomach but couldn't feel any contractions so we thought it was pain from the infection. I had pains on and off all Sunday night and didn't get much sleep.

On the Monday morning I was taken to the scanning department and the sonographer took one look at me and said to my husband "If your wife doesn't give birth today you risk losing her as well as the babies". My poor husband was devastated. How can you cope with that? I was then rushed back to the maternity unit and put on a drip to speed up contractions. My husband called my mum who came up to support and help.

My husband said he had to get away for 10 minutes to collect his thoughts but he actually went to the chapel and said some prayers. We are not religious at all but he felt he needed to do it.

The birthing room was like Piccadilly Circus – there were so many consultants and nurses. I gave birth to my daughter at 9.38pm. She had a very traumatic birth – she had been in my birth canal for 24 hours and started to come out sideways so they had to break her arm to turn her around so she came out head first. She was black and blue and didn't make much noise. She weighed 1lb 1oz and was immediately resuscitated and put into an incubator.

I then gave birth to my son at 9.50pm. By then I had got the hang of pushing and he shot out and covered the nurses and midwives in blood and amniotic fluid. He looked much better, had a nice colour to him and was mewling noisily. He was also put into an incubator and they spent about half an hour making sure everything was okay before letting me see them and taking them off to the NICU (Neonatal Intensive Care Unit).

We were left on our own for 10 minutes and my husband, my mum and I howled the place down. I felt so empty, I had been through all of that and didn't have the chance to cuddle them.

I was then moved to the ward but luckily was given a room to myself BUT right next door to a woman who had newborn twins. I felt so angry that I screamed at

the ward sister to find me another room but they didn't have one so I had to lay there and listen to those babies crying.

### **The loss of our daughter**

Once our babies were stabilised we were allowed into the NICU to see them. We were told that our daughter was extremely poorly and was just being kept alive by machines. We had to let her go, so we told them that we wanted her baptised first. The hospital chaplain came and baptised both of them for us and even he was crying.

After he left we let the nurses turn off my daughter's life support machine and she was gone in seconds. She was dressed and brought to me in a side room and I was then able to have a cuddle. We undressed her to make sure she had all her fingers and toes and then we had a cuddle and asked the nurses to take her away.

We managed to make our way back to our room on the maternity unit and just sat and cried and cried and cried for hours until we were completely exhausted and both fell asleep.

### **Our hopes for our son**

Both our parents arrived the next morning which created lots of problems as the security guard wouldn't let more than 2 people in at a time. For some reason the sister forgot to tell him about us so I ended up screaming at him "My babies have just f\*\*\*ing died, let my parents in". After that he was very accommodating and we all sat around and cried and cuddled.

We took both sets of parents to see our daughter in the morgue first and then we took them to see our son who was apparently doing quite well in the circumstances. I was allowed to stroke his hand and his Dad stroked his other hand and his tiny fingers curled round my husband's little finger. He was so tiny but absolutely perfect in every way. We had a good long chat with the NICU director about the way forward and agreed that as long as our son was stable, they would carry on treatment, but if things took a turn for the worse then we would have to re-evaluate the situation.

### **The loss of our son**

That afternoon I was allowed to leave hospital as the doctors and nurses thought I would be better off at home away from all the newborn babies. So, armed with 3 different types of antibiotics, we went home. What an empty place home felt like. I managed to eat some cereal and went to bed.

We both work up early the next morning, about 7.30am and said to each other that our son must be doing okay as we hadn't had any phone calls during the

night. Ten minutes later the phone rang and they asked us to go to the hospital immediately.

We rushed to the hospital as fast as we could – I was still in my pjs. When we got to the NICU, we were taken off to a side room and told that our son had very high levels of potassium in his blood, which is very dangerous, and he had had a lung and brain haemorrhage. They were giving him morphine to make him comfortable. When they told us they were giving him morphine, we told them that we couldn't let them carry on. Giving morphine to a tiny baby like that wasn't right in our eyes. They said that if we carried on treatment he would most likely be physically and mentally disabled, probably blind and deaf. We didn't have to think more than 30 seconds. To do the right thing we had to let him go and be with his sister in heaven.

We asked the hospital to wait until both sets of parents arrived so we could all say goodbye together. Once they all arrived, they said their goodbyes and waited in a side room. Our son was taken off the life support machine and given to me. He took a few final breaths and died in my arms. My husband's sister then came back and carried him in to our parents as I said I couldn't carry my dead son to his grandparents, it just all seemed so sick.

The staff at the hospital were very good to us and gave us time to say our goodbyes to our son and even brought us tea and cake!

### **Lack of answers**

We found out that both twins died of chorio-amnionitis, which is an infection of the amniotic fluid caused by either the funnelling of my womb and infection setting in or the piercing of the amniotic sac when the emergency stitch was put in. We will never know for sure.

I never knew how I would laugh again in the days after they died. We were on autopilot. We had to register their deaths and the registrar never said a word to us – I felt really angry with her. I felt angry with everyone.

### **The funeral**

The twins' funeral was arranged for early December. We found a lovely white coffin and had them both laid as they were in the womb, wrapped in a shawl that my mum had crocheted. We put in a picture of us on our wedding day and a letter for each of them. The weather was terrible on the day of the funeral: thunder, lightening and rain. The service was lovely and we managed to sing a few Christmas carols as well as it was near to Christmas. As we left the church to walk over to the cemetery the clouds cleared and the sun shone which made us all feel a little better.

### **The aftermath**

Two days after the funeral my husband and I flew abroad for a week's holiday to get away from everything. We cried every day on the beach, in the pool, at the bar and in the restaurant, but we didn't care. It helped a hell of a lot and we came home with a glimmer of hope.

I managed to go back to work at the beginning of February and that was very hard as there were quite a few pregnant girls working on the same floor, but there are pregnant women everywhere so I just had to get on with it.

We had one frozen embryo that we tried in March, but it didn't survive the thawing process. Looking back, it would have been way too soon to be pregnant again.

### **The present and the future**

Seven months later my husband got a job abroad and moved out. I followed shortly afterwards and it's been the best thing we could have done. We haven't tried treatment again as we needed to let ourselves heal mentally and for me, physically, but we plan on trying again later on this year. This time I will INSIST that only ONE embryo gets replaced.

Not a day goes by when I don't think about my gorgeous babies and how much they looked like their dad and what they would be doing now at 17 months old. I still have a good cry every few weeks or so. Everyone said to me at the beginning that time heals and I wanted to punch them all, but it's true, it does.

Putting this story down on paper has been very hard. It took me two weeks to write because I kept breaking down. If my story makes just one couple think about eSET then it has been worthwhile.