

## **Rachel's story**

During my twin pregnancy my husband often joked that we had a BOGOF, that, after IVF treatment, we had bought one baby and got one free. After years of trying to conceive, of miscarriages and one failed cycle, it was only human to feel some relief at the prospect of having the ideal family in one go. After twins, there would be no more baby sex, no more visits to fertility clinics, no more grappling with injections, or plastic containers, and a picture of our two longed-for babies would join the others prominently on display in the clinic. But, while we prayed that our babies would arrive safely, we never took it for granted, indeed there were many days when neither of us could smile, let alone crack awful jokes.

### **My decision on embryo transfer**

The decision to put back two embryos was not easy. Just before my treatment began, much publicity had been given to a study published in the journal Human Reproduction<sup>1</sup>. This found that transferring a single embryo was as likely to result in a birth in women aged 36 to 39 as younger recipients of fertility treatment, so at 37 I was eager to discuss its findings with my clinic. But, as it was a subsequent cycle, my first meeting to discuss it was with a nurse and she was most reluctant to offer any opinion. Although she conceded that, if I insisted, I could see my consultant, I was made to feel that I was complicating proceedings and that opting for a single embryo transfer is a decision for younger women to ponder.

The main reason I was so uncertain what to do was because we had sailed through our first cycle of treatment. Not only had I produced a good quantity of eggs, the two put back were top-grade embryos, which the clinic stressed was most unusual, and I did not need to be reminded by the nurse that the cycle had failed.

I felt very alone. My husband said it was for me to decide, and I could only discuss the latest research with a doctor if I made a fuss, so it was with much discomfort that I made the decision to put back two embryos.

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

Confirmation that both had implanted came a few days earlier than the scheduled 7 weeks scan. After experiencing niggling pains, I asked to be scanned as soon

as they could see me, and as I had lost two pregnancies at the same gestation, one of them ectopic, they understood my paranoia. When two tiny, miraculous lights flashing on the screen showed a twin pregnancy, it seemed obvious what was causing the pain. Staggering out of the room, fearful of bursting into tears, I could only nod and hold two fingers up to my mother in the waiting room when she asked if I was pregnant.

### **Early complications**

Exhausted by the news that I was carrying twins, not miscarrying, I went to bed as soon as I got home. When I got up again a stream of blood was unleashed, and though I had no pain it seemed obvious I was miscarrying. Fortunately, the clinic was still open and my husband rushed me back there where, mute with shock, we sat gawping at the two heartbeats twinkling back at us.

We had to wait to be scanned the next day at the Early Pregnancy Unit (EPU) before it was explained what was happening. I had a haematoma (collection of blood, usually as a result of internal bleeding), under the developing membranes, and with the EPU's scanning equipment we could see it looming over our babies, threatening them and our dreams of being parents.

All we were told was that there was an increased risk I would miscarry and that they would scan me at regular intervals. Desperate to understand why I was bleeding, whether it was likely to reoccur, whether it was related to the removal of the ectopic pregnancy and tube, and for any statistics that quantified the risk that I would lose one or both babies, I turned to the internet. It seemed ludicrous that I found myself handing over my credit card details to a society of American gynaecologists to buy a report on a study into bleeding in pregnancy that had been carried out by a team at a London hospital! But my £20 was largely wasted – the study excluded twins – and I searched in vain for anything really useful or reassuring.

The bleeding continued for two weeks – all the blood that had collected above the cervix had to drain away. I was fortunate that having a family had become my job because I found it hard psychologically to move about much. Nobody had told me whether or not it made any difference spending most of my days lying on the sofa getting through a pile of books and bunches of bananas, but I felt it was the

best I could do for my babies. I longed for the days to pass so I could see on a scan if they were both still alive.

### **An anxious time**

Seeing lights flashing from two jellybeans at 8 and 10 weeks brought tears to my eyes, and jokes from my husband, but the second twin was much smaller than the first. It was only at the 12 weeks scan, when we also had the Nuchal Fold Translucency test (where ultrasound is used to measure the fluid between two layers of skin at the back of the baby's neck to help calculate the risk of the baby having Down's Syndrome), that it was explained to us what the diamond and three little lines that appeared at the bottom of the printouts we were given after each scan represented. Except it wasn't really an explanation. "This is the range that babies should be at this stage, this is the average, and this is where your baby is!" shrieked the sonographer, pointing to the diamond that showed our second twin was smaller than more than 95% of babies at that gestation, then she hurried out the room to confirm that the next day we would be seeing a consultant for the first time.

That consultant was a twins specialist, but although we went in expecting to talk about our smallest baby's restricted growth, about the likelihood that I would bleed again, that I might suffer a late miscarriage or an extremely or very premature delivery, he did not. The time that was left after I had told him my history was devoted to talking about the results of the tests for Down's Syndrome. It was plain that it was a standard appointment to discuss those tests, not one specially arranged because the pregnancy caused concerns.

The consultant had a box to tick, he wanted to be able to say he had made it clear to us that, no matter how many happy faces the Down's Syndrome Association put up on their website, some children are severely disabled. We were mystified why he was so focused on the subject. Both my test results showed better odds than the standard tables in pregnancy books give for someone my age. I could not believe that, when one of his colleagues had told us we would be very lucky to achieve a pregnancy after IVF treatment with odds of 20%, the consultant was trying his utmost to convince us we had good reason to be worried when the likelihood one baby would have Down's Syndrome was less than half a per cent!

I wanted to point this out to him but kept quiet as, not only am I not particularly assertive, my question about how many amniocentesis tests (where a sample of amniotic fluid is taken from the womb and examined in a laboratory to detect certain abnormalities) the hospital carried out on twins each year was rebuffed by the question, “How many are carried out in the whole country?”

We limped out of the hospital, unable to believe how little information and reassurance we had come away with.

### **Further complications**

Two days later the bleeding started again, and the first person we saw was a GP who was able to detect two speedy heartbeats. Had he not managed this, the misery of not knowing if they were still alive would have been prolonged several more days until we could have been seen at the hospital, but I was back there before I had an appointment.

I had woken early in the morning in great pain, pain just as intense as I had experienced when I had miscarried, and convinced that I was losing my precious babies, I asked my husband to take me to hospital. I wanted to be in hospital when a 13-weeks-old twin pregnancy came away; I did not want it to drag on any longer than was absolutely necessary; and I was inconsolable.

I spent most of the day waiting to be scanned. When a doctor could be released from the delivery ward to confirm if the babies were alive, they were both merrily, remarkably, tumbling round inside me. The doctor squealed when our smallest baby waved his hand, and she printed off a picture for me to take home. I prayed it would one day be put beside a plaster cast. And to this day, I cannot understand how the pregnancy continued; all I know is that a pregnancy can survive heavy bleeding and stomach-clenching pain.

When we saw our consultant three weeks later, he seemed unable to comprehend why I was exhausted and emotional. A woman who had suffered a heavy period for more than three weeks would, I thought, have had grounds to moan to her GP, never mind a woman pregnant after years of trying and losses. Still, he said little and I left feeling I was an obsessive old nag.

### **Concerns for the smaller twin**

To my great relief the bleeding stopped soon after. A Doppler scan (an ultrasound test that allows blood flow to be assessed) revealed the reason why our second twin's growth was so restricted: he had a single artery in his umbilical cord, not two. "Usually we wouldn't worry too much, but with twins we'd be a bit more concerned," the consultant said, though that was as much as he was prepared to say. So, when I got home I logged on to the internet again. While nothing I read made me overly concerned, and subsequent scans provided reassuring news, I could not help being preoccupied with my smallest, underdog baby and I prayed he would catch up with his twin.

### **Nearing the summit**

When I reached the third trimester it felt like I was on a mountain looking up at clouds starting to peel away from the summit. The odds had finally swung in my babies' favour, and at last I dared look at things I needed to buy. I had no intention of ordering a pram before 30 weeks, but my mother and I could finally go shopping for baby things for the first time, and the temptation to buy things was too great to resist. I bought a few neutral outfits and blankets.

But the summit was much closer than I imagined, and when at 28 weeks and 2 days I woke in a pool of blood at 4:00 am, I was petrified and did not dare stand up. I begged my husband to call an ambulance, and soon afterwards two paramedics eased me into a wheelchair and calmly sped me to hospital where I was taken to a delivery room.

### **My treatment in hospital**

Initially, I was seen by a young doctor who gave me an injection of surfactant to help the babies' lungs mature, and later a consultant came by. "Twenty eight is not as good as thirty, but better than twenty six," he whistled through his teeth, and before he left he told me I would be visited by a neonatologist. Unlike my consultant, whom I could hear in the corridor outside and who noticed my husband, the neonatologist saw me a few hours later, but the onus was on me to ask questions and it was difficult to think of anything but the most obvious – like have you got room for twins at the moment?

I spent the final two weeks of my pregnancy in hospital, bouncing up and down between the ward and the delivery suite. The question I asked most was about the availability of beds in the neonatal unit (NNU). I was well aware of the risk that either I would be shoved into an ambulance and taken thirty miles to the region's largest hospital, or that my babies would be rushed there in their incubators – a prospect that terrified me.

As to my questions about why blood ebbed and flowed, I never got a clear answer. I was deeply frustrated that at times it seemed that, no matter how much I lost, so long as the cannulae (small plastic tubes usually inserted into a vein) stuck in my hand wasn't needed for a transfusion, I wasn't bleeding that badly. On one occasion when the doctor examined me it came out in such a torrent that, watching the exchange of looks between doctor and midwife, I thought "Oh, God help me!" They were convinced the twins were on their way, and nobody could explain why I didn't go into labour.

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

I had been in hospital exactly two weeks when I was, beyond doubt, in labour. I had experienced severe pain for twenty four hours, but each time I was hooked up to a monitor, I was told the same thing, "You're not in labour yet. You've just got a very irritated uterus." I must have seen every midwife the hospital had. Most were exceptionally attentive and pleasant, but I had begun to feel that too much reliance was put on machines. After a night in agony I demanded to see a doctor the moment the morning shift began.

The doctor I saw seemed convinced I was demanding to be induced. "Do you know how serious this is?" he demanded. "Yes!" I gasped, exasperated. He then disappeared and my consultant came to see why I was making such a fuss. "We'd better examine you," he said. And only seconds later he muttered, "We'd better get you downstairs quickly."

In the delivery suite, the consultant I had seen two weeks earlier was on duty. "Thirty weeks, is better than twenty eight. Not as good as thirty two..." he said as he rummaged around inside me to check the position of the first baby. He was so far on his way that I was informed the epidural being prepared was in case an emergency caesarean was needed for the second twin.

As the anaesthetic slowed labour down, my husband and I were then left in a delivery room with a midwife checking on me. When the contractions were advanced enough, I was wheeled back into the operating theatre where 10 people were waiting. Two incubators were ready to cocoon the twins in the trip upstairs to the NNU.

A consultant poked his head around the door, but a cheery doctor wielding forceps had everything under control. When my elder son was born, bawling in protest at being dragged out, she held him up to me before handing him to a neonatal nurse.

The second delivery was more complicated. The baby was breeched. It was difficult enough trying to push when the epidural numbs so much feeling, without 10 people urging you to get on with it! But when he was pulled out by his tiny feet, my younger son did not complain much. He was brought to my side, spitting out blood. He strained to see me and blinked at the lights as he followed the sound of my voice. I had been convinced he was a girl, but the surprise at seeing our second son was momentary. He was tiny, but exquisite, and nothing had prepared me for the whoosh of emotion that came over me. Later, I was told that it is the practice to show the compromised twin to its mother, and I am grateful for that as it was the most precious moment of my life.

### **In the NNU**

My elder son weighed 1.6kg, my younger one 1.06kg, but to everyone's relief the initial assessments of their condition were positive. Though they were helped to breathe by the less intensive system of Continuous Positive Airway Pressure – CPAP (where generated airflow is directed to the airway by tubes in the nostrils or by a mask), it was only required for the first 24 hours. Nurses and doctors were convinced the twins had been helped enormously by a vaginal delivery, but I winced at the sight of needles poked into my youngest's purple feet.

It is life-changing to see your tiny, fragile baby in an incubator, covered in wires attached to monitors beeping away. In the days that followed we listened anxiously to everything the doctors said and to the nurses who watched over them all day, meticulously recording vital data. We were encouraged to change nappies and to talk to them, but took them out of their incubators only a few times

for 'kangaroo care' when my younger son burrowed into my chest as if he wanted to climb back inside me.

### **Caring for premature twins**

I was urged to breastfeed and was fortunate to be helped at first by an exceptionally patient midwife. Two people are really needed: mum to manually express and a helper to catch those crucial droplets of colostrum (the first fluid produced during breastfeeding—it is easily digestible, rich in proteins and fats, and contains antibodies) with a syringe.

But I couldn't produce enough milk for two, and while my youngest was fed exclusively on my milk, my elder son had to be supplemented with formula or donor milk. Still he was making good progress, and unlike his brother needed only a little phototherapy (treatment with ultraviolet light, often used for jaundice in newborn babies).

My poor younger son seemed permanently under UV light, wearing his little mask. Nevertheless, when the consultant saw them at five days old he said he would have been delighted if someone had told him on the first day that this would be the situation. That was the first time I dared relax; I told myself that, at last, everything would be fine. I felt so positive I discharged myself from hospital.

### **A scare**

The next day things swiftly changed. In the evening a nurse told me she had found blood in my younger son's stool. "It could," she told me, "still be some of yours coming out, but we need to do some tests." Terrified, I rushed home, and after we had spoken to a doctor, we knew we would not be sleeping that night. At two in the morning, we were in our car, speeding down the motorway.

When babies are born, their intestines are sterile and are then colonised with bacteria. For a premature baby with immature intestines this is a risky process, and my younger son had contracted necrotising enterocolitis (known as NEC), an infection that mostly affects low birth weight babies. It eats away at the lining of the intestines and can lead to a hole developing, which allows the contents of the gut to leak into the abdomen. This is what happened to my younger son.

### **Desperate measures**

Surgery was the only chance of saving him, and the nearest hospital with a surgical unit was over seventy miles away. But first a specialist transfer team had to come from another hospital to transport him there, and they had to prepare him for the journey – a process which was hideous to watch. Doctors crowded round his incubator, all gowned up, trying to insert lots of fine tubes inside him, and we were advised to go on ahead to the hospital. There we waited for hours longer than anybody had anticipated.

The relief that he had made it was tempered by the shock at the contrast between the two NNUs. The intensive care section was very cramped in comparison to the hospital we had come from, and the only space left for my son was right beside the door, which people were rushing through. There was also a large, brightly lit desk, and added to the noise of machines beeping and pumping everywhere, there was no peace and quiet for desperately ill babies.

The biggest shock was that nobody had told us the surgical unit was in a nearby children's hospital, so our son had gone from a hospital incubator to a travel incubator to another hospital incubator, and would have to be transferred to yet another incubator to be taken to an operating theatre on another site. Our heads spun.

Anxiously, we waited for the team of surgeons, and when they talked to us they were extremely cautious. My son's blood pressure was still very low, and it was not possible to operate until it improved. Somehow, they decided at two in the morning that they were going to operate, and we jumped out of the bed we were lucky to have been given in the unit when someone rapped on the door to tell us. However, half an hour later they changed their minds, and for the next hour I sat with my poor son in my lap, willing the figures on the monitor to improve.

### **An agonising decision**

But they never did, and after lengthy discussions with the surgeons and his consultant we were faced with a choice. We could send him to the operating theatre, in which case, we were warned, there was a high probability he would die there, or we could agree to palliative care – which meant letting him slip away gently.

After such a long period of low blood pressure, we were informed, it was also highly likely that our son had suffered brain and organ damage, so my husband and I were in complete agreement. Our son had suffered enough, and we could not bear the thought of him dying under a knife, or in a corridor. When they left us, we clung to each other and sobbed.

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

We were shown to a small room where, wrapped in the shawl his grandmother had knitted for his christening, our longed-for son lay in my arms until we signalled to his nurse that we were ready to let him go; after the neonatologist came in and took his breathing tube away, I kissed then rocked him as he left us.

I was offered the chance to dress him, but did not have the strength to do so. His breathing tube had disfigured his face, and I was convinced that was not the way I wanted to remember him, so I left it to the valiant nurse to dress him in the tiny cardigan his grandmother had knitted. ("Let's pray to God you never have a baby that small!" she had said when I asked her to knit a premature baby size.)

I went to the expressing room while my husband talked to the doctor about paperwork, and when that was done we returned to the room to find him laid out in a Moses basket. We said our last goodbyes, then left with a snippet of his hair, prints of his feet and broken hearts.

### **Life after loss**

Eight weeks after our twins were born we took our surviving son home and, like every day since, our joy was tinged with sadness. We are blessed to have a beautiful, healthy boy, but our younger son touched us so deeply that we are always thinking of him. A nurse had told me that grief was something I could see as a box, that I could choose when to open it and to think about my lost son. Maybe that will be the case some time far in the future, but not now.

I think about him every time I put his brother to bed at night and when he smiles at me when I get him up again. I often lie awake at three in the morning thinking back to what it was like being with him in a crowded intensive care unit at that same ungodly hour. When the thundercloud of depression descends it can be crippling.

## **Coping with loss**

There is little advice available on coping with the loss of a twin. I haven't found even such basic information as when and how you tell the survivor he once had a special partner. I was offered counselling shortly after my younger son's death and from what I have learned from others' experiences, this is not always the case. I took it up after my elder son had been home a few months. It was a valuable opportunity to just talk about my younger son and how much he meant to me with someone who was not desperate to change the subject.

This is what comes across most on the baby loss websites I sometimes visit: no matter how close people are to you, they don't feel comfortable talking about your loss and can say the most insensitive things. With lone twins, being told 'Well, you've got one!' is a fact of life. Family, friends, doctors, strangers to whom

you can't help blurting out your sad secret when they remark how small your son is, all say it. You cannot let it get to you otherwise you will go mad.

People also say sometimes that it is better to have loved and lost than never to have loved at all, but to me that is an egocentric view. What matters most is how my younger son lived; he must have been in agony as the NEC gnawed away at him and that will haunt me for the rest of my life. (It is small comfort that, as his post mortem showed, the infection was so far advanced surgery would not have saved him.)

He was not a BOGOF, he was a special, spirited, adored little boy who fought so hard to live from the first weeks of his existence. A very experienced neonatal nurse struggled not to cry when she told me how much of an impression he had made on her, and I was deeply touched. It takes courageous and compassionate people to work in an NNU, and everyone we met did everything they could for our boys.

People planning fertility treatment may read this and think, "It'll never happen to me." But I never thought I would need treatment, and I certainly never imagined that one day I would take time out every weekend to tend my son's grave. I have buried both my father and son, and the tears I cry for my son and the life he might have had are much harder to bear. I miss him desperately.

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