

Jo's Story

I was 34+5 weeks into my third pregnancy with my baby daughter when I found that I had developed obstetric cholestasis, as I had with my previous pregnancies. On bank holiday Monday I felt unwell and that something had changed with regards to my condition and attended the ward at my request. I was monitored and had bloods taken. I then went home.

The results were elevated when they arrived and I was requested to attend the ward, where I was told by my consultant that I would have to remain as an inpatient to be monitored and to try medication to lower the bile acid levels. I was prescribed ursodeoxycholic acid 250mg BD. I requested oral vitamin K as a prophylaxis against haemorrhage, which is a complication of obstetric cholestasis affecting both mother and baby, but was denied this as my consultant stated that vitamin K is not licensed in pregnancy and was unnecessary. I remained on the ward undergoing CTGs three times a day but otherwise received no investigations or interventions except for two injections of steroid 12 hours apart. I asked to go home as my husband has epilepsy and should not be left as the sole carer for our two year old son or our twelve year old daughter who has autism, but was told that I needed to stay in hospital to "rest my placenta". We subsequently learned that there is no evidence whatsoever to validate this requirement, and have failed in all attempts to find any research to support this claim.

On Friday morning at about 08:30 I was returning to my bed following a very warm soak in the bath when the midwife arrived to attach me to the CTG monitor. I requested that she wait until I cool off a little as both mine and the baby's heart rate were probably elevated as I was hot, but she refused. She then noted that the foetal heart rate was a little elevated, although otherwise OK. After a few minutes, she felt that there had been one deceleration and seemed a little worried so called my consultant. It was arranged that he would come to see my husband and I at 12.00.

My husband was with me when my consultant arrived. At least four other members of staff joined him, but were not introduced and we were not told why they were there. I was in bed attached to the CTG monitor in my nightdress, which was pulled up, with at least five people stood around me, most of whom did not introduce themselves or tell me why they were there. I recognised one of them as the midwife who had delivered my last baby, and another member of staff had an identical uniform so felt that she must also have been a midwife. I felt extremely vulnerable at this point. My consultant told me that my baby needed to be delivered this day because of the deceleration on the CTG and that the medication that I was taking had not succeeded in reducing my blood bile acid levels. We agreed to this, as we were worried about our baby suffering sudden intra uterine death due to my condition, and thought that I would be induced as I had been successfully before, with just a cervical sweep at 37 weeks. Premature labour and rapid response to induction are a feature of obstetric cholestasis.

My consultant then told us that I needed to have a caesarean section. My husband and I expressed our surprise and stated that a caesarean section was the one thing that we really did not want to happen and, given my previous history of two rapid, uncomplicated and premature vaginal deliveries, felt that I could labour. We requested a chance for me to be induced and labour as I had with my previous births but were informed by the consultant that it was not possible for a lady who was only 34+5 weeks pregnant to labour as the baby's head would be too high and would not descend into the birth canal, although I

had not been examined by him to confirm the height of our baby's head. One of the staff in the team, who I believe must have been a midwife as she wore the same uniform as the midwife I knew, although she did not introduce herself and was flitting in and out of my room, told us that if I tried labour I "Might have gone (laboured) eighteen hours and then still needed a section but that I would probably have given up my daughter's chance of having a special care cot in the event that she needed one as it would probably have been given to another baby." My consultant stated that a caesarean section was the only option for a safe delivery and that our baby would require a brief assessment by the paediatric team before being returned to me. He was apologetic that he could not do the surgery himself, as he was unavailable due to teaching commitments. We were then told that I must remain on the bed attached to the monitor. I asked my consultant for his assurance that the section was being performed in my best interests, and not for convenience, as I suspected, which he gave. He then left my room. I was scheduled to go to theatre at 16:00.

When he had gone the senior midwife who had been present at this consultation and had induced and delivered my last baby, urged me to ask if I could have a trial labour. I replied to her that I would. I then called the ward midwife and requested the same. She went away and told my consultant of my request. My husband left me, to arrange leave from work for the rest of the day. Before my husband came back, my consultant returned to my room with his entourage and I stated to him that I felt that I could labour effectively as I felt baby was very low and I had examined myself and found my cervix to be effaced and that I could insert a fingertip into the opening of my cervix. I requested a vaginal examination but this was refused, as was my request for him to palpate my abdomen. At no time during my pregnancy was I examined vaginally to assess the progress of my pregnancy. My consultant dismissed my request to labour, even though I reminded him that my previous children had been born normally at 34 and 37 weeks gestation respectively.

The midwife caring for me on the ward arrived with a ranitidine tablet and told me to take it prior to the section. I stated that I did not yet know whether I would be needing the section, as I was under the impression that the senior midwife who had urged me to try to labour would return as I thought she was going to support me in my attempt to labour. She told me to take it anyway and, as I had terrible heartburn at the time, and felt that the tablet would do me no harm, I did.

It is documented in my medical notes that I was given ranitidine 150mg at 11.10. I refute this. I was given it much later, when the caesarean was decided, and to confirm this, it is also documented that I had coffee at 11:30, which is correct. Why would I have had coffee at 11:30 if it was known that I was having a section? My consultant had not even seen us at that time, let alone decided upon a caesarean. There are many things wrong with the documentation, much is not documented and some things, such as times and results, have been altered and not signed or initialled / timed.

My husband returned at this point. He was distressed and questioned me regarding the need for a caesarean. I told him that I did not want one either, but we did not have a choice, we believed the consultant's explanation and believed that, in his position as a consultant, he was far more knowledgeable than us, and that he knew best. We respected and trusted his position. Mr X, a staff grade surgeon attended later to obtain my consent. He did not go through the procedure with us, other than informing us of some risks associated with a caesarean, such as bleeding PV, pain, infection, clots, and operation injury to

bladder/bowel, which I read on the consent form, as he said that my consultant had already spoken to us. He advised me to get up as soon as I was able, (he stated that his wife had had a section and he advised her the same way). I was continuously monitored and the CTG showed no further decelerations. There was also strong regular uterine activity and one midwife commented that it looked like early labour. I was then informed that the section had been brought forward to 14:30. The midwife hurriedly shaved my pubic area, she would not allow me to do myself, and gave me a gown to put on. I was somewhat overtaken by events.

My husband and I walked to theatre at 14:30 accompanied by a midwife from another ward who I had never met before as my midwife on my ward informed me that they were all too busy with labouring women. The midwife accompanying me did not appear to be familiar with the procedure or layout as we lost our way once and I was wandering through public corridors dressed in my theatre gown. I was taken into the preparation room and my husband was told to change into theatre clothes. He did this as quickly as possible as he wanted to be in the preparation room with me. I wanted my husband to be with me for support but was told that he had to get changed into theatre clothes and that there was not much time due to pressures on the theatre time. My husband stated that he had already changed into the theatre clothes, but was still not allowed entry when he requested, and had to stand in the corridor for several minutes. I wanted my husband's support and he wanted to be with me but this was denied which we both found very distressing. I received a spinal anaesthetic, which was excruciatingly painful, and then I was catheterised without my consent or prior warning or explanation with one nurse catheterising and another two holding a leg each with the male anaesthetist present and other staff in the room, which I found deeply offensive. I was wheeled into theatre with my lower half naked (I know this because the chrome operating light reflects like a mirror and the patients can unintentionally witness their own surgery) and baby was delivered at about 15:00. When my baby was delivered she appeared well but soon developed breathing difficulties and my husband and I were informed by a paediatric doctor that she would need an assessment in special care. She was then taken away.

I was returned to my room, in a normal bed, as the special electric ones provided for post caesarean patients were too large to fit in the room and left alone with my husband to recover. Over one hour later, we had still not had any word regarding our daughter's condition and had not seen her except for a brief glimpse in the operating room wrapped in a blanket, so my husband went to the special care department to see how she was. He soon returned in a state of alarm to inform me that she was in intensive care and was receiving high levels of oxygenated air via a ventilator. After about 1 hour a midwife checked my wound, which was noted to have seeped a large amount, enough to soak through the bedding. Taping a large sanitary towel across my dressing by way of a pressure bandage was the care I received.

I received no more wound checks and the next day was instructed to have a bath and remove my own dressing and that it was not necessary to have a midwife look at it. When I removed the dressing, I was shocked by how wide the cut had been, from one side of my pelvis to the other, much larger than any I have ever seen. There was also a wedge of flesh, which was hanging over the wound like a 'spare tyre'. The sanitary towel, which had been taped to my wound, was soaked through with blood. My wound also had a large haematoma right across the top and was purple/black.

My consultant visited later that day and examined my wound; He seemed happy with it, and enquired about our baby. I told him that she was being ventilated, but he didn't comment. As he left, he smiled and said, "You couldn't have laboured" but didn't elaborate and left the room.

Our daughter remained in special care for two weeks, which were at times very distressing and worrying. She was very ill and also required treatment for suspected sepsis. The staff in special care asked me why I had had a caesarean, as they could not find any reason for it. I replied that my consultant had told us that I needed one. We were informed by several members of staff in special care, independently of each other, that our baby had very probably developed breathing difficulties as a direct result of being delivered by caesarean section and that if I been allowed to labour she would probably have been alright even if it had ended with a section as the pressures exerted on our baby's chest would have cleared her lungs of the excess fluid. I was also shocked to learn that our baby was put at an increased risk of having a brain haemorrhage as a result of having been surgically delivered, a procedure that was described as "risky" by the ultrasonographer who examined her.

During this time, my caesarean wound was not healing well and had become badly swollen. After about a week it broke open and was gaping in places. I sought the advice of the midwifery staff who assured me that it would heal well. Two days later I woke in bed to find that I was laying in a pool of bloodstained fluid, which had soaked into my mattress. The wound had burst and was now oozing serous fluid. I contacted a midwife and was again reassured. My wound burst open again several times, each time spurting around 100mls of clear, serous fluid, but received no care for this except reassurance that it would heal eventually.

At my six week check my consultant offered reconstructive surgery if my wound continued to be unsightly. He stated during this check that I had been sterilised. I expressed my surprise at this, as this was definitely not at my request and is against my beliefs, and he apologised and said that he was mistaken in this.

To summarise, my overall experience of the family services department is dismal to say the least, with overstretched staff, some of whom appear to have lost their basic humility. I was subjected to remarks such as "Don't you have any nighties, Jo?" from a midwife when I had to wear a gown as all of my own things were dirty and "Have you taken root here?" from a health care assistant who hadn't realised that my baby had been born and was in special care. It must however be said that the majority of the ward staff were committed to providing the best level of care that they could under the impossible circumstances that they were placed in by the demands of their work area.

We obtained a copy of my medical and obstetric notes, including all other documents on computer or microfilmed.

In these notes, there is nothing documented to say that we objected to a caesarean section being carried out. There is no reference to my request to labour or to be examined. There is nothing to say this was anything other than an ordinary delivery. There are also inconsistencies in the notes, such as incorrect times and dates, and changes to some parts that are not authorised by initials.

The nursing records are very poorly kept, with no care plans and charts not maintained. My observations were not recorded adequately post operatively, with the timing of the first changed to one hour earlier than previously recorded.

In the course of our own investigations, we found that the dose of ursodeoxycholic acid, given to me to treat my case of obstetric cholestasis, was inappropriately low. We have received confirmation of this from experts in this field. They stated that the old way of dosing was 10-15 mg/kg. I was prescribed 8mg/kg equating to 576mg. This was rounded down to 500mg by my consultant equating to only 6.9mg/kg. The method of calculating a dose by weight is no longer used in treating obstetric cholestasis, instead a blanket dose of 750-1000mg/day is given. My consultant's knowledge was outdated and inaccurate, and his incorrect treatment failed in avoiding the need for the premature delivery of our baby.