



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, AGEING AND COMMUNITY
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Submission Cover Sheet

Inquiry into Maternity Services in the ACT

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The Committee Secretary
Standing Committee on Health, Ageing & Community Services
Legislative Assembly for the ACT
GPO Box 1020
Canberra ACT 2601

Dear Madam or Sir,

This submission is related to my experience giving birth to my stillborn baby after termination at 25 weeks due to a genetic condition. Our private obstetrician referred us on to the Foetal Medicine Unit to manage the termination and birth of our baby. I found the FMU to be supportive and helpful in navigating this process and have only positive things to say about the department. The FMU took the time to review our case with us, discuss options and to go over details related to scheduling the delivery, what medications are used to induce labour, the facilities in the birthing facility for stillbirths (such as the cold cot) and community support services in the postpartum period (such as counselling run by Red Nose Grief and Loss).

I was scheduled to deliver my baby two days after the termination and the meeting with the FMU. We arrived at noon as we had been instructed and I felt that I was given a 'hard time' by the check-in officer as I was a private patient in a public hospital. They repeatedly went on about how I should not be using a public hospital for my delivery and that I was going to have to pay if I insisted on using my own obstetrician in the birth suite. The FMU had already told me this would be the case and honestly I didn't really care about it at the time.

After being 'checked in' we were moved to a birthing suite. Once there a nurse checked in on us, introduced herself and said she would be back with the medication to start the labour. Four hours later we were still waiting in the room and had not been visited at all during that period. We went searching for a nurse and were told that the FMU had written the wrong dosage for the medication to induce labour and that the doctor on the ward would not review our case as they were opposed to terminations and so they had to wait for the FMU or our obstetrician to send through a new script and that there was a possibility they would just send us home for the day. Please understand that carrying a dead baby in your belly and having spent the previous few days preparing ourselves for the birth, and for the process of meeting and saying goodbye to our baby is extremely difficult, and being told we might have to 'come back and try again another day' was quite distressing.

On hearing this, I contacted my obstetrician directly to notify them of the situation and ask if they were able to contact the ward and sort out the medication issue. They immediately called and within 10 minutes the nurse came into the room and rudely told me off for contacting my obstetrician directly rather than leaving it to them sort it out. Nevertheless, this meant that the medication was now sorted and induction started within the hour.

At some point I was also told by the nurse that because we had opted for an autopsy they would have to take the baby from us immediately after birth and that we would not get to spend any time with it. This would have been extremely distressing if it were not for the fact that by this stage I really was just not interested in taking what they said at their word. I insisted that we had been told by the FMU that we could be with him for as long as we wanted to and had checked this information with a family friend who confirmed this to be the case. I can't imagine how terrible it would have been if they had taken our baby from us immediately after birth and sincerely hope that this has not happened to anyone else as those few hours will be treasured for a lifetime and were such an important part of the grieving process. In addition to this I wish in hindsight that I had asked directly for the cold cot so that we could have had more time with our baby and am disappointed that it wasn't just offered to us. I would also have liked to be told about the professional photographers that offer their services as we did not have a proper camera with us and it would have meant so much to us to have a decent family photo with our baby.

Later that evening a new nurse came in and introduced herself as the night nurse. Although I was relieved that the same nurse who had told me off was not going to be the one helping me to deliver my baby, I was a bit confused as the FMU had told us that we would have the same nurse throughout. Labour progressed quite well over the next few hours, however I had not eaten since before arriving at noon and when offered Panadol for pain relief I promptly threw it back up. I explained that I was hungry but told that I had arrived too late in the day to be added to the dinner order so they had no food for me.

I delivered the baby in the early hours of the morning and was so appreciative of the nurse who spent time with us to dress the baby and take some prints of their feet. Luckily we had brought a wrap for our baby the day before as the FMU had told us that their birthing suite would have donated clothing for premature babies, however, we were never offered anything. The nurse eventually left us to spend time alone with the baby at around 5:00am.

By 9 am we were getting ready to leave as I was very hungry and it was becoming clear that the baby needed to be cooled for preservation and sadly we had at no point been offered the cold cot that the FMU had told us about. My mother went to find a nurse (new shift) and to find out about breakfast for me. She located a group of four nurses at the nurse station and asked about breakfast and discharge. She was told to take a breakfast tray off the stack as the staff were too busy to deliver them to the rooms (all the breakfast trays were still there when my mother grabbed one for me).

As a side note, in the morning I noticed a vial of Endone and unused syringe on the bedside table. I assume this was brought into the room at some point during labour but not used in the end. I was surprised that it was left at the bedside and not taken away.

We were eventually told that we could leave around noon the next day and were only visited by a Social Worker on departure where they handed us the folder with forms/documents for registering birth and local services. A family friend who is a Social Worker in another jurisdiction was very surprised that a Social Worker did not visit us earlier on and that they did not have a longer discussion with us to see how we were coping and if we required assistance.

We were asked to return the next day to receive a Rhesus injection (I had to enquire about whether I needed this and it was agreed I did, but if I had not asked I would not have got this). We arrived in the birth suite around lunch time and were asked to wait in the kitchenette area. In the area there were about 5 nurses having a lunch break, as well as another gentleman eating his lunch (whom I assumed was a partner of a woman giving birth). Everyone could hear the screams of a woman in labour down the hall and one of the nurses said she didn't know why the person was making so much noise and the others agreed with her. It wasn't until another nurse sat down with the group who said 'actually labour is really painful, so she can scream all she wants' that the group moved on to what they were doing on the weekend (going out clubbing etc.). I hated to think that the man eating his lunch beside us could possibly have been the partner of the 'screaming woman'. Not to mention I was that screaming woman just 24 hours before. All I could think was that there really needed to be a separate area for the nurses to take their breaks as it felt that their lunchtime banter was extremely unprofessional and as a patient I would rather have not been a witness to it.

All in all, I was disappointed by the support and care we received during the birthing process. Giving birth to a stillborn baby is a terribly sad time for everyone and a little compassion goes a long way. Instead we were made to feel unwanted, possibly the worst feeling of all for the situation.

One big gap in our care was the fact that as first time parents we were not educated on the birthing process including stages of labour, delivery of the placenta, pain relief options, ways to move, use of shower/bath/massage/breathing etc. to help manage the pain. We went in blind and this added to our feelings of being overwhelmed and out of control with what was happening to us. I would strongly encourage the development of materials for parents to be able to read through when delivering a stillborn or premature baby. This material could cover some of the applicable topics generally discussed in ante-natal classes, as well as information specifically relevant to these circumstances. Being able to read through such material I believe would have been a comfort and a help in preparing for our time in the birth suite. It would have informed us of such things as the process of delivering a baby, facilities in the birthing suite, use of a cold cot or a professional photographer, role of social workers, importance of post-natal care. Other information such as tips and recommendations like bringing snacks along and clothes for the baby to wear (that would fit their small size) would also be very helpful. These are the sorts of things that we had not known to ask about.

I have carried this story with me for the past few years and am grateful for the opportunity to provide feedback of my experience to ACT Health in the hope that other families in the future may have a better experience in giving birth to their stillborn babies. Despite our overall experience those few hours spent with our child were so precious and were our only opportunity to build the memories that must last a lifetime. Compassion for the family going through the tragedy of losing a child and information on what the journey entails can go a long way to helping patients through what is a very tough time.

We have gone on to have a second baby where the pregnancy was managed through shared care between the FMU and the CATCH program. They personalised care, with our history in mind, which went a long way to helping us manage the anxiety and fear around a second pregnancy. Our only feedback for improvement would be to continue to explore how the partner can be incorporated into the ante-natal care model, including mental health support in the ante-natal and post-natal period. The baby was delivered in the birthing suites at The Canberra Hospital and the care we received from all staff during labour was professional and supportive.