LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, AGEING AND COMMUNITY SERVICES

(Reference: Inquiry into maternity services in the ACT)

Members:

MS B CODY (Chair)
MRS V DUNNE (Deputy Chair)
MS C LE COUTEUR

TRANSCRIPT OF EVIDENCE

CANBERRA

TUESDAY, 9 JULY 2019

Secretary to the committee:
Mrs J Moa (Ph: 620 50136)

By authority of the Legislative Assembly for the Australian Capital Territory

WITNESSES

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Amended 20 May 2013

The committee met at 10.01 am.

CAMPTON, MR JONATHAN
BUXTON, MS CLAIRE

THE CHAIR: Good morning everyone, and welcome. I declare open the first public hearing of the Standing Committee on Health, Ageing and Community Services inquiry into maternity services in the ACT. Before we proceed I would like to take a moment to acknowledge that we meet on the lands of the Ngunnawal people. I pay my respects to elders past, present and emerging, and to the continuing contribution of their culture to this city and this region.

Today the committee will hear from individuals and families who have experienced maternity services provided in the ACT. On behalf of the committee, I would like to thank all witnesses for making time to appear today. I remind witnesses that the proceedings are being recorded by Hansard for transcription purposes and will be made available on Assembly on demand. I note that all witnesses appearing today are appearing as private citizens.

We will now move to the first witnesses appearing today, Mr Jonathan Campton and Ms Claire Buxton. Thank you for appearing today and for your written submission to the inquiry. I would like to remind you both of the protections and obligations afforded by parliamentary privilege and draw your attention to the pink-coloured privilege statement that is before you on the table. Could you please confirm for the record that you have read and understood the privilege implications of the statement?

Mr Campton: Yes, I have read it, and I understand.

Ms Buxton: Yes, I have; thank you.

THE CHAIR: Before we proceed to questions from the committee, I note that the committee has decided not to disclose the names of medical officers, including midwives and doctors. Witnesses need to try to refrain from identifying medical officers while giving evidence. The committee has also decided not to publish the names of children. If witnesses do wish to disclose the names of their children, please remember that your evidence being provided is on the record and will be published on the Assembly website. Would you like to make a brief opening statement before we get started?

Mr Campton: I thank the committee for taking the time to inquire into the maternity services in Canberra Hospital. We have had a number of children in the ACT. We know the health system can be very good in areas, particularly accident and emergency, but our experience in maternity is quite different. We take our written submission largely as read.

We would probably recognise that we come from a very privileged position in that we had the intellect, the finances and the ability to get up and remove ourselves from the state system, and we had a very good health outcome. However, we are abundantly aware, from talking with other parents with multiple births, that, with respect to the

experience that we first encountered at Canberra Hospital, had we not had that choice, we would have had a very poor outcome with regard to the birth of our twins. It is quite clear from the conversations we had with the medical staff at the Canberra Hospital that we were playing Russian roulette with the lives of our twins and with the mental health of my wife. Perhaps Claire could make some comments.

Ms Buxton: By way of background, we have five children. The first was born in Canberra in 2010 at Calvary John James; the next two were born in Sydney in RPA. When we found out we were having twins, we thought, "We can't have five children in Sydney," so we made the decision to come back to Canberra.

Because we had been in the public system in Sydney, we thought, "That's what we'll do." It was at that point that we started encountering problems, in that it was very difficult even to make an initial appointment. I had to call multiple times. It became obvious that both my twins were breech. There was no real consideration given to the fact that I had had three uncomplicated vaginal births before. They automatically wanted to give me a caesarean.

As Jonathan alluded to, we were very lucky because we were able to articulate our concerns with that approach and question why this strict policy would necessarily apply to me. I continually said, "I understand the policy; I understand what that's based on, but how does that apply to me? I'm an individual. You're not taking into account my previous birth history, my uncomplicated pregnancy." I was very healthy; the twins were really healthy. I was fit. Other than the fact that I was having twins, I had absolutely no complications in my pregnancy.

I was expressing strong concern about having to have what is sometimes a very necessary medical procedure, having a caesarean. In my case, with no family support in Canberra, and with Jonathan having no access to any kind of leave, I would be having this big operation and then having no family support and having to care for my three older children, who at that point were six, four and two. So we had five children aged six and under, and I did not want to be recovering from a caesarean while trying to care for all of these children.

I was also concerned about my mental health, and I said that a number of times. The incidence of post-natal depression is naturally higher in multiple births, anyway. The fact is that I felt very much coerced into having a procedure that I really did not want to have. I questioned the doctor at the time about what would happen if I arrived in labour at Canberra Hospital, and he said that, basically, it would depend on who was on on that day. That was just not a risk that I was willing to take.

Thankfully, Jonathan called Calvary John James and the midwife there, without having met me, and having no personal understanding of who I was, rang a bunch of obstetricians in Canberra to find an obstetrician who might be interested in taking on my case. At that point things started to get better.

Mr Campton: At that point you were 36 weeks.

Ms Buxton: Yes, I was 36 weeks pregnant with twins. Most twins are delivered roughly at 35 weeks.

Mr Campton: So being thrown out of the public health—

Ms Buxton: At my very last appointment the female obstetrician said to me, "Don't worry about your pain; we'll manage your pain." I said, "The pain is not what I'm concerned about. I'm concerned about all of these other consequences that this will have on my life."

I had to make a follow-up appointment and there were not any appointments available for, I think, the next week. They said, "We'll call you back." I never heard from them again. They did not ever call me back in the intervening period. Obviously, if I needed that appointment, I would have followed up on it. At the end of the day I just went into a bit of an ether, and no-one ever followed it up. Jonathan contacted Calvary John James, and that is where I ended up having my twins.

The first thing that the obstetrician there said—and at no point had they said this in the other hospital—was, "I'll do a scan and see what their breech position is, and that will show whether we try a vaginal birth." At the Canberra Hospital it did not matter to them what position they were in. They were breech; therefore it was a caesarean.

MRS DUNNE: What you are saying is that not all breech births are the same?

Ms Buxton: That is right. I think that there are three breech birth positions: frank, which is where they are in a pike position; complete, which is where they are kind of cross-legged, almost like in that sort of yoga pose; and then footling, which is where their feet are coming first. It was interesting. The girls were both in the complete breech position and the obstetrician said, "I prefer frank." Apparently it is better when they are like that. But the paediatrician said, "Complete is better for the baby."

THE CHAIR: That is interesting.

Ms Buxton: Yes, it is. It was interesting. At the end of the day I arrived at hospital—it was a Saturday—and I was met by the midwife and the obstetrician. My twin A was born first about 40 minutes after arriving in hospital, no medication, very little intervention—none, I think—and her sister was born 16 minutes later. She had minor foetal distress but was born pretty quickly.

They both had really good Apgar scores. Neither of them required oxygen, neither of them required any time in the nursery. They were 40 weeks and one day. Twin A was 3.2 kilograms, and twin B was 2.9 kilograms. That is a pretty good sizes for twins. It was a really positive outcome for us. The girls have always been, except when they have got a bit of a cold, really well and developing very much on course. There is no issue with premature birth or anything like that.

At the end of the day we had a really positive outcome but there were a couple of weeks, from about 32 weeks to about 36 weeks, when it was a really stressful time for us trying to really consistently advocate for what we felt strongly was the best outcome for me physically and mentally and overall for our families. I do not know what the word is—"happiness", I suppose.

MRS DUNNE: Wellbeing.

MS LE COUTEUR: Wellbeing.

Ms Buxton: Wellbeing, that is right. I am happy to answer any questions on that.

MRS DUNNE: Could I ask: how long were you in hospital after the birth of the twins?

Ms Buxton: I think five days or something.

Mr Campton: Yes, but I had to push her to take those five days in the hospital.

Ms Buxton: I think just because they had been twins and the midwives were conscious that I had other children at home they were keen to keep me in longer. But I could have probably gone home a bit earlier than that.

MS LE COUTEUR: Did the hospitals, or Canberra Hospital in particular, offer you any social worker-type support? You were saying you had no family support in Canberra—and that appeared to be a major part of your stress level—and that would seem to be, regardless of the medical stuff, what you actually needed.

Ms Buxton: Yes. It is a really interesting question. At one point I actually said to the female obstetrician we saw, "If I am going to have a caesarean can I speak to a counsellor about how I can personally manage it and how I can come up with some strategies for my own mental health?" Without being disrespectful to her—she had had a caesarean, and she told me that—she did not see it as an issue. And of course it is not an issue for some women; every woman needs to make her own decisions about her health, including their maternal health.

I was in tears in that appointment, pleading with her to see a counsellor or ask her if she could refer me to one. She did not do that, and I am not sure why that was. I did not ask for a social worker but I asked for some kind of counsellor and it was not forthcoming.

MRS DUNNE: You had three children under six?

Ms Buxton: The eldest was six.

MRS DUNNE: Six and under.

Ms Buxton: Six, four and two.

MRS DUNNE: There was no-one saying, "You have got a large family with lots of little kids; so you might need this sort of assistance." And there was no-one that actually said you could go to this agency or this agency or fill out this form—

Ms Buxton: No.

MRS DUNNE: Or financial assistance or whatever?

Ms Buxton: No. I did not even know that there would be anything available, to be honest. Otherwise I probably would have asked. But no I did not. I am not sure.

MRS DUNNE: Your story is one of, as you described it, lack of autonomy and lack of effective choice in the public hospital system. Mr Campton, you say in your submission that you were told that there was some deskilling at the hospital so that obstetricians were not skilled in dealing with breech births. Was it breech births or breech births that involved twins?

Mr Campton: I think it was breech births full stop. That was the first appointment Claire attended by herself. After that appointment I attended all the other ones with her. But Claire is probably best able to say what the doctor said.

MRS DUNNE: Yes, sorry.

Ms Buxton: No, that is fine. I cannot remember his exact words but I raised with him the fact that they were not skilled in breech birth should not negatively affect me. I think he said that there were one or two doctors who were able to do breech births, and I think that is breech births full stop, to be honest. In fairness, I think if I was just having a baby, and not twins, they might have been slightly more forthcoming.

MRS DUNNE: "Let's see how it goes."

Ms Buxton: Yes. I think because I had had three other children vaginally I was really a prime candidate for a positive breech birth outcome.

Mr Campton: They were large babies.

Ms Buxton: Yes, and there are all these things they like breech babies to be. They like them to be at a certain gestation, they do not want them too big and they do not want them too small. They were both fitting in within all those categories.

But he openly said to me, "Yes, there has been a deskilling." I appreciated his frankness, to be honest. And that is why he said, "It will just depend on luck of the draw. If you arrive in labour and one of us"—there are, I think, two doctors who are comfortable with breech births—

THE CHAIR: Just to reconfirm, that is comfortable with breech births vaginally and by caesarean, or just vaginally?

Ms Buxton: I do not know. I do not think it makes a difference with a caesarean. Their position is not relevant with a caesarean.

THE CHAIR: It did with my caesarean. It made a big difference.

Ms Buxton: Is that right?

THE CHAIR: That is why I asked.

Ms Buxton: Okay. I imagine if I was having a caesarean they would have scheduled me in and put me on a list with someone I would have been happy with. But vaginally there were, I think, the two doctors who would have been happy with or comfortable to deliver a breech birth. As Jonathon alluded to, because we had the means, I suppose, to find a private obstetrician I did not want to run that risk of arriving at the hospital and effectively being given an emergency caesarean because there was not a doctor on staff who could deliver the babies. This way we had a little more control over the situation.

It frustrates me that there are other women who may well be in my situation medically but lack the means and they have no choice but to have a caesarean. I do not think that that is a real choice. My personal view is that your income should not dictate your health outcomes.

THE CHAIR: Thank you very much for your time today and for sharing your experience. The committee is very grateful. When available, a proof transcript will be forwarded to you to provide an opportunity to check the transcript and suggest any corrections where you may have been misquoted. I thank you both for appearing today.

Mr Campton: Thank you very much.

MOLONEY, MRS SARAH

THE CHAIR: We will now move on to our next witness, Sarah Moloney. Thank you for appearing today and for your written submission. I remind you of the protections and obligations afforded by parliamentary privilege and I draw your attention to the pink privilege statement before you on the table. Once you have read that, can you confirm for the record that you understand the privilege implications of the statement?

Mrs Moloney: Yes.

THE CHAIR: Just for the sake of all witnesses, I again note that the committee has decided not to disclose the names of medical officers, including midwives and doctors. Witnesses need to refrain from identifying medical officers while giving evidence. The committee has also decided not to publish the names of children. If you wish to disclose the name of your child, please remember that your evidence is being published on the Assembly website.

Mrs Moloney: Yes.

THE CHAIR: Thank you, Mrs Moloney.

Mrs Moloney: I thank members of the committee for enabling me to share with each of you some further insights into the issues raised in my submission. I have shaped my opening statement to try to provide insight into my experience and share reflections on what my journey through the ACT health system with both my pregnancies was like and what I believe the key issues are for consideration by the committee. The intent of my submission and my attendance today is to try to help mothers in a similar situation to mine—sorry—

THE CHAIR: That is okay.

MRS DUNNE: It is okay.

Mrs Moloney. Be better informed—

MRS DUNNE: Sarah, have you got someone here with you?

Mrs Moloney: Yes, my dad.

MRS DUNNE: Would you like to go and sit with her?

Mrs Moloney: I am fine. It would be worse for him. The intent of my submission and my attendance today is to try to help mothers in a similar situation to mine to be better informed, more confident and more demanding on the health providers, to enable them to be able to experience more appropriate levels of comfort, control and attention in their pregnancies as individuals in the system, more so than I experienced with both of my pregnancies.

I have had two fairly recent experiences with the services provided by the Canberra

Hospital. The first was just over four years ago with my daughter and the second was just over two years ago with my twins. With Olivia it was identified early in the pregnancy that I had a low-lying placenta. This meant that unless it shifted prior to birth, I would be having a caesarean or risk a birth that would lead to the loss of my baby or me. This would be due to the serious blood loss if the placenta ruptured during the birthing process.

Despite knowing this at a reasonably early stage, I continued to be encouraged and led to believe by the midwifery service that I should be aiming at a vaginal birth. This advice continued, even when admitted on a number of occasions due to vaginal bleeding at different points in my pregnancy. These bleeds required monitoring and assessment at the Canberra Hospital.

At no point was I ever properly educated on how serious a low-lying placenta was, nor was I educated on the process of a caesarean. This advice continued up until very close to the actual birth day. As I was still bleeding frequently into the last stages of my pregnancy, I was referred to the foetal medicine unit for an internal ultrasound to confirm that the bleeding was in fact coming from the low-lying placenta.

The midwives told me that it would be from this scan that they would determine if I would be birthing vaginally or via C-section. During this internal ultrasound, the stenographer told me that there was in fact no low-lying placenta at all and that because I was so young it would be stupid of me not to proceed with a vaginal birth as recovering from a C-section is a nightmare. It was later confirmed that this was in fact completely incorrect and that in fact my placenta was dangerously low. I chose to trust my instincts and I pushed for a C-section. I was bleeding almost every second day and I knew something was not right. I could feel it.

I thank my lucky stars every day that I trusted myself and that I pushed for what I knew was right for both me and my daughter. Then I chose to disregard the bullying of the midwives, who were pushing for a birth that I was never going to be able to safely carry through with. During my C-section, it was confirmed that my placenta was in fact extremely low. I still remember my surgeon at the time saying, “Thank goodness you pushed for this.”

I still think every day about what would have happened if I had not made this decision. Perhaps I would not be here today making this statement in front of you. My low-lying placenta would have made a vaginal birth extremely dangerous, which again was confirmed by the delivering physician. During and following the delivery I haemorrhaged to the point of almost needing a blood transfusion.

I move on to my twin pregnancy almost two years later. The fundamental issue with my twin pregnancy was that the advice appeared to me to be based on the belief that twin pregnancies never go to term. So potential issues that I understand become risks, the closer you get to full term, were not ever properly discussed and any kind of plan put in place. In my case, the full risks were never laid out to me until virtually the final weeks, meaning that the stress and anxiety levels skyrocketed for me at what would always have been a stressful time. It finally became apparent that I was dealing with almost full term twins with no plan B as an alternative, because twins never go to term.

I again made the decision, on my own, to opt for a C-section. I mentally had to prepare myself four days before surgery that this was again going to be how I brought my babies into this world. The conflicting belief of several doctors led me to make this decision. During the entire length of this pregnancy, the initial plan had been to opt for a VBAC, which is a vaginal birth following a C-section. This was recommended by one of the obstetricians that I saw in the twin clinic at the Canberra Hospital. It was recommended so my recovery would be easier seeing as I would have two newborn babies and my other daughter to care for. They briefly discussed induction with me throughout the pregnancy. However, everyone's assumption was that, again, I would go into labour without the need to be induced.

As my term date grew closer, it was apparent that I was not going into labour any time soon. After three failed stretch and sweeps, my babies growing at a rapid rate and no sign of labour approaching, it was only then that they decided to discuss with me the risks associated with actually inducing me, after my relatively recently C-section with my first.

This takes me to three key points that I would like to make that are common to both of my pregnancies. Firstly, the advice provided to me was largely driven by midwives and, to me, always focused on natural birthing even when apparently obvious issues that might make that approach risky were identified. Right up until the delivery date, I was being fed constant advice that despite what was going on with scans and bleeding, I should plan to birth naturally. This apparently conflicting advice stressed me significantly and took away from the ability to enjoy and be excited by my first pregnancy. In reality it would have put both myself and my daughter at risk.

Secondly, there does not appear to be a centralised, consistent plan for a patient-centred approach to each pregnancy. Dependent upon when you are scheduled or required to attend for a check-up or present with a problem, there does not seem to be a single point of professional opinion or assessment and no coordinated treatment plan. Basically, to me it appears that you turn up, your file is reviewed and whoever is on shift tries to figure things out, often relying on you to tell them what has been going on.

Finally, and for me most importantly, the process around pregnancy focuses on physical health and wellbeing pre and post-birth but never on your mental wellbeing in the lead up to and post the birth. Both of my pregnancies and births have been risky. My anxiety and stress levels and those of my husband and family were very high pre and post-birth. There was no social welfare or counselling assistance provided to me at all. This was despite my finding out with my first birth that both my daughter and I could have potentially died, and with my second birth having to watch my son be resuscitated at birth and having to spend a number of days in NICU, including an emergency operation six hours after he was born for a deflated lung.

Since giving birth to my twins—sorry—I have been diagnosed with severe postnatal anxiety. I suffer from PTSD after I watched my baby being resuscitated, lying limp and not a single person ever checked in with me. I was wheeled to recovery alone, terrified and scared, and no-one was ever telling me anything about my son. I remember repeating over and over to the staff in the surgery room, "Please tell me

that my baby is going to be okay." The lack of reassurance still astounds me to this day. I have never felt so helpless or empty in my entire life. My family believe this could have been minimised or averted with proper counselling and support post both of my pregnancies.

How can the system know that these types of trauma occur with pregnancies yet have no apparent procedure and service to deal with them? I was sent home three days after my first traumatic birth and five days after the birth of my twins. In fact, my surgeon pointed out to me on day three after the birth of my twins that there was a woman in the room next to me whom he had operated on the same day as me and she was up and walking around. Not only was he referring to a woman who had birthed a singleton, but he was also forgetting that my mental state was crushed at this point. Instead of encouragement and reassurance that I would recover with time, I was made to feel like I had failed.

The last point that I would like to make in this opening statement is that post the first birth, I was actively encouraged by attending doctors and nurses to make a formal complaint to the Canberra Hospital. Given the risks associated with my birth and the advice given to the lead-up, I did make a complaint. A process was conducted to consider my issues, resulting in an apology letter in fairly general terms.

My concern is that medical professionals felt that it was important for me to complain formally. Shouldn't they be able to raise these issues themselves and be properly heard without what I have interpreted as possible fears or having their issue simply heard without being brushed under the carpet?

Canberra Hospital has never cared. I was nothing more than a number in their system. The impact of both my births will be with me for life and my only hope is that by using my voice today, I can prevent another mother having to go through this. Thank you for listening. I am happy to answer any questions you may have.

MRS DUNNE: Take a breath. Take a drink.

Mrs Moloney: Thanks.

MRS DUNNE: Sarah, can I just ask this, because sometimes these things do not sink into my brain: when did you discover that you had a low placenta?

Mrs Moloney: It was discovered at my 20-week scan, the big 20-week scan.

MRS DUNNE: And you had had bleeds before then?

Mrs Moloney: They started after that, about three weeks after. The first one was quite substantial. Any bleed when you are pregnant is substantial.

MRS DUNNE: Terrifying.

THE CHAIR: And scary.

Mrs Moloney: It freaks you out every time. The first one was on my birthday, so I

remember it clearly. I was taken in for observation and they confirmed with a bedside ultrasound that it was a low-lying placenta. I think they were trying to make sure that the baby was fine. I was fine other than the fact that I was scared. They continued, I would say maybe every fortnight, and then the bigger I grew it was maybe every second day.

THE CHAIR: Were you considered high risk at that point?

Mrs Moloney: No. I am not sure what they call it anymore. The midwifery program there is where you basically birth as naturally as you possibly can with minimal intervention. I was in that until my husband told them to give my file back and that they were not going to be looking after me anymore.

THE CHAIR: And that is when you ended up in the foetal medical unit?

Mrs Moloney: That was after the foetal medicine unit. The foetal medicine unit did an internal ultrasound. I was still under the care of that midwifery program, and that was to see if it had moved. I do not know how they ever thought that it could have moved, and even the fact that I was bleeding: I do not know why I was never considered high risk from the get-go. The internal ultrasound showed that it had miraculously moved, which, in my opinion, was just an untrained sonographer looking at something that was not there, because as soon as they opened me up—and they opened me up without expecting to see a low-lying placenta there—they knew that I was in for a C-section because I had pushed for it and I was bleeding.

MRS DUNNE: My summation is that you feel that you should have been offered a caesarean.

Mrs Moloney: I should have been educated on a caesarean.

MRS DUNNE: You should have been educated so that you could make that choice. You eventually opted for a caesarean.

Mrs Moloney: Correct.

MRS DUNNE: The summation is that you felt that you were fighting against a—

Mrs Moloney: The whole time.

MRS DUNNE: The whole time, to get that, and you were not supported in that decision.

Mrs Moloney: No.

MRS DUNNE: When you had the caesar, they went, "Oops, that really is a low placenta."

Mrs Moloney: Yes. I remember being on the operating table. My surgeon, who delivered my daughter, my first, was amazing. He was one of the surgeons who pushed me to make a complaint to Canberra Hospital, which, again, ended up being

nothing anyway. When he opened me up, he said, "Thank God you did this, because this is about as low as they get." As a result, I lost a lot of blood in surgery and then I haemorrhaged following the delivery and recovery.

MRS DUNNE: Was it your submission where you said that there were no records in your patient records that you had had bleeds?

Mrs Moloney: I think there were very few recorded bleeds. I would call my midwife. The program was that you would ring your midwife directly. It is to make the mother feel as though they have this one support person, which in theory is a great idea, but it does not work like that. Basically I would ring her every time I had a bleed. If I am completely honest, I think that towards the end, she just did not really care because they were happening so frequently. Every time we would go in and I would be checked, it was almost as if I was wasting her time.

MRS DUNNE: How many times do you think you presented to the hospital?

Mrs Moloney: I cannot even remember.

MRS DUNNE: You cannot remember how many times you presented to the hospital?

Mrs Moloney: No.

MS LE COUTEUR: More than a dozen?

Mrs Moloney: No; probably not that many. Sometimes I would ring her and say, "I am bleeding. What do you want me to do?" It was usually just: "Put a pad in and monitor it."

MRS DUNNE: How old were you when this happened?

Mrs Moloney: I had just turned 22. When I was pregnant, I was 21.

THE CHAIR: Did they give you an idea of what you were monitoring; how much blood loss is acceptable?

Mrs Moloney: She would always say things like, "If you fill a pad within this certain amount of time, that is considered a lot." But try telling a mother that.

THE CHAIR: I completely understand that.

Mrs Moloney: That is fine.

MRS DUNNE: When you went to the foetal medicine clinic, you got professional advice from the sonographer that said that you did not need a—

Mrs Moloney: There were two women in there. One was the sonographer and one, I am going to pray, was someone who was educated enough to make a statement. They both said the exact same thing. They were both older women, I think, with the belief that I was really young and that I should probably not be pregnant. That was definitely

the impression that I felt when I was there.

MRS DUNNE: When did you personally make the decision that you felt you needed a caesar?

THE CHAIR: How far along with the pregnancy?

Mrs Moloney: I think I delivered at 38 and a few days. I feel as though it was maybe made a week before I went in for surgery. That was through an obstetrician who eventually saw me at the very tail end of all of this. In my opinion, most of the obstetricians at the Canberra Hospital are pro-caesarean, and thank god, because that was what I needed to have done.

MRS DUNNE: Is that the first time you had seen an obstetrician?

Mrs Moloney: That was the second.

MRS DUNNE: When was the first time you saw an obstetrician?

Mrs Moloney: The first time was after a number of my bleeds. The midwife eventually decided to refer me to an obstetrician. He had never seen me for my entire pregnancy; when I saw him, all he was working off was what the midwife said. The midwife also has to attend that appointment. She sits there the entire time giving her opinion on the matter. By this stage, he also had the foetal medicine ultrasound, so he was going off that as well. But he trusted what I was saying, and I said, "This just is not right." In his opinion, I was considered high risk just for the fact that I was bleeding and no-one could explain to me why.

MRS DUNNE: How far apart were those obstetrician appointments?

Mrs Moloney: I am going to say about a week; they were pretty close.

MRS DUNNE: But you did not see the same obstetrician twice?

Mrs Moloney: Yes, I did. I think that was only because he was the head of the obstetricians at that particular time. We were creating a bit of stir at the hospital just because we were—

MRS DUNNE: You and your family?

Mrs Moloney: Me and my husband, and my dad. By this point, I had had so much conflicting information and was so unsure as to how I would be delivering my baby that I was starting to demand answers rather than just sitting back.

MRS DUNNE: Did you contemplate going elsewhere?

Mrs Moloney: No. I was so far into the pregnancy, it was the last thing. I just wanted to deliver my child and to stop bleeding.

THE CHAIR: Then you fell pregnant with twins?

Mrs Moloney: They are two years apart, so yes.

THE CHAIR: Again, did you feel that you had to go back to Canberra Hospital, that there was not another option; or was that the best place?

Mrs Moloney: No. I was really reluctant and really scared when I had to go back, but I had been informed by my GP that I would probably be under far more care and supervision given the fact that I was a high-risk pregnancy just for the fact that I was carrying twins.

MRS DUNNE: Twins, and you had had a caesar.

Mrs Moloney: Correct. I would say that most of my care at the beginning with the twins was okay, and it was a fairly smooth pregnancy compared to my first. It was just that towards the end of the pregnancy people were giving me really conflicting advice. No-one seemed to agree on anything, ever. I remember that I was in there at maybe 37 weeks and I was having what I think were just really strong Braxton Hicks, but because I was so far along in the pregnancy they were monitoring me.

THE CHAIR: They all assumed.

Mrs Moloney: Yes. And my babies were huge; they were both born at three kilos. They tested me twice for gestational diabetes.

THE CHAIR: We are comparing the size of your shoulders and how tiny you are.

Mrs Moloney: You can imagine how I felt. I remember saying, "Thirty-seven weeks is term with twins. Please just get them out of me. I have had enough. Why can't you just induce me?" That is when all of this stir started to happen, all of a sudden. Being induced after you have had a caesarean is really dangerous.

THE CHAIR: Is it?

Mrs Moloney: Yes, so close.

THE CHAIR: Right.

Mrs Moloney: I think uterine rupture is what can happen when they induce you. Again, they were relying on the fact that I would just go into labour naturally, and that was never going to happen.

MRS DUNNE: We saw with the previous witness that she had twins at 40 weeks.

Mrs Moloney: Yes, I know.

THE CHAIR: Plus.

MRS DUNNE: And a day.

Mrs Moloney: Which is really dangerous. Sometimes I wonder if my twin B came out not breathing because my placenta was not working the way it should have been. You can read this on Google. If you are pregnant with twins and you get to a certain point, your placenta just stops working. Their placentas just stopped being as efficient as they are if you are carrying a singleton. They knew that. They were just hoping that it would happen on its own.

MRS DUNNE: So that you could have a vaginal birth?

Mrs Moloney: Yes.

MRS DUNNE: Were you strongly committed to a vaginal birth?

Mrs Moloney: I was neither. On my very first appointment, I went in there saying, "I am happy to have a C-section". My obstetrician said, "You have a little one at home; you are going to have two newborns. Why don't you consider a VBAC?" That was her advice. It was never mine; I could not have cared either way. But it is more when you get to a week before you are supposed to be delivering these babies and the entire time you have thought that you are going to be doing it one way and then you are not.

THE CHAIR: By the sounds of things, you saw obstetricians more frequently during your twin—

Mrs Moloney: Yes. You mostly only see obstetricians. I think towards the end I saw a twin midwife, whatever that is. She performed a stretch and sweep, and said—

THE CHAIR: Can you explain what a stretch and sweep is.

Mrs Moloney: Basically, they go inside you, internally, and try to manipulate the cervix into thinking that something is happening. It works for some; it does not work for everyone. With my third one, I basically said, "Don't touch me again. This isn't happening; my body is not ready."

MRS DUNNE: So you showed no signs of going into labour?

Mrs Moloney: None.

MRS DUNNE: But at 37 weeks?

Mrs Moloney: I was having Braxton Hicks. They were not consistent at all.

THE CHAIR: When did you deliver?

Mrs Moloney: Just on 39, from memory. Term with twins is 37 weeks.

MRS DUNNE: The twin B birth was traumatic, and he was ill. What you described in your opening statement was that basically you were left alone without any sort of communication.

Mrs Moloney: Obviously, there was a very sick baby in the room, and I do not expect

that the attention was not supposed to go to him, because basically the whole room flocked to him. I do not know if any of you have had caesareans, but you are pretty much incapacitated: you are lying there; you cannot move your legs; you cannot really move at all, especially on the operating table. I knew he was sick—I could see—and no-one ever came to me ever. I get that, but all I needed was just one person to tell me that he was okay. I said to my husband, "Go and be with him. If he dies, he needs to have someone there." I remember that they were trying frantically to get me out of that room, the theatre, because they needed to bring the next person in. Thank God for some of the NICU staff. They said, "She's not going anywhere until we get her baby okay and she can see that. I don't care if you need to delay the rest of the surgeries for the rest of the day. Let her be here; let her see her baby." Once they had stabilised him to some extent, he was wheeled out, rushed, to NICU with my husband, and I was by myself.

MRS DUNNE: Where was the other twin?

THE CHAIR: Twin A.

Mrs Moloney: She was being monitored. They obviously check your twins; I do not want to say it is more thoroughly, but I think they are a bit more stringent with how they test your babies. She was not given to me until recovery, for whatever reason.

THE CHAIR: Sometimes you have heard that people receive their babies in the theatre? Is that correct?

Mrs Moloney: Yes. I never had that option, and I feel robbed of that. Obviously not my son, but both my daughters were healthy and fine and they should have been given to me.

THE CHAIR: I was not given my son either; I did not realise you were able to.

Mrs Moloney: Some women can opt for it. I think they sort of push. That is great—they are looking out for the health of your child—but there comes a point where it is "Give her to me."

THE CHAIR: You have just given birth to these babies.

Mrs Moloney: They never checked in with me to see how I was at all. They knew that my son was extremely sick. For three days there, and definitely the night of his birth, it could have gone either way.

MRS DUNNE: So the summation is that you did not feel supported?

Mrs Moloney: Never.

MRS DUNNE: Since you left hospital—you have now presented with these symptoms of post-birth anxiety and PTSD—what assistance are you getting?

Mrs Moloney: It happened six months afterwards, and I think it happened then because in those first six months you are just on autopilot: you have these two new

babies and you just have to keep them alive and love them.

THE CHAIR: And a two-year-old as well.

Mrs Moloney: Yes. As they started to get independent, I started thinking about it more. I have an amazing GP and an amazing psychologist, but again it was everything that I had to do on my own.

MRS DUNNE: What assistance did you get from home visits, MACH nurses et cetera?

Mrs Moloney: I got one from a MACH nurse.

MRS DUNNE: One visit?

Mrs Moloney: Correct. At home.

THE CHAIR: For the twins?

Mrs Moloney: Correct.

MRS DUNNE: And for your first birth?

Mrs Moloney: For Olivia, I got none.

THE CHAIR: I am sure that there are some more questions but we have completely gone over time. I would like to thank you very much for sharing your story with us and for taking the time to be here with the committee. When available, a proof transcript will be forwarded to you, to provide an opportunity to check the transcript and suggest any corrections.

Short suspension.

SCHLAGE, MRS KAREN

THE CHAIR: We will now move to our next witness appearing today, Mrs Karen Schlage. Thank you for appearing today and for your written submission to the inquiry. I remind you of the protections and obligations afforded by parliamentary privilege and draw your attention to the pink-coloured privilege statement that is next to you on the table. Could you confirm for the record that you have read and understood the privilege implications of the statement?

Mrs Schlage: Yes, I have.

THE CHAIR: Thank you. Before we proceed with questions from the committee, I would like to note that the committee has decided not to disclose the names of medical officers, including midwives and doctors. Witnesses will need to refrain from identifying medical officers while giving evidence. The committee has also decided not to publish the names of children. If you wish to disclose the name of your child, please remember that your evidence is being published on the Assembly website and will be made available. Would you like to make a brief opening statement?

Mrs Schlage: Thank you. I am very grateful to the committee for the opportunity to appear before you today. As you are aware, my submission deals with the loss of our son Charlie in October 2018. My submission is not a complaint about the care that I received. I received good medical care within the system as it currently exists. I did not feel unsafe at any time. However, I did keenly feel the inappropriateness and the loss of autonomy that came with some of my experience.

An emergency department or surgical ward are not the most appropriate places for a woman to labour and deliver any baby, but particularly not a deceased baby. A maternity unit is also not the most appropriate place, emotionally, for a woman to deliver a deceased baby. Referring to a baby using terminology such as the "products of conception" may be medically accurate but it does not reflect the way that many women think of their babies.

The ACT does not currently provide consistent, all-encompassing care during the loss of a baby. Clear, consistent, clinical pathways are required in all ACT hospitals that provide maternity services. These clinical pathways need to address all forms of perinatal loss at any gestation and must focus on both assistance provided over the telephone and assistance to a woman presenting to the hospital. The system itself must evolve and a facility dedicated to perinatal loss needs to be established. This is a facility where dignity, comfort, autonomy and the quality of life and death are at the forefront.

Unfortunately, there is sufficient demand in the ACT for such a facility. The most recent Australian Institute of Health and Welfare statistics indicate that there are, on average, 2.65 known perinatal deaths per week and up to 116 foetal deaths per week in the ACT and surrounding regions. The women of the ACT and surrounding regions must be afforded a facility that provides an active, holistic and multidisciplinary approach to care during the loss of a baby at any stage.

In order to progress this concept I have met with senior ACT Health, Canberra Hospital and Calvary hospital representatives, who support, in principle, the need for such a facility. I have met with the previous minister for health, who also supported, in principle, the need for such a facility, and who asked me to contact some senior people within ACT Health to draft a model of care concerning my proposal. I intend to meet with the new minister for health as soon as possible, in the hope that the new minister will also support this concept, in principle, and will support my approach to the officers recommended by the former minister.

I would now like to consider submission 20, which was written by a mother who laboured and delivered following a termination for medical reasons. Firstly, I wish to particularly note the mother's bravery in relaying her experience and to convey my heartfelt condolences to her and her family for their tragic loss. There are many aspects of this mother's experience that are absolutely unacceptable and which further demonstrate the lack of consistent holistic care in the ACT during the loss of a baby.

Many of these unacceptable aspects would be addressed through the use of a dedicated facility, with staff who are committed and trained to assist women and their families during any form of perinatal loss. These aspects include the provision of timely education and information for first-time parents in particular, regarding labour and delivery upon arrival at the hospital. There should be dedicated access for the woman and family to vital equipment and services during perinatal loss, including the provision of clothing or wraps for the baby, and the use of cuddle cots, photographers and access to social workers. And there needs to be more compassionate service delivery, irrespective of the circumstances of the loss. This includes understanding the stress and difficulty caused by carrying a deceased baby and ensuring that induction or other medical intervention occurs without undue delay. Compassionate care must be delivered without judgement by all medical and ancillary staff.

Pregnancy loss is still largely unspoken about within our community, but the lack of conversation and lack of awareness as to just how frequently it occurs do not mean that something should not be done to provide consistent and dedicated care.

I note here that the *Canberra Times* yesterday published an article regarding my proposal. Since then there have been hundreds of comments and indications of support for the concept across a number of social media platforms. Women are telling their stories, and some of them are horrifying. Babies have been referred to as "medical waste" and have been handed back to women in specimen jars. Women have spent days grieving in rooms on maternity wards, while listening to other people's babies and their happy celebrations. Following discharge from hospital, some women have been required to sit in antenatal clinics for check-ups, surrounded by pregnant women.

I know that the health system cannot protect grieving mothers from everything, but some compassion needs to be demonstrated in the face of such significant loss. I know firsthand the immeasurable grief that comes from losing a baby. I have also experienced the medically appropriate but emotionally inappropriate care that the ACT health system currently provides during pregnancy loss.

The system change that I described in my submission is progressive, but the ACT is

really good at being progressive. I therefore respectfully call on the committee to make recommendations regarding the establishment of a dedicated perinatal hospice to service the women and the families of the ACT and surrounding regions.

THE CHAIR: Would you like a glass of water?

Mrs Schlage: I will take a sip.

THE CHAIR: Forgive my ignorance but are there support networks currently operating in the ACT for—

Mrs Schlage: Yes, there is a variety of support networks. For example, I think that Red Nose and PANDSI have provided some submissions. There are a number of different bodies, but those bodies are largely involved once you have lost the baby. They are not involved in the process of delivering your baby or the initial stages of grieving for your baby while you are in hospital.

THE CHAIR: I read your submission and thank you also for your opening statement. From memory—I apologise if I have misunderstood this—there was not a lot of counselling or support whilst you were in the hospital?

Mrs Schlage: No. A social worker did come to visit me the day after. But in terms of—for me it was more about—

THE CHAIR: During.

Mrs Schlage: during and also advice about things like funeral services and things like that. They were things that my husband and I needed to explore for ourselves.

MRS DUNNE: You navigated that yourself?

Mrs Schlage: Yes, we did.

THE CHAIR: Using your own support networks?

Mrs Schlage: Our own network, that is right.

MRS DUNNE: Mrs Schlage, did you know that your baby boy had died in utero before you went into labour?

Mrs Schlage: Yes, we had been advised the evening before that—

MRS DUNNE: Right, so it was a very short time—

Mrs Schlage: Yes.

MRS DUNNE: But when that happened, what happened? How were you prepared for what would happen next?

Mrs Schlage: The plan at that stage was that at 9 o'clock the next morning we would

meet my obstetrician at the hospital in the maternity section and things were to have progressed quite differently. She would arrange for an induction and that would occur within the maternity unit. But we were also told that if my waters broke or if I started bleeding or anything like that, we should go to hospital. At 20 past 5 the next morning, my waters broke. We initially rang maternity. Despite the arrangements that had been made with my obstetrician, because of my gestation, which was only 15 weeks and three days, I did not qualify to be directly admitted to maternity. So I had to go to the emergency department.

One of the issues, which has since been rectified after I spoke with the directors of the relevant units, was that with some of the current clinical pathways, literally the paperwork for them was available at the maternity ward for pregnancy loss under 20 weeks, but it was not available at the emergency department. Yet the emergency department is the place you have to go to if you are at less than 20 weeks. They undertook to ensure that that clinical pathway paperwork would be available in the ED.

MRS DUNNE: But they have not suggested that a more appropriate clinical pathway might be that everyone who suffers pregnancy loss goes to maternity rather than—

Mrs Schlage: No, that is—

MRS DUNNE: That is not considered?

Mrs Schlage: No.

THE CHAIR: You just said in your opening statement that you are not sure that is the most appropriate—

Mrs Schlage: No, I think it is appropriate, obviously, in terms of the care there being dedicated to maternal care. But from an emotional perspective, to be situated in a ward where basically everybody else is celebrating and you are not is extremely difficult. There have been many women in the past day or so talking about the experiences that they have had. They talk about basically being in a silent room with their family and hearing everything else down the corridor.

MRS DUNNE: You have also done a lot of work in this space in the past few months. I congratulate you on that. You have used this as an opportunity to make improvements. You described labouring in a cubical in accident and emergency. I have had other feedback from people who perhaps miscarry earlier in the process, but doing it in that sort of fairly open public environment. Have you had much conversation or feedback from people in that category about how that might be done and handled more appropriately and more sensitively?

Mrs Schlage: Not in a specific sense in terms of changing the approach within the ED. Most of my discussions have been around the idea of having a dedicated facility. It has been nice to see that in terms of those discussions people have not really been trying to turn that back to, "Let's change this or that here or there." People are still looking at this as a positive potential.

MS LE COUTEUR: Did you see the dedicated facilities being collocated with the Canberra Hospital?

Mrs Schlage: Yes, following the discussions that I have had with the hospitals, I think that it would have to be. You would need to allow very quick access to theatres in case somebody needed that—if there were a retained placenta or something like that. You would also want the skills and the expertise that are available within maternity to be available to the facility—

THE CHAIR: Nearby, yes.

Mrs Schlage: but just not in the maternity unit. I describe in my submission that I volunteer at Clare Holland House. It needs to have that sacred space the same as Clare Holland does. It does not need to be freestanding, but everybody needs to know why they are there. That includes the staff, the visitors and the people who sadly need to attend. But it is a place dedicated to looking after them and making sure that their quality of life and death is—

THE CHAIR: Thank you so much for speaking to us today and for sharing your story, your experience—

MRS DUNNE: And your thoughts—

THE CHAIR: and your thoughts on perinatal needs. When available, a proof transcript will be forwarded to you to provide an opportunity to check and to suggest any corrections should they be required. Again, thank you for appearing today and I would like to thank all witnesses for appearing today.

MRS DUNNE: Thank you very much.

The committee adjourned at 11.10 am.