



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, AGEING AND COMMUNITY SERVICES
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Submission Cover Sheet

Inquiry into Maternity Services in the ACT

Submission Number: 47

Date Authorised for Publication: 19.09.19

The Committee Secretary
Standing Committee on Health, Ageing and Community Services
Legislative Assembly for the ACT
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Dear Committee,

Re: Inquiry into Maternity Services in the ACT

Thank you for the opportunity to provide a submission into your enquiry into maternal health services in the ACT.

My submission relates to the following terms of reference:

- Models of care for all maternity services offered at the Centenary Hospital for Women and Children (CHWC) and Calvary Public Hospital (CPH), including, but not limited to, the Birth Centre, the Canberra Midwifery Program, and the Home Birth Trial and whether there are any gaps in care;
- Provision of private maternity services including centre and non-centre services;
- Management of patient flow, including, but not limited to, wait lists, booking services, and capacity constraints;
- Management of patient birthing preferences, including, but not limited to, professional advice offered to patients, and the practices associated with birthing emergencies;
- The efficiency and efficacy of maternity services;
- Patient satisfaction with the services;
- The impact on staff including, but not limited to, rostering policies and practices, staff-to-patient ratios, optimum staffing levels, and skills mix;
- The impact of technological advances and innovations;
- Relevant experiences and learnings from other jurisdictions; and
- Any related matters.

Background

I gave birth to twin boys who were at 24 weeks and 3 days (K) and 25 weeks (T) and who both passed away in the Centenary Hospital for Women and Children at Canberra hospital in 2015, 12 hours and 36 hours respectively after birth. Am currently pregnant with my third son.

This opportunity to make a submission is a not an easy one as it requires treading down a difficult path. However, I could not waste this opportunity as this is the first and possibly the last chance I may have to be heard about my experience with the maternity and allied services in the ACT. I hope it is not the final opportunity I have to help other future parents.

The focus of my submission will be on the treatment of mothers in the system and hope to provide some options for improvement of care provided. As I am no expert in the care of premature babies, I have no choice but to defer to trained, professional people who work in a

difficult environment every day as to whether the care provided to my boys was appropriate and not detrimental to the outcome.

Connection with fertility service providers

My sons were conceived through IVF and my experience at the time and now is that there is limited to no connection between the IVF clinics, the private service providers, and the public hospital system. For the IVF clinics, most view their role in the conception process as completed a few short weeks after confirmation of pregnancy.

There is limited information provided through the clinics about the public health system and pathways for antenatal care. I recall the clinic provided a one page black and white photocopied piece of paper about what foods to eat and avoid and useful websites. As a first-time mother, I had no idea how to navigate the health system. Internet searches were all I had, but these did not help identify what service was right for me. I wonder whether because women have gone through the IVF clinics there is a pre-conception that any care we choose after will continue to be through private pathways.

For this reason, I would recommend greater connection between the public health system and these IVF providers to ensure seamless transfer of care and information to parents for options of care.

Antenatal services / Information sessions

Through the public health system, at the Centenary Hospital for Women and Children, I was enrolled in the Twins Clinic. Phone calls prior to being accepted into the Twins Clinic often went un answered – I would estimate 90% of the time. Over the course of 12 weeks the planned care I received included: a meeting with a midwife for 30 minutes (after long wait), a doctor for 15 minutes (after long wait), another doctor for 15-30 minutes (after long wait) and exercises program for 45 minutes. That is a total of 1 hour planned medical care in 12 weeks.

No scans to determine cervical length, no blood or urine tests – all significant factors in premature birth and would have been valuable – especially given this is a high likelihood with twins.

The most extensive of the appointments being the second doctor who asked much more detailed questions than the first doctor who should in fact have been the one to ask these pertinent questions and taking measurements, but for some reason neglected to do so. My overwhelming feeling at the time and today is there was a laissez faire attitude towards patients. Maybe it was that first doctor's years of experience, maybe it was fatigue, I do not know, but communication, detailed care and conveying of information, as am sure you have received in other submissions, was grossly inadequate.

Pre-admission

Two to four weeks prior to my admittance to hospital, I presented myself to the Emergency department at least twice and another service (the exercise class I believe).

The first time I attended was regarding severe pain in my lower back, lower abdomen and outer thighs. No scans were taken or suggested. The doctor was reluctant to take an internal exam and I was told I could go home and to take aspirin. The second time was regarding the same issue with blood spotting and I was referred to the hospital physiotherapist, who I saw.

On reading my patient records, it states I indicated my pain level as an 8 out of 10. Two weeks later, my membranes ruptured, my waters broke and I went to the hospital in labour. To this day I wonder why I was not referred for a scan to find out if these were, what I now know as clear, indications of pre-labour, via a cervical length test and more managed care would have hopefully followed.

On arrival at the hospital the night my waters broke, I had no idea what contractions or braxton hicks were (although I was continually being asked by nursing staff during my stay which one I was experiencing). I had no idea that my waters had broken but I was bleeding and knew that was not a good sign. I was constantly expected to have answers to questions related to birth for which I could not possibly answer.

For this reason, I would ask that antenatal information sessions be not limited only to those parents whose babies have reached a certain gestational age, e.g. 26 or 28 weeks. I wonder how many children would have survived if parents had access to information sessions before pregnancy and in early pregnancy. I would strongly recommend consideration of early or pre-pregnancy information sessions especially given premature birth is a leading cause of infant mortality.

Categorisation of high-risk patients

One of the questions I had when I returned to the hospital after the death of my sons for the interview was, why was I not categorised as a high-risk patient? No answer was ever given – just silence. I did not even know there was a pathway for such patients until that meeting. I was over the age of 35, I had a twin pregnancy and conceived through IVF – individually all are risk for prematurity and combined I would imagine were a clear signal of increased risk of complications.

For this reason, I would recommend pre-emptive access to high risk services for patients such as myself – as opposed to waiting for a pregnancy loss or condition to show in later pregnancy in order to access these services.

I would also ask the Committee to consider access to increased frequency of scans for women at high risk or with a multiple pregnancy.

Birth and care during stay

My overwhelming impression is that any kindness or compassion shown to me during my time at the hospital was due to individual nurse who had that as a personal trait rather than a foundational professional practice. In the 10 days in hospital, I was seen to by at least 10-15 different nursing staff – a clear possibility of inconsistency of care. I am a pretty amenable person and defer to experts, yet I often felt treated by doctors and nurses/midwives at best as a body and at worst as a nuisance.

There was no regular communication about what was happening, decisions that were being made and why. I felt I had no say in the decisions being made about my care. When and if a doctor saw me, I believe I met two different doctors in 10 days, three times. I had a maximum of 5 minutes with the second doctor, whose name is all over my records, after the birth and death of my second son and only after I insisted to speak to someone. For example, a decision was made not to "stitch me", but to wait and see. I understand this may have been to avoid possible infection to me or the boys, but I did not know this was a choice and was never asked.

All that was done for my care was blood tested and temperature checked – it was a routine. I was a body and not a person. I recall in the birthing suite, sometimes hours would go by before a nurse would see me. Often, I bled into the plastic disposal mat and would sit in blood until I was able to move, or my mother visited and I could get another one to replace it.

Post-birth

After the birth of my first son (K) and still pregnant with my second (T) with contractions coming and going, I was moved to the post-natal ward, alone, in a bed with a broken buzzer for the entire day, which meant if I did require attention or was going into labour, there was no way for me to contact the staff. I mentioned this to the nurse on hand at the beginning, but nothing happened. Luckily my mother and friend arrived at the hospital in the evening to keep me company.

I believe I was wheeled between the birthing room and postnatal approximately five times during my stay (a couple because the birthing room was needed).

The only time I felt true care was shown was for my sons, by a midwife in the NICU who, I would imagine because of her years of experience, took it upon herself to take countless photos of my sons when I was away either in the birthing suite or post-natal rooms. Today I have tens of photos of them and also of me with each of them when they were alive or had passed and I was bathing them – only because of her care. This midwife also arranged for the precious boxes and clothes provided by SANDS. I will never be able to thank her enough.

The NICU nurses were incredibly professional during my sons' stays. I did not doubt that they were doing their best for them. I recall what I can only state as a swarm of people coming in to my birthing suite each time they were needed. What was disconcerting was I was often then left alone. From a room of 7 people to no-one. Am not an expert and cannot state whether decisions taken aided my sons or were incorrect at the time, but I can say the staff were very professional and efficient in what must be one of the most difficult jobs.

For this reason, my recommendation is improved communication with patients. Greater empathy and more staffing. Neither of these can occur overnight, but may improve patient outcomes.

Welfare and psychological services

Pastoral care was limited and inconsistent. When I was wheeled to see my first son (K) in NICU – the first thing a nurse said to me was, your son is very, very sick. A few minutes later she asked if I would like to have him baptised. An odd question given my surname that is specifically of another religion, but a kindness I now understand because instantly I comprehended the gravity of the situation as one where I had to prepare myself to say goodbye.

When my second son (T) passed away six days later, I was offered a visit from the hospital social worker, who stayed with me for 15 minutes and unfortunately had to leave because she was required by another patient. I believe she was asked to visit after my first son passed, but was unavailable due to high demand during those days.

Someone from psychological services came to see me for distress after the death of my first son and birth of my second. My recollection of that time was the psychologist suggested I go through mindfulness exercise as a way of calming myself – “imagine you’re stroking sand like the lines you see in the pot of bonsai plants” was the advice I received.

The hospital kindly contacted SIDS and Kids, as they were known at the time, and put me in touch with a support worker who called and offered to specifically help me with the funeral arrangements. After several attempts, I was unable to reach that person and she did not return my calls until the weeks after the funeral. I arranged the funeral alone.

For this reason, I recommend improved support services during hospital stay and post hospital release.

Post-hospital care

Post-hospital care was non-existent. I recall I had to call the hospital several times in the days after leaving because they had failed to call me, as required, in order to check my condition to make sure I was not physically unwell and not suffering any potential health issues. Definitely no home visits for me. The lack of interest and condescension is something that is difficult to comprehend to this day.

After the leaving the hospital, I offered to partner with the hospital to write information sheets (given my professional background) for patients about premature rupture of membranes as it may be useful for other parents admitted or those who attend clinics or emergency. The head midwife agreed and stated it was a good suggestion and we should work together to produce one. Subsequent emails and phone calls to this person went un-returned or without a reply to this day. Am happy to share this communication if ever required.

For this reason, I recommend information sessions earlier in pregnancy or information sheets on a variety of topics be provided to patients who present to emergency with pregnancy-related conditions.

Record keeping

The record keeping is.. appalling. Last year I requested the records of myself and my sons. As the entire experience had been quite traumatic, I felt that it would help me to review what happened from “objective” records”. What I have found is that:

- On discharge from the hospital, the patient sheets I received about my sons had so many blank / unfilled spaces or did not include a child’s name or other information. This showed a complete disregard for their existence and have often wondered whether staff felt so little of them and of me that they could not be bothered to capture correct information.

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- Records related to my first son (K) are listed under my second son (T) and vice versa (this matters because they were born 4 days apart and their conditions and treatments were completely different).
 - Records relating to the date and time of the birth of my second son (T) are completely inconsistent. Some notes in the records under my name and (incorrectly) under his brother's name indicate he was born on the 7th, while others state he was born on the 6th. This is disconcerting as my record states I received some treatment or was observed on the 6th and 7th before his birth when in fact he had already been born. You can imagine my distress also at wondering whether the date I have on their headstone for his birth is now incorrect.
 - On the record for my first son K (incorrectly identified as T), a midwife or doctor was asked to write a retrospective note over a month after my son died because there had been discussions during one of their meetings that the timeline of the record of events / actions that evening after he was admitted to NICU were not clear. You can also imagine my shock on reading this note that stated that the "Baby Doctor" had left the hospital 1 hour after my son had been born with extreme prematurity and had to be called several times for advice on what to do. They had called the doctor two to three times in order to extract blood for testing (he died from bleeding due to pricks being made to his skin to extract blood and a suspected brain haemorrhage which was never proven as the doctors did not take him for a scan as the scan was unavailable). Leaving me to wonder who was in charge of his care during this time while I was still in the birth suite waiting to see if I would give birth to my second son that night also.

I would strongly recommend improving patient care records for transparency, respect, governance and professionalism.

Another thought I have often had is whether my race played a part in my treatment. Whether it being the disregard of the seriousness of the pain I had presented at hospital on multiple occasions or care during my stay. It is a thought too difficult to reckon with, but I know from studies in the United States and other Western countries that mother and infant mortality of those from non-white backgrounds is significantly higher than for those who are white.

I would strongly recommend cultural safety, bias and patient respect training.

As you may (or may not) imagine, the experience and trauma of giving birth to and losing two children in the course of 10 days is horrific. Sadly, this pain was compounded by the lack of care, compassion and what I perceive as indifference, that I experienced during my stay. The notes above are only a small portion of what I experienced, one which ultimately led me to leave the ACT.

Being pregnant again, I am often asked if I would return to Canberra to give birth. I categorically state no. I would love to say that all my children were born in the same hospital, but sadly, there is no way that I could return to that building and the organisation that runs it. I hope for the sake of other parents that things have changed.

Thank you again for this opportunity and I wish the Committee well.