Submission No 225

INQUIRY INTO BIRTH TRAUMA

Name: Sharon Coulton Stoliar

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Today, on 3rd August 2023, I make this submission to the Parliament of NSW Inquiry into Birth Trauma as a midwife turned mother, sharing a deeply personal journey that changed the course of my life. Like for almost all mothers, the birth of my son was a pivotal moment for me.

My submission draws attention to the cost of not listening to women, and the long term consequences of disrespectful maternity care. To highlight the need for policy change, I need to provide some context into what happened during the birth of my son.

I was a midwife before I became a mother. His entry into the world was marked by 16 hours and 51 minutes of established labour, culminating in an emergency caesarean section due to what the medical world labels a "failure to progress."

Within 24 hours of giving birth, I developed an acute compartment syndrome in my right lower leg. A rarity during the postpartum period, this condition demanded urgent intervention – a life-saving fasciotomy – to prevent further damage and the unthinkable prospect of amputation. Despite its gravity, the definitive diagnosis eluded my doctors until day 10, even though a neurologist had suspected it on day 2. By the tenth day, the window for surgery had closed. By this time, all the damage had already been done.

As a direct result of the delayed diagnosis, the peroneal nerve that runs down to the big toe is dead from the point of the knee because it was crushed from the increased pressure in the compartment. Most of the muscle in the anterior compartment in my right lower leg is scar tissue. I developed severe contractures in my toes and ankle and later in 2013 required tendon lengthening surgery. Because the nerve was damaged, my balance was significantly affected. My ankle would roll in a lot and I would fall, maybe 5-6 times a day for the first year and a half, unless I was extremely careful. To this day I don't have any control over my big toe, it drops and I trip over it if it catches on an uneven floor surface. But I don't fall nearly as much these days because my body has learned to adjust and compensate for it.

After 15 days in hospital, I got discharged home with a foot drop splint and a rollator frame, with a new baby. It was a horrible feeling to need a rollator frame at the age of 26. Wearing the foot drop splint meant buying two pairs of the same shoes so that the bigger sized shoe would allow space for the splint.

Because of how severe the deficits were in my leg, I wasn't able to stand up and hold my baby, or walk safely with him in my arms, or even get up and go to the bathroom myself. I needed help with every single thing. All I could do was breastfeed my son, and thank God I at least had that to cling on to. I couldn't do anything else for him. And that was soul crushing to me.

father, was working night shifts at the time and didn't have much time off. Clearly, I couldn't look after my baby, and someone needed to look after me. So the only option we had was to move into my parent's home. After the first visit to the orthopaedic clinic, the orthopaedic registrar who saw me wasn't sure if I'd ever be able to walk without a foot drop splint. We didn't know how long recovery would take.

Any couple who has become parents would understand what it is like to try to transition from being in a couple to new parents with a baby. Instead of what should have been a beautiful transition into motherhood, to me it felt more like I was transitioning back to being a dependent child. dependant on everyone for everything. It was a real shock to my system to lose all my independence.

Over the years, my left side has learned to carry more of my weight and compensates really well for the weaknesses in my right side. As a result, the muscles in my right leg and the whole side is weak unless I continue with strict exercises and physiotherapy, to stop the muscles wasting away any more than what they already have. My orthopaedic surgeon says that I will likely have to work at keeping my right side strong for the rest of my life otherwise my ability to keep my balance will deteriorate. Despite needing ongoing physiotherapy to this day, my recovery and continued gains in strength has been remarkable.

While there are definitely some physical deficits and consequences, like the development of arthritis in my foot, it is quite miraculous just how well I can walk now, considering I could have lost my leg.

It’s now been almost 12 years since this all happened and you can’t tell anymore just by looking at me and how I walk, that I live with physical pain every single day. Each step I take hurts. It hurts to drive for more than an hour. It hurts to stand for more than 30 minutes. And while my son was younger, it would hurt to jump and run and do all the fun, crazy things that kids like to do with their mummas.

But every single time I feel the pain in my leg and foot, I know that it is nothing short of a miracle that I still have a leg to feel the pain in. And that I didn’t develop renal failure. They said that because I had age on my side, and that my peripheral circulation was so good that it kept my leg alive. I am thankful to God that I still have my leg, that I can still walk and drive and live my life.

Nothing could have prevented the compartment syndrome from developing but listening to me could have significantly changed the outcome. I often thought that maybe if they listened to me, I could have had the surgery that I needed, in time, and I wouldn’t have the physical restrictions and pain that I have lived with for so long. Maybe.

When I first complained of pain in my leg, the morning after the caesarean, my right leg was markedly swollen compared to my left. I had an Obstetrics and Gynaecology (O&G) review and a resident came to assess my leg. She said all the usual things: mobilise and then elevate my leg, use a heat pack, use an ice pack, analgesia, etc. She concluded “you must have bumped it in labour. Many women do.” Although I told her I hadn’t, she didn’t seem to want to listen to what I was saying. It was condescending. I now know that this was obstetric gaslighting.

I just felt so frustrated because she wasn’t taking me seriously. My Midwifery Groups Practice (MGP) midwife came to visit me later that afternoon and I asked her, just to make sure that I hadn’t completely lost the plot. I had begun to second guess myself. Had I bumbed my leg? Did something happened that could explain this worsening pain in my leg? Had I passed out during labour? I was questioning my own reality. This is what happens in gaslighting.

But even my MGP midwife confirmed that I had not bumped my leg. I didn't know what to do. All I knew from my experience as a midwife, as short lived as that may have been, was that this wasn't normal post-caesar oedema or pain.

Throughout the rest of the evening, on the afternoon shift in that hospital postnatal ward, I had a midwife who made it very clear to me that I was just another bed number on her handover list. I could sense that I frustrated her because I was constantly telling her that the pain was worsening, and I was constantly needing to press the patient buzzer because I couldn't do anything for myself. I could feel that she expected me, especially because I was a midwife, to just get on with it and not complain. And believe me, that was all I wanted to do. Because a busy, noisy postnatal ward was not the place I wanted to be in after having my baby. It was a workplace for me. This was not a place where I wanted to experience my early days of motherhood. I didn't have much of a birth plan but the only thing I wanted was to push my baby out and go home within 4 hours. This was all I wanted. I was there for 15 days.

As that afternoon shift progressed, I kept complaining and my ability to walk and weight bear continued to deteriorate. But she wasn't doing anything about it. She would answer the buzzer and either roll her eyes, or in an exasperated tone, "what do you need now?" And I could tell that she was annoyed with having to deal with me.

I needed pain relief but the pain relief wasn't working. I needed someone to pick up my son when he cried and pass him to me. And that annoyed her. She was sighing, rushing in to cancel the buzzer with all the body language of frustration. I could tell. I could read body language just like many other women who come in and watch the way we provide care for them. And I knew that language well because I remember with guilt and shame, the times during some of my busy shifts when I had behaved just like that.

At the time of the first O&G review at 2pm, I could still weight-bear but by the end of the afternoon shift, I couldn't weight-bear any longer. The swelling had worsened, I had a burning pain down the front of my leg and the skin was tight and had turned a shiny red colour. I was seen by an O&G registrar on their afternoon rounds but they only assessed my caesarean wound. They didn't seem interested in assessing my leg because it was looked at in the morning... and deemed a muscular injury from a bump to my leg.

I kept telling that midwife that the pain was worsening but for some reason I don't think she really believed just how much pain I was in. I didn't get the feeling that she believed me at all. I think she just saw me as lazy and not wanting to get up or do anything for myself.

Overnight, the pain had got so bad that I needed to pull my TEDS stockings off. My mum was in the room with me and helped me take it off. I still remember the moment like it was just yesterday. My leg instantly ballooned. It was the most agonising pain I had ever felt in my life. Nothing helped with the pain. At least with labour, I got a break between contractions. But with this – not even a second to breathe. It was constant. They tried to reposition my leg on a pillow, they tried to put an ice pack on it. It didn't work. The pain was agony. I just wanted it gone. Just to have a leg was painful. If I had a knife with me, I would have cut my leg off myself. I was crying. My foot was curving inwards and I had lost control of it- I had foot drop. I couldn't move it. I couldn't move my toes or ankle. I couldn't lift my leg up. I couldn't let them touch it. It was raging red. You could see the red on my brown skin.

It was swollen like I had never seen before. I was petrified because I didn't know what was happening to me, and I just wanted the pain to go away. They got an urgent O&G review in the middle of the night. The registrar couldn't even touch my leg because of the pain. Every time she laid a finger on my skin, I screamed. She took some bloods, started me on antibiotics and put it down to cellulitis. They gave me 7.5 mg of subcut morphine. 15 minutes later it hadn't touched the pain. An hour later, I remember telling the midwife that it still hadn't touched the pain. I was still crying in pain but the registrar had said to give it even more time to work. I couldn't understand why they weren't doing anything, why they weren't listening.

I remember thinking, "wasn't morphine supposed to work sooner than this?" Somewhere in my clinical brain, I knew that morphine should work sooner, but in that moment of extreme agony, I just couldn't articulate it. I couldn't think straight to question it at that moment. Because it was non stop, excruciating, muscle and nerve crushing pain that did not end.

Didn’t they believe the agony I was in? It’s not like I was making it up. It was visible that something serious was going on.

Skip to day 9. When the neurologist saw me for the second time, I finally got an MRI confirming that I had in fact had an acute compartment syndrome. And all while this was happening, over the course of my hospital stay, I was becoming more and more depressed because I wasn’t coping, I was in a lot of pain, I was bedbound, needing to use bed pans, and I had this beautiful baby boy in a cot beside me whom I couldn’t do anything for. I felt like a failure of a mother. I felt like a failure of a midwife. I felt useless and hopeless. All I was good for was breastfeeding.

And I felt like I had lost my identity. I wasn’t allowed to speak up as a midwife, with my own knowledge because if I did, I was afraid that I was being mocked and that they would be thinking “oh it’s that midwife who thinks she knows everything.” I was afraid to make a fuss, to rock the boat. I suppose as women, society somewhat expects us not to rock the boat or be loud or demand the care that we need. While on the one hand, I didn’t feel allowed to use me insider knowledge to speak up and advocate for myself, on the other hand, when the diagnosis was given to me, it was as if they relied on me to use my own midwifery knowledge to sort myself out. When I was finally given my diagnosis in the middle of the night by an O&G registrar I had never met in the preceding 10 days, she came in and said: “you’re nurse-trained aren’t you?” I said yes. “You have compartment syndrome but you probably know more about it than me. The surgeons will see you in the morning.” As she was walking about, I remember asking her, as ridiculous as it may sound, “will my leg burst open between now and when they come to see me?” and she responded “I sure hope not.”

And that was that. When that doctor left the room, my mum who was staying the night with me, asked me what compartment syndrome was. All I could do was cry. I pulled up the Wikipedia page on compartment syndrome on my phone and just handed it to her, and cried some more because I was terrified of losing my leg. There's a lot more to the story of my 15 day hospital stay following childbirth, but I have written all about this in my book, Scars of Gold.

In this submission to the Parliament of NSW, I want to emphasise the importance of the attitude of maternity care providers when providing care for birthing women, birthing people, and their families.

Nothing could have prevented me from developing a compartment syndrome, but listening to me, believing me, and taking me seriously, could have changed the outcome of the complication. I could have been seen earlier by specialists who could have performed surgery sooner and prevented the permanent functional restrictions and pain I now live with.

The way maternity care providers talk about women makes a big difference. I know "that" midwife was complaining about me to the other midwives in the handover room. I felt it. And when one of the other midwives that I knew came to see, I told her I don't want "that" midwife to look after me anymore. She reassured me that she won't be. I told her, "I bet she's always whinging about me in handover." And with a sad look on her face, she said yes.

But I didn't need her to confirm that to me. I already knew it was happening. Because I am guilty of having done the same thing when I was frustrated about the amount of times some women had rang the buzzer all night long. When I couldn't sit down for more than 5 minutes before another buzzer went off and they just didn't want to get up and do things for themselves. I remember thinking those horrible things. It was common to vent in handover to your colleagues. There is a culture within midwifery, nursing, and even medicine, to vent or complain about our patients to our colleagues in handover.

But let me make it abundantly clear. **That culture and attitude has a cost.**

Not listening to women has a cost.

I lost so many things that were precious to me as a direct result of this.

The last shift I worked before going on maternity leave was the last ever shift I did as a clinical midwife. Because of the balance problems that I have as a result of the nerve damage, my ankle still rolls in sometimes, I still do trip and fall. Even if now, it is only occasionally, I cannot risk that one time when I trip being the moment when I am holding someone else's newborn in my arms. No hospital would employ me knowing that I have permanent damage in my leg.

I can't even begin to explain how this affected my marriage. The pressure was enormous. We never really got the chance to adjust to the role changes under normal circumstances. Eventually the pressure from all of this significantly contributed to the end of my marriage. I never thought that the circumstances and consequences of childbirth could entrench itself so deeply that it could destroy the relationships that are so dear to you. I never thought I'd be a single mother doing this journey of motherhood on my own.

But I have had and still have the most supportive, loving and patient family. My parents and siblings have who always been there for me whenever I need them, and for them, I am forever grateful to God.

For me, it wasn't the agonising pain of compartment syndrome, or even the loss of my career or my marriage, as painful as all of it was. The physical consequences that affected my ability to carry my son, and provide care for him, challenging my identity as his mother, was what destroyed me the most.

Because I couldn't stand up on my own without help, my baby slept in my parent's room for most of the first year of his life. At night time, my dad would come to my room, help me walk to their room, I would breastfeed on their bed, and then they would help me walk back to my room. I couldn't have him in my room because when he cried at night, I couldn't stand up and carry him out of the cot to settle him myself. I missed out on all of that. I feel like I was robbed of those precious things that I so desperately wanted to do for him.

The thing that really crushes me, even to this day, is that when he cried, it was someone else who ran to him to pick him up out of his cot and settle him back to sleep on their chest, in their arms, not mine. Even though it was my own family, it still wasn't me that attended to his needs, except breastfeeding. It wasn't my face that he saw first when he cried at night, or even at daytime. It wasn't me, because I couldn't get up. I had to watch others comfort and reassure my baby. I remember working night shifts on the postnatal wards, putting other women's babies to sleep, rocking them in my arms, pacing corridors with them in my arms, longing for time when it would be my child I was putting back to sleep in my arms, against my chest. But when that time came, it wasn't me who did that for my child. With everything that happened, that is the thing that still causes me so much heartache. That is the thing that I still have a hard time dealing with and coming to terms with. Because I will never get that back. No amount of money from litigation will bring that back to me.

I felt like those early years of motherhood were taken away from me, simply because they didn't listen to me.

I want to share a few more thoughts with the Committee, to make bring attention to the urgent need for policy change and intensive education to maternity care providers on the impact they have on women and their families.

When I was wearing my work uniform and work badge, what I said mattered. My words carried weight. I had the power to make things happen. But the moment I was the birthing woman in that bed, wearing a patient gown instead of my work uniform- suddenly nothing I said mattered or carried any weight.

Even with my knowledge and background of midwifery, even with the midwives and doctors knowing full well that I was a midwife, because I had done my midwifery training at that very hospital, with those very midwives, and worked with those doctors. Even with all that, I felt like I wasn't listened to.

So how much harder is it for the woman who doesn't have the same knowledge and background in midwifery as I do? Despite having that knowledge, I still felt so vulnerable and disempowered, my life in the hands of these health care workers, some of whom I felt didn't truly care or want to listen to me. If it was that hard for me, then how hard must it be for the multitudes of women who walk through the doors of our maternity services, to be listened to, to be heard, to be believed in, and taken seriously?

When maternity care providers don't listen, they strip a woman of her power and identity. When they don't take her seriously, there is a cost. And this is happening to women on a daily basis, all across the state, country, and the world. The research is glaringly obvious that birth trauma is a public health emergency – a silent epidemic, that is sweeping through our mothers. And birth trauma from disrespectful maternity care is entirely preventable and it is imperative that something is done to educate maternity care providers on the power they have over women and their families.

When they complain about a woman in the handover room, they colour the other midwives' and doctors' perception of that woman, and could potentially affect the rest of her care. When they do that, (and they do this all the time), they take away her right to unbiased, non-judgemental, unprejudiced, woman centred care. I am guilty of having done this very thing to women when I worked as a midwife. But I have also felt the impact of this. That is the reason why I am sharing my story. When that midwife complained about me to everyone else, it affected how seriously they all took me when I kept complaining of pain. They were annoyed, saying to each other "she's complaining about her leg again." How do I know this?

I know that because that's what one of the O&G registrars told me. That is what other doctors in other medical teams, anaesthetics, infections diseases, had been saying about me.

Most maternity care providers will probably never see an acute compartment syndrome in a postpartum woman and I hope they never will. But they certainly will see a woman who presses the buzzer because her pain relief isn't working, because she can't get up and pick up her baby, because it's too painful and hard to walk to the bathroom, because she is struggling to come to terms with how her labour turned out and she doesn't know how to cope with it all, and suddenly she has a little human being relying on her for everything, and she is exhausted. When she presses that buzzer, she needs her midwife. And how that midwife walks in to that room to answer that buzzer really matters. Maternity care providers need to know this. They need to understand the significance of their actions. It might just be another shift to them, but for that woman, she will remember how she felt and how was were treated. She will remember for a very long time.

Even with being a midwife and having worked in the system, it was still so hard for me to speak up and have a say in the care I received. How much harder must it be for a woman who doesn't have the same knowledge that we do as midwives?

1 in 3 women experience their birth ad trauma. The literature has cited it to be as high as 48% of women around the world. And interactions with their maternity caregivers has a big impact on how they perceive their birth experience. Traumatic reactions to childbirth is an important public health issue. Considering the short- and long-term consequences of traumatic births that are well documented in the literature, I implore you to see it for what it is and do something about it. It is a public health emergency that must be addressed.

My birth experience changed the course of my life. It almost broke me completely but it didn't. Instead I have chosen to let it make me. Even though I sometimes do get emotional about it, I am not stuck in the place of my pain anymore.

But I want to finish my submission with an excerpt from my book:

On 12 June 2019, the day I was officially diagnosed with PTSD, I wrote the following entry in my journal:

Today, I was finally diagnosed with chronic PTSD relating to the events that took place hours after the birth of my son. It's taken seven and a half years to have the courage to see a psychiatrist. My healthcare providers have been trying to get me to see a psychiatrist ever since this happened, but I have resisted for so long.

I knew I had PTSD. It was obvious. But I just didn't want to go and see anyone. Over the years, certain events have triggered my severe reactions. When I had the tendon-lengthening surgery, I thought I could feel my leg swelling under the bandage. The rational part of my brain knew that it wasn't, but the paranoid part fully believed it was blowing up inside there. I was scared of *getting another compartment syndrome, but then again, there was that part of me that didn't want to cause a fuss and be 'that' annoying patient. I wanted to be the perfect patient after all the drama of being inside a hospital for fifteen days after giving birth and seeing how one of my midwives reacted to me, knowing how she complained about me in the handover room. This time, I wanted to be the patient that no-one could complain about. After all, I am a perfectionist. My need for perfectionism has slowly tamed itself the longer I have been a mother, but the perfectionist's ugly head rears itself sometimes. I remember before the tendon-lengthening surgery, I put on a brave face the whole time until my surgeon asked me if I had any questions, and I crumbled into tears, asking him if this was going to happen again. He reassured me and promised me it would not.*

Then there were the two pregnancies I had after the birth of my son. Although I desperately wanted to have another baby, 99% of me just freaked out about another compartment syndrome happening again. I became so scared and worried about losing my ability to be a mother to this new child if I had another untreated compartment syndrome, it was the only thing going through my mind. I was devastated when I miscarried, but there was relief, too. Because there was no way in the world I would survive another ACS and what it would have meant to go through all of that rubbish again. I couldn't bear to even think of having to lose my independence again, lose those early years of motherhood again, be a burden to everyone around me again, and go through all of it. I just couldn't.

One of my miscarriages ended up in a dilatation and curettage in the operating theatres because although my baby died inside me, my body didn't expel the foetus. I had to go under anaesthetic and have my baby removed. Shortly after that, I had to have another dilatation and curettage to investigate the reasons for having multiple miscarriages.

Before each dilatation and curettage, I freaked out on the inside about having my legs in stirrups—in the lithotomy position—because that is a known risk factor for developing ACS. My clinical brain knew that the risk for ACS is dependent on the length of time my legs are in the lithotomy position, but my PTSD brain wasn't able to reconcile any of that when it came to my absolute fear of ACS occurring again.

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Then there was the surgery I needed in 2016 to correct a deviated septum (really crooked cartilage in my nose). I wasn't able to breathe properly, so it was finally time to get this fixed. At that time, I hadn't had a panic attack in eight months. I had even just enrolled in a PhD, and I was fine. I had been totally and completely fine. And I believed that.

Then the night before the nose surgery, I flipped out and almost cancelled it. I was driving myself mad that night, worrying about developing ACS after the surgery. I called a friend, who talked me through it and calmed me down. But the next morning, while waiting in the waiting room to be taken into the operating theatre, I was so anxious that I cried there, pacing the room in a total fluster in front of everyone else waiting to be taken in for their operations. In the pre-op room, when they inserted the cannula into the vein of my hand and asked me my name and date of birth for the tenth time, I became hysterical again. The surgeon didn't know how to respond to me and said, 'I've never seen someone quite so anxious before such a simple procedure.'

In the hysteria triggered by being in that pre-op room again, taking my mind back to being in the pre-op room just before I had the caesarean, I couldn't care less what he thought of me. 'Promise me,' I demanded through tears, 'that you will keep an eye on my leg.'

'What do you mean?' he replied, confused. 'I'm not going anywhere near your leg.'

'I know that, but for goodness' sake, can you just tell me you won't let anything happen to my leg? I need you to say that you won't let anything happen to my leg; otherwise, you can't take me into that operating theatre.' I was a disaster.

The poor man looked bewildered, unable to understand where this fear was coming from. So I told him what had happened to me, and he finally understood my reactions.

When I woke up after the operation, the first thing I asked was, 'Is my leg there?' I didn't care about my nose. I didn't care how that operation went. I cared only about my leg.

Throughout the years, I would be 'fine' for a while. Sometimes, months would go by between panic attacks. But whenever I felt even the slightest pain in either of my legs, my thoughts went straight to ACS. It was completely irrational to the rational mind, but to the PTSD mind, it made perfect sense. If my leg was sore at night, I simply would not sleep. I couldn't sleep. I was too terrified to sleep. Why? Because of how the pain progressed in the middle of the night when the ACS happened. It started off with a dull ache and slowly progressed to the most horrendous pain I have ever experienced in my entire life.

Still, I had never seen a psychologist about my birth trauma. I can give you a million reasons why I didn't go to see anyone for help. And they all made sense to me at the time. I don't need help. I'm fine. I can do this. I'm strong. I don't have time to see a psychologist.

Life went on. My body started to compensate for the physical deficits caused by the permanent damage to my right leg. I lived in physical pain every day, and still do, but I just had to get on with it …

And get on with I did, until my son's surgery, when my carefully compartmentalised headspace came crumbling down around me. When he went into the theatre, I walked in

there with him. Seeing the big, bright lights above the operating table took me straight back to being under those lights when they did the caesarean on me.
Not too long after that, my son had to have another surgery on his foot, and I was retraumatised being in there. He wasn't coping, too. He was hungry because he had been fasting before the operation. He was screaming for food in the theatres. I held it all together in front of him, but the moment he was inside the operating room, all my emotions came out. I could feel I was emotionally slipping, barely holding it together. To make matters worse, I also had to have another operation. Within two months, we had been in hospital three times. It was freak-out central in my head. This time, the surgeon and anaesthetist knew my history, were both a lot more understanding about my fears, and promised me I wouldn't be in stirrups for too long.

I came out fine, but my head was still a mess to the point where I had lost my ability to empathise. I remember another woman in my church had just had a baby and suffered a horrible two-litre post-partum haemorrhage. Listening to her story sent my mind spinning, and I found myself needing to excuse myself from listening anymore.
What the heck has happened to me? Have I lost my ability to empathise? What have I become? I knew I needed to get my head sorted out. I was normally an empathetic and compassionate person, especially when it came to other women's birth experiences. I just couldn't handle it now. Finally, I knew that if I was going to be of any use in giving a voice to the women I was doing this PhD for, I had to sort myself out so that I could actually be of use and service to others.

I finally went to see a GP, who started me on medications for anxiety and what he said was postnatal depression … seven years on. My national survey for my PhD was soon due to be released, and I knew I couldn't possibly read about other women's birth stories. The GP ordered six months of urgent leave to get help and get myself back together. I was sent to crisis care with a psychologist and started treatment with a psychiatrist who specialised in PTSD in healthcare workers.