

Supplementary Submission

Since my submission I have undertaken further research in relation to our circumstances and would like to mention some additional relevant information. I have searched for NT clinical guidelines for the management of PPRM and preterm labour, questioning the care and treatment we received from the obstetrician. I have not been able to find any published online so will reference WA, QLD, SA and NSW guidelines to highlight the areas in which our care and treatment did not meet them. If similar guidelines are in place in the NT they certainly were not adhered to in my case. If there are no guidelines in place, it is imperative to have them established. I am also unsure if a private hospital operates differently in regards to set guidelines.

The QLD Perinatal care guidelines for conveying complex information include-

"holding conversations in quiet, private and physically comfortable spaces

involving both parents at the same time wherever possible

and including a person NOT involved with giving information who is able to support the family."

The SA guidelines also include "to sensitively counsel parents about realistic options and provide written information".

Being told over the phone that your baby will die or being flippantly mentioned that we could have been offered a termination if I was under 20 weeks, from an obstetrician you have never met while you are standing in front of the elevator doors to go to the maternity ward for observations certainly does not adhere to those guidelines nor did the way further information was delivered to us. The manner in which this phone call took place was an extremely traumatic experience that myself and my husband have relived many times highlighting why guidelines such as these are so important.

I do not know why the doctor would not prescribe medication to suppress contractions on the first night when there was no confirmation of PPRM at that time or signs or infection (or ever meeting me to make an assessment himself) but would like to note the utmost importance of ensuring these kinds of decisions are conveyed to a patient with detailed reasons to why, of which was not done in our case. I asked but was told "he will not prescribe anything". We felt completely powerless and are left with many questions. I wish I was aware of Ryan's rule at the time as I would have requested it.

After finally diagnosing PPRM with an ultrasound there was no mention of a suppressant plan and no real discussion of an expectant management plan. We were told our options were to wait for labour to progress on its own or assist it. I have discovered that the induction of labour in my situation is not in line with the VIC, SA and WA pprom guidelines. I was desperate to fight for our baby and I asked what if I got to 24 weeks which is the marker for viability. I was told even if I got past 30 weeks our baby would not be able to survive so it was a matter of when he would die. I have since found many stories (and whole facebook pages dedicated to this) of mothers who had PPRM before 20 weeks and went on to deliver healthy babies contrary to the medical advice we were given. The American allegiance of PPRM also cites research papers showing high levels of survival of successfully delivered babies after 24 weeks following prolonged PPRM between 18-24 weeks and states that gestational age at birth rather than gestational age at rupture is the key predictor of survival after PPRM. Given these findings, I do not understand why we were given a 0% outlook. If it was a lack

of knowledge it is imperative all doctors remain up to date with medical information. The SA Management guideline for PPRM before 23 weeks states “it is important to consult with neonatologists for up to date data to inform clinical decision making” and question if this was done. If it was not, I question how the option to induce labour of an alive baby that will subsequently end their life can be given without a second opinion.

While we made our decision to assist labour based on the medical advice we were given at the time, we now have to live the trauma and guilt we carry from our decision that took all chances of survival away from our baby, chances that we only now know may have been there. We will forever be haunted by numerous “what if” questions. We feel like there was never an attempt made by the doctor to try save our baby.

I have recently received my medical file after requesting it but want to make a note that it cost nearly \$100 to be given a copy of it which has been an additional sting.

I have read in the transcripts that the stillbirth payment has been discussed, and would like to mention we were unable to access the payment as we did not qualify for it. We felt that it was very unfair that it was income tested on the previous 6 months, which is by no means indicative of what is ahead, which in our circumstances was true with my business suffering after Elliott's loss and my husband lost his job a couple of months later. The payment would have greatly helped with the financial strain we were placed under. It also felt like we were not entitled to grieve because of our income. If he was born alive we would have been able to access a benefit, with the govt recognising the additional needs of a baby, so it is hurtful that it a payment is income capped when they die.