Committee on Reproductive, Maternal and Paediatric health services in Tasmania

We write to you as parents who experienced the loss of our son. Our son [redacted] was born on [redacted] at 23+6 weeks old. We share our story in the hope that we can effect change and assist those who will unfortunately be in the same position as we were. Our experience is not an isolated one, however, we hope that you will hear our story and act to implement change in our hospitals for families who's journey of birth is not one where their child returns home with them.

I wish to tell you the story of [redacted] and the impact he has had on our lives. [redacted] was conceived through IVF and genetic testing was undertaken for both myself, and my husband Adam. Our testing came back clear and there was no concern for the embryo, our son [redacted] My pregnancy was one that was difficult with daily progesterone to maintain the pregnancy and many trips to the hospital starting at 8 weeks.

Our obstetrician (OB), who I will not name owing to processes pertaining to the care they provided my family, advised that the usual 12-week scan could be undertaken between 13-15 weeks. Our scan was undertaken on 17 January [redacted] at Newstead at which time I was 14+2 weeks.

Following this scan, we received a call from our OB on the Saturday advising [redacted] NT measurements were large, and that we were to be seen for a second scan and opinion. On the Monday, a thorough scan was undertaken, and we were opined all appeared fine, and the NT measurements were within normal range.

Call it want you will, I however felt that something was not right and requested an amniocentesis. The decision to proceed with an amniocentesis was not undertaken easily due to the invasive nature of the test. After deciding to proceed with an amniocentesis, we were then faced with the added complication of the procedure being unable to be undertaken due to a rare complication of a retroverted/incarcerated uterus. After two failed attempts with an Obstetrician we were referred to, the complications started to cause myself issues at which point I was admitted to the maternity ward for 3 nights. I feel this could have been avoided, if the OB in charge of my care had taken the advice of another Obstetrician on how to resolve the complication in a quick and, considered to be a minor procedure where I would be placed either under general anesthetic or an epidural for a short time to attempt to correct the issue. Instead, my OB provided many options but did not act. Each time I advocated to have this procedure undertaken, my OB dismissed my requests and the concerns I held for the safety of my son. I believe the care whilst I was a patient in the Tasmanian hospital system should not have occurred. I wonder could the trauma experienced by our family have been avoided somewhat had there been a specialist panel for patients with complex pregnancies to be medically considered and reviewed? If there was board compiled, would it be reasonable to consider that this board is required to implement change and initiatives to avoid ongoing trauma that is being caused within the maternity unit of the hospital symptoms. For too long woman's concerns have been dismissed as part of their maternity care and birthing their children. Whilst I can appreciate that women carry and birthing a child may not have medical knowledge, we do know our own bodies and all too often, our concerns are being dismissed. This needs to change so women coming for care in the hospital system can have confidence in the care they are receiving and, that their concerns will be taken into consideration with care and compassion.

Following comprehensive testing of the sample taken on 15 February [redacted] through the amniocentesis, we received confirmation that [redacted] had micro-duplication of chromosome 14 which was likely disease causing, in addition to an extra chromosome. Furthermore, upon our 20-week scan on 8 March [redacted] we were advised [redacted] had a heart condition.

After collation of all information and further tests to confirm the chromosomal condition was not inherited and speaking at length with medical professionals, with their support, we made the incredibly difficult decision to end our pregnancy. There was a limited time in which to make this decision as if the pregnancy went to 24 weeks gestation, we would have required Tribunal approval. The care we received from our OB following our decision was atrocious along with incorrect advice given, for what we can only assume, was to scare us into changing our minds and making us wait until after 24 weeks whereby we would need to have Tribunal approval to proceed with ending the pregnancy. To this day, Adam and I remain convinced that our family would have ended up falling through the gaps in care afforded to us in the Tasmanian health system. Had it not been for the amazing care we received from

Dr [redacted] we would not have been referred to another Obstetrician in time. We hold grave concerns that we would have been pushed toward certain options that would have caused additional trauma for our family as we were only provided one option without consideration being given to seeking a second opinion or, case conferencing with other Obstetricians to consider viable options for our family in a timely manner. I hold significant concerns for future families who may be the in the same or similar circumstances to us and, they too have their concerns dismissed with substandard care and advise being given.

[redacted] was born via Caesarian section on [redacted] whilst I was under general anaesthetic. This was a choice by both Adam and I, after being through years of IVF and a stressful pregnancy with both our daughter and [redacted] we both could not handle giving birth whist I was awake and feel his life leave his little body.

Since we are located in Launceston and the Obstetrician we was referred to was in Hobart, we made the journey down and were admitted to the Hobart Private Hospital. Walking into the maternity ward, seeing baby pictures and hearing the cry of newborn babies, I wanted to be anywhere in the world than there in that ward. My surgery was scheduled late Friday night, being wheeled to the surgery room and leaving Adam our whole world came crashing down. I felt shame, guilt and tremendous pain. In the waiting bay for surgery, a midwife comforted me, whilst I said my final goodbyes to my son. Some may say we made the wrong choice, but we did the best for our son who would have only known pain.

Following the birth of our dear son [redacted] we were situated in the maternity ward, we had no idea where to start making memories that we would treasure forever. Whilst many families have a lifetime to make memories with their child, we had only a few days. Our experience of making memories is significantly different and consideration needs to be given to families like ours following the birth of their children. In the midst of our grief, we did not know what we needed or what we should be doing. We were given the options of photos, foot and handprints and molds which I will forever hold dear. Reflecting upon our experience, I have many regrets and wishes that cannot be changed. Weeks after [redacted] birth, our daughter started asking why she did not meet her baby brother? It was something we had not considered as it has not been suggested to us. Trying to explain to our then 3-year-old that her baby brother was no longer with us, that he would not be coming home and, that she will never meet him was excruciating. In hospital we were not provided with any information or resources on how to navigate these questions and our life after [redacted] We were alone in our grief with it consuming our every thought and decision. We strongly advocate that there are specialists available to sit with families in their times of grief to speak with that about options available to them and their extended families as to how to make memories with their child. Whilst many families make plans to introduce their child to their families following their birth, no one expects to be in the position we found ourselves and in light of this, we had no idea how to make memories or, how to introduce [redacted] to his sister.

This was also made all the more difficult owing to the fact we were on the maternity ward. The maternity ward is not designed for families like ours who are grieving the loss of a child. Whilst we cannot fault the care of the midwives who provided our care, being located on the maternity ward, there were reminders everywhere that this space was not intended for families experiencing loss. I chose not to leave my room as I didn't want to have continual reminders that I would not be taking [redacted] home with us. Further to this, I didn't think it was appropriate for me to leave my room for fear of impacting upon other families during their special time. I can appreciate that this may not have been the case however, in my mind at that time, this is how I felt. This was a particularly challenging time for Adam who was required to come and go from the ward witnessing families leaving with their children and happy family members coming to meet newborns.

The days following [redacted] birth, neither Adam or I were provided with any mental health care and as a direct result, my mental health declined dramatically. Whilst I can appreciate that this is hypothetical, I wonder had there been a designated mental health professional available to our family following [redacted] birth, would my mental health have suffered as significantly as it did had there been someone available. This is not something we will never know. What should never occur is families being left to deal with traumatic events such as the loss of a child by themselves and, when things go wrong staff are left scrambling to pick up the pieces. Due to being a weekend when complications occurred, I was transferred over to the Royal Hobart to be seen by the appropriate specialists.

In the weeks and days following my discharge, [redacted]). We were not provided with any information regarding what had occurred or, what to do next. Adam spoke with the funeral homes to organise the transfer of our precious boy whilst caring for me both physically and mentally whilst trying to feel his own grief and take care of our daughter. Fortunately for us our Obstetrician ensured we were back into the care of Dr [redacted] and the Bubble who called us the same day as discharge and organised appointments in the following days. In our appointments with the Bubble, we were provided with much needed mental health care for both of us, advice to tackle each day and invaluable resources. The first resource was the Bears of Hope information and secondly A Little Help from Jack. The Little Help from Jack is a resource which needs to be provided to each family suffering from loss. It provided help to us when we needed it more than ever, including appropriate books which we brought our daughter to assist her with her grieving process. The other resource kindly gifted to me was a care box from the organisation now known as Beyond the Rainbow. This care box provided special self-care and memory items for myself whilst also reminding me I wasn't alone.

Our story is impactful and, is but one of many within our community. In speaking with others, it's clear that our experience is not isolated and there are many who have an experience not unlike our own. I hold concerns that many women do not wish to come forward and share their stories as to do so, is once more traumatising and, they don't believe that the hospital will listen to their concerns owing to the dismissive treatment that received whilst a patient. In much the same manner as Queensland has Ryan's Rule, is there scope to consider a similar implementation for maternity services in Tasmania so that women who are hold concerns about the care they are receiving, can initiate this and a specialist panel are convened to review the patient? I appreciate that there may be a Care Call available within the Tasmanian Health Service however, resources regarding this were not made readily available to our family.

Reflecting on my story and our experiences of maternity care within the Tasmanian Health Service, we strongly advocate for the following:

1) A Board or Panel is convened to oversee all maternity services in each region, inclusive of both private and public patients.
2) Ensuring adequate support is provided to grieving families in hospital including midwifes trained in bereavement.
3) Mental health care is provided to not only the mother but also the partner immediately following the loss. If the care is declined a plan can still be in place if circumstance change.
4) A separate safe place for families experiencing all baby loss away from the maternity ward or, rooms for bereavement only which are designed for families to be able to feel comfortable and not in a clinical setting as they make memories.
5) Implementation of a rule similar to Ryan's Rule in Queensland or, highlighting the options available to patients to have their conditions reviewed by someone other than the health care practitioner providing immediate treatment if there are concerned regarding their care.
6) Ensuring an adequate discharge plan is in place from the hospital including follow up care and handover care to GP and/or mental health care provider.
7) Having all appropriate resources available in the hospital to be provided to families immediately, including both A Little Help from Jack and Beyond the Rainbow. Ensuring all maternity staff are educated and trained to assist with providing these valuable resources.
8) That woman's concerns about their body, and their baby, are taken into consideration as part of their care and not dismissed. That their concerns are addressed with compassion and empathy and not dismissed by health practitioners when a patient is advocating for themselves. Empowerment of women within the maternity system is vitally important to ensure that transparent and comprehensive treatment is afforded to all.

We cannot fault the care of the midwives that attended to us, along with the care and compassion of the obstetrician who undertook the caesarean. Those involved in our care following the birth of [redacted] deserve commendation for their empathy and compassion.

If you have any queries, please do not hesitate to contact me.

Kind Regards

Emma Deane