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Submission 96

16 September 2024

The Secretary
House of Assembly Select Committee on Reproductive, Maternal and Paediatric health services in Tasmania
Parliament of Tasmania
Parliament House
HOBART TAS 7000

Via email: rmphs@parliament.tas.gov.au

Dear Secretary

I write to the Select Committee in regards to my personal experience with the Tasmanian health system, both public and private, with regards to miscarriage treatment and support.

In early [redacted] I was subjected to numerous occasions of medical incompetence throughout the process of treating my miscarriage. The failings of the health system have left me with emotional distress that, coupled with the grief of the loss of my first baby, has resulted in considerable ongoing anxiety.

I know that I am not alone in my journey of grief after miscarriage, with 110,000 women each year who experience a miscarriage[1]. Therefore, I am writing this submission in the hopes that the mistakes I endured are not repeated for others in Tasmania.

Summary

In early [redacted] I was advised of a missed miscarriage of my 14-week baby (the baby had unknowingly not survived past approximately eight (8) weeks). Treatment resulted in a dilation and curettage, commonly referred to as a 'd and c', through the Royal Hobart Hospital (RHH).

Despite suffering from ongoing pain and bleeding after the procedure, my concerns were dismissed by a private practice GP. My concerns were also ignored by a private gynaecologist after getting concerning blood tests from an afterhours GP clinic.

It wasn't until I sought treatment at a private hospital that it was confirmed I had retained products of conception and a uterine infection. It was at this time that I transitioned my care to the private system.

A second dilation and curettage procedure was performed after days of antibiotics to control the infection. The result of being on significant quantities of antibiotics led to the contraction of a bacterial infection in my colon which required two lots of expensive antibiotics to get under control.

It would later be confirmed that I had suffered a partial molar pregnancy, where an embryo has too many chromosomes (two sperm fertilise an egg instead of one). Molar pregnancies are a type of gestational trophoblastic disease where tumors grow inside a uterus.

[1] Department of Health and Aged Care https://www.health.gov.au/ministers/the-hon-ged-kearney-mp/media/breaking-the-silence-on-miscarriage

Delay in diagnosis of the partial molar pregnancy after the initial dilation and curettage at the RHH was considerable, with no communication made until six weeks later that there was an issue, despite evidence that the hospital was aware of a potential issue when the private gynaecologist made contact with RHH after my second dilation and curettage had suspicious tissue.

When RHH finally made contact, it was to advise I needed an appointment to 'discuss my molar pregnancy'. If I had not already been seeking support privately, this would have been the first I had heard of a molar pregnancy. Essentially, I was provided a diagnosis on the phone by an administrations officer, who was unable to tell me anything further. It can be assumed that anyone would then 'google' their diagnosis once off the phone, where they would find that molar pregnancies can lead to cancer requiring chemotherapy.

It is unimaginable pain to miscarry, but coupled with the thought you might have cancer as a result of the pregnancy carries further agony and anxiety. One should never be told that they have suffered a molar pregnancy over the phone by an untrained medical professional who cannot provide support and answers questions.

I was fortunate to be seeking private medical support, but for those less fortunate, this is unacceptable way of finding out that one has miscarriage complications.

I was lucky and after weeks of regular blood tests monitored by the private gynaecologist, I was cleared of my molar pregnancy in [redacted].

Reproductive health service failures

- Failure of RHH to properly advise of potential retained product risk from procedure.
- Failure of RHH to undertake the procedure on the scheduled day, with inadequate communication causing significant mental stress, undue anxiety and suffering.
- Failure of RHH to provide mental health support for a miscarriage, to support patients dealing with grief and minimise anxiety, depression and shame that often comes with a miscarriage.
- Failure of staff to discuss discharge documents appropriately, particularly given the emotional nature of the procedure.
- Failure of RHH to discuss the outcome of the procedure with the patient. This included complete absence of contact either prior to or after the procedure from the surgeon/doctor.
- RHH failed to properly undertake a dilation and curettage resulting in retained products of conception and uterine infection.
- It can be assumed that if the significant antibiotic treatment for the uterine infection hadn't been required than the subsequent Clostridioides difficile infection would have never occurred.
- Failure of private practice GP to consider possible issues with the initial dilation and curettage procedure despite my explanation of continuing severe pain and ongoing bleeding.
- Failure of private gynaecologist to take action on the possibility of retained products of conception, leaving patient to go into the weekend after 14 days of pain, ongoing bleeding and test results that showed likely retained product.
- Failure of RHH to make contact for six (6) weeks that there was a molar pregnancy diagnosis. Despite the private hospital reporting initial results in nine (9) days.

- Complete failure of RHH to communicate diagnosis of molar pregnancy in a professional and supportive manner.
- Overall there was a series of failures which led to an increase in hospital visits in a health system already at capacity. If the initial dilation and curettage had been performed adequately, and other various medical practitioners had not dismissed concerns, the number of visits and cost to the health system would have been significantly reduced.

Individual outcomes

Note that all of the individual outcomes below could have been avoided had the RHH performed the initial dilation and curettage adequately, and other various medical practitioners had not dismissed concerns raised by me (as the patient).

- Ongoing medical anxiety including extreme anxiety in relation to personal health requiring treatment of daily prescription medication and ongoing support from a psychologist. I also note that this experience had a considerable toll on my partner who supported me through these failings. He too suffered anxiety as a result of this experience.
- Considerable amount of leave from work. This included time off for ongoing pain post the first dilation and curettage, time off for hospital admission for the second dilation and curettage and both bouts of Clostridioides difficile infection. Ongoing regular days off for anxiety about potential reoccurrence of the symptoms of Clostridioides difficile reoccurring at work (sudden onset diarrhoea).
- Significant personal financial cost, including:
  - Afterhours GP appointment
  - Private hospital emergency department fee
  - Private hospital admissions fee (excess from private health)
  - Private gynaecologist fees for appointments pertaining to the second dilation and curettage
  - Out-of-hours ultrasound to confirm retained products of conception
  - 2 x courses of specific antibiotics at $90 & $96 respectively
  - Private gynaecologist for all future treatment due to extreme anxiety around conception and pregnancy.

I would like to take the opportunity to state that the majority of the health care staff throughout my journey were incredibly supportive and professional. There were particular medical professionals, such as the after-hours GP and the private gynaecologist who undertook my second dilation and curettage, who listened to me and validated how I was feeling at such a tumultuous time. I would also like to thank my psychologist, my current private GP and my current private obstetrician practice who have understood the trauma I have gone through and have supported me through the past year and a half as I struggle with ongoing anxiety.

Thank you for the opportunity to make a submission,

[redacted]

To provide a thorough understanding of these failures, a summary of the events in chronological order are noted below:

14 November [redacted]

- Had a pregnancy dating scan at Women's Imaging, which confirmed a heartbeat and a gestation of approximately seven (7) weeks.

4 January [redacted]

- At 14 weeks gestation a miscarriage was diagnosed via ultrasound at Women's Imaging. The ultrasound indicated the fetus had stopped growing at eight (8) weeks (six (6) weeks earlier), and no heartbeat could be found.
    - Traditionally an ultrasound is performed at 12/13 weeks, however due to the Christmas/New Year period Women's Imaging were closed and the ultrasound was done at 14 weeks.
- To find out the next steps I called the midwife I had been assigned through the RHH Midwifery Group Practice program. She sought advice and provided a referral to the RHH Early Pregnancy Clinic to seek advice about undergoing a dilation and curettage.
- **As someone who did not have a private obstetrician, I found that after the Women's Imagining appointment, I was confused and overwhelmed at the next steps. Even when I called the RHH midwife, she admitted that this was a first for her and hence why she needed to seek advice on next steps.**
- **Consideration for better support for women who discover they have miscarried at appointments such as those at Women's Imaging, or through the RHH midwifery group.**

5 January [redacted]

- Contacted by the RHH Early Pregnancy Assessment Service with an appointment on 10 January [redacted]
- **There seemed to be no urgency in getting the miscarriage tissue removed given an appointment for a consult (not even a procedure date) was offered six (6) days after diagnosis. Considering that I was carrying unviable tissue since approximately eight (8) weeks gestation, and it was now six (6) weeks on, it was clear that 'expectant management' of a miscarriage wasn't going to occur and medical treatment was required. Waiting for a miscarriage to occur was and is emotionally draining.**
- **Consideration should be given to triaging miscarriage appointments at the RHH pregnancy clinic, particularly those with a significant missed miscarriage timelines where medical treatment is required to minimise the possibility of complications including infection.**

10 January [redacted]

- The doctor at the Early Pregnancy Assessment Service advised that I was eligible for a dilation and curettage given the time passed since the fetus had stopped growing without my body passing the tissue naturally.
- The doctor informed me that I was booked in for surgery on 12 January [redacted] I was informed that I was the only person scheduled on the procedure list this day, and if anything changed it would be moved to the following day with RHH admissions confirming my procedure date on the 11 January.

- The doctor provided minimal advice in relation to the procedure. Aside from generic risks associated with general anesthesia procedures, the doctor made mention of possible bowel perforation, but there was no discussion of retained product.
- **Failure to discuss common risks, in particular the failure to mention the potential risk of retained product and symptoms to look out for. Consideration should be given to a review this process.**
- **The process of going into the RHH Pregnancy Clinic was horrendous for someone who was seeking treatment for a miscarriage. Being confronted with heavily pregnant women and mothers with small children was incredibly traumatic. Consideration should be given for a separate area for those who are grieving a loss from a miscarriage.**

11 January [redacted]

- I was called by the RHH (presumably an admissions administration officer) and was informed I was on the morning theatre list for [redacted] and was confirmed for surgery.

12 January [redacted]

- I was admitted into RHH at approximately 8.30am after fasting all night/morning. Was placed in surgery gown, including compression socks and placed in the surgery waiting bay.
- At approximately 12.50pm I was informed by a doctor that the procedure would not go ahead that day as they had run over with other procedures/patients. I had been waiting since being admitted early in the morning and had no communication or updates provided to me prior to 12.50pm.
- The staff member advised that I could wait but that there was a full afternoon list that would take precedence over me and there was a possibility that I could wait all day but still not receive the procedure that day.
- Given the variable nature of that option, I agreed to leave and return to be on the morning list the following day.
- It is also noted this was my birthday and the event happening on this day had a significant mental health toll. I was visibly distraught when told about the delay and subsequent 'waste' of a morning on my birthday waiting for the removal of my baby – a baby I had longed for.
- At this point, I had carried unviable tissue for seven (7) weeks and it was eight (8) days since diagnosis.
- **Failure to undertake the procedure on the scheduled day, with inadequate communication causing significant mental stress, undue anxiety and suffering.**
- **No mental health support was offered to me at this time despite being visibly distraught. Consideration should be given to provide support to those suffering a miscarriage, particularly those who are visibly upset by the impending procedure.**
- **Staff should have available to them information about mental health support services that they can provide to distraught patients.**

[redacted]

- Once again I was admitted into RHH for the procedure on the morning list. This time the procedure went ahead as planned.
- No doctor or specialist spoke to me about the procedure prior to or following my surgery.
- The nurse who read through the standard 'handouts', skipped over the section regarding the timeframes of when to attempt conception again. The nurse instead stated that this 'does not apply to you'. I understood this to mean that the nurse mistakenly believed that I was

attending the hospital for an abortion, rather than an unplanned miscarriage. Due to the emotional state I was in, I did not correct her.

- I was told by the nurse to follow up with my private practice GP in two (2) weeks.
- **Failure of staff to discuss discharge documents appropriately, particularly given the emotional nature of the procedure.**
- **Failure of RHH to discuss the outcome of the procedure with me. This included complete absence of contact either prior to, or after, the procedure from the surgeon/doctor.**
- **As a matter of course, the doctor should always speak to the patient either before or after a surgery to not only confirm the procedure about to be undertaken but to provide comfort and support.**

14 January [redacted]

- A nurse from the RHH called in the afternoon to discuss how I was feeling post-op. It was in this conversation that I stated I didn't have a visit by or consultation with a doctor directly before or after my procedure so I had no idea how the procedure went. The nurse looked up the file notes to confirm it was a dilation and curettage undertaken and told me words to the effect of "it was nothing special".

15 January [redacted]

- Ongoing suffering from significant shooting pains in my stomach since the procedure including significant pain when passing a bowel movement and mild pain when urinating. I was also still bleeding a significant amount.
- As a result, booked a private practice GP appointment to discuss.

18 January [redacted]

- Discussed pains and ongoing blood loss with GP, and noted that they had been ongoing since the procedure. Made it clear this wasn't cramping type pain as I had been told to expect but rather sharp pain.
- The GP listed that these were normal post operative pains. He read over the report from the RHH that had been provided, and confirmed there was nothing out of the ordinary in the report.
- I felt dismissed and was very upset.
- At this same appointment I also requested a referral to a private obstetrician for any future pregnancies as I knew that I would not have the confidence to go through the public system again and because the lack of continuity of care was confusing.
- **Failure of GP to consider that possible issues may have been caused by the dilation and curettage procedure despite my explanation of continuing severe pain and ongoing bleeding.**

26 January [redacted]

- After suffering from three (3) days of extremely painful headaches alongside the pain and bleeding I had already been experiencing, I sought a further opinion from an after-hours GP at a different practice. This GP referred me to have blood tests completed which indicated retained product due to elevated hormone levels (human chorionic gonadotropin) along with heightened infection markers.
- The GP advised that I needed to seek an ultrasound as a matter of urgency and offered to provide a referral back to the Early Pregnancy Clinic. Due to the trauma around the initial

dilation and curettage, I made a choice not to return to the public system for fear of a repeat experience.

- I informed her that I had recently been given a referral to a private obstetrician and I would phone the office of the obstetrician in the morning. The GP agreed, however, reiterated the urgency of the matter.

27 January [redacted]

- Contacted the practice of the private obstetrician I had the referral for and explained the pain I had been experiencing and the advice of the GP from the day prior. The reception staff looked up my blood results from the day before and sent them through to the obstetrician alongside my symptoms.
- Later that day I was told by reception staff that the obstetrician wasn't too concerned about the hormone levels as they can take a long time to come down. I was told that they would try and fit me in for a scan if the obstetrician thought it was necessary. I was never contacted again that day. I went into the weekend feeling dismissed once again and was starting to feel very deflated and exhausted after feeling unwell and bleeding continually.
- **Failure of private gynaecologist to take action on the possibility of retained products of conception, leaving patient to go into the weekend after 14 days of pain, ongoing bleeding and test results that showed likely retained product.**

28 January [redacted]

- I made the decision to go into Calvary Hospital emergency department as I strongly felt that this pain was not normal post dilation and curettage.
- I underwent an afterhours ultrasound and it was confirmed I had an infection in my uterus and retained product.
- Due to a private health insurance error that could not be resolved until the next business day, I was not admitted but was provided IV antibiotics and oral antibiotics to try and get the infection under control before I would undergo a second dilation and curettage.
- **Failure of RHH to successfully perform the objective of a dilation and curettage (to remove products of conception) as confirmed by ultrasound performed at Calvary Hospital emergency department.**
- **This failure subsequently caused an infection in the uterus post-procedure.**

30 January [redacted]

- Was admitted into Calvary Hospital for a uterus infection and retained product of conceptions.
- IV antibiotics were administered for 24 hours prior to surgery being performed to allow for the infection to subside prior to another dilation and curettage.

31 January [redacted]

- Second dilation and curettage was performed with a private gynecologist from the hospital.
- I was admitted into Calvary for a total of two (2) nights.

8 February [redacted]

- Had significant diarrhea and body aches that persisted all day. Decided to take myself back to Calvary Hospital emergency department for fear of another uterine infection.

- Various tests were undertaken, and I was discharged after fluids were administered to await test results at home.

9 February [redacted]

- Was still very unwell at this stage but I already had a follow-up gynecologist appointment for this day with the private gynecologist who performed the second dilation and curettage.
- Gynecologist advised that my test results from the day prior advised that I had contracted Clostridioides difficile, also known as C Diff, a gastrointestinal infection caused by a combination of picking up a bacteria alongside significant antibiotic use from the week prior. Specific expensive antibiotics are used to treat this infection which are not covered by the PBS.
- I was also advised at this appointment that the laboratory who had received the retained tissue (a standard approach to miscarriage tissue) had concerns about suspicious tissue which appeared to be a molar pregnancy. The tissue was to be sent off for chromosomal testing.
- The gynecologist followed up with the RHH about my first procedure, who confirmed that there was also suspicious molar pregnancy tissue from the first procedure (noting that RHH had not contacted me to discuss this finding).
- **It can be assumed that if the significant antibiotics treatment for the uterine infection hadn't been required than the subsequent Clostridioides difficile infection would have never occurred.**
- **Failure of RHH to make timely contact with a patient that there was a potential issue with the pregnancy. In contrast the private hospital reported initial results within nine (9) days.**

20 February [redacted]

- Clostridioides difficile infection returned despite finishing the full course of prescribed antibiotics.
- Another course of antibiotics was prescribed.

24 February [redacted]

- Received a call from a woman from RHH who said that she had booked me in for an appointment the following week to see a doctor. After inquiring as to what the appointment ascertained too, I was told it was about my 'partial molar pregnancy'.
- By this time, it had been over one month since the dilation and curettage procedure with no contact from RHH during this time.
- I declined the appointment and explained I was seeking treatment privately.
- **Complete failure of RHH to communicate diagnosis of molar pregnancy in a professional, timely and supportive manner.**

1 March [redacted]

- Private gynecologist called to confirm that results had come back and were indeed a partial molar pregnancy.

- Told that I would now require monitoring by way of a regular blood test to ensure that my hormones dropped to required 'non-pregnant' level. Noting that treatment for levels that do not return on their own usually requires treatment via chemotherapy.[2]

4 April [redacted]

- Was cleared from my partial molar pregnancy after returning to normal hormone levels just short of three (3) months since the initial tissue was removed.

[2] Royal Women's Hospital Victoria https://www.thewomens.org.au/health-information/pregnancy-and-birth/pregnancy-problems/early-pregnancy-problems/hydatidiform-mole