



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 007

Submitter: Name withheld

Date authorised for publication: 10 February 2026

I am writing to share my experience of living with endometriosis in the ACT. From the onset of symptoms at age 11 in 2013, to surgical diagnosis (of Stage 3 endometriosis) in 2025, it took 12 years to receive adequate care. This diagnosis path highlights the barriers in the health system as well as the implications of medical misogyny, and the differences in treatment options in the ACT compared to other jurisdictions.

ToR (Terms of Reference) 2: The Barriers in the ACT to Getting a Diagnosis...

This outlines my experiences until August 2024:

- Despite seeking help frequently from age 11 by going to the GP, my symptoms of dysmenorrhea (painful periods) and menorrhagia (heavy bleeding) were dismissed as “normal”.
- One year, around 2016, I was given a referral to an ultrasound. When this ultrasound came back as clear, I was told I did not have endometriosis. This is actually incorrect – an ultrasound cannot be used as a means to rule out **or** to diagnose endometriosis. However, I was 14 at the time, and did not know any better. All I knew in my gut was that something was wrong.
- I was never referred to a gynaecologist – The most I was offered (beyond the incorrect ultrasound) was birth control, or heavier pain medication. I was quite young and worried that long term birth control use would have potential negative impacts. So, I took nothing. I did not know how to advocate for specialist help at the time.
- Throughout the years, I even tried going to different doctors and different clinics for a different outcome. I was repeatedly dismissed. It was not until August 2024 where a doctor went through the correct process that led to my diagnosis in April 2025.
 - Even the diagnosis process was quite lengthy due to long wait times.

ToR 3: Treatment Options Available in the ACT vs other Jurisdictions

- When I finally saw a gynaecologist in 2024, I was recommended to see an endometriosis specialist in Sydney due to the “complex nature” of my endo.
- I was told that while the surgeons in the ACT are good, for more complex cases it is better to go interstate and be “in better hands”.

ToR 4: Medical Misogyny

- As highlighted in the above section, there was an overarching lack of concern or care for my symptoms. There was almost an underlying expectation that I should just push through with it.
- The best example I have of this was one doctor in particular, who I visited because she had “womens health” as her main focus. I told her all my issues, and I was told since my blood tests came back clear I didn’t have PCOS and might have “a little endo”. There was no further clinical action after this, suggesting that this was just something I should live with.
- For 11 years, practitioners were focused on masking my symptoms (birth control/pain medication/dismissal) rather than figuring out the why.

ToR 5: Economic and Social Impacts

- I am lucky to be fortunate enough that I was able to afford private healthcare on a consistent basis. I roughly estimated that my diagnostic journey (from Aug 2024 to Apr 2025) cost around \$15,000 in expenses. This included specialised imaging,

specialist appointments, surgery, hospital stay, interstate travel etc. This highlights that a timely diagnosis is only accessible to those with financial means.

- This figure above doesn't include all those years I visited the doctor looking for answers, or the countless birth control pills I tried in my later years.
- On the first day of my cycle, I am practically bed bound. Throughout my education, I would frequently miss days of school, have to leave early, or have a significant drop in productivity on these days. A similar outcome is reflected on days where I have work.

ToR 7: Trials in Australia and Opportunities in the ACT...

- While I have nothing specific to say on this, if there was a trial in the ACT, I would be very interested in taking place. I would love to contribute to be able to help others. Unfortunately, my lengthy diagnostic experience is far too common.

As a note, I am unsure if I want this to be confidential or not. If you publish this, could you remove my name please, so it stays anonymous.

I am happy to chat with the committee at a hearing to share about my experience. Please feel free to contact me.

Kind regards,

A large black rectangular redaction box covering the signature and name of the sender.