Legislative Assembly for the
Australian Capital Territory
Standing Committee on Social Policy

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 018

Submitter: Name withheld

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From: [redacted]
To: LA Committee - SP
Subject: Public submission // endometriosis
Date: Friday, 10 April 2026 5:20:03 AM

Dear committee,

Thank you for this enquiry and the opportunity for input.

I was diagnosed in 2023 at age 36 with extensive endometriosis - it was a surprise diagnosis, following laparoscopic surgery in an ACT hospital. The surgery was intended to remove a polyp, which had been identified as a possible cause of otherwise unexplained secondary infertility. In advance of the surgery my surgeon had placed a query on endometriosis on my file. Until that point, no medical professional had identified that endometriosis was something that might have been relevant to me, and therefore I hadn't considered it myself either. They found endometriosis adhesions had spread to multiple organs, including my bowel, bladder, and a kidney was being 'pulled down'. The surgeon removed what they could.

Looking back, I have had clear endometriosis symptoms since age 9. At its worst, I would regularly faint and vomit on day one of my period. My periods have always been long and heavy. I experience pain that stops me in my tracks and daily bowel pain, in addition to some far less common symptoms that can also be attributed to endometriosis. Over the years I've sought medical input, and ultimately was always advised that what I was experience was "unfortunately unpleasant, but normal for you".

I experienced unexplained secondary infertility from age 30, and ultimately the medical intervention I sought at age 36 in the ACT is what led to my endometriosis diagnosis. The subsequent IVF treatment failed.

Since the diagnosis, I've had no support to discuss the diagnosis itself, or endometriosis management or treatments. My surgeon was part of an IVF clinic, who only queried whether I wanted to go though another IVF cycle, which was not possible for me due to an overseas posting for work.

I truly believe that if I hadn't sought medical intervention for unexplained secondary infertility, I would still not know that I have endometriosis. To me this reveals serious gaps in our medical system, and suggests a diagnosis is somewhat reliant on having the personal funds and tenacity to query infertility. A diagnosis at age 36 is too late, and also unfortunately this age bracket tends to coincide with critical junctures in the lives of professional women where choices between career versus family growth seem acutely time critical on both fronts.

There is too much still unknown about endometriosis and how it affects people, particularly for something that actually seems so widespread.

I would prefer for my submission to remain anonymous please if drawn on.

Kind regards,

[redacted]

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