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: 040

Submitter: Name withheld

Date authorised for publication: 28 April 2026

From: [redacted]
Sent: Friday, 17 April 2026 4:57 PM
To: LA Committee - SP <LACommitteeSP@parliament.act.gov.au>
Subject: Re: Submission to the ACT Legislative Assembly

> You don't often get email from [redacted]

To be clear, I do not consent for my name, email or phone number being published. I note that the submission page states that 'Submissions received by the committee may be published online, but personal contact details will be removed' but names have not been removed on all submissions. If my name, phone number or email is published or disclosed, I will be taking legal action.

On Fri, Apr 17, 2026 at 4:52 PM [redacted] [redacted] wrote:

Submission to the ACT Legislative Assembly

Inquiry into Endometriosis and Other Pelvic Pain Conditions

Re: Barriers to treatment, policy impacts, and reproductive consequences

I am writing to contribute to the Inquiry into endometriosis and other pelvic pain conditions, as outlined in the Terms of Reference . My experience directly relates to several key areas under consideration, particularly barriers to treatment, access to care, and the broader social and policy impacts of these conditions.

1. Lack of Affordable and Accessible Treatment

There is effectively no affordable or accessible pathway for the treatment of endometriosis and adenomyosis in the ACT.

- Specialist care is limited, expensive, and often requires long wait times. I had to go to Sydney for diagnosis as the wait time in Canberra was around 6 months for a deep endometriosis ultrasound. There was no wait time in Sydney despite them both being private services.
- Evidence-based treatments (such as excision surgery, hormonal suppression, or fertility-preserving strategies) are not equitably accessible through the public system.
- Ongoing management—particularly for adenomyosis—is largely left to patients to navigate privately, at significant personal cost.

For many patients, including myself, this results in delayed treatment, disease progression, and worsening symptoms over time.

2. Barriers to Diagnosis and Ongoing Care

The pathway to diagnosis and treatment is fragmented and difficult to navigate:

- Long delays in diagnosis remain common.
- Access to multidisciplinary care (pain specialists, fertility specialists, imaging, surgery) is limited.
- There is insufficient coordination between services, particularly for patients requiring both pain management and fertility care.

This creates a situation where patients must advocate for themselves within a system that is not designed to support complex, chronic conditions.

3. Impact of Legislative Changes on Health Outcomes

Recent changes to donor conception laws in the ACT had significant unintended consequences for my health.

The introduction of a limited transition period (six months) for the use of donor sperm created urgency and pressure to undertake additional IVF retrieval cycles in a compressed timeframe. This was not a medically driven decision—it was driven by legislative constraints.

As someone with adenomyosis, repeated ovarian stimulation and IVF cycles can exacerbate the condition. In my case:

- I underwent additional retrieval cycles to preserve reproductive options before the transition period expired.
- This substantially worsened my adenomyosis causing me agony.
- The progression of my disease contributed to adverse pregnancy outcomes, including the loss of all my pregnancies.

This highlights a critical gap in policy making: legislation that affects reproductive care must consider the medical realities of patients with complex conditions. The ACT government introduced changes to donor conception laws in the ACT without any consideration of how this would affect women with endometriosis and adenomyosis.It is difficult to believe that anyone could make changes to legislation that so clearly disproportionately affected single and LGTBI people by mistake.

4. Gender Bias and Systemic Issues

Endometriosis and adenomyosis are conditions that disproportionately affect women, yet they remain underfunded, under-researched, and poorly managed within the healthcare system.

There is a broader pattern of:

- Minimisation of women’s pain

Delayed diagnosis
- Lack of urgency in treatment access
- Limited investment in research and innovation

These issues align with the Inquiry's consideration of gender bias and medical misogyny.

5. Economic and Social Impact

The impact of these conditions extends far beyond physical symptoms:

- Significant financial burden from private treatment
- Lost productivity and work disruption
- Emotional and psychological distress, particularly in the context of infertility and pregnancy loss

In my case, the combination of disease progression, repeated medical interventions, and pregnancy loss has had profound personal and financial consequences.

6. Recommendations

I was harmed by the legislation changes made by the ACT government and the lack of diagnostic and treatment options for endometriosis and adenomyosis in Canberra. There is no redressing the harm I have suffered, moreover, no one in ACT Health or government cares. However, to help others in the future I recommend:

1. **Improved access to publicly funded specialist care** for endometriosis and adenomyosis, including surgery and multidisciplinary management.
2. **Better integration of fertility and pelvic pain services**, recognising the overlap between these conditions.
3. **Policy impact assessments** for reproductive legislation, ensuring that changes do not inadvertently harm patients with complex medical needs.
4. **Extended and flexible transition periods** for donor conception law changes in the future, allowing decisions to be made based on medical advice rather than arbitrary deadlines.
5. **Increased investment in research and education**, including for healthcare providers, to improve diagnosis and treatment pathways.
6. **Recognition of adenomyosis as a serious and progressive condition**, not just a secondary or lesser diagnosis.

Regards

[redacted]

[redacted]