



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 031

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Date authorised for publication: 28 April 2026

Submission to the ACT Legislative Assembly Inquiry into Endometriosis and Other Pelvic Pain Conditions

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Date: 16/4/2026

1. Introduction

I make this submission as a resident of the Australian Capital Territory living with Endometriosis, and as a law graduate with experience in legal research and structured analysis.

This submission draws on my lived experience navigating the ACT and broader Australian healthcare systems. It addresses the Terms of Reference of this Inquiry, particularly in relation to barriers to diagnosis and treatment, the effectiveness of available treatment options, economic and social impacts, education of healthcare professionals, and the role of research and systemic bias in shaping patient outcomes.

2. Barriers to Diagnosis and Access to Treatment (Terms of Reference 2)

Access to diagnosis and treatment for endometriosis in the ACT is significantly delayed in both the public and private systems.

After being referred to a public endometriosis clinic, I was advised the wait time exceeded 24 months. During this period, I continued to experience ongoing pain and irregular bleeding without access to specialist review. Seeking private care reduced the wait, but still involved a delay of approximately 12 months.

These timeframes are not clinically appropriate for a progressive and painful condition and reflect systemic capacity constraints.

There is also no standardised or enforced referral pathway for suspected endometriosis within primary care. As a result, escalation to specialist care is inconsistent and often delayed, requiring patients to self-advocate to access appropriate treatment.

3. Treatment Options, Effectiveness, and Impacts (Terms of Reference 3)

Treatment pathways for endometriosis are limited and not universally effective.

My treatment has included multiple hormonal approaches, including various oral contraceptive pills, an intrauterine device (IUD), and Visanne (dienogest). Despite

trials a range of options, these treatments have not fully controlled my symptoms and have been associated with side effects.

Access to alternative treatments, including surgery, is constrained by both cost and availability of appropriately skilled specialists. This limits patient choice and can result in prolonged reliance on treatments that are not effective.

4. Economic and Social Impacts (Terms of Reference 5)

The financial burden associated with endometriosis treatment is significant.

Despite holding comprehensive private health insurance with Bupa, I face substantial out-of-pocket expenses for consultations, investigations, and potential surgical treatment.

While I was a student, I was frequently forced to choose between seeking medical care for endometriosis and meeting basic living expenses such as paying rent. At times, I also had to choose between attending medical appointments and attending classes or work. These trade-offs caused significant financial stress and delayed access to necessary care.

Endometriosis has also impacted my ability to consistently engage in work and education, affecting both productivity and long-term financial stability.

5. Gender Bias and Systemic Issues (Terms of Reference 4)

My experience reflects broader systemic issues in the treatment of endometriosis, including the impact of gender bias in healthcare.

I have experienced dismissal of my symptoms by medical professionals of both genders across hospital and clinic settings. Symptoms were often minimised or not treated with appropriate urgency, contributing to delays in diagnosis and treatment.

This pattern of dismissal reflects a broader issue in which conditions affecting women are not consistently taken seriously. As a result, patients are often required to repeatedly justify their symptoms and advocate for appropriate care.

These experiences have had a lasting impact, contributing to significant distrust in the healthcare system and the development of medical trauma, including symptoms consistent with medical PTSD.

6. Education and Awareness (Terms of Reference 6)

There is a need for improved education and awareness among healthcare professionals.

The lack of consistent referral pathways and delayed recognition of symptoms suggests gaps in GP and primary care education. Improved training is necessary to support early diagnosis, appropriate management, and timely referral to specialists.

7. Research and Clinical Standards (Terms of Reference 7)

There is a significant lack of investment in endometriosis research, which directly impacts the quality of care available to patients.

Endometriosis remains under-researched compared to other chronic conditions. This contributes to delays in diagnosis, limited treatment options, and inconsistent clinical practices.

The absence of a strong evidence base results in variability in practitioner approaches and patient outcomes. Without sufficient research funding and consistent clinical guidelines, patients remain vulnerable to inconsistent care and suboptimal treatment.

There is a clear opportunity for increased research investment and the development of evidence-based clinical standards within the ACT.

8. Additional Matters – Multidisciplinary Care and Fertility Impacts (Terms of Reference 8)

Endometriosis frequently involves multiple systems and requires coordinated care across specialties.

However, existing services do not consistently provide timely, integrated multidisciplinary care. Patients are often required to independently coordinate care across providers, increasing both financial burden and delays in treatment.

As my condition has progressed, I have also developed fertility-related concerns. The uncertainty surrounding future fertility, combined with delays in accessing appropriate care, has added significant emotional distress and complexity to my experience.

9. Impact on Mental Health

The cumulative impact of these barriers extends beyond physical symptoms.

Prolonged pain, uncertainty, financial pressure, and repeated delays in accessing care have had a significant and ongoing effect on my mental health. Navigating a system where treatment is inaccessible, unaffordable, or delayed creates sustained distress and instability.

The experience of repeated dismissal within healthcare settings has compounded this impact, contributing to ongoing anxiety around seeking care and reduced trust in medical professionals.

Endometriosis is not only a physical condition—it is one that, when inadequately treated, can affect fertility and erode mental wellbeing over time. A system that allows preventable delays and barriers to persist is not only failing to treat the condition, but compounding its harm.

10. Recommendations

- 1. Increase resourcing and capacity within existing public endometriosis services**
Including reducing wait times and improving access to specialist care.
- 2. Implement standardised GP referral pathways**
To ensure early recognition and timely referral.
- 3. Expand public access to specialist consultations and surgical care**
To reduce reliance on private providers.
- 4. Improve transparency and affordability of treatment costs**
Including clearer disclosure of out-of-pocket expenses.
- 5. Invest in GP and primary care education**
To improve early diagnosis and management.
- 6. Increase funding for endometriosis research**
Including research into diagnosis, treatment, and fertility outcomes.
- 7. Develop and enforce consistent, evidence-based clinical guidelines**
To improve quality, safety, and accountability in endometriosis care.

11. Conclusion

My experience demonstrates that barriers to endometriosis treatment in the ACT are systemic.

Excessive wait times, financial burden, fragmented care, and insufficient research continue to prevent timely and effective treatment. Without targeted reform, these issues will persist.

A coordinated, evidence-based, and adequately funded approach is necessary to ensure equitable access to care.

The cumulative impact of these barriers extends beyond physical symptoms. Prolonged pain, uncertainty, and repeated delays in accessing care have had a significant and ongoing effect on my mental health. Navigating a system where treatment is inaccessible, unaffordable, or delayed creates sustained distress and instability.

Endometriosis is not only a physical condition—it is one that, when inadequately treated, can affect fertility, and erode mental wellbeing over time. A system that allows preventable delays and barriers to persist is not only failing to treat the condition but compounding its harm. Addressing these barriers is essential to prevent ongoing and avoidable physical and psychological harm.

12. Further Participation

I would be willing to provide further evidence or appear before the Committee if required.