Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 004

Submitter: Louise Reid

Date authorised for publication: 10 February 2026

Submission to the Legislative Assembly for the Australian Capital Territory

Standing Committee on Social Policy

Inquiry into endometriosis and other pelvic pain conditions

5 January 2026

Submitted by:

Louise Reid
[redacted]

1. Introduction

I am a 44-year-old ACT resident living with Stage IV endometriosis. I am making this submission to outline my lived experience of severe disease, the cost and inaccessibility of treatment, the lack of excision specialists in Canberra, gaps in GP knowledge, and the economic and employment impacts of living with a chronic, progressive condition.

Despite multiple surgeries, extensive out-of-pocket costs, and years of seeking care, I have faced ongoing barriers that reflect broader systemic failures in diagnosis, access, workforce capacity, and post-treatment support in the ACT.

I was not diagnosed with endometriosis until my 30s, after experiencing difficulty conceiving.

Prior to diagnosis, I sought care from multiple medical professionals over many years and was variously diagnosed with irritable bowel syndrome, prescribed hormonal contraception to manage heavy bleeding, and referred for investigations unrelated to endometriosis. I underwent gastrointestinal assessments, imaging for back pain, dietary testing including gluten intolerance and SIBO, and sought allied and complementary care, including acupuncture, in an effort to manage debilitating symptoms that had persisted for years.

At no point during this period was endometriosis or adenomyosis raised as a possible diagnosis.

Endometriosis was first identified during my initial laparoscopy, at which time I was diagnosed with Stage IV disease and advised that it was unlikely I would be able to conceive. I have never been able to conceive.

This delayed diagnosis contributed to disease progression, organ involvement, and irreversible impacts on my fertility, health, and economic participation.

2. Diagnosis and Access to Appropriate Imaging

Timely and accurate diagnosis of severe endometriosis in the ACT is limited by the absence of publicly accessible advanced diagnostic imaging capable of identifying deep infiltrating or organ-involving disease.

At present, expert diagnostic ultrasound for severe endometriosis is available only privately, with costs set by individual providers. This creates a two-tiered system in which access to diagnosis is determined by financial capacity rather than clinical need.

Delayed or inadequate diagnosis directly contributes to disease progression, organ involvement, and poorer long-term outcomes.

3. Lack of Excision Specialists and Public Surgical Pathways

There is a critical shortage of appropriately trained endometriosis excision surgeons in the ACT.

People with complex disease involving organs have no viable public surgical pathway locally. In my case, I was forced to travel to Sydney to access an excision surgeon with expertise in complex, organ involving disease, undergoing bowel and bladder resection in a private hospital.

The out-of-pocket cost of this surgery was approximately $15,000, with private health insurance (top tier cover) covering hospital costs only, and less than $2,000 of surgical and specialist fees. For many patients, total costs exceed $20,000. Those unable to afford private care are left with no alternative but to continue living with severe, debilitating, progressive disease.

In addition to cost, the absence of a public pathway for complex endometriosis results in prolonged delays to care. For people with progressive disease, waiting years for diagnosis or surgery can result in irreversible organ damage, escalating pain, and loss of fertility.

4. Post-Surgical and Ongoing Care Costs

Surgery is only one component of treatment. Following excision surgery, I was advised to engage in ongoing allied health care, including:

- Pelvic floor physiotherapy (~$200 per session)
- Psychological support (~$170 per session)
- Osteopathy (~$170 per session, often monthly or more frequently)

These services are clinically recommended and essential to recovery and long-term management, yet they are largely inaccessible due to cost and limited rebates.

Ongoing care also includes specialist reviews, imaging, pain management, and fertility investigations - all of which represent substantial cumulative financial burden over time.

Prior to accessing definitive surgical treatment, pain management often relies on repeated medication rather than addressing the underlying disease, contributing to physical and psychological burden.

5. Employment, Fatigue and Workforce Participation

Endometriosis significantly impairs a person's ability to participate consistently in work due to chronic fatigue, heavy and unpredictable bleeding, pain flare-ups, and recovery periods.

For many people, continued employment is only possible where genuine workplace flexibility exists, including flexible hours, the ability to work remotely when required, and management understanding of fluctuating symptoms associated with chronic illness.

In my case, symptom severity, surgeries and recovery, and daily unpredictability meant I was unable to continue operating my small business, a florist, resulting in loss of income and independence.

I am currently employed full-time in a senior professional role aligned with my other qualifications, working within the healthcare sector. However, a key consideration in my employment choices is the availability of flexibility and organisational recognition of women's health conditions. I have also made deliberate decisions to seek employment in female-dominated workplaces, where awareness and accommodation of conditions such as endometriosis are more likely.

This illustrates that even for people who are employed in professional roles, participation in the workforce often depends on employment choices to manage chronic illness. Failure to recognise endometriosis as a chronic condition with functional impacts places the economic burden on individuals rather than on systems, contributing to underemployment, career limitation, and inequity.

6. Scale of the Issue and Systemic Inadequacy

Endometriosis affects approximately 1 in 7 people assigned female at birth in Australia (Endometriosis Australia; Australian Bureau of Statistics, National Health Survey).

Despite its prevalence, the ACT system is characterised by delayed diagnosis, limited access to trained specialists, prohibitive treatment and recovery costs, no public pathway for complex disease, and insufficient recognition of employment impacts.

For a condition affecting such a significant proportion of the population, the current response is grossly disproportionate to need.

6A. Inequity in Access: Geography and Funding

National hospitalisation data indicates that access to endometriosis diagnosis and treatment is strongly influenced by both geography and funding, rather than reflecting true differences in disease prevalence.

The age-standardised rate of endometriosis-related hospitalisation in major cities is 1.5 times higher than in remote and very remote areas. This contrasts with the pattern for all female hospitalisations, where rates are higher in remote and very remote areas than in major cities. This divergence suggests that lower endometriosis hospitalisation rates outside major cities reflect barriers to diagnosis and specialist care, not lower prevalence of disease.

Endometriosis care is also disproportionately delivered through the private system:

- Around 57% of endometriosis-related hospitalisations are partly funded by private health insurance
- Only 31% are treated as public patients
- Almost two-thirds (65%) occur in private hospitals

Compared with all female hospitalisations, endometriosis-related care is significantly more likely to rely on private funding and private hospitals.

Together, these data demonstrate that access to endometriosis diagnosis and treatment is shaped by location and ability to pay, rather than clinical need, particularly disadvantaging people with complex or organ-involving disease.

Source: Australian Institute of Health and Welfare (AIHW), endometriosis-related hospitalisations, 2022–23.

7. Recommendations

The following recommendations are informed by lived experience, national data, and observed gaps in the ACT health system.

Diagnosis and Access

- Establish publicly accessible diagnostic pathways in the ACT for suspected endometriosis.
- Develop clear referral pathways from primary care to specialist services.

Surgical Care

- Improve transparency regarding specialist training and experience in endometriosis excision surgery, recognising that advanced excision for complex disease requires additional, specialised training beyond general gynaecology.
- Support nationally consistent, evidence-based guidance on the qualifications and experience required to manage complex endometriosis, to assist patients in making informed decisions.
- Ensure public information reflects current evidence that excision surgery is associated with improved outcomes for many people with moderate to severe endometriosis, while recognising that treatment must be individualised.

Cost and Post-Surgical Support

- Increase access to rebated allied health services for recovery.
- Recognise post-surgical care as essential treatment.
- Address long-term financial burden of imaging and fertility-related care.

Employment and Economic Participation

- Recognise endometriosis as a chronic condition with functional impacts.
- Promote flexible work arrangements.
- Model best-practice employment supports within ACT Government.

Education and Awareness

- Improve GP and primary care education.
- Support public awareness initiatives.
- Incorporate age-appropriate education on menstrual health, endometriosis, and pelvic pain conditions within school health curricula, to support early recognition and help-seeking.

8. Conclusion

Endometriosis is a serious, chronic disease with profound health, economic, and social consequences.

In the ACT, access to diagnosis and treatment is too often determined by financial capacity rather than clinical need. Without systemic reform, people with severe disease will continue to lose livelihoods, experience irreversible health impacts, and be denied equitable care.

Endometriosis should not require people to choose between managing their health and maintaining a livelihood.

9. Willingness to contribute further

I would welcome the opportunity to contribute further to this inquiry or any related work undertaken by the ACT Government.

As someone with lived experience of severe endometriosis and its health, economic, and employment impacts, I am keen to support consultation, co-design, or advisory work aimed at improving diagnosis, access to care, and support pathways in the ACT.

I am available to participate in hearings, roundtables, or other engagement activities should the Committee consider this helpful.