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

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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1. Introduction

This submission is made to the ACT Legislative Assembly Inquiry into Endometriosis and Pelvic Pain. It draws on over twenty years of lived experience managing endometriosis, adenomyosis, and complex pelvic and systemic health conditions, primarily within the ACT healthcare system.

It highlights systemic shortcomings in diagnosis, care coordination, informed consent, and post-surgical outcomes, and advocates for structural reforms to improve how endometriosis and chronic pelvic pain are understood, managed, and treated.

2. Prevalence and Under-recognition (Term of Reference 1)

My experience reflects broader systemic under-recognition of endometriosis, adenomyosis, and related conditions within the ACT.

The invisibility and normalisation of symptoms, combined with limited specialist access in the ACT, likely means official prevalence figures substantially underestimate the true number of people affected. Many people live for years with unmanaged symptoms, often without a formal diagnosis, and therefore remain absent from datasets.

Delayed diagnosis, symptom dismissal, and limited clinical frameworks contribute to significant underreporting. Individuals whose symptoms are complex, non-visible, or not primarily pain-based may not be captured in prevalence data, despite experiencing substantial functional impairment.

3. Barriers to Diagnosis and Treatment (Term of Reference 2)

It took more than two decades for me to receive a diagnosis of endometriosis and adenomyosis.

During this period, I consulted numerous general practitioners, gynaecologists, and specialists, alongside allied health professionals. I incurred substantial out-of-pocket costs for consultations, scans, medications, and procedures, amounting to at least the equivalent of a home deposit. While I received mostly a lot of valuable support and understanding from allied health professionals, my experience with GPs and Gynecologists and other medical professionals in the ACT has been extremely disappointing.

Symptoms were frequently attributed to stress, anxiety, or “normal” experiences of menstruation. I was advised to relax, accept pain, or consider pregnancy as a solution, which often felt frustrating as I believed it would not be responsible to bring a child into the world if I barely had energy to care for myself.

These experiences demonstrate systemic barriers to timely diagnosis and appropriate care within the ACT.

Key barriers included:

- repeated dismissal or minimisation of symptoms
- narrow diagnostic frameworks focused almost exclusively on “pain severity,” excluding other systemic presentations.
- repeated reliance on standard imaging despite evidence that endometriosis often does not commonly appear on routine scans.
- prioritisation of diagnostic investigation primarily when fertility or conception is being actively pursued
- very brief specialist consultations despite extremely high costs
- lack of continuity of care
- absence of coordinated, multidisciplinary treatment pathways

4. Treatment Options, Effectiveness, and Risks (Term of Reference 3)

My experience raises serious concerns about the safety, effectiveness, and appropriateness of current care models for endometriosis.

I underwent multiple surgical procedures that lacked clear clinical justification, did not improve symptoms, and resulted in worsened outcomes, including increased pain.

Despite years of uterine imaging, endometriosis was not identified until I travelled to Sydney for a specialised deep infiltrating endometriosis (DIE) scan. However, my ACT-based gynaecologist did not provide guidance on endometriosis as I requested and instead focused solely on removing a suspected uterine polyp, recommending surgery with urgency.

I was hesitant, having undergone a similar procedure six months earlier with minimal findings. During this time, the gynaecologist contacted my GP without my knowledge, overstated clinical concerns inconsistent with imaging, and characterised my hesitation as irresponsible. I was subsequently pressured to proceed and did so reluctantly.

After surgery, I was told three polyps had been removed. No follow-up care was offered for endometriosis, and I was dismissed when I sought further support. The pathology report later showed evidence that the samples were not polyps, directly contradicting what I had been told. When I asked for support on how to manage endometriosis I was told “you are a smart girl you’ll work it out” and then when I sought further appointments the staff told me the specialist didn’t need to see me anymore.

This procedure cost over $3,000 out-of-pocket, in addition to recovery time and lost income, despite lacking clinical necessity.

Due to limited confidence in local care, the following year I sought treatment interstate with a specialist endometriosis surgeon with an apparently good reputation. This experience also raised serious concerns.

Immediately prior to anaesthesia, I was encouraged to consent to sterilisation, with claims it would prevent disease progression and reduce cancer risk. This was presented without adequate time or evidence to support informed consent.

Following surgery, I was told I had widespread “Stage IV” deep infiltrating endometriosis “everywhere” and the most severe form of the disease and was billed accordingly. I awoke in excruciating pain and later discovered nerve damage affecting my bladder. My symptoms worsened significantly, with new complications not present prior to surgery.

At follow-up, I was advised to undergo further surgery only 6 months later. Instead, I sought a second opinion by another interstate gynaecologist, which disputed both the severity of the diagnosis and the necessity of the surgery.

This surgery (including anaesthetist fees and travel costs) resulted in over $8,000 in out-of-pocket costs despite private health insurance. I have since discovered via APHRA that the practitioner is under review.

I have since been diagnosed with a connective tissue disorder and central sensitivity syndrome. Research shows that patients with this condition who have endometriosis are much more likely to have poorer surgery outcomes. Central sensitivity syndrome is apparently very common among women with endometriosis, but not often diagnosed. And even if there is a diagnosis it isn’t usually considered or mentioned by specialists in decision making about surgery.

5. Gender Bias and Medical Misogyny (Term of Reference 4)

When I wasn’t being “over surgerised”, throughout my care, symptoms were frequently attributed by GPs or specialists to psychological factors despite evidence of physiological dysfunction.

I was repeatedly advised to “relax more” or to have children as a solution. These recommendations were made without regard for my personal circumstances, capacity, or consent.

Care was often implicitly conditional on prioritising fertility, creating a coercive dynamic that undermines patient autonomy.

These experiences reflect broader patterns of gender bias and medical misogyny that act as barriers to appropriate care.

6. Economic and Social Impacts (Term of Reference 5)

The economic and social burden of managing these conditions are profound and ongoing:

- I worked part-time for much of my adult life to manage symptoms, significantly reducing income and career progression. I have been apprehensive to seek higher level roles due to difficulty in managing energy and health.
- I incurred substantial out-of-pocket expenses for medical appointments, surgeries, interstate travel, scans, tests, allied health, and complementary therapies.
- Productivity losses were compounded by exhaustion, cognitive fog, unpredictable symptoms, and frequent medical appointments.
- I concealed my condition at work due to fear of stigma, limiting access to workplace accommodations.

Despite holding private health insurance, out-of-pocket expenses exceeded many, many thousands of dollars.

There have also been significant impacts on my:

- lifestyle and social life
- domestic duties and productivity
- daily functioning
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financial stability

- potential family life (I didn’t think it would be responsible to have children as I barely had enough energy to look after myself, let alone one or more children)

7. Education and Awareness (Term of Reference 6)

My experience highlights significant gaps in education for both medical professionals and patients.

Clinicians often relied on narrow frameworks and when they did acknowledge the possibility of endometriosis they often focused solely on pain severity, overlooking systemic and non-pain-dominant presentations or they over-emphasised often unnecessary surgical interventions..

There is a need for:

- improved training on complex and overlapping conditions among GPs and gynecologists. Many allied health professionals have extensive experience in this area and could share valuable knowledge with medical professionals.
- greater awareness of co-morbidities such as connective tissue disorders, autoimmune conditions, central sensitisation and neurodiversity
- trauma informed care
- enhanced education for young people regarding menstrual and pelvic health
- understanding of how endometriosis can impact women in the workplace and how they can be supported and accommodated

8. Research and Innovation (Term of Reference 7)

There is a clear need for greater investment in research and translation into clinical practice.

Key gaps include:

- understanding of co-morbid and intersecting conditions (eg hypermobility, autoimmune conditions, connective tissue disorders, central sensitivity syndrome, hypermobility, neurodiversity)
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investigating other diagnostic approaches

- effectiveness of non-surgical interventions
- ways to coordinate together with allied health providers.
- predictors of surgical outcomes

Expanding research and clinical trials within the ACT would improve both care quality and health outcomes.

9. Additional Matters (Term of Reference 8)

My experience also highlights:

- fragmented care requiring patients to self-coordinate treatment
- limited access to subsidised allied health services (currently capped at five sessions annually under Chronic Disease Management Plans)
- lack of recognition of lived experience as a valuable source of clinical insight

Value of Allied Health and Listening-Based Care

In my case, the most meaningful improvements in my quality of life have come not from surgical intervention, but from allied health practitioners with expertise in endometriosis, and connective tissue disorders, and central sensitisation.

This includes pelvic physiotherapists, osteopaths, women’s health exercise physiologists, acupuncturists, Bowen therapists, and dietitians. These practitioners consistently:

- take the time to listen
- work collaboratively
- prioritise informed consent, pacing, and complexity
- support patient self-advocacy

communicate with other providers as part of a team-based approach

Many have extensive experience supporting women following unsuccessful or difficult surgical and medical interventions, and demonstrate a deep understanding of the lived experience of endometriosis.

This approach stands in contrast to many specialist consultations, which are often brief and intervention-focused, with limited opportunity for meaningful patient engagement.

While access to five subsidised allied health sessions under Medicare is valuable, it is not sufficient. Effective care for complex conditions typically requires ongoing, multidisciplinary input that far exceeds this cap across multiple modalities within a single year.

10. Recommendations

I recommend that the Committee consider:

Diagnosis and Access to Care

- Expanding indicators beyond pain-centric models, and surgical only diagnosis
- Improving understanding of and access to multidisciplinary care within the ACT

Clinical Practice and Patient Safety

- Mandatory, standardised training on informed consent, particularly in relation to surgical and reproductive decisions.
- Routine, evidence-based screening for co-morbid conditions prior to surgical intervention.
- Greater integration of existing evidence into clinical decision-making. This includes recognition that patients with endometriosis and central sensitisation syndrome may experience poorer surgical outcomes, and that those with connective tissue disorders often require modified surgical approaches and perioperative care.
- Strengthened oversight, transparency, and accountability in surgical decision-making and billing practices.

Education

- Enhanced training for medical and allied health professionals
- Specialist training in chronic pain science and multidisciplinary care models.
- Increased public education on menstrual and pelvic health

Research

- Investment in research on complex and comorbid presentations
- Expansion of clinical trials within the ACT
- Long-term outcomes beyond short-term surgical success
- Intersections between endometriosis, connective tissue disorders, hypermobility, autoimmune conditions and neurodivergence

Economic and Social Support

- Expand access to allied health beyond five subsidised sessions per year for chronic pelvic conditions.
- Invest in multidisciplinary care models that value listening, continuity, and patient-reported outcomes.
- Recognise lived experience as clinical knowledge.
- Provide policies and supports for women in ACT workplaces with endometriosis and other pelvic conditions. For example, reproductive leave is being introduced in some national workplaces for women with pelvic conditions. In the ACT Government menstruation leave exists, but it is not any different from personal leave (ie it is taken from the same leave pool, you can just optionally title it differently). This is tokenistic and not sufficient or a helpful support for women.

System Reform

- Recognition of lived experience as a legitimate form of evidence
- Formalised collaboration between gynaecologists and pain physicians, pelvic physiotherapists, and mental health professionals.
- Development of integrated, patient-centred care models
- Addressing structural gender bias in healthcare systems
- Standardised care pathways aligned with the National Action Plan for Endometriosis.

Other issues

- **Informed consent and accountability**
  Processes surrounding major surgical and reproductive decisions require reform. Consent obtained under time pressure or fear is not informed consent.
- **The value of listening-based care**
  The most healing aspects of my journey occurred when clinicians listened without rushing to “fix” me. Systems need to value relational care, continuity, and patient-defined outcomes, not just procedures.

11. Conclusion

Endometriosis and chronic pelvic pain are not niche or purely gynaecological issues. They are complex, systemic conditions with profound personal, economic, and social consequences, that require humility, listening, and integrated care.

Meaningful reform must move beyond awareness to structural change across healthcare delivery, education, and research.