



# Submission cover sheet

## Inquiry into endometriosis and other pelvic pain conditions

Submission number: 030

Submitter: Michelle Barclay

Date authorised for publication: 28 April 2026

# Submission into the Inquiry into endometriosis and other pelvic pain conditions

Michelle Barclay [REDACTED]

Thank you for the opportunity to provide this submission into the ACT Government's *Inquiry into endometriosis and other pelvic pain conditions*.

I am providing a submission into this inquiry as a lived experience advocate, having been diagnosed with both endometriosis and adenomyosis.

## The number of women and other people in the ACT who suffer from endometriosis, and adenomyosis

In the ACT approximately:

- 32,000 women have endometriosis; and
- between 23,000 and 63,000 women have adenomyosis.

Based on the best available evidence, tens of thousands of people in the ACT are living with endometriosis and/or adenomyosis.

National prevalence data from the [Australian Institute of Health and Welfare \(AIHW\)](#) indicates that around 1 in 7 women (approximately 14%) have endometriosis and adenomyosis is estimated to affect between 10% and 28% of women ([Adenomyosis Australia](#) and [Sydney Fibroid Clinic clinical review](#)).

This means that approximately 32,000 women in the ACT have endometriosis and between 23,000 and 63,000 may be living with adenomyosis (based on [Australian Bureau of Statistics 2025 data \(Estimated Resident Population, ACT by sex\)](#)).

Despite this scale, both conditions are routinely missed, dismissed, or diagnosed far too late, leaving many women to suffer needlessly without timely care or effective treatment.

## Barriers I experienced in the ACT getting a diagnosis and gaining access to treatment, including primary care, specialist clinics and ongoing pain management for endometriosis and adenomyosis

It took me 27 years to be diagnosed with endometriosis and adenomyosis. Despite multiple hospital presentations, GP visits and scans, I was never proactively referred to a gynaecologist.

From the age of 12, I encountered significant barriers within the ACT health system that delayed my diagnosis and access to treatment for endometriosis and adenomyosis. My first hospital

presentation at 12 years old – where I was rushed in with suspected appendicitis – resulted in me being sent home with no diagnosis and no follow-up plan, despite the severity of my symptoms. This set the tone for the decades that followed.

In primary care, my experiences were characterised by dismissal and normalisation of symptoms that were anything but normal. Throughout my teens and twenties, I was repeatedly told that heavy bleeding, debilitating cramping, and missing school or work were simply part of menstruation. At 15, I was placed on the contraceptive pill as a default response rather than as part of any diagnostic process.

Over these 27 years I visited multiple GPs, and although they ordered scans, these scans consistently reported a “normal” pelvis. Despite my consistent pain, not one GP in 27 years suggested a referral to a gynaecologist to investigate my pain further. The absence of understanding of endometriosis and proactive referral pathways in primary care was a major barrier that prolonged my suffering.

Access to specialist care was another significant obstacle. I ultimately received my diagnosis in 2022 at the age of 39 only because my pain had become so severe that I was forced to leave a job I loved. Reaching the point where I could no longer work made it clear that I could not continue without answers, and it pushed me to advocate for myself and insist on a referral to a private gynaecologist. After paying the expensive consultation fee for this gynaecologist, they then referred me to a private endometriosis specialist. This was not the result of a coordinated or responsive system of care; it was the product of personal persistence in the face of escalating, unmanaged symptoms. When I finally had surgery in the ACT, I was diagnosed with stage 4 endometriosis and adenomyosis. The disease was severe: both fallopian tubes and my appendix were removed, and endometriosis was excised from my ovaries, bowel and bladder.

The long wait times in the public system create a two-tiered model of care in which timely diagnosis and treatment are effectively dependent on personal financial capacity. The only reason I was diagnosed and had surgery within 12 months was because I could afford to go private. In my teens and twenties, I could not afford to go private, which is the same for many women in the ACT. Friends and family members with similar symptoms have waited years – while in constant pain and without adequate support – for a public gynaecology appointment.

The long wait times in the public system have created a two-tiered model of care, where timely diagnosis and treatment depend not on clinical need, but on a person’s ability to pay. I know people who have waited years to get an initial appointment to see a gynaecologist in the public system.

My experience reflects systemic issues in the ACT: inadequate clinical awareness in primary care, inconsistent referral practices and limited access to specialist clinics (private and public). These barriers resulted in a 27-year delay in diagnosis and management – an outcome that is preventable with a system designed to recognise, investigate, and treat women’s pain seriously and equitably.

## **The treatment options and supports available in the ACT compared to other jurisdictions, their evidence-based effectiveness and potential side effects and impacts**

My Canberra endometriosis specialist referred me to Sydney because they did not trust local imaging. My surgery is too complex for ACT surgeons, so I need to travel interstate for my operation. As my endometriosis involves the bowel, I also had to undergo a colonoscopy in Sydney with the colorectal surgeon who will be part of my surgical team.

In my experience, the ACT does not have the supports needed for people with complex endometriosis. Private ACT surgeons frequently decline to operate on advanced cases, and this has been reflected in my own treatment.

Once my symptoms returned after an earlier endometriosis excision surgery, I waited months for an appointment with a private Canberra endometriosis specialist. This specialist referred me to OMNI in Sydney for a transvaginal scan because they did not trust the accuracy of local imaging.

Unfortunately, my upcoming surgery is beyond the capability of ACT surgeons, requiring me to travel interstate for operative care. This has delayed my care by approximately four months. I am not alone; many fellow endometriosis sufferers also travel interstate to ensure they get the best treatment for their condition. Because my endometriosis involves the bowel, I also had to undergo a colonoscopy in Sydney with the colorectal surgeon who will be part of my surgical team. This has meant that I must travel to Sydney on at least three occasions as part of my care, including a week stay in Sydney for my surgery.

At the time of this submission, I have been unable to work for five months and many days I have difficulty completing normal household tasks and care giving responsibilities. I am extremely lucky to have the support of my husband and family during this time. It is expected that I will need 11 months off work in total if I include the recovery time from my surgery.

These experiences demonstrate the urgent need for investment in specialist workforce capacity, advanced imaging and multidisciplinary surgical teams. Without this, people with endometriosis and adenomyosis will continue to face delayed care, avoidable suffering, and the financial and social burden of travelling interstate for essential treatment.

## **The economic and social impacts of people in the ACT with these conditions, including education, employment and lost productivity**

The economic and social impacts of endometriosis and adenomyosis directly intersect with several priority domains of the ACT Government's [Wellbeing Framework](#) (the Framework). Improving care for Canberrans with endometriosis, adenomyosis and other pelvic pain conditions is essential to advancing wellbeing in the ACT.

Below I have summarised my experience of the impact endometriosis has had on me and how it relates to the relevant Framework domains.

- **Education and long-life learning** – repeated school absences, reduced engagement, and early withdrawal from activities which undermined my ability to participate fully in education. This directly conflicts with the Framework’s goal of ensuring equitable access to learning and supporting Canberrans to thrive.
- **Economy** – lost productivity, reduced workforce participation, and extended periods away from work – such as the eleven months required for my upcoming surgery. This impacts both my individual financial security and the broader ACT economy. The Framework emphasises secure employment and economic resilience; delayed diagnosis and inadequate care erode both.
- **Living standards** – high out-of-pocket costs for imaging, specialist care, allied health, and interstate travel place significant financial strain on individuals and families. In the past six months alone, to manage and treat my symptoms I have required appointments with GPs, endometriosis specialists, bowel surgeons, acupuncturists, pain specialist, pelvic physio and an osteopath, as well as traveling interstate for an intravaginal scan and a colonoscopy. As a result, I am out of pocket thousands of dollars despite Medicare rebates and having private health. This undermines the Framework’s focus on affordability, financial security, and equitable access to essential services. If I had waited to go public, I would still be waiting to be seen by a gynaecologist.
- **Health** – chronic pain, delayed diagnosis, limited specialist capacity, and fragmented care pathways directly compromise physical and mental health – 27 years before obtaining a diagnosis is unacceptable. The Framework prioritises access to quality healthcare and the ability to live a healthy life – both of which are currently out of reach for many people with endometriosis and adenomyosis.
- **Social connection** – persistent pain, fatigue, and uncertainty, reduced participation in family life, community activities, and social relationships. For me this has meant the inability to play sports with friends, go hiking, enjoy gardening, participate in family activities and being unable to do simple daily tasks. This diminishes the sense of belonging and connection that the Framework identifies as essential to wellbeing.

Persistent pain, fatigue and uncertainty from delayed diagnosis and treatment has meant: repeated school absences and the inability to participate fully in education; reduced workforce participation, lost productivity and less income due to extended periods away from work; high out of pocket health expenses; and reduced participation in family life, community activities and social relationships which is essential to my wellbeing.

By addressing the systemic gaps in diagnosis, imaging, specialist capacity, and multidisciplinary care, the ACT Government would not only improve health outcomes but also advance multiple domains of the Framework simultaneously. This makes investment in endometriosis and adenomyosis care a whole-of-government opportunity to strengthen

education, economic participation, financial security, social connection, and overall community wellbeing.

## **Education available to medical professionals, allied health professionals, young women and others, on these conditions and treatment options**

Persistent myths about endometriosis and adenomyosis are costing people timely care. Without stronger education across health and community settings, symptoms will continue to be minimised and treatment delayed.

In my experience, understanding and education on endometriosis and adenomyosis remains limited across the ACT. Many medical professionals, allied health practitioners, women, and community members still believe endometriosis is simply “bad period pain,” rather than a complex, whole-body systemic disease for which there is no cure. This lack of understanding leads to symptoms being dismissed or normalised, contributing to delayed diagnosis and inadequate care.

Strengthening education and training across healthcare and community settings is essential to ensure people are believed, supported, and able to access timely, evidence-based treatment.

### **Recommendations**

1. Investment in training specialist workforce capacity, including:
  - a. specialist training for all ACT public health sonographers and radiologists to increase their expertise in diagnostic imaging for endometriosis and adenomyosis; and
  - b. specialist training for all public GPs, emergency department health staff, gynaecologists and medical management on the treatment and diagnosis for endometriosis and adenomyosis.
2. Investment in additional advanced imaging equipment to reduce wait times and remove the need to travel to Sydney for imaging for the diagnosis of endometriosis and adenomyosis.
3. Investment in more staff for public health teams diagnosing and treating endometriosis and adenomyosis to help reduce public wait times.
4. Investment in longer appointments with GPs – longer appointments are needed to treat the complexity of endometriosis and adenomyosis.
5. Allowing GPs to refer suspected endometriosis patients straight for a laparoscopy if certain criteria is met – this will help reduce costs for patients, lead to earlier diagnosis of endometriosis and ease the long waitlists to see endometriosis specialists.

6. Ensuring the ACT Government utilises all Commonwealth funding opportunities for women's healthcare.
7. Incorporate endometriosis, adenomyosis, PCOS and other pelvic pain conditions in sexual health talks with ACT high school students.