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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Submitter: Name withheld

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To the members of the Standing Committee on Social Policy and other Members of the ACT Legislative Assembly,

Thank you for the time you are investing in the Committee's Inquiry into endometriosis and other pelvic pain conditions, reading my submission and your consideration of the others you will doubtless receive. I am the loving partner of a woman diagnosed with advanced endometriosis, cousin to several women who suffer from endometriosis, and a friend to many others.

My partner is a young woman whose strength is only surpassed by her intelligence, compassion and courage. She studied psychology as an undergraduate before completing a masters degree in secondary education. She has devoted her adult education and career to the service of others to better our communities. She epitomises what we should expect of our public servants in her work for a Commonwealth department. She is committed to helping others, and her legacy will be a world that is better in some small measure than when she was born. This background highlights the reality that endometriosis is not a disease that chooses its victims. It viciously and insidiously affects at least 1 in 7 women and people assigned female at birth irrespective of their background, identity, status, employment, family circumstances or life choices.

I address **terms of reference 2-7** of the Inquiry and a suite of recommendations in my submission. I have provided a summary here:

In relation to the second and fourth terms of reference, I observe that the journey to a formal diagnosis of endometriosis is needlessly protracted despite its prevalence. I note this in the context of the severe difficulties my partner faced, but also to myself in providing her with support when confronted by a slow-moving and hard-to-navigate system. I also recognise that once a diagnosis was obtained, the care provided to my partner by nearly all nursing staff was beyond reproach. There were, however, doctors whose conduct was far less so.

I recognise that pain management is a difficult task given that my partner's symptoms were not ameliorated by surgery, as many others' are. The amount and variety of medications she must take to alleviate just a fraction of her pain cause numerous physical difficulties – including nausea, lack of sleep and others – as well as practical ones, including the fact that she is often rendered unable to drive safely (or at least legally), further complicating an already complex situation.

I also state that the current resourcing for endometriosis patients in the ACT is painfully inadequate. Individual staff may be outstanding, but the current capacity for care does not inspire confidence in patients and those supporting them that they can receive timely and effective treatment, centred upon their experience of their condition.

In relation to the third term of reference, I highlight the significant limitations in the availability and quality of endometriosis treatment options in the ACT compared with other jurisdictions. I specifically outline that surgeons in the ACT public system tend to rely on ablation rather than excision surgery, potentially due to limited training and experience. While evidence comparing patient outcomes is mixed, ablation cannot remove deep infiltrating endometriosis, raising concerns that long surgical wait times may allow disease progression, resulting in increased pain, reduced quality of life and potential loss of fertility. These risks may be mitigated through targeted upskilling and recruitment of surgeons capable of performing excision surgery.

I also identify gaps in pain management options. Despite promising research, the ACT trails other states in access to modern and trial treatments. The withdrawal of pelvic floor botox from the public system has forced patients to rely on expensive private providers, exacerbating inequity and financial strain. Additionally, medicinal cannabis remains unavailable as a pain management option in the ACT, with no local trials and unfair road rules discouraging its use even when prescribed. Together, these shortcomings limit effective pain management, deepen social isolation and restrict patients' ability to work and participate fully in daily life.

In relation to the fifth term of reference, I note the significant financial impact endometriosis has had on my partner and the economic consequences for the broader Australian community. She is only able to work four days a week, limiting her earning potential as well as her opportunities for professional advancement and career satisfaction. These pressures create further strain in addition to the intense physical toll already caused by endometriosis and the cost of care to manage her symptoms.

I also observe that, due to the volatility of endometriosis – monitoring for flare-ups, planning holidays or even visits to friends and family around the proximity to a hospital and more – this condition has a deep impact on the social lives of the person that suffers from it as well as those supporting them. It is a profoundly lonely disease. The results of this inquiry must address these social and economic issues as much as the physical and medical ones. The former may be caused by the latter, but are no less significant for it.

I conclude my submission with a series of recommendations that also encompass the sixth and seventh terms of reference, covering professional medical education, access to and quality of care, expanding treatment options and research and clinical trial opportunities. I hope that my submission and those of others in the community serve as a catalyst for unprecedented funding for women's health in the ACT so that people suffering in the community today are the last generation to experience the misery of endometriosis.

As you read my detailed submission below, please remember the following: first, consider how crippling endometriosis must be for the partner of someone who has been diagnosed to take the time to write such a personal account. More importantly, consider how you might feel if you, your partner, or child were a victim of this disease. Ask yourselves what support they would need to live a full life.

TOR 2 - the barriers in the ACT to getting a diagnosis and gaining access to treatment including primary care, specialist clinics and ongoing pain management for these conditions, and; TOR 4 - the role of medical misogyny, underlying gender biases in healthcare and cultural norms that create barriers for women with these conditions

Journey to diagnosis and gaining access to treatment through primary care and specialists

My partner's diagnosis from the onset of her persistent pain was comparatively rapid, however it had been over a decade since the first warning signs of endometriosis. Months of heavy bleeding every day, period pain considered 'normal' that really was not, and even a presentation to hospital. Most Australian women wait more than 6 years for their endometriosis to be diagnosed (Endometriosis Australia), and while I initially was heartened that the time elapsed between her first constant pain and surgery was two years, I soon came to realise that my partner had in fact been suffering for more than a ten years.

My partner developed consistent pain symptoms early in our relationship during the COVID-19 lockdowns of 2021. After management with regular painkillers proved inadequate, I supported her in presenting to Canberra Hospital's emergency department where, after several hours, staff suggested that her pain was caused by an unidentified gastrointestinal upset that would soon pass. Her pain was so intense that she was prescribed intravenous morphine, monitored and sent home once her pain had subsided. This did not last long, and she presented to hospital again in the coming weeks and months where she received similar treatment and rapid discharge, characteristic of our health system (especially during the upheaval of the pandemic).

I was dismayed that it took more than 18 months of investigations by several Canberran gynaecologists (including those at the precursor to the Canberra Endometriosis Centre) for endometriosis to be suggested. I was even more distressed to learn that in early 2023, despite my partner's ongoing, severe and progressively worsening pain, she had been labelled a Category 2 patient (semi-urgent, requiring surgery within 90 days - AIHW, p. 8) for exploratory pelvic surgery to diagnose and remove any endometriosis lesions. Despite her triage category, she was told that she would likely wait more than 18 months for her surgery to be performed publicly, so we considered seeking the procedure privately. However, as young renters balancing work with our studies, the exorbitant cost was out of our reach.

I was excited one Wednesday in August 2023 when I received a call from Canberra Hospital Services offering my partner surgery the following Monday after a short-notice cancellation. My partner had been unable to take the initial call – she was on placement at a local Canberra school. Faced with an end-of-day deadline to accept the offer of surgery, my partner rescheduled the remainder of her placement and was operated on the following Monday.

The care she received throughout the surgery was exemplary. The surgical team and ward nurses treated her with dignity and respect, going above and beyond in recognising the importance of my company and support as her first post-surgery visitor despite visiting hours having ended much earlier in the day. She was diagnosed with advanced endometriosis – Stage IV – which had been excised entirely during the surgery and was then discharged the following day. Her recovery was slow and agonising, however we clung to the hope that my partner would be one of the ~70% of women whose symptoms improve following surgery. This was not to be.

Endometriosis care in the ACT

When this inquiry was proposed in the ACT Legislative Assembly in December 2025, the Minister for Health noted the following with respect to the Canberra Endometriosis Centre:

- A dedicated project officer has been assigned to the Centre staff on a temporary basis to February 2026, with the possibility of a 6 month extension as a measure to shorten the wait time for patients seeking treatment and advice;
- Efforts have been made to 'improve Centre staff capacity';
- The Centre offers bi-weekly group support sessions for patients;
- Two full-time psychologists who deliver group support sessions;
- Ethics assessments are being conducted into the possibility for formal research to be conducted through the Centre, and;
- Announced that two nurses at the Centre have completed specialised training for endometriosis patients delivered by the Australian College of Nursing.

This does not excite or reassure anyone with endometriosis in the ACT that they can receive timely, effective and patient-centred care. Based on 2021 ABS Census results and current research, approximately 19,098 women aged 10-49 in the ACT live with endometriosis.

***It is unacceptable** that anyone in government could consider the Centre – at its current capacity and capability – to be an effective public health initiative without significant reform, expansion and additional funding.*

Ongoing pain management

My partner is among the roughly one-third of endometriosis patients whose pain did not improve following surgical intervention (The Royal Women's Hospital). She has trialled countless hormonal birth control medications to ease her symptoms, however these have been ineffective. Her goal has shifted to seeking pain management from finding a medication that slows regrowth of endometrial lesions with the fewest negative side-effects while preserving her fertility. As a 26 year old following her traumatic treatment as a gynaecology patient at The Canberra Hospital, she was placed into temporary, pharmaceutically induced menopause to reduce her pain. This too failed, while the side-effects of other medications have resulted in significant gastrointestinal symptoms requiring concurrent investigation and ongoing management.

We present to Canberra Hospital's Emergency Department several times each year where we are treated with exasperated compassion. Nurses who have seen so many people like my partner offer a wincing smile while applying all that they have learned to make her more comfortable. These visits are preceded by a gradual escalation in medications at home that starts with my partner's daily cocktail of medication, which merely allows her to function while still in significant pain. Then opioids are introduced. By this stage the pain is so intense and unremitting that she is nauseous and takes an anti-emetic. If this is still not sufficient to ease her pain and discomfort enough to allow her to fall asleep, then a sleeping tablet is added.

For her own safety and that of those around her, she is often unable to (legally) drive to work, necessitating short-notice flexibility or sick leave. I have lost count of how many times we have presented to hospital having exhausted the medications available at home, unable to safely to take any more. Our hospital visits are far outnumbered by the times I have found my partner collapsed on the floor, eyes scrunched in pain, unable to breathe and fearing unconsciousness. Again. In the Australian state or territory with the highest median income (Australian Bureau of Statistics), it is cruelly surreal that safe and effective endometriosis pain management is so lacking in the ACT.

Barriers to and quality of care in Canberra, including medical misogyny

In the two years since her surgery, my partner has been threatened by a prominent Canberra specialist who suggested they would refuse to treat her because she had not followed the instructions which the same specialist had never provided to her. The same leading Canberra gynaecologist suggested she consider pregnancy immediately to mitigate possible infertility later in life when she may want to have children, as well as to ease her physical pain. She has been admitted to Canberra Hospital and treated alongside mothers celebrating the safe arrival of baby loved ones while wondering whether endometriosis has robbed her of the possibility of having her own children. Her tears of fear and agony have been dismissed by a female gynaecologist at The Canberra Hospital (leading a group of trainee doctors) as being nothing more than the result of anxiety and prescribed Valium not to treat her pain or muscular spasms, but her supposed emotional state during a prolonged flare. This reflected a shamefully outdated and invalidating notion still widely held across healthcare: that women’s pelvic pain is exaggerated and that female patients complaining of discomfort are ‘hysterical’, drug-seeking or mentally ill.

The quality of care in Canberra has solidified the reputation of the public health system as being unable to treat patients in a timely fashion nor recruit suitably competent specialists and surgeons. No doubt understaffing is part of the reason that surgeons in Canberra are unable to perform procedures (endometrial lesion excision) that have been proven to be more effective in removing and slowing regrowth of endometriosis tissue than ablation. However, the culture and work environment within The Canberra Hospital's Gynaecology and Obstetrics Department has been publicly recognised as damaging to patient care and outcomes. Recent failures to receive training accreditation from the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), resulted in provisional arrangements and rushed recruitment to meet remediation deadlines. Three years later, issues continue to plague the Gynaecology and Obstetrics Department including failures to meet RANZCOG standards concerning safe and respectful workplace behaviour, staff rostering, trainee supervision, team structuring, a lack of surgical opportunities for trainees and paid CPD. The consequences of these shortcomings are an unconscionable and persistent barrier to women in the ACT who suffer from endometriosis and pelvic pain receiving high-quality care befitting of our nation's capital.

TOR 3 - the treatment options and supports available in the ACT compared to other jurisdictions, their evidence-based effectiveness and potential side effects and impacts

I address some aspects of the ACT public health system's shortcomings with respect to available endometriosis treatment and pain management options, surgery wait times and the Canberra Endometriosis Centre earlier in this submission. The following section relates to the availability of surgical options, pain management and allied health support in the ACT.

Surgical options available in the ACT

Anecdotally, gynaecological surgeons in the ACT's public health system have limited training and ability to perform excision surgery on endometriosis lesions in women, instead relying on ablation surgery to remove abnormal tissue growth. While there is little peer-reviewed evidence suggesting that one surgical approach is better for pain relief and improving fertility, a study has shown that ablation surgery cannot remove deep infiltrating disease. Instead, it is unclear whether more severe endometriosis can be effectively removed. Noting the protracted delay between first consultation and diagnostic surgery/removal of endometriosis lesions for women in Australia, it is reasonable to infer that the longer women with endometriosis wait for surgery, the greater the likelihood that the endometrial lesions may progress from superficial to deep-infiltrating disease. The consequences of this may include increased pain, poorer quality of life and decreased/loss of fertility, all of which could be addressed by an upskilling/recruitment of surgeons in the ACT to perform excision surgery.

Endometriosis and pelvic pain management options available in the ACT

Ongoing research into endometriosis and pelvic pain management options in the ACT reflect a more progressive approach to women's health in the medical community. However, the ACT trails other jurisdictions in Australia with respect to modern and trial pain management options. Notably, this includes the withdrawal of pelvic floor botox as a pain management strategy available through Canberra Health Service. This decision continues to receive significant attention from the local endometriosis community and medical professionals who agree that it is an effective option that worthy of reconsideration. It is the subject of a current petition to the ACT Legislative Assembly, which I encourage the Committee to review and investigate as part of this Inquiry. The absence of this pain management option through the public system has allowed for the monopolisation of pelvic floor botox among the few gynaecologists in the ACT trained to perform the procedure safely. In turn, this has forced women whose earning power may already be limited by the physical constraints of their pain to self-fund such procedures, the pricing of which can be exorbitant and beyond reach for many in the community. It is imperative that this is addressed to avoid situations similar to the one outlined here, in which an endometriosis patient has needed to crowdfund to afford surgery to improve her quality of life.

Medicinal cannabis as a pain management option for endometriosis remains underutilised and poorly understood in the ACT. To date, the ACT has not supported any trials into the use of medicinal cannabis as a pelvic pain management alternative. Academic research being undertaken at several universities continues to explore the efficacy of medicinal cannabis for pelvic pain management in both NSW and Victoria, however participants from the ACT are unable to participate. Furthermore, despite the ACT's progressive stance towards the possession and personal use of cannabis and other illicit drugs among the community, no provisions exist in the current road rules (see p. 23) that allow a driver to operate a vehicle with traces of medicinal cannabis in their system when it has been prescribed by an Australian doctor and does not impair their cognition. This remains a key barrier to endometriosis and pelvic pain patients seeking to explore medicinal cannabis for pain management, exacerbating both their social isolation and ability to attend work legally and independently.

TOR 5 - the economic and social impacts of people in the ACT with these conditions, including education, employment and lost productivity

Economic impact

My partner works a 4 day week so that she can attend medical appointments and hydrotherapy on a Friday, or else try to recover from the pain she has masked throughout her week at work. Endometriosis has robbed her of 20% of her possible income on this basis alone, setting aside diminished superannuation earnings, delayed progression and bias in her workplaces for needing to take sick leave or flexible working arrangements. This disease is the key barrier to greater financial security and merited professional progression during an unprecedented cost of living crisis. It is among the decisive barriers to her ever pursuing a career as a teacher in a time when society needs so many more in her mould. Her ongoing work as a public servant is recognised within and beyond her department, benefitting the wider community, but only at 80% of what could be. This disease and our failure to find safe, ethical and affordable treatment and management options in the ACT is costing my partner and society in unequal measure.

Add to this that high-quality gynaecological care for endometriosis is hard to find in Canberra. So rare that my partner and I now travel to Sydney for specialist care. Her medications cannot be dispensed in useful volumes, necessitating almost weekly visits to local pharmacies to purchase restricted prescription medications, one of which was only added to the PBS in 2025. Combined with regular pelvic physiotherapy appointments, hydrotherapy, GP visits and other related costs, my partner spends a spectacular amount of her already reduced income simply trying to survive the week, let alone preserve her fertility, mental health, continue affording rent and maintaining our relationship while supporting other family members.

Social impact

Endometriosis has shrunk our lives almost beyond recognition. My partner is a devoted daughter, granddaughter, aunt and cousin, yet every family engagement is marred by contingency planning for flares, questions about whether she is safe to drive based on medications she has taken, her fatigue and mood. Not a day passes that I do not ask my partner about her pain, and very few go by without similar concerns from loved ones. We are unable to spend quality time with family and friends because we must pace ourselves, choosing whether what little of our remaining energy and patience can be spared for our inner circle or needs to be preserved so that we can manage another week without opioids, or increasingly, a hospital visit. Our first consideration when travelling away from home is never packing clothes or refuelling. It is the proximity of our accommodation to the nearest hospital.

Endometriosis is a profoundly lonely disease despite its prevalence. Family and friends can offer little more than words of encouragement and well-intended questions concerning pain management. Most helpful are the meals cooked by loved ones. This seems absurd for a young couple without children in their late twenties. This is what we hope for and expect in support of aging relatives, not people in what ought to be their best years. This loneliness affects me as my partner's primary support person, but is far worse for her. I am at a loss to quantify how many hours we have spent in tears wondering how this experience can be so damaging and distressing in spite of our support network.

Meanwhile, the strain endometriosis continues to place on our relationship is immeasurable. The pain I feel as my partner's helpless confidante, carer and supporter is only exceeded by her physical agony and misplaced guilt for burdening me with the responsibility of looking after her. Endometriosis has exhausted us beyond all measure and frustrates us more than we care to admit, threatening our senses of self. The lines in our lives between person and disease, partner and carer are continuously blurred. The tension within and between us often feels too much to bear, but we are lucky to share a strong and loving bond. I challenge you to imagine your lives being similar to ours, or even worse, like my partner's but all alone in our community. Endometriosis has – for now – claimed much of our quality of life and many of our aspirations. This is a shared experience in the endometriosis community and for some, it can have even more tragic consequences.

Recommendations:

The harm of this debilitating disease is not limited solely to social impacts or financial consequences. Our quality of life has declined in the years since my partner's endometriosis pain became constant. No medication or surgery has ever eased her pain. We are plagued by anxiety about what our lives might look like if her symptoms continue to decline on this trajectory. It is impossible to believe that endometriosis affects at least 1 in 7 Australian women (almost 2 million women nationally) without a cure, effective management or hope, while diabetes affects 1.3 million Australians and has deservedly been researched to the extent that it can be managed safely without side-effects using lifestyle modifications, medications and/or injections.

It is a common trope in the dark humour of the endometriosis community that there would have been a cure decades ago if this disease affected men. This Committee has the opportunity to make meaningful recommendations based on this Inquiry that will help endometriosis and pelvic pain sufferers and their support people in the ACT. I encourage the Committee to consider among these the following:

- *Canberra Health Services endometriosis education*
    - Incorporating comprehensive, evidence-based contemporary endometriosis training for all emergency department and public hospital gynaecology ward nurses, doctors and allied health staff, and;
    - Offer additional financial and/or career progression incentives (beyond hours towards annual continuing professional development to maintain AHPRA registration) unique to the ACT to encourage nurse enrolment in the Australian College of Nursing's Endometriosis and Pelvic Pain unit of study.
- *Changes to endometriosis diagnostic and management services in the ACT*

    - Reinstatement of pelvic floor botox as an endometriosis and pelvic pain management approach available through the public healthcare system, and;
    - Invest in developing and establishing a gynaecological workforce and facilities (both in the public and private systems) capable of performing deep infiltrating endometriosis (DIE) ultrasound scans to reduce the burden on public surgery waitlists and the Canberra Fetal Assessment Centre (only able to conduct transvaginal ultrasounds, not DIE scans) for diagnostic laparoscopies by supporting the detection of endometriosis lesions and regrowth. *This recommendation notes that surgery remains the gold-standard diagnostic tool to diagnose and remove endometriosis lesions*.
- *Improvements to ACT endometriosis care investment, research and reform*
    - Investment in/incentivising endometriosis research through the public healthcare system's Canberra Endometriosis Centre. Possible partnerships include opportunities to collaborate:
        - **Locally** with the ANU School of Medicine and Psychology (and its Research School of Biology, currently researching the structural basis of endometriosis) and UC's Research Institute of Sport and Exercise (conducting studies on the psychology of endometriosis pain and deep brain stimulation for endometriosis pain management);
        - **Nationally**, with the Ainsworth Endometriosis Research Institute (AERI), the National Endometriosis Clinical and Scientific Trials Registry (NECST) and other Australian medical research institutes and universities, and;
        - **Internationally**, such as with the World Endometriosis Society.
    - Investment to attract, train and retain compassionate and skilled gynaecologists trained in endometriosis excision (not just ablation) and the administering of pelvic floor botox to Canberra Health Services to expand the surgical workforce and alleviate wait times for public patients;
    - Employ an improved model of care that incentivises more gynaecologists in the ACT to work in both public and private settings, providing more equitable access for people with suspected endometriosis to high-quality treatment.
- *Inclusion of endometriosis in ACT primary and secondary school curricula*

  - Mandating clearer, more detailed gynaecological education as part of the sexual health curriculum in all ACT schools to empower young women with the awareness and knowledge of what endometriosis is and to recognise when they may be experiencing pelvic pain and period symptoms that warrant safe conversations with a medical professional.

- *Proposed ACT legislative and regulatory reform*
  - Amend legislation prohibiting patients who use prescribed medicinal cannabis from driving. An ongoing inquiry in NSW and emerging research suggest that medicinal cannabis does not impair cognition when driving any more than other medications that are not prohibited for drivers in the ACT. Medicinal cannabis already offers relief to chronic pain sufferers and may become a standard treatment option for endometriosis patients pending the outcomes of current research.

I am eager to appear in person before the Committee as part of its inquiry to elaborate on this submission and answer questions based on my experience as the partner of someone living with endometriosis. I consent to this submission being published by the Committee, **however I do not want my name to be included when this document is uploaded to the Legislative Assembly website.**

Please take this opportunity to strive for better endometriosis and pelvic pain care.

Yours sincerely,

[redacted]