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

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 032

Submitter: Name withheld

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Dear Committee members

Thank you for undertaking this inquiry on endometriosis and other pelvic pain conditions, this is important and timely.

I was recently diagnosed with Endometriosis and Adenomyosis through the ACT health system at the age of 35.

I am happy for my submission to be published but would prefer to be anonymous due to the personal detail I have included.

I have attached my personal diagnosis timeline and have responded to your terms of reference. Please feel free to reach out if I can be of further assistance.

Thank you again for the opportunity to make a submission, I am optimistic that even a small change that comes as a result of this inquiry will make a positive impact to many in the ACT.

Kind regards

[redacted]

[redacted]

[redacted]

My diagnosis timeline:

I have had painful periods my whole life and I have been on and off hormonal birth control in my adult years.

In 2012-2015 I began to have migraines and uncontrollable vomiting. At the time it was very hard to get into a regular GP in the ACT as many were not accepting new patients, so I was attending walk-in centres when I could not stop vomiting to receive treatment for my migraines, get my contraceptive scripts renewed etc. Eventually I got into a regular GP in 2015 and was informed that I needed to come off my contraceptive pill because it was a combination pill with estrogen and I was having migraines with a visual aura -this meant I was at risk of having a stroke and could be sensitive to the estrogen.

I came off the pill, tried the mini pill and it made me feel very emotionally unstable, I had started getting abdominal pain during other times in my cycle, not just my period, my doctor thought it was stress – I started seeing a psychologist for anxiety. I came off the mini pill as it was not improving my emotional state and my doctor put me on Implanon. The Implanon worked, but my cystic acne returned even worse than before and I gained a lot of weight. I did a course of Accutane for the acne.

Further, after a painful pap smear, my GP noted that I may have vaginismus and to see a women's health physio. This was helpful and improved things somewhat for that condition.

In 2020, I began to experience severe sciatic pain daily. An MRI showed a bulged disc in my lower back. I saw an osteopath and a physio ongoing for many years with some good improvement in mobility and pain, but it would come back every couple years.

When my osteopath initially saw my MRI in 2020 (provided from the GP) he noted that there was reference in the radiologists notes that there was a cyst on my ovary and I should get checked for PCOS. I spoke with my GP about the cyst as this was never brought up with me when we reviewed the scan and he said that sometimes cysts can just disappear and it may not be anything to worry about.

In 2022, I had to leave a job I had worked hard to get because I could not manage my daily sciatic pain and period pain adequately and was unable to work from home. I felt I couldn't say the real reason why I was leaving due to the stigma and also not being able to explain why I was in pain.

In 2024 my back pain came back more intensely, previously my back pain would flare up and it would take 3-6 weeks to see a change. I had to take 2.5 months off work this time around because the pain and inflammation would not settle and I had loss of mobility. I was still seeing my osteopath and physiotherapist, and I also saw my GP who would not give me more pain relief after the initial 4 weeks – I was initially on Mobic but she said I should take Panadol if I was still experiencing the pain. I was able to return to work thanks to my wonderful osteo and physio.

In 2025, I began having more persistent abdominal pain having to take Panadol/ibuprofen every day to cope with daily tasks. My period pain was getting so bad that I was having to use naproxen, heating pads and a tens machine just to get through the day and even then I was still in pain. My osteopath suggested that I should look into endometriosis.

I raised this with my GP, she agreed that it would be worth looking into and I was referred to CFAC for a transvaginal ultrasound. I had to wait 5 months for an appointment. My GP did not talk with me about pain relief, she just said to keep doing what I was doing.

I began to miss a lot of work whenever I had my period and had to plan my whole life around only having maybe 1 good week a month where I was not in pain. Thankfully, I am in a job where I feel confident to ask for accommodations like working from home so I could still work and do pain management/be comfortable when I needed it.

My scan at CFAC was fantastic, I just wish it was less of a wait. The technician was very kind about my pelvic pain and vaginismus, and I had a pain-free scan because of her patience. My ultrasound showed endo and possible adeno plus the same cyst on my ovary from the MRI was likely an endometrioma.

I went back to my GP who referred me to a gynaecologist – I feel very lucky that I have friends who have endo, and they helped me work out who I should see and who to avoid – I felt like I had to go armed to this GP appointment with exactly what I wanted in terms of referral because I had not been listened too before, or been made to feel like I had missed out on things being picked up on because I hadn't specifically raised them. I was pressured to get the Mirena, which I did not want as I was having more issues with vaginismus and pelvic pain and didn't want to add another thing into the mix without consulting a specialist.

I did not expect to be grilled by my GP and asked to justify why I did not want the Mirena, or have so much pressure put on me about deciding to have children or not. I was clear with her that my goal was to improve my quality of life, reduce the amount of pain I was in and everything else was secondary. The whole appointment felt very pushy and she even wrote in my referral letter to encourage the specialist to speak to me about the Mirena and decision-making about fertility. I had to ask about alternatives to the Mirena before she would take me through other options like Slinda. I have since changed to a new practice after attending the same practice for over 10 years.

I had to wait another 3 months to get into the specialist, but from that appointment it was much more straightforward. I had a surgery date and she confirmed that I did not need to go on the

Mirena, that often Slinda could be just as or more effective. She also was not insensitive about fertility – she listened to my choice and did not question or doubt my decision. Based on the ultrasound she provided me a range of options from least to most intensive. I decided to go ahead with a laparoscopy and excision and once we had more info from that, make a choice about hysterectomy or not (for the adenomyosis).

I had my surgery in December 2025, and I'll have to go back again for the hysterectomy and a bowel resection as there were too many adhesions to do the bowel without a colorectal surgeon present. I'm feeling much better than I was before surgery and it has improved my life immensely.

My new GP is amazing, she's very hard to get an appointment with though which is hard when you have a chronic illness. She informed me about doing a chronic condition plan for allied health appointments (my previous GP never mentioned this) and pointed me back to the pelvic physio who thinks my ongoing sciatic pain may be caused from having a tight pelvic floor and referred pain from the pelvic region "guarding" due to my pain and trauma over the years.

Going to your specific terms of reference:

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;

Using my story as a case study, at no point was there anyone who joined the dots except for my allied health care team right at the end, who went the extra mile for me and helped to review my medical history and point me in the right direction. (Big thank you to Macquarie Osteopathy)

I think another barrier is cost – I was able to go privately for my surgery and afford the specialist endometriosis scan and all my non-bulk billed GP appointments, and have private health for my allied health appointments. I think this helped with getting treatment faster once I has in the correct "pipeline".

I also think that there is a lack of consistency when accessing primary healthcare through GPs. I was attending the same clinic for 10 years and I was often unable to get in for appointments for weeks at a time, or had to see different GPs and repeat my whole medical history again. The focus was almost always trying to categorise one problem into a body system rather than looking at the big picture of medical history. Appointments were expensive, rushed and not built for people with complex issues or if you have too many questions they would charge for a longer appointment. My issues were minimised and I was rushed out.

If I had to summarise this, I'd put it into four categories:

Factors influencing long diagnosis times

- Normalisation of pain: Patients and healthcare providers may treat debilitating pain as "normal" menstrual issues.
- Lack of holistic big picture view from GPs: symptoms treated in body individual systems (e.g. neuro, muscular, skeletal etc)
- Lack of Biomarkers: There is no easy, non-invasive diagnostic test, making diagnosis reliant on imaging or surgical laparoscopy.
- Socioeconomic Factors: Costs of private care and access to specialists impact how quickly patients get a diagnosis.

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 felt like I was in so much pain that I could not cope with travelling, so I opted to stay in the ACT. I found the Qendo ACT support group on facebook to be the most useful place to get information and recommendations.

I am concerned, especially following the 4 corners investigation, about the qualification of specialists available in Canberra – how do we know if they are specialists for endometriosis and adenomyosis or just gynaecologists? It feels a lot to take that on as a patient.

There are only a handful of specialists here and many more based in Sydney. If I had to wait longer for my appointment with the specialist I would have considered going to Sydney.

There is a special ultrasound in Sydney that has much faster wait times as well.

4) the role of medical misogyny, underlying gender biases in healthcare and cultural norms that create barriers for women with these conditions;

Reflecting on my story, I think I did experience medical misogyny several times. The minimisation or dismissal of pain or symptoms is incredibly frustrating, and tiring. I have avoided going to emergency because I know how my friends have been treated and I'd rather ride out the pain in bed at home than be ignored in a waiting room and made to justify why my pain scale is different from someone who does not have endo and not receive adequate care or get labelled as "drug seeking".

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

I believe that the most impactful outcome would be to classify or define endometriosis as a disability (the NDIS doesn't currently do this), so it affords women appropriate protections at work and the ability to access additional support.

Workplace impacts:

Personally, in the last 2 years (in the peak of my chronic pain) I have taken about 4 or 5 months off work from endo related pain, referred pelvic pain or recovery from surgery. Again, I am in the fortunate position to have banked a lot of personal leave with my job and to have a boss who is understanding about allowing me to work from home on high-pain days, so I don't always need to take the day off work.

Generally, we know that Endometriosis drives up absenteeism and lost productivity at work leading to over **$9.7 billion** in costs to Australian society annually. Nearly two-thirds of this is from lost productivity (absenteeism & presenteeism).

For people with endo, 1 in 3 have been passed over for a promotion. 1 in 6 have lost their employment. I have had to leave a job because of endo (although I didn't know it was endo at the time).

Inflexible work environments often force employees with endometriosis to take more sick days, reduce their hours and shoulder financial strain. For employers, this results in higher absenteeism, lower retention and lost productivity, issues that can be prevented with supportive workplace practices.

I have advocated for a trial of the EndoThrive program to be run in my workplace this year (EndoThrive Workplace Accreditation for Endometriosis - Endometriosis Australia)

Personal financial impacts:

In the last 2 years (my most intense period of endo symptoms):

- $4,953 in allied health appointments
- $263 on medications and chemist products (e.g. voltaren or arnica creams, scar gels after surgery etc)
- $710 on GP appointments at my previous practice
- $634 on GP appointment at my new GP's practice (since October 2025)
- I have received $1,073 in Medicare benefits
- I spent approximately $7k on my surgery and $500 on my anaesthesiologist in December 2025.
- My ultrasound cost $320
- My specialist appointment was $450

I have not included the cost of sanitary products, supplements, my purchases of heat devices or tens machines as it is hard to estimate this accurately. I have also not included things that my partner has purchased on my behalf.

At a lower-end estimate I've spent about <u>$13,757</u> over the last 2 years. Not everyone can afford this – I am in a dual-income no kids family.

Social impacts:

I have had to stop playing community sport and had to stop volunteering at and attending my church due to pain. This is a really isolating disease, I pretty much go to work and then the fatigue takes over so I spend my weekends recovering and don't have a social life. My extended family lives in Melbourne and I haven't been able to travel to see them in the last 2 years because I'm frequently unwell. My sciatica makes it difficult to drive and so I am often reliant on my husband for transport. It places an additional burden on my husband to manage the domestic duties when I'm unwell, drive me to appointments and take time off work to care for me following surgeries.

6) <u>education available to medical professionals, allied health professionals, young women and others, on these conditions and treatment options;</u>

I felt like I have had to earn my own honorary medical degree to be able to adequately advocate for myself and suggest scans or medication to my GP to get any action. I feel like GPs can do much better than they are doing, this condition affects 1 in 7 women and those presumed female at birth… for comparison, the ABS says that in Australia approx. 12-13% of females have asthma and 4.9% have diabetes. Just over 14% of women have endo and it is still not well known.

It is also worth noting that if someone has a chronic illness they are likely to have other conditions – people with endo are more likely to have heart issues for example.[1]

7) research and trials currently being explored in Australia and opportunities for this to take place in the ACT; and

I don't have anything specific to say on this – I get targeted advertising on social media to take part in trials through UNSW, Deakin and Flinders Uni on various endo-related subjects like medical marijuana, hypnotherapy, wholistic programs to reduce pain etc. However, I am ineligible to participate as I've just had surgery. None of these are Canberra based.

I am particularly interested in the link between GLP1s and the inflammatory pathways (which is a hallmark of endometriosis) and using this to reduce systemic inflammation, reduce pain, manage blood sugar instability and decrease estrogen production that drives lesion growth. I have included some relevant studies in the footnote.[2] This is an area of emerging research that could suggest GLP1s can help manage endo symptoms although is not a direct treatment.

This is my general summary of why I think we have gaps in women's health research and less understanding of conditions like endo, PCOS and menopause – it's under-funded and under-studied:

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[2] Desai, S. N., Reed, C. C., Mendez, Y., Yang, Q., & Guan, X. (2026). The Hidden Link Between Endometriosis and Obesity: A State-of-the-Art Review. *Cureus*, *18*(2), e102896. https://doi.org/10.7759/cureus.102896
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- Persistent Data Gap & Underrepresentation: Female cohorts are underrepresented in clinical trials, with even basic lab research historically relying on male cells, limiting understanding of sex-specific physiological differences.
- Delayed Diagnoses: On average, women are diagnosed four years later than men for various health conditions, including diabetes and cancer.
- Underfunded Conditions: Conditions exclusively or predominantly affecting women—such as menopause, endometriosis, PMS, and certain cancers—make up 14% of the disease burden but receive less than 1% of research funding.
- Male-Centric Medical Standards: Diagnostic tools and treatments are frequently tailored to male symptoms and bodies, leading to poorer health outcomes for women.
- Menopause Research Void: Despite its universality, menopause remains a taboo subject with substantial gaps in scientific knowledge regarding its treatment and management.

Women's health research suffers from a significant funding and data gap, with only 3.3% of government research funding dedicated to women's health in 2023-24

Research heavily relies on male biology, causing delayed diagnoses for over 700 diseases and leaving conditions like endometriosis, menopause, and PCOS under-studied.

Closing these gaps could yield seven additional healthy days per woman yearly and unlock up to $1 trillion in global GDP by 2040 (*Source: World Economic Forum*).