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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[redacted]

From: [redacted]
To: LA Committee - SP
Subject: Submission for EPPC inquiry
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Dear Inquiry members,

My name is [redacted], and I'm a Canberra teacher who spent 15 years trying to get answers for pelvic pain that was eventually diagnosed as endometriosis and adenomyosis this year. I'm writing this submission because the delays, the dismissals, and the gaps in care have shaped my life in ways that were completely avoidable — physically, emotionally, financially, and professionally.

I first started seeking help for pelvic pain 15 years ago. Over that time, I repeatedly raised symptoms that were severe, disruptive, and clearly not normal: chronic pelvic pain, heavy bleeding, inflammation, bowel symptoms, and pain that would spike without warning, sometimes resulting in fainting or vomiting. Despite this, I wasn't diagnosed until this year.

Fifteen years is a long time to live with pain that no one is willing to properly investigate. It affects how you move through the world, how you plan your days, how you trust your own body, and how you trust the medical system.

I'm a [redacted] teacher, which means I can't just quietly push through pain at a desk. When the pain spikes, it's immediate and incapacitating. There have been days where I've had to take leave at short notice, and other days where colleagues have had to step into my classroom while I waited for pain medication to kick in. It's embarrassing, unpredictable, and professionally disruptive.

I've lost count of the days I've had to take off because the pain was too severe to stand, teach, or even drive safely. Teaching requires consistency and presence, and chronic pelvic pain makes both incredibly difficult.

Over the years, I've spent thousands of dollars on GP appointments, specialists, scans, and tests — often with no real answers. One of the clearest examples of the system failing patients is the fact that I had to travel to Sydney for a Deep Infiltrating Endometriosis (DIE) pelvic ultrasound because the wait time in Canberra was seven months. I couldn't wait that long, so I paid for the scan, the travel, and an overnight stay. That's a significant cost for something that should be accessible locally and in a timely way. When you're already exhausted from pain, adding financial stress and interstate travel just to get basic diagnostic imaging is unreasonable.

One of the most difficult symptoms to talk about — and one that was never taken seriously — is the severe cramping I experience after orgasm. It has had a major impact on my dating life and my ability to form intimate relationships. It's not something people talk about openly, and because clinicians rarely ask, I spent years thinking it was something I just had to tolerate. Sexual pain and post-orgasm cramping should be recognised as legitimate symptoms of pelvic pathology, not something patients are left to navigate alone.

The first gynaecologist I saw this year was a turning point, but not in a good way. Despite knowing I have an eating disorder history, she:

- pushed weight loss as the primary solution
- suggested weight-loss surgery as the only way I would lose weight
- refused to perform the surgery I needed until I lost weight
- didn't explain the findings clearly
- charged over $500 for a half-hour appointment that left me distressed and ashamed

For someone with an eating disorder, this kind of interaction isn't just unhelpful — it's dangerous. It also delayed my access to appropriate care. Weight bias in gynaecology is a real barrier, and it has real consequences.

For years, I was also the primary carer for my parents. My father was emotionally and psychologically controlling, and the stress of managing his care — on top of my own untreated pain — took a huge toll. When he moved into supported care, my health noticeably improved. That alone says something about how chronic stress and chronic pain interact. Caring for others while your own health is deteriorating adds a layer of physical and emotional strain that the medical system rarely acknowledges.

My experience isn't unusual, and that's the problem. Based on what I've lived through, I believe the ACT needs:

• earlier access to diagnostic imaging, including DIE ultrasound, without interstate travel
• gynaecologists trained in eating disorders, trauma-informed care, and weight-neutral practice
• recognition of sexual pain and post-orgasm cramping as key symptoms
• multidisciplinary pelvic pain clinics that don't require patients to coordinate everything themselves
• accountability for excessive specialist fees
• clear pathways so patients aren't left navigating years of uncertainty

Fifteen years is too long to wait for a diagnosis. The physical pain is one thing, but the emotional, financial, and professional impacts compound over time. I hope this inquiry leads to meaningful change so that people in the ACT don't have to fight this hard, for this long, just to be believed and treated.

Regards,
[redacted]