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: 046

Submitter: Name withheld

Date authorised for publication: 28 April 2026

ACT Legislative Assembly
Inquiry into endometriosis and other pelvic pain conditions
LACommitteeSP@parliament.act.gov.au

Please withhold my name from publication.

I am writing this submission based on my personal experience of living with persistent pelvic pain as a result of childhood trauma, and being diagnosed in my late 20s with vaginismus, dyspareunia and persistent pelvic pain. I note that while these conditions overwhelmingly affect women, men and LGBTQIA+ people also experience pelvic pain disorders and I believe everyone should have equal access to treatment.

Unless otherwise specified, all medical experiences I describe in this submission took place within the ACT.

Medical conditions

Several years ago in my late 20s, I received a formal diagnosis of persistent pelvic pain, vaginismus, and dyspareunia (pain during sex). I was also previously diagnosed with irritable bowel syndrome (IBS). Vaginismus is caused by a bio-psycho-social event which can include rape or sexual assault, and is an involuntary response by the body to trauma. Pain commonly lasts for years or decades after the initial event, and it is not necessary to have been 'injured' to develop vaginismus, persistent pelvic pain, or dyspareunia as a result. Vaginismus is one of the leading causes of dyspareunia, and IBS is a common co-morbidity of persistent pelvic pain.

Overview

At the age of six I was the victim of a one-off sexual assault which, aside from the distress of the original experience, did not seem to particularly affect me throughout childhood or into adulthood. It was only through sharing medical experiences with female friends, and later accessing appropriate specialised medical care, that I came to understand that this assault had long-term impacts on my health and my body.

It was only after I was referred to specialised treatment that I was able to recognise in hindsight I had experienced painful symptoms throughout childhood and adulthood. I found that early in the treatment was the most difficult part for me, as I became acutely aware of the pain that I had been experiencing every day and perceiving as normal. Although it ultimately provided relief, the treatment could be painful and tiring. It was a slow and stilted process over the course of months and years, not weeks.

From the beginning, I was advised by my specialist physio to undergo psychological therapy at the same time as this treatment to address the mental health side of my condition. I was able to access subsidised therapy through a Mental Health Care Plan, but have still spent thousands out-of-pocket for my ongoing treatment. I have taken longer breaks in between appointments to save money, even though I benefit most from regular appointments of both therapy and physiotherapy.

I feel it is important for treatments to be available according to the individual needs of the patient, rather than limited to an arbitrary timeline. If I had only been able to afford a year of treatment with the specialist physio, my condition would have plateaued or deteriorated after that point. It is a years-long (or even lifetime) process. So far my symptoms have been managed, not cured. I am fortunate that I was in a position to pay out of pocket for specialised care at the time that I needed it. If I had needed treatment ten years earlier, it simply would not have been an option for me.

Timeline and medical experiences

In my case, all medical professionals I have dealt with have been women.

Around 2019, I saw a GP for my first recommended pap smear with no knowledge at the time that I had vaginismus. It was a physically and emotionally traumatic experience due to the pain of my conditions, history of trauma, and a lack of concern from this GP.

In hindsight, I do not feel that I was able to give informed consent as I had no prior knowledge of what was going to happen. I also did not feel able to stop the procedure when I was in extreme pain, and had no idea that this pain was abnormal. It was a painful and distressing experience for me and as a result, I chose not to see this GP again. I was especially concerned that this had happened to me with a GP who had a special interest in women's health.

It wasn't until speaking to other female friends two years later that I learned that this extreme pain during a pap smear wasn't typical. It was also around that time that I made the connection between the painful procedure and my experience of extremely painful sex (later diagnosed as dyspareunia). I had also only become aware of the existence of vaginismus after reading a magazine article about the condition.

Similar to our healthcare knowledge, I and many of my female friends rely on being told by other friends the names/practices of particular doctors or specialists that they have had good experiences with. Likewise, we warn each other about who to avoid when we have bad experiences. There are almost as many warnings as recommendations.

Referral and treatment

Fortunately, after raising my symptoms with my workplace physio she referred me to a specialist physio who worked on pelvic and sexual dysfunction. As there would be a waiting time, she suggested I first see a less specialised physio who focused on pelvic health. I went to one appointment with this first physio, but was alarmed by the suggestion of an internal examination at the first appointment, and did not return. In hindsight, this physio did not have a trauma-informed approach and I did not feel safe seeking treatment there.

In contrast, the specialist physio that I have seen for years now has a careful and trauma-informed approach, which I now consider the gold standard for what I expect from healthcare providers. Treatment for my condition required slowly building trust with my specialist, and knowing that my consent would always be sought, and could immediately be withdrawn. I have highly recommended this specialist to friends with endometriosis and related conditions, but most have been deterred by the cost of treatment which is entirely out-of-pocket.

I strongly believe that providing a trauma-informed approach to medical care benefits all patients, regardless of whether they have experienced sexual or other trauma. It has allowed me to feel more confident in advocating for myself in other medical contexts, as well as providing me with hope in the medical system.

Access to sedation for painful procedures

I had learned through word of mouth from a female friend that I could access a bulk-billed IUD insertion under general anaesthetic by travelling interstate. I was also able to have a pap smear while sedated, which would otherwise have been impossible for me (this was prior to at-home testing being available). Note: I had initially been referred by my GP to a private gynaecologist in the ACT for this procedure as they had a short waiting time, but was advised by a female friend that she had a very negative experience with this gynaecologist and I cancelled the appointment as a result.

Greater research into pelvic pain is required

While the procedure under anaesthetic was painless, the pain in the following weeks was severe, to the point that I missed around two weeks of work over the course of a month. As my pelvic area was highly sensitive and could interpret any pressure as pain, the IUD unfortunately triggered severe pain in the aftermath, and regularly during menstruation. This well outweighed the benefits of reliable contraception, and I had the IUD removed under general anaesthetic less than 18 months later. I would likely have not attempted this option if I was aware that it could trigger or worsen my symptoms.

Personal impact

Aside from chronic pain impacting my quality of life, this condition has significantly affected every physical relationship I've ever had and greatly impacted my approach to seeking a life partner. I am fortunate that I do not want my own children, because I could not imagine attempting pregnancy and childbirth with this pain condition and just one experience of medical trauma.

I am acutely aware that while I have had negative experiences with my health and with parts of the healthcare system, my experience pales compared to those of countless other women with endometriosis, adenomysis and persistent pelvic pain. My main barrier was a lack of education and financial access, not being disbelieved by medical professionals and facing a hostile system.

Access to treatment was life changing for me. It has greatly improved my standard of living, significantly reduced my chronic pain, and provided a pathway to having a physical relationship.

Accounts from other people in the ACT

- During COVID, one friend had to beg her doctor to push for her endometriosis surgery to be moved forward. It had been delayed as an ‘elective’ procedure during lockdowns, she was experiencing unbearable pain and could not psychologically cope with another period.
- Another with advanced and debilitating endometriosis was informed that she could not obtain a hysterectomy to permanently treat her condition yet, as she was not old enough for the ACT’s minimum age cap on elective hysterectomies.
- Other female friends suffering from endometriosis, adenomyosis and polycystic ovarian syndrome are often faced with a lack of research, limited treatment options, and intense stress about their fertility and relevant life planning.

Recommendations

- Subsidised healthcare that is **not limited to an arbitrary timeline**. For example, appointments per month/year with extensions available to patients where needed, and basing treatments on patient need rather than age guidelines.
- Baseline training and an expectation of **trauma-informed healthcare**, particularly for sexual and reproductive healthcare.
- Access to **subsidised anaesthesia or sedation** for patients with pelvic pain conditions, to enable them to access gynaecological healthcare they would otherwise avoid or be unable to access.
- **Greater funding for research into pelvic pain conditions** is required in order to provide adequate care to people suffering from these conditions, the vast majority of whom are women.

[redacted]