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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I am a woman based in the ACT with lived experience of significant, inadequately treated pelvic pain over an extended period of time, with real detriment to my life and that of my family. I am sharing my story with this inquiry in the hope that the ACT government will improve the care and education it provides women like me.

I first experienced pelvic pain 8 years ago, after the birth of my second child. The pain was constant and aggravated by everyday requirements such as waistbands of pants. At this time, my periods were debilitating; I could not stand or effectively care for my children until each period was over. At that time, I saw a general practitioner (GP) who referred me for an ultrasound. This ultrasound suggested that the issue could stem from adenomyosis and my GP therefore treated me for this (insertion of an IUD). This was initially effective at bringing the pain to a manageable level.

Toward the end of the period that the IUD was able to remain in for, the IUD moved. Initially this caused pain only when I lifted things, but this gradually progressed to a point where I was unable to stand due to the pain. My GP referred me to the Pelvic Pain Clinic at the Public Hospital and I was placed on a waiting list for an appointment in March 2023. When the pain became too much, I was unable to get a GP appointment quickly so I removed the IUD myself. This helped immensely, and for about 12 months I was in a manageable amount of pain. I was still unable to wear tight-fitting clothes without pain, but was able to walk around and do usual things.

I then began experiencing severe abdominal pain, fever and nausea. I went to see my GP, who sent me for various tests (blood and urine) to assess whether I may have had a urinary tract infection (UTI) or other issue. I appeared to have a UTI and was treated for this. However, my symptoms remained and after a few weeks the pain became so severe that I could not move. At this point I went to hospital, where it was discovered that my appendix was inflamed, and was removed.

Since the appendectomy I have been in near-constant pain (8 months). My first menstrual period following the surgery was the worst I have ever experienced; I was in extreme pain (despite taking pain killers), even when doing simple activities like moving from the house to the car. I saw my GP who referred me for an updated pelvic ultrasound, which was inconclusive.

I then was contacted by the Pelvic Pain Clinic (in August 2025) and was booked in for an appointment. To say the least, I found the experience of this appointment very distressing. At this point I understood that I had adenomyosis and my understanding of the disease is that the only cure is a hysterectomy. The health professional I saw, who did not have access to my prior medical records, was of the opinion that I did not actually have that condition, and that I didn’t need to see a gynaecologist. They suggested that I go to OMNI in Sydney to get more advanced imaging. They said that the only way to get that imagining in Canberra was through the Foetal Medicine Unit (FMU) at the hospital. The FMU did not have any available appointments for six months (something I found frustrating when my close friend got a same-day appointment when having pregnancy concerns).

In October 2025 I presented at the Emergency Department with pain and fever after an extended period of bleeding. They did some tests which revealed a random unrelated infection and sent me home with antibiotics. I have since presented to the ED with other distressing symptoms and pain, and have been repeatedly informed that my pain is not serious and is probably genealogical.

I went to OMNI in Sydney to have the imaging done. They confirmed that there was adenomyosis and also located endometriosis.

Following this, I attended an appointment with a private gynaecologist (which was 4 months from the time of booking) after frustration waiting in the public system. I had no information from the public system about whether I was going to see a gynaecologist until a couple of days before this appointment. The public appointment was made for March 2026, and was then rescheduled to May 2026 (so I have still not seen a gynaecologist through the public system, even though my referral was three years ago).

At the private appointment, I was placed on the public waiting list for a hysterectomy/ excision of endometriosis. I was advised that the wait was about 12 months. Since then I have been in significant levels of pain constantly, which I manage by taking pain killers and limiting my movements. The impact on my life and the life of my husband and family has been horrific. My children regularly vocalise that they would do anything to “fix mummy”.

My health has also had significant economic impacts on my family. We have spent thousands of dollars on medical expenses (including where care was covered by Medicare and the Pharmaceutical Benefits Scheme, and where it wasn’t), and I have not been able to work to my full capacity. I am fortunate to have a reasonably flexible job and a supportive husband who works full time, but this still puts strain on us financially. I expected, following my children both being in school, to be able to increase my work hours. However, through a combination of my pain and therapy my capacity has not increased and I have almost completely depleted my paid leave.

If I had known that the wait to see a public gynaecologist in Canberra was three years, I wouldn’t have waited and I would have seen one privately much earlier. I could have gone to OMNI earlier, had I known it existed. I could have gone on the public waitlist for an excision of endometriosis, and perhaps would have been able to delay having a hysterectomy. A one year wait for a laparoscopy, and then a subsequent wait for a hysterectomy would bring my total time with adenomyosis to ten years, which is far too long. I cannot keep continuing on in this way, so I feel as though my only option is to have everything out.

My mental health has been severely impacted by my physical illness, and in particular by the dismissive way I have been treated by various medical professionals. Medical concerns are routinely not taken seriously as it is likely “just your endometriosis”. I feel horrifically angry for me and all the other women who are out there just coping with this; why on earth is this societal hatred of women allowed to continue in a progressive city such as Canberra?

My GP wrote a letter the private gynaecologist with concerns around my mental health and ability to deal with the significant wait ahead of me. I am yet to hear back as to whether my place in the ‘queue’ has been altered as a result of this; my GP was sceptical, due to her experiences with public health, that it would make a difference.

I note that I dictated this letter to my friend as recalling and retelling this felt extremely distressing. It is particularly distressing as many of my friends and family have recently shared their positive experiences of various health services in Canberra with me. I can barely remain upright for more than a couple of minutes, and am still yet to have seen a gynaecologist through the public system that I have previously championed. I am deeply disappointed and believe that I and other women deserve better.