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Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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SUBMISSION TO THE ACT LEGISLATIVE ASSEMBLY

Standing Committee on Health and Community Wellbeing

Inquiry into Endometriosis and Pelvic Pain

Submission from a Person with Lived Experience

Introduction

I am writing to share my lived experience with pelvic pain and suspected endometriosis as someone who has sought care through both the ACT public and private health systems for nearly a decade. I hope that by describing my experiences honestly, I can contribute to the Committee's understanding of the challenges faced by people seeking diagnosis and care for pelvic pain in the ACT. Despite years of seeking answers, I remain without a confirmed diagnosis. I submit this in the hope that the inquiry can help improve the experience for others in similar situations.

I have chosen to submit anonymously due to the sensitive and personal nature of my experiences, though I am willing to discuss my submission further with the Committee if required.

Background: Years of Symptoms Without Answers

I have experienced extremely painful periods, irregular and erratic bleeding patterns, and recurring ovarian cysts since I was a teenager. These are recognised symptoms consistent with endometriosis and other serious gynaecological conditions. Despite this long history, I have never received a confirmed diagnosis, adequate investigation into the underlying cause of my symptoms, or a treatment plan aimed at understanding and resolving what is actually wrong.

Over the years, my symptoms have not remained static. In addition to pelvic pain and irregular bleeding, I have developed significant pain in my lower right back, on the same side as my pelvic pain. Critically, these symptoms are cyclical: I experience pain flare-ups in my lower right abdomen and lower right back simultaneously, typically just before or during my period. The pattern is consistent and recurring, and I believe it is clinically meaningful. I have raised it with clinicians, but my experience has been that symptoms tending to cross traditional specialty boundaries are treated in isolation. I have been told, for example, that the pelvic pain and the back pain (occurring at the same time, on the same side of the body, in a clear cyclical pattern) are unrelated: the back is a physiotherapy matter, outside the scope of gynaecological care. I understand that specialists have defined areas of practice, but I would encourage the Committee to consider whether the current system adequately supports a whole-body approach to pelvic pain, particularly where symptoms may share a single underlying cause.

The cyclical nature of my symptoms also has an important clinical implication that I want to name directly: symptoms like mine are at their most diagnostically informative at the time of a flare. Investigations conducted days or weeks after a pain episode, when symptoms have settled, are less likely to capture what is happening.

This matters for how and when investigations are arranged, and I will return to this point later in my submission.

A Referral That Led Nowhere: The Public System and Nearly Ten Years of Silence

In 2017, my GP referred me to the ACT public health system to see a gynaecologist. I never received an acknowledgement, an appointment, or any follow-up communication. It has now been almost ten years. I do not know whether my referral was received, whether I was placed on a waitlist, or what became of it. To my knowledge, it simply disappeared.

I raise this not to assign blame, but because I think it illustrates a meaningful gap in how referrals are tracked and followed up within the public system. I would ask the Committee to consider what mechanisms exist for ensuring gynaecological referrals are received, actioned, and communicated to patients, and what obligations the system has to follow up when an appointment has not eventuated within a reasonable timeframe.

Seeking Care: A Consistent Pattern of Symptom Management Over Investigation

In the absence of specialist gynaecological care through the public system, I have sought help from multiple providers over the years, including my GP on several occasions and ACT Sexual Health and Family Planning (SHFPACT), including their pelvic pain clinic. I appreciate that these services exist and that the clinicians I have encountered have generally been trying to help. However, the care I have received across all settings has tended to follow a similar pattern: hormonal contraception has been offered to manage my symptoms, rather than as part of a broader plan to investigate their underlying cause.

I currently have a Mirena IUD, inserted by SHFPACT as a recommended approach to managing my pelvic pain and irregular periods. I understand that hormonal contraception can provide meaningful symptom relief for some people, and I do not discount its value. However, for me it has not resolved my symptoms, and across my care journey it has consistently been offered in place of investigation, rather than alongside it. Symptom management and diagnosis are not the same thing, and one should not substitute for the other.

There is one experience from the pelvic pain clinic that I want to describe specifically, because I think it illustrates a broader issue with how pain is approached in these settings. On one occasion, a nurse advised me to work on retraining my nerves, with the goal of reducing how frequently pain signals are sent and lowering the perceived intensity of pain. I understand this advice came from a genuine desire to help me manage my symptoms. However, in the context of years without a diagnosis, without investigation into the root cause of my pain, and without a treatment plan directed at understanding what is actually wrong, this advice had an unintended effect: it reinforced the feeling that my pain was something I needed to work on in my own mind, rather than something the medical system needed to investigate and treat. The message I took away, however unintentionally it was conveyed, was that the problem was my perception of pain, rather than the pain itself. That is a difficult message to sit with when you have been seeking answers for years.

Over the past decade, I have also spent considerable time and money pursuing care through the private system, including consultations with private specialists and repeated ultrasounds and investigations. Despite this sustained effort and expense, I remain without a confirmed diagnosis or a clear path forward. For many people, the cost of this kind of prolonged private care would be prohibitive, and I am conscious that my experience likely reflects a wider inequity in who is able to keep pursuing answers.

The most significant development through private care came when my GP referred me to a private gynaecologist, whom I was able to see following an acute episode I describe below. The gynaecologist performed a deep scan for endometriosis. The report noted probable endometriosis, as well as unexplained cervical inflammation. I had hoped this finding would open a pathway toward further investigation. Instead, I was offered an additional hormonal contraceptive pill (on top of the Mirena I already have) as the recommended next step. No further investigation into the probable endometriosis finding or the cervical inflammation was arranged.

The Human Cost: Living with Undiagnosed Pain

Living with undiagnosed, ongoing pelvic and back pain has affected many areas of my life. I have missed days of work and operated at reduced capacity on many others. My ability to participate in physical activity and exercise has been significantly curtailed by pain, which has affected my general health and wellbeing. My social life and relationships have also been impacted. There have been periods where I have felt unable to continue with day-to-day activities, including caring for my young child. The distress of not being able to be fully present as a parent, because of a condition that remains unresolved, has been considerable.

My symptoms, and the experience of navigating the health system over many years, have contributed to ongoing anxiety and depression. I want to name this directly, because I think the mental health consequences of chronic undiagnosed pain are often underestimated. The uncertainty, the repeated consultations without resolution, and the recurring sense of not being fully heard have taken a toll that extends well beyond the physical.

One of the more difficult aspects of this journey has been the experience of having my pain, at times, not taken fully seriously. Across multiple providers and settings, I have found my symptoms normalised or responded to with hormonal management rather than genuine inquiry. Over time, this has caused me to question and second-guess my own experience of pain. I have wondered whether I am describing it accurately, whether I am overreacting, whether my concerns are reasonable. That kind of self-doubt is an uncomfortable thing to carry, and I do not think it should be an expected part of seeking healthcare.

The cumulative effect of years of normalised, unacknowledged pain has had real clinical consequences. My pain threshold has become so elevated that during my pregnancy, I did not realise I was in labour until my contractions were five minutes apart. I had dismissed twelve hours of pain as the kind of pelvic discomfort I have simply learned to live with. I share this not to alarm, but because I think it illustrates what years of unacknowledged pain can do to a person’s ability to interpret their own body’s signals. When pain becomes your baseline, you lose the ability to recognise when something is acutely wrong.

A Critical Moment: The Emergency Department Presentation and Its Lasting Impact

With the above context in mind, I want to describe an acute episode in 2025 that I believe illustrates several of the system’s shortcomings in a single sequence of events.

When the episode began, I sought help promptly. I attended SHFPACT, where a doctor assessed me and referred me for an ultrasound. The earliest available private appointment was more than ten days away. I booked it. The doctor advised me to go to the emergency department if my pain worsened in the meantime. My pain did worsen, significantly, and I followed that advice.

When I presented to the North Canberra Hospital emergency department, my pain was rated at 8 out of 10. I was unable to stand or sit without folding over. A bedside ultrasound was performed, and clinicians noted free fluid in my abdomen, which can be a clinically significant finding in the context of acute pelvic pain. However, the treating doctor used my existing private ultrasound booking (still approximately one week away at that point) as part of the reasoning for discharging me without further investigation. I was advised to continue taking Panadol and Nurofen and to attend my scheduled appointment.

I want to highlight the particular difficulty with this reasoning. My symptoms are cyclical in nature. Pain and other signs of pathology, in conditions like endometriosis, are often most detectable during a flare. The decision to defer investigation to an appointment booked a week into the future, after the acute episode had passed, meant that the window in which investigation was most likely to be informative was allowed to close. When I attended the private ultrasound approximately one week later, the free fluid was no longer visible and no signs of concern were identified. The most diagnostically meaningful moment had passed. My ongoing symptoms, including acute one-sided pelvic pain, post-coital bleeding, and irregular bleeding, continued regardless.

I understand that the existence of a follow-up appointment may have been a relevant consideration for the treating team, and I do not suggest the decision was made carelessly. However, in the context of a patient presenting in significant pain with a clinical finding, being discharged with only over-the-counter pain relief and no interim safety netting was distressing. It left me feeling that even at my worst, the level of care available to me was the same: manage the pain and wait.

The impact of that experience has extended well beyond the episode itself. Following the ED presentation, I found myself increasingly reluctant to seek emergency care in subsequent episodes of severe pain. When my symptoms have flared to a similar or worse degree in the months and years since, I have hesitated to present to the ED again. The experience taught me, in a practical sense, that attending the emergency department in significant pain would not result in meaningful investigation or a different outcome. That belief has shaped my behaviour, and I am aware that it may not be in my best interests. But it is a rational response to what I experienced. I can no longer justify organising to be taken to the hospital while experiencing acute pain, spending hours sitting in rather uncomfortable chairs in the ED waiting rooms, only to be told to go home and do exactly what I would have continued doing without hours of hassle and inconvenience anyway.

I would ask the Committee to consider the broader implications of emergency presentations that do not result in appropriate care: the message it sends to patients about whether it is worth seeking help, and the longer-term risk to those who, as a result, delay or avoid seeking care when they genuinely need it.

What I Would Encourage the Committee to Consider

Based on my experience, I would encourage the Committee to consider the following areas:

- **Improved tracking and follow-up for gynaecological referrals.** It would be valuable to understand whether the ACT public health system has robust mechanisms for tracking referrals, notifying patients of their waitlist status, and following up where a referral has not resulted in an appointment after a reasonable period.
- **A clearer diagnostic pathway for people with pelvic pain.** People presenting with symptoms consistent with endometriosis or other gynaecological conditions would benefit from a clear, accessible pathway that includes timely specialist review and diagnostic investigation, not symptom management alone. This pathway should actively prioritise investigation during symptomatic periods, when findings are most likely to be informative.
- **Review of emergency department care for acute pelvic pain.** It may be worth examining how ED presentations involving acute pelvic pain and clinical findings are managed, particularly where the patient has a known history of gynaecological symptoms. Discharge decisions that defer investigation beyond the acute episode may inadvertently foreclose the most diagnostically useful window, especially for cyclical conditions. Ensuring patients leave with appropriate safety netting and meaningful follow-up is important, both clinically and in terms of the signal it sends about whether seeking emergency care is worthwhile.
- **Clinician education and a culture of investigation over management.** Improved training for GPs, emergency clinicians, and specialists in recognising endometriosis symptoms, understanding diagnostic delay, and treating hormonal contraception as a complement to investigation rather than a substitute for it, may meaningfully reduce the time patients spend without answers. Equally important is a clinical culture that treats patients' reported pain as a starting point for inquiry, not a perception to be managed.
- **Support for multidisciplinary and whole-body care.** Where patients present with symptoms that cross traditional specialty boundaries (such as cyclical pelvic and back pain occurring together), the system should support a coordinated approach rather than directing patients to seek separate, unconnected assessments. Fragmented care risks missing connections that may be clinically significant.

- **Recognition of the mental health impact of chronic undiagnosed pain.** The anxiety, depression, and erosion of self-trust that can accompany years of undiagnosed pain deserve acknowledgement within the care system. Pathways for pelvic pain should incorporate access to mental health support as a standard component, not an afterthought.
- **Attention to the chilling effect of inadequate emergency care.** When patients present to the emergency department in acute pain and leave feeling that their presentation was not taken seriously, there is a risk that they will not seek emergency care again, even when it is genuinely warranted. This is a patient safety issue that deserves consideration in how pelvic pain presentations are managed and followed up.

Conclusion

I have lived with undiagnosed pelvic pain for the better part of my adult life. I have sought help through multiple channels, in both the public and private systems, and I am grateful for the care I have received along the way. At the same time, I have found the experience of seeking a diagnosis to be lengthy, fragmented, and at times discouraging. After almost ten years, a probable endometriosis finding on imaging, and an acute episode that resulted in an ED presentation and a clinical finding, I remain without a confirmed diagnosis or a plan for what comes next.

I recognise that I am not alone in this experience. Diagnostic delay for endometriosis is well documented, and many people describe a similar journey: pain that is normalised, symptoms that are managed rather than investigated, and a long road toward understanding what is happening in their own bodies. I hope that by sharing my experience with the Committee, I can contribute in a small way to improving that journey for others in the ACT.

I thank the Committee for undertaking this inquiry and for the opportunity to contribute. I hope it leads to meaningful improvements in how the ACT health system recognises, investigates, and supports people living with pelvic pain and endometriosis.

Submitted anonymously

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