



# Submission cover sheet

## Inquiry into endometriosis and other pelvic pain conditions

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## **Inquiry into Endometriosis and other Pelvic Pain Conditions**

Thank you for taking the time to read my submission to the ACT Legislative Assembly Standing Committee on Social Policy Inquiry into Endometriosis and other Pelvic Pain Conditions.

My name is Ella McAuliffe, I am twenty-four years old, and I have been living, working and studying in the ACT for the past six years. I am writing this submission to share my lived experience of someone living with persistent pelvic pain.

The social and economic impacts of this condition, difficulty with accessing services in the ACT and experiences of medical misogyny that I have experienced are not particularly unique. Indeed, 1 in 7 people assigned female have endometriosis, and persistent pelvic pain is estimated to affect a further 15–25% of people assigned female.

Since I first got my period, I have always struggled with long and painful periods. However, as I got older the severity and number of symptoms I experience have increased. It was whilst I have been living in the ACT that I started to seek medical assistance for these symptoms and tried to understand what was causing them.

However, as a university student with limited income, this very quickly began to feel like an impossible task. It became increasingly difficult to find a GP that would bulk bill and even harder to access an affordable specialist. But I did my research and asked a GP (that did bulk bill, but had never heard of the service) to refer me to the only endometriosis and pelvic pain clinic available at the time, the Canberra Endometriosis Centre.

It was three and a half years before I got a text letting me know an appointment was available.

By the time got that text, I had been forced to seek medical assistance through alternative options. The increasing symptoms and the pain had not waited for the Canberra Hospital's availability.

In this time I had seen other GPs, been admitted to hospital on one occasion, been to two private gynaecologists, has several ultrasounds, travelled to Sydney for a more specialised endometriosis ultrasound (that I otherwise needed to wait a year in the ACT for), got another referral to SHFPACT's pelvic pain and endometriosis clinic, received assistance from a psychologist, and attended physiotherapists specialising in pelvic conditions.

All of this has come with thousands and thousands of dollars in healthcare costs.

I find it difficult to reconcile the story we tell of Australia's healthcare system, as one that is affordable and fair, with my experiences. This condition requires an interdisciplinary approach to treatment, but very often does not have bulk-billed options. My access to a psychologist or a physiotherapist are medical appointments that I cannot access without significant out of pocket costs. Whilst it is true that I could have waited over three years to be seen in the public system and accessed more services through this; a system that forces one to wait for this long, in pain and without treatment, cannot be considered affordable or fair. My life could not be put on hold – I had study, work, a social life, and dreams that needed to happen in this time.

This condition requires an interdisciplinary approach to treatment, but very often does not have bulk-billed options. This includes access to psychologist and physiotherapists, medical assistance that I cannot access without significant out of pocket costs.

I also wish to discuss my experiences of medical misogyny and gender bias in relation to seeking medical care for my persistent pelvic pain.

When I first started seeking medical care, I was told, "this is normal", I was told "it was part of being a woman". When I was twenty-one and in my third year of university, I was told by a GP that I should get pregnant, and soon". She promised that this would fix, what she called, "my period problems". The myth that pregnancy will address "period problems" is horrifyingly

widespread.<sup>1</sup> A 2023 study found over 50% of people in Australia surveyed had been told by a healthcare provider to get pregnant or have a baby to manage or treat their endometriosis.<sup>2</sup>

Like many other appointments, she then offered me a script for another type of Combined Oral Contraceptive to wrap the appointment up. This was not only despite my previous objections that I didn't want to try another form of contraception, and if knowing what I wanted wasn't good enough, that they had previously caused significant side effects.

I was often confused that in a room with trained medical professional that I seemed to be the only one in there who wanted to know what the medical problem was, rather than finding another bandage for it.

I know that a condition causing chronic pain for men at the rate of endometriosis or persistent pelvic pain would never be tolerated in the way that we tolerate this pain. We also would never tolerate the social and economic inequities that it causes, nor the dismissal when one does access medical care.

It is my ask that genuine change comes from this inquiry. Whilst it is unacceptable that this lack of access to affordable and timely medical care is allowed, it is worse to ask for our experiences and then fail to act on them. It is my hope that it will be better for the ones who come after me.

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<sup>1</sup> Sirohi Diksha, et al., "Patient experiences of being advised by a healthcare professional to get pregnant to manage or treat endometriosis: a cross-sectional study." *BMC Women's Health* 23, no. 1 (2023). doi:10.1186/s12905-023-02794-2.

<sup>2</sup> Ibid.