



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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To: LA Committee - SP
Subject: Inquiry into endometriosis and other pelvic pain conditions

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Good afternoon, my name is Xanthe Lockyer, and I am a 23-year-old Canberran, born and bred, living with endometriosis.

My first interactions with this disease began when I got my period around 14 years old. Unbeknownst to me at the time, these were not meant to cause immense pelvic pain, cramping, nausea, heavy bleeding or impact my High School studies. I vividly remember on one occasion, whilst staying with my aunt, pain so intense that I was curled on the floor in a fetal position, crying until it passed.

As I had no education on the disease at the time, nor the money to see a specialist, I lived with this pain. When I was 16 years old, I saw my first GP and was prescribed an oral contraceptive pill for the pain, which caused me acne and an array of side effects.

At 18, it occurred to me that I was unable to manage my pain with ibuprofen efficiently and that maybe I wasn't overreacting to the pain I had consistently endured. I now had a small amount of savings and treated myself to my first ultrasound and subsequent \$300 gynaecologist appointment. A different oral contraceptive pill was prescribed to me, and I was told to come back six weeks later to see if a cyst that I had on my ovary would dissolve.

Six weeks later, at my next gynaecologist appointment, I was told that the cyst was gone. Apparently, this was the likely cause of the pain, but the next step would be to have a Mirena IUD inserted, as the second oral contraceptive pills were also leaving me with side effects. Endometriosis had only been loosely mentioned by the gynaecologist, and I was charged \$150 and rushed out of my appointment after five minutes as my gynaecologist had someone else to tend to.

I was left feeling down beaten and that my pain was likely just a bad period. I felt silly that I was raising this issue, as all women probably had period pain- I thought.

A month later in October 2020, I had my first Mirena IUD inserted by my GP (as I could not afford another gynaecologist appointment) with hopes that this would finally help my pain. Spoiler alert- it didn't.

Over the years, particularly through High School and College, I had been concerned with brain fog and physical fatigue I had suffered. I'd sought four general blood tests to try and find a cause; however, doctors had never found anything abnormal.

Four years later, in late 2024, I was working as a Police Officer on night shift when I had a wave of stabbing pains in my abdomen, which increased over several hours to the point where I vomited from the pain. I had to be picked up from work and went straight home to bed because I couldn't move without suffering unbearable pain.

These episodes became more regular until they were monthly by March 2025 and lasted 6-12 hours each time.

On one shift, I was Policing at the Enlighten festival when the stabbing pains began. I ended up having to vomit under a tree and then into a bin in public view, which was extremely embarrassing.

On one shift, I was on a hospital guard and over the course of several hours, the stabbing pains had intensified to the point of uncontrollable vomiting. Whilst at the hospital, I vomited approximately six times. Even the anti-nausea tablet the nurses kindly gave me wouldn't stay down.

To the best of my knowledge at the time, these were gas pains or indigestion, though they were beginning to impact my ability to perform my role. The anticipation and fear of the pain of an episode began to give me daily anxiety.

In May 2025, I awoke with stabbing pains and, several hours later, had vomited five times. By now, I was frustrated and in the most extreme pain I had ever felt. I was taken to the Emergency Room and given a drip containing anti-nausea and anti-inflammatory medication, fluids and muscle relaxants. Blood test results showed inflammation but an ultrasound showed nothing of concern. A few hours later, after a doctor told me that I was "not going to die", I was discharged with no answers or advice on who I should speak to for further testing.

I decided to visit my GP again, and she mentioned endometriosis to me. She suggested I consider having a Deep Infiltrating Endometriosis (DIE) scan. This was new technology (not available in Canberra) and would cost approximately \$700.

Over the years, I'd now had three ultrasounds which had not shown anything of interest, but I was determined for answers, so in June 2025, I made the trip to Penrith, NSW.

At the next appointment with my GP, she diagnosed me with endometriosis. The relief of finally having a diagnosis temporarily overpowered the reality of being diagnosed with a chronic, progressive disease with no cure. I was prescribed a pain relief containing codeine and a daily progesterone hormone.

Over the next several months, the usual monthly episodes continued, leaving me curled in a ball in excruciating pain for up to 12 hours at a time at all hours of the day or night and vomiting to the point that my abdominal muscles would be sore for days after.

Other symptoms had gotten worse, and I now had an abdominal/pelvic burning or throbbing sensation, nausea, diarrhoea and extreme bloating up to several times a day- even when I was not experiencing an episode.

I was forced to leave my role as a Police Officer because the physical stress of shift work on my body, including carrying heavy equipment, had taken a toll on my fatigued, inflamed body. My brain fog/mental fatigue had gotten so bad that I could no longer focus for 10-18-hour shifts. My body was exhausted.

I saw my GP again and explained that my symptoms had gotten worse. We discussed a referral for a new public endometriosis clinic however, she advised me that she had heard from patients that the wait list had been over a year. I could not wait this long, so I also obtained a referral for a private gynaecologist.

In November 2025, I finally saw a new gynaecologist, was prescribed a nerve pain medication, charged \$300 and sent on my way. I was told that surgery would be the only other option; however, the public wait list was often years long.

I decided to have the surgery privately and my next appointment with the gynaecologist was for a pre-op ultrasound (which showed nothing). The appointment took about 20 minutes and I was charged \$700.

The next week I was booked in for surgery with a cost of \$8,300.

After the surgery, I was unable to work for two weeks, and as I had recently started a new full-time job, I had to take unpaid leave.

Several weeks later, at my post-op gynaecological appointment, I was diagnosed with extensive stage two endometriosis with endosalpingiosis. I was charged \$300 and sent on my way.

I have worked full-time since I was 18 years old and have always been wise with my finances, but I had never expected to have to spend over \$12,000 on medical bills. I sought financial assistance whilst I was unable to work from Services Australia, but as I had savings, I was ineligible.

I began to do research and learned that there is no financial relief available for sufferers of endometriosis in situations similar to my own, and endometriosis is not recognised as a disability under the NDIS.

I now fear for my future as I suffer from chronic brain fog, fatigue and physical pain despite exercising frequently and eating healthily. These symptoms (particularly the brain fog) impact my ability to work full-time, keep my body in a constant state of burn-out and have taken an extreme toll on my mental health.

Unfortunately, I cannot afford to not work full-time so this is something I will have to suffer with for my entire life, as there is no financial support available to me. To date, I have spent approximately \$15,000 to diagnose and manage my disease. This is a price that will rise over the course of my life, as there is no treatment and expensive surgeries often only provide temporary relief.

My partner and family have also paid the price for my lack of Government support by having to take time off work to take me to appointments and hospitals, leaving me feeling like a burden. They have also been generous enough to offer me financial support, which I have refused as they should not have to suffer for my condition.

I am extremely disappointed in Canberra's lack of funding for endometriosis sufferers. Extremely long wait lists in the public system prevent women from being able to access endometriosis clinics for pain/symptom management, and wait lists for public surgery again prevent women from being provided necessary surgical intervention. These wait times not only mean women are forced to live in extreme pain, but can also cost women their fertility.

The lack of adequate technology to be able to diagnose the disease is also an issue in Canberra. Standard ultrasounds are notorious for being unable to locate the disease, and Women should not be forced to travel interstate to pay \$700 for a chance at an accurate diagnosis. I should not have to be grateful that my diagnosis for a chronic condition that affects up to 10 per cent of Australian women took eight years; however, I am aware that they often take even longer.

I am also disappointed in the cost of essential medications for endometriosis sufferers. I have now spent hundreds of dollars on medications such as Dinasane and Gabapentin (progesterone and a nerve pain medication) and will have to take these daily for the rest of my life.

Endometriosis is such a painful, debilitating condition that affects such a high percentage of women, costing them their livelihood, productivity and fertility, yet there is so little known about it. The ACT Government needs to invest in its own residents by providing more funding for endometriosis clinics and making the surgical treatment of the disease accessible for those who need it. Healthcare is a right, and women should not have to fight for affordable treatment.

Thankyou for your consideration,

Xanthe Lockyer

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