



# Submission cover sheet

## Inquiry into endometriosis and other pelvic pain conditions

Submission number: 041

Submitter: Name withheld

Date authorised for publication: 28 April 2026

My name is [REDACTED]; I have suffered from endometriosis and adenomyosis and now another pelvic chronic pain issue due to multiple surgeries over many years.

I am writing about the inquiry into endometriosis and other pelvic pain conditions, as I would like to assist in any way possible to provide a voice for women who are suffering and bring to attention how the health system is completely failing women in the ACT, disregarding and not addressing how serious these diseases are and the vast impact it has.

I have had five surgeries, four in four years. The impact on the body, mind and emotions is immense and having the health system completely ignore and gaslight women who are voicing their pain and concerns needs to be addressed and action needs to be taken.

I have years of stories to share about my experience in the health system in the ACT and now in NSW as my current specialist and surgeon is in Sydney.

Please see timeline below.

After suffering from pain and going to the doctors for two years for the pain in ACT, I finally found a GP who listened and referred me to a specialist Dr [REDACTED], in 2018, I then had a consult and had a laparoscopy booked for May 2019. The surgery was at Queanbeyan hospital as that is where she performed public surgeries, following the surgery I was diagnosed with endometriosis, I was told it was all removed. Not long after about a year following that I started experiencing the pain again, I was put on zoladex, an injection which induced menopause, I became very ill, I was a single mother in my early 30s working full time, the side effects were impacting my life significantly, so I had to stop taking it, I then tried slinda which also caused bad side effects. I then stopped treatment and went down the path of herbal remedies. It was not an affordable approach for me to be consistent with.

In 2022 I went back to my specialist explaining I now had bowel issues, and developing symptoms, she told me to wait 6 months to see if anything changed, 6months later the pain was far worse, and I was then listed for surgery August of 2023.

In this surgery the endometriosis was more advanced and had impacted the bowel, bladder and urethras. I also had an infection following the surgery, which I only had confirmed at the four week appointment, and was given antibiotics, the antibiotics did not work, I contacted the surgery and was told to make an appointment again which would incur a consult fee of \$300, I could not afford it so I had to go to my GP, who prescribed the correct antibiotic.

A few months after surgery I began experiencing pain (much worse and different) I contacted the surgery and was told I had to wait as Dr [REDACTED] was booked out for months, I had a consult booked for March which then changed to April, I had visited ER with severe pain which was not usual practice and at that point I realised something was

wrong. The consult booked in April was cancelled by Dr [REDACTED] who sent me a letter stating that she could no longer consult me as it was out of her scope. I was then left with no specialist. I was suffering immensely with pain and having to go to ER on many occasions, often told, see your specialist, when I no longer had one. On one occasion in September 2024 I was in hospital for 5 days waiting in the surgical ward being told I might have appendicitis and will need surgery, there were two teams looking after my case, the genealogical team took two days to see me, neither teams communicated with each other, I had to kept on telling the team I had an ongoing gynaecological issue, I even had a scan previously and told them to look at those results, I was constantly gaslit, after all those days I was then told I could go home because in fact it was gynaecological and there is nothing they could do. Following that I had to work with my GP to find a new specialist. Every Canberra gynaecologist dismissed my referral for one reason or another. Leaving me with no choice but to go to Sydney.

The specialist in Sydney told me I needed a hysterectomy within 3 months, as my symptoms were in line with adenomyosis. I was in shock despite all my symptoms Dr [REDACTED] did not check for adenomyosis, I was in fear of the surgery, the cost and the impact on my physical and mental health. One week prior to surgery I passed out and my sister found me, she drove me to hospital and I was admitted, for some reason I was put in the birthing ward, in a room full of posters for new mothers, I was in absolute shock. A doctor came in to speak to me and asked me if I am having a hysterectomy in a week and I answered yes, to which she responded, "your very young for that". Placing a woman in a ward for birth is not what I would consider respectful to women who are losing their ability to have children.

The Canberra health system cannot and does not accommodate women with pelvic conditions, regardless of how many times you go in, they will ask numerous questions whilst the patient is in agony unable to breathe and talk, pain relief should be administered first, there is no place to women to lay down, and they spend hours in wait rooms to then be dismissed or given morphine and fentanyl and then sent way. In 2024 I went to hospital numerous times without receiving a pelvic scan.

In December 2024 the hysterectomy was scheduled, I had asked for December so work was not as impacted in the holidays period, I had just started a new role in October 2024 in the Department of Industry and Science, when I told my boss that I needed to have surgery and it was a hysterectomy I was dismissed from the role, and told that as a single mother and having a major surgery its best I find a flexible role. I was in absolute shock that this could happen to me. I then had to go on stress leave as I could not handle the stress of finding a new role, preparing the finances for surgery and caring for my children and facing another surgery which would take away the dreams of having more children.

The surgery went ahead, my uterus pathology came back as severely diseased with adenomyosis which explained the severe pain and heavy bleeding, I had endometriosis on my bowel and bladder, which cannot be explained as I had surgery to remove it in September 2023. The surgery took a large toll on me. I found another job and commenced in February 2025. Unfortunately, not long after I was still experiencing pain and the issue escalated again, I went to my surgeon in Sydney in March 2025 and I was told I would need another surgery. I would have to wait until August 2025. During that time I was in hospital many times, even with a ruptured ovary, I told the ACT health system I was in immense pain daily and waiting for surgery, I appealed to my surgeon to bring the surgery forward but he could not as he was going on a holiday to Europe in June/July.

I was put on endone daily for the pain, constantly in a cycle of needing scrips, being unable to get scripts on time, running out of pain relief going to ER, being sent away, all whilst holding down a job in Parliament house and single parenting two children.

In the months leading up to the surgery and the cycle I was in of pain, pain killers chasing scrips, getting nausea from the pain, I got a fine for parking in a motorcycle bay, when I went to get a script from barton, there was no where for me to park and get to the pharmacy in the pain I was in, I missed the payment for my car registration, I couldn't keep up with everything. Why aren't women suffering with chronic pain waiting for surgery, given a disabled sticker so they do not have to walk far to get pain medication in agony? Why aren't scrips given on repeat, so women do not run out and end up in ER on morphine and fentanyl missing out on work?

The surgery in August resulted in adhesions from scar tissue binding the bladder, bowel and impacting the left ovary. I was not informed about this complication, I was never sent to a pelvic physio, given advice or proper after care.

I have now had a surgery in April 2026 for the exact same issue and lost my left ovary. The pain I am in is immense, due to having so many surgeries in a brief time. In February 2026 I went to the urgent health care clinic that Labor talks about, I drove myself from Parliament house following immense stabbing pain in my left abdomen, I called the clinic and explained the pain and asked if someone could come outside with a wheelchair to get me inside, no one came to my aid upon arrival, I got into the clinic waited in the wait room crying and shaking in pain, was seen by a nurse and doctor who then told me they have no pain relief on site and I will have to go to emergency, I asked if there is a service that can take people from the urgent care clinic to ER and I was told only ambulance. I was very puzzled as to how an urgent care clinic cannot provide strong pain relief, I was given bascopan via injection to calm my muscles and I drove North Canberra hospital in agony. I waited one hour for pain relief, I was admitted and I spoke to a gynaecologist male who had a heavy accent, who asked me the following questions. 1. Have you tried anti-depressants? 2. Do you plan on have any more children? 3. Have you tried hormonal birth control? I explained that the pain was exactly what I had experienced the year before and

I was certain I would need surgery. I stayed over night and felt so disheartened by the discussion with the gynaecologist, I waited in the morning to speak to a team of gynaecologists, the scan had come back with adhesions again impacting the bowel bladder and left ovary, I was told that despite the pain and the severity of having organs stuck together, I would be a category 3 and would have to go on a wait list, I explained that it would be an injustice to make someone wait and go back to taking pain killers daily until a surgery date. I was told that's just the way it is and unless I have cancer or a life-threatening issue, I would not require urgent surgery, Basically I would have to suffer in silence again and go through the same ordeal as the year before. I waited a day to speak to a pain management specialist, he told me I should try another drug, I then waited five hours to get discharged from hospital at 10pm and given a script for endone after discussing that I would no longer take endone. I left the hospital feeling mentally distraught and defeated.

I never heard from the public health gynaecological team, and spoke to my private surgeon in Sydney, who booked a surgery as a category 2.

I am now two weeks post operation; I have been looking for a pelvic physio to help prevent and manage my adhesions. There are none available in the ACT privately for months and via the public system there is a very long wait. Where are the preventative measures for these pelvic conditions? What is the point of the Endometriosis centre if it cannot offer services?

- Going to ER waiting in pain to be given the same pain relief your already on- endone
- Telling my endure story to doctors again on repeat, one doctor replied "noted" when I stated that the system provides drugs and send women away with no help or answers.
- There is no after care.

In June 2024 I had an interview with a journalist, and the article was published in the Canberra Times *Endometriosis struggle: Canberra woman battles healthcare*. I have been trying to raise awareness for years in what feels like a very helpless situation. I read stories and posts by women online in the ACT who are sharing horrific stories about what they are experiencing in the system, it is inhumane and I don't think there is enough insight on these stories.

I would like to offer my voice and stories to help this inquiry or am willing to assist by being a witness.

I work in Parliament House for a Minister, it is extremely important to listen to the voices of the Australian public, provide improvement, respect, acknowledgement and bring justice for women who are suffering in the health system.

I have suffered immensely for years, as have hundreds of women in the ACT, please recognise our suffering, and listen to our voices.

Kind regards,

[REDACTED]

[REDACTED]