



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 001

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Sent: Tuesday, 9 December 2025 9:58 AM

To: LA Committee - Environment

Subject: Submission - Inquiry into endometriosis and other pelvic pain conditions

Good morning,

I was thrilled to hear on the radio this morning that the ACT Legislative Assembly is launching an inquiry into endometriosis and other pelvic pain conditions. I would like you to hear my story as I'm sure I am not alone, and other women should not have to suffer for as long as I have.

Apologies for the long email ahead but thank you on behalf of women experiencing this.

I have been struggling with endometriosis, adenomyosis and polycystic ovarian syndrome (PCOS) since I first started getting my period at around 12 - 13 years old, I am now almost 27.

So much time and money have been wasted every time I went to the doctor or even emergency with intolerable pain, only to be told that there is nothing wrong with me and I should go and see a dietician for irritable bowel syndrome.

I have been on many different contraceptive pills to try and manage what I was told was 'just normal period pain', even when the pain was present between periods.

I did not get formally diagnosed until 2023 when I finally got a referral to see a Gynaecologist. I was not aware that at this practice, I could not use my private health. So there went \$450 (with a tiny Medicare rebate). I was then sent to OMNI in Sydney to have an ultrasound (I had already had about 7 or 8 ultrasounds here in Canberra) and was put on Slinda and told to skip my period, but I would bleed anyway even when 'skipping' my period correctly.

I was then put on a different pill called Visanne and was told this one was not a contraceptive and to use other methods of contraception. But I had gone years without using contraception and never had a pregnancy scare. So, I was convinced I could not have children which was quite depressing for me as I had always wanted

them.

Funnily enough, I did fall pregnant and am now a proud mother to a beautiful now 18-month-old girl.

About 6 months after she was born, my symptoms came back worse than ever. I went back to the same Gynaecologist, and she basically told me that I should just have another baby. I was utterly astounded that she did not offer any further treatment options, so I left, paid my \$250 for the appointment and made a doctor's appointment to get a referral to a different Gynaecologist.

Got my new referral and sent it to this new Gynaecologist. I waited a week with no response, so I followed up with another email. I also tried calling multiple times and the phone just did not get answered. I was starting to lose hope, when finally, they responded offering me an appointment in November (I enquired in June).

At this appointment I felt like I was finally listened to, and everything was explained to me in a way that I could understand, all my questions were answered, and I felt validated that I had indeed been suffering with this for years. I now have surgery booked in for February to have a laparoscopy and hysteroscopy.

It's been a long tough road, but I am hopeful that this will be the best treatment for me and am thinking positively about the future.

I would be more than happy to provide any more detail if required. I am very passionate about this and really hope this pushes the ACT Government to have a serious think about better options for women like me.

Thank you,
Maddi Ciuffetelli

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