



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 021

Submitter: Lisa McInnes

Date authorised for publication: 21 April 2026

Dear Committee Members,

Re: Submission to ACT Legislative Assembly Inquiry into Endometriosis

Lisa McInnes

[REDACTED]
[REDACTED]
[REDACTED]

I am submitting this letter regarding my daughter's ongoing experience with suspected endometriosis and the impact it's had on our family over the last few years. My daughter has experiences pelvic pain that is persistent and ongoing. At times, it gets to 10/10 pain and we have presented to ACT Emergency Departments more than 10 times in the last 2.5 years.

We do not have a confirmed diagnosis to date. This is not surprising, my research has led me to believe that it takes on average, seven years to get one. We have had intervention from her GP, a local gynaecologist, additional consultation with Professor Rebecca Deans (Sydney). She has had specialist imaging undertaken interstate using MRI and dye contrast. We even tried to perform an internal ultrasound. This was traumatic for her and abandoned due to her intolerance for the procedure.

With specialist support she has trialed six different oral contraceptive pills. We have to pay out of pocket \$220 a month for a medication because she is under 18 without a confirmed diagnosis of endometriosis. This feels unfair. She is in pain and we pay a lot too. Here's a summary of some of the categories of ways she's impacted.

Education and Development

- 2026 School attendance reduced to approximately 10%
- 2025 School attendance reduced to 50%
- Significant disruption to secondary education
- Inability to participate in age-appropriate social and employment opportunities

Health System and Finances

- Out of pocket we have sourced the support of specialists in gynaecology, paediatrics', gastroenterology, psychology, psychiatrist, pain specialist, osteopathy. These are all out of pocket and a strain financially. Last year my child hit the safety net in September.
- Repeated Emergency Department presentations without coordinated follow-up pathway. It's a frustrating rinse and repeat of control pain and send her home, hopeless and with no ongoing care.
- We were turned away from CAMHS services after an assessment based on the fact my daughter had a private psychologist. At this time she had suicidal ideation based on medications that had been prescribed for her by the ACT Pain specialist centre in Deakin. Their solution was to tell me to go to Emergency.

Family and Employment Impact

- Significant use of carer's leave
- Breakdown of family unit over conflicting parental beliefs on managing complex health needs
- Ongoing strain on employment sustainability. I need to care for my daughter in personal care aspects, washing her hair and supporting bathing. No teen parent wants this to be in their ongoing future and no teen wants to have such little autonomy.

Please focus on finding solutions to for children and adolescents with chronic health conditions including endometriosis in the following ways:

- Increase ACT residents' access to adolescent-specific pain management that specialises in chronic health conditions. Our experience of ACT Pain centres has been that professionals believe pain is psychosomatic
- Develop escalation pathways for repeated Emergency Department presentations, especially when presentations have a rhythm and pattern that establishes medical need
- Provide financial support mechanisms for families during prolonged diagnostic periods. Hitting our safety net last year and then resetting the next year leaves us further out of pocket, with the same medical leave. This is stressful and we have the same level of need in January as was the case in December last year.

My daughter is experiencing ongoing, severe pain without diagnosis or effective management. The current system response has been fragmented, costly, and insufficient. Earlier intervention and coordinated care are essential to prevent long-term educational, health, and social consequences. This experience has effective the quality of my life and our whole family. It's hard and we need a system that recognises and supports, financially, medically and socially. Thank you for considering this submission.

I am very happy to provide more information in any format that contributes to change and supports being developed in a more humane way. The adversity my daughter has experienced needs to be improved for other girls entering puberty. Please contact me if I can support your Inquiry further.

Yours sincerely,
Lisa McInnes