



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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Submitter: Name withheld

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Dear Standing Committee on Social Policy

INQUIRY INTO ENDOMETRIOSIS AND OTHER PELVIC PAIN CONDITIONS

Firstly, thank you for undertaking this inquiry. As a woman who has had endometriosis for other 20 years and multiple surgeries, including a hysterectomy I am thrilled to see the improved awareness and acknowledgement of this condition and all the impacts it has, not just on fertility.

I moved to Canberra 16 years ago. I had already been diagnosed with endometriosis and had had two surgeries by that time.

I do not intend in this submission to make a comparison between the care I received in Sydney and the care I have received in Canberra as this would not do credit to either and in my opinion misses the opportunity here to improve how we treat people with endometriosis and other pelvic pain conditions.

I will give a shout out to Dr Menakaya who has been nothing but empathic, caring, attentive and respectful of my wishes and concerns.

I will also note the importance of ensuring health professionals and others do not try and fit people with endometriosis into a single box of symptoms. I have been told by some medical professionals in the ACT that I do not meet the criteria to have endometriosis despite having a diagnosis and supporting pathology and subsequent surgeries where significant endometriosis was found.

I am thrilled to see the work the Jean Hailes Foundation has done and the checklist they have developed which includes several of the symptoms I have that were not considered to be “typical endometriosis symptoms”.

The actions I would like to see out of this inquiry are:

1. Improvements in the accessibility (not just financially) of co-ordinated holistic care for those with endometriosis and other pelvic pain conditions. It is so often left to the individual to navigate this and create a health care team around them and make sure they are all working together.
 - a. Health care teams generally consist of:
 - i. GP
 - ii. Physiotherapists
 - iii. Mental health professionals
 - iv. Natural therapies such as acupuncture
 - v. Dieticians/nutritionists
 - vi. Exercise programs
2. Greater discussion of the unspoken symptoms: pain on intercourse, the monthly cold, the reflux, the swollen and sore breasts, the mental toll, brain fog (unable to find the right words or remember the words for things), the toll on personal relationships not just intimate relationships but friendships, the nausea, the dizziness, the sensitivity to smells, the incomplete emptying (bladder), interstitial cystitis (frequency, urgency, burning sensation), fanny farts, farting in public (not able to control especially when the bowel is involved).

3. More supportive workplaces: Not grouping menstrual, fertility and menopause into one category and one policy approach.
4. More balanced reporting on the benefits and disbenefits of a hysterectomy for endometriosis so that patients can make an informed decision and the best decision for their circumstances. I decided to have a full hysterectomy at 40 and it has resulted in a significant reduction in my pain. I still have endometriosis and have flare ups, but they are further apart and less intense. This enables me for the first time in 20 years to have a regular exercise routine which not only assists with the endometriosis but my mental health and overall well-being.
5. Earlier discussions around options such as removal of one ovary. My left ovary stuck to the abdominal wall, my bowel and my bladder right from the outset. 10 years after it first stuck, I managed to find a surgeon who agreed to remove the left ovary. I got immense relief. However, I was already 35 years old and thus any benefits I got in terms of energy and thinking maybe I could look after a child then ran into age alone related fertility challenges. In my case I had limited chance of falling with one or both ovaries.
6. Focus of health care on the overall wellbeing of the individual not solely on their ability to have children. We need to have the discussion about fertility in the context of the person's overall health and feeling able to have the responsibility for a child when fatigued, in pain and suffering brain fog.

Regards,

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