



# Submission cover sheet

## Inquiry into endometriosis and other pelvic pain conditions

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**Standing Committee on Social Policy**  
**Inquiry into endometriosis and other pelvic pain conditions**

Dear ACT Legislative Assembly,

Thank you for inviting submissions from women of the ACT and for taking the time to read mine.

I was diagnosed with Polycystic Ovarian Syndrome (PCOS) when I was 16. From age 16, I was placed on birth control and my pain dismissed by many GPs, mainly at Fisher Family Practice (Dr. Nicola Murphy was the only GP who took my pain and overall health seriously). There was never acknowledgment of the pain (a number reports, including painful intercourse and pain that would reduce my ability to work or participate in recreational activities) or education around the condition, pain, remedies etc.

I have received no further investigation from GPs, often labelled as difficult or dramatic with regards to my pelvic pain complaints. Since the age of 16, I have been sent for an ultrasound twice. Once at diagnosis and once to investigate my endometrial lining. It was never to investigate the pain I encounter on a recurring basis.

I have had recurring pain for the last nearly 20 years of my life. It interferes with my ability to work, participate in recreational activities and impacts personal relationships. The only remedies I have found to minimise my pain has been Over The Counter (OTC) products such as Naproxen and Mefenamic Acid as well as heat packs, pressure therapy etc. I do often worry about potential damage to my liver with having to rely on OTC medications as much as I need to.

After having many side effects with different birth controls, I was advised the IUD might be a good option for myself. I had an IUD placed approx. two years ago and it has only made my condition worse. The only good experience I had on birth control was the combined pill, which will not be prescribed to me due to being overweight (a common side effect of PCOS due to insulin resistance) and my mother suffering a pulmonary embolism, which was a result of suicide. However this explanation has never been listened to and birth control should never be the only option to manage a condition.

Within the last 2 years, I had to attend The Canberra Hospital (TCH) after presenting to the Weston Creek Walk in Centre (WIC) with abdomen pain, which grew in to severe pelvic pain. It impacted my ability to walk and the pain caused me to have to pull my car over while driving to avoid fainting behind the wheel. This is a scary situation to be in at any age. I was referred to TCH due to the WIC being unable to perform an ultrasound and they were concerned about either my ovaries or my appendix.

At TCH, I was in crippling pain, barely able to walk, communicate etc. I saw many people who arrived after I did and were able to walk around and communicate etc. be triaged and seen before me. I was at TCH for approx. 12 hours,

during this time I had a nurse walk out of my triage consultation, leaving me waiting for approx. 30 minutes and then when I was eventually taken through, it took hours to be seen by a Doctor, who advised me he would not complete a scan of any form and that my "bloodwork was normal" (my bloodwork indicated there was signs of inflammation and infection). He then proceeded to reference my pain being in my "private parts" and spoke to my partner, not myself. He also advised I could go and be managed by the community and I had a follow-up on the Monday following. I informed this doctor that this was a community health therapy appointment and they were not resourced to follow-up these kinds of things. I was however dismissed and told to go home. I left the hospital at nearly 0300, still in pain and was not sent home with any kind of pain management or further follow-ups through the ACT Health System.

Upon reading my discharge summary (which I am happy to provide), I noticed the doctor had used the terminology "private parts" in the discharge summary and had noted the incorrect pain scale (significantly lower than what I reported).

I suffer with chronic pain, so if I am at hospital reporting a pain scale of 8, it's generally something serious that should be investigated. I'm sure you will hear from many other submissions that when you live with pain, your pain scale is skewed and it's hard to explain to a doctor that something like an 8 on the scale is almost crippling, when other people might report that as a 10.

I have come to suspect that the incident I noted above was burst ovarian cyst, I have had another 2 episodes like this since and I've not bothered to present to an ED due to the way I was treated and that my pain has been dismissed for the last 20-odd years. While I use this incident to highlight my experiences, there have been many similar experiences with my pelvic pain being dismissed or not investigated or even acknowledged.

I have complex mental health conditions, and I believe it's exacerbated by grieving a life I envisioned for myself. It's unlikely I will ever be able to have children due to the amount of time my pelvic pain and condition has been ignored by doctors etc. I was referred to one fertility specialist once, I was told to lose weight and come back (after paying a hefty sum for a consult). It's hard to continuously explain that I can't go a social event or work because of pelvic pain.

I attempted to refer to the pelvic pain clinic but due to starting a new job having a heavier office presence, I was unable to proceed to a consult. I am deeply appreciative this is an option for women in Canberra and I would like to see it grow as a service.

To summarise, in my experience women's pain is never taken seriously, especially in Canberra by the medical practitioners I've encountered. I'm disheartened in thinking the next generation will encounter the same problems and issues unless we stand up and demand better for ourselves, our daughters, our sisters, our wives and our mothers.

Warm regards,

