Legislative Assembly for the
Australian Capital Territory
Standing Committee on Social Policy

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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Hello,

Can I please request my name be removed before submission?

I would like to submit a personal experience of endometriosis which I believe highlights how proactive it is necessary to be as a patient, in order to be diagnosed or receive proper care for endometriosis and pelvic pain.

I am currently 37 and have lived in the ACT since I was 19.

At 17 my periods regularly became very painful and caused me to curl up, immobile, sweating, shaking and often vomiting for hours at a time every month. No one suggested that I seek medical help. I was aware that my pain was worse than my peers but thought it must be within "normal" parameters. I started the pill at 18 and that did help my symptoms quite a bit.

At 23 I stopped the pill and started to experience worse periods again, along with deep dyspareunia. By this point I had heard of endometriosis, and thought I might have it. I asked two different GPs on separate occasions if I might have endometriosis and both said it was very unlikely, did not suggest any further investigation, and just told me to take more painkillers when on my period. I took their advice and didn't make any further enquires.

At 29, I had a large ovarian endometrioma suddenly rupture, requiring emergency surgery in which my appendix and part of one ovary had to be removed. I was very ill after the surgery and recovery was difficult and protracted. I lost a lot of weight and suffered pain, fatigue and digestive issues for many months afterwards. I was subsequently diagnosed with stage 4 endometriosis with deeply infiltrating lesions in my bowel and uterosacral ligaments. This diagnosis came thirteen years after my first symptoms, and some 6 years after explicitly asking a GP about the condition.

In the case of ovarian endometrioma, there is good evidence to suggest continued OCP use can significantly reduce the risk of developing cysts. In my case, delayed diagnosis and 6 years of not taking birth control very likely increased my risk of having a large cyst develop and rupture. This is not desirable. The contents of an endometrioma are highly inflammatory and promote adhesions, plus the rupture and removal of the cyst damaged my ovary, impacting fertility.

Since this episode I have seen multiple GPs and multiple specialists in order to find practitioners knowledgeable enough to help me. One Canberra GP suggested in 2020 that I try pregnancy as a treatment. This is bad, outdated and irresponsible advice. Having since been pregnant, I can categorically confirm that in my case, it did not provide a cure.

I now get specialist help in Sydney after a bad experience with a Canberra endometriosis specialist. I had a HyCoSy procedure with a Canberra endometriosis specialist who knew my history of pelvic pain and who recommended I take two ibuprofen before the procedure. I really cannot emphasise enough how unpleasant this experience was. I was in so much pain I thought I would vomit or pass out and both my arms went numb - from shock, the dr suggested during the appointment. When the procedure was finished there was blood all over the floor and I felt very unwell and had trouble driving myself home due to the muscles in my back and legs spasming. I don't understand why I wasn't offered stronger pain relief or even a general anaesthetic, given the level of pelvic pain I presented with. I had a very bad pain flare after this for a few months. This Canberra specialist was also very expensive. I was quoted $7000 out of pocket for an excision surgery, whereas my current specialist (who is regarded very highly, as one of the best endometriosis surgeons in Australia) quoted $2000 out of pocket for the same surgery. Keep in mind it is very difficult to get these kind of price comparisons. It can cost upwards of $400 just for a specialist consult (more like $700 if they do a TVU during the consult) and can take a year to get an appointment, even when paying privately.

I have gone through several years of debilitating symptoms including pelvic pain, pain in my legs, back and chest, fatigue, digestive issues, bladder issues and brain fog. At my worst I have been unable to work, unable to sit in a chair and almost confined to bed.

I now have a team of GP, pelvic floor physiotherapist and exercise physiologist in Canberra and an endo specialist in Sydney and my symptoms are at the moment quite well controlled. It is expensive to maintain the appointments, and I feel like I really had to fight hard and do a lot of research to find this team and get good outcomes. But I am finally happy to have found the right professionals, medications and treatments to restore reasonable quality of life.

I wish GPs had a better understanding of endo, that I might have been referred and treated sooner. I also wish there were standardised training/qualifications for an endo specialist to have in order to be able to use that title. It would have helped me find a suitably qualified specialist more easily. I would also have appreciated more transparency around pricing. It would be useful to know average pricing for items such as TVUs, standard specialist consults, various surgical options, so that you could tell more easily whether a particular specialist is abnormally expensive.

I really appreciate the attention being given to this issue in this inquiry.

Thank you,

[redacted]