Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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From: [redacted]
To: LA Committee - SP
Subject: Endometriosis inquiry submission
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Hello,

Please find below my submission to the inquiry into endometriosis. I would prefer if my name would please be kept confidential when publishing this response. My contact details can be found in my signature block at the bottom of this email.

I was 31 when I was diagnosed with polycystic ovary syndrome (PCOS), endometriosis and uterine fibroids. I am now 33.

I moved to Canberra when I was 18. Before that I resided in NSW. I had a laparoscopy to look for endometriosis a few months before I moved to Canberra for university, and nothing was found. I do not know how much it cost for my medical bills at that time as I had access to bulk billing and my parents private health insurance and my parents paid for everything.

I first got my period when I was 12. I did not have a regular period, as in one each month. When I did get my period it was very heavy and I experience growing amounts of pain each time I got it. I tried contraceptive pills once and experienced significant weight gain and so decided not to continue with using these, as they had been prescribed by my doctor for acne. I remember when I went to the University of Canberra open day it was excruciating driving along the then unsealed road between the coast, Nerriga and Canberra. Each time the car went over a bump I was in pain.

Upon moving to Canberra, I had a number of worries about my period. I regularly did not have my period and so was regularly having to do pregnancy tests to make sure my partner and I did not accidentally fall pregnant. I thought that this was normal as the education I had in school all said that periods would be irregular while a teenager, so I didn’t think much of it.

I started using oral contraceptives again when I turned 23. This was because my partner and I were getting married and I wanted to have some more pregnancy protection for when we went overseas for our honeymoon and my period pain was at the point of nearly passing out when I did get my period. After being assured that weight gain would not occur and that my irregular periods and pain were normal, I started the oral contraceptives. Using these was the first time I had my period for multiple months in a row.

I used the oral contraceptives until I was 29. I experienced regular periods and a reduction in pain. The pills were quite expensive though, and could be sold out at multiple pharmacies. I remember having only 1 pharmacy in the Gungahlin and Belconnen region I could get the pills from 1 month and that it cost me over $100 to fill.

At about 28/29 i had several months where I started to not get my period. This was concerning as the instructions on the pills warn of pregnancy if periods are missed. When I saw my doctor they advised that this was a normal side effect of taking the pill for so many years. I explored other options for contraceptives with my doctor and was recommended Mirena as an option. After investigating Mirena I decided to give it a go as it was cheaper, lasted longer and had a higher level of protection against pregnancy.

When I had the Mirena inserted, it was not a small pinch like the nurse advised. It felt like I was being punched through my vagina up into my belly, even after taking painkillers preemptively based on recommendations I read online (not the advice from anyone in the medical centre). When I walked home (about 150m from the medical centre, so not far), it felt as if I was again being punched repeatedly.

The pain eventually became tolerable after a few days. The Mirena seemed to be working ok, except that my pains started to get worse with each period I had. About 1 year after having the Mirena inserted I started to have my period every 2 weeks and it started to get heavier. I raised this with 2 different doctors, a male and a female. The female brushed it off as normal and would not listen to me when I said it wasn't. The male doctor said it can be normal, but that I should have a blood test and an ultrasound to be sure.

Following the blood test and ultrasound I went back to the female doctor for the results. She reviewed my scans and blood work and said that everything was normal but she could refer me to a gynecologist if I wanted. I asked for the referral and was handed a bunch of paperwork with no instructions on what to do next.

After a few weeks I reached out to the gynecologists clinic. After a few failed times of sending them the correct paperwork i was informed it would be a few months until I could be scheduled for an initial consultat- forMemory it was going to be december for the consultation when I reached out to them in September.

I was lucky that someone cancelled their appointment and I was able to get in to see the gynecologist months earlier. I was thankful to my manager at the time who let me leave work early with minimal notice so I could attend this. At the time, I had progressed to having bad pain where I could barely walk when cramps occurred, I did not know when my bladder would be full so had to regularly go to the bathroom or risk an accident, and defacating was painful.

When I walked into the gynecologist office, the first thing the doctor said toe was that I have PCOS and most likely endometriosis. She identified my insuline resistance levels were very high (I had a number of 17 even after fasting for 22 hours, and the normal level is in single digits). She also pointed out my acne and additional body hair I have on my face that is a result of PCOS. She explained that it is a misconception that you have to have cysts to have PCOS which is why no doctors had ever diagnosed me. She also noted that my Mirena was completely depleted of the hormones, even though at the time of the blood test it was less than 2 years old.

I was sent for an endometriosis scan in Sydney, the closest location to Canberra that does actual endometriosis ultrasounds. This meant my husband and I had to take a day off work and travel to Sydney and back for this. During the scan the ultrasound technician was able to tell me right away that I had endometriosis.

Following my diagnosis I had a day surgery to get a sample to check I did not have cancer, as PCOS and endometriosis combined can heighten a risk of this according to my gynecologist. I also had my Mirena replaced. In the following months I tried several different contraceptives in combination with the Mirena. These had different effects, from one causing short term memory loss, to increased pain and bleeding with my period. I also experienced pain when I didn not have my period.

While the Mirena was replaced in January 2023, I had it removed in July 2023. It was not working for me and causing more problems than being helpful. I also started dienogest to prevent the endometriosis . I had Laparoscopic surgery to remove the endometriosis in August 2023. This surgery also revealed that I had uterine fibroids, which had not been on any of my scans 9 months prior. I was lucky that I was able to get in for the surgery in what I thought was quick, about 5 weeks in the private system. I was also lucky that I knuckle down and just get through the pain and do not take sick leave when I experienced bad pains, so I had the sick leave balances to take paid leave from work.

After the surgery I had a positive diagnosis of endometriosis and so was able to get Vissane through the PBS. This went from about $90 per month to the PBS standard cost. I have been on this since.

I experienced minimal pain in the months following the surgery, but still had tenderness. In a follow up ultrasound it was found that my ovaries have adhered to my uterus as a result of the scarring from the surgery. I also experience pain when having intercourse and if I move or sit down in certain ways. The pain is slowly getting worse over time and I have the worry that I have endometriosis coming back. I believe this may be because of the uterine fibroids coming back, though without any scans I will not know.

2 years on from the surgery, I have to work hard to bring my weight down as this will reduce my pains, but it is hard because of the pain from my ovaries and the PCOS. I regularly experience pain and have to take care when having intercourse with my husband so that I do not get hurt or fall pregnant. Even though I do not want children and would happily have everything removed, this could cause issues or not remove my endometriosis or PCOS

issues since these are more hormone not organ based issues.

Overall, I have spend thousands of dollars to get diagnosed and to receive treatment. In Canberra there is a lack of hulk billing, with the doctors costing about $90 each time I saw one. My gynecologist cost between $200-$250 per visit. The scans in Sydney cost over $500, and did not include the travel cost. The two surgeries I had were thankfully partially covered by Medicare and my private health insurance. If I did not have my private health insurance each stay in the hospital would have been in the thousands, if not tens of thousands. I would estimate that for my diagnosis and surgery along I have spent about $10,000 out of pocket. This does not include how much I have spent on contraceptives and painkillers.

I count myself as lucky. I got a diagnosis. I have practices in place to help me. I have given up some activities and am lucky to have the world's best, most understanding husband. Even though I have spent so much, have worries about unwanted pregnancy, pain from my ovaries adhered to my uterus and have to deal with the hormonal, mental and physical effects like fatigue and weight issues from my PCOS, endometriosis and fibroids, I think I am lucky as I got a diagnosis. I know what is wrong. And I was lucky enough that I am very careful with my money so I could afford all of my treatments and appointments. I don't know of many people who could afford this at my age.

I have experienced being told I worry to much, I am imagining it, that it is normal and that nothing is wrong by family, friends and medical professionals. I know I have to live with this for the rest of my life. I worry that I will experience complications and that medical professionals will just wave me off again. I am super lucky to have my new GP who is supportive, and gynecologist who didn't give up on me. If it wasn't for those two and my husband I would probably still be experiencing excruciating pain and would be ignoring the irregular bleeding because I was not believed when I told doctors that what I was experiencing was not normal.

Thank you for inviting submissions for this inquiry. I hope that better access, cheaper treatments and better education for medical professionals and the public come from this inquiry and that it is not brushed off. This is a massive issue seriously impacting women, those who support them and workplaces which employ women. More support for menstural issues, not just menopause, is greatly needed, with more support in Canberra being needed. There should be no need for us to have to leave our state of any form of treatment.

Regards,

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