

Submission
No 559

**INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO
HEALTH AND HOSPITAL SERVICES IN RURAL,
REGIONAL AND REMOTE NEW SOUTH WALES**

Name: Name suppressed
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Partially
Confidential

My name is _____ and I am writing to share my story about endometriosis and Adenomyosis in a rural setting. I moved to Tamworth in January 2020 after living in rural Victoria for 3 years. My partner was a soldier who discharged from the Army. In July of 2018 after years of struggling with pain during menstruation from the age of 11, the pain became constant. I was lucky in finding a GP who listened to me and who said “it could be endometriosis” who then referred me on to a Gynaecologist who was experienced in the subject.

I was admitted for laparoscopic surgery and stage 4 endometriosis was confirmed. I had my second surgery to remove more growth in Oct 2019. Laparoscopic surgery is the gold standard for endometriosis. There is no cure and the pain is women deal with on a daily basis is immense. Currently it is thought that 1 in 10 women suffer from endometriosis across the world. That number is starting to come closer to 1 in 9.

Upon moving to Tamworth I was trying to be proactive by researching gynaecologists in the region and found one who said on their website they were knowledgeable within this topic. I had my appointment and after a very short appointment was told I needed a hysterectomy and a colostomy bag (I have endo on my bowel).

A hysterectomy does not fix endo. So I left feeling disheartened by my appointment. I then went in search of a new GP to help me with my prescription medication that I was on for both depression and pain. I was on Targin 30/60 at the time for 2 years. The first GP I saw said she wasn't going to prescribe me anymore. When I asked about going through withdrawal she told me you cannot withdrawal from Targin. A statement I know is not true.

I saw another GP at the same clinic who told me “you need to get off the Targin and look for a cure”. I am not a medical scientist nor IS there a cure. I finally found a GP who was willing to work with me. I saw a pain specialist that was costing me a lot to see who while she did what she could, was limited in her advice. She had me on a ketamine infusion for 6 days after I had researched and requested we try it. Unfortunately it failed and I was back to square one. I was taken off the Targin and put on Palexia instead.

On particularly bad days usually upon menstruation I would present to the hospital. I always took my medical history with me to every hospital visit to prove that I did indeed have endometriosis and the treatment I was getting. I have had nurses treat me like a drug seeker, Drs who have dismissed me until a nurse has stood up for me and I have had some amazing treatment also. But the bad experiences have left me anxious about seeking treatment when I am at my worst, curled up in a ball crying and vomiting from the pain.

It has gone to the point where I had to drive myself 6 hours away to see a specialist in Sydney to get the care I needed. A drive that ended up being a waste of my time and money and having to drive 6 hours back all while in immense pain. The drive had me in bed for 5 days afterwards. There needs to be more access to women's health and better pain management options available. I understand that opioids are looked at as a big bad monster, but for some people they are the only thing that will work to help them function even at the smallest level every day.

These are women who want to work, who have families and friends and who live with chronic pain every single day. The inability to function and The cost of care has put so much of a financial and emotional stress on my relationship that we are no longer together. I thank you for taking the time to read this.