Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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Submitter: Amanda Emerton

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To whom it may concern

I am the mother of two adult daughters, both of whom have diagnosed Endometriosis. My 32 year old has stage 4 Endo and was diagnosed about 15 years ago. Since this time she has had 4 laparoscopies, the last being in 2018. My 28 year old has had one laparoscopy and was diagnosed with stage 2 endo.

I will firstly say that I am encouraged by the fairly recent community and medical exposure about endometriosis, and inquiries such as this will hopefully work to improve the lives of so many people affected by this terrible and life changing disease. The increased funding going into endo research gives us further hope.

I wish to detail some of our experiences with the medical services in Canberra. I will also state that both my daughters have private health insurance (Gold level to access reproductive services) funded by me and my husband. I can only imagine how difficult it is for so many people who have no medical insurance and have to rely on the public system. This access to private medical has enabled the girls to receive certain treatments with specialists fairly quickly. People without private health insurance can wait for treatment for months/years.

Of course, the very nature of endometriosis means that help often needs to come in the form of emergency pain relief in ED. To us, this is the absolute worst case scenario. My eldest daughter will suffer for up to a week with extreme pain before finally relenting and presenting at ED. We commonly go to North Canberra Hospital ED as it is our closest and also her gyneacologist works in the maternity area. Going to ED is like playing Russian Roulette, you can only hope you might receive some compassion, kindness, understanding and appropriate care.

Here are some of our experiences -

Triaged to sit in the waiting room, no pain relief offered. Waited a considerable time to be called in to an examination room to lie on a bed/table, no pillow cold vinyl. Young male Dr comes in and sits at the desk with his arms crossed and legs splayed wide open. First comment out of his mouth is “OK, how are we going to play this game?”. My daughter responds with anger saying that this is not a game, this is her life! After some heated exchanges I demand to speak with his boss and refuse to have anything further to do with this failure of a Dr. This was one of many experiences where my daughter has been made-out to be a drug seeking loser by medical staff in the ED. Formal complaint was lodged.

Another occasion, she finally received a bed in ED, was provided minimal amounts of pain relief and after an hour or so was told by the Dr treating her that "couldn’t she go home now” as the ED was for acute treatment. No, how are your pain levels? Do we need to increase the pain relief? Should she go to Short Stay? No, you’ve had your time and it’s now time to leave.

Recent presentation at ED, middle aged male Dr comes in and asks about her pain, symptoms, how long has this been going on, acknowledges that she has a fairly high dose of opioid medications prescribed so she probably has a high tolerance at this time. Does an external abdominal examination and presses so hard she calls out in pain. Dr goes on to chart

morphine a total of 6mls, to be administered in 2ml doses. When this proves to be totally useless (as we knew it would be) he refuses to administer anything else. I requested the Consultant on duty come to see us and she apologised profusely and agreed to further pain relief.
She also told us how frustrated she was with so many of the ED's Dr's having little to no knowledge of both endometriosis and pelvic pain and that she hoped to set up some seminars covering the topic.

I could go on with so many experiences like this. Women are seriously traumatised by the treatment they so often receive by the medical profession, my daughter has PTSD I have no doubt.

It appears that often the problems are - under trained Doctors (often men), a discriminatory view that women are coming to ED to seek pain killers (because they apparently like them, not that they are in horrific pain and need them), a lack if training in how to provide the correct pain relief for individuals. A Dr that actually asks "what usually works for you" and then listens and acts, can get an endo patient out of ED feeling much better with no admission necessary, within hours.

Training and more training is what is required to ensure better treatment for people with endometriosis and pelvic pain, along with a big dose of compassion and care.

In closing, a little more information on the impact of endometriosis in my elder daughter's life - she has been unable to work for over 5 years, she held a graduate position with the Taxation Department and was wrongfully dismissed due to medical absences. This was overturned with an apology and offer of another Grad year however she was so traumatised by the event she has been unable to work since. Two lost relationships, it's tough being a partner and a carer. She is now living on a disability pension and requires assistance with paying rent, bills and medical costs. Her pharmacy costs are between $300-$400 per month, paid by us. She sees a pain specialist in Sydney as our experiences of pain specialists in Canberra was terrible.

Thank you for your time,I hope some if this information may be useful in providing some detail of what people with endometriosis go through.

Kind regards
Amanda Emerton