Endometriosis Campaign Speech 14.11.2021

One may feel that women of today are living in an era of empowerment, self-determination, and financial liberation, but is that really our lived experience? Or, is it just a perceived reality?

When discussing women's rights with my grandmother who was a nurse, midwife, and mother of 5 in the 1950's, she felt that women have a lot more autonomy today. As she said this to me, I sat opposite her not feeling the same sense of freedom and autonomy she presumed I had.

I am grateful for many social improvements, which have occurred during the women's rights movement, however, I am frustrated that I need to be thankful for such "progressive" advances in the first place. Why are there so many marginalised groups in society *still*?

As someone who suffers from Endometriosis, I can empathise with the physical, social, emotional, and financial strain this condition has on every individual. As a Nurse and Midwife, I have had many conversations with women about their medical experience relating to Endometriosis. Many women report they are dissatisfied with their medical care in primary and tertiary settings.

Gender bias in medicine is well documented in literature and has an impact on Endometriosis sufferers. An article states that 'women are less likely than men to receive more advanced diagnostic and therapeutic interventions in medical care'. The article goes on to say that 'gender order' in society means that a 'normal' human being, is assumed to be male.

In 1977 the US Food and Drug Administration recommended women of childbearing age be excluded from clinical research studies due to a variation of hormones during the menstrual cycle. Hormonal changes were deemed as a "complication" when undertaking clinical research as sample sizes would need to be larger, thus incurring additional cost to fund the research. Therefore, male-only studies were justified by the belief that what would work for men, would also work for women. This assumption has had catastrophic results for many women.

Historically, menstruation has been a taboo subject. A topic which has been perceived to be 'socially inept' to discuss. For centuries, women have been under patriarchal rule and have been told to 'be quiet' when it comes to "disturbing" and "gross" conversations about periods.

Women have a right to autonomy and self-determination. Unless we talk about women's health, we may never reach that shared goal.

Firstly, we must acknowledge and address current system failures within healthcare.

Healthcare has been built on hierarchical and patriarchal culture – meaning, “doctor and institution knows best”. Insidiously ingrained cultures are perpetuating gender biases in healthcare which are affecting women’s health.

Sadly, many women are *still* being treated as “hysterical” when presenting to health care facilities with an array of different medical conditions. I have witnessed this as a nurse and also as a patient who suffers from endometriosis, adenomyosis and interstitial cystitis myself. I recently wrote an article to the Mercury about inequities and inequalities women endure in healthcare systems. Sadly, what was shared was only the ‘tip of the iceberg,’ so-to-speak.

As I am mindful of not breaching patient confidentiality, I will only share with you my own personal experiences as a patient. However, keep in mind that my experience is not a unique one.

I presented to a GP’s clinic during extreme menstrual pain. I couldn’t book in to see my regular GP due to extensive waiting periods, so I had to attend a different clinic. I sat in the waiting room pale, vomiting into a bag, and I was feeling extremely dizzy, all because I had my period. I had a heat bottle strapped to my abdomen and another heat bottle tucked into the back of my pants, providing some, but minimal comfort. In the waiting room, I received scornful looks as I rocked back and forth appearing like I was in labour. I sat there under people’s watchful eyes feeling vulnerable, exposed and critisised. Finally, I was called into the GP’s office. I sat down feeling relieved. Help was on its way. I was wrong. The doctor told me I was “clearly drug seeking” and using my period as ‘an excuse’. I had no words because I was shocked someone could suggest such a thing. He said that because I was asking for Panadeine Forte from a doctor that wasn’t my regular GP, it looked “suspicious”. When I explained I was unable to make an appointment with my regular GP, he told me that “excuses” like that were a part of “drug seeking behaviours”. He threatened that if I tried to “seek opioids again”, he would report me to AHPRA.

I walked into that clinic exhausted, sick, and vulnerable and I left feeling humiliated, disempowered and $80 out of pocket for absolutely no help.

Throughout my journey living with Endometriosis, I have undergone four laparoscopies for ovarian cysts and endometriosis, five cystoscopies and dilatations and six DSMO treatments for interstitial cystitis. However, it took many years to receive a formal diagnosis of Endometriosis. I had all the symptoms, but the endometriosis was not physically seen until my third laparoscopy.

During a follow up appointment after one of my procedures, I had a specialist tell me that "there was nothing wrong with me and that my pain was due to past trauma" - implying I had psychological pain, not physical pain with underlying pathology. Their exact words were "go and live your life and be happy." As I got up to walk out of their office, they said "Amanda, I never want to see you in my clinic again."

Once again, I left feeling disempowered, humiliated, vulnerable and $140 out of pocket.

I felt like I was constantly at the mercy of healthcare providers who made me feel like I was crazy. I started googling Munchausen disease to see if I had that. I was so disheartened and felt I had nowhere to turn for support.

I have spent thousands of dollars on naturopaths, dietitians, non-pharmacological pain management, pharmacological pain relief, mindfulness courses – basically anything that would help me survive menstrual and ovulation pain. I have tried an array of contraceptive pills and other methods to avoid my period. Unfortunately, I seem to be very sensitive to progesterone and have Pre-Menstrual Dysphoric Disorder as well. When I tried contraceptive pills, I became very aggressive and depressed. One doctor said to me "You are probably going to need to suck it [depression and suicidal ideation] up if I wanted to stop the pain."

I felt crazy trying to treat a condition I hadn't even been diagnosed with yet. When debriefing to a healthcare worker how disheartened I felt at the lack of autonomy I had, he wrote in my clinic notes "*patient experiencing anxiety*". Months later when I presented to the hospital, I was told by nurses and a doctor that I needed to "stop being so anxious" and to "calm down" when I was simply just stating my medical symptoms during an examination. I had been labelled with a condition [anxiety] which I didn't even have.

Finally, after my third surgery (with a different specialist), I received an official diagnosis of Endometriosis and Interstitial cystitis - A condition which affects the bladder. This condition meant I was passing urine over 40 times a day and I developed insomnia as a result.

I had multiple surgeries, weekly treatments and tried many different, and very expensive medications to treat this condition.

About three months after a treatment, I started passing frank blood when voiding. I went to a GP, who wasn't my usual GP. This doctor laughed at my diagnosis of interstitial cystitis. He even put the diagnosis in quotation marks on an ultrasound form because he didn't believe the diagnosis. He said to me "Who the hell gave you that diagnosis?" He was completely undermining the healthcare professional who diagnosed me. He then proceeded to deviate the conversation and asked me how my sex life was. When I questioned him if he was asking this in relation to me suffering endometriosis and potential dyspareunia, he laughed and said "Oh, I guess that too"

I was in pain, exhausted, bleeding from my bladder and he was more interested to know personal and intimate details about my sex life, which was not relevant to my current medical presentation.

He walked me out of his office and said to his receptionist, in front of all the patients in the waiting room, "there is nothing wrong with this one - charge her the full amount!". You know the drill by now – humiliated, vulnerable and $100 out of pocket.

There was in fact something wrong. During a procedure, a catheter balloon ruptured in my bladder. Overtime, the large piece of catheter (which we didn't know was left in my bladder) had solidified into a 2cm sized "stone". This resulted in trauma to my bladder causing pain and frank blood to pass every time I voided. Instead of timely treatment, I went weeks and weeks passing blood because a doctor didn't believe me. I had provided him with a urine jar full of blood-stained urine, which I saw him throw in the bin instead of sending it to pathology.

On another occasion, I presented to ED in extreme pain. I explained to the doctor I felt like I had another ovarian cyst. He laughed. "How could *you* possibly know that?" He said it was likely "*just* period pain" … I explained to him it is a bit tricky to have period pain unless one actually has their period… His ego took a knock.

After an ultrasound, it revealed I had a large ovarian cyst. The cyst was 0.1mm off needing to be surgically removed. He told me there was nothing to be done and to go home. While I was in ED, I had been administered Panadeine Forte, Endone, Morphine and non-steroidal anti-inflammatory injections to help reduce the unbearable pain… he had the audacity to tell me to just take some Panadol when I got home... When I explained that I wouldn't have presented to ED if all I required was Panadol. His response was "I will be documenting in your patient notes that you have been aggressive towards me today." He told me to take out my own cannula and be on my way. My own colleagues and friends heard this conversation take place. Once again, I was humiliated.

Hunched over, I limped out of hospital that day with silent tears streaming down my face. No one will listen to me.

There are many more stories of health inequalities which I have experienced and have also witnessed. It is deflating, degrading and inhumane. It is not okay to accept that women will just suffer in silence. Whenever the words "patriarchy" come out my mouth, people often react by rolling their eyes. They tell me they are sick of hearing about it. Well, women are sick of experiencing it.

Erectile dysfunction has been considered more of a health priority than many other chronic gynaecological conditions. How terrible it is when a man can't enjoy sex. Penile pumps have been created for men post prostatectomy. There are obviously people out there with time on their hands who think of these things. Where is the equivalent level of dedication to make sure a woman can still enjoy sexual pleasure with Endometriosis and pelvic pain? Why is sexual satisfaction, free from pain for women, not considered equally as important than correcting a flaccid penis?

With health inequities, there are also financial inequities.

Radio host and Endo sufferer Brigit Hustwaite stated during a podcast that she had calculated she spent approximately $9000 in one year due to Endometriosis. In Victoria Devine's book "She's on the Money" she states that women on average must work an extra 52 days per year to earn the same income as a man. When we consider that 1 in 9 women experience endometriosis and that the average cost may be about $9000, where is the financial equity and equality?

The majority of women have 10 sick days per year. There are 12 months in the year. How many menstrual cycles does that cover? As a result of frequent sick leave due to Endometriosis and pain, women often face unnecessary and detrimental comments in their workplace regarding their 'professionalism'. I too have also experienced this. Female senior colleagues (who are nurses) have contacted me via social media or spoken with colleagues who I associate with outside of work, to question the validity of my sick leave. Women as well as men are perpetuating a hierarchical and patriarchal cultures which discriminates against female employees with Endometriosis.

Women who miscarry are often only afforded two days paid leave… *two*. 1 in 4 women miscarry and 1 in 4 women have an abortion. Women with Endometriosis rarely have sick leave accrued. This is a facet of the gender pay gap. A female nurse in Launceston recently shared with me she miscarried whilst at work and continued to work due to fear to professional repercussions if she asked to go home. There are many women among us who have continued to work in the depths of grief to maintain financial stability, and there are also women who have taken time to grieve, but are not being financially supported to mentally, emotionally and physically heal from a pregnancy loss.

Women are being denied income protection due to Endometriosis. I know this because I have been denied income protection due to having Endometriosis. Are 1 in 9 women being denied financial security due to Endometriosis?

Some private health insurances have removed acupuncture, naturopathy, and osteopathy from insurance cover – alternative therapies which many women with Endometriosis access.

Another financial burden.

To access a chronic pain service in Tasmania, one would have to travel to Hobart or interstate to seek support. Further expenses.

Women are paying for doctor’s appointments, only to walk away feeling humiliated., gaslit and disempowered - more money down the drain!

There is no place for sexism or misogyny in healthcare. Historically, women have been, and often still are, being treated as if their chronic menstrual pain is a normal physiological part of being a woman.

If only women’s gynaecological health was taken as seriously as a flaccid penis, we may have already had a cure for Endometriosis by now.