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(SHE/HER)

Amelia is a Naarm/ Melbourne-based artist, writer, and arts worker living with chronic illness. She is fond of all things art and history, is passionate about socio-politics, and values the importance of an inclusive arts industry. She is an avid tea-lover, adores a good op-shop, and thinks twilight is the best time of day.

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IMAGE DESCRIPTION:

A close-up portrait of a woman who is smiling and standing in front of a gallery wall. She has light brown hair that is in a bun, and is wearing a black and white striped top, as well as round silver glasses. There are small artworks with illustrations and text in the background.



'Hysteria' Is Not Dead: The Continuing Dismissal of Women and Non-Binary people by a Sexist Medical System

Content warning: Medical dismissal, medical sexism, mentions of 'hysteria', misogyny.

Most people would rightly like to think that when they need healthcare, they will be able to access it without bias. When thinking of modern medicine, it is understandably often assumed that logic and scientific reasoning should be what informs decision making, and that archaic notions of 'femaleness' and mistrust of women are no longer part of any diagnostic process. Unfortunately, however, this isn't true for many women and non-binary people.

Despite progress having been made in relation to medical sexism, navigating the healthcare system still comes with plenty of problematic experiences. Such interactions are usually underpinned by this continued prevalence of entrenched misogyny and bias. This bias has a strong foundation in social history, and is enabled by the ingrained power imbalance between patients and the institution of medicine — an institution that seems to refuse impartial scientific reasoning. In other words: medicine is sadly not only influenced by science, but by human prejudice, which negatively impacts women and non-binary people's engagement with healthcare.

This gender bias in medicine has been increasingly acknowledged in recent years. Women and non-binary people are telling their stories of being dismissed by health professionals, especially when it comes to "invisible" chronic illnesses.



Books such as Maya Dusenbery's *Doing Harm*, Alice Hattrick's *Ill Feelings* and Kylie Maslen's *Show Me Where It Hurts*, among others, are creating much overdue awareness. Conditions such as chronic pain and Endometriosis have been given increased media coverage and research attention, which will hopefully benefit many people with the condition.

However, there remain many conditions and health issues which disproportionately affect women and many non-binary people, such as autoimmune diseases and conditions like Postural Orthostatic Tachycardia Syndrome (POTS) that remain under-acknowledged, under researched, and to which health practitioners are still often not well informed about [1]. Autoimmune conditions, for example, affect about 8% of the population, but 78% of those with these conditions are women [2].

To add to this, conditions often present differently or require a different approach to treatment in women than men. An example of this is with heart attacks. Women tend to experience symptoms different from those experienced in men, yet most of the research was typically conducted by men on male subjects. This is at least part of the reason why women are twice as likely to die after a heart attack [3]. Part of this difference is biological, part stems from social factors surrounding gender, but ultimately it means women (including trans women of course) and non-binary people are not always getting the care they need.

Given the increase of post-viral conditions from the current pandemic — a group of illnesses that also tend to affect women more frequently — this topic is a timely issue.





The lack of knowledge around how sex and gender impacts health leaves many dismissed and even gaslit when attempting to seek care, and this is something that has flow on effects for overall health and wellbeing.

The dismissal of women's illnesses, pain and knowledge of our own bodies, is a problem shrouded in a history that is continually repeated. Recently I was re-watching the 2017 documentary film *Unrest* by American filmmaker and activist Jennifer Brea on the often post-viral condition Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), of which approximately 75-85% of patients are women [4]. I was reminded of a powerful scene in the film which depicts historical photographs and videos of women diagnosed with 'hysteria'. The viewer is simultaneously talked through the history of hysteria as Jennifer comments that she was misdiagnosed with the modern version of this diagnosis, known as a conversion disorder, and more recently referred to as Functional Neurological Disorder (FND). Unfortunately, she is not alone in her experience.

It is a far too common experience for women and non-binary people with chronic invisible illnesses to be labelled as psychosomatic, and far from a new phenomenon. For centuries, illnesses like Multiple Sclerosis (MS) were often deemed psychosomatic, when really their true cause and biological basis had simply yet to have been discovered or readily diagnosed. In such situations, medicine seems intent on blaming anxiety, mood or even blaming the person for simply not making the effort to get better. Those affected are often too unwell to raise a mutiny against this behavior and so the cycle continues. If you're a woman with an invisible illness, particularly if it's one that's hard to diagnose or less common, it's likely you've experienced comments such as:



"It's probably just stress", "Are you sure you're not anxious", or something along the lines of "You won't find an answer, so stop looking".

Stress, anxiety and mental illnesses are potentially serious problems that deserve their own attention and are by no means the fault of the patient. However, they are not the cause of every physical symptom a woman experiences. The solution here is rather simple: believe women. If we tell you what we are experiencing feels different to stress, then this should be the key going forward. Medicine continues to prioritise biomedical expertise at the cost of lived experience [5]. Afterall, despite all the wonderful scientific testing modern medicine has, it is not a substitute for personal experience. Women should not be dismissed, gaslit and demeaned, nor given the nonsensical title of 'hysteria'.

Coined by French neurologist Jean-Martin Charcot in the late nineteenth century, the term 'hysteria' was taken from the Greek word 'hystera', meaning 'uterus' [6]. This derived from the Ancient Greco-Roman 'wandering womb' theory written about by Hippocrates in the 4th and 5th centuries. It was thought that when the female reproductive system was inactive (in other words: the woman wasn't fulfilling her purpose of producing children) and so her womb went wandering and caused illness [7]. You might have heard some version of this tale. It was thought that the womb would wander around the body pressing on organs and thus cause symptoms. Hysteria became a catch-all diagnosis for women experiencing symptoms, such as, faintness, anxiety, weakness, paralysis and seizures.

Using the new photographic technology of the nineteenth century, Charcot had images of his patients taken to show the physicality of their symptoms



and provide scientific evidence. The book containing these images has become somewhat infamous in more recent times [8]. Charcot also expected patients to 'perform' at his famous Tuesday lectures, where under hypnosis they were tormented and at times bribed into exhibiting symptoms to fulfill the doctor's expectations. It was later that Sigmund Freud (who had been a student of Charcot) and his partner Joseph Breuer falsely asserted that cases of hysteria did not originate from the nervous system physically, but were a disorder of the mind, brought on by some sort of emotional trauma [9].

The problematic expectation created by these medical photographs was that women were fragile and weak, predisposed to erratic and 'hysterical' thoughts and behaviour, which is something many people likely see as irrelevant to our present day lives. However, the notion of women being unreliable witnesses of our own illnesses is something still deeply entrenched in modern medicine. Even though the medical understanding of female biology has progressed, cultural ideas of the expectations of women and of female bodies, reflect the dominant social thought of the time [10]. Given we still have a gender pay gap of 13.8%, high rates of sexual assault against women and girls and numerous parts of the world are revoking access to safe abortions, the dominant social thoughts of our time may not be as progressive as we sometimes think.

Optimistically, the ground is perhaps finally starting to shift with increased awareness of sexism more generally, and it seems some progress exists in recognising the need to believe women and non-binary people's pain. Although, as a society we are grappling with the ongoing realities of institutional misogyny and prejudice, the reality is that there is still a significant way to go.



This progress depends on our ability to question and re-evaluate so many of the narratives ingrained in the cumulative psyche. One of these narratives is that of the 'hysterical' woman. Structural and ingrained systemic issues of discrimination or dismissal are, of course, not going to be quickly solved in medicine, healthcare or anywhere else. However, the more people become aware of the problem, the more long held beliefs and structures can gradually be shifted and women and gender diverse people start receiving the care they deserve.

