

Rebecca Smart.

Premenstrual Dysphoric Disorder Petition (P-06- 1399)

Written Evidence submission.

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Foreword.

Dear members of the petition committee.

I would like to thank you for taking the time to discuss the petition on the inclusion of Premenstrual Dysphoric Disorder (PMDD) into postgraduate medical teaching.

I wish to make it known to the petitions committee that the petition aims have already been achieved, through a collaborative partnership between Health Education and Improvement Wales, Fair Treatment for Women of Wales and two patient experts: myself being one.

A PMDD CPD e-learning module has been co-developed and will be available for healthcare and other allied health professionals, and those in medical education, on the HEIW learning module platform on April 24th. An on-demand version will be available once Welsh translation has been completed.

I would also like to pay thanks to Professor Arianna Di Florio of Cardiff University, who has, for years, tirelessly worked to push for PMDD and PME to be a mandatory part of undergraduate medical student teaching. In the weeks after the petition launched, Arianna, was informed that PMDD and PME was to be included within the core teaching curriculum and to be included in final year exams. This sits complementary to an SSC module on PMDD which provides a patient perspective and was developed by a Cardiff University medical student who recognised there was a need for further education.

To complement the ongoing work within the medical community, I have included four recommendations. These recommendations are solely patient focused and place emphasis the availability of information about PMDD, particularly through the medium of Welsh language.

Finally, I would like to thank the Health Minister for her response to the petition and for the continued work on Women's Health in Wales.

I do feel it is necessary to note that PMDD treatment does not fall within the scope of pelvic health. However, this is something that is welcomed within the PMDD community, especially those transitioning through chemical and surgical menopause, and those with co-morbid gynaecological conditions.

I would like to draw your attention to pages 3, 4, 5 and 6.

A letter of support has been provided by Fair Treatment for Women of Wales on page 7.

I look forward to your response.

Kindest regards,
Rebecca Smart.

Premenstrual Syndrome.

It is thought that as many as 80% of the menstruating population will experience Premenstrual Syndrome (PMS) at some point in their lives.

While PMS may interfere with a woman/assigned female at birth (AFAB) individuals' life, it is more often easier to manage, not requiring medical intervention and is not life threatening.

Our society perpetuates jokes about PMS causing moodiness in women/AFAB individuals, a stereotype deeply ingrained in our culture. This stereotype is further reinforced by inadequate media representation.

Chrisler and Caplan, feminist psychologists, argue that PMS is not a biological, but a culturally bound one, similar to hysteria. They argue that the symptoms of PMS are a representation of women's frustration and anger who have a justifiable right to feel frustrated with life, having been subjected to the harsh realities of societal suppression and expectations.

Premenstrual Dysphoric Disorder, an overview.

Premenstrual Dysphoric Disorder (PMDD) was added to the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 2013, as a depressive disorder. Prior to this, it had been listed in the appendix as a condition to further study. The World Health Organisation (WHO) validated PMDD as a recognised diagnosis in the International Statistical Classification of Diseases and Related Health Problems (ICD) in 2019. This provided a global acknowledgement of PMDD as a legitimate medical condition.

PMDD is a chronic cyclical hormone-based mood disorder for which there is no cure. It is thought to be a disorder of the neuroendocrine system. Symptoms are triggered by ovulation. Those with PMDD have a hormone sensitivity, causing an abnormal reaction in the brain to the natural rise and fall of the sex hormones, oestrogen, and progesterone. These fluctuations create debilitating mental, emotional, and physical symptoms that threaten every aspect of the person's life.

It is as common as diabetes in females/AFAB individuals, effecting 1 in 20 people who menstruate.

Whilst a bilateral oophorectomy (surgical removal of both ovaries) and, in severe cases, a total hysterectomy with bilateral salpingo-oophorectomy (removal of both ovaries, uterus, womb, and cervix,) may be perceived as a cure, the hormone sensitivity remains. Post-surgery, people with PMDD experience prolonged periods of extreme mental and emotional anguish with minor changes in hormone levels or adjustments, compared to those without the disorder.

There are no blood, saliva, or imaging tests to diagnose PMDD. For this reason, the disorder is often overlooked by professionals or misdiagnosed as bipolar disorder due to the similar characteristics of cycling mood states. Those with PMDD go longer without safe treatments, and support and spend longer with a poor quality of life.

Diagnosis throughout the UK takes an average of 12 years, and there is a need to see approximately six healthcare professionals before PMDD is accurately recognised and treatment plans or referrals are in place.

According to Stats Wales, 1,585,674 women/AFAB individuals aged 15-49 lived in Wales in 2021. PMDD has a prevalence rate of 5.5%, it can therefore be deduced that in 2021 there could have been up to 87,212** living with PMDD.

Those with PMDD are at a 50% higher increased risk for suicidality than those with major depressive disorder. 86% (*75,002 in Wales) of individuals with PMDD experience suicidal thoughts, and 1 in 3 (*26,163 in Wales) will attempt suicide during episodic periods (*representative as of 2021).

**There are currently no available statistics for how many are thought to be living undiagnosed or with a misdiagnosis, however a recent meta-analysis by Reilly et al. (2024), suggests up to 3.2% of the menstruating population may be living undiagnosed.

There are currently no statistics available within Wales for how many women/AFAB individuals with PMDD have died by suicide.

My journey with PMDD.

I was finally diagnosed with PMDD in 2019 at the age of 32 after struggling for 18 years without a correct diagnosis.

During my teen years, PMS was considered a regular part of womanhood that every person who had periods would experience. What I experienced went beyond that. A hormone-sensitivity that made me want to end my life, month after month. Yet one that is shrouded in stigma of mental health and the taboo of menstrual health. One, we are belittled for speaking openly about.

During school we were taught to expect minor symptoms like feeling bloated, having sore breasts, craving certain foods, and maybe feeling a little emotional or experiencing acne breakouts. However, no one ever prepared me for the immense darkness and suffering that I would experience month after month.

I felt like I was being controlled by an entity that I had no power over, and my views of the world became distorted and dissociative. I was not aware that my hormones were not supposed to spark a war with my brain, using my own body as their battleground, with death being the goal.

Prior to receiving an accurate diagnosis, I was misdiagnosed and treated for various conditions such as bipolar disorder, personality disorder, depressive disorder, anxiety disorder, post-natal depression, complex-post traumatic stress disorder, and panic disorder. However, none of the treatments prescribed helped me overcome my symptoms.

Moreover, I was often dismissed and not taken seriously by healthcare professionals who attributed my symptoms to being a teenager from a broken home, PMS, or mere attention-seeking behaviour.

Over the years, I tried to end my life multiple times, and two of those attempts were severe enough to require hospitalisation. It wasn't until I received my PMDD diagnosis I could slowly begin to piece my life back together, but that also came at a cost.

My story is not uncommon. Unfortunately, there is still a lack of awareness about this condition, both within the medical community and society.

Recommendations.

It is a common experience for those with PMDD to stumble upon crucial information unintentionally. The truth is, they should not have to rely on chance social media scrolling or random google searches to get informed. PMDD is a real and severe condition that deserves more attention and awareness.

If we want to ensure that patients, their loved ones, and the younger generation can access information, support, and treatment guidelines for PMDD, we need to act. That's why I propose four recommendations to complement the ongoing efforts to educate medical professionals and students. By implementing these recommendations, we can make targeted awareness and education about PMDD more widely available. This in turn, can empower people to recognise the link between hormones and mental health and provide crucial insight into recognising where changes are needed.

- Information about PMDD must be available on every health board website. It is concerning that those seeking support through the medium of Welsh face a significant disparity. While Mind Cymru and IAPMD offer some resources in Welsh, they are limited and do not adequately cater to the needs of those who speak Welsh as a first language. It is crucial that information about PMDD is through the medium of Welsh language on every health board website with links to IAPMD and Mind Cymru. This information must include "What does PMS look like for you?" to help individuals identify their symptoms. It is also essential to highlight the differences between PMS and PMDD, to empower individuals to seek appropriate care. I recommend ensuring this is available in English also but emphasise ensuring that Welsh is a priority.
- A full page on the NHS 111 website with information about PMDD. The current A-Z page has a small write-up that links to the MIND webpage, and a brief mention under the depression heading that links to the PMS page. But PMDD deserves to be recognised as a real diagnosis, with its own dedicated page on the NHS 111 website. It's time to dispel the misconception that PMDD is just PMS. This dedicated page should provide comprehensive information on symptoms, PMDD-specific treatments, details of when to see a GP, information on symptom tracking along with the menstrual cycle, and links to PMDD peer-support groups such as IAPMD, PMDD POD Wales Peer Support, and Fair Treatment for Women of Wales. This information must be available in both English and Welsh.
- Include age-appropriate education about Premenstrual Disorders (PMDD and PME) in the RSE curriculum for Wales. Educating about menstruating within the school setting is limited. My experience of lacking education throughout school is just one of hundreds of thousands. While I may have left school many years ago, these stories are still being echoed today. Young people must be made aware of what is not normal throughout their reproductive years and the impact hormones can have on their mental health. It's crucial to equip young people with the knowledge they need to recognise early warning signs of PMDD and PME. Additionally, it is essential to ensure that educators are well-informed on how to approach these topics and how to best support their students. I recommend seeking advice from patient experts and third sector organizations on best approaches to education. By doing so, we can empower students to seek help and support safely, which is vital for their well-being.
- A task and finish group. It is evident that women and AFAB individuals face significant challenges when it comes to their health and wellbeing. From seeking a diagnosis to

accessing information and support, they often experience disparities that can make their lives more difficult. A task and finish group, as part of the all-Wales planned care programme's Clinical Implementation Network for Gynaecology, with specific focus on Premenstrual Disorders can explore what works well inequalities women/AFAB individuals with PMDD are still facing. This group has the potential to make a real difference in the lives of those with PMDD and PME in Wales.



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Dear Jack Sargeant MS, Chair of Senedd Petitions Committee

We are delighted to lend our support to Becci Smart's recent petition, '**Health Education & Improvement Wales to make PMDD a mandatory CPD module in postgrad medical teaching**' and to supply further information for you and the Committee to consider as part of your deliberations.

FTWW: Fair Treatment for the Women of Wales is a pan-Wales patient-led charity and disabled people's organisation, dedicated to achieving health equity for women and people registered female at birth. We support and advocate for those who are disabled and / or living with long-term health issues, of which PMDD (Premenstrual Dysphoric Disorder) is one. FTWW also Chairs the third sector Women's Health Wales Coalition, whose evidence has led to the Health Minister's commitment to a 10-year Women's Health Plan. That evidence included several recommendations to improve care for patients living with PMDD, and we look forward to their being fulfilled in good time.

Becci is a long-standing member of FTWW and one of our volunteer Champions for PMDD. As such, we are pleased to be working with her and Health Education & Improvement Wales (HEIW) to deliver a training webinar on PMDD this month, PMDD Awareness Month, which will be shared with general practitioners and other healthcare

professionals in the coming weeks. We believe this goes some way to ensuring the petition's key aim is met. However, we would also like to apprise you of three additional / follow-up recommendations which would make a huge and positive difference to the experiences and lives of those living with PMDD in Wales in the hope that the Committee will be able to facilitate further work in these areas – thank you in advance for your attention to these, as follows:

- Each health board website to contain information about PMDD, with signposting to both the International Association of Premenstrual Disorders (IAPMD) and FTWW. This should include the key question, 'What does PMS look like for you?' and explain the differences between PMS (premenstrual syndrome) and PMDD. It must be available in both English and Welsh.
- A specific page on the NHS 111 website to be dedicated to PMDD, with information on PMDD-specific treatments, when to see your GP, details on symptom tracking alongside the menstrual cycle, and links to peer-support groups (POD Wales Peer Support and FTWW.) It must be available in both English and Welsh.
- A task and finish group to be set up (potentially as part of the all-Wales planned care programme's Clinical Implementation Network for Gynaecology), including clinicians and patient advocates, to look at existing barriers to optimum care for PMDD and PME (premenstrual exacerbation) and take forward measures to address them. It is vitally important that intersectional inequities in care are considered, including geographical variation across Wales, so that all patients, regardless of postcode, can expect to receive the same high standard of care going forward.

We would like to reiterate our thanks to you and the Committee for considering the above, and for playing a key role in improving the lives of those experiencing PMDD and PME symptoms across Wales.

We very much look forward to hearing the outcome of the Committee's deliberations on April 22nd.

Kind regards

Debbie Shaffer, Director of Policy & Research

FTWW: Fair Treatment for the Women of Wales

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