

For years, Laura Murphy, 41, knew her period made her volatile.

Starting at sixteen years old, Murphy's mood collapsed for two weeks each month. She lashed out at others, or slept for eighteen hours straight. By the time she was an adult, her period affected all parts of her life. She lost jobs. Her relationships fell apart.

"When I was twenty six, I was living with someone and I remember him saying, 'it's like living with a different person for a week every month," Murphy said. Murphy grew up just outside of London and has a pleasant English accent. She knew she had bad symptoms prior to her period, but she blamed it on herself. "It was like a personality defect. I was a horrible person."

When she was thirty three, Laura Murphy finally learned that her shifting moods weren't her fault. A doctor explained that she had a little-known but surprisingly common condition called premenstrual dysphoric disorder, or PMDD. PMDD is a more severe form of premenstrual syndrome, or PMS. Many people live through PMS right before their period, but for a few, the symptoms are so overwhelming that they have psychological effects. Doctors call PMS that interferes with daily life PMDD.

Murphy felt a huge relief knowing the cause of the changes and that there was something she could do about it.

"By this point, I'd lost jobs, and I'd been out of work for a long time and lost relationships. And then to actually have a final answer to it just felt really, really huge," she said. "It meant a lot to be like, 'Okay, this is biological. I'm not broken.' And from that point, you can start building yourself again."

¹ Interview with Laura Murphy, on April 28, 2021.

² "Premenstrual Dysphoric Disorder (PMDD)," womenshealth.gov, March 16, 2018, https://www.womenshealth.gov/menstrual-cycle/premenstrual-syndrome/premenstrual-dysphoric-disorder-pmdd#:~: text=Premenstrual%20dysphoric%20disorder%20(PMDD)%20is,days%20after%20your%20period%20starts.

³ Interview with Laura Murphy, on April 28, 2021.

Like Murphy, many other people with PMDD struggle for years before understanding what's happening to them. Doctors overlook PMDD and then people with the disorder suffer needlessly.

Up to 2-8% of people who menstruate have PMDD symptoms. That's around 150 million people worldwide. Despite how widespread PMDD is, few people have heard of it. More people have heard of PMS, which affects about three quarters of people who menstruate. Both PMS and PMDD set in at the end of the menstrual cycle due to reproductive sex hormones.

At the beginning, the hormone estrogen rises in the body for about two weeks. Then, halfway through the cycle, estrogen levels drop steeply. PMS symptoms set in during the third and fourth weeks of the cycle.

The hormone change has physical effects throughout the body, like cramps, acne, breast tenderness, and more. But estrogen doesn't just regulate bodily functions. It also has effects in the brain.

Estrogen increases happiness levels by increasing serotonin receptors in the brain. When estrogen drops halfway through the period cycle, serotonin levels also drop. Many people don't notice the lack of serotonin before their period. For some, that serotonin drop causes the PMS symptoms of moodiness and irritability. While the estrogen drop is the same in everyone who menstruates, a person with PMDD has extreme psychological effects from the lack of estrogen.⁴

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⁴ "Premenstrual Dysphoric Disorder" womenshealth.gov.

They may face depression, anxiety, and a lack of motivation in the two weeks before her period. Around 37% of people with diagnosed PMDD contemplate suicide, as compared to 13% of people who menstruate, but don't have PMDD.^{5 6}

For Laura Murphy, she felt normal for the first two weeks of the month. "You're just rolling from day to day," she said. But then, "Suddenly you crash, it seems so spontaneous."

For two decades, different mental effects dogged her in the ten days leading up to her period.

"There was a decline for about two or three days. Down into a bereavement every month. Literally, the world was just pulled out from under your feet," she said. "Fatigue like walking through treacle. I'd be exhausted. I'd have brain fog, or forget how to drive. I'd forget my way home."

The classic sign of PMDD is a monthly switch between contentment and depression or anxiety, like what Murphy went through. Symptoms show up for two weeks a month, every month. These signs of PMDD appear to be self evident. Despite that, misdiagnosis of PMDD by doctors is common.

One reason PMDD isn't diagnosed is its cultural history. Many people have never heard of PMDD as it's relatively new. Medicine has known about the broader syndrome PMS for years. For years, doctors told people who had terrible PMS symptoms that they couldn't be suffering as much as they were describing. Doctors dismissed complainants and told them to suck it up. In

⁵ Corey E Pilver, Daniel J Libby, and Rani A Hoff, "Premenstrual Dysphoric Disorder as a Correlate of Suicidal Ideation, Plans, and Attempts among a Nationally Representative Sample," Social psychiatry and psychiatric epidemiology (U.S. National Library of Medicine, March 2013), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3774023/.

⁶ E. Osborn et al., "Suicidality in Women with Premenstrual Dysphoric Disorder: a Systematic Literature Review," Archives of Women's Mental Health (Springer Vienna, September 16, 2020), https://link.springer.com/article/10.1007/s00737-020-01054-8.

⁷ Interview with Laura Murphy, on April 28, 2021.

⁸ Interview with Laura Murphy, on April 28, 2021.

1986, the idea that PMS caused only minor symptoms changed. A team at the University of Michigan realized that PMS is a spectrum, with a variety of symptoms felt from person to person. This team was the first to suggest that some people have depression and anxiety prior to their period. They called this PMDD.⁹

One person who has been studying PMS since the 1980s is Dr. David Rubinow, a psychiatry professor at UNC. "When I first started studying PMF in 1980, people looked at me like I was crazy," he said. Culture wars in the 1980s still influence the current understanding of PMS and PMDD.¹⁰

"There was a concern that there were behavioral trends associated with a menstrual cycle which would lead to further stereotyping of women," Dr. Rubinow said. "But are you going to throw out the well being of people who are currently suffering?" 11

Feminists are right to be concerned about such behavior. It's belittling to blame mood changes on hormones only. People shouldn't ask others "are you on your period?" every time someone appears a bit moody.¹²

Even though the University of Michigan team identified PMDD in 1986, official recognition was a while away. Some researchers resisted the idea that hormones alone cause depression and anxiety in some people. As the evidence mounted up, those researchers relented. Finally, nearly two decades later, American Psychiatric Association added PMDD to the Diagnostic and Statistical Manual of Mental Disorders.¹³

⁹ Roger F. Haskett, "Premenstrual Dysphoric Disorder: Evaluation, Pathophysiology and Treatment," Progress in Neuro-Psychopharmacology and Biological Psychiatry (Elsevier, November 6, 2002), https://www.sciencedirect.com/science/article/pii/0278584687900509?via=ihub.

¹⁰ Kathy Kendall, "The Politics of Premenstrual Syndrome: Implications for Feminist Justice," *The Journal of Human Justice* 2, no. 2 (1991): pp. 77-98, https://doi.org/10.1007/bf02636788.

¹¹ Interview with Dr. David Rubinow, May 4, 2021.

¹² Suzanne Latham, "The Social Construction of Premenstrual Syndrome," *Social Science & Medicine* 35, no. 1 (1992): pp. 49-56, https://doi.org/10.1016/0277-9536(92)90118-a.

¹³ "Diagnostic and Statistical Manual of Mental Disorders (DSM–5)." DSM-5. Accessed May 19, 2021. https://www.psychiatry.org/psychiatrists/practice/dsm.

Nowadays, the cultural understanding has morphed. People know that PMS is real. Most people know that PMS exists and its common symptoms. However, the scientific understanding that PMS is a spectrum has not quite caught on in the general public. Generally speaking, many people now view PMS as something that's not a big deal: take Advil for the cramps, eat some chocolate, and move on.

People who have PMS, as well as PMDD, may not want to take their symptoms seriously to avoid acting weak. They dismiss their own ordeal. Worse, the belief that PMS isn't serious may mean that anyone who has serious symptoms won't even think to tie their symptoms to their cycle at all.

Even if people understand that they should seek help, their doctor may diminish their pain due to implicit biases. In one study, ¹⁴ doctors gave men in the emergency room painkillers after an average of 49 minutes while women waited an average of 65 minutes. ¹⁵ Doctors then may undercount PMDD symptoms. In this scenario, patients realize that their menstrual cycle affects their emotions. However, the doctors say the symptoms can't be that bad, to move on with their lives.

Doctors and patients miss PMDD when symptoms aren't connected to the menstrual cycle. A patient with PMDD goes to a doctor or psychiatrist and explains that they're depressed and don't recognize that their condition tracks with their cycle. The doctor takes it seriously. However, it doesn't occur to the doctor to ask about menstruation. The doctor then diagnoses the patient with depression or anxiety. In some cases, the doctor or the patient realizes that the

¹⁴ Chen, E. H et al. "Gender Disparity in Analgesic Treatment of Emergency Department Patients with Acute Abdominal Pain." Academic emergency medicine: official journal of the Society for Academic Emergency Medicine. U.S. National Library of Medicine. Accessed April 28, 2021. https://pubmed.ncbi.nlm.nih.gov/18439195/.

¹⁵ Paulyne Lee et al., "Racial and Ethnic Disparities in the Management of Acute Pain in US Emergency Departments: Meta-Analysis and Systematic Review," *The American Journal of Emergency Medicine* 37, no. 9 (2019): pp. 1770-1777, https://doi.org/10.1016/j.ajem.2019.06.014.

symptoms turn off and on and tell the patient they are bipolar. The symptoms of PMDD don't match bipolar disorder; people with PMDD don't go through manic episodes, only through depressive episodes. ¹⁶ ¹⁷ More doctors and psychiatrists could avoid making such drastic mistakes if they knew to correlate depression and anxiety symptoms with the menstrual cycle.

Getting diagnosed can be even more difficult for people diagnosed female at birth. "There's no research," on how PMDD affects transgender and gender variant folks who were assigned female at birth, said Dr. Mary Jane Minkin, a gynecologist at Yale. 18

Laura Murphy also struggled with determining why her hormones were affecting her. She said that many of the doctors she went to weren't helpful. From when she was sixteen years old, she knew her period affected her mood. But instead, her doctor diagnosed her with severe anxiety. Her doctor dismissed her PMS as "part of being a woman."

In hindsight, "I'm not sure if it would fit under gaslighting because I don't think they knew that they were doing it," Murphy said. "I don't think they were diminishing my symptoms deliberately."

Murphy tried everything to have less abrupt mood changes. She went to different doctors, who prescribed her different antidepressants. The hormonal cocktails in birth control pills can help some with PMS, so her doctor recommended many types of pills. But she still felt controlled by some mysterious force that she didn't understand.

Her experience with mental health all came to a head when she decided to stop taking hormones by mouth. However, she did need a birth control option and tried using a Mirena IUD. While birth control pills can affect the brain with hormones, a gynecologist inserts a Mirena IUD

¹⁶ Victoria Hendrick and Lori L. Altshuler, "Recurrent Mood Shifts of Premenstrual Dysphoric Disorder Can Be Mistaken for Rapid-Cycling Bipolar II Disorder," *The Journal of Clinical Psychiatry* 59, no. 9 (1998): pp. 478-480, https://doi.org/10.4088/jcp.v59n0907c.

¹⁷J. Studd, "Severe Premenstrual Syndrome and Bipolar Disorder."

¹⁸ Interview with Dr. Mary Jane Minkin, May 3, 2021.

into the uterus. The Mirena IUD should only affect the hormone balance there. But it turned out that for her, going back to her natural hormonal state didn't work.

"The Mirena was a very, very bad experience for me," Murphy said. "I was suicidal for eighteen months and had to give up work. I was very ill."

This episode marked a turning point for her. She knew her periods had a bad effect on her, but she'd never felt suicidal before. She had to get help and figure out a treatment that worked for her.

Desperate, she began seeing a new therapist. That therapist convinced her that no PMS could ever be that bad, and referred her to a specialist. Unfortunately, the specialist lived an hour and a half away from her, in London. But she was desperate.

That specialist diagnosed her with PMDD.

"I remember getting outside and just sobbing in the street," she said. Cars honked around her, but she didn't care. "Because it would be the first time in seventeen years, I'd sat in front of someone who listened and understood the experience."

The diagnosis marked a turning point in her life. She was able to start treatments knowing she had a serotonin deficit for part of the month.¹⁹

Once a diagnosis happens, the battle isn't over. The lack of medical understanding around PMDD also makes life difficult for women with PMDD. General practitioners and obgyns often don't treat PMDD. Instead, people have to make appointments with specialists. These can be costly and uncovered by insurance.

Then, the treatment process can be a long and drawn out process. Dr. Minkin noted that there's not much research into which treatments are better than others. There is no

¹⁹ Interview with Laura Murphy, on April 28, 2021.

one-size-fits-all cure. A woman newly diagnosed with PMDD might try many strategies before finding a way to manage her symptoms; what might work for one person might not for another.

PMDD affects some people and not others due to both genetics and general lifestyle factors. Sometimes, a stressful lifestyle is turning PMS into PMDD. Then, the first line of defense against PMDD is to change daily habits. Eat healthier, exercise more, and get more sleep. Stress management techniques are challenging for many, and near impossible to fit into their life.²⁰

Beyond lifestyle management, there are several medical interventions for PMDD. The medical treatment that works for most people with PMDD is antidepressants. Two thirds of people with PMDD feel their symptoms go away when they take a specific type of antidepressant that helps increase levels of serotonin in the brain. Most people who take antidepressants take them every day. In contrast, people with PMDD with a prescription for antidepressants often take a very small dose, and only in the week leading up to the period. This short term stop gap helps combat the drop in serotonin levels created by the dropping estrogen.²¹

In Murphy's case, the specialist knew that antidepressants could help. Her doctor suggested she try them again.

However, Murphy had an extreme case of PMDD. Antidepressants didn't work well for her. She'd already tried hormonal birth control pills, so her doctor chose not to have her try them again. Her doctor suggested she try an experimental solution to keep her hormone levels from changing. Instead of having rising and falling levels of estrogen, she took estrogen pills so that the level was steady throughout the month.

²⁰ Interview with Dr. Mary Jane Minkin, May 3, 2021.

²¹ Interview with Dr. Mary Jane Minkin, May 3, 2021.

"Essentially, it's used to flush your hormone levels steady, so that you don't have any fluctuations," she said. This treatment was promising, but some PMDD symptoms persisted. "I was losing about half a month, every month to the condition by that point," she said.²²

Most people don't try this experimental solution to PMDD as Murphy did.²³ Instead, PMDD sufferers whose symptoms don't resolve with antidepressants choose to remove the menstrual cycle. Five years after her PMDD diagnosis, Murphy chose that route and underwent medically induced menopause. She had estrogen in her body, but at steady, unchanging levels.

Finally, her PMDD disappeared. Not only did she feel cured, but it was a final confirmation that she did have PMDD after all. Without any hormone changes, she was fine. She could live her life without feeling blindsided monthly by a force beyond her control.

However, Murphy needed to keep going to the doctor to get injections to maintain the false menopause. For Murphy, it was hard to imagine continually getting shots for a full decade. But she liked no longer having any hormones in her body.

That's why, three years ago, Murphy decided to go through menopause for real. She was about a decade away from hormonal menopause, so she underwent surgery. She removed her ovaries and uterus in a full hysterectomy, and ended the cyclic nature of PMDD for good.²⁴

Many people aren't willing to make the tradeoff of becoming infertile to get rid of PMDD. A full hysterectomy also trades PMDD for menopause symptoms, which do include mood changes.²⁵ But Laura Murphy felt that leaving PMDD behind her was worthwhile.

²² Interview with Laura Murphy, on April 28, 2021.

²³ Interview with Dr. Mary Jane Minkin, May 3, 2021.

²⁴ Interview with Laura Murphy, on April 28, 2021.

²⁵ Interview with Dr. David Rubinow, on May 5, 2021

She underwent surgical menopause five years after her PMDD diagnosis, and twenty-two years after she first began feeling symptoms. For her, it was a long, hard road to eliminate PMDD. And it affected her life permanently.

"It means I chose not to have children," she said. "I lost years to PMDD."

But now, for the first time in a decade, she holds down a full time job. Murphy is now the director of education at the International Association for Premenstrual Disorders. She helps people navigate their lives post diagnosis and understand PMDD, which they might not have heard of before. Often, she ends up speaking to people who, like her, spent decades searching for answers to their problems.

Many people feel emotionally overwhelmed by the time they come to her. "The amount of people who say, 'I look back at jobs I walked out of or relationships I left. Crying in work toilets. All these things that you look back on. Oh, my goodness, that's totally correlated," Murphy said. Now, Murphy raises awareness about PMDD and helps clear the fog around an overlooked disorder. 26

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²⁶ Interview with Laura Murphy, on April 28, 2021.

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