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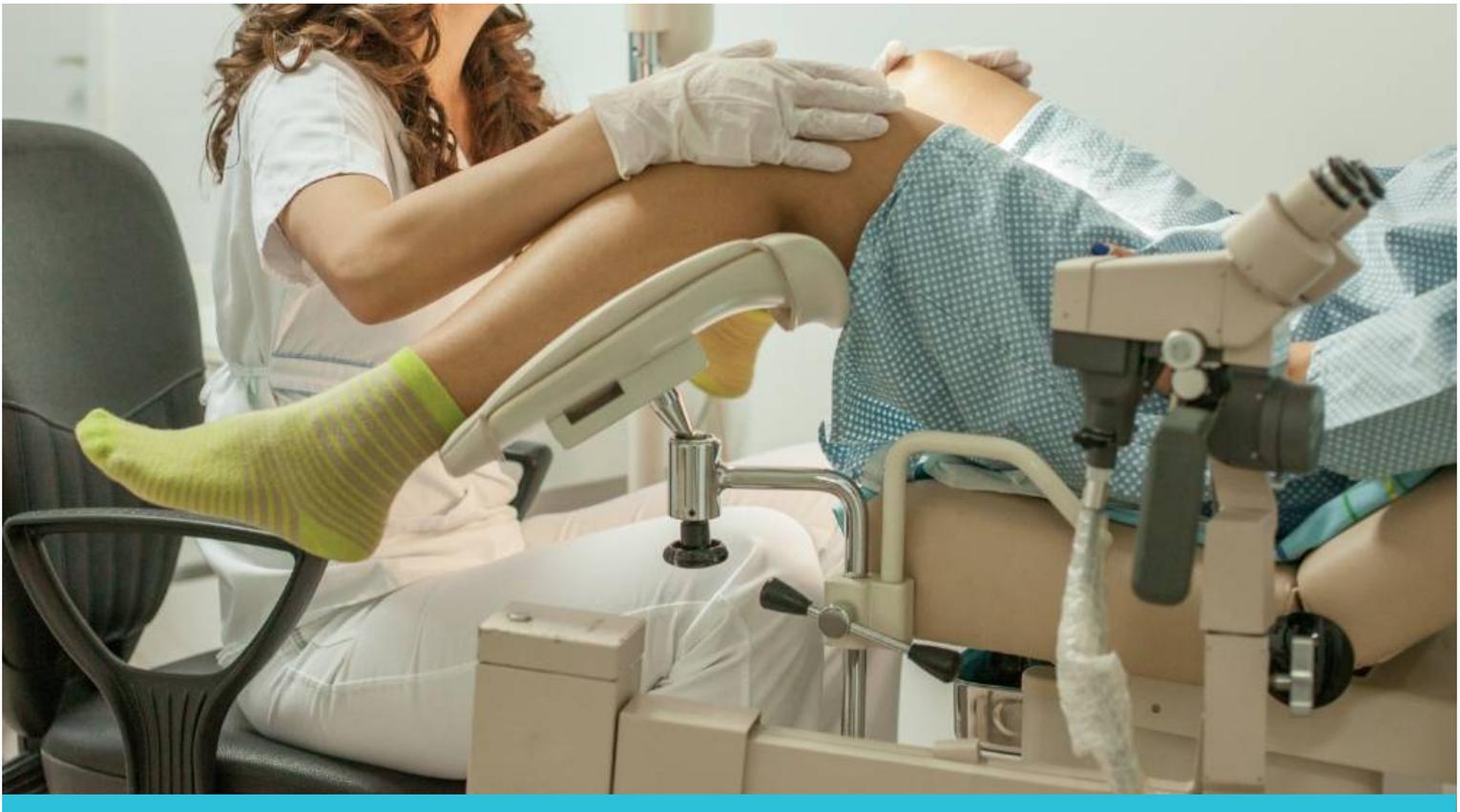
When Your Period Causes Blinding Pain and ~~Broodly~~ Takes It Seriously



by Quinn Moreland

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A chronic condition that affects one in ten women, endometriosis can result in agonizing pain and infertility. There are still no known causes and no known cure.

I never paid much attention to my uterus until the day it became the most evil presence in my life. The exact day I knew something was wrong was on December 31, 2012, but my relationship with my uterus had grown sour long before in a very *Rosemary's Baby*-type way: something wicked was happening within me, but no one took my agony seriously, myself included. That New Year's Eve was the night I learned I have a chronic illness called endometriosis, something I rarely talk about but is always on my mind.

During a normal menstrual cycle, the endometrium—the inner tissue layer of the uterus—thickens to prepare for implantation. If the egg is not fertilized, the endometrium sheds and a period occurs. For women with endometriosis, this tissue does not exit the body during menstruation. Instead, it can attach to the organs in the pelvic cavity—meaning, to the uterus, ovaries, fallopian tubes, or, more rarely, the bladder, bowel, large and small intestines, appendix, or rectum.

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It's as unpleasant as it sounds. Your body responds to parts of the uterus growing in foreign places, resulting in persistent pelvic pain, horrible cramps, heavy and long periods, bowel and urinary disorders, nausea or vomiting, pain during intercourse, and infertility. The tissue grows into lesions while continuing to behave normally: thickening and shedding with each menstrual cycle, only unable to exit the body. The result is extremely agonizing.

Cramping and pelvic pain are typical problems during many women's cycles, so when I first began experiencing these symptoms when I was 18, I figured it was no big deal. I attributed the sudden physical discomfort to the emotional stress surrounding me at the time: in the span of a few months I began college, my then-boyfriend's mother perished after a fire, the father of a close friend passed away suddenly, and my mother's best friend died in a car accident. Emotional stress certainly does not help hormone-induced discomfort, so I created plausible excuses for my pain and pushed it aside. At the time, my friends and I never discussed our menstrual troubles with each other, so I figured maybe everyone always felt this way and just never talked about it.



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Over the summer of 2011, my abdominal pain increased from a frequency of a few days a month to every single day. I grew withdrawn, stopped leaving my house, and soon barely left my bed. I was hesitant to talk about my extreme discomfort for fear of assuming the stereotype of a menstruating girl, constantly complaining about an invisible pain. But one night the feeling that my abdominal organs were simultaneously being twisted into a knot and stabbed with knives was so intense that I finally begged my parents to take me to the emergency room.

The summer devolved into weekly visits to various doctors, monthly trips to the emergency room, blood tests, routine vaginal ultrasounds, and a close relationship with my gynecologist's speculum. Cancer was casually mentioned, and a wide variety of surgeries were discussed. I grew angry and frustrated—both with my body and the doctors who were unable to give me a clear answer about why I was so often in agonizing pain.

There is no known cause of endometriosis, nor is there a known cure. The only way to confirm the disorder is a diagnostic laparoscopic surgery, during which any existing lesions will be removed at their root. My own surgery came maybe eighteen months after my initial twinges of abnormal abdominal pain. My gynecologist-turned-surgeon warned me before the procedure that it was merely exploratory, but that if anything suspicious was found lurking around my uterus, it would be removed. I awoke several hours later with small scars dotting my pelvis and the confirmation of endometriosis. I received a small booklet with pictures of my ovaries pre-and-post excision, which I gleefully shoved in people's faces at parties until I became bored of my own organs.

In the three years since my diagnosis, I have met very few women who suffer from endometriosis—or perhaps I have and they, like myself, deal with their pain privately. The first time I came across another woman with the same diagnosis was when I read Lena Dunham's memoir *Not That Kind of Girl*. In a chapter titled "Who Moved My Uterus?", Dunham reveals that she too suffers from endometriosis, the pain of which she describes as being "shot in the crotch." Dunham never writes if she had a laparoscopy to confirm her doctor's diagnosis and she doesn't mention the disease's impact on her daily life, but I was thrilled that the book shed a sliver of light on the disorder.

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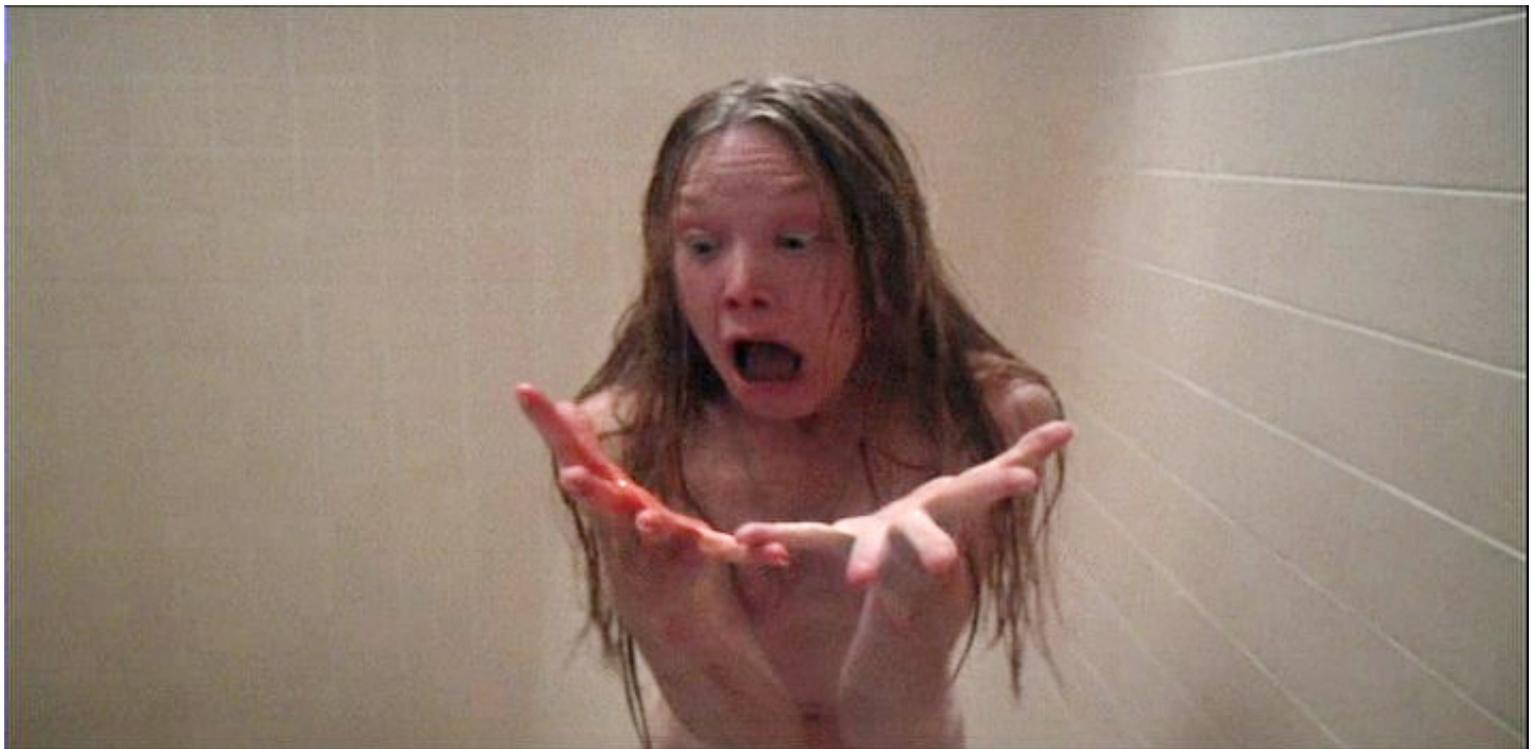
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In October of 2015, I attended a panel at NYU's Langone Medical Center focused on updates in endometriosis research. I was clearly the youngest woman at the conference and certainly the least experienced in terms of complications. Fellow attendees took turns standing up in the large lecture hall to describe their ordeals: Some women spoke of up to seven laparoscopic surgeries, hysterectomies, and removed uteruses and ovaries. I felt relieved to have had only one simple surgery, but I was terrified for what the future could hold. Besides the fear of a lifetime of debilitating chronic pain, the main concern for many women with endometriosis is infertility. Approximately 30 to 40 percent of women with the disorder are infertile; it is often not until a woman is trying to become pregnant that she is diagnosed. I try not to think about this potential problem because it's difficult for me to face, but every once and awhile I get sucked into that awful "what if" mindset.

While research is ongoing, the only treatment for endometriosis is a rigorous symptom management plan. Specialists at NYU advocated for a "team approach," meaning a multidisciplinary treatment plan that could include birth control to alleviate symptoms, pain relievers, acupuncture, yoga, and physical therapy, in addition to regular meetings with doctors and a pain management specialist.

Since there is no medical cure, the most effective way to battle endometriosis is to diagnose the disease as early as possible. Although endometriosis affects 176 million women worldwide and 1 in 10 women in America, it can take an average of 10 years to be diagnosed, according to the **Endometriosis Foundation of America** (<http://www.endofound.org/endometriosis>). And, because the symptoms of endometriosis are similar to those of other pelvic illnesses, women are often misdiagnosed, which prevents them from receiving proper treatment. But perhaps the most basic way to help women get diagnosed is by convincing people to take female pain—menstrual and otherwise—seriously.



Carrie in the shower. Image via Carrie (1976).

That menstruation has previously been stigmatized in our society is a clearly demonstrable fact. Think back to the opening scene of 1976's *Carrie*: The eponymous character is showering in her high school locker room when suddenly she gets her period. Having never learned about menstruation, Carrie understandably flips out, waving her bloody hands in her classmates' faces and shrieking hysterically. The other girls laugh and throw tampons and pads at the cowering Carrie, chanting "Plug it up, plug it up" as she sinks into a corner, crying. Menstruation has long been considered something to be plugged up, to bear silently. As Simone de Beauvoir writes in *The Second Sex*, "the human body has many other more repugnant servitudes in men and women: they easily make the best of them because as they are common to all they do not represent a flaw for anyone." According to the French writer, menstruation became taboo through culture's perception that it is a

distinctly "other" condition, a female problem. According to de Beauvoir, "menstrual periods inspire horror in adolescent girls because they thrust them into an inferior and damaged category."

The comment now feels outdated, but the stigma has not totally disappeared. Although women hopefully are not being pelted with tampons on locker rooms, they still face serious judgment surrounding menstruation. When Kiran Ghandi ran the London Marathon without a tampon, for example, she was called "disgusting" and "unladylike." In a **blog post** (<http://kirangandhi.com/2015/04/26/sisterhood-blood-and-boobs-at-the-london-marathon-2015/>) detailing her experience Ghandi wrote, "This reaction taught us two things: that period stigma runs deep and that we have a lot of work to do as a society to build together a world that is more loving and inclusive of women's bodies." As Erika L. Sánchez points out in *Al Jazeera* (<http://america.aljazeera.com/opinions/2015/5/menstruation-stigma-is-a-form-of-misogyny.html>), "menstruation stigma is a form of misogyny." This, ultimately, is a major difficulty of diagnosing endometriosis.

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In March 2015, the *New York Times* (<http://well.blogs.nytimes.com/2015/03/30/endometriosis-is-often-ignored-in-teenage-girls/>) reported that endometriosis is often ignored in teenage girls. One woman interviewed for the piece, Senie Byrne, claims she saw 22 doctors over the years, from when she first started feeling pain at 15 to her eventual diagnosis at 21. "They told me that

it was all part of being a woman, and that there was nothing they could do for me," Ms. Byrne said. One doctor even told her the pain was all in her head, recalling the stigma of female hysteria.

This belittling reaction to female pain is not abnormal; in fact, studies show that it is all too commonplace. A 2001 report, "**The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain**" (http://digitalcommons.law.umaryland.edu/cgi/viewcontent.cgi?article=1144&context=fac_pubs) found that men and women "experience and respond to pain differently," but whether this is a result of biological or psychological reasons remains to be determined. A majority of the studies referenced in the report show that women report higher levels of pain that last longer and occur more frequently. Yet, research also shows that women are less likely to be treated with the same urgency given to men and that their pain is "discounted as 'emotional' or 'psychogenic' and, therefore, 'not real.'"

I am lucky to have received a relatively speedy endometriosis diagnosis, and I am lucky to have received it at a young age. One way to ensure that other women are given the same opportunity is to raise awareness that excruciating cramps are not normal and should not be written off! As Tamer Seckin, surgeon and co-founder of the Endometriosis Foundation of America, **told** (<http://www.lennyletter.com/health/a160/the-sickest-girl/>) Lenny, "It's cultural misogyny. These women think that having pain of all degrees — to the extent of tortuous pain — is part of being a woman. That suffering and pain is part of their sexuality. But this pain is not normal, and the taboo that surrounds it must not be either."

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