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Life without Lemons: The Daily Battle of Interstitial Cystitis and Vulvodynia

Emily Dodson has Interstitial Cystitis, a condition that up to eight million women in the U.S. are estimated to have. She's ready to talk about it.

Small, colorful tattoos of a lemon and a lime decorate the upper part of Emily Dodson's arm. For her, it's a way of trying to reclaim the little slices of joy associated with these fruits that she once experienced before her medical diagnosis.

Where it all began:

In 2016, Emily was a freshman at West Virginia University and found herself in excruciating pain on the bathroom floor of her college dorm after an eventful week, which consisted of sexual intercourse for the first time, drinking alcohol at a party, and culminating in a large, freshly-squeezed lemonade from the campus food court. While the pain had initially begun after sex, her partner at the time dismissed it as something to be expected. The pain continued over the next few days, and Emily dismissed it herself as what she thought to be a urinary tract infection. The final straw was the lemonade.

"A few hours after I drank the lemonade I was doubled over in pain, and I thought I needed to go to the emergency room," Dodson said. "I'll never forget, I went to pee and it was straight red."

Emily would soon discover that the common triggers for her pain are primarily found in citrus fruits, alcohol and sexual intercourse. Even in the absence of these triggers, her pain

continued and would become unbearable. She was eventually diagnosed with Interstitial Cystitis (IC). This is a chronic health condition involving the bladder that anywhere between three to eight million women in the United States are estimated to have, according to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Symptoms of Interstitial Cystitis (IC) vary by person but often include pain, pressure and spasm-like sensations in the bladder, especially when a person has to urinate, according to the NIDDK. The path to a diagnosis is not always linear and [treatment options differ](#). The Interstitial Cystitis Association says that there isn't a specific diagnostic test for IC and that it is commonly misdiagnosed. For Emily, her IC co-exists with vulvodynia, which is chronic pain in the vulva – the outer part of the female genitals, according to the Mayo Clinic. The baseline level of anxiety that many women feel when they see the glint of a speculum at a gynecologist is understandably magnified.

"I just felt like I was running a marathon and not getting anywhere," Dodson said. "I can't keep count of how many doctors I've seen, I think I lost count after like 11 or 12."

Treatment options for her have ranged from medication therapy to lidocaine gel and experimental Botox injections in her pelvic muscles for symptom management. All of these options have had varying degrees of success, but nothing has ever fully taken her pain and discomfort away. She still spends a considerable percentage of her days curled up on the couch with a heating pad during her symptom flare-ups, thinking of the life she used to have as she looks out the window.

“It really took a toll on me mentally, too, especially with this going on in my early 20s,” Dodson said. “That’s supposed to be the time where you’re discovering yourself, you’re going out and having fun...and I feel I missed out on a lot of things.”

Emily feels that the largest amount of progress she has seen is due to a suggestion she received from her urogynecologist at the Cleveland Clinic to see a [pelvic floor physical therapist](#). Many IC and vulvodynia patients have a difficult time with physical intimacy in their relationships due to their symptoms. Pelvic floor therapy has helped Emily feel a greater sense of agency in her life, especially when it comes to her relationships.

“It wasn’t until 2020 that I went to see my current physical therapist, and she changed my life, truly,” Dodson said. “Her own daughter has IC and she [my therapist] has autoimmune issues, so she was able to listen really well and give me tips on how to reduce inflammation... that was truly when I was able to begin to reclaim my life.”

Researchers are paying attention:

The exact cause of both IC and Vulvodynia remains unknown, and there is no cure. Some researchers, including Dr. Joseph J. Barchi Jr of the National Cancer Institute’s Chemical Biology Laboratory, have laid foundational groundwork toward understanding how IC functions and how it may even be exploited for positive purposes moving forward.

Dr. Barchi and his colleagues began IC-related research in the 1990s; they would go on to discover a peptide in the urine of patients with IC in the early 2000s that is directly linked to the breakdown of normal cells in the bladder wall.

“It’s called ATF, we call it the antiproliferative factor,” Dr. Barchi said. “And so it turns out that it’s really probably one of the main causative agents for IC.”

Interestingly, ATF also restricts tumor growth; this is an area of interest specifically for Dr. Barchi and others in cancer research. With research and therapeutics advancing over time, Emily feels encouraged and has also come to a place of both acceptance and advocacy with the help of others in the chronic illness community.

“I have seen this community and information [about IC] come so far in the last eight years,” Dodson said. “I’ve met so many different people of different backgrounds that are dealing with the same issues and it really helps me feel not alone, and I think that the only way that anything has changed is because people are talking about it. I was ashamed to talk about it and a lot of people are ashamed to talk about it because it’s a very personal issue... now, we have people speaking up.”

Note: Words that would be theoretically linked to outside sources are red and underlined

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