

Endometriosis afflicts millions of women, but few people feel comfortable talking about it

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[Endometriosis](#) causes physical, sexual and emotional pain. About [190 million people around the globe](#) have endometriosis, [including one in 10 American women](#), but there has historically been [a deafening silence](#)

about the disease and the pervasive impact it can have on a person's life.

While [endometriosis](#) is a chronic gynecological illness that can affect anyone with a uterus—women, transgender men and nonbinary individuals—it often goes undiagnosed because its symptoms can be attributed to other physical or psychological concerns. Patients presenting with this [pain](#) are often told it is "all in your head."

However, endometriosis is becoming a more visible illness, thanks in part to celebrities such as Lena Dunham, Chrissy Teigen, Amy Schumer, Whoopi Goldberg and others who have [begun sharing their stories publicly](#). After going undiagnosed for 23 years, Padma Lakshmi, a popular cookbook author, actress and host of the TV show "Top Chef," founded [EndoFund, previously Endometriosis Foundation of America](#), in 2009 so that others do not have to go through what she did.

I am a [couple and family therapy professor, clinician](#) and [researcher](#). My own endometriosis diagnosis at the age of 19 has inspired my work exploring how this illness affects others beyond the [physical symptoms](#).

To better understand the impact of endometriosis on relationships, I interviewed 10 couples about their experiences of diagnosis, treatment and living with this disease. Through their stories of how endometriosis-related pain can affect every aspect of daily life, including their [intimate relationships](#), I provide some specific recommendations. The quotes I have included in this article [are from my doctoral dissertation research](#).

The basics of endometriosis

When a person has endometriosis, the [endometrial cells](#) that line their uterus "implant" in places outside the uterus, such as the ovaries, fallopian tubes and the lining of the abdomen—called the [peritoneum](#). At the end of each menstrual cycle, the uterus sheds its lining, which

exits the body via the cervix and vagina. The "misplanted" endometrial cells also shed, but they have no place to go—resulting in internal bleeding, inflammation and pain.

An endometriosis diagnosis is described in stages related to the visual presence of the disease, from minimal, or Stage 1, to severe, or Stage 4. However, there is no connection between the stage and the experience of pain.

One symptom of endometriosis is [intense pain during the menstrual cycle](#). Another is pain with sex. Because pain with menses or sex can be attributed to "normal" pain, a history of sexual abuse or psychiatric reasons such as a dislike of sex, some people with endometriosis wait an average of seven years for diagnosis, which can [be visually confirmed only through](#) a procedure called [laparoscopy](#).

In addition to these and other types of severe pain, endometriosis [can also cause infertility](#), and patients who want to have children must often undergo [medical or surgical interventions](#) to conceive.

Impacts on school, work and sex

Physical pain from endometriosis can be debilitating. Adolescents with endometriosis may struggle to keep up with their classes, friends, homework or [extracurricular activities](#) when the pain becomes too severe. They may [shift to home-schooling or virtual learning to complete their studies](#).

The pain can also deeply affect a career trajectory. "I almost lost my job because of time off," one interviewee told me. "In fact, when I had to get my hysterectomy, I walked in to tell my manager and he goes, 'Well, I hope you're not going to tell me that you have to have a hysterectomy and have to be out for six weeks!' And I just broke down in tears."

All of my participants shared experiences where doctors [dismissed complaints](#) of sexual pain—called [dyspareunia](#)—from endometriosis. This can delay diagnosis and treatment.

Sex and intimacy often become nonexistent, while some couples shared that they have come to accept that [pain is part of sex](#). One woman shared with me: "I don't want to be touched or have my naked body seen because I feel bloated and ugly and I'm in horrible pain!"

Partners can also be affected emotionally. "I just feel horrible," one told me. "There are times when we are having sex that I actually feel guilty that I know that I am hurting her and I know she is going to be in pain and it makes me unhappy."

These experiences of pain, of not being believed by doctors and professionals, of negative effects on education and career and of intimacy destroyed create a heavy emotional burden on individuals and relationships.

Breaking the silence around endometriosis

When I was diagnosed with endometriosis, it changed the course of my life. My partner and I learned to expand our definition of intimacy and to redistribute household responsibilities when I was incapacitated. As the risk of infertility only increases without intervention, we started conversations about having children earlier than anticipated. My diagnosis also led me to focus my professional identity as a medical family therapist to help others deal with endometriosis and chronic illnesses.

Based on this experience, here are some ways to break this silence:

- Learn about endometriosis. It directly helps when one's support

systems are educated.

- Separate the person from the disease. When the pain you are experiencing from endometriosis is debilitating, help those around you who are also affected to understand that it is because of your endometriosis and it is not personal.
- Speak from your own experience, saying, "I ..." rather than "You ..." When we do this, it decreases the other person's defenses and opens up the communication, making space for connection.

Recommendations from people living it

My research participants shared their own recommendations with me, especially the importance of [believing that their pain is real](#); accept that what they are sharing is their very real experience, and let them know that they are believed.

Bestselling author and social work researcher [Brené Brown has said](#), "Empathy fuels connection, sympathy drives disconnection." Approaching someone with endometriosis from a position of empathy sends a message that you [want to work with them collaboratively](#).

By practicing these important relationship skills, we can break the silence around endometriosis.

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