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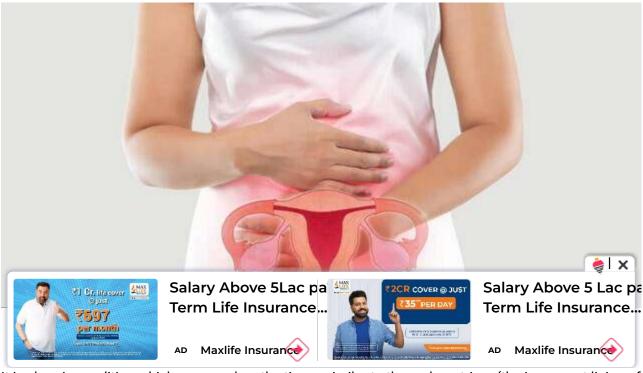
From painful sex, being confined to bed, taboo, to mood swings: Women on how endometriosis is 'more than just painful periods'

There is no guaranteed way to prevent endometriosis from developing. However, maintaining a healthy lifestyle with regular exercise, a balanced diet and avoiding toxins and chemicals may help reduce the risk

Written by Saumya Rastogi
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It is chronic condition which occurs when the tissue similar to the endometrium (the innermost lining of the uterus), grows outside of the uterus. (Source: Freepik)

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She was only in Grade 10 when Sakshi Gupta experienced painful periods for the first time. Dismissing it as a "normal symptom" of the menstrual cycle, she started taking over-the-counter painkillers. But things only got worse, and she was forced to visit a gynaecologist. However, there was still no solution in sight for a long time. "My condition was repeatedly misdiagnosed, and often my symptoms were also discounted — until finally, in 2018 — I was told I have **endometriosis.**"

While the diagnosis came as a relief (in anticipation of accurate treatment), the years of physical pain and mental stress had already wreaked havoc on her day-to-day functioning. "I was always lagging behind at work because of the pain and mental fog that came along with the ailment. It also precipitated feelings of depression, and I would often feel anxious," the 31-year-old model said, adding that it was difficult for her family to understand her condition as "they were not aware of the nuances of the disorder which is more than just painful periods."

"Additionally, my partner also had a difficult time gauging my emotions around sex being too painful, along with my extreme mood swings. As a result, most of my relationships also did not work out then," Gupta told indianexpress.com, adding that the societal taboo around endometriosis made her feel even more isolated.

"People would question my prospects of getting married in the future as they believed I would not be able to conceive a baby naturally," she said.

Things were no different for Shilpa Rao, a dentist, who after "multiple episodes of fainting because of **period cramps** along with gastrointestinal issues such as diarrhoea, constipation, indigestion, and abdominal pain" was diagnosed with endometriosis after more than two decades when she landed up in the hospital with an intestinal block. Immediately acting upon her diagnosis and her resolve to not let the condition worsen, the 43-year-old started moderate exercises to ease her symptoms, taking medications on time, and eating healthy.

Echoing something similar, Sneha Khedkar, a 27-year-old journalist, said that while most women get "four weeks a month to enjoy their lives, I have to adjust my work and social plans to three weeks. That is because I am unable to do absolutely anything during my cycle and remain confined to my bed," she told indianexpress.com, adding that one of the main reasons behind a "delayed diagnosis" is the "stigma attached to the condition".

What is endometriosis?

Endometriosis is a chronic condition that occurs when the tissue similar to the endometrium (the innermost lining of the uterus), grows outside of the uterus, in areas such as the ovaries, fallopian tubes and other organs in the pelvis. "This causes an inflammatory reaction that may result in the formulation of scar tissue within the pelvis and can start at a person's first menstrual period and last until **menopause**," said Dr Loveleena Nadir, Senior Consultant, Obstetrician and Gynaecologist, Apollo Cradle & Children's Hospital, Chirag Delhi, New Delhi.

Endometriosis affects roughly 10 per cent (190 million) women and girls of reproductive age globally, as per the World Health Organization. In fact, in a survey by the Alliance of Endometriosis, 90 per cent of people with endometriosis feel disbelieved, dismissed or ignored by others. More than 40% of respondents said that their discussions with healthcare professionals were neither open nor productive, while 70% believe that medical experts have limited awareness of the impact of endometriosis on patients' lives.

Adding, Dr Shabreen Sahar, Gynaecologist, Even Healthcare said that while the

exact cause of endometriosis is not fully understood, there are several factors that can cause it. "The earliest theory is that retrograde menstruation, where menstrual blood carrying endometrial tissues flows back into the pelvic cavity, leads to the disorder. Other causes could be the transformation of peritoneal tissue, hormonal impact, inflammation, oxidative stress and genetics," she told indianexpress.com.

What are the common signs?

Some of the most common signs and symptoms of endometriosis include severe dysmenorrhea (painful periods), deep **dyspareunia** (painful intercourse), chronic pelvic pain, painful ovulation, infertility, chronic fatigue and dyschezia (painful defecation). "Moreover, a significant proportion of affected women are asymptomatic," said Dr Sahar.



The earliest theory is that retrograde menstruation where menstrual blood carrying endometrial tissues flows back into the pelvic cavity leads to the disorder. (Source: Freepik)

Common misconceptions around endometriosis

Experts said that the most common misconception that women with endometriosis hear is that they will have trouble getting pregnant. "In reality, about 2/3rd women with the condition have no problem conceiving. Even if they have an issue with

fertility, they often respond well to **IVF treatments** and other reproductive technologies," said Dr Seema Jain, Director, Obstetrics and Gynaecology, Robotic Surgery, Max Super Speciality Hospital, Shalimar Bagh.

Another myth associated with the condition is that the symptoms of endometriosis are a regular part of menstruation. "When women seek help, they are sometimes deemed as overreacting to regular menstrual symptoms. But in reality, it is much more serious than period cramps or heavy bleeding," noted Dr Krupa Patalay, Senior Consultant, Obstetrics and Medical Director, Fernandez-Bogulkunta.

Adding to this, Dr Duru Shah, Director, Gynaecworld, The Center for Women's Health and Fertility said, "Endometriosis is oftentimes misdiagnosed or diagnosed very late giving rise to many taboos and myths surrounding it. One of the myths is that pregnancy cures endometriosis, however, it only gives temporary relief from the symptoms. Moreover, it is believed that only women at a certain advanced age can have it, whereas studies have shown that women as young as 20-30 years can present with the disease."

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Is there a cure?

There is no permanent cure for endometriosis, however it can be managed with a combination of treatment methods, including:

- *Pain medication to ease painful menstrual cramps
- *Hormone therapy such as birth control pills and patches help control the hormones responsible for the buildup of endometrial tissue each month
- *GnRH agonists block the production of ovarian-stimulating hormones, thereby lowering oestrogen levels and preventing menstruation. This causes endometrial tissue to shrink.
- *Progestin therapy included an IUD device with levonorgestrel, contraceptive device or progestin pills
- *Laparoscopy surgery to remove endometriotic implants while preserving the

ovaries and uterus

*Fertility treatments

*Hysterectomy with removal of ovaries

Concluding, Dr Patalay said, "There is no guaranteed way to prevent endometriosis from developing. However, maintaining a healthy lifestyle with regular exercise, a balanced diet and avoiding toxins and chemicals may help reduce the risk. Women who are experiencing symptoms of endometriosis should consult with their healthcare provider to discuss treatment options and management strategies."

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