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WHAT IS ENDOMETRIOSIS?

Endometriosis is a common condition defined as the presence of tissues that resemble those that line the inner layer of the uterus, outside the uterus. The inner layer of the uterus (endometrium) is the one that is shed during menstruation. Presence of these tissues outside the uterus causes bleeding wherever the tissues are when the affected individual menstruates, pain and formation of scars.

It is classified depending on where it affects: superficial endometriosis, ovarian endometriosis (endometriomas), and deep endometriosis.

Endometriosis is highly associated with another condition; adenomyosis (where the tissue is within the uterus but not along the inner lining as it should be). Size may vary, ranging from microscopic to large cysts (fluid collections which are referred to as endometriomas) and nodules.

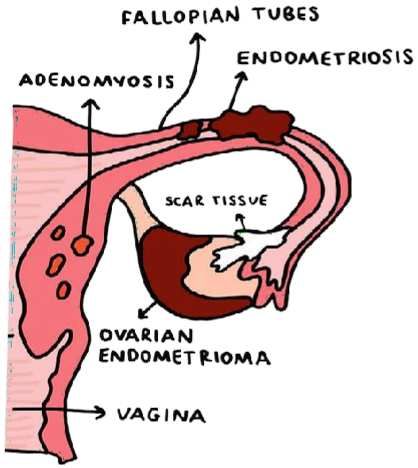


Image showing the locations of both endometriosis and adenomyosis. Image courtesy of (The Endometriosis Foundation., 2025)

WHAT DO THE NUMBERS SAY ABOUT ENDOMETRIOSIS IN AFRICA/KENYA?

Based on the available data, the prevalence of endometriosis in Africa is likely higher than previously thought, with varying subtypes. There is a long diagnostic delay of endometriosis among African women. Additionally, endometriosis care in Africa from the general population and health practitioners is poor; this can be attributed to the high diagnostic cost, scarcity of trained specialists, as well as patients’ inability to express their symptoms due to societal taboos surrounding menstrual health. Public sensitization on endometriosis may help improve endometriosis diagnosis and care in Africa (Mecha, 2022.).

In Kenya, limited data exist on the prevalence of endometriosis. However, two related topics to endometriosis—menstruation, and infertility— remain highly stigmatized and thus oftentimes are kept hidden. For example, research conducted with school-aged girls in Western Kenya found that girls are often unprepared for menarche and hold beliefs that frame menstruation as secret or shameful. This might pose challenges to their willingness to share menstruation-related concerns, including concerns about heavy bleeding that could be early signs of endometriosis (Bergen S, 2023.).

WHO DOES IT AFFECT?

Endometriosis typically affects young women, with a mean age of 25-29 years although it is not uncommon among adolescent girls. It also affects women in menopause.

Potential risk factors include family history and short menstrual cycles. As to whether there is racial association is still controversial.

WHAT ARE THE SIGNS AND SYMPTOMS OF ENDOMETRIOSIS?

- Infertility/sub fertility- endometriosis is present in 40% of women with infertility.

- Pelvic pain- individuals may experience pain during sexual intercourse, painful menses, long standing pain or abdominal pain. The pain may also not be associated with menses.

- Unusual symptoms- diarrhoea, bleeding from the rectum, constipation, bowel obstruction | frequent urination, urgency to urinate, blood in urine | chest pain, fluid in the chest, coughing blood associated with menses, air in the chest wall.

- Some individuals may be asymptomatic.

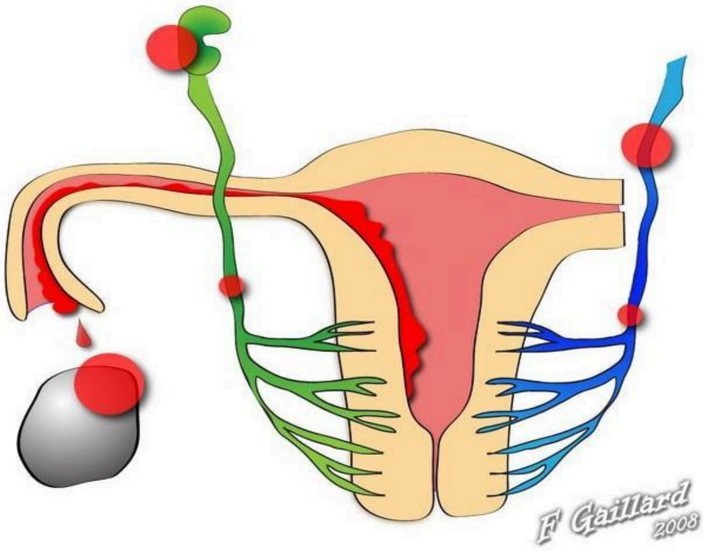
WHAT CAUSES ENDOMETRIOSIS?

The cause of endometriosis is unclear and subject to debate but there are theories that explain the potential causes;

Theory 1; that these misplaced tissues reach these unexpected locations via backflow of blood during menstruation.

Theory 2; that presence of these tissues may be caused by transformation of a type of cell to another cell type, in this case, transformation of cells in a particular region to cells that are similar to those that line the inner lining of the uterus.

Theory 3; that during menstruation certain substances may be released that induce the presence of tissues that line the inner lining of the uterus elsewhere.



Backflow of blood during menstruation and various channels of spread of endometriotic tissue. Image courtesy of (Yang N, 2025)

WHERE CAN ENDOMETRIOIS OCCUR?

The most common location for endometriosis is the ovaries and the next commonest is in the pelvic region. Other less common locations are caesarean section scars, deep abdominal tissues, gastrointestinal tract, bladder, chest and tissues beneath the skin (such as the umbilical region), cervix and labia.

HOW DO WE DETECT ENDOMETRIOSIS?

It involves a combination of procedures that start with a pelvic exam by your doctor, however, a procedure called laparoscopy is the gold standard for detection of endometriosis.

Imaging techniques such as Ultrasound (involves the use of sound waves to generate images of the body) and MRI (involves use of magnets to generate images of the body-did you know your body has trillions of tiny magnets?) may also be used. Ultrasound imaging may be of two types; transabdominal (an imaging ’camera’ is placed on your lower abdomen) and transvaginal (an imaging ‘camera’ is inserted via the vagina to
visualise the uterus and adjacent structures that may not be visible through the abdominal approach).

However normal imaging findings do not completely eliminate the possibility of endometriosis and your doctor may still request a laparoscopy if he/she has high suspicion for endometriosis.

HOW IS ENDOMETRIOSIS TREATED?

Treatment can be conservative, through surgery or medication and will depend if the main problem is pain and/or issues with fertility and factors such as severity of symptoms, the size of the endometrioma, age, and whether the individual is trying to conceive.

In some cases, simply keeping an eye on symptoms can be a suitable option, especially if there isn’t significant discomfort. Regular follow-up scans are however important to monitor for any signs of rapid growth, changes, or worsening of pelvic endometriosis.

Treatment by medication usually targets hormonal regulation and may involve the use of hormonal drugs or contraceptive pills to control the menstrual cycle or to suppress bleeding during menses. Drugs may be also administered for pain relief.

Surgical treatment on the other hand may involve laparoscopy (a thin, lighted tube with a camera called a laparoscope is inserted via small incisions on the abdomen/pelvis) or laparotomy (open surgical procedure involving a large incision) that may entail surgical removal of the ovaries or uterus.

WHAT ARE THE OBSERVED EXPERIENCES OF PEOPLE LIVING WITH ENDOMETRIOSIS

A study done to investigate the experiences of women living with endometriosis in Kenya revealed three themes: 1. Stigma and disruption to quality of life, 2. Barriers to acceptable healthcare, 3. Reliance on self-efficacy and social support to cope with the disease.

Stigma:

Symptoms of endometriosis disrupted their quality of life across multiple domains of well-being, including education, professional lives, social and romantic relationships, and mental health.

'One time in primary school I had too many cramps that I started rolling on the floor feeling very powerless. I could not even speak. I was rushed to the dispensary and got an injection, but it made everything more painful. Teachers and doctors were so afraid I would die in their hands and my parents had to be called to pick me up as soon as they could. I missed school for two more days and was behind in my studies. (Story 37 aged 27).'

The impact of endometriosis on educational experiences was also described as traveling beyond class performance. Some women shared the ways in which the school administration and the social environment compounded their negative experiences of the disease. In several cases, women remembered school as a site of formative stigmatizing experiences related to their symptoms. As one woman described:

'Our school matron would give me some painkillers, but they never worked. I would barely move and just wish to die. I would question God why I had to go through so much pain, yet my fellows would just act normal. I experienced low self-esteem as my school principal would even announce during assembly that I was seeking attention and threatened to suspend me from the school if I didn't change. I used to miss classes and other activities. (Story 24 aged 26).'

These experiences ranged from being pressured to share their entire medical history with an employer to justify their workplace engagement to the decision to seek employment online:

'Because of my on -off working schedule and the criticism from others, also the guilt I feel for being so unreliable, I decided to stop going to work altogether. Been trying to do some online jobs and I'm happy since I'm able to pace myself and when I don't feel well, I can rest without feeling guilty and resume when I feel up to it. (Story 26 aged 28).'

A number of women shared more specifically how endometriosis disrupted their intimate relationships and caused insecurity and discomfort around sexual relationships:

'My friends started discriminating [against] me because I couldn't hang out with them when I was on my period. I became self-conscious and feared sex because of fear of starting bleeding during the act. I faced rejection every time I raised my period issues to a potential lover. (Story 14 aged 25).'

Barriers to acceptable healthcare:

Many women described how their pain was dismissed by those around them as “normal” menstrual cramping, which they felt invalidated their experiences and thus intensified their mental suffering.

For some women, the normalization of menstrual pain by friends and family served as a barrier to seeking medical care. For others, the normalization of pain posed challenges once they had entered the medical system. Women described having their experiences dismissed by medical professionals, and further, that their symptoms were psychological.

Many women felt that their doctors were not knowledgeable about endometriosis while others described feeling frustrated by the lengthy experience of visiting many different doctors and receiving multiple misdiagnoses before finding the “right” doctor and a proper diagnosis.

Beyond a lack of knowledge, diagnostic delays were exacerbated by myths and misinformation shared by doctors such as advise to have a baby or that endometriosis was for the affluent.

Several women emphasized the high cost of medical care for those without adequate insurance.

Other women highlighted geographic challenges in their journeys to a diagnosis especially for those in rural areas without adequate access to care.

Reliance on self-efficacy and social support to cope with the disease:

Participants wrote about the need to gain a sense of belief in one’s ability to achieve a desired outcome, through self-knowledge of their own bodies and independent research about their symptoms. This, they felt, would allow them to advocate for themselves in medical encounters, including making sure that the wrong care was not received.

They shared that although many in Kenyan society may not understand the disease, it is still possible to be supported on the painful and oftentimes lonely journey.

Peer support was described as critical for the women in emotionally and physically managing and surviving their journeys i.e. support groups.

WHAT ARE SOME OF THE COMPLICATIONS & CONSEQUENCES ASSOCIATED WITH ENDOMETRIOSIS?

Endometriosis causes inflammation and formation of scars and if these scars occur in the fallopian tubes, it may lead to infertility. If endometriosis affects the intestines, it may lead to constipation and bowel obstruction.

Although rare, there is possibility of transformation of endometriosis to cancer.

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