

Extrapelvic endometriosis: A guide for people with endometriosis



Overview

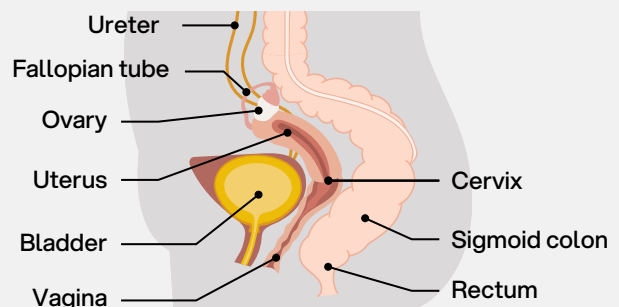
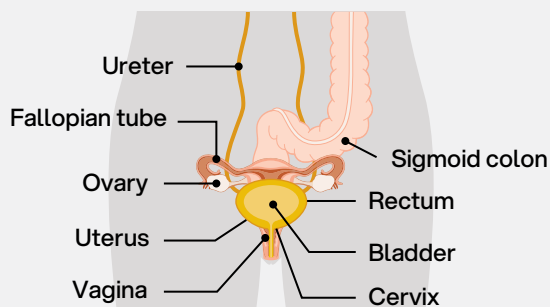
The purpose of this resource is to describe different types of extrapelvic endometriosis (when endometriosis growths are found in areas of the body outside the pelvis). This resource also discusses how extrapelvic endometriosis is diagnosed and treated.

What is pelvic endometriosis?

Endometriosis is often found in the pelvis, which is the area inside the body between the hips, from the belly button down to the vagina. The pelvis contains gynaecologic organs — the ovaries, uterus, fallopian tubes, cervix, and vagina — along with the muscles and ligaments that support them. The pelvis also contains non-gynaecologic organs, like the bowel and bladder.

In the pelvis, endometriosis is most commonly found on gynaecologic organs and their supporting structures, followed by the sections of the bowel called the sigmoid colon and rectum. It is less common, but possible, to have endometriosis growing on the bladder, or on the tubes connecting the kidneys to the bladder (the ureters).

PELVIC ORGANS



What is extrapelvic endometriosis?

Extrapelvic endometriosis is endometriosis growing in areas outside of the pelvis. Endometriosis has been found in every part of the body, from the skin, to the muscles, nerves, and organs.

Because there hasn't been enough research on extra-pelvic endometriosis, we don't know exactly how often endometriosis is found in various parts of the body. Extrapelvic endometriosis is less common than endometriosis in the pelvis. More research is needed to understand how often extrapelvic endometriosis happens.

Types of extrapelvic endometriosis include:

Thoracic endometriosis

Thoracic endometriosis means that endometriosis growths are in the chest — usually in or near the lungs, and/or on the muscle below the lungs that helps with breathing (the diaphragm). Thoracic endometriosis can cause:

- Lung collapses that may or may not happen at the time of menstruation.
- Fluid in the chest.
- Build up of blood inside the chest at the time of menstruation.
- Coughing up blood at the time of menstruation.
- Growths of endometriosis in the lung, called lung nodules.

The most common symptoms of thoracic endometriosis include:

- **Chest pain**, often at the time of menstruation.
- **Shoulder pain**, often at the time of menstruation.
- **Shortness of breath**, often at the time of menstruation.

Abdominal wall endometriosis

This occurs when endometriosis growths are on or in the skin, fat or muscle layers of the abdomen, which is the area of the body from the hips and belly button, up to the lower ribs. This usually forms after a previous surgery. There are different types of abdominal wall endometriosis including:

- **Cesarean scar endometriosis.** This is endometriosis on or near the scar from a previous Cesarean section (a surgery where a cut in the abdomen is made to deliver a baby). This is the most common form of abdominal wall endometriosis.
- **Umbilical endometriosis**—endometriosis on or near the belly button.
- **Inguinal endometriosis**—endometriosis in muscles in the groin (bikini line area).

Symptoms of abdominal wall endometriosis include:

- **Swelling or a lump** where the endometriosis is located.
- **Pain** where the endometriosis is located.
- **Bleeding** from the endometriosis growth.



People used to say that endometriosis had been found in every part of the body except the spleen. What was so different about the spleen that it was not affected by endometriosis?

It turns out that there is nothing different about the spleen! Endometriosis has been found on the spleen as well. The first case of endometriosis on the spleen was reported in 2022.

Abdominal organ endometriosis

Endometriosis can grow on organs in the abdomen, including the:

- Small intestine.
- Appendix.
- Kidneys.
- Pancreas.
- Liver.
- Gallbladder.
- Spleen.

Abdominal pain is the most common symptom of endometriosis on the abdominal organs. There may also be other symptoms depending on the organ that is involved. For example, endometriosis on the kidney may cause pain in the side of the body, between the ribs and the hips, blood in the urine, and kidney infections. The kidney can also be affected when the ureters (tubes that carry urine from the kidneys to the bladder) become blocked from pelvic endometriosis.



Vulvo-perineal endometriosis

Endometriosis has been found on the skin of the vulva — the outside area of the genitals — and the perineum, which is the skin between the vagina and the anus. Symptoms of vulvo-perineal endometriosis include:

- **Swelling or a lump** where the endometriosis is located.
- **Pain** where the endometriosis is located.
- **Bleeding** from the endometriosis growth.

Muscle and joint endometriosis

Endometriosis has been found in many muscles and joints around the body, including muscles in the chest, arms, legs, shoulders, hips, abdomen, and pelvis, as well as the shoulder, wrist, and knee joints. However, endometriosis in muscles and joints is not very common. Muscle and joint pain in people with endometriosis are usually caused by something other than endometriosis. Symptoms of muscle and joint endometriosis include:

- **Swelling or a lump** where the endometriosis is located.
- **Pain** where the endometriosis is located.



Peripheral nervous system endometriosis

The peripheral nerves are like a network of tiny cables running throughout the body. Most of the reported cases of peripheral nerve endometriosis involve the sciatic nerve, which is a nerve that runs from the lower back, through the buttocks, and down the leg. Symptoms of sciatic nerve endometriosis may be present all the time, but usually are worse at the time of menstruation. These symptoms include:

- **Pain** in the lower back, buttocks and down the leg.
- **Leg weakness or numbness.**
- **Trouble walking.**



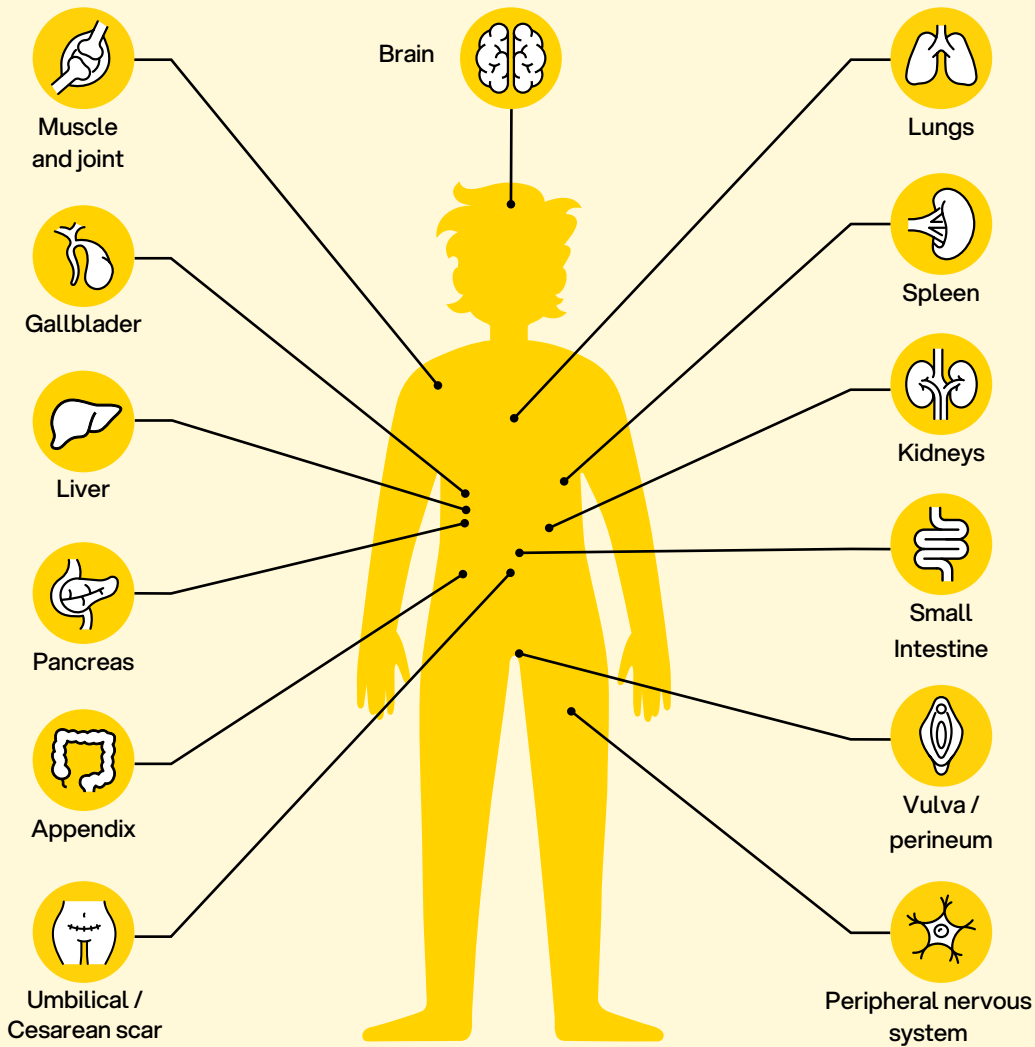
Some people with extrapelvic endometriosis have pelvic endometriosis as well, and some have only extrapelvic endometriosis.

Central nervous system endometriosis

Endometriosis has been found in the brain and nerves in the spine. Fewer than 10 cases of this have been reported. Endometriosis in the brain can cause seizures at the time of menstruation. Endometriosis on the nerves of the spine can cause back pain, as well as numbness, tingling, and bowel and bladder problems.

Sometimes extrapelvic endometriosis grows at the site of a scar from previous surgery. This can happen with Cesarean section surgery (Cesarean scar endometriosis), with laparoscopic surgery (umbilical endometriosis), and episiotomy — when the tissue between the vagina and anus is cut during childbirth (vulvo-perineal endometriosis). But abdominal wall endometriosis and vulvo-perineal endometriosis can also happen in people who have not had any surgeries.

WHERE EXTRAPELVIC ENDOMETRIOSIS CAN BE FOUND



Note — these are only some examples of where extrapelvic endometriosis can be found; this is not a complete list.

How is extrapelvic endometriosis diagnosed?

It can be difficult to get a diagnosis of extrapelvic endometriosis. There is low awareness of extrapelvic endometriosis among healthcare providers who do not specialize in endometriosis.

The diagnosis of extrapelvic endometriosis is usually made through a biopsy — a surgical procedure where tiny pieces of tissue are removed from the body. The tissue is examined by a specialist in a laboratory.

Imaging may also be used as part of the investigation into the cause of symptoms in people with extrapelvic endometriosis. Depending on the location of the disease, different types of imaging may be helpful including:

- Ultrasound.
- Magnetic resonance imaging (MRI).
- computed tomography (CT) scan.

How is extrapelvic endometriosis treated?

Extrapelvic endometriosis is usually treated with surgery to cut out the endometriosis (excision surgery). You can learn more about surgery for endometriosis [here](#).

There is not very much research on the use of endometriosis medications to manage the symptoms of extrapelvic endometriosis, but medical treatments can be tried if that is your preference. If medications are used to manage extrapelvic endometriosis, symptoms usually come back after the medication is stopped. But, if medical treatments are effective and you don't want to have surgery, you may be able to continue using medications instead.



Endometriosis can affect any part of the body. It is very important that people with endometriosis and their doctors are aware of the signs and symptoms of extrapelvic endometriosis. This can ensure that people will get the correct diagnosis and timely treatment.

Before obtaining a biopsy of a mass in my lungs, I was unable to relate my chest pain, shortness of breath, and bleeding from my belly button to any known illness.

The severe symptoms of extrapelvic endometriosis are often under-diagnosed and should be discussed to stop the myth that it is rare.

Denise
diagnosed at age 35

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