Frequently Asked Questions (FAQs) Endometriosis

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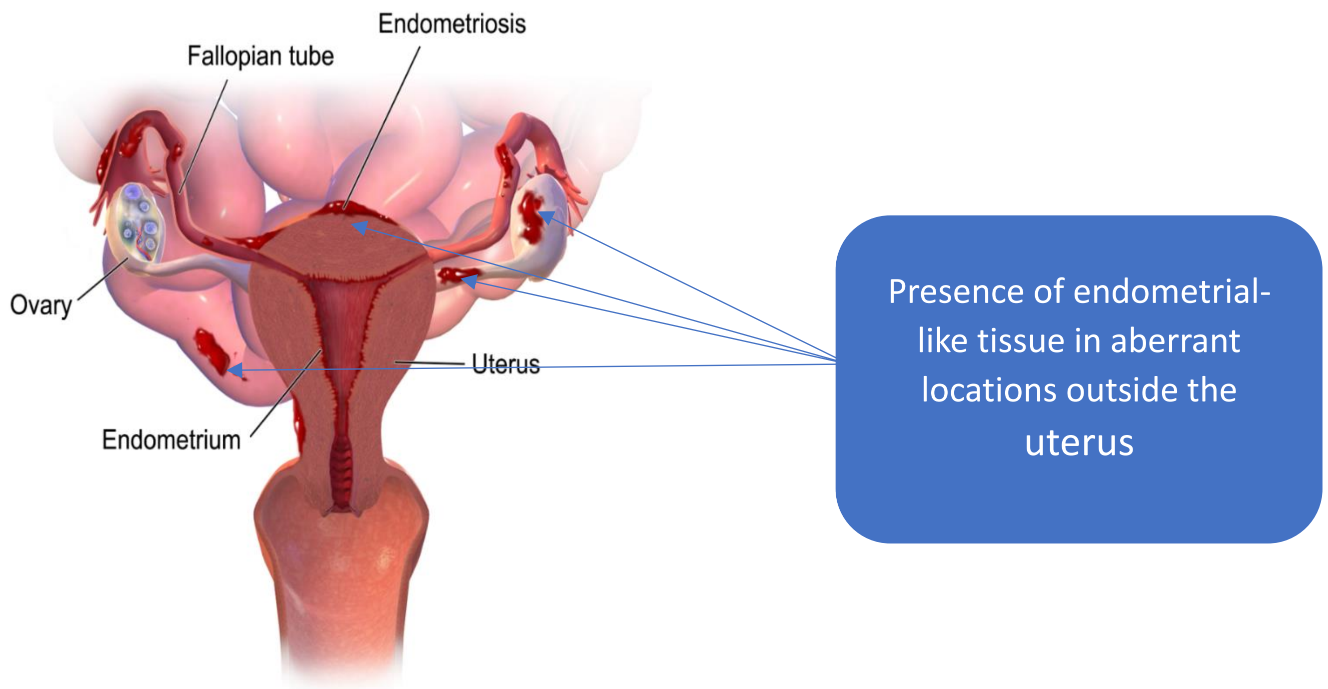

Is endometriosis the only cause of gynecological pelvic pain?

Endometriosis is a very common cause of pelvic pain, but is not the only one. Any gynecological organ can potentially be a source of pelvic pain.
Common conditions leading to pelvic pain are:

- Vulvodynia: A condition where pain occurs at the vaginal entrance.
- Adenomyosis: In this condition there is endometrial-like tissue invading the wall of the uterus causing heavy and painful periods.
- Fibroids: In this condition, benign tumors arise from the wall of the uterus also causing heavy periods.
- Pelvic Inflammatory disease: this is a condition in which the fallopian tubes become inflamed and tender from infection.
- Cancer from any gynecological organ: cancer can arise from the cervix, the uterus, ovaries and rarely fallopian tubes, leading to chronic pelvic pain.

It is important that your doctor considers all potential gynecological cause of pelvic pain. A full evaluation includes a detailed history taking, physical exam, sometimes bloodwork, and imaging such as ultrasound, a machine that uses sound waves to take a picture of the pelvis.

Does endometriosis present alone as a chronic pelvic pain condition?

Endometriosis can present alone. However, more often, endometriosis presents with other chronic pain conditions at the same time. These conditions are known as chronic overlapping pain conditions and they are fibromyalgia, migraines, chronic fatigue, chronic low back pain, temporomandibular joint disorders, vulvodynia, irritable bowel syndrome and interstitial cystitis which is also known as bladder pain syndrome. These conditions frequently show up at the same time and are more frequent in women than men. Usually, endometriosis is most often found along with irritable bowel syndrome and bladder pain syndrome. Another frequent condition found in patients with endometriosis is myofascial pain syndrome. This is a problem where the muscles of the pelvis and the abdominal wall are weak and spastic causing pain. Is very important to be aware that all these conditions can happen at once so that they can be treated along with treating endometriosis.

Do I need surgery to make the diagnosis of endometriosis?

Endometriosis is diagnosed with surgery. The surgery is called laparoscopy. In this type of surgery, a very small camera and instruments are inserted into the abdomen through small scars. The surgeon then looks around the pelvis and can take biopsies of pelvic tissues to see if they have endometriosis. The tissue is then sent to a pathologist who then confirms the presence of endometriosis.

It is important to note that surgery is not needed to start treatment for endometriosis. Sometimes, if the symptoms you have are very consistent with endometriosis, the doctor may recommend treatment before surgery, to not delay treatment. Making the diagnosis of endometriosis without surgery is common because medications can help the symptoms even without surgery. Also, surgery has risks, and time is needed for recovery, so it may be better to do medical treatment first. Surgery can be useful to diagnose endometriosis in cases where the diagnosis is not clear, or when medical treatments do not help the pain, or when one of the symptoms is infertility.

What kind of medications can be used for endometriosis?

Stopping menstruation helps reduce pelvic pain. This is because when menstruation is stopped, the uterus stops cramping but also the inflammation and irritation caused by endometriosis is reduced. So, stopping menstruation decreases pain, and in most cases, it keeps the disease from progressing. It is also important to understand that there are two hormones that the body makes that regulate menstruation. One hormone is called estrogen and the other is progesterone. Estrogen can *increase* endometriosis growth while progesterone usually stops endometriosis growth. Although both hormones are needed to prevent menstruation and pregnancy, it is only the progesterone component that stops endometriosis.

Endometriosis medications come in several forms, some have hormones and others have compounds that just stop the body from making hormones. These medications come as pills, injections, and implants that can be placed under the skin, in the uterus or in the vagina.

The most common medications used to stop menstruation and manage pain are birth control pills or the birth control vaginal ring. They can have two hormones, estrogen, and progesterone, or they can just have progesterone alone. When taken every day, birth control pills take 3-6 months to stop menstruation and before that menstrual bleeding can become more irregular. Pain relief usually occurs ***after*** menstruation is stopped. It is safe to stop menstruation with birth control pills for as long as needed, but many women experience breakthrough bleeding after they have been on birth control pills for a long time. So, women who use birth control pills to stop menstruation may have to change from one pill to another.

Progesterone injections or implants are another way to stop menstruation. These methods are also good to prevent pregnancy, even though they only have one hormone, progesterone. These types of medications may cause some irregular bleeding at the beginning, but they usually stop menstruation after 3-6 months of use. These medications can also be safely used long term. Some implants, like the one that goes inside the uterus, may even have less side-

effects than birth control pills and lasts as long as 3 to 5 years! Implants have the major advantage in that there is no need to take a pill every day.

There is another class of medications that are different. They are called GnRH modulators, and they do not have estrogen or progesterone, instead, they keep the body from making these two hormones. GnRH modulators can be taken as pills or they can be an injection. Another class of medications is called Aromatase inhibitors, and they prevent the body from making estrogen. When these types of medications, the ones that stop hormone production, are used the side-effects may include hot flushes, difficulty with sleep, mood changes, and mild bone loss. To prevent these side-effects, GnRH modulators and Aromatase inhibitors may be combined with a little progesterone.

Regardless of the medication that is used, research shows that to prevent endometriosis from progressing and causing pain, menstruation should be stopped continuously and for long periods of time. It is important to note, that stopping menstruation also prevents pregnancy, so this type of treatment may not be possible if a woman is trying to get pregnant. This is a case where your doctor may recommend surgical treatment instead.

How long can I safely stop menstruation?

So far research tells us this is not harmful to stop periods and for a long period of time. Women who have endometriosis may sometimes need to stop menstruation for years, except for times when they are trying to get pregnant. Stopping menstruation can be safely done as early as adolescence and all the way until menopause. In fact, research shows that regularly menstruating with severe pain, without treatment, can lead to chronic and worsening pain. It can also prevent women from living their life and achieving their career and education goals.

Do I eventually need a hysterectomy?

A hysterectomy is a surgery where the uterus, and sometimes the ovaries, are removed. This type of surgery is offered to women with endometriosis other treatments have not worked and when childbearing is completed, not desired or not possible. A hysterectomy helps stop menstruation permanently and it also helps with cramping, or the pain that happens during menstruation. However, if you have other pelvic conditions that cause chronic pelvic pain, such as irritable bowel syndrome, painful bladder syndrome or pelvic floor myalgia, a hysterectomy will not be enough to stop the pain. If you suffer only with cyclical menstrual pain and heavy bleeding, a hysterectomy is very effective for those symptoms. However, if you have pelvic pain all the time, at times other than menstruation, there is a chance that a

hysterectomy may only partially help with your pain. In some cases, a hysterectomy makes the pain better for a shot time, but then the pain returns. In other cases, a hysterectomy may not help the pain at all or may make it worse. The decision to have a hysterectomy should be carefully considered and discussed with your healthcare professional. In the end, you are the only one who can decide whether to have a hysterectomy. However, in the case of endometriosis, it is important to know that a hysterectomy may not end in a 100% pain cure. So, discuss your goals, objectives, and what to expect after the surgery, with your surgeon.

Do I need my ovaries removed?

Your ovaries are important organs because they make estrogen, and estrogen is important for the health of your entire body but especially the bones, heart, and the brain. The estrogen produced by the ovaries can also make endometriosis grow. Sometimes endometriosis grows on the ovaries.

The ovaries can be removed with surgery. Removing the ovaries stops estrogen production and this is believed to help with endometriosis pain. The ovaries can be removed on their own, or at the same time as a hysterectomy. Removing the ovaries may provide some additional pain relief, however, the side-effects are very significant and should be carefully considered. Other than not being able to get pregnant, and stopping menstruation, removing the ovaries will immediately put you in menopause. As a result, women who have their ovaries removed, experience symptoms of menopause such as hot flushes, night sweats, vaginal dryness, mood swings, increased risk of osteoporosis and fractures, increased risk of cardiovascular disease and stroke. You may even experience depression, anxiety, and sexual dysfunction. The closer you are to menopause, the less impactful these side effects could be in the long term, and the benefits of removing your ovaries might outweigh the risks. However, the younger you are, the higher the risks of severe side effects from lack of estrogen. Research shows that removing the ovaries before age 45 may not offer any additional pain relief in women with endometriosis. Make sure you discuss with your surgeon your goals and priorities and you ask all the questions you have.

Resources for management of endometriosis

Endometriosis.org: www.endometriosis.org

International Pelvic Pain Society Patient Education Pamphlets: www.pelvicpain.org