

Endometriosis

Gynaecology

Endometriosis is a common condition in which tissue similar to the lining of the uterus, grows outside the uterus. This can cause symptoms such as abdominal pain or pain during menstruation. The severity of symptoms varies. In this leaflet, you can read more about endometriosis, its possible causes, and treatment options.

What is endometriosis?

Endometriosis is a condition in which tissue similar to the lining of the uterus is found outside the uterus. It can cause painful periods, chronic pelvic pain, and in some cases fertility problems. Many women with endometriosis have few or no symptoms. Treatment is only necessary if symptoms are present. Treatment options include medication, surgery, or a combination of both.

Endometriosis can occur in different locations, including:

- in the pelvic cavity
- on or within the ovaries
- on the ligaments that support the uterus
- between the uterus and the bladder
- between the uterus and the rectum
- deep within the muscular wall of the uterus (adenomyosis)
- in other parts of the body

The lesions may be superficial or grow deeper into surrounding organs. In the ovaries, blood-filled cysts can develop. These are known as endometriomas.

The tissue outside the uterus often responds to hormones in the same way as the uterine lining. During menstruation, it may therefore thicken and bleed. However, unlike menstrual blood from the uterus, this blood cannot leave the body through the vagina. As a result, inflammation, scar tissue, and adhesions may develop, which can cause symptoms.

The amount of endometriosis present does not always reflect the severity of symptoms. Some women have extensive endometriosis with few symptoms, while others experience significant symptoms despite having relatively small areas of disease.

Who can develop endometriosis?

Endometriosis occurs almost exclusively during the reproductive years and usually becomes less active after menopause. Approximately 20% of menstruating women have endometriosis. The risk of developing endometriosis is higher if the condition runs in the family. Women whose mother or sister has endometriosis are five to eight times more likely to develop the condition themselves. Long-term exposure to oestrogen also increases the risk. As a result, endometriosis is more common in women who started menstruating at an early age, experience menopause later in life, have had few or no pregnancies, or have short menstrual cycles and therefore menstruate more frequently.

Causes

The exact cause of endometriosis is not known. Several factors may play a role, including:

- hereditary factors
- menstrual blood flowing back into the abdominal cavity
- embryonic tissue growing in the abdominal cavity
- immune system disorders
- the spread of endometrial cells through the lymphatic system
- environmental influences, such as diet

Symptoms

Endometriosis may cause symptoms, but not everyone experiences them. The type of symptoms often depends on where the endometriosis is located. Common symptoms include abdominal pain, lower back pain, pain when urinating, pain during bowel movements, pain during sexual intercourse, reduced fertility and fatigue. Symptoms vary from woman to woman and can change over time. Endometriosis can be mild, moderate, or severe. The extent of the disease does not always correspond to the severity of the symptoms. However, symptoms may become more severe if the endometriosis grows deeper into surrounding organs.

Pain during menstruation

Endometriosis can cause pain during menstruation. This pain often becomes more severe over time. In some cases, the pain starts before menstruation begins and may eventually occur at other times during the month as well. The medical term for painful menstruation is *dysmenorrhoea*. Symptoms can be severe enough to interfere with daily activities.

Sudden abdominal pain

When endometriosis affects an ovary, a blood-filled cyst may develop and gradually enlarge. In some cases, the cyst may bleed or rupture. An enlarged ovary can also twist around its supporting tissues (ovarian torsion). This may cause sudden abdominal pain.

Pain during sexual intercourse

Endometriosis can cause pain during sexual intercourse. This is most common when endometriosis is present in the ovaries, between the uterus and bowel, or between the uterus and bladder. The pain is often felt deep in the pelvis or vagina. The medical term for this symptom is *dyspareunia*.

Bowel symptoms

Endometriosis can cause pain or problems during bowel movements. These symptoms may occur only during menstruation. You may also experience diarrhoea or constipation. In rare cases, blood may be present in the stool. This may indicate that endometriosis has grown into the wall of the bowel.

Urinary symptoms

Endometriosis can cause pain when urinating. You may also feel the need to urinate more frequently. In rare cases, blood may be present in the urine. This may indicate that endometriosis has grown into the bladder.

Reduced fertility

Approximately three out of ten women with fertility problems have endometriosis. The condition can range from a few small lesions to extensive endometriosis with scar tissue and adhesions. In general, the more extensive the endometriosis, the lower the chance of becoming pregnant naturally. Your gynaecologist can advise you and discuss available treatment options.

Examinations

If endometriosis is suspected, the doctor may recommend one or more tests. These tests can help identify signs of endometriosis and assess how extensive the condition may be.

Gynaecological examination

During a gynaecological examination, the doctor may sometimes be able to see or feel signs of endometriosis. Using a speculum, small endometriosis lesions may occasionally be visible behind the cervix. These lesions often appear as purple-blue spots. During an internal examination, the doctor may also detect endometriosis between the uterus and rectum or around the supporting ligaments of the uterus. Small nodules or irregularities may sometimes be felt. The examination may also reproduce pain that is typical of endometriosis.

The doctor can also assess whether an ovary is enlarged, for example due to an endometrioma (a blood-filled cyst in the ovary). In some cases, the gynaecologist may perform an additional rectal examination. It can help assess endometriosis located between the uterus and the rectum. Endometriosis is often easiest to identify and assess during menstruation.

Ultrasound examination

An internal ultrasound scan cannot always detect endometriosis. Superficial or mild forms of endometriosis are usually not visible on ultrasound. More extensive endometriosis can sometimes be seen, particularly when the ovaries are affected, for example by an endometrioma (a blood-filled cyst).

Blood tests

Blood tests may sometimes show elevated levels of certain markers. These elevated levels can indicate inflammation or irritation associated with endometriosis. However, an elevated result alone is usually not enough to diagnose endometriosis. For this reason, blood tests are often combined with other investigations.

Laparoscopy

To confirm whether you have endometriosis, your gynaecologist may recommend a laparoscopy. This is also known as a diagnostic laparoscopy or keyhole surgery. The procedure is performed under general anaesthesia. In most cases, the doctor will take a small tissue sample (biopsy). The result of the tissue examination is usually available after approximately two weeks. After the procedure, you may experience abdominal pain, shoulder pain, or tiredness for a few days. Most women recover within one to two weeks.

Treatment

If you do not have any symptoms, treatment for endometriosis is usually not necessary. Regular follow-up appointments are often not required either. If symptoms develop later, treatment can still be started. This does not mean that treatment has been delayed. A healthy lifestyle, including regular physical activity and a balanced diet, may help reduce endometriosis symptoms. Some women notice that certain activities, body positions, or foods can affect the severity of their symptoms.

The course of endometriosis varies from person to person and is difficult to predict. Together with your doctor, you can discuss which approach is most suitable for your situation. The most appropriate treatment depends on your symptoms and whether you wish to become pregnant. Treatments may also have limitations and side effects. The possible treatment options are described below.

Waiting

Waiting may be a good option. The course of endometriosis varies from person to person and is difficult to predict. Some women have few symptoms or no symptoms at all.

Pain relief medication

Pain-relieving medications such as diclofenac, ibuprofen and naproxen can help reduce menstrual pain caused by endometriosis. About half of women experience pain relief with these medications. For the best effect, start taking them when your period begins, or if possible one day before. Side effects are usually limited. If you use these medicines around the time of ovulation, ovulation may sometimes be delayed or may not occur. As a result, it may be more difficult to become pregnant during that menstrual cycle.

Hormonal treatment

Hormonal treatments can slow the growth and activity of endometriosis. As a result, symptoms such as pain often improve. Several hormonal treatment options are available.

- The contraceptive pill
The contraceptive pill often makes periods lighter and less painful. It also reduces the build-up and shedding of the uterine lining, which may help keep endometriosis inactive. This treatment is generally most effective for mild endometriosis and less effective when, for example, there is an enlarged ovary. Sometimes your doctor may advise you to take the pill continuously so that you do not have a monthly bleed. The pill also acts as a contraceptive, making pregnancy very unlikely.
- Progesterone
Treatment with progesterone is another option. This can be given as tablets or injections. Continuous use of progesterone may cause irregular bleeding (breakthrough bleeding). Some women may also experience fluid retention.
- GnRH agonists
GnRH agonists mimic menopause, the stage of life after the final menstrual period. This treatment can be given by injection, nasal spray or a small implant placed under the skin. In general, GnRH agonists are not prescribed for longer than six months because they may lead to bone loss. If treatment continues for a longer period, your doctor may prescribe additional hormones to help reduce this risk. Possible side effects include hot flushes and vaginal dryness.

Surgery

Endometriosis can be removed surgically through keyhole surgery (laparoscopy) or, less commonly, open abdominal surgery. During the procedure, endometriosis lesions are removed or destroyed using electrical energy or laser treatment. In general, the more endometriosis tissue that is removed, the lower the risk of the condition returning. However, more extensive surgery may also increase the risk of complications. For example, damage to the bowel or bladder can occur. In some cases, it may be necessary to remove an ovary. Your gynaecologist will discuss these risks with you beforehand.

Depending on the location and extent of the endometriosis, surgery may be performed in collaboration with a surgeon or urologist. After surgery, your gynaecologist may advise hormonal treatment to help reduce the risk of the endometriosis returning.

Pregnancy and endometriosis

Endometriosis can affect fertility. Women with mild endometriosis often have a good chance of becoming pregnant naturally. In general, the likelihood of spontaneous pregnancy decreases as the severity of endometriosis increases. If pregnancy does not occur naturally, fertility treatment may be considered. Possible treatment options include:

- **IUI (intrauterine insemination):** During this procedure, sperm is placed directly into the uterus.
 - **IVF (in vitro fertilisation):** In this treatment, eggs are fertilised by sperm outside the body.
- The treatment that is most suitable for you depends on your individual circumstances.

Resuscitation

All patients at DC Klinieken will be resuscitated in an emergency situation. If you have a “do not resuscitate” statement, or if you have discussed with your doctor that you do not want to be resuscitated, it is important that you inform us.

Emergency after visiting DC Klinieken

In case of an emergency, call: 088 0100 998.

Insurance

DC Klinieken has contracts with all health insurers. This means that almost all care is reimbursed, just like in the hospital. You do need a referral from your (general) doctor. Please be aware of your own deductible. More information about reimbursements and possible exceptions can be found at: www.dcklinieken.nl/vergoedingen.

Questions

For more information and answers to frequently asked questions, go to: www.dcklinieken.nl/contact or contact our Service and Information Centre at 088 0100 900.