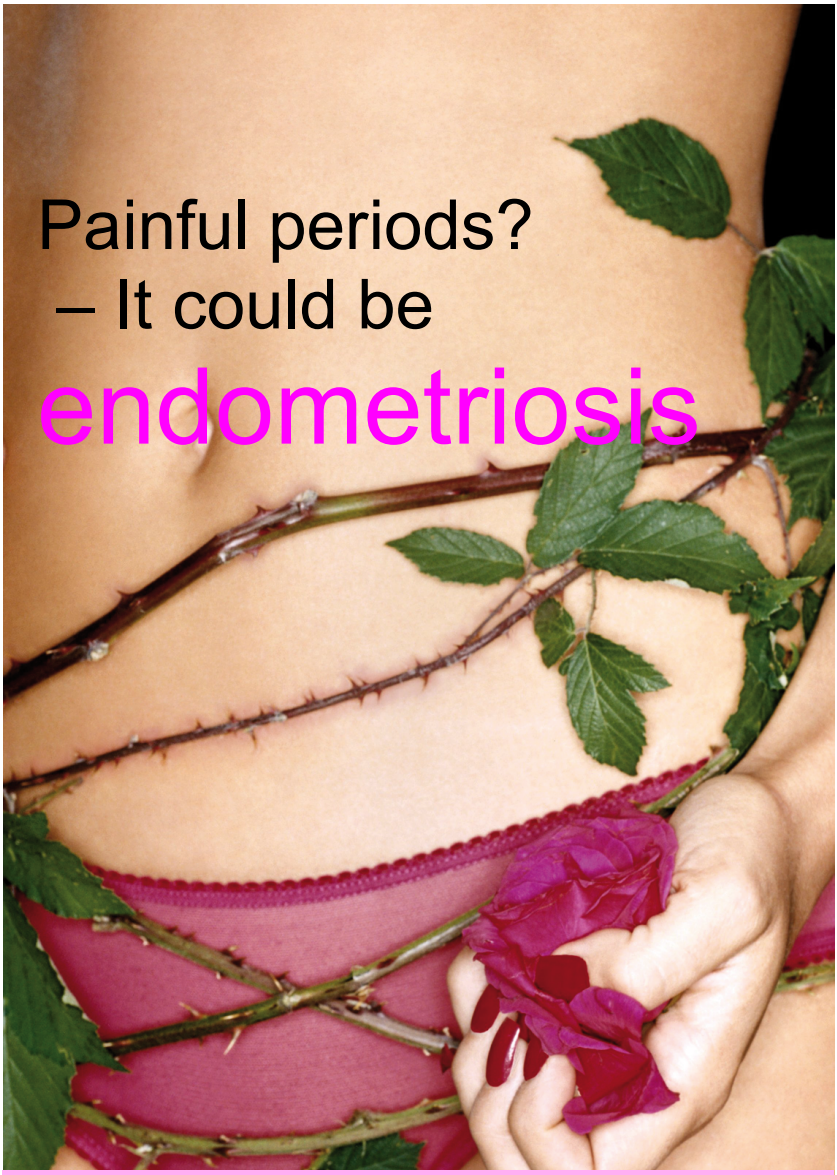

Patient-information about endometriosis from the Swedish Endometriosis association

What is endometriosis?

In every individual born with female genitalia, the endometrium with its endometrial cells and glands is located inside the uterus. Endometriosis is caused when tissue similar to the endometrium is found outside of the uterus e.g. ovaries, fallopian tubes, and ligaments holding the uterus in place.

Normally during menstruation, blood together with dead and dying cells from the endometrium are pushed out from the uterus primarily via the vagina, though some goes through the fallopian tubes out into the abdominal cavity. Specialised types of white blood cells, the macrophages, residing in the abdominal cavity normally become activated and remove these endometrial cells in the same way as they clean up after, for example, a bruise or a wound.

Sometimes the activated macrophages fail to remove all endometrial cells in the abdominal cavity. These cells can therefore adhere to different tissues and organs in the abdominal cavity. The activated macrophages secrete a number of inflammatory factors and thus initiate an inflammation in the abdominal cavity. The inflammation may recede after a few days but the endometrial cells remain and cause endometriotic lesions to develop.

Illustration: Karin Grundler; after original by Nils Peterson

Macrophages are unable to clear the endometrial cells in the abdominal cavity. The macrophages secrete inflammatory factors that cause pain.
The local inflammatory environment does have negative effects on the surrounding tissues, e.g. on the quality of the oocytes.

Eventually, the body tries to disarm the endometrial cells by encapsulating them in fibrotic tissue (scars). It is not unusual that adhesions develop (tissue and/or organs adhere to each other via fibrotic tissue). However, the inflammation continues and develops into a chronic inflammation. Usually, both the chronic and the acute inflammation are present in endometriosis.

Endometriosis is a chronic disease

Although endometriosis is a chronic disease it does not always mean that it is symptomatic. Some affected by endometriosis have no obvious or very mild symptoms of the disease, some are symptom free after one medical treatment while others require repetitive treatments that can stretch over many years.

Endometriosis and risk factors

The cause of endometriosis is not known at present time.

There is a strong genetic component; several genes are probably involved and most likely in combination with environmental factors. Families with endometriosis have an increased risk of developing the disease.

Other risk factors such as long menstruations and heavy menstrual flows can also be signs of endometriosis.

Endometriosis and symptoms

The most common symptoms are:

- Painful menstruations
- Deep pain during or after intercourse
- Pain associated with urination or emptying of the bowels
- Pain in the lower back region
- Diarrhea or constipation (in particular in connection with menstruation)
- Fatigue
- Heavy and irregular menstrual bleedings
- Abdominal bloating

However, it is very individual which symptoms you experience and they may vary with time.

30-40% of patients with endometriosis are sub-fertile. However, more than 75% conceive but it can take a longer time to become pregnant and may require the help of assisted reproductive technologies.

Endometriosis and diagnosis

To date the most conclusive way to verify the presence of endometriosis is a laparoscopy. Ultrasound can also be used for endometriosis on the ovaries and behind the uterus and MRI (Magnetic Resonance Imaging) for deeper endometriosis. However, the lesions must be larger than 3 mm to show up on an MRI.
The doctor or surgeon preforming any of the procedures should be well trained in endometriosis.
Endometriosis cannot currently be diagnosed via a blood sample.

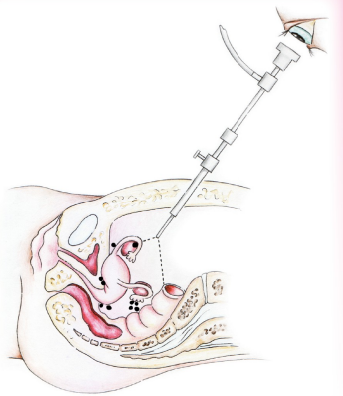

Illustration: Malin Erixson

Laparoscopy: a laparascope with a camera and a lens is inserted through a small cut below the navel into the abdominal cavity. The method gives a good overview of the uterus, fallopian tubes, ovaries and the peritoneum.

- Marks the most common places for endometriosis.

Endometriosis and treatment

Endometriosis can be treated with surgery or hormonal medication or a combination of both.

Surgery: The surgery (usually laparoscopy) aims to reduce endometriosis-associated pain by removing all visible endometriosis and adhesions when possible.
There is a great risk that the endometriosis will reoccur with time and it is therefore important to complement surgery with a hormonal treatment. Hysterectomy is a drastic surgery removing the uterus and sometimes also the ovaries. This option might be considered when nothing else works and you do not want to have children. But there is no guarantee that a hysterectomy will remove all endometriosis-associated symptoms.

Hormonal treatments: Endometriosis is an oestrogen-dependent disease. Therefore the goal with hormonal treatments is to remove the oestrogen production by the ovaries. When no oestrogen is produced the oestrogen dependent endometriosis cannot grow and thus wastes away. The treatment can contain progestines, which are a group of drugs that behave like the female hormone progesterone or GnRH-agonists, which are a modified version of the naturally occurring gonadotropin-releasing hormone.

Endometriosis and treatment

Progestines come in many different variants and are also known as gestagens, progesterones or progestagens.
Some are part of combined contraceptive pills (progestines and oestrogens) or in so called mini-pills (progestines), which can be used as treatment for endometriosis. Others are used in stronger doses as treatment for endometriosis. They can be administered by different methods e.g. pills, injections or mirena coil, and in different doses.

GnRH-agonists also come in different variants though they are chemically very similar. They can be administrated via injections or nasal spray at different doses. To reduce potential side effects one may take GnRH-agonists together with add-back therapy in form of a low dose of oestrogen. The dose of oestrogen is so low that it does not affect the efficiency of the GnRH-agonist.

It is very individual which medical treatment is best and you may have to test a few different strategies to find the optimal treatment.

Which type of treatment, combination thereof and dose that suits you should always be discussed with your gynaecologist.

Endometriosis and treatment

Side effects of hormonal treatments

Both types of hormonal treatments may have side effects. The severity and which side effects that occur are individual and also vary depending on type and dose of treatment.

Progestines: The side effects and their severity vary from progestine to progestine depending on their chemical composition and the dose. Some examples are moodiness, depression, fatigue, nausea, weight gain, irregular bleeding, acne etc.

GnRH-agonists: As for progestines, the side effects and their severity vary from GnRH- to GnRH-agonist. The side effects are largely the result of the low levels of oestrogen in the body and many are similar to symptoms associated with menopause. Some examples are hot flushes, insomnia, decreased libido, headaches, mood swings, acne, muscle pains, depression etc. The most serious side effect of GnRH-agonist treatments is thinning of the bones. Add-back therapy with low dose of oestrogen prevents or minimises the side effects of GnRH-agonists, including the bone thinning.

If you experience side effects, discuss with your doctor options to handle and minimise them.

Endometriosis and treatment

Painkillers: Many with endometriosis experience different levels of pain. Painkillers are therefore often required as part of the treatment to reduce the symptoms and pain management.
Non-steroidal anti-inflammatory drugs (NSAIDs) and paracetamol are the first choices but from time to time stronger painkillers are required. Discuss with your doctor the best pain management strategy.

Other pain management methods that may work are acupuncture and TENS (Transcutaneous Electric Nerve Stimulation) and cognitive behavior therapy. Heat, physical activity and stretching might also reduce the pain cause by chronic inflammation.

Endometriosis and infertility

If you are wishing to conceive, discuss other treatment alternatives with your gynecologist since you cannot conceive during hormonal treatments.
It is also advisable to discuss your pregnancy plans with you gynecologist in case assisted reproductive techniques (e.g. IVF) are needed and thus avoid unnecessary delays and prolonged periods without treatment when the endometriosis might cause more damage.

Summary

Endometriosis can manifest itself in different ways, from no to severe symptoms. Therefore, it is paramount to do a careful examination to make the correct diagnosis and offer the best treatment.
This pamphlet provides brief information about endometriosis, which examinations are performed and the most common treatments used in Sweden.

If you want to find out more

The endometriosis association, Sweden, is a non-profit patient association with the purpose of spreading knowledge about endometriosis and support persons that have the disease. You can read more and become a member on our webpage: www.endometriosforeningen.com
Most of our information is in Swedish but if you have questions you can email us on info@endometriosforeningen.com and we will answer your questions in English.

Endometrios föreningen

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The Swedish text was originally written by Dr Agneta Bergqvist and updated by Dr Christine Bruse, 2012.

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