

Endometriosis – a disease often missed

E n d o m e t r i o s i s. A difficult word for a common inflammatory disease that affects persons born with female genitalia.

It is estimated that 10% of persons born with female genitalia have endometriosis. That corresponds to approximately 200 000 individuals in Sweden, and at least 10% of that number is teenagers. Endometriosis is more common than cancer, rheumatoid arthritis (RA) and diabetes.

Endometriosis causes, among other things, pain in the lower pelvic area, menstrual cramps and deep pain during intercourse. About half of those suffering from endometriosis have symptoms whilst some are unaware and diagnosed upon an infertility investigation. The disease can be divided into different stages: severe, moderate, mild and minimal. These stages describe how endometriosis appears in the abdomen and does not necessarily reflect the magnitude of symptoms.

If you have so much pain during your period that ordinary, non-prescription painkillers do not help, you should talk to your school nurse, school doctor, parents, and preferably see a gynaecologist for help. Often the doctor dismisses the symptoms for ordinary menstrual cramps. If you feel that your doctor/gynaecologist does not take you seriously, go to a different doctor/gynaecologist.

Why is such a common disease so unknown?

Yes, it is strange. Endometriosis has long been recognised by the medical society, but it has been difficult, even for specialists, to absorb the knowledge about the disease since it can be difficult to understand, diagnose and treat.

Menstrual cramps are often perceived as something normal, and therefore endometriosis sufferers seldom complain about their problems. If you believe that something is normal, you often become more reluctant to complain. It can also be embarrassing to talk about pain associated with your female parts and upon sexual activity. Thus, many tend to keep up an appearance that all is well and speak very little or not at all about their symptoms.

Also, there is a general attitude in society, even among caregivers, that it is normal to have abdominal and pelvic pains, particularly in conjunction with periods. When those affected by endometriosis seek help, they are often met with disbelief from school, work, family and friends. Usually an endometriosis sufferer seeking medical

help needs to see many doctors before the symptoms are taken seriously. Not to be believed puts further pressure on individual.

On average, it takes 7-8 years from the time point at which an endometriosis sufferer understands that the pains are not normal until a proper endometriosis diagnosis. Many have incorrectly been diagnosed with urinary tract infection (UTI) and/or irritable bowel syndrome (IBS). We, with expertise in the field, know that symptoms reminding of UTI and IBS are common among endometriosis sufferer. If endometriosis is detected earlier, the patient will get appropriate treatment quicker, which will not only minimise the sufferings but also might give the disease a milder course.

What is endometriosis?

Endometriosis is caused by cells similar to the endometrial tissue (the inner lining of the uterus) found outside of the uterus, i.e. elsewhere in the body. The most common locations are ovaries, fallopian tubes, peritoneum (the pelvic side-wall), bladder and lower intestine. These cells start to grow and cause inflammations in the pelvic cavity that in turn can lead to abdominal pain, scar tissue and adhesions.

Adenomyosis is a type of endometriosis that grows inside the uterine wall.

It is yet unclear why endometriosis develops. Retrograde menstruation is an often-mentioned theory. Retrograde menstruation is when menstrual tissue flows backwards through the fallopian tubes and deposits in the pelvic cavity. There, the tissue fragments start to grow and cause inflammations etc; causing endometriosis to develop. Interestingly, 90% have retrograde menstruation, which clearly shows that other factors and/or mechanisms also are crucial for the development of endometriosis.

The scientific society does not yet know why patients develop endometriosis. Studies have shown that there are genetic components. It is approximately 7 times increased risk for a child born with female genitalia to develop endometriosis if the mother or grandmother has the disease. It has also been shown that there is an increased risk if the disease is present on the father's side.

Most likely there is a combination of several genetic and environmental factors that causes endometriosis.

Symptoms of endometriosis

The most common symptoms are pain at, before and during menstruation. The pains can be so severe that you vomit, faint and are debilitated for several days.

When should you suspect that you have endometriosis and not ordinary menstrual cramps?

- If you have so much pain that you cannot attend school or work, lies at home with severe pains, then you should go to a gynaecologist, says Matts Olovsson, professor in obstetrics and gynaecology and chief physician at Endometrioscenrum, Akademiska Hospital, Uppsala.

Here we have listed the most common symptoms for endometriosis:

- Severe pain before and/or during menstruation
- Pain upon ovulation or at other points between menstruation
- Pain despite non-prescription pain killers
- Abundant, long and/or irregular menstruation
- Deep pain during intercourse
- Pains when you urinate or during bowel movements
- Diarrhoea or constipation
- Fatigue
- Pain in the groin and/or lower back that radiates out to the legs
- Reoccurring UTI where antibiotics do not help
- Difficulties in becoming pregnant

It is individual which symptoms an endometriosis sufferer experiences, some do not have any symptoms at all. The symptoms may also alter with time.

It is important to remember that you can have some of these symptoms without having endometriosis.

Diagnosis of endometriosis

If you feel that something is wrong, it is important that you go to a doctor, preferably a gynaecologist, for a thorough medical exam and discuss the symptoms you have. Thereafter, your doctor will make a medical assessment. If the doctor suspects endometriosis, it is advisable for you to start a treatment.

A laparoscopy is needed to fully ensure that it is endometriosis but that is often only preformed if the initial treatment strategies fail or if the surgery is required for other reasons.

Doctors often mistake the symptoms as ordinary menstrual pain, UTI, IBS or something else. It is not uncommon that endometriosis sufferers have visited 2-4 different doctors before receiving appropriate help.

Treatment

Currently there is no cure for endometriosis. However, there are several ways to treat and relieve symptoms.

- *Pain treatment*

An efficient pain treatment is important for many with endometriosis. This can be achieved via different types of painkillers. A general basic treatment is paracetamol (e.g. alvedon and panodil) and NSAIDs (e.g. ipren, orudis, diclofenac, naproxen); continuously, in periods or when needed. Opiates should be used with caution due to the risk of addiction.

- *Hormonal treatment*

Endometriosis needs oestrogen for its growth and maintenance. Thus, endometriosis can be subdued by minimising or removing oestrogen from the body. This can be achieved via different types of hormonal treatments with the goal of eliminating the menstrual bleeds and inhibiting ovulation. The most common forms of hormonal treatments are ordinary contraceptive pills (p-pill) that are taken without breaks (i.e. you do not have any periods) or different types of progesterone (also called gestagens, progestins). A different type of hormonal treatment is GnRH-agonists that induce an artificial menopause that sometimes can have a good effect.

It is individual which treatment is best and it is the efficiency and side effects that direct where you end up. Studies have shown that one type of hormonal treatment is not better than the other. The treatment should be maintained until a wish for pregnancy or until the natural menopause is closing in.

- *Surgery*

A surgery can be necessary if the symptoms do not become manageable with the above approaches. Your doctor will then go into the abdomen, often via laparoscopy, and surgically remove endometriosis, adhesions etc. Surgical removal of endometriosis does, however, rarely solve the problems over time. Sometimes there might be a need to remove the ovaries and uterus (a hysterectomy) but this is not a primary option, especially in young patients. Approximately 80% undergoing a hysterectomy experience an improvement or complete loss of symptoms afterwards; every 5th with

endometriosis does not experience symptom relief and sometimes the symptoms become even worse.

Which type or combination of treatments that works most efficient is individual and something you have to discuss with your doctor.

There may be new treatments in the future. Already now new drugs are being tested that seem more effective and milder as treatment for endometriosis. Ask your doctor about treatment alternatives that currently are the best.

Pregnancy

Some endometriosis sufferers have difficulties in becoming pregnant. However, most with endometriosis become pregnant on their own or with assisted reproductive treatment (e.g. in vitro fertilisation (IVF)) and obtain the number of children they wish for. 75% of all with endometriosis become pregnant and the remaining 25% can also have other underlying causes (e.g. other diseases, issues on the male side, unexplained infertility not related to endometriosis, decision of not having children).

Complementary treatment options

There may also be other ways to alleviate the symptoms. Many with endometriosis experience improvement of symptoms by:

- Pain relief via heat, e.g. warm pads.
- Pain relief via TENS: Transcutan electric nerve stimulation; a method for pain relief based on nerve stimulation via weak electric currents.
- Pain relief via acupuncture.
- Change in diet: Many with endometriosis have noticed that certain food products increase the symptoms. Therefore a change in diet may alleviate symptoms. One way is to keep a food diary and exclude products that lead to increase of symptoms.
- Training/Physical activity: Physical activity is good for everyone; the body and psyche become stronger. Also, physical activity can lead to pain relief and might be an effective tool to handle the disease. One tip is to try different types of exercise/physical activity and find the forms that work best for you.
- Relaxation exercises, cognitive behavioural therapy (CBT), etc. can help you deal with pain and other symptoms.

It is individual what works and sometimes, different things work at different times.

Endometriosis – a socio-economic disease

According to a report "*Burden of illness in women with endometriosis*" with Matts Olovsson as main author (professor in obstetric and gynaecology and chief physician at Endometrioscenrum, Akademiska Hospital, Uppsala), an endometriosis sufferer costs between 40 000 SEK and 90 000 SEK per year. Approximately 50 000 SEK is direct health care costs for doctor visits, medications, admissions, surgeries etc. 40 000 SEK is indirect costs of increased sick leave and absence from work. There are about 200 000 endometriosis sufferers in Sweden and roughly 20% require medical and/or surgical treatment. To show how much this costs society we multiply 40 000 individuals with the approximate total cost of 90 000 SEK - the sum reaches 3.6 billion SEK per year. Endometriosis is thus a disease that affects not only the patient physically but also strikes against the patient's, but also the society's, economy.

Relatively little research fundings are invested in the field of endometriosis. More knowledge about endometriosis is required for faster diagnosis and how the disease can best be treated. For example, we need new kinds of efficient treatments that produce fewer side effects. This would improve the quality of life for endometriosis sufferers and enable them to contribute to the national economy.

Hope for the future – take the pain seriously!

Do not give up, there is hope and it is possible to manage the disease!

Several studies have shown that endometriosis sufferers have a decreased quality of life as compared to healthy persons. Endometriosis can involve a great suffering and the disease does not only affect the patient but can also have negative effects on family life, school, employment, economy and intimacy.

The knowledge about the disease has to increase among health care workers and society in general so that the thought of endometriosis comes earlier.

It is extremely important that individuals with symptomatic endometriosis are taken seriously and that they receive the help and support they are entitled to. It is important with information to relatives, partners, friends, teachers and other school staff, classmates, employers and colleagues. Knowledge must also improve among politicians, health care professionals and people in general.

When the diagnosis is made, an important step is to learn about the disease and what it means to live with it. Accurate information makes it easier to actively participate in the discussion of treatment options and managing the disease.



The more attention we give endometriosis, the brighter the future will be for the endometriosis sufferers, their families and the community at large.

On www.endometriosisforeningen.se, our homepage, you will find more information about the disease; treatments; complementary treatments that might alleviate symptoms; tips on how to cope with the disease; material that can help you prepare for doctor visits; and much more. You also find information about members meetings, seminars etc.

The majority of the information material is in Swedish. However, you can write questions to us and we can answer them in English.

About the Endometriosis association

The Endometriosis association, Sweden is a non-profit patient association that has been working for several years:

- to support endometriosis sufferers
- to inform society, health care professionals, politicians and others with the purpose to increase the knowledge about endometriosis.
- to influence politicians and decision makers in health care to improve the care and treatment.

This work will lead to an earlier diagnosis, better care and increased research.

