

Deep Endometriosis

Patient Information Series – What you should know, what you should ask.

What is endometriosis and more specific Deep Endometriosis (DE)?

Endometriosis is a gynecological condition affecting 6% - 10% of women of reproductive age. In this disease, tissue similar to the lining inside of the uterus (called “the endometrium”) is found outside the uterus. DE is defined as lesions with more than 5mm infiltration depth, whether or not infiltrative in the surrounding organs such as the bladder or bowel. Symptoms include pain and/or infertility.

What causes endometriosis?

The exact cause of endometriosis remains unknown. The most accepted theory is the so-called retrograde menstruation theory. During menstruation, pieces of the inner lining of the uterus arrive in the abdominal cavity through the fallopian tubes and stick to the inner lining of the abdomen or to the ovaries. These endometrial implants develop into endometriotic lesions. The hormone estrogen is crucial in this process as it is one of the key hormones controlling the menstrual cycle. Genetic and immune factors may also play an important role in the development of the disease.

How is the diagnosis of DE made?

Presence of DE can be suspected based on clinical history and pelvic examination. Diagnostic laparoscopy is the gold standard, however this is invasive and costly. DE can be accurately detected through imaging techniques such as a gynecological ultrasound and/or MRI. In experienced hands, gynecological ultrasound can also assess the extent of the disease.

What does it mean for me in long term?

Deep endometriosis is not associated with an increased risk of cancer. Although endometriosis is a benign gynecological disorder, it can have a negative impact on your quality of life and fertility.

How can DE be treated?

1. Medical treatment is based on suppression of symptoms (i.e. to relieve the pain): non-inflammatory steroidal inflammatory drugs, contraceptives or GnRH-agonists, can be used.

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2. Surgery (often laparoscopic or “keyhole” surgery) may be considered in cases of failed medical treatment, women with contraindications for contraceptives, couples seeking natural conception, patient preference, or specific indications such as bowel stenosis or ureteral stenosis.

Will it happen again?

Yes, DE can recur. From 5% - 25% of women who undergo surgery for deep endometriosis will have a relapse after 2 years. You may be prescribed medication for long term prevention.

What other questions should I ask?

- Is there a medical reason for an intervention (for example in case of bowel or ureteral stenosis)
- What are the benefits and the side effects and other risks of the treatment proposed?
- How will treatment impact on my fertility?

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