



ENDOMETRIOSIS

Endometriosis is a common gynecological problem. It is not a cancer and is not dangerous, but can cause pain and difficulty in getting pregnant. It can be found in women who have had children and in women without symptoms.

What is it exactly?

Endometriosis is where cells similar to those in the lining of the womb (called endometrium) have seeded themselves inside the abdomen and pelvis. Why it starts is not known. It is thought that fragments of the period blood pass down the Fallopian tubes and that these fragments can seed inside the pelvis.

These cells (called implants) look like pepper sprinkles inside the abdomen. They can vary in color from clear to red to black. These implants go through a period cycle similar to the lining of the womb. They swell in the days before a period and bleed inside the abdomen. This causes the typical symptoms of pain before a period and often excruciatingly painful periods. Endometriosis can be found on the skin lining the abdomen and pelvis (called the peritoneum), the ovaries, outside of the womb (uterus), bladder and bowel. It has also been reported in the lungs and in the umbilicus.

Endometriosis can result in cysts in the ovaries. These cysts are inside the ovary, like a yolk inside a hard-boiled egg, and are not, as is commonly thought, sticking out from the outside. These cysts can be as small as a pea or as large as a grapefruit. The ovary is stretched around the cyst, but will still be able to work to produce eggs and ovulate.

Endometriosis causes irritation and inflammation. This can result in one structure sticking to another (called adhesions). Adhesions can be fine like cobwebs or can be more like superglue sticking one structure to another. In the most severe endometriosis, the adhesions can bind the womb, tubes, ovaries and nearby intestines together. The egg gets trapped in the adhesions which reduces the chance of getting pregnant.

Who gets it?

Endometriosis is common. It is linked with periods and is rare before periods begin or after the menopause. It used to be called 'the career woman's disease', but this may simply be the effect of more periods. It is most commonly found between the ages of 25 and 45, but has been reported in teenagers and in women after the menopause taking hormone replacement treatment.

What are the symptoms?

Any pain which varies with the period (menstrual) cycle is likely to be due to endometriosis.

- Pain in between the periods, especially in the days leading up to the period;
- Painful periods (dysmenorrhea);
- Pain during intercourse, usually deep inside;
- Pain deep inside on opening the bowels (dyschezia) suggests endometriosis affecting the bowel.

I think that I may have endometriosis. How do I get treatment?

You should speak to your family doctor. Explain your symptoms and how they are affecting you.

How is endometriosis diagnosed?

Some women are found to have an endometriosis cyst on ultrasound scan and this is the first time they hear about it. A normal scan does not rule out endometriosis as the small spots of endometriosis cannot be seen on scan.

A vaginal examination can assist in making the diagnosis. The doctor may be able to feel tender nodules of endometriosis or an enlarged ovary. The only sure way to diagnose endometriosis is by laparoscopy.

Laparoscopy/laparoscopic treatment of endometriosis

Laparoscopy is an operation to look inside the abdomen and pelvis. A small cut is made inside the umbilicus and a thin telescope, called a laparoscope, is passed through this cut. Through the telescope, your surgeon can see the organs inside your abdomen and pelvis. To create some space inside your abdomen, your surgeon will inflate it with carbon dioxide gas, so there is room to look around. The gas is released before you wake up. The bowels surround the pelvic organs, so your surgeon will make a second incision and use an instrument to lift the bowels out of the way so that the view is clear.

Endometriosis is graded according to the area affected and the presence of adhesions. The more is the number of adhesions, the more severe is the endometriosis. The severity indicates



the chance of your getting pregnant naturally. The severity is not linked with the amount of pain, and it is possible to have minor endometriosis and severe pain and the opposite, severe endometriosis and minor pain.

Before the operation your surgeon will discuss surgical treatment of endometriosis. Spots or implants can be cut out or treated by laser or diathermy. Adhesions can be cut to release the pelvic organs. An endometriosis cyst can be 'peeled out' from inside the ovary.

It is commonly thought that a laparoscopic operation is just a minor operation, but laparoscopic surgery for severe endometriosis carries significant risks to the internal organs especially if there are adhesions to bowel. Your surgeon may carry out an initial operation and make a plan with you for a second more extensive operation having seen inside your abdomen.

Bowel endometriosis

The only treatment for endometriosis affecting the bowel is to surgically remove it. Endometriosis commonly coexists with irritable bowel syndrome which can be managed by following a healthy diet with plenty of fruit and vegetables. Peppermint water or an antispasmodic bought over the chemist counter may help.

Will I be able to have children?

Most women with endometriosis will conceive without any problem.

Women being investigated for fertility problems by laparoscopy are commonly diagnosed with endometriosis. This is often minimal endometriosis and laparoscopic treatment has been shown to improve the chance of getting pregnant. It is thought that the endometriosis produces chemicals that reduce the chance of the sperm fertilizing the egg.

If there are adhesions, these reduce the chance of the egg getting down the Fallopian tube. The egg gets trapped in the adhesions. Surgical release of these adhesions can improve the chance of getting pregnant naturally.

If you have had treatment already for endometriosis and haven't got pregnant on your own, then there is the option of fertility treatments and *in vitro* fertilization (IVF). The fact that you may have endometriosis does not appear to alter the success of fertility treatment.

There is endometriosis in my family. Will I get it too?

You are more likely to have endometriosis if your mother or sister(s) have endometriosis and the endometriosis may be more severe. It doesn't always run in families.

What is the treatment?

There are two natural cures for endometriosis. One is pregnancy and the other is the menopause. Neither is a practical solution if you are trying for a pregnancy or are 25.

Hormone treatments for endometriosis imitate pregnancy or the menopause. Treatment is usually for 6 months. Periods usually stop during the treatment and start again within a few weeks of finishing the treatment. All the hormone treatments are very effective for treating pain. Hormone treatments are not recommended if you are trying to get pregnant unless they are to treat pain or are a preparation to further surgery. They are contraceptive and do not improve your chance of getting pregnant after the treatment.

The birth control pill

The pill has been proved to be as effective as the more powerful hormone treatments in reducing pain due to endometriosis. It can be taken in the normal way with a 7 day break or by running one or more packets of pills together to give you fewer periods.

Mirena system

The Mirena system is a hormone coil containing progestogen. It is coil shaped to be able to hold the hormone in the lining of the womb, but it is hormonal in the way that it works. It prevents the lining of the womb from building up. Periods are lighter and less painful. There may be some troublesome bleeding for the first 3–6 months while the hormone works on the lining of the womb.

Progestogens

These hormones are taken by mouth as a tablet or given as an injection. Possible side-effects include water retention and weight gain.

Danazol and gestrinone

These hormones are taken by mouth as a tablet. Possible side-effects include water retention and weight gain. There have been reports of coarsening or thickening of the body hair and even deepening of the voice, so these drugs have largely been replaced by gonadotropin releasing hormone agonists.

Gonadotropin releasing hormone agonists or antagonists

These medicines are completely digested if taken by mouth, so are given as an injection or a nasal sniff. Side-effects are those of the menopause. These vary from woman to woman, but typically include hot flushes and night sweats. These side-effects can be minimized by adding back a small amount of hormone replacement. This small dose does not reduce the good effect of the treatment and appears to be safe.

**How do I get the best pain control?**

Pain control is better if you stay 'ahead of the pain' by taking your pain relief medicine regularly. Anti-inflammatory drugs (such as ibuprofen) provide good pain control and can be combined with paracetamol. If this combination is not strong enough, then the paracetamol can be replaced by a paracetamol and codeine combination. This can make you feel a bit drowsy. You should not drive or operate machinery while taking this. All of these medicines can be bought over the chemist counter. Your pharmacist is a good person to ask for advice.

Complementary treatment

These have not been scientifically proven in directly treating the endometriosis, but many women find that complementary therapies such as acupuncture or relaxation therapies help them in managing the symptoms of endometriosis.

What if I leave the endometriosis untreated?

Research suggests that endometriosis can get better as well as get worse over time. If your symptoms are not severe and you have finished having your family, you might decide not to have treatment.

Will the endometriosis come back after treatment?

Whatever type of treatment you have had for the endometriosis, research suggests that endometriosis slowly comes back over time, perhaps giving you several months or years before needing more treatment. If you had surgical treatment the first time, it may be possible to repeat this or

try one of the medical treatments. Some of the medical treatments can be continued long-term if you have not yet had a family. If you have finished having children, you might decide to have a complete hysterectomy removing the womb and ovaries.

Endometriosis can affect your work and your family life. Talk to your family doctor who may be able to help. Get in touch with your local support group – just knowing that you are not alone can be a real help. Some support groups offer a 'meet and greet' service. If you feel nervous going along on your own, ask if you could meet a support member before the meeting and go in together.

Useful addresses

Endometriosis UK. A Charity supporting women with endometriosis in the UK

<http://endometriosis-uk.org>

Information on endometriosis from the Royal College of Obstetricians and Gynaecologists UK

<http://www.rcog.org.uk/index.asp?pageID=2278>

Information on Endometriosis from the American College of Obstetricians and Gynecologists USA

http://www.acog.org/publications/patient_education/bp013.cfm