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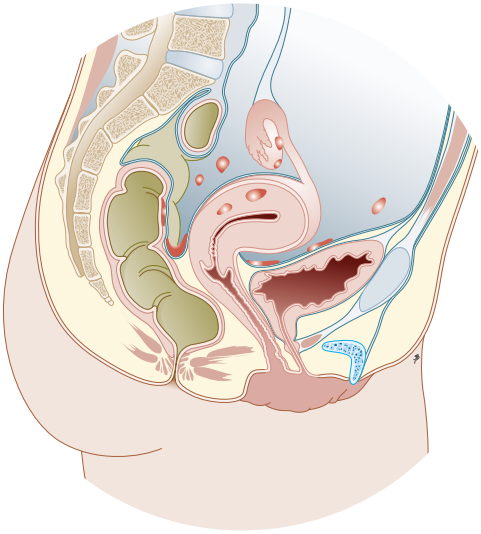


Endometriosis

Patient Information

Introduction

This brochure provides information about endometriosis, how it develops, what the symptoms are and how it can be treated. Should you have any further questions after reading this brochure, please do not hesitate to contact us. The doctors and midwives at the Leuven University endometriosis centre will be happy to provide further information.

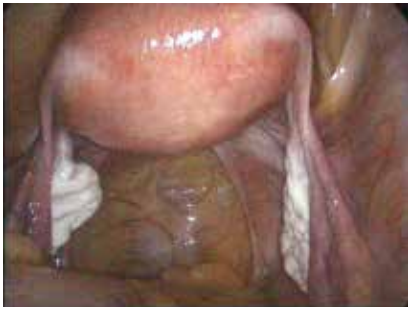
WHAT IS ENDOMETRIOSIS?

Endometriosis is a gynaecological disorder in which cells from the endometrial lining (endometrium) normally found on the inside of the uterus also occur on the outside, usually in the abdominal cavity, on the peritoneum and the pelvic organs.

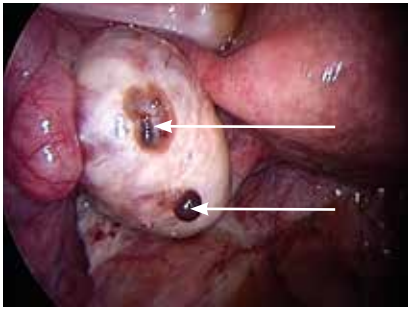
It is estimated that approximately one in ten women between the age of 15 and 50 suffers from endometriosis to a larger or lesser extent. Early diagnosis and treatment are particularly important to ensure that the treatment is successful, and that fertility is maintained.

Women suffering from endometriosis may have painful periods, or feel pain during sex, when urinating or passing stools.

Left untreated, endometriosis can lead to infertility.



normal abdominal cavity with uterus, ovaries, oviducts



endometriosis lesions on an ovary

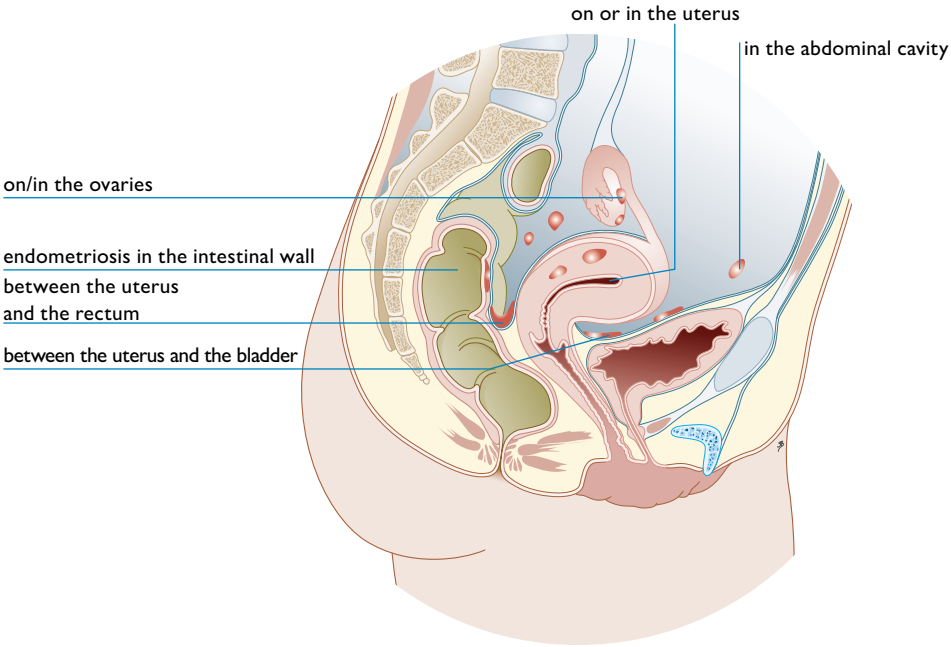
HOW DOES ENDOMETRIOSIS DEVELOP?

Endometriosis is associated with oestrogen dominance. It is not yet entirely clear exactly how it develops, although there are several potential theories.

One theory maintains that as a result of retrograde menstruation the blood does not only leave the body via the cervix during menstruation, but that it also ends up in the abdominal cavity via the fallopian tubes. In all probability several endometrial lining cells are not eliminated by the immune system and embed themselves in the abdominal cavity, leading to endometriosis.

It is not clear why some women suffer from endometriosis and others not. Genetic and/or environmental factors may play a part in this process.

WHERE DOES ENDOMETRIOSIS OCCUR?



Endometriosis usually occurs in the lesser pelvis: on the outside of the uterus or on the fallopian tubes, ovaries, intestine, bladder, ureters or peritoneum. Endometriosis lesions can also be found close to the navel or on the abdominal side of the midriff.

Endometriosis can manifest itself in three different ways:

1. Superficial endometriosis: isolated level lesions on the peritoneum
2. Deeply infiltrating endometriosis: nodules that can grow into surrounding organs such as the bladder, urinary tracts, intestine – even through the vaginal wall
3. Endometriosis cysts or endometriomas: cysts in the ovary or between the ovary and pelvic wall

SEVERITY OF ENDOMETRIOSIS

The severity of endometriosis is diagnosed on the basis of four stages.

- Stage I (minimal): < 3 cm^2 total surface area (superficial endometriosis)
- Stage II (mild): > 3 cm2 total surface area (superficial endometriosis)
- Stage III (moderate): one ovary with endometriosis cysts (sometimes in combination with superficial endometriosis on the peritoneum)
- Stage IV (severe): both ovaries have endometriosis cysts or there are signs of deeply inflitrating endometriosis (sometimes in combination with superficial endometriosis on the peritoneum)

SYMPTOMS

Cells from the endometrial lining can occur anywhere in the lesser pelvis, sometimes as small patches on organs, but they can also embed themselves into the walls of surrounding organs. During menstruation tissue fragments formed by these cells will also bleed and this causes inflammation, resulting in abnormal growths. This inflammatory reaction caused by the bleeding of the endometriosis lesions can lead to severe pain, usually around the time of menstruation.

Pain caused by endometriosis manifests itself as severe menstrual pain, pain when urinating and passing stools (particularly during menstruation), pain during sex, chronic lower abdominal pain and excessive tiredness. This type of pain can have a significant impact on the patient's quality of life.

Note: some patients with severe endometriosis experience no pain, but some patients with minimal or mild endometriosis suffer pain so severe that they can no longer function normally. In other words, there is not always a direct link between the extent of the endometriosis and the severity of the pain.

EXAMINATIONS AND DIAGNOSIS

Endometriosis can only be diagnosed with certainty during a laparoscopy. A number of examinations can be carried out to provide a clear picture of the location and extent of the endometriosis.

Your first consultation will provide the opportunity for a detailed discussion. You will first have to complete a questionnaire at home, in preparation for the consultation. The specialist midwife or gynaecologist will ask specific questions during the consultation to gain a clear insight into your situation.

If endometriosis is suspected one or more of the following standard examinations will be arranged. The examination phase may take several months.

- Gynaecological ultrasound scan

  This type of examination uses ultrasound waves to produce cross-sections of the female pelvis and provides a detailed picture of the uterus and ovaries. An internal vaginal ultrasound scan will highlight endometriosis lesions and cysts. To check potential endometriosis lesions in the bladder it is important to ensure that your bladder is sufficiently full at the time of the scan.

- MRI

  This type of pelvic scan uses a magnetic field to produce cross-sections of the female pelvis and highlight endometriosis lesions and cysts.
  You may have to follow a specific diet for a number of days in preparation for this examination to drastically reduce the production of stools.
  The evening before the examination you will have to do a preparation to empty the intestines.
  A IV will be used during the examination to inject a contrast medium. Ultrasound gel will be applied via the vagina and contrast water anally in order to produce a clearer picture of endometriosis lesions that have established themselves in the vaginal or intestinal wall.

If the above mentioned examinations do not produce a definitive diagnosis, additional examinations will be arranged.

- X-rays of the large intestine

  To obtain more detailed information on the growth of endometriosis in the wall of the large intestine section in the pelvis, X-rays will be made of the large intestine using a contrast medium. You will have to follow a specific diet for a number of days in preparation for this examination to drastically reduce the production of stools. The evening before the examination you will also have to ingest an enema type drink to empty the intestines.

- X-rays of the kidneys and urinary tract

  To obtain more detailed information on the impact of endometriosis on the urinary tract, X-rays will be made of the kidneys and urinary tract. A IV will be used during the examination to inject a contrast medium. The urinary tract can be photographed using X-rays when this contrast medium is excreted via the kidneys and urinary tract to the bladder.

ENDOMETRIOSIS TREATMENT

Once a clear picture has been obtained of the extent of the endometriosis, the gynaecologist/endometriosis surgeon will discuss the examination results with you.

HORMONAL THERAPY

To develop, endometriosis requires oestrogen, the female hormone produced by the ovaries. By halting the functioning of the ovaries, the oestrogen level can be reduced and consequently 'dry out' the endometriosis. The inflammatory reaction around the endometriosis outbreaks in the abdomen will be reduced or disappear altogether, which will also greatly reduce (or eliminate) the pain.

However, ovulation will cease when drugs are taken to stop the ovaries from functioning, and you will consequently not be able to get pregnant. Once you stop taking the hormonal medication the ovaries will resume their normal function.

- a regular contraceptive pill will suppress the menstrual cycle
- a progesterone-only pill: a hormone also produced by the female body but when administered daily it will halt the functioning of the ovaries, similar to a regular contraceptive pill
- a hormonal IUD combined with a contraceptive pill: the combination suppresses the functioning of the ovaries and stops the uterus from bleeding.
- monthly injections so that you enter into a kind of artificial menopause for the duration of the injections

If you have already undergone several endometriosis interventions, hormone therapy will be initiated as part of the symptom therapy, e.g. with painkillers. To do so we collaborate with a gynaecologist/ endocrinologist to find the best hormonal balance. After all, redo surgery will not guarantee an improvement of the pain symptoms.

SURGERY

Removing endometriosis lesions in the abdomen during surgery involves a laparoscopy, via a CO^2 laser and – if the endometriosis is affecting the wall of the intestine, urinary tract or bladder – a multidiscipline surgical team. The operation will take place at a time when the surgeons specialised in the organs that are affected by endometriosis are all present. This will ensure that all the endometriosis outbreaks can be removed during a single surgical intervention.

The doctor will decide upon the extent of the operation on the basis of the results of the examination. The stage of the endometriosis will define the duration of your hospital admission and the time needed to recover fully following the operation.

PREPARATIONS FOR THE OPERATION

An extensive endometriosis intervention requires considerable preparation.

HORMONE SUPPRESSION

To prepare for the operation you will be asked to take medication to stop your menstrual cycle, because the female hormone produced by the ovaries stimulates endometriosis. Technically it is easier to completely remove the endometriosis if it has first been 'dried out' as a result of the interruption of the menstrual cycle, i.e. by ensuring that the ovaries are 'at rest'.

If minimal to mild endometriosis is suspected, taking a contraceptive pill will suffice to prepare for the operation.

If the endometriosis surgeon suspects that you have moderate to severe endometriosis, your GP will be asked to administer monthly injections for three months before the operation to ensure that the abdomen is 'as dry as possible'. These injections temporarily halt the functioning of the ovaries and consequently induce an 'artificial menopause'. You may well suffer from typical menopausal symptoms as a result, e.g. night sweats or hot flushes. To alleviate these symptoms induced by the injections as much as possible, you will be prescribed tablets that you can take for as long as the injections are administered.

BOWEL PREPARATION

You will be asked to follow a diet for about five days before the planned operation to ensure that the production of stools is minimised. On the day before the operation you are expected at 2 pm and the bowel preparation will be started .to empty the bowels completely.

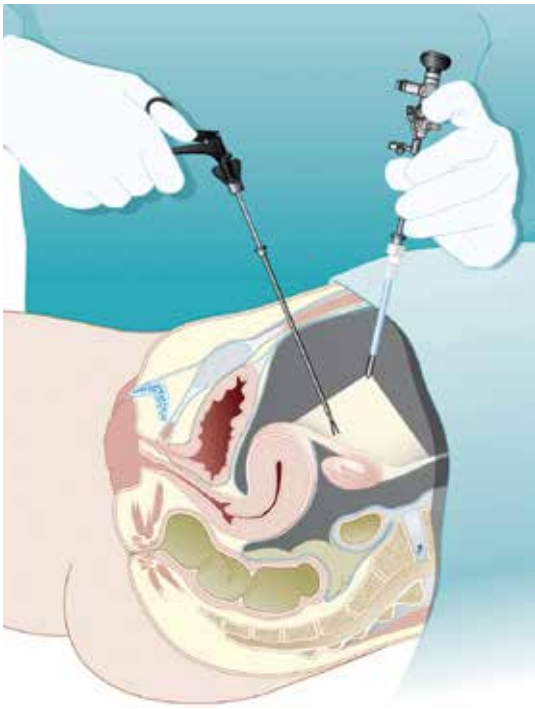
The intestine takes up considerable space in the abdomen. If the endometriosis has also grown into the wall of the intestine and the surgeon decides to remove it, the intestine may have to be opened up. The colorectal surgeon will then remove the affected section and repair the intestine. That is why there should be very few or no stools at all in the colon.

OPERATION

LAPAROSCOPY

During a laparoscopy a camera is inserted into the abdominal cavity via the navel to examine the gynaecological organs.

If the condition of the pelvic area deviates from the norm a CO^2 laser is used to cut away any abnormal tissue and return the anatomy to its normal state where possible.



BENEFITS OF USING A CO^2 LASER DURING LAPAROSCOPIC ENDOMETRIOSIS SURGERY

A CO^2 laser produces an energy beam. When this beam is directed at a cell the water in the cell will almost immediately be vaporised. Vapour has a larger volume than water resulting in the cell 'bursting open' or 'vaporising'.
The energy beam itself is converted with extreme accuracy into a very fine beam, which means that certain cells can be 'vaporised' without affecting any surrounding healthy cells. This way healthy tissue can be separated from affected tissue and any tissue impacted by endometriosis can be 'peeled off' and removed in its entirety.

MULTIDISCIPLINE SURGICAL TEAM

Because endometriosis can also affect the wall of the intestine, urinary tract and bladder, an operation for widespread endometriosis will involve a multidiscipline surgical team.

- ✔ At the core is a gynaecologist whose task is to remove all endometriosis lesions and restore the normal anatomy of the reproductive organs in the lesser pelvis where possible.
- ✔ If there are lesions on the intestine the gynaecologist will be supported by a colorectal surgeon and, in the event of lesions on the bladder or urinary tract, by a urologist, both trained in laparoscopic surgery.
- ✔ The anaesthetist will manage the anaesthetic.
- ✔ If endometriosis is suspected on the midriff and/or lining of the lungs, a thoracic surgeon (specialised in operations on organs in the chest) will make a diagnosis during a separate operation and remove the endometriosis lesions.

Collaboration between surgeons from different disciplines will ensure that widespread endometriosis is completely removed, with minimal risk of complications during/after the operation, minimal risk of recurrence and maximum chance of fertility being restored. Maximum removal of the endometriosis lesions will alleviate any pain it may have caused, which in turn will lead to optimum post-operative quality of life.

STOMA?

In some cases when the colorectal surgeon has removed and repaired a section of the bowel affected by endometriosis, they may decide to provide a stoma to temporarily disable that particular section of the bowel and give it chance to recover. After 6 to 12 weeks the (temporary) stoma will then be sealed from the outside, without the surgeon having to access the abdominal cavity.

PROGRESS AFTER THE OPERATION

Following the operation, you will remain in hospital until the doctor in charge of your treatment decides, in consultation with you, that it is safe for you to continue your recovery at home.

A consultation with you will be arranged several weeks after the operation to discuss your progress.

PREGNANCY

Endometriosis reduces the chances of becoming pregnant. Once the endometriosis has been surgically removed your chances of becoming pregnant will increase.

After the operation, the endometriosis surgeon will discuss with you what your chances of spontaneously becoming pregnant are. They will also indicate whether fertility treatment would be advisable and which fertility treatment would be best.

PREVENTING RECURRENCE OF ENDOMETRIOSIS

If, following an (extensive) laparoscopy to remove endometriosis, you do not want to become pregnant immediately, or not at all, it is advisable to minimise menstruation. This requires hormonal medication, i.e. taking the contraceptive pill, inserting a hormonal IUD or a combination of the two. This medication can be stopped as soon as you enter the menopause.

If you are prescribed a regular contraceptive pill, you will be advised to take it on a permanent basis. If it is not possible to continue taking the pill without having a bleed, you will have to stop taking it for five days and then restart again.
If necessary, a contraceptive pill can be combined with a hormonal IUD. This combination suppresses the functioning of the ovaries and prevents the uterus from bleeding.

Whereas a contraceptive pill contains both oestrogen and progesterone, a progesterone-only pill is also an option. This type of pill has to be taken daily at the same time of day and without interruption.

LEUVEN UNIVERSITY ENDOMETRIOSIS CENTRE

A hysteroscopy (a camera inserted into the uterine cavity) and a laparoscopy (a camera inserted into the abdominal cavity) are used to check the uterine cavity and reproductive organs in the pelvis for abnormalities that might have an adverse effect on fertility.
A surgical hysteroscopy and surgical laparoscopy are used to restore the normal anatomy where possible to optimise the chances of pregnancy either spontaneously or with fertility treatment.

Because more than half of all patients who underwent a laparoscopy to inspect the pelvic organs due to fertility problems, are diagnosed with endometriosis, Prof. Dr. Christel Meuleman adopted a multidiscipline approach in conjunction with a colorectal surgeon and a urologist to be able to completely remove the endometriosis with, where possible, a full restoration of the normal anatomy. In fact, it was noted that the endometriosis had grown into the wall of the intestine, urinary tract and bladder in a third of all endometriosis patients. The result was a 'multidiscipline radical resection of endometriosis'.

Prof. Dr. Christel Meuleman's doctoral research showed that this 'radical' approach improved the quality of life, considerably alleviated or eliminated the pain, led to few complications during and after the operation despite often extensive surgery, minimised the risk of recurrent endometriosis and produced a high chance of a spontaneous pregnancy (providing there is at least one functioning oviduct, a regular cycle with ovulation and acceptable sperm quality).

The multidiscipline surgical team has now been enlarged with the addition of a second endometriosis surgeon, Prof. Dr. Carla Tomassetti. In her doctoral research project she researched fertility in endometriosis patients.

The 'Endometriosis Fertility Index' (EFI) is a new score system based on 0 to 10 points. The score is calculated at the end of a surgical intervention for endometriosis lesions and predicts the chances of pregnancy without resorting to IVF treatment.

Her doctoral research demonstrated that the predicted chances of pregnancy by allocating an EFI score is reliable for clinical use.

Prof. Dr. Carla Tomassetti, Prof. Dr. Christel Meuleman and Dr. Celine Bafort

Insemination treatment is a type of fertility treatment often used for women with milder forms of endometriosis, although its usefulness has not been irrefutably demonstrated. Research has shown that rapidly initiating insemination treatment does not benefit the chances of pregnancy. That is why we are inclined to decide that surgical treatment is initially sufficient for women with a high EFI score.

IVF/ICSI treatment is another type of fertility treatment that is part of the approach to infertility in the event of endometriosis, particularly for more extensive forms or if the fallopian tubes are affected. We also suspect that preliminary surgical treatment may improve the likely outcome of IVF/ICSI.

The endometriosis centre focuses in particular on innovative techniques and improvement of patient care based on a specifically scientific foundation. We consequently support scientific research that in the long term should provide a better insight and offer potential benefits to young women who have been diagnosed with endometriosis and who might want to become pregnant (in the future).

Dr. Celine Bafort is continuing the research within the multidiscipline team with studies focused on the diagnosis of endometriosis using ultrasound and surgical studies focused on functional post-operative results (quality of life, progress of pain symptoms, bowel/bladder function, ovarian function, chances of pregnancy, recurrence, etc.). Using these studies, we aim to evaluate existing (diagnostic and surgical) techniques and subsequently develop a staged plan based on scientific data for the surgical treatment of different types of endometriosis.

In addition to gynaecologists specialised in laparoscopic fertility surgery, the multidiscipline endometriosis team includes colorectal surgeons and urologists, all of whom are trained in carrying out laparoscopic operations. A thoracic surgeon deals with the surgical treatment of endometriosis lesions on the midriff and pleural membranes.

Radiologists focus on visualising endometriosis using X-rays and a magnetic field. The team also includes specialists in gynaecological ultrasound techniques for endometriosis.

Midwives with specific training for this disorder pass on information to patients. Our nurse consultant ensures that patients without any problems progress through consultation starting from the first time they register via the website. She is the contact of the endometriosis centre. During the examination stage, planning of the operation and follow-up, she will coordinate your dossier in conjunction with the endometriosis team. Various administrative employees ensure that the dossiers and insurance documentation of patients – particularly if they come from abroad – are correct and up to date.

Our fertility psychologists, psychomotor therapist and pain clinic can also be consulted if, after the removal of all visible endometriosis, the patient still suffers pain or discomfort (usually due to the fact that following years of endometriosis or several operations the pelvic area has become 'oversensitive').

FAQS

- **What if I suffer spotting or blood loss whilst taking a contraceptive pill?**
  If you take more than one strip of the pill some blood loss or brown discharge may occur. If it persists for several days all you need to do is stop taking the pill for five days. If you start taking the pill again after a five day interruption the blood loss should cease.

- **What if I don't feel very well when taking the contraceptive pill?**
  Unfortunately, there is no pill that suits everybody. Together with the surgeon we will try and find the most appropriate pill for you.
  Your body will have to adapt each time you try another pill. You will, therefore, have to finish at least two strips to assess how you feel with a particular pill.

- **Is there a link between the severity of the pain symptoms and the extent of the endometriosis?**
  Some endometriosis patients don't feel pain. Others suffer severe pain with a moderate level of endometriosis or suffer moderate pain even though the endometriosis is widespread.

- **Can I have a single room?**
  If you prefer to be admitted to a private room, please let us know during the consultation or when you receive your hospital admission letter. Private rooms are allocated subject to the level of occupancy.

- **What are the side effects of monthly hormonal injections?**
  Sometimes women will suffer blood loss after the first injection, which can be severe and painful and can last up to a week. You may also suffer side effects as a result of the artificial menopause induced by the injections. Known side effects include mood swings, headaches, vaginal dryness, night sweats and/or hot flushes. You can take tablets daily to suppress these side effects somewhat.

- **When will I know the date of the operation?**
  The date of the operation will be confirmed when you receive your admission letter by post, approximately three months before the actual date of the operation. This package will also include practical information concerning your admission to hospital and where applicable prescriptions for the medication you need to take in preparation for the operation.

- **Can endometriosis recur following an operation?**
  A recurrence of the endometriosis soon after an operation is usually due to the fact that it was not completely removed during the operation.
  Unfortunately, a recurrence of endometriosis can never be eliminated altogether. The risk of recurrence is reduced by taking a contraceptive pill.

- **Is redo surgery advisable?**
  It does not make sense to continue having operations as postoperative complications are more likely with another operation.
  A radical approach to endometriosis during the first operation is particularly important.

- **Can lifestyle coaching help?**
  Pain can have an impact on day to day functioning and wellbeing, which is why a healthy lifestyle in terms of exercise and diet is advisable. Therapies such as homeopathy, acupuncture, physiotherapy and relaxation exercises can also help you to manage symptoms and to find a balance in terms of your general wellbeing.

PRACTICAL INFORMATION

Leuven university endometriosis centre
Leuven university fertility centre

Endometriosis treatment appointments to be made via the website:
www.uzleuven.be/nl/afspraak-aanvragen-endometriose

Case Manager: Julie Mellaerts
E-mail: **endometriose@uzleuven.be**
Administrative queries: +32 16 34 36 50

Urology
Appointments: +32 16 34 66 85

Colorectal surgeons
Appointments: +32 16 34 48 50

Thoracic surgery
Appointments: +32 16 34 48 50

Interesting websites:
www.uzleuven.be/endometriose
www.uzleuven.be/kostenraming

Endometriosis patient associations

Belgium: EndoHome

EndoHome is a Belgian patient association, which aims to support, consult, inform and represent anyone affected by endometriosis.
Website: www.endohome.be
E-mail: info@endometriose.be

The Netherlands: Endometriose Stichting (Endometriosis Foundation)

endometriose.nl

France: EndoFrance

www.endofrance.org

Scientific websites

endometriosis.org
endometriosisfoundation.org

NOTES

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Please send comments or suggestions relating to this brochure to communicatie@uzleuven.be.

Publisher
UZ Leuven
Herestraat 49
3000 Leuven
tel. 016 33 22 11
www.uzleuven.be