## **Endometriosis**

## **General Introduction**

ROKITANSKY first suspected Endometriosis as an illness in 1861 and it was first described by RECKLINGHAUSEN in 1893. Today this illness is still underestimated, both in its frequency and in the consequences it has on the affected patients. Endometriosis can now be laparoscopically diagnosed with a minimal invasive technique. Endometriosis appeared to be completely treatable with the development of various hormonal preparations. Hormone treatment was the therapy of choice after diagnosis of endometriosis. Looking back on many years of hormonal preparation (in the face of the considerable sideaffects the various preparations have), it does not seem to be the appropriate treatment. Endometriosis remains a frequently occuring and serious illness as it requires differentiated and sometimes complicated operative therapy. Added to this is the patients increased body awareness.

In modern society young women are more career orientated and socially engaged. Due to the pressure exerted by the affected patients the up to now concealed "womens' illness" is becoming more actual and has been pushed more and more into conciousness of society. Endometriosis seems to occur more frequently and in more complicated forms in women, so that it is not only a serious problem for the affected women but for society on the whole. Frequent Doctor's notes and invalidisation due to endometriosis could have relevant socio-economic consequences.

#### 1. Definition

One understands endometriosis as being a functioning endometrium or endometrium similar tissue outside of the normal localisation. The ectopen (=foreign position, in this case, outside the endometrium) mucosa centres partake in the normal cyclical and pathological changes of the endometrium. That means that the mucosa is subject to the hormonal fluctuations of the ovary, or hormonal preparations (pill, GnRH-Analoga) just like the normal mucosa. The hormone therapy of endometriosis is based on this knowledge, but has the same effect on the normal mucosa and fertility (possibility of a woman to become pregnant) is impaired. When such a therapy is discontinued (e.g. to make pregnacy possible for the patient) both the normal mucosa and the endometriosis reform again. Therefore, on one hand the hormone therapy for endometriosis and on the other the patient's desire for children seem to exclude each other.

#### The following forms of endometriosis can be differentiated:

- Endometriosis genitalis interna (also known as Adenomyosis uteri et tubae): the endometriosis
  passes through small wall channels into the myometrium (the uterus muscle) or to the fallopian tubes,
  frequency: 31-47% of cases
- Endometriosis genitalis externa: these are endometriosis herds that have settled into the various organs in the pelvis (ovaries, douglas, uterus bands). Endometriosis of the ovaries occurs in 30% of all endometriosis.
- Endometriosis extragenitalis: endometriosis of the other non-genital organs (intestine, ureters, liver, lungs).

The classification of the endometriosis into the three forms is irrelevant as the endometriosis interna and externa are practically inseparable. The endometriosis extragenitalis is a rarer manifestation, but is also the most dangerous form of endometriosis.

### 2. Epidemiology

It is very difficult to estimate the frequency of endometriosis. In premenopausal patients who undergo a laparotomy for gynaecological reasons, endometriosis occurs in 10% of the cases (*Eskenazi B. Obstet Gynecol Clin N Am 1997, 24: 235-258*). Endometriosis is found in 30-60% of infertile patients. There are no clear numbers known in the general population, as not every endometriosis causes problems. 20 years ago symptomatic endometriosis effected women between the age of 30 and 45, today 70-80% of the patients are younger than 35 years. In scientific literature it is noted that 10% of the patients are under 20 years, although the so called "premenstruation syndrome" (normal abdominal pain just before menstruation) in younger women is also a form of endometriosis. Endometriosis never occurs before puberty and is seldom symptomatic in postmenopausal patients when the women do not take Oestrogen as part of a hormone replacement therapy. The persistence of active endometriosis in a postmenopausal patient without hormone replacement therapy is evidence of an

indigenous Oestrogen production. In these cases an Oestrogen forming ovarian oder suprarenal glandular tumour must be ruled out.

Direct risk factors in the development of endometriosis are not known, but genetic disposition seems to play a role. This is indicated by:

- over 90% of the patients suffering from endometriosis are darkhaired
- an over 7 generations occurence of endometriosis in a family

The ethnographic differences in the frequency of endometriosis can also be attributed to genetic factors: the frequency in India and Africa is significantly lower than in Europe or the USA. Socio-ecologic causes also come into question: different ages when the first period occurs and when menopause occurs, parity (number of pregnancies) duration of the period or amenorrhoe phase (absence of the period) during pregnancy or lactation (breast feeding). The wearing of tight clothes (Dickinson CJ; British journal of Obstetrics and Gynaecology. 1999, 106:1003-1005) the raising of intraabdominal pressure seems to be favourable for endometriosis. This is also valid in the use of tampons (Darrow SL, Epidemiology, 1993, 4:135-142) or intrauterine Pessars (Sangi-Haghpeykar, H. Obstet Gynecol. 1995, 85:983-992).

#### **Pathogenesis**

There are various theories on the development of endometriosis, but there is no clear proof of one or the other etiology (cause in the formation of this illness). The juxtaposition of various factors in a patient is also possible.

#### The implantation Theory – the Sampson's Theory.

This theory is based on the spreading of endometrium cells into the abdominal cavity by retrograde menstruations above the fallopian tubes (*Sampson J. Am J Obstet Gynecol 1927, 14:422-469*). In 76 to 90% of healthy women with inconspicious fallopian tubes endometrium cells are found in the douglas during menstruation. That endometrium cells can implant and grow in far places can be proven in the occurence of endometriosis in the abdominal wall after amniocentesis (amniotic fluid examination during pregnancy) (*Kaunitz A. Obstet Gynecol 1979, 54:753-755*) or in episiotomy scars (= Episiotomy during a vaginal delivery) (*Wittich AC, J Am Osteopath Assoc 1982, 82:22-23*) and in caesarian sections (*Rovito P, Surgery 1986,100:118-120*). While in the case of healthy women without endometriosis these cells are recognised and destroyed by the immune system, in women with endometriosis the deficit in the local immune system is responsible for the implantation of these ectopic cells. It is unclear if this immunological peculiarity is the cause or the effect in women with endometriosis.

#### The Invasion Theory - The Cullen's Theory

This theory is based on a direct invasion of endometrium cells through the uterine musculature. Cullen could prove a direct continuity between the endometriosis herds in the uterus musculature and the endometrium in 98% of patients with Adenomyosis uteri (Cullen TS, Philadelphia, PA: WB Saunders 1908)

#### The Zoelemic Metaplasy Theory

This theory is based on the examination of embryology (teaching of prenatal development of humans) which has proven that the definite structure of the internal organs (the so named "Müllerian Canal", the mesenchymal epithelium of the ovaries and the bowel peritoneum) develop out of the same embryological structures (mesenchymal cells) (Gruenwald P, Am J Obstet Gynecol 1942,44:470-474). The mesenchymal cells are found everywhere in the abdomen and can develop into endometrium cells later on.

#### **The Induction Theory**

This theory postulates that through retrograde menstruation substances enter the abdomen which release a differentiation of the omnipotent mesenchymal cells in endometrium tissue.

### The remaining embryonal tissue Theory

Recklinghausen and Russel first suspected that endometriosis comes from remaining embryonal cells, which change under the influence of (unknown) stimuli.

#### The lymphatic and vascular metastasis Theory

Sampson (Sampson JA, AM J Obstet Gynecol 1925, 10:649-664) reports on the development of endometriosis herds by means of vascular or lymphatic spreading of endometrium cells. This theory can explain the rare pulmonal, neural or muscular endometriosis (Hobbs JE, Am J Obstet Gynecol 1940, 40:832-843).

#### **The Composite Theory**

#### Javert (Javert CT. Cancer 1949,399-410) summarises various ideas in his theory:

- 1. The endometriosis cells infiltrate the myometrium and so can reach the neighbouring organs (bladder and rectum)
- 2. They disseminate during menstruation through the fallopian tubes into the abdomen in order to implant themselves into various organs in the pelvis.
- 3. they reach neighbouring organs (urinary bladder, rectum and ureters) via the lymphatic channel
- 4. Via haemangiatic spreading to further organs (muscle, bones, lungs and kidneys)

## Clinic

#### Ca 15-30% of patients suffering from endometriosis are asymptomatic:

- 64-67% of endometriosis patients with infertility are asymptomatic (Moen MH, Hum Reprod 1995, 10:8-11)
- 93% of postmenopausal endometriosis patients are also without complaints (Kempers RD, surg Gynecol Obstet. 1960,111:348-356)

Endometriosis as the cause of certain symptoms is often later taken into consideration in the differential diagnosis, especially in young patients. (Ballweg ML, Obstet Gynecol Clin North Am. 1997,24:441-453): medicational-hormone therapy is often started on a hunch. This procedure saves the patient perioperative morbidity and the cost of a operative resolution, but delays the histological confirmation of an endometriosis (Carter JE, Female Patient, 1995,20:13-20 – Walker JJ, Gynecol Ostet Invest 1998, 45:6-11)

#### The diagnosis of endometriosis is based on three factors:

1. **Pain**There is no correlate between the spreading of endometriosis and the intensity of the pain: small endometriosis herds in the peritoneum can cause serious pain in the hypogastrium through the secretion of PgF2. On the other hand, some patients with larger findings complain less as they have been suffering from these complaints for years and their sensitivity to pain has changed.

#### 2. Clinical examination

As the endometriosis findings change during the female hormonal cycle, or under hormone treatment, a patient with suspicion of endometriosis should be examined directly before or after menstruation, as at this point the endometriosis herds are most swollen or secrete blood. For this reason endometriosis should optimally be operated on around or during menstruation. An operation should not take place during hormone therapy. Endometriosis shrinks during hormone therapy, so that a part of the endometriosis is not recognisable by the surgeon and cannot be removed. A recurrence is preprogrammed.

#### 3. Medical history

All monthly recurrences of symptoms are suspect for the presence of endometriosis.

#### 1. Pain

#### Dysmenorrhoea

The main symptom of endometriosis is peritoneal pain before and during menstruation. This pain is described differently by the patients: they start as an uncomfortable tension in the peritoneum and develop to strong cramp style pain which forces the patient to bed and to taking analgesics. The "pain" varies within one day, caused by the secretion of PgF2, a substance which affects the smooth musculature of the body. Different concentrations of PgF2 effect the cervix, causing it to open or to contract, so that the blood collects in the uterus and is discharged intermittently. The patients then complain of cramps in the peritoneum, partly spreading to the back and the discharge of large amounts of blood from the uterus. In the time in between the pain and the bleeding lessens until the next crisis.

#### Dyspareunia

In endometriosis genitalis externa the rectovaginal spatium can be effected. This is tough endometriosis that is found between the rectum and the vagina, usually directly below the cervix and normally affects the dorsal uterus bands (see Liga. Sacrouterina). This result can be seen on vaginal inspection. During menstruation these herds bleed exactly like the tissue in the uterus. The blood collects unter the vaginal skin and forms small, visibly blue coloured vaginal cysts below the cervix. This endometriosis can be palpated as a tough more or less large lump during manual examination. When these lumps and the Ligg. Sacrouterina are touched during sexual intercourse they cause the patient dyspareunia (pain during intercourse).

#### **Backpain**

Backpain is not an uncommon symptom of endometriosis. This pain can have various causes. First of all one must think of kidney congestion on one or both sides. The endometriosis in the rectovaginal septum or the sacrouterine ligaments can laterally expand into the retroperitoneal space. This infiltration occurs mainly along the uterine vessels to the Ureter, which can be affected and narrowed. Typically it is a very slow occlusion of the ureter, so that the patients do not suffer the cramps and acute pain as with a kidney stones, but this pain is chronic and is normally classed as "normal endometriosis pain". Over a long period of time this occlusion causes a destruction and the complete loss of a kidney (figure 1)





Figure 1: pronounced left urether occlusion In the x-ray occlusion of the left kidney (x-rax on the left) Intraoperative: narrow stenosis (occlusion) of the ureter (right, OP-picture)

The retroperitoneal form can also infiltrate the pelvis wall or the coccyx which can also cause back pain. In the above mentioned contraction of the uterus with the intermittent expulsion of blood, backpain also occurs which the patients describe as labour contractions or similiar to contractions during a miscarriage.

#### Leg pain

When the endometriosis expands to the side in the direction of the pelvis wall the Plexus sacralis is effected. Then homolateral leg pain occurs. In extreme cases neurological disorders (sensitivity disorders and restriction of movement) of the leg can be determined.

#### Other pain

A lot of pain can be led back to the previously mentioned secretion of PgF2. The endometriosis herds are recognised as foreign bodies (at least in this position) in the abdomen. Monozytic cells and macrophages gather around the endometriosis so that a local inflammation (without abscess formation) occurs. The resulting PgF2 effect the smooth muscle cells of the body. Smooth musculature is found in:

- Brain vessels, so that the patients often suffer from migraines, headaches or mood changes during menstruation
- Bowel muscle so that the patients often complain of stomach pain and of a swollen abdomen.

#### 2. Further symptoms

#### Affect on the bladder

The bladder is rarely affected. The patients rarely complain of elective bladder problems "everything hurts". Sometimes the patients classify endometriosis of the bladder as a reccuring bladder infection. Cyclical haematuren (bleeding from the bladder while urinating during menstruation) occur very rarely. This form of

endometriosis can be confirmed by a bladder speculum. Blue cysts are found at the base of the bladder during menstruation. If the bladder is affected can also be determined by an abdominoscopy where characteristically both Ligg. Rotunda (front uterus bands) are pulled over the cervix to the bladder. This form of endometriosis is extremely seldom and is associated with an Adenomyosis of the uterus.





Fig. 2: Endometriosis of the bladder Left: the blue herds can be seen in the Cystoscopy

Right: these bladder endometriosis are resected by an abdominoscopy

#### Affect on the intestine

The characteristic symptoms of an affected rectum is rectal bleeding during menstruation. These symptoms are very rarely observed, as the majority of endometriosis respects the intestinal tissue (only in 5% of cases is the intestine wall infiltrated). The patients nearly always complain of chronic obstipation. Obstipation is not solely a typical endometriosis symptom as a lot of women without endometriosis suffer from this disorder. There are a few characteristics that differentiate the endometriosis patients from the usual cases of obstipation. The rectum is fixated or narrowed due to the endometriosis so that they complain of obstipation during the whole month. They describe their bowel movement as "small and hard like rabbit stool". Shortly before and at the start of menstruation the intestinal wall swells so much that the patients have no bowel movement. After 2-4 days the intestinal contents liquidefy and the swelling in the intestinal wall reduces. The patients now have softer bowel movement and "it works better than between menstruations". An endometriosis is seldom visible in an abdominoscopy and a "compression of the intestine" is described. This examination is necessary to exclude the possibility of intestinal cancer.

The endometriosis can affect other areas of the intestine but has a preference for the Coecum (connecting point between the large and the small intestine) and the appendix. The pain can then occur under the aspect of an appendix inflammation.



Fig. 3: pronounced effect on the rectum
The intestinal wall is completely infiltrated and the rectum is narrowed

#### Affect on the pelvic nerves.

Spatium rectovaginal is a body region through which both motoric and sensitive nerves run. The nerves which supply the bladder and the rectum rise from the pelvis wall and run through so called uterus bands to their organ destination. When the septum rectovaginal is affected these nerves are also affected. Luckily in the upper area of the vagina – where endometriosis is most frequently localised – the nerves are mostly of a sensitive nature (responsible for sensation, feeling and pain) while the motoric nerves for miction (urination) and defaecation run

lower down. This is the reason why patients feel pain when the vaginal vault is touched. There is an operative technique in which the sensitive nerves are separated in order to hypo or anaesthesize the upper vaginal vault. This operation is a purely symptomatic treatment (less pain) but is not a curative therapy for the endometriosis. If there is further destruction of the nerves due to the endometriosis, the patients suffer from sensation disorders in the bladder and the rectum. These changes are normally not noticed by the patients as it sets in very slowly and do not hinder the patients in their daily lives. It is possible to ask about these changes with specific medical history questioning:

- Does the patient have the feeling that her bladder is full but when she goes to the toilet only a small amount of urine is released.
- or the patient hasn't the feeling that her bladder is full, but when she goes to the toilet "litres" of urine is released.
- The patients doesn't feel the usual "burning sensation" while urinating, despite a confirmed bladder inflammation.
- The same changes can be observed in defaecation

#### When the motoric nerves are affected depletion disorders occur:

- Chronic obstipation
- The patients sometimes have to use the stomach press in order to empty their bladder.
- Incontinens (overflowing bladder) or the inability to properly deplete the bladder.

# **Therapy**

As we still do not know the exact genesis of endometriosis, one cannot offer a causal therapy. The actual treatment of endometriosis is based on three components:

#### 1. Symptomatic therapy

The endometriosis itself is not treated, but the symptoms caused by endometriosis. In the symptomatic medication therapy Analgetica (usual pain medication), low dosed Gestagen or prostaglandinsynthesis-Inhibitors (medication to prevent the production of PgF2, e.g. Aspirin, Indomethazin) are used. The operative symptomatic therapy of the endometriosis is based on the severing of the sensitive nerves of the cervix/vagina with an abdominoscopy (LUNA technique, see above).

#### 2. Endocrine therapy

As the endometriosis cells are just as dependant on the ovarian Oestrogen synthesis as the uterus tissue, this therapy is based on the lowering or the suppression of the hormones produced in the body. As a result atrophic and decidual changes occur both on the uterine endometrium and on the ectopic endometriosis herds. This also means that by completely suppressing the ovarian hormone production amenorrhoe occurs and after many months a regression of the endometriosis. When a hormone therapy is completed, the patients menstrual cycle returns thanks to a regeneration of the endometrium cells. Unfortunately, the endometriosis cells also regenerate themselves. It is for this reason that there is no substance that is capable of curing the endometriosis. Of course one can indefinitely prescribe such hormonal therapy, but under this therapy the patients cannot become pregnant. Aside from this, such radical suppressive hormone therapy should only be prescribed for a few months due to the many side effects.

A hormone therapy that only lowers the the hormone production (but does not reduce it completely) unfortunately has no sure effect and must be practically prescribed for a lifetime. The menopause is no natural border anymore as the majority of postmenopausal women have hormone preparations prescribed so as not to suffer from menopausal complaints. This hormone replacement therapy can actually promote endometriosis.

The hormone therapy of endometriosis of the Septum rectovaginal has brought very little success, the localisation of the endometriosis must normally be operated on. A postoperative hormone therapy can eventually be an adjuvant but not a curative option.

The gestagen emphasized oral contraceptiva:
 Oestrogen-Gestagen-combination with low oestrogen- and high gestagen parts are prescribed for a continual suppression of ovarian function.

- Gestagentherapy
   Gestagen with oestrogen are less effective in respect to ovarian suppression as the combination
   preparations. They are effective in the treatment of pain symtoms with less side effects.
- Danazol
   This medication works both through a central reduction of the hypothalamo- hypophysis FSH- and LH-production and also by a direct reduction of ovarian hormone production. The various side effects involve various organs and are of a general form.
- Gonadotropin-releasing-Hormone-Analoga (GnRH-Analoga)
   These preparations cause a reversible medication detention of ovarian function with a long lasting hypogonadotrope and hypogonadal condition. The ovarian Ostradiol production is also suppressed. This therapy is very effective especially in respect to the reduction in the endometriosis complaints. They should not be prescribed for longer than 6 months because of the many and partly severe side effects. Normally the complaints reoccur after coming off this therapy (virtually always in endometriosis of the septum rectovaginal), and it is not seldom that it is even worse than before as if the endometriosis is avenging itself.

## 3. The ablative therapy

An operation is mostly unavoidable with endometriosis, as it serves as a diagnostic method (the diagnosis "endometriosis" is a histological diagnosis) and a therapeutic measure. The operative therapy involves the complete removal of the endometriosis herds and the replacement of the normal anatomy, as far as this is possible. Endometriosis is not cancer, but can destroy neighbouring structures like a malignant tumor. Therefore the anatomy of these patients is sometimes totally altered which causes difficulty in many surgical proceedures, especially as the majority of the young patients still have a desire to have children. These proceedures must have the radicality of a cancer procedure, but without the morbidity of a tumor operation. The abdominoscopy has won status in this area. On the one hand it is minimally invasive in its surgical approach and on the other hand facilitates a high laparoscopic radiacality. A partial resection of the intestine-/ureter-/ and bladder and the restoration of organ continuity has become laparoscopically possible (Possover M. Obstet Gynecol. 2000,96:304-307 - Possover M. Ambulant operieren. 1999, 2:46-50). Especially due to the optical magnification during endoscopic surgery much less blood is lost than with a laparotomy (this is of importance in regard to the development of postoperative adhesions). Deep in the pelvis the millimeter sized nerves responsible for the bladder- and intestinal function as well as sexuality can be identified more successfully with an abdomoninoscopy than with a laparotomy (where the majority of these nerves are not recognisable) (Possover M. Oncology, 2000,79: 154-157). These factors have a significant effect on the postoperative morbidity.

The normal "total operation" of endometriosis should only be seen as the ultima ratio as it is not effective on extrauterine und extraovarian endometriosis. There is no organ preserving operative proceedure that can be successful in the case of an Adnenomyosis uteri as the endometriosis herds cannot be exstirpated out of the uterus wall. The therapy choice is either a hormone therapy and, when family planning is finished, the removal of the uterus.

Unfortunately surgery cannot promise a 100% cure as the surgeon can only remove the endometriosis herds that he is can see (therefore it is important to operate during menstruation and not to prescribe preoperative hormone therapy. When the uterus and the fallopian tubes are preserved the endometriosis can expand every month through the uterus/the cervix and the fallopian tubes into the abdomen.

Even when the decision to undergo surgery is not made lightly by the affected patient or the doctor, the endometriosis of the septum rectovaginal with rectum, bladder or ureter affection should always be operated on so that time is not lost trying out various medications.

#### Too long a delay could

- lead to kidney destruction from chronic ureter occlusion.
- low lying endometriosis of the septum rectovaginal with an affected rectum can only be totally removed with a permanent Anus praeter.

This list of therapy possibilities should not be seen as a therapy recommendation. Every patient should be seen as an individual —"endometriosis patient" and be treated in the same way.

## **Endometriosis and the desire for children**

The possible sterility factors in endometriosis are varied and increase the problems of the patients. If it was easy for a patient to become pregnant as the often cited leitmotif "just get pregnant and then everything will get better"

it would be easier to bare. Unfortunately endometriosis has various barriers which are an obstacle to bearing children:

- The dyspareunia clearly impairs the sexual life of the couple. The woman feels pain at the vaginal vault
  which makes an orgasm impossible for her. Sexual intercourse becomes a nuisance and she finds any
  excuse to avoid it. The partner notices this tension in his wife which can cause him difficulties with an
  orgasm or ejaculation. The couple can drift apart, a not very stable marriage could be endangered.
- A mechanical barrier:
   The endometriosis can effect and occlude the fallopian tubes (adenomyosis tubae). The endometriosis can indirectly effect the ovaries and cause adhesions around the fallopian tubes, these can effect the function of the tubes and can lead to their occlusion.
- An endocrinological barrier:
  The secretion of PgF2 generally influences the smooth muscular system. The muscular system of the spermatozoides is impaired by the PgF2 in the vagina or the uterus, which leads to a motility disorder of the spermatozoides. Under the same influence the cervix closes. The motility of the fallopian tubes is inverted, which means that there are small "cilien" which transport the fertilized egg to the uterus; under the affect of PgF2 these cilien change their motility in the other direction. Ovulation occurs in the middle of the cycle. The rupture of the follicle in the ovary occurs through a contraction of the ovary tissue. PgF2 prevents this contraction so that the "endometriosis patients" have less ovulations than "normal" women. This leads to a collection of mature eggs in the ovaries. In an ultrasound the ovaries seem to be polycystic (= many cysts with fluid content) the so called LUF-Syndrome.
- An immunological barrier

It is very difficult, if not impossible to tell a couple if pregnancy is possible or not. What is definite is that the chances of pregnancy in the months following surgery with complete macroscopic removal of the endometriosis (especially endomtriosis of the septum rectovaginal) is at its highest. No hormone therapy has proven reliable in increasing the fertility of the patients. On the contrary, "no therapy" often has better results than any hormone therapy (in relation to the desire for children). Unfortunately there are still patients who have had their endometriosis completely removed or only have a few endometriosis herds who despite everything do not become pregnant. After an appropriate waiting period one should not hesitate to give nature a bit of a hand:

- First step: Insemination (= injection of the sperm directly into the uterus of the patient) with or without induction (= ovulation assistance) or stimulation (=oogensis assistance)
- Second step: Artificial insemination. This way is definitely not the easiest way, but the chances of a woman over 40 with endometriosis to become pregnant is best with this technique.

# The loneliness of the "Endometriosis patient"

We have tried to show that the "endometriosis patient's" life is interfered with in many ways. A lot of these patients have not known a normal life since their first menstruation. It all started with normal abdominal pain during menstruation. These young women could do very little for a few days a month, they normally lay in bed with a hot water bottle on their stomach. They had to cancel school and sports lessons or other appointments. "She has her female problems again!". On the family side "get on with it, my mother, my grandmother and I all had this pain and we didn't go to the doctor more often with it ...... we didn't have the time to feel sorry for ourselves". The young women couldn't hide their pain from their surroundings and probably were ashamed of themselves. They developed their own personality, probably started to hate their body. "Why wasn't I born a man, they have it much easier". It is therefore not unusual that endomtriosis patients develop or wish to develop a form of masculinity and often have difficulties in mother-daughter relationships. The young women are confronted with hormones for the first time. In most cases the endometriosis is restricted to the uterus and the peritoneum and various hormonal preparations can help.

In patients with endometriosis of the septum rectovaginal the following course often occurs: The first hormonal prepartion can make the complaints tolerable for a certain length of time. After that, all possible hormone therapies are tried, usually without any success. The GnRH-Analoga bring relief for 6 months although the side affects of these preparations are very uncomfortable. After 6 months the intake of these prepartions must be stopped due to their side affects and the pain and complaints begin again. Sometimes it seems like the endometriosis is avenging itself and causes more pain than before. The doctors despair, they do not know what else they should do with the patient. "You are too young for a total operation, but how else can I help". After the failed hormone treatment the operative treatment begins. Surgery on endometriosis patients is a challenge:

- For the surgeon: He must operate radically in a patient with a "non-malignant illness" with an eventual
  desire for children. In a cancer patient one must accept the possibility of an anus praeter or a bladder
  disorder, but in tumour surgery it is a life or death situation. It is different with endometriosis patients.
  Maybe the morbidity is worse than the endometriosis itself?. The surgeon is confronted with the situation
  "young woman/desire for children/endometriosis/radicality". When the patient herself has not realised her
  situation, the hands of the surgeon are tied.
- For the patient: She should undergo surgery, which in a case when the rectum is affected they could be afflicted with an anus praeter, independent of the experience of the surgeon. When the endometriosis is located very low down in the septum rectovaginal dysfunction of the bladder or the necessity for self catheterisation of the bladder could result. The patient should take this morbidity into account for an illness that really "only is painful".

In the meantime the patient has married and wishes to have children. Unfortunately this is impossible during hormone therapy. A further problem develops in the marriage. Her husband loves her, but he has a wife that is sick for one week a month and is not capable of doing things. This can lead to incredible tension in the marriage. Added to this are headaches, bad temperedness of the endometriosis patient during menstruation (see chapter "further pain"). The patient has acute pain once a month before she had an appointment again at the doctors. She becomes more and more isolated. She has to listen to "get pregnant first and then everything will be all right". "Sorry it doesn't work" or " do I have to give up my training/position to try to become pregnant as the therapy choice against endometriosis?

A counter-reaction could occur. The patient does not feel understood and doesn't want to trouble her husband with it anymore. She starts to ignore her complaints despite the pain. She claims that "she is fine and doesn't feel any more, or much less pain". The situation does not improve because of this and eventually the patient decides to undergo a total operation and gives up her wish for children. This step is not a successful therapy in the case of endometriosis of the septum rectovaginal. The pain remains and in the end the patient ends up in the "psychosomatic" stream.

When the patient has had successful surgery she has to learn to live without Endometriosis. Endometriosis – her "enemy"- has developed into her "friend": "I can't go to the meeting, you know why, my endometriosis, I am in pain.....". The patient has gotten used to using her Endometriosis as an excuse in certain situations. She must learn to live without this ungrateful friend .....

At this point I would like to thank my wife Silke. You found me, gave me your love, promised me everlasting faithfulness and led me on the road in the fight against endometriosis. Without you these words would never have been written.....

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