understanding endometriosis

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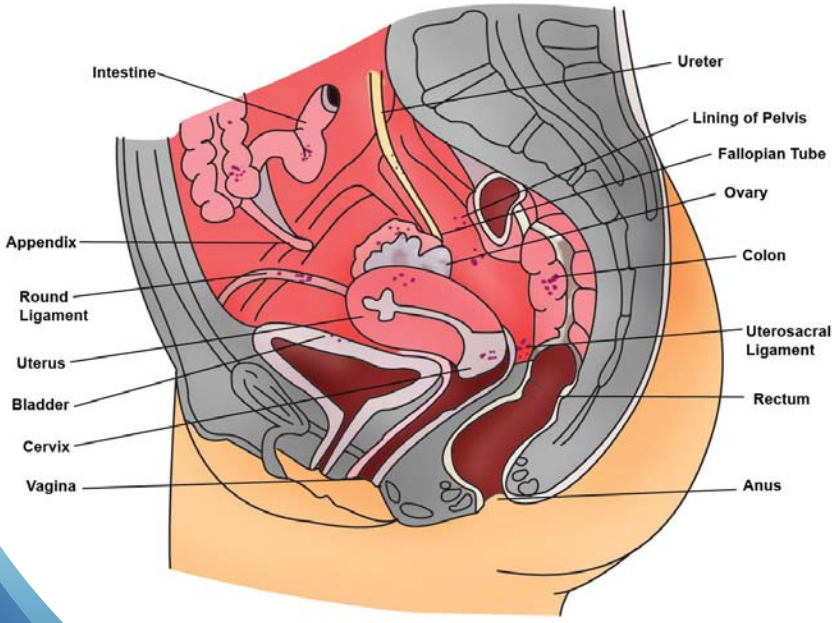
in this booklet

What is endometriosis?

The inside of the uterus is lined with tissue called the endometrium. The endometrium thickens in response to hormones produced during the monthly menstrual cycle. As hormone levels fall, the lining is shed and passed as the menstrual period.



What is endometriosis?

Endometriosis is a disease in which endometrial tissue is found outside the uterine cavity.[1] The common sites for these abnormal deposits are the peritoneal (outer) surfaces of the reproductive organs (uterus, fallopian tube and ovaries) and the rest of the pelvic cavity.[2] In severe cases these may be found over the bowel or bladder.[2]

The endometriotic deposits respond to hormones and undergo cyclical changes similar to the endometrium.[3] As a result of cyclical bleeding from these ectopic (misplaced) endometriotic implants, a local inflammatory reaction occurs.[4]

This eventually leads to scarring, with adjacent organs becoming adherent (attached). In some patients large collections of blood may accumulate, especially in the ovary.[4]

- Endometriosis is seen frequently amongst women investigated for infertility (20 - 40%).[3,5]
- About 33 - 82% of patients with chronic pelvic pain and 25% of women undergoing hysterectomy will have endometriosis.[3]
- It is found in women from all ethnic and social groups.

What causes endometriosis?

Endometriosis is a modern epidemic and appears to be growing rapidly. The disease seems to be occurring earlier in life and more severe cases are often seen. The condition is common in women of child bearing age, but the exact prevalence is unknown.[6]

The exact cause of endometriosis is unknown. One theory is that of retrograde menstruation. The theory of retrograde menstruation proposes that endometrial cells flow backward via the fallopian tubes into the peritoneal cavity during menstruation. The peritoneal cavity is a fluid filled potential space that surrounds the abdominal and pelvic organs. Although retrograde menstruation is a common phenomenon, not all women who have this will develop endometriosis.[6]

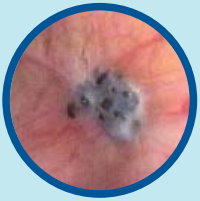
An alternative explanation is that the normal cells in the peritoneal or abdominal cavity undergo change and differentiate into endometrial cells (this is known as metaplasia). These mechanisms may work together and may be assisted by abnormalities in the immune system or the influence of toxins.[6]

Who gets Endometriosis?

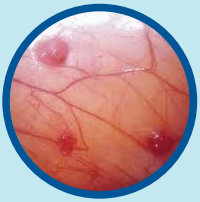
- It is found in women from all ethnic and social groups.
- Endometriosis tends to run in families. With a positive family history the disease occurs earlier in life and is likely to be more severe.[6]
- Endometriosis is seen more frequently in women with short menstrual cycles (less than 27 days), and prolonged menses (bleeding for more than 7 days at a time).[3]

What does endometriosis look like?

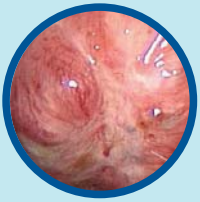
Endometriotic implants may vary in appearance from typical blue / black spots to reddish patches or clear vesicles. With time, scarring may occur and isolated white patches may be seen.[1,7]



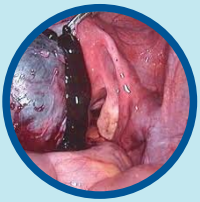
CLASSIC BLUE-GRAY SPOTS



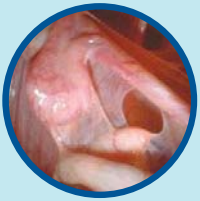
HAEMORRHAGIC VESICLES



FLAT OR RAISED WHITE TISSUE



CHOCOLATE CYSTS



ADHESIONS

DEEP
ENDOMETRIOSIS

What does endometriosis look like?

If scarring involves adjacent organs, web like adhesions may bind these organs together and hence, the tubes / ovaries / uterus and intestines may become attached to one another.[1]

With repeated bleeding into a confined space, blood may accumulate and form cysts especially in the ovary. With time the blood darkens in colour, hence the description 'chocolate cyst'.[4]

Endometriosis may invade tissue and form deep nodules of glands and inflammatory tissue. Endometriosis may grow into the wall of the intestine, bladder and vagina.[1]

Note: Although endometriosis may invade tissue and sometimes spread to distant organs like the navel and lung, it is not a cancer.

Common symptoms of endometriosis

The severity of the disease does not always correlate to the severity of the symptoms.[1] Although more than 20% of women have no symptoms, symptomatic endometriosis can be a chronic and debilitating disease.

1. **Pain is the most common symptom.** It occurs mainly in the lower abdomen and back but may radiate to the groin and legs. It usually occurs just before and during the menstrual period. Deep pelvic pain may occur **during** intercourse (dyspareunia) and in some cases the discomfort may last several hours after sexual activity.[5,7]

2. **Heavy and prolonged periods**. Some patients experience pre-menstrual spotting for several days. Periods may last longer than 7 days.[5,7]

3. **Infertility.** This may be the only symptom in some patients

4. **Pain and bleeding when passing urine and/or stools.** This may be due to endometriotic nodules in the bladder or bowel. These symptoms usually occur at the time of the menses.

Menopause and Pregnancy

Menopause

Because endometriotic implants grow in response to oestrogen, the symptoms tend to improve following menopause (and the decrease in oestrogen production).

Pregnancy

Pregnancy tends to improve endometriosis and many women find their symptoms improve for a long time after pregnancy.[8]

However, pregnancy does not cure endometriosis.[8]

Diagnosis

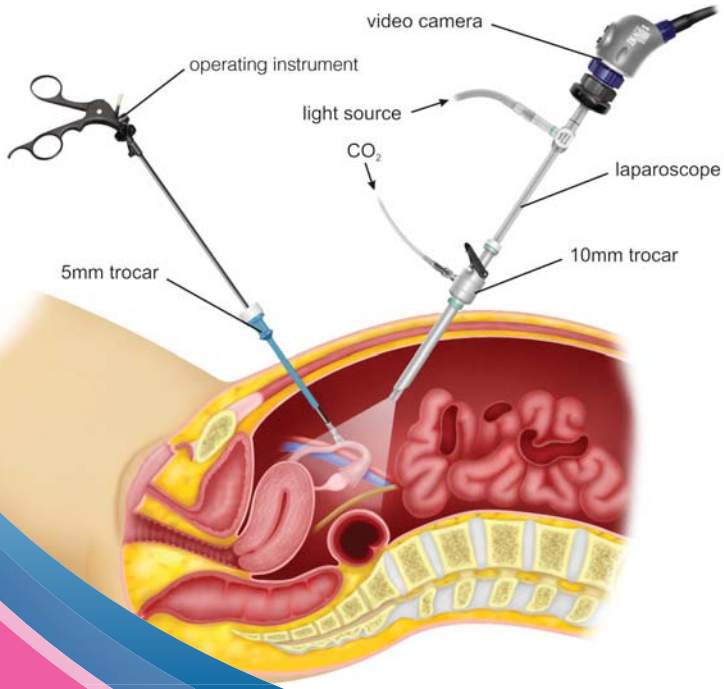
- Endometriosis is often suspected purely based on the symptoms the patient experiences.
- A pelvic examination by a gynaecologist may reveal tenderness, tender nodules and decreased mobility of the pelvic organs.[7]
- Ultrasound examination especially a trans-vaginal ultrasound will only be useful in the presence of chocolate cyst. [7,10]
- Specialised tests like MRI/Ba enema/CT scans are required in special circumstances only (to assess the depth of invasion of deep nodular disease especially with bowel involvement).[10]

A recent survey of patients experience revealed that some women might have symptoms for many years before a diagnosis is made.[7,9] This is due to the fact that endometriosis can only be conclusively diagnosed by direct visualisation of the peritoneum and pelvic organs.[7] This is achieved by laparoscopic examination 'and biopsy' performed under general anaesthesia in theatre.[7]

Laparoscopy

A laparoscope is a thin telescope that is inserted into the abdomen through a tiny incision (cut). A light and camera is attached to the telescope and the image of the inside of the abdomen is viewed on a video screen. The abdomen is inflated with a harmless gas (CO_2) in order to separate the abdominal wall from the internal organs to allow better visualisation.

Operating instruments may also be inserted through other small incisions in order to operate and remove the endometriosis. All tissue removed is examined in the laboratory to confirm the diagnosis. After surgery the gas is removed and the incisions closed. The patient is usually discharged on the same day of the surgery and the average recovery period is about a week.[11]



Staging

The severity of the disease does not always correlate with the severity of the symptoms. There is also no ideal staging system.[7]

The most common staging system used is the revised American Fertility Society system. It rates the disease as stage I to IV (minimal / mild /moderate / severe).[7]

It however does not take into account deep nodular disease which usually accounts for the most painful symptoms.

The staging depends on the size and number of deposits, the size and number of cysts and the extent of pelvic adhesions.

Treatment Options

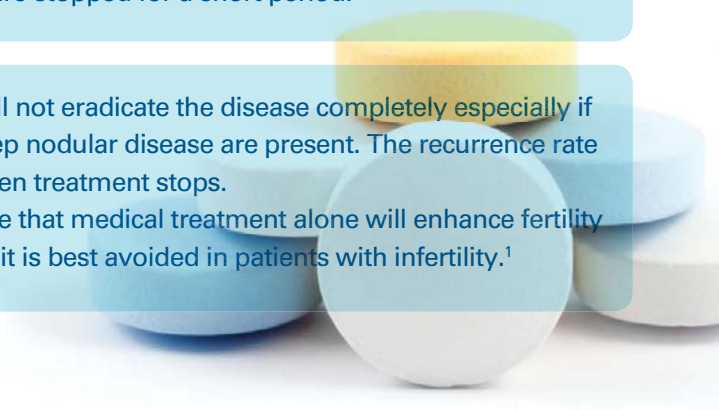
The aim of treatment is to relieve symptoms, improve quality of life, improve fertility where desired, limit disease progression, and delay recurrence.[1] Few of the treatment options are entirely satisfactory and therefore patients must be involved in this discussion and decision-making.[1] Choice of treatment will depend on the patient's age, severity of the disease, symptoms, previous treatment and fertility plans.

Pain killers may control symptoms effectively in some patients especially if combined with exercise and psychological support.[12] Ovarian suppression by hormone therapy limits the growth and bleeding from the normal endometrium and endometrial implants.

Ovarian suppression by hormone treatment limits the growth and bleeding from the normal endometrium and the endometriotic implants.

The combined oral contraceptive may be used in patients with mild disease and who do not desire immediate fertility.[13] This form of treatment is especially effective if active tablets are taken for a prolonged period so that menses occurs infrequently.[13] By using the pill in this fashion endometriotic deposits do not bleed each month.[13] Menses/ withdrawal bleeds occur only when the active tablets are stopped for a short period.[13]

Medical treatment will not eradicate the disease completely especially if endometrial cysts or deep nodular disease are present. The recurrence rate of symptoms is high when treatment stops.
There is also no evidence that medical treatment alone will enhance fertility prospects and therefore it is best avoided in patients with infertility.[1]



Hormone Therapy

Progesterone treatment may be given as tablets or injection.[14] They are effective in relieving painful symptoms but the side effects, especially with use of the tablets, may be troublesome e.g weight gain, abnormal bleeding and acne.[14]

The use of an intrauterine device impregnated with progesterone has led to good relief of pain in some patients.[14]

Most patients on continuous progesterone injections eventually stop having menses.[14]

Gonadotropin releasing hormone (GnRH) analogue treatment in the form of a subcutaneous depo injection (monthly or 3 monthly) or a nasal spray (daily) induces atrophy (shrinkage) of ectopic endometrial tissue by stopping the production of oestrogen from the ovary.[15] This, in effect, causes a temporary menopausal state.[15]

A GnRH analogue is very effective in relieving pain associated with endometriosis, but long term use is limited by the risk of osteoporosis.[15] It is generally not advised for more than 6 months.[15] Temporary side effects include hot flushes, headaches and vaginal dryness all of which are easily treatable.[15]

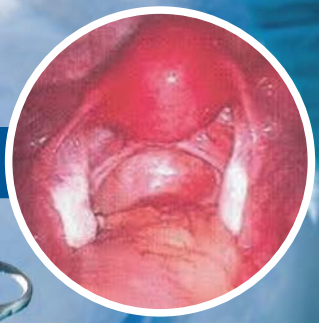
In selected patients, GnRH analogues may be used for longer than 6 months if oestrogen and progesterone treatment is added to prevent osteoporosis.

Danazol & Gestrinone are testosterone (male hormone) derivatives and the side effect profiles have limited their use.[16]

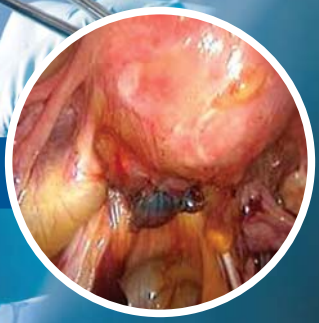
Surgery

Surgery is the most common treatment for endometriosis.

Laparoscopic surgery enables both diagnosis and treatment procedures to be performed at the same time.[7] The goal of the surgery is to remove and destroy (with cautery or laser) any visible deposits of endometrial tissue and cysts and to restore normal anatomy, which may have been distorted by scarring.[11] The success of surgery in treating endometriosis is believed to be higher than medical treatment, but a combined approach may be beneficial to some patients.



Laparoscopic view of the normal pelvis

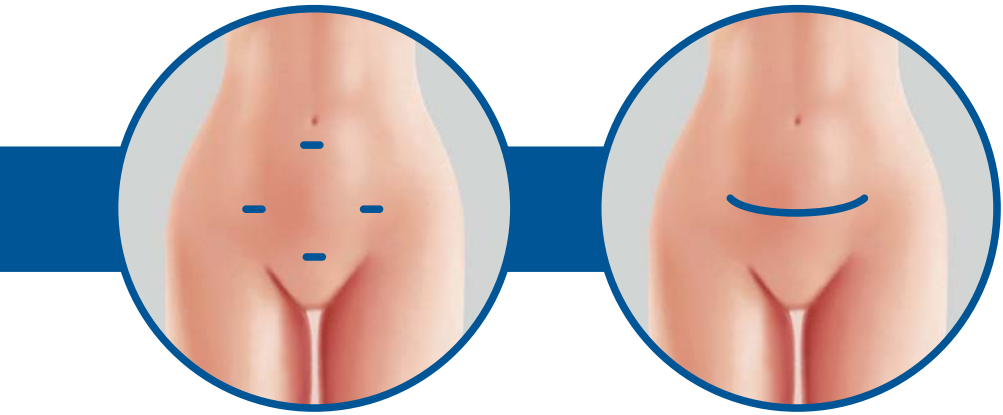


Laparoscopic view of a pelvis with endometriosis

Surgery

Hysterectomy with or without bilateral oophorectomy (removal of uterus and both ovaries) is sometimes indicated for severe pain in women who have completed their families.[11] **A hysterectomy alone will not cure endometriosis - all deposits of endometriosis need to be removed at the same time.**[11]

A laparotomy (open surgery with a larger incision in the abdomen) is sometimes necessary especially if bowel surgery is required.[11] Recovery after laparotomy may take 4-6 weeks.[11] Surgery is best performed laparoscopically as the magnification and access to the pelvis afforded by the laparoscope allows for more precise surgical excision of these lesions and hence better results.



Laparoscopy incision sites

Infertility

Although the relationship between severe endometriosis and fertility can sometimes be explained on the basis of adhesion formation or scarring and damage to tubes and / or ovaries, the relationship between mild endometriosis and infertility is less clear.[1,17]

If a pregnancy is not achieved during a reasonable waiting period following laparoscopic surgery, assisted reproduction is indicated. Intrauterine insemination (IUI) with ovulation induction may be effective in mild endometriosis.[7] IVF is indicated if the fallopian tubes has been compromised.[7]

Pain Relief

Pain relief can be achieved in a number of ways and complementary medical treatments may be worth investigating.

- Stress reduction by relaxation technique, yoga, reflexology and massage bring relief to some patients.[7,18]
- Homeopathy, traditional Chinese medicine, acupuncture and aromatherapy may help.[1,7]
- Good nutrition is important, antioxidants, omega 3 & 6 fatty acids and vitamin supplements may improve the immune system.[7,18]
- The psychological support from group discussion is immense.[1]
- The use of antidepressants may contribute greatly to the overall success of a treatment program.[3]
- Physical exercise provides a feeling of well being and enhances immunity.[18]

Coping With Endometriosis

Endometriosis is an enigma - we do not know the cause of the disease, we do not know why some patients have extreme symptoms and others not.[19] Irrespective of the severity of the disease, we do not know why some patients have residual symptoms despite the best efforts of the expert endometriosis surgeons and appropriate medical treatment.

Endometriosis is incurable.[19] Many women would have undergone repeated surgeries and long term medical treatment and still have residual pain symptoms.[19] The chronic pain, the side effects of medication, the financial impact of treatment and loss of work days and the damage to interpersonal relationships all contribute to a diminished quality of life.[20]

Recent research has noted that patients with endometriosis have a high incidence of other medical conditions e.g. autoimmune diseases, allergies, chronic fatigue, chronic thrush, interstitial cystitis, irritable bowel syndrome and certain malignancies.[3,10]
Many patients will have to accept that they may have some degree of chronic pain and or infertility.
The first step in coping with this disease is to fully understand the disease and to set realistic expectations.
Membership of support groups, where available, is extremely useful in this regard, due to the psychological support they provide.

There is a vast body of knowledge on the internet and some useful sites to visit are: www.endometriosis.org & www.endometriosiszone.org
South African support group: http://www.endpain.co.za

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