What is Endometriosis?

Endometriosis is a condition where tissue similar to the inner lining of the womb (known as the endometrium) is found elsewhere, usually in the pelvis around the womb, ovaries and fallopian tubes. It is a very common condition, affecting around 1 in 10 women.

Endometriosis usually affects women during their reproductive years. It can be a long-term condition that can have a significant impact on your general physical health, emotional wellbeing and daily routine. However, for many ladies the condition can be managed with hormonal and/or conservative measures and women can function normally.

What are the common symptoms?

- Chronic pelvic pain (defined as a minimum of 6 months of cyclical or continuous pain).
- Period-related pain (dysmenorrhoea) affecting daily activities and quality of life
- Back pain.

(Endometriosis can cause pain that occurs in a regular pattern, becoming worse before and during your period. Some women experience pain all the time but for others it may come and go. The pain may get better during pregnancy and sometimes it may disappear without any treatment.)

- Heavy periods.
- Irregular periods.
- Deep pain during or after intercourse
- Cyclical pain and/or bleeding on opening bowels or passing urine.
- Pain on opening bowels; incomplete motion or pain after motion.
- Pain in the top or back of your legs.
- Infertility linked with one of the above symptoms.
- Fatigue

It is often useful to keep a symptom diary. This can help with future appointments to see if there is any pattern to the pain. An example of a symptom diary or symptom tracker can be found at

www.endometriosis.co.uk and https://endometriosis.cymru/diagnosis/symptom-tracker/

What causes Endometriosis?

It is possible that during menstruation, some endometrial tissue shed from the uterus wall fails to pass out of the body and passes backwards along the fallopian tubes towards the ovaries. It can then reach the abdominal cavity and implant. Genetics can play a part, the condition tends to run in families, and affects people of certain ethnic groups more than others. There are also some theories that endometriosis is linked to your body's immune system and that endometriosis cells spread through the bloodstream.

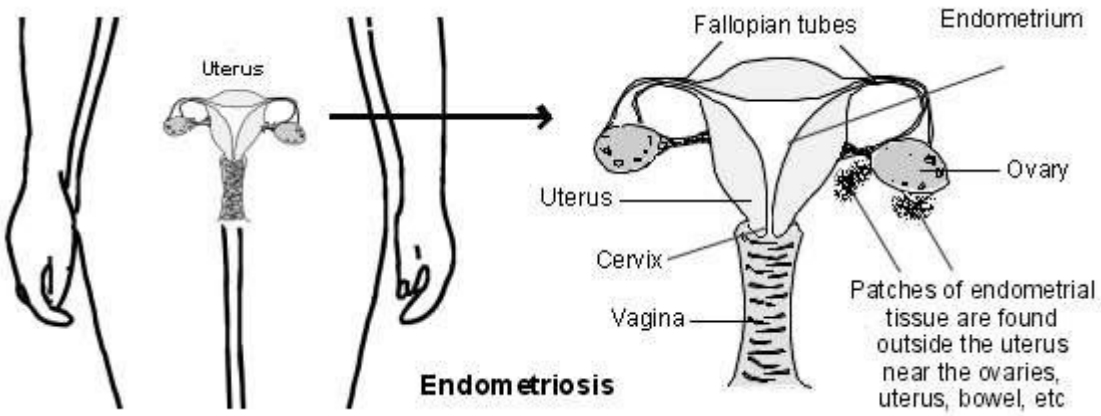
None of these theories fully explain why endometriosis happens. It's likely the condition is caused by a combination of different factors.

The exact cause of endometriosis is not known but we do know it is hormone dependent. Just like the endometrium (the lining of the womb) responds to hormonal changes causing a period each month, the endometrial-like tissue located outside the womb also bleeds. This bleeding can collect causing pain, inflammation and scarring.

With time scar tissue can form filmy fibrous bands called 'adhesions' and can distort internal organs, interfering with their normal function. Less commonly, endometrial tissue and adhesions attach to the bowel or bladder causing abdominal swelling, pain during bowel movements, bleeding from the rectum (back passage) during menstruation, bowel obstruction or pain when passing urine.

Occasionally blood collections form in cysts and these can leak, rupture (haemorrhage) or twist (torsion) causing sudden severe abdominal pain, sometimes requiring emergency surgery.

Where Endometriosis is commonly found



Endometriosis tissue can be found anywhere in the pelvis,

- Most commonly it is found on the ligaments that support the uterus (the uterosacral ligaments)
- Endometriosis may be found on the ovaries, where it can form cysts (often referred to as endometriomas or 'chocolate cysts')
- In the peritoneum (the lining of the pelvis and abdomen)
- In or on the fallopian tubes
- On, behind or around the womb
- In the area between the vagina and the rectum.
- Bowel
- Bladder
- Diaphragm
- Old surgery scars
- Endometriosis can be found in other parts of the body such as the lung and breasts but this is very rare.
- Endometriosis can also occur within the muscle wall of the womb (this is known as Adenomyosis)

There are varying degrees of endometriosis. Some women may only have few spots of endometriosis (mild endometriosis) while in others the disease may be widespread throughout the pelvis. In very severe cases the pelvic organs such as womb, bowels and ovaries can become fixed and attached to each other and made immobile by the scar tissue. This we believe can lead to severe pain. However, severity of symptoms does not mean severe disease. So you may have severe pelvic pain, but either no endometriosis or mild disease, where as some women have severe endometriosis with very little symptoms.

How is Endometriosis diagnosed?

There are no blood tests used in the clinic to diagnose endometriosis.

Endometriosis can be a difficult condition to diagnose. A detailed history will enable diagnosis and assessment. The symptoms of endometriosis vary so much. The symptoms are common for many women and can be similar to pain caused by other conditions such as irritable bowel syndrome (IBS) or pelvic inflammatory disease (PID). Different women have different symptoms and some women have no symptoms at all.

It is often useful for women to keep a symptom diary. This can help with future appointments to see if there is any pattern to the pain or a link between pain, bleeding and other factors, i.e. diet/sexual history etc.

A new resource provided by the Welsh Government WG provides a symptom tracker

https://endometriosis.cymru/diagnosis/symptom-tracker

What tests might I be offered?

A vaginal examination will allow the healthcare professional to check that the cervix appears normal. They may offer you vaginal swabs to be taken to rule out any chances of a sexually transmitted infection if you think you may be at risk. An internal vaginal examination using the healthcare professionals' finger will often be performed (with consent) to rule out that there are no large cysts or endometrial nodules that can be felt.

Tests usually include a pelvic ultrasound scan. This may be a transvaginal (meaning a small sterile probe is inserted into the vagina) to check the uterus and ovaries. It may show whether there are any cysts and to check that the uterus appears normal. Ultrasound scans and MRI scans can suggest a diagnosis of particular types of endometriosis, such as endometriomas or chocolate cysts in the ovaries or severe endometriosis involving bowels, but may not always diagnose the common form of mild endometriosis.

You may be offered a laparoscopy, this is the only way to get a definite diagnosis of endometriosis although in the younger women this may result in a false negative result. If this is an option you would consider then a separate leaflet will be given regarding the operation.

Treatment for Endometriosis.

There is unfortunately no known cure for endometriosis.

The main aims of treatment are to improve symptoms such as pain and heavy periods and to improve fertility if this is affected. Choice of treatment of the condition with medicines and/ or surgery will depend on age, symptoms and pregnancy plans as well as the extent of the disease. All these factors will be discussed with you.

Self-care action plan

Some women with endometriosis have no symptoms and need no treatment.
When the principal symptom is mild lower abdominal pain, stress may make the pain worse. Therefore, some form of relaxation therapy, such as yoga may be helpful to release and stretch adhesions.

Using heat pads may be beneficial please be aware of burns from the use of hot water bottles.

Transcutaneous electrical nerve stimulation (TENS) Machines. (See leaflet on website)

Although there is only limited evidence for their effectiveness, some women may find the following therapies help to reduce pain and improve their quality of life:

Pelvic Physiotherapy
Reflexology
Vitamin supplements
Acupuncture
Homeopathy.
Exercise/reducing BMI.
Nutrition and omitting certain foods such as dairy or wheat products from the diet
Psychological therapies and counselling. such as Mindfulness and cognitive behavioural therapy

Pain-relieving medication

Please speak to your G.P or Pharmacist before commencing medications you are unsure of.

If your symptoms are mild, over the counter painkillers alone may be fine.

Over the counter paracetamol and ibuprofen help many women when they are on their period and at times when their pain flares up.

You can speak to your pharmacist about over the counter co-codamol which can be used to treat more severe pain. Caution is advised as they can become addictive and may result in constipation.

Stronger opiate and nerve blocking medication can be prescribed from your G.P but close monitoring of side effects is required. It is important that if your pain is not controlled that you seek medical advice.

In more severe situations, you may be referred to a specialist pain management team.

Hormone treatments

Hormone treatments usually work well to ease pain but do not enable fertility. Surgery may be needed if infertility is caused by endometriosis.

Overall, the hormone treatment options all have about the same success rate at easing pain. However, some women find one treatment better than others. Also, the treatments have different possible side-effects. You may try one and it may be fine. However, it is not unusual to switch from one treatment to another if the first does not suit.

Medical treatment is simulating the hormonal background of either pregnancy or menopause, because symptoms associated with endometriosis, settle during those times.

These treatments will reduce the amount of bleeding you have and the times you ovulate. This in turn decreases hormone stimulation and shrinks the endometriosis hopefully in turn reducing the pain and symptoms associated with it.

Some hormone treatments that may be offered are also contraceptives and will stop you becoming pregnant.

They include

- the combined oral contraceptive (COC) pill or patch given continuously without the normal pill-free break; this usually stops ovulation and temporarily either stops your periods or makes your periods lighter and less painful
- an intrauterine system (IUS/Mirena®), which helps to reduce the pain and makes periods lighter; some women using an IUS get no periods at all
- progestogens in the form of injection, the mini pill (POP) or the contraceptive implant.

Other hormonal treatments are available but these are not contraceptives. Therefore, if you do not want to become pregnant, you will need to use a contraceptive as well. Non-contraceptive hormone treatments include:

- progestogens in the form of tablets
- GnRH (gonadotrophin-releasing hormone agonists), which are given most commonly as injections. They are very effective but can cause menopausal symptoms such as hot flushes and are also known to reduce bone density. To help reduce these side-effects and bone loss, you may be offered 'add-back' therapy in the form of hormone replacement therapy (HRT).

As discussed above laparoscopic surgery may also be recommended to treat endometriosis as well as diagnose.

Fertility treatment

The relationship between endometriosis and fertility is not yet fully established or understood. There are many women with endometriosis who become pregnant without difficulty but endometriosis is found in 1 in 4 women who are undergoing investigations such as a laparoscopy for subfertility.

The longer you have endometriosis, the greater the chance of reduced fertility. You may need to take this into account if you have plans for having children. If your family is complete, your treatment options will be wider.

Getting pregnant can be a problem for some women with endometriosis. Hormonal treatment is not advisable when you are trying to conceive, and surgical treatment may be more appropriate. You will be provided with information about your options and arrange timely referral to a fertility specialist if appropriate.

Future Life with Endometriosis

Endometriosis is **not** a cancerous condition.
Endometriosis spontaneously subsides after the menopause as the ovaries become less active. Before the menopause, symptoms may improve considerably or even disappear after drug treatment or surgical removal of the misplaced endometrial tissue. The available limited evidence from research studies suggest that untreated endometriosis may get better in 3 out of 10 women. Many women experience mild symptoms and this remains unchanged throughout their reproductive years.

At present there is no curative treatment for endometriosis but we cannot predict if your endometriosis is likely to worsen if left untreated. Even with treatment, endometriosis can recur, but some women with severe untreated endometriosis may be at risk of complications such as obstruction or blockage of the ureter (the tube between the kidney and bladder). These issues need to be considered when choosing the treatment options.
Endometriosis can be a difficult condition to deal with, both physically and emotionally.

As well as support from the CAV UHB Endo team you may find it helpful to contact a support group, such as https://www.endometriosis-uk.org and https://www.ftww.org.uk for information and advice.

In addition to detailed information about endometriosis, Endometriosis UK has a directory of local support groups, a helpline on 0808 808 2227, and an online community for women affected by the condition.

https://endometriosis.cymru is a recently launched information resource for women and their support network through the Welsh Government. Each Health Board in Wales has now employed an Endometriosis Clinical Nurse Specialist to provide support and information to anyone affected by this condition.

Other sources of information

National Institute for Health and Care Excellence (NICE) – Patient decision aid: Hormone treatments for endometriosis symptoms. What are my options:
Https://www.nice.org.uk/guidance/ng73/resources/patient-decision-aidhormone-treatment-for-endometriosis-symptoms-what-are-my-options-pdf4595573197

NHS conditions: Endometriosis:

www.nhs.uk/conditions/Endometriosis/Pages/Introduction.asp

ESHRE: Information for women with endometriosis:

https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosisguideline/Patient-version.asp

British Society for Gynaecological Endoscopy:

http://bsge.org.uk/

RCOG Laparoscopy leaflet:

www.rcog.org.uk/en/patients/patient-leaflets/laparoscopy