Mersey and West Lancashire Teaching Hospitals NHS Trust

Endometriosis

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إذا احتجت إلى هذه النشرة بلغة أُخرى، أو بتنسيق
يسهل الوصول إليه، يرجى التحدث إلى أحد الموظفين لترتيب ذلك لك.

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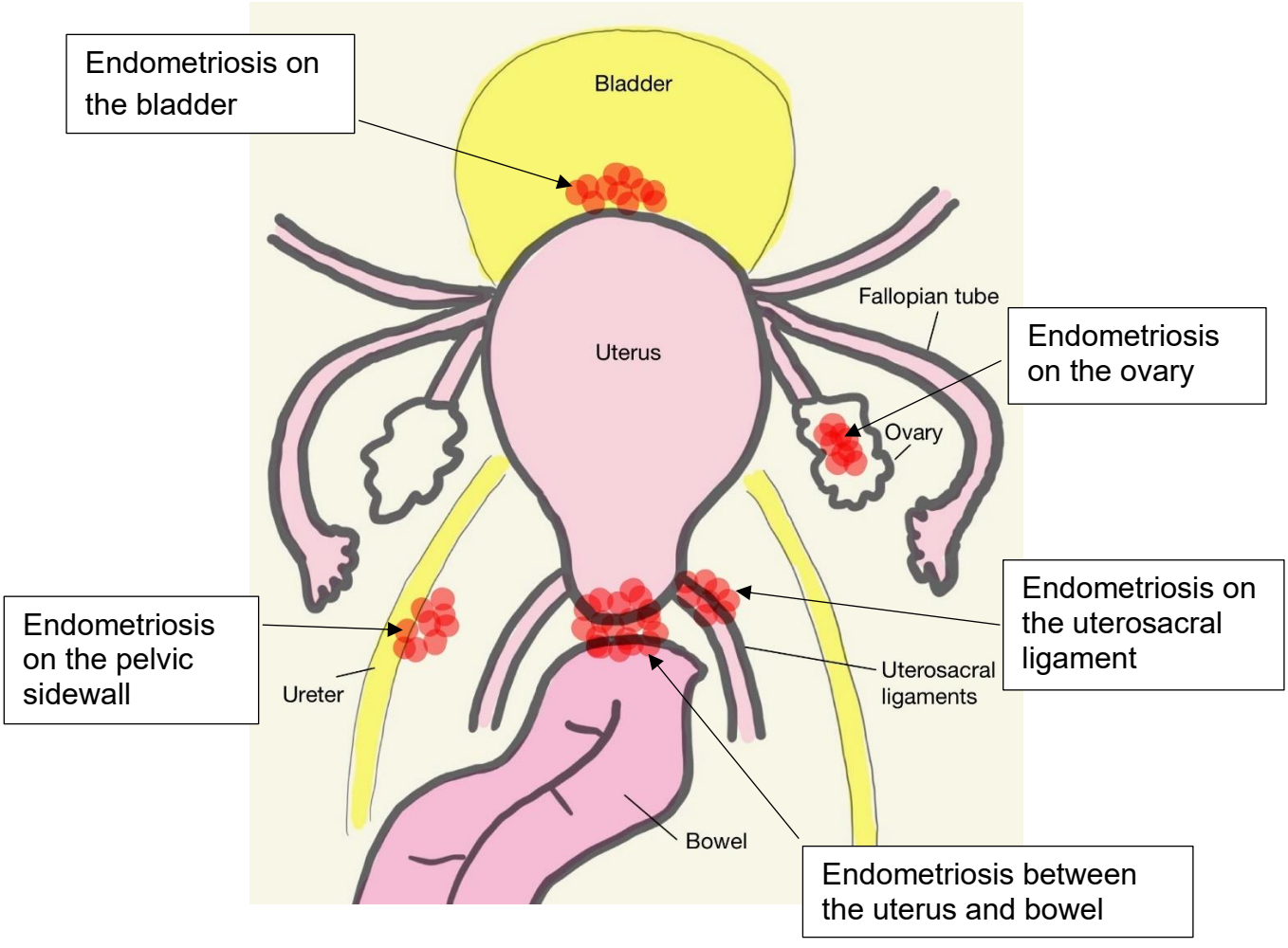
What is endometriosis?

Endometriosis is a condition where cells that are usually found on the inner lining of the uterus (endometrium), grow in places outside of the uterus. The cells can be found anywhere in the pelvis, most commonly on the ligaments that support the uterus (the uterosacral ligaments), on the ovaries or fallopian tubes, the pelvic sidewalls and in more severe cases on the bladder, bowel or ureters (tubes that carry urine from the kidneys to the bladder).

Sometimes endometriosis can be found within the muscle of the uterus, which is known as adenomyosis. Endometriosis can form cysts within the ovaries known as 'endometriomas,' which are commonly referred to as 'chocolate cysts.' Endometriosis can also be found in the abdominal wall, usually in surgical scars or in the belly button. Less commonly, it can be found in other areas of the body such as the diaphragm, appendix, near the liver and very rarely in the linings of the lungs. It is a longstanding condition that often causes pain and other symptoms that can have a significant impact on physical, emotional and mental wellbeing.

The below image shows the pelvic organs and common places to find endometriosis



How common is endometriosis?

About 10% of women in the general population are affected by endometriosis. It is more likely to affect you if your mum or sister(s) have it.

The chances of having endometriosis are higher, up to 30-50%, in women who are experiencing infertility.

What causes endometriosis?

The cause of endometriosis remains unknown. There are several theories, but none of them have been entirely proven. The most accepted theory is called ‘retrograde menstruation.’ During a period, menstrual blood flows backwards, through the fallopian tubes and into the abdominal cavity. This allows endometrial cells to implant into the pelvic linings and organs, resulting in endometriotic lesions.

It has also been suggested that endometriosis is a genetic disease, since endometriosis can be found in multiple female members within the same family. However, an ‘endometriosis gene’ has not been discovered.

The hormone oestrogen stimulates endometriotic tissue and plays a big role in the growth and progression of endometriosis over time. During the menstrual cycle, the ovaries produce oestrogen which stimulates the uterine lining to thicken, bleed and shed in what is known as a menstrual period. In the same way, the areas of endometriosis are stimulated by oestrogen. With each cycle, endometriosis grows and bleeds which causes repeated inflammation around the pelvic organs. Over time this can lead to the formation of scar tissue and adhesions, which means that the pelvic organs such as the uterus, ovaries, bowel and bladder can become abnormally stuck together. This may lead to chronic pain and bowel or bladder symptoms. When the fallopian tubes and ovaries become damaged, fertility can also be affected.

What are the symptoms of endometriosis?

The symptoms of endometriosis can vary greatly and often overlap with other health conditions. The most common symptom is pelvic pain, but whilst some women with endometriosis experience severe pelvic pain, others have no symptoms at all or regard their symptoms as simply being ‘ordinary menstrual pain.’ As we know that endometriosis is stimulated by oestrogen, the pain and other symptoms can vary during different times within the menstrual cycle and are often worse leading up to, or during periods.

The most common symptoms are:

- Pain in the days leading up to a period (premenstrual pain)
- Painful periods (dysmenorrhea)
- Pain during intercourse (dyspareunia)

Other symptoms include:

- Background pelvic pain
- Low back pain or pain radiating into the legs
- Heavy periods
- Painful bowel motions (dyschezia)
- Pain on passing urine (dysuria)
- Infertility
- Fatigue
- Abdominal swelling

Less commonly:

- Bleeding from the back passage or bladder during a period
- Scar swelling and pain

Rarely:

- Lung symptoms during menstrual periods such as cough, chest pain, breathing difficulties and coughing up blood (haemoptysis)
- Shoulder tip pain
- Bowel obstruction

When a woman reaches menopause, the ovaries stop producing oestrogen and menstrual periods naturally stop. Endometriosis becomes suppressed after the menopause and symptoms usually resolve.

How is endometriosis diagnosed?

The diagnosis of endometriosis can be challenging as symptoms may not be present or may only become apparent once endometriosis has become fully established. For this reason, endometriosis may not be picked up until it has reached a more advanced stage. On average, it can take up to 8 years to diagnose endometriosis.

When you attend your gynaecology appointment, the doctor will take a full history of your symptoms and may offer to perform an internal vaginal examination. Based on your signs and symptoms the diagnosis of endometriosis can be often assumed, and medical treatment can be started. The following investigations may be used to help diagnose endometriosis:

- Pelvic ultrasound scan – This is usually the first line investigation, offered to all women to look at the pelvic organs for signs of endometriosis. It is usually performed internally (transvaginal) as this gives the best views of the uterus and ovaries. An ultrasound is very good at detecting endometriomas (cysts of endometriosis on the ovary) and adenomyosis. It may also show pelvic adhesions e.g. if the ovary is stuck to the back of the uterus. Ultrasounds may

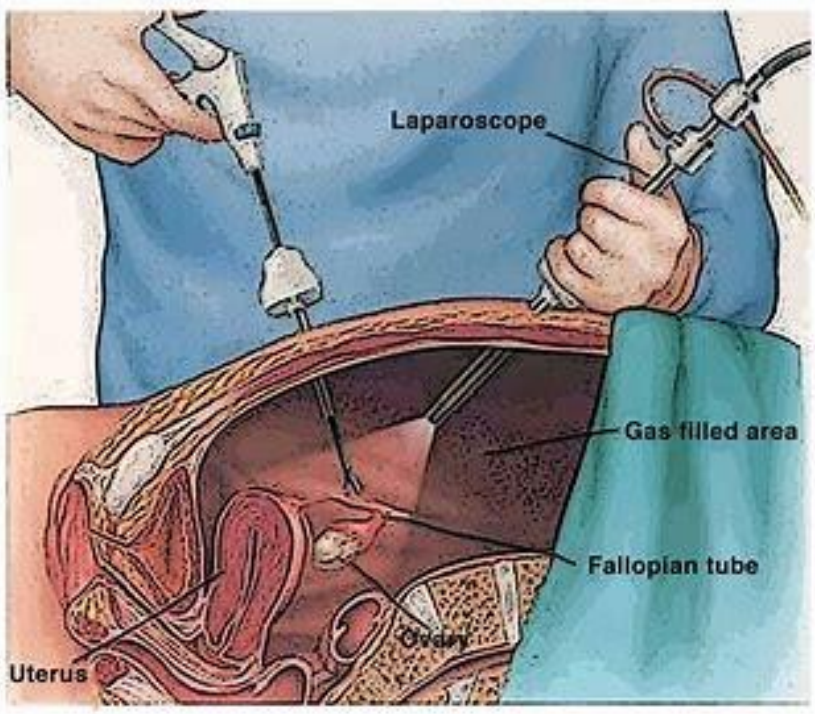
not detect small or superficial areas of endometriosis. Therefore a normal ultrasound does not completely exclude endometriosis.

- MRI scan – This is often used when severe endometriosis is diagnosed, to assess the depth and extent of involvement of the surrounding pelvic organs e.g. bowel, bladder and ureters. It can be helpful when planning surgery to remove endometriosis.

- Diagnostic laparoscopy – This is a keyhole surgical procedure performed under general anaesthetic, to look inside the abdominal and pelvic cavity for signs of endometriosis. A small cut is made inside the belly button and the abdomen is filled with gas. A surgical camera is inserted to inspect the pelvic organs. Further small cuts can be made to insert surgical instruments which may be used to treat endometriosis or take biopsies which are sent to the laboratory to confirm the diagnosis.

  At the time of diagnostic laparoscopy it may be possible to treat mild to moderate endometriosis. Severe endometriosis may not be treated at the time of an initial laparoscopy, as this may require a more extensive operation to be planned at a later date. Diagnostic laparoscopy may be 'negative' meaning that endometriosis is not present and no cause of pain is found.

Image showing laparoscopy and inspection of the pelvic organs



Traditionally, a laparoscopy was considered as the gold standard investigation for diagnosing endometriosis. However, with advancements in diagnostic techniques, it is now agreed that endometriosis can be diagnosed without laparoscopy and many patients can be successfully treated without any surgery at all. Diagnostic laparoscopy is often reserved for when endometriosis is suspected but scans are normal and medical treatment did not improve the symptoms.

Other investigations – It is important to rule out other causes of pelvic pain; you may be offered genital swabs to ensure that infection has been excluded. If endometriosis is suspected to be deeply affecting the bowel or bladder, you may be referred to see a specialist in this area and may be offered further tests such as a camera into the bowel (sigmoidoscopy) or camera into the bladder (cystoscopy).

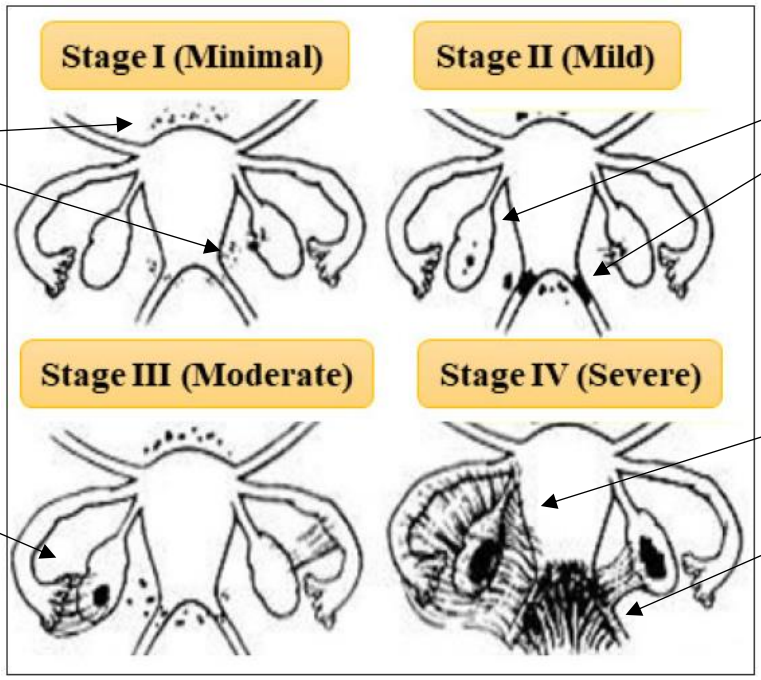
How is endometriosis staged?

Endometriosis can be staged according to how severe it is, in terms of its depth and degree of involvement of the pelvic organs. However, it is important to recognise that the severity of pain does not always correlate with the stage of endometriosis; whilst some women with mild endometriosis experience severe pelvic pain, other women with severe endometriosis have no symptoms at all. Therefore, the treatment of endometriosis is based on symptoms, rather than the stage of the disease.

The most commonly used staging system is the American Society of Reproductive Medicine (ASRM*)* classification, which grades endometriosis from stage 1 to 4:

- Stage 1 – Minimal endometriosis. A few superficial, small lesions with no surrounding scar tissue or adhesions.
- Stage 2 – Mild endometriosis. More lesions, which are superficial but at a deeper level and there may be some scar tissue or adhesions.
- Stage 3 – Moderate endometriosis. Lesions are deeply infiltrating. The ovaries are often affected with cysts (endometriomas) on one or both sides. Extensive scar tissue and adhesions.
- Stage 4 – Severe endometriosis. Lesions are deeply infiltrating with dense adhesions and extensive scar tissue. There are also large cysts on one or both ovaries/fallopian tubes. Other organs such as the bowel and bladder are affected.

Image showing the different stage of endometriosis



Superficial areas of endometriosis on and around the pelvic organs.

Superficial and deeper areas of endometriosis, shown here affecting the uterosacral ligaments and ovaries.

Deep areas of endometriosis and an endometrioma within the ovary. Adhesions between the ovary and fallopian tube.

Deep, extensive endometriosis with endometriomas on both ovaries and severe adhesions between the fallopian tube, ovaries and space behind the uterus.

What are the treatment options for endometriosis?

Endometriosis is a chronic illness for which there is no cure. Even with treatment, endometriosis may return. The aim of treatment is to ease symptoms and improve quality of life.

Treatment is not required for everyone and may not be necessary if endometriosis is mild and symptoms are minimal. We know that when left untreated, it is possible for endometriosis to get better in one third of patients. However, in the remaining patients, it may become worse or remain unchanged. It is not possible to predict which patients endometriosis would get worse if left untreated.

There are many different treatment options for endometriosis. Finding the right treatment option for you should be based on an individualised decision, taking in to account the following:

- Your symptoms and how severe they are
- The extent of your endometriosis
- Whether you are planning pregnancy
- Your personal preferences
- Your doctor's advice

Communication is key. You should discuss the options with your doctor and ask any questions you may have, before you come to a decision.

The main categories of treatment are pain medications, hormone medications and surgery. The different types of treatment are often combined to get the best outcome. Some patients also find complementary or alternative therapies helpful.

Pain medications (analgesics)

Pain medications influence how the body experiences pain. They do not have any effect on suppressing or treating the underlying endometriosis like hormone therapies do.

Simple pain medications are recommended as they can be very effective with little side effects and are easily accessible over the counter. It is advisable to start with paracetamol and Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) such as ibuprofen. Long-term use of NSAIDs can be associated with stomach problems. Therefore, a tablet for stomach protection should be taken alongside them e.g. lansoprazole, omeprazole or similar.

If required, stronger pain relief may be prescribed such as opiate based medication (e.g. codeine, tramadol, morphine). It is advisable to avoid using opiates unless necessary and restricting them to the minimum required due to their side effects. They can cause severe constipation and if opiates are taken for a long time, the body can become used to them (known as tolerance). This means that higher doses are needed to control the pain and over time, it is possible to become addicted to opiates.

When living with pain for a long time, the body can start to experience pain in an abnormal or exaggerated way. Pain modulators (e.g. amitriptyline, pregablin or gapapentin) can be used to try and restore how the body experiences pain, as well as reducing the amount of pain. They work differently from conventional pain medications, by working on the nerves to alter the way that pain impulses are carried to the brain. These medications are not suitable for women who are trying to get pregnant.

If your pain has not responded to initial pain medications or you have complex pain needs, you may be referred to a pain specialist.

Hormone medications

We know that endometriosis is stimulated and grows under the influence of oestrogen. The aim of hormone treatment is to reduce the levels of oestrogen produced by the ovaries. This results in suppression of endometriosis which reduces pain and inflammation. Menstrual periods will often stop or bleeding will become reduced whilst taking hormone medications. Most hormone medications have a contraceptive effect, so they may not be suitable if you are actively trying to get pregnant. Hormone medications do not harm your fertility in the long term but, unfortunately, they cannot improve your fertility either.

All types of hormone treatments may result in side effects such as headaches, acne, weight gain, irregular bleeding, fatigue, and hot flushes. The side effects vary between the different treatment options and from one patient to the next. As a result, a certain treatment can be a good option for one woman, but the same treatment can cause unacceptable side effects in another woman. Therefore, it may take some time and patience to find the right treatment for you. It is recommended that when starting a new hormone medication, you give it at least 3-6 months to determine the effect it has on your symptoms. If symptoms are controlled with hormone treatment, you may be able to reduce or stop pain medications and surgery may be avoided.

Hormone treatments come in many different forms including pills, patches, coils, injections and implants. There is no strong medical evidence that one treatment is better than the next. They all have their pros and cons and work in different ways. Your doctor will discuss the options further and will help you to make a decision, about which treatment option is the most appropriate for you. Below is an overview of the options available.

First line hormone treatment options

These treatments are offered as the first options and can be started by your GP or gynaecologist.

- Combined hormonal contraception – These contain both oestrogen and progestogen hormones and come in the form of a pill, a patch or vaginal ring. They can be used continuously or with a 1 week break each month. They make your periods lighter and less painful.

- Progestogen only contraceptives – These contain progestogen only. They may stop your periods completely, but it is possible to experience irregular bleeding with these options. By suppressing periods, they also reduce pain. They come in different forms, including:

    - The Progestogen Only Pill (POP**)** – A tablet taken every day, without a break.

    - The contraceptive injection (depo-provera) – Administered every 3 months.

    - The contraceptive implant (nexplanon) – A small plastic rod which is fitted into the upper arm. It needs replacing every 3 years.

    - The hormone coil (mirena) – A small plastic T shaped device, fitted into the uterus. Progestogen hormone is continuously released, to thin down the uterine lining, often resulting in periods stopping or becoming significantly lighter. It is an effective treatment for heavy periods and improves pelvic pain. It needs replacement after 5-6 years.

- Progestogen tablets (e.g norethisterone or medroxyprogesterone acetate/provera) – They can be given continuously and are very effective at stopping periods. They contain a higher level of progestogen hormone and can often have more side effects such as acne, bloating, mood changes and weight gain. For this reason, they are not preferred as a long-term treatment option, but can be very effective when used in short courses (2-3 months) to get symptoms under control.

Second line hormone treatment options

These treatments are used when first line treatment options have failed to control symptoms and need to be started by a gynaecologist.

- Dienogest (zalkya) – It is a type of progestogen-based hormone tablet taken every day without a break. It is specifically licensed for the treatment of endometriosis. It is not licensed as a contraceptive, a barrier method contraception is recommended alongside it. Dienogest has been found to be very effective in improving endometriosis related pain, reducing the size of endometriomas and delaying the recurrence of endometriosis after surgery. It may also be recommended to you before undergoing surgery to suppress endometriosis before it is excised.

- GnRH antagonist tablets (Ryeqo) – It is a daily tablet containing a unique combination of medications including a hormone blocker, alongside a small amount of progestogen and oestrogen Hormone Replacement Therapy (HRT). Ryeqo is licensed specifically for the treatment of endometriosis, but can also be relied upon for contraception after the first month of use.

  It works by suppressing endometriosis through blocking the production of oestrogen, whilst providing a small amount of HRT to prevent menopause side effects. It has been shown to be effective in stopping menstrual periods and reducing endometriosis related pain.

- Gonadotrophin Releasing Hormone agonists (GnRHa) injections e.g. zoladex or prostap – These are injections of hormone blocker medication given once a month or once every 3 months. They stop your ovaries from producing hormones and induce a temporary menopause state. On stopping the injections, the effect will wear off and your ovaries will begin to function normally, unless you have gone through the natural menopause.

  The injections are very effective at stopping periods and suppressing endometriosis. They are often used before surgery, to shrink endometriosis or may be recommended after surgery to reduce the chances of endometriosis recurring. A low dose of HRT is usually given at the same time to prevent symptoms of the menopause. Due to the side effects, GnRHa injections are not used as a long-term treatment option. They are usually given in courses of up to 6-12 months, but many women experience the benefit from them for many months/years after stopping treatment.

Risk of reduction in bone density

Due to their effect of blocking the production of oestrogen from the ovaries, GnRHa injections (zoladex or prostap) carry a risk of reducing bone density (thinning the bones). When given in short courses of up to 6-12 months, upon stopping the injections, bone density is able to recover, with no long-term effects. Younger women are at greater risk, as they may have not yet reached their maximum bone density. It is therefore advisable to avoid the use of this medication in women less than 25 years of age, unless other treatment options have failed or were not tolerated. Ultimately, the decision to commence GnRHa injections and the length of time on this treatment, is a decision made between you and your gynaecologist, taking in to account the risks and the benefits. If you have been using this treatment for a prolonged period of time (more than 12 months), you will require a bone scan to check your bone density.

The risk of reduction in bone density also applies to other second line treatment options, including dienogest and ryeqo, but probably to a lesser extent. If taking either of these therapies for more than 12 months, a bone scan will be required.

Surgery for the management of endometriosis

Surgical treatment involves the removal of areas of endometriosis, by cutting it away (excision) or destroying it with heat treatment (ablation). Endometriomas (chocolate cysts) can be removed or drained from the ovaries and scar tissue/adhesions can be separated. This is usually done through a keyhole approach (laparoscopy) which has the benefits of less pain, a shorter hospital stay and a quicker recovery. The type of surgery you may be offered for your endometriosis will depend on your individual situation.

It is important to consider that surgery carries a risk of complications and there is no guarantee that it will cure your symptoms. Your gynaecologist will discuss the risks and benefits with you and will help you to make an informed decision about surgery.

Surgery aims to reduce endometriosis related pain and is effective for many patients. In some cases, surgery may not improve the pain or may only improve it partially/temporarily. It is not possible to predict who will or will not benefit the most from surgery. Approximately one third of patients who had improvements in symptoms from their surgery, will develop recurrence of symptoms later and may require further surgery. Performing surgery for mild cases of endometriosis often does not provide any additional benefit over hormone therapy, in terms of relieving symptoms or preventing endometriosis from returning.

The evidence for surgery to improve fertility is less clear; it may be possible to improve fertility in some cases, but not always. There is a risk that fertility may be worsened with surgery, for example, through the loss of ovarian reserve when removing endometriomas from the ovaries.

To improve the outcome of surgery, you may be offered hormone treatment post-operatively, with the aim of further reducing pain and to prevent recurrence of endometriosis. If you desire pregnancy shortly after surgery, you may prefer to avoid hormone treatment.

At the time of surgery, we may find more complex endometriosis than expected. An example would be if it is deeply affecting your bowel/bladder. In this case, full treatment may not be performed, because the risks associated with surgery are higher. As such, your endometriosis may need to be treated with a further operation, planned at a later date and may require input from bowel/bladder specialist surgeons.

- Hysterectomy (removal of the uterus) – If you have completed your family and other treatments have not worked, you may be offered a hysterectomy with or without removal of the ovaries. This is usually reserved as a last resort option, as it is an irreversible procedure with permanent loss of fertility. If the ovaries are removed at the same time, menopause will occur. HRT may be needed and having a combined preparation (containing both oestrogen and progestogen) may be advised to reduce the chances of endometriosis returning.

  A hysterectomy is an effective cure for adenomyosis, but will not necessarily cure endometriosis. Hysterectomy without removal of the ovaries carries a 40% risk of recurrence of endometriosis after 5 years. Hysterectomy with removal of both ovaries can reduce the risk of recurrence to 5-10%. There are risks and benefits of having your ovaries removed and this decision will depend on your age and your individual circumstances; you should discuss this with your gynaecologist to come to the right decision for you.

  It is important to consider that a hysterectomy is a major pelvic surgery, with a risk of complications (e.g. risk of bleeding, infection and injury to pelvic organs including bowel, bladder, ureters and nerves). In the presence of endometriosis, the surgery may be technically more difficult and the risks are higher. For more information about the specific risks of surgery, please see separate information leaflets on laparoscopy and hysterectomy.

- Endometriosis specialist centres – Some hospitals offer a service, providing treatment for women with complex endometriosis within specialist teams made up of gynaecologists (with a specific interest in endometriosis), colorectal (bowel) surgeons, urologists (bladder specialists), radiologists, pain team and a specialist endometriosis nurse. The team meet regularly to discuss individual cases and decide on the best treatment for each patient. If severe endometriosis is diagnosed (e.g. when bowel or bladder is affected), you may be offered a referral to a specialist endometriosis centre for your surgery.

Alternative treatments for endometriosis

There are many alternative therapies and although they have not been scientifically proven, many women with endometriosis have tried them and feel that their symptoms have improved. Therapies such as acupuncture and reflexology may be helpful.

Making lifestyle changes, such as regular exercise and diet modifications can help. There is an overlap between endometriosis and Irritable Bowel Syndrome (IBS). Many patients with endometriosis have functional bowel symptoms such as bloating, pain and alternating stools. Eliminating certain types of food and switching to a low FODMAP diet (Fermentable Oligo-, Di-, Monosaccharides And Polyols) may improve pain and bowel symptoms (more information can be found on the British Dietetics Association website www.bda.uk.com). Some medications may help to relieve bowel cramps, including hyoscine butylbromide (also known as Buscopan) and peppermint water or capsules (colpermin), both of which can be purchased over the counter.

Contact Information

Whiston and St Helens hospital sites

Gynaecology secretaries
Womens Offices, Whiston Hospital
Tel no. 0151 676 5289
Gynae.secs@sthk.nhs.uk

Gynaecology Ward 3E
Level 3, Whiston Hospital
Tel no: 0151 430 1522

Southport and Ormskirk hospital sites

Gynaecology secretaries
Tel no. 01695 656658

Gynae assessment bay (E ward)
Tel no. 01695 656901

Support and further information

You may find the following websites and organisations useful:

Endometriosis and women's health support

National Institute for Health and Care Excellence (NICE) - endometriosis: diagnosis and management (www.nice.org.uk/guidance/ng73)

ESHRE (European Society of Human Reproduction and Embryology): Information for women with endometriosis (www.eshre.eu)

BSGE (British Society of Gynaecology Endoscopists) accredited endometriosis centres (www.bsge.org.uk)

Endometriosis UK (www.endometriosis-uk.org)

Endometriosis net (www.endometriosis.net)

Bladder and bowel community (www.bladderandbowel.org)

Fertility network UK (www.fertilitynetworkuk.org)

Menopause (www.menopausematters.co.uk) or (www.womens-health-concern.org)

Psychological support and counselling

Counselling directory (www.counselling-directory.org.uk)

Relate (www.relate.org.uk)

Mind (www.mind.org.uk)

Samaritans (www.samaritans.org)

Pain management and support

The British pain society (www.britishpainsociety.org)

Pain toolkit (www.paintoolkit.org)

Nutrition and alternative therapies

British nutrition foundation (www.nutrition.org.uk)

The Complementary and Natural Healthcare Council (CNHC) (www.cnhc.org.uk)

British acupuncture council (www.acupuncture.org.uk)

Whiston Hospital
Warrington Road,
Prescot, Merseyside, L35 5DR
Telephone: 0151 426 1600

St Helens Hospital
Marshall Cross Road,
St Helens, Merseyside, WA9 3DA
Telephone: 01744 26633

Ormskirk Hospital
Wigan Road,
Ormskirk L39 2AZ
Telephone: 01695 577111

Southport Hospital
Town Lane, Kew
Southport PR8 6PN
Telephone: 01704 547471