

Homerton Fertility Centre



Endometriosis and Pelvic Pain Clinic



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Homerton University Hospital Endometriosis and Pain Management Clinic aims to operate an outpatient clinic with a comprehensive patient centred approach to the care of women with endometriosis and pelvic pain.

THE TEAM

Mr Anil Gudi

Lead Clinician in fertility and specialist in endometriosis



Mr Christian Barnick

Specialist in laparoscopic surgery and endometriosis



Mr Amit Shah

Specialist in infertility



WHAT WILL HAPPEN AT YOUR FIRST APPOINTMENT?

At the first appointment a detailed history will be taken. You will be asked about your symptoms and the extent to which your lifestyle is being affected. This will form the basis upon which the treatment will be planned. A detailed treatment plan will be made at this visit.

Information will be given about endometriosis and available treatment options. At this appointment you will have the opportunity to discuss about your treatment and any fertility concerns.

Any necessary investigations will be arranged (ultrasound scan and blood tests) and a laparoscopy (looking inside the abdomen) or hysteroscopy (looking inside the womb) will be arranged.

Where appropriate a further appointment will be made in four to six weeks time to discuss the results of the investigations and plan the treatment .

RELEVANT LINKS

As a part of the services offered by the Endometriosis Centre, you may also be referred to see one of the other specialities

- Fertility Unit (Homerton fertility centre)
- General surgical team for bowel problems

What is endometriosis?

Endometriosis is a condition where tissue similar to the lining of the uterus (womb) is found elsewhere in the body usually the pelvis. It is a benign (non-cancerous) but a very painful condition which is characterised by the presence of endometriosis deposits mainly in the pelvis (the ovary, areas around the womb, on the bladder and the intestines).

Each month this tissue outside the uterus breaks down causing internal bleeding which has no way of leaving the body. This leads to inflammation, pain and the formation of scar tissue.

In the ovary the endometriosis tissue can bleed and cause fluid contained areas which are called endometriomas (endometriotic cysts). These cysts are usually detected by an ultrasound scan.

It is estimated that endometriosis is present in between 10% -25% of young women and may be as high as 35% in women with fertility problems.

What are the symptoms / signs of endometriosis?

Any woman in the child bearing period and who is having periods can be affected. Endometriosis can usually improve with the onset of pregnancy or menopause.

Although women may not show any signs of endometriosis, the common symptoms of endometriosis include:

- Painful and or heavy periods.
- Painful sex
- Pelvic pain
- Moderate to severe pain at the time of ovulation
- Premenstrual pain
- Difficulty in becoming pregnant
- Pain when passing urine and or bleeding
- Pain and difficult with opening bowels
- Bleeding from the bowel with the periods
- Fatigue

The majority of women with this condition will experience some of these symptoms. Some women will have no symptoms.

The amount of endometriosis does not always correspond to the amount of pain and discomfort.

A small amount of endometriosis can be more painful than severe disease. It depends on the site of endometrial deposits.

Not being able to get pregnant may be the only symptom in some cases.

Endometriosis is:

- Not an infection
- Not contagious
- Not cancer

Endometriosis is very common affecting two million women in the UK.

Why does endometriosis occur?

The exact cause is unknown, although a few theories have been put forward:-

- **Retrograde menstruation**

Some of the menstrual blood flows backwards down the fallopian tubes and into the pelvis. Some of this endometrial tissue implants and causes endometriosis.

- **Lymphatic or circulatory spread**

Endometrial tissue is carried by blood vessels and lymphatic channels.

- **Genetic predisposition to the condition**

Researchers are looking into the gene which could identify women predisposed to endometriosis. A woman who has a mother or sister with endometriosis has a six times greater risk of developing endometriosis.

- **Immune dysfunction**

There are theories which look at the immune response of the body which could lead to the development of endometriosis.

How is endometriosis diagnosed?

- **History**

A thorough history may highlight suspicion about endometriosis.

- **Ultrasound Scan**

An ultrasound scan may show the presence of endometriosis cysts, although not all cysts are caused by endometriosis and some types of endometriosis may not be seen on a scan.

- **Laparoscopy**

This is the only definitive way to diagnose endometriosis. In this operation a telescope is inserted into the pelvis under general anaesthesia via a small cut near the navel. This allows the surgeon to see the pelvic organs and any endometrial spots or cysts.

Treatment for endometriosis

For effective long term treatment of endometriosis various treatments are available.

The treatment varies according to various factors:-

- Age
- The severity of symptoms
- The desire to have children
- The severity of the disease

The treatment is carried out as a partnership between the patient and the medical advisers.

The aim of the treatment is

- pain relief
- reducing endometrial growth
- preserving and restoring fertility
- delaying the recurrence of the disease

Treatment options are:

Wait and see

- If the symptoms are very mild or if menopause is approaching, this approach may be suitable

Drug treatment

- Often these drugs may bring about an improvement in the pain symptoms
- May shrink or slow down the progression of the condition
- Delay the recurrence of the disease
- Not effective as long term treatment
- Commonly used before surgery or before IVF treatment

Commonly used drugs

Testosterone derivatives

- Danazol
- Gestrinone
- Progestogens
- Medroxyprogesterone (Provera)
- Dyhydrogesterone (Duphaston)
- Norethisterone (Duphaston)

GnRH analogues

- Triptorelin (Gonapeptyl)
- Goserelin (Zoladex)
- Leuprorelin (Prostap)

Other Hormonal

- Combined oral contraceptive pill
- Mirena coil
- Depo- Provera

All hormonal treatments have side effects. With the exception of the Mirena coil, Depo-Provera and the oral contraceptive pill, the rest of the drugs do not offer effective contraception and you are advised to use the barrier method.

Side effects

- Hot flushes, sweating, vaginal dryness
- Mood swings, sometimes anxiety
- Symptoms of endometriosis and cyst size may increase with the first injection
- The first period after the injection may be irregular and painful. This usually settles after the second injection

Surgical Options

- Diagnostic laparoscopy with or without treatment.
- Conservative surgery which aims to remove the endometrial tissue or destroys it, usually via a telescope or rarely via a laparotomy (When a larger cut is made). This can be achieved by diathermy/laser/excision or ablation depending on severity.
- Radical surgery that includes removal of the ovaries and the uterus. This is considered only if the symptoms are extremely severe and all other forms of treatment have been exhausted including surgery. And you do not desire any more children.

Combination

- Often if the surgical treatment has to be divided into two stages, you may be offered Gonapeptyl depot 3.75mg on a monthly basis between operations.
- These drugs help in making the endometriosis less bloody, thus enabling a complete excision at the second operation.
- If we are already aware that you have endometriosis , you may be given these drugs prior to your operation.

Pain Management

- Pain Killers
 - Neurofen
 - Diclofenac (Voltarol)
 - Codeine
- Neurogenic pain
 - Nerve blocks etc

Complementary Therapies

Many women will seek to use complementary therapies to help with their endometriosis. This may often help, though at present there are no trials. Options include acupuncture, Chinese or western herbs, homeopathy and dietary changes.

Surgical Treatment

Laparoscopy and Treatment

Laparoscopy

This is a technique in which a thin telescope is inserted into the abdomen to inspect the pelvic organs. A 1cm incision is made under the umbilicus and the abdomen is filled with gas. This distension allows the surgeon to inspect the pelvic organs to confirm the diagnosis of endometriosis. Another small incision is made close to the pubic hairline.

If any endometriosis is seen then a further incision is made to allow treatment to the affected areas. The surgeon would then either burn out or remove the affected areas.

Usually you would be discharged on the same day, though in some cases overnight stay may be needed. The duration of stay depends on the extent of endometriosis. It is important to realise that extensive surgery can be achieved through the telescope, though sometimes a longer duration of stay may be needed.

Treatment centres at Homerton Hospital

- Pre-assessment Clinic, prior to surgery where you will be told about the care in the hospital and details about your admission and stay. This is a nurse-led clinic and prepares patients for surgery.
- Day Stay Unit (DSU), is an efficiently managed unit with well trained staff who aim to achieve endometriosis treatment in a day care setup.
- Surgical Centre aims to achieve a fast and efficient way to preparing patients for surgery. This ensures that it is very unlikely that your operation will be cancelled for lack of beds.
- Acute Gynaecology Clinic, a weekday service staffed by experienced doctors and nurses who will be able to see you either the same day or the next day if you are referred by your GP with pain.

Aims of treatment

- Reduction of pain
- Fertility improvement/preservation
- Reduction of recurrence
- Long term relief

All the treatments are discussed and treatments are individualised. Detailed explanation about the procedure will be given. You will also be made aware to any other procedures which may need to be carried out. In cases of extensive endometriosis the procedure may be done in two stages to achieve a significant cure.

If you are trying to get pregnant or are thinking of it in the near future, we will check for any fertility problems at the same time and would be able to give you more information. If advanced fertility treatment is needed you would be managed by our fertility unit which can advise you regarding the treatment. You may wish to continue your fertility treatment at the Unit. Quite often the health authorities may fund the treatment.

Your Treatment

Bowel preparation

You may be given medicine to clean up your bowel to reduce the change of bowel damage during surgery.

Minor surgery

Minor surgery will involve inspection and burning away the endometriosis tissue or spots.

- Adhesions(Scar tissue) would be divided or removed
- An endometriomas or chocolate cyst (Cyst filled with Endometriotic fluid) will be opened and drained. The cyst will then be removed. Care will be taken to preserve as much normal ovarian tissue as possible.

Major surgery

This may still be laparoscopic.

- Cutting away the endometriosis affected tissue
- Releasing ovaries
- Releasing adhesions and removing the tissue affected by endometriosis around the back and the side of the uterus, around the bladder and ureter and the space between the rectum and the vagina
- Dissecting the ureters(Tubes that carry urine from the kidneys to the bladder) to be able to remove endometriosis tissue

Bladder disease

If severe endometriosis affects the bladder (**Anterior disease**) or is found close to the bladder then

- A cystoscopy (Inspecting the bladder with a scope) may be done
- The bladder may need to be opened to remove the endometriosis
- A catheter may be retained inside the bladder and the bladder will be rested for about 10 days.

You will be advised by the consultants in the urogynaecology department.

Bowel disease

If you have severe disease involving the bowel, you will be offered an appointment at the University College London endometriosis Unit. This unit specialises in the laparoscopic treatment of severe endometriosis involving the bowel.

A referral will be sent to the UCLH and a date for surgery will be arranged by the UCLH. This will avoid a long wait for surgery.

We will discuss the surgery with you and explain the procedures which may need to be undertaken. There is a possibility that you may need two surgeries to clear the endometriosis.

During surgery

- The bowel will be dissected free and the endometriosis may need to cut away.
- If this happens the bowel may need to be rested for around one week.
- There is a possibility if a cut on the abdomen and a temporary colostomy (getting the bowel out through the abdomen) may need to be carried out. This may require another surgery to reverse the colostomy.
- If this is a possibility of this happening, we may not carry out the procedure at the same time, but may remove as much endometriosis as we can and plan the bowel surgery at another date after you have seen the bowel surgeon and are made aware of the recovery and effects of the surgery.
- If you have been through repeated surgery elsewhere and if the bowel is involved in endometriosis, this form of surgery may be needed to relieve your symptoms.

Surgical risks

This will depend on the type of surgery and extent of endometriosis. As with all surgery the associated risks may include. These risks are very small and in mild to moderate disease may occur in 1:500 cases for severe complications.

- Damage to bladder and ureters. If the ureters are damaged then a major surgery will have to be carried out and a stent may need to be inserted

- Damage to bowel and correction
- Damage to nerves and blood vessels
- Infection
- Risk to delayed complications including bowel injury and haematoma (Collection of blood in the abdomen) which can occur up to two weeks after the procedure.

If any of these complications occur, a laparotomy (open surgery through a larger cut) may need to be undertaken to correct the damage or to stop bleeding.

If you experience sudden or increasing pain at home, or have vomiting or feel unwell please seek medical advice immediately.

During daytime hours you may contact the acute gynaecology service and the accident and emergency out of hours.

The use of GnRH analogues (Gonapeptyl) in the treatment of endometriosis

Gonapeptyl (triptorelin) virtually stop all ovarian activity. They stop the ovaries working and thus reduce the production of oestrogen. This results in a temporary but reversible state of menopause (not actual menopause).

These drugs are used prior to surgery to shrink and reduce the vascularity in the endometriosis and to facilitate surgical treatment.

These drugs are used two to six months but may be sometimes used longer. Most women feel better at the end of the treatment. If the drug is used longer, additional hormone replacement therapy is given to prevent osteoporosis and menopausal symptoms.

Gonapeptyl is given as an injection once a month for two to six months.

It is important that you are not pregnant when you begin the treatment.

In the initial stages of the treatment, symptoms may get worse due to the initial rise of hormones but will reduce as treatment continues.

- Gonapeptyl is not a cure, as the symptoms recur when the treatment is discontinued, although the interval of reappearance of symptoms varies.

Contraindications

Gonapeptyl or Zoladex must **NOT** be taken if:

- You are pregnant or suspect that you are pregnant
- You are breast feeding
- You have undiagnosed abnormal vaginal bleeding

The use of Gonapeptyl or Zoladex does not guarantee contraception.

Side effects

- Hot flushes
- Decreased sex drive
- Mood changes
- Insomnia
- Headache
- Breast tenderness
- Insomnia
- Osteoporosis with longer use

Within a few weeks of completing treatment the side effects reduce.

Endometriosis and infertility

There is a definitive link between endometriosis and infertility. Endometriosis is seen in about 20 to 25% of women referred to the fertility clinics worldwide.

Endometriosis and infertility is often linked. Endometriosis causes infertility in various ways:

- Distorts the pelvis organs
- Changes the position of tubes and ovaries and creates adhesions
- Alters hormonal functions make the local environment worse
- Interferes with Ovulations
- Causes decreased implantation

For endometriosis with pelvic pain a combination of medical and surgical treatment is the standard.

The treatment of endometriosis in infertile women leading to clear improvement is more complex and should be under the care of fertility team.

Stage 1 and 2 endometriosis

These are early stages of endometriosis and can cause infertility. Surgical treatment of stage 1 and 2 endometriosis improves pregnancy rates. Excision or ablation of endometriosis both improve pregnancy rates.

How long should I wait after surgery to get pregnant?

This depends on your age and how long you have been trying for a pregnancy. If you are over 34 years of age then waiting for a long time after surgery will not improve pregnancy rates. Generally fertility rates decrease after 35 years of age, but in women with endometriosis, the decline in fertility rates may be earlier.

It is important that you have a FSH test done (Baseline hormones) and Anti-Mullerian Hormone (tests ovarian reserve). This will give us an idea about your ovarian reserve and whether you have time to wait or should think of earlier treatment.

There is evidence that proceeding with treatment either

1. Stimulation of the ovaries and insemination of sperm (IUI)
2. In-vitro fertilisation (IVF)

It is important for you to ask questions regarding your concerns about infertility. Often women go through repeated surgeries before being referred to the fertility department. At this clinic you can have your fertility assessed and avail of fertility advice if required.

Stage 3 and 4 endometriosis

These represent the more severe form of endometriosis. There is adequate evidence that repeated surgery does not improve the chances of pregnancy.

1. If pelvic pain and fertility both are a concern, then surgery followed by fertility treatment gives the best result
2. In cases where previous surgery has been done or there is long standing infertility, IVF gives better results. We would recommend that you should seriously consider fertility treatment following surgery.

IVF treatment removes gametes for a hostile environment created by endometriosis and maximises conception

Are success rate with endometriosis lower in IVF?

Compared to other patients, there is some evidence that pregnancy rates in IVF may be lower in women with endometriosis. There is evidence that women require a higher dose of drugs to stimulate the ovaries in endometriosis.

Ovarian reserve may be decreased in women with severe endometriosis and stimulation of ovaries may produce fewer eggs. There is recent evidence that in women with endometriosis, implantation of the pregnancy may be affected.

Can pregnancy rates be improved in endometriosis?

There is evidence that in cases of severe endometriosis, long suppression of ovaries by Gonapeptyl or such drugs may improve implantation.

Before you proceed for your ivf cycle, you will be given three courses of Gonapeptyl after which you will be started on the IVF drugs. This is a variation of the **long protocol**.

We will also be checking your AMH (Anti-mullerian hormone) which will allow us to fine tune your IVF drug dose and may improve pregnancy rates.

We will avoid operating on small cysts, since it may further decrease ovarian reserve.

Can endometriosis worsen after fertility treatment?

During fertility treatment, the medications make the ovaries enlarge and the hormonal rise may worsen endometriosis in some women. This is a short term rise many women will feel relieved of the symptoms in a few weeks.

If you were to fall pregnant these symptoms will get better.

Endometriosis cyst (endometrioma)

This is the commonest cyst in the ovary that requires treatment. Endometriomas can cause pain and infertility. Repeated surgery on endometriomas, will decrease ovarian reserve and thus decrease fertility.

These ovarian cysts can either be treated by cyst removal (cystectomy) or cysts destruction (drainage and coagulation).

Which type of surgery is better?

Cystectomy – reduces the risk of the cyst coming back (Recurrence) but there is a possibility of more ovarian tissue being destroyed

Draining and coagulation (burning) – this destroys less ovarian tissue and may be better for fertility treatment. The risk of the cyst coming back is higher.

This decision would be made during discussion with you and your desire for having a baby.

There is good evidence that treatment of the endometriosis cyst does improve pregnancy rates if the tubes are open

It is extremely important that you tell the doctor that you are keen to consider fertility treatment after the surgery. This will allow you to get a tailored treatment plan that will give you the options of fertility treatment and whether it can be funded on the NHS.

Preventing recurrent of endometriosis

Endometriosis is a disease that can recur with the painful symptoms coming back.

About 25% of women are likely to have recurrence of endometriosis within five years. In a few women, this recurrence comes earlier. It is important to discuss the various methods of reducing the risk of recurrence.

The different methods are set out below.

Suppressive treatment

In this treatment the ovarian hormones are suppressed, thus lowering the risk of endometriosis recurring. Painkillers reduce pain but do not prevent the recurrence of endometriosis.

1. Combined contraceptive pill - these given in three monthly courses are the most effective means of suppressing endometriosis. It may cause some breakthrough bleeding and may not be advisable in women who cannot take the pill.
2. Progestin only pill - these contain only one hormone and have reasonable effectiveness
3. Gonapeptyl Depot - these drugs should not be given for more than six months continuously. There is a risk of osteoporosis with its over six months usage.
4. Depo-provera – is reasonably effective, but can cause abnormal bleeding,

5. Mirena contraceptive device – if other drug preparations are not possible then the Mirena system may be used

Mirena for endometriosis

Mirena is a small T-shaped intrauterine contraceptive device that has been used for endometriosis. It contains the hormone progesterone which is released into the uterus over a period of 5 years.

It is a very effective contraceptive and few studies indicate that it is effective for the treatment of endometriosis

How does it work?

The Mirena probably works by suppressing the growth of the endometrial implants causing it to waste. It may also reduce some endometriosis induced inflammation (swelling).

The Mirena can some times stop ovulation, although this is not always the case.

Small clinical trials have indicated that the Mirena reduces period pain over three years and the most improvement is seen in the first 12- 18 months.

Often you will be offered this coil when you consent for surgery. If you do not desire any children in the immediate future it is extremely important that a plan be made to reduce the risk of endometriosis recurring.

For further information:

Please contact Mr Christian Barnick or Mr Anil Gudi if you wish to discuss any aspect of the information outlined in the endometriosis leaflets or your treatment in more detail.

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Author – Mr A Gudi
Date – May 2010
Review Date – May 2012

