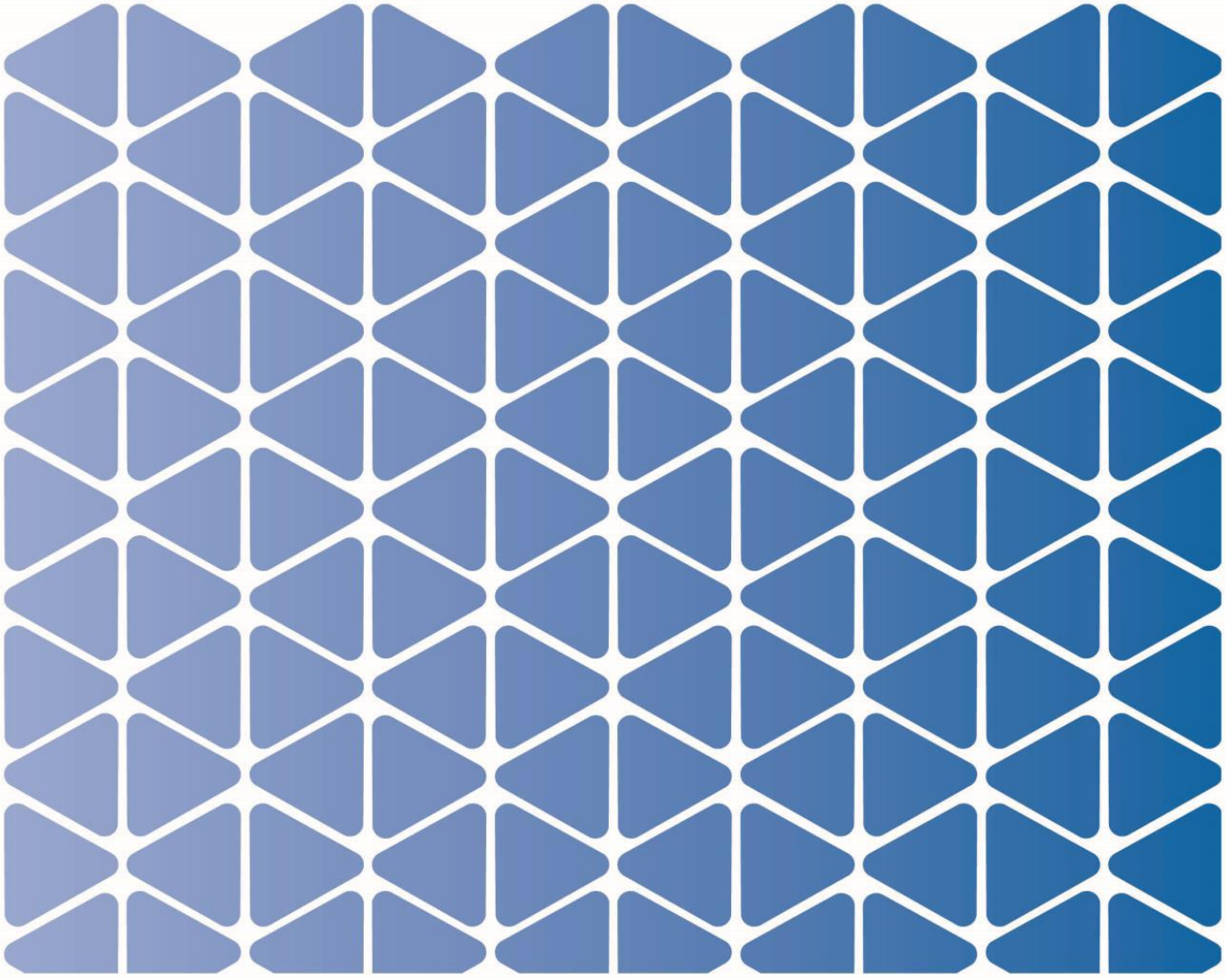
PATIENT INFORMATION

ENDOMETRIOSIS



What is Endometriosis?

Endometriosis is a condition where endometrial tissue, normally found only in the lining (the endometrium) of the womb (uterus), grows outside the uterus, most commonly in the pelvis. It is not known why the endometriosis grows in the wrong place.

Endometriosis tissue can implant anywhere in the pelvis, most commonly it is found on the ligaments that support the uterus (the uterosacral ligaments) or on the ovaries. Other places endometriosis can implant include on the bowel, bladder or the top of the vagina affecting their function. Sometimes endometriosis can be found within the muscle of the uterus (adenomyosis). Rarely endometriosis can be found in surgical scars or elsewhere in the body.

About 10% of women of childbearing age are affected by endometriosis. It is more likely to affect you if your mum or siblings have it.

It can take many years to get a diagnosis and it can be a long-term condition that can have a significant impact on your physical and mental wellbeing. Specialist endometriosis centres like here in Worcester have been set up to provide expert care for women with suspected and confirmed endometriosis.

What are the symptoms?

The most common symptom of endometriosis is pelvic pain:

- Pain before a period starts
- Pain during periods
- Pain during or after intercourse

Pelvic pain can come and go with a regular pattern or may be constant.

Other symptoms caused by endometriosis

- Irregular or heavy periods
- Pelvic pain on opening bowels (in rarer cases where the bowel is involved)
- Pelvic pain on passing urine (in rarer cases where the bladder is involved)
- Referred pain to the tops of the legs or back
- Fatigue
- Difficulty getting pregnant (subfertility)

The severity of the pain and other symptoms of endometriosis can vary greatly; some women with extensive endometriosis have no symptoms, whereas others with minimal disease have severe symptoms.

How does endometriosis produce symptoms?
Each month in a normal menstrual cycle the lining of the womb thickens (and later bleeds) in response to oestrogen made by the ovaries. In the same way endometriosis grows and bleeds in response to the oestrogen. This growth of endometriosis and bleeding causes trauma and inflammation to the surrounding tissues which causes pain. As the tissues heal scar tissue can form which can stick down normally freely moving organs such as the ovaries, bowel and bladder which can cause chronic pain.

Damage to the ovaries and fallopian tubes can also contribute to subfertility.

Endometriosis on the ovaries can form cysts containing old blood called endometriomas (or chocolate cysts). These cysts cause pain as they increase in size, they can leak causing pain, and occasionally they can cause the ovary to twist causing sudden severe pain which sometimes requires emergency surgery to save the ovary.

How is Endometriosis Diagnosed?
Endometriosis can be a difficult condition to diagnose because the symptoms of endometriosis vary so much with different women presenting with very different symptoms, and the symptoms are common and can mimic other conditions such as irritable bowel syndrome (IBS), painful bladder syndrome or pelvic inflammatory disease (PID).

When you are seen in clinic by one of our endometriosis specialist team members, we will carry out the following:

- Ask you to complete a questionnaire outlining the main symptoms you are suffering from and to what extent they affect your quality of life
- Take a full medical history including asking questions about your periods, previous children or plans for future pregnancy, treatment already tried, and any ongoing medical problems.
- Offer to examine your abdomen and perform an internal vaginal examination. A chaperone will be present. Examination can be very helpful in pinpointing specific areas of pain and identifying abnormalities that suggest endometriosis which help guide treatment.

We will then discuss what we have found, further tests which we could consider and the different treatment options available. You will be able to discuss any concerns and

you will have an opportunity to ask other questions. We do our best to begin initial treatments from the first time we see you in clinic so that there is no delay in improving your quality of life, even if we are awaiting further tests or surgery.

Further tests we offer

- Ultrasound scan – This can look at the womb and ovaries, particularly looking for endometriomas (endometriosis cysts on the ovary), but small areas of endometriosis cannot be seen. An ultrasound will be offered to most women if this has not been performed recently.
- Laparoscopy – This is key hole surgery performed under general anaesthetic. A camera and surgical instruments are placed through small holes in the abdomen to look in the pelvis for endometriosis and scar tissue which could be causing the symptoms. At Laparoscopy a biopsy can be taken to be looked at in the lab to confirm the diagnosis. Endometriosis can also be treated during the laparoscopy. However a laparoscopy does not need to be a first line treatment and some women can be successfully treated without surgery.
- MRI scan – These scans are sometimes offered prior to surgery if advanced/deep endometriosis is suspected.
- Other tests – These include a camera to look into the bowel (sigmoidoscopy) or the bladder (cystoscopy) which are sometimes arranged when looking for deep endometriosis.

How is Endometriosis Treated?

There is no cure for endometriosis. The aim of is to improve your quality of life by treating the symptoms you are experiencing. This can be done with pain medications, hormonal medications and/or surgery. There are some life-style changes that may also help to alleviate symptoms.

Pain relief medications

We advise starting with simple over the counter pain relief such as paracetamol and non-steroidal medications such as ibuprofen. Studies show non-steroidal medications alone can reduce pain by 50%. If required prescription pain relief can be tried and in severe cases advice can be sought from pain medicine specialists.

Hormonal medical treatment

We know when the ovaries are not functioning and not producing oestrogen endometriosis symptoms improve. Naturally in life the ovaries are not working before puberty, and they stop in pregnancy and after the menopause. Hormonal medical treatments are used to temporarily stop the ovaries making oestrogen.

Traditional contraceptive medications are the first line hormonal treatments. These include the combined contraceptive pill (containing oestrogen and progesterone), the mini pill (progesterone only pill), the injection, implant and intrauterine coil. There is no strong evidence that any contraceptive is superior to any other in treating pain, however they work in different ways and some have additional benefits such as effects on improving heavy periods. The doctor will discuss each option with you to find the most suitable option for you. Which ever option is tried it is recommend to use the treatment for at least 3-6 months to assess the effect the treatment has on symptoms. If symptoms have improved on treatment there may be no need for any additional treatments.

Second line treatments called Gonadotrophin releasing hormones (GNRH) come in the form of either an injection or nasal spray. These cause a temporary menopause state by temporarily stopping the ovaries functioning. Hormone replacement therapy (HRT) is usually given at the same time to prevent symptoms of the menopause. These medications are normally only used short term (no longer than a year) as prolonged use can lead to osteoporosis.

Studies have reported pain scores before and after treatment, where a pain score of 0 is no pain and 100 is the worst pain imaginable. Medical therapies can improve the pain score by an average of 15 points.

Surgical Treatment

Laparoscopy (key hole surgery) can be used to diagnose and treat endometriosis. At the surgery endometriosis and scar tissue can removed by cutting it away or destroying it with heat. Treatment at laparoscopy can improve pain in a significant number of women. Combining the surgery with a contraceptive can improve symptoms further and keep symptoms away for a longer period of time.

0-100 pain scores have been shown to be improved by 25 points with surgery alone and up to 50 points combining a hormonal therapy with the surgery.

A repeat operation is sometimes needed when symptoms have not sufficiently improved after the initial operation or deep extensive disease has been identified. When deep disease is seen additional planning may be needed with further investigations such as MRI scans before arranging a further operation which may require joint operating with a bowel or bladder surgeon. In some women where cutting away the endometriosis has not sufficiently improved their symptoms more extensive surgery may be offered. Approximately a third of women who had improvement in symptoms from an initial operation will develop recurrence of symptoms later and may

require further surgery. This may involve removing the uterus (if adenomysosis is suspected) and or potentially removal of the ovaries and fallopian tubes.

Before any operation the surgeon will discuss the specific risks of the operation with you and any alternative treatments available. The standard discussed risks of laparoscopy are:

- Temporary abdominal and shoulder pain and bruising and around the scars is very common after surgery.
- Infection occurs in up to 5% patients.
- Risk of significant bleeding, or developing a hernia in one of the scars occurs in around 1% cases.
- A serious complication such as injury to bowel, bladder, ureter or blood vessels or needing a laparotomy (open surgery with a big cut) occurs in about 1:500 laparoscopies.
- Very rarely patients can develop life threatening blood clots or other complications.

Some patients will have a laparoscopy and either no cause for their pain will be found or pain will continue despite treatment.

Endometriosis and Fertility

There are many women with endometriosis who become pregnant without difficulty, but endometriosis is found 25% of women who are undergoing investigations for subfertility. Consultation with an infertility expert is initially sought to guide treatment of the endometriosis. Hormonal treatment is not advisable when you are trying to conceive and surgical treatment may be more appropriate, but the type of surgery may depend on whether the intention is to conceive naturally or use assisted methods such as IVF. Pregnancy itself is a good treatment for endometriosis.

Lifestyle modifications

Some women have found the following measures helpful:

- Exercise, which may improve your wellbeing and may help to improve some symptoms of endometriosis
- Cutting out certain foods such as dairy or wheat products from the diet
- Psychological therapies and counselling.

Further information and support

- National Institute for Health and Care Excellence (NICE) – Endometriosis: Diagnosis and Management:
  - www.nice.org.uk/guidance/ng73
- 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-aid-hormone-treatment-for-endometriosis-symptoms-what-are-my-options-pdf-4595573197
- NHS conditions: Endometriosis:
  - www.nhs.uk/conditions/Endometriosis/Pages/Introduction.aspx
- ESHRE: Information for women with endometriosis:
  - https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline/Patient-version.aspx
- Endometriosis UK:
  - www.endometriosis-uk.org
- British Society for Gynaecological Endoscopy:
  - http://bsge.org.uk/
- RCOG Laparoscopy leaflet:
  - www.rcog.org.uk/en/patients/patient-leaflets/laparoscopy

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PET@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.