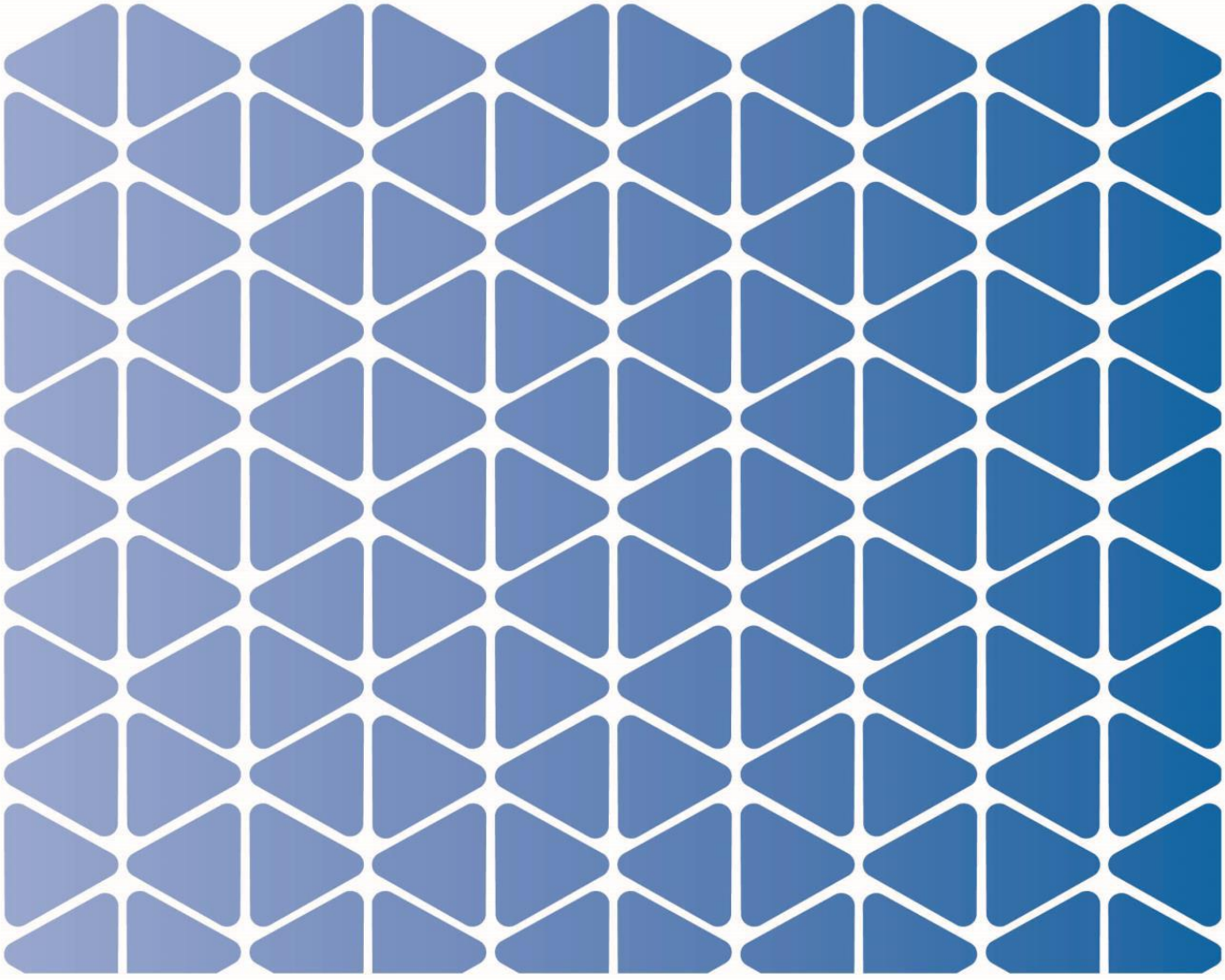
PATIENT INFORMATION

ENDOMETRIOSIS: DEEP DISEASE



What is the purpose of this information leaflet?

This leaflet discusses the way specialist endometriosis centres like here in Worcester investigate and manage deep endometriosis. The treatments and procedures discussed are more advanced and more complex than for treating most cases of endometriosis.

For patients without deep disease, we have produced a patient information leaflet on endometriosis. For patients with deep disease the information leaflet on endometriosis supports this leaflet and should have been provided to you as well.

What is deep endometriosis?

There are lots of ways endometriosis is described. Endometriosis can be relatively easy to remove surgically when it sits in the pelvis away from other organs. Sometimes the endometriosis can embed deeper into the tissues putting it closer to other important structures including the bowel, bladder, nerves and blood vessels. This endometriosis is more likely to cause significant symptoms. Unfortunately, it is also more difficult to treat surgically with an increased risk of injury to the nearby organs.

We use the term deep disease going forward in this leaflet, but you may also read other documents or hear people using the terms ‘severe’, ‘stage 4’, or ‘advanced disease’ which are all used somewhat interchangeably. The National Institute for Health and Care Excellence (NICE) in the UK defines deep endometriosis as a nodule at least 5mm below the peritoneum (lining of the organs and abdominal wall).

Diagnosing deep endometriosis

Symptoms

Symptoms of endometriosis can vary, but the common symptoms are pelvic pain which can be intermittent or constant. Commonly it is worse before or during periods, or during or after intercourse.

Symptoms which increase the likelihood of deep disease include:

- Bowel involvement - Pelvic pain on opening bowels, or rectal bleeding
- Bladder involvement - Pelvic pain on passing urine, or visible blood in the urine
- Deep nerve involvement - Referred pain into the legs, back or shoulder

Examination

In clinic the doctor will also offer to perform examinations of the abdomen, an internal pelvic examination and occasionally a rectal examination. These examinations can identify areas of tenderness and the presence of nodules of endometriosis at the top of the vagina which increase the risk of there being deep endometriosis.

Ultrasound

Ultrasound scans are routinely performed in patients with suspected endometriosis. These predominantly look for endometriosis cysts on the ovaries (called endometriomas) which can cause pain themselves but also their presence increases the risk of deep endometriosis also being present.

Further investigations

If from any of the symptoms, examination findings and ultrasound scan suggest the possibility of deep endometriosis further investigations may be offered prior to arranging definitive surgical treatment. The other investigations which may be offered are:

- MRI scan
    - This is a scan of the pelvis where the patient lies on a bed with a ring like machine around the pelvis. It does not use radiation (X-rays and Ct scans do). The machine does not touch the patient but takes lots of pictures over about 40 minutes to build up a very detailed picture of the pelvis and the internal organs. The MRI can show deep endometriosis, involvement of other organs and adhesions between organs.
- Sigmoidoscopy
    - For patients with significant bowel symptoms or rectal bleeding a sigmoidoscopy is offered. This is a tube inserted into the rectum to look at the internal aspects. It is performed with the patient awake and only takes a couple of minutes to perform. Endometriosis invading into the bowel can be seen. Other causes of bowel pain and bleeding can also be seen if endometriosis is not the cause.
- Cystoscopy
    - For patients with bladder symptoms or blood in the urine a cystoscopy may be offered. This is a camera inserted through the urethra (urine outflow tube) into the bladder to look for endometriosis or other causes of symptoms. It is performed with the patient awake and only takes a couple of minutes to perform.
- Laparoscopy
    - After discussing all the options some patients will be offered a diagnostic laparoscopy. This is a 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.
    - While the definitive treatment of deep endometriosis is often done at laparoscopy these operations can take many hours and require a number of surgeons and need to be performed in specific hospitals. A diagnostic laparoscopy can be performed by a single surgeon in a greater number of hospitals. Like the other investigations above a diagnostic laparoscopy can

help to identify the extent of the disease and what definitive procedure should be offered.

- At this initial laparoscopy some treatment of endometriosis can be performed, such as draining large endometriomas and removing superficial endometriosis. Doing this can improve some symptoms and make a subsequent operation more straight forward.
- Occasionally symptoms may have improved sufficiently that a patient then feels another operation is not necessary.
- Many patients have already had at least one laparoscopy prior to being seen by a specialist, so the operation notes and photos can be obtained from the previous procedure to guide the subsequent treatments.

Multi-disciplinary meetings

In specialist endometriosis centres like Worcester patients with suspected or confirmed deep disease are discussed at regular team meetings. At these meetings specialist endometriosis gynaecology surgeons, nurses, radiologists, bowel surgeons and bladder surgeons review each patient's case and investigations to decide what the possible treatment options are. The team may also suggest additional tests to gain more information before offering surgery.

Alternative treatments to surgery

The standard treatments for endometriosis include lifestyle changes, pain relief medications, hormonal/contraceptives, basic laparoscopic surgery and occasionally Gonadotrophin releasing hormone (GNRH) injections or sprays. Commonly patients have already tried all or the majority of these treatments without sufficient success prior to considering more extensive surgery. But if symptoms are adequately controlled using other treatments there may be no need to treat deep endometriosis with surgery.

Surgery

If surgery is proposed for deep endometriosis you will be seen in clinic by your gynecologist to fully discuss what operation can be undertaken with the risks, benefits and recovery period explained. It may be necessary for bowel and/or bladder surgeons to meet with you prior to the surgery to make sure you are fully happy with the part of the operation they will be undertaking and the associated risks involved.

The planned operation is likely to be a laparoscopy with excision of deep endometriosis plus removal of other causes of pain such as adhesions or ovarian cysts. Depending on whether your family is complete and other factors your surgeon may also discuss the option of having a hysterectomy (removal of the uterus) and or removal of the tubes and ovaries at the same time.

The benefits

Studies show that patients report significantly better pain and quality of life following surgery. On average patients reported their quality of life as 55/100 before the operation, improving to 80/100 after the operation and maintained at 2 years after the operation. Patients who had pain opening their bowels or during intercourse reported that this pain was 6/10 before surgery, reducing to 1/10 after. Similar improvements were seen in patients with pelvic pain, period related pain and low back pain. It is important to remember that these are averages, some will have better results, some unfortunately will not see the same improvement.

The risks

All patients who have a laparoscopy will have small scars where incisions are made to perform the procedure. It is very common for temporary bruising to develop around these incisions. It is also common to develop temporary abdominal pain and pain in the shoulder for a couple of days following the surgery.

- 50:1000 (5%) risk
    - A small infection. The risk of developing a severe infection or pelvic abscess occurs in less than 1 in 200 patients.
- 10:100 (1%) risks
    - Blood loss more than 1 Litre. Significant blood loss may require a blood transfusion
    - Laparotomy (large cut in the abdomen/ open surgery) to manage an emergency complication
    - Hernia
- 5:1000 (0.5%) risks
    - Unintended injury to an organ including:
        - Bowel
        - Bladder
        - ureters (tubes that carry urine from the kidney to the bladder)
- 2:1000 (0.2%) risks
    - Injury to a major blood vessel
    - Requiring an emergency colostomy or ileostomy (stoma bag). This would likely be temporary but may be permanent.
    - Leakage from bowel or urinary leak which may require another operation as an emergency.
- Very rare (less than 1:5000, 0.005%)
    - Life threatening blood clot in the leg or lung
    - Death

There may be additional or increased risks for the individual patient which their surgeon will discuss with them in addition to the ones mentioned above. One example of this is the risk of bowel injury when surgery is required to remove endometriosis off the bowel:

- Shaving endometriosis off the bowel - 1% risk of injury
- Segmental bowel resection - 4% risk of injury
- Disc resection of bowel - 9% risk of injury

If an injury occurs some of these can be repaired laparoscopically, but some will require open surgery and or stoma formation.

Another risk of pelvic surgery for deep endometriosis is nerve injury. Depending on which nerves are injured affects the complications. Nerve injury is thought to be uncommon but has not well studied to provide an accurate risk. Some patients have developed difficulties with passing urine shortly after surgery which is often temporary; others have developed more permanent urinary symptoms many years after surgery.

Proceeding with surgery

After discussion if both yourself and your surgeons agree to proceed with planned surgery a date will be set for the surgery. You will attend a pre-operative appointment where blood tests are taken and a final suitability or surgery and anaesthetic is checked. You will likely also be provided with dietary advice and medications to take before the surgery to prepare your bowels to reduce the risk of injury and complications if injury occurs. On the day of surgery, you will again meet your surgeon prior to the procedure. Some patients are able to go home on the same day as the surgery, with the majority being discharged within 24 hours of the surgery. Most patients are back to normal activities within 2-4 weeks of the surgery.

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.